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ORIGINAL ARTICLE

Adult Clinical Outcomes, Diagnostic Loss and Predictors in Individuals Diagnosed With Autism in Childhood

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Abstract

Purpose Increasing numbers of individuals diagnosed with autism spectrum disorder (ASD) in childhood are now reaching adulthood, yet knowledge of their long-term outcomes remains limited. This study evaluated adult clinical characteristics, outcomes, and prognostic factors in individuals diagnosed with ASD in childhood.

Methods Eighty-seven adults participated, including five (5.7%) in whom loss of autism diagnosis (LAD) was identified. The remaining participants ($n = 82$) were classified by their initial childhood diagnoses: autistic disorder (49.4%), pervasive developmental disorder–not otherwise specified (20.7%), and Asperger's syndrome (24.7%). Adult outcomes were assessed using a structured functional and psychosocial rating system.

Results Subtypes differed significantly in age at first sentence, regression history, age at diagnosis, and initiation of special education. Individuals with Asperger's syndrome and LAD had higher university attendance and graduation rates. Overall outcomes were very poor (5.7%), poor (55.2%), fair (24.2%), good (8%), and very good (6.9%), with significant group differences. Poor outcomes were significantly more frequent among individuals with intellectual disability (ID), regression history, co-occurring psychiatric conditions, and older age at first sentence. ID and regression significantly predicted poor outcomes, while absence of ID predicted LAD.

Conclusion Findings highlight the heterogeneity of ASD trajectories across the lifespan. While some individuals lose the diagnosis, outcomes vary widely depending on individual characteristics and diagnostic subtype. ID and regression emerged as key predictors for poorer outcomes. These findings offer clinically relevant insights by clarifying prognostic markers and long-term outcomes, informing diagnostic assessment and intervention planning, and emphasizing the need for tailored support strategies.

Keywords Autism · Autism spectrum disorder · Outcome · Loss of autism diagnosis · Adults

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by differences in social communication and interaction, along with repetitive, stereotyped behaviors and restricted interests, with symptoms typically present from early childhood (APA, 2013). In the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV-TR), autistic disorder (AD), Asperger's syndrome (AS), childhood disintegrative disorder, Rett syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS) were classified under the category of "pervasive developmental disorders" (APA, 2000). In the Fifth Edition (DSM-5), all of these diagnoses—except Rett syndrome—were consolidated under the single umbrella term ASD (APA, 2013).

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Considering the heterogeneity in the clinical presentation and etiology of ASD, which is a lifelong disorder, individuals experience varying degrees of difficulties across school, work, and social life (Steinhausen et al., 2016; Mason et al., 2021). Studies have indicated that, in general, autism characteristics decrease with age, social skills and adaptive abilities improve, non-speaking individuals may acquire limited but meaningful verbal expressions, repetitive behaviors and sensory problems diminish, and intellectual functioning remains stable or shows a slight increase (Howlin et al., 2004, 2014; Cederlund et al., 2008; Magiati et al., 2014; Pickles et al., 2020).

Meta-analyses have shown that approximately one-fifth of individuals demonstrate good outcomes, about one-third fair, and nearly half poor outcomes (Steinhausen et al., 2016; Mason et al., 2021). Factors found to positively influence the outcome include higher intellectual functioning, earlier development of language skills, well-developed joint attention and adaptive skills, absence of co-occurring psychiatric conditions, and early diagnosis and intervention (Magiati et al., 2014; Steinhausen et al., 2016; Mason et al., 2021). Additionally, autism subtype is recognized as an important factor influencing the outcome; however, since DSM-5 consolidated these subtypes under a single diagnosis, their distinct trajectories have often been overlooked in research (Steinhausen et al., 2016).

The vast majority of children diagnosed with autism retain this clinical diagnosis throughout their lifetime. However, some individuals have been reported to lose the diagnosis over time (Turner et al., 2007; Helt et al., 2008; Fein et al., 2013; Mukaddes et al., 2014; Eigsti et al., 2023; Sevin et al., 2025). Loss of autism diagnosis (LAD) has been associated with early diagnosis, participation in intensive educational programs, higher intellectual functioning, early language development, and the early acquisition of fundamental social skills (e.g., index-finger pointing, joint attention, and establishing an initially warm relationship with parents) (Helt et al., 2008; Fein et al., 2013).

According to data published in 2025 by the Centers for Disease Control and Prevention (CDC), the prevalence of ASD has increased to as high as 1 in 31 children, and continues to increase (Shaw et al., 2025). In the United States, a 2020 study estimated the prevalence of ASD among adults to be 2.21% (Dietz et al., 2020). In parallel with the rising prevalence, the number of adults with ASD is expected to grow steadily in the coming years. However, current knowledge about the clinical status and life circumstances of this expanding adult population remains limited, and only a few studies have examined ASD outcomes in adulthood. Against this backdrop, the present study examines individuals diagnosed with ASD in childhood who have reached adulthood, with the aims of investigating their clinical status and autism characteristics in adulthood, assessing overall outcomes including LAD, comparing results across different autism subtypes, and exploring prognostic predictors.

Method

Sample

This study utilized data obtained from the initial adult assessments of 87 individuals diagnosed with ASD in childhood and enrolled in the Kocaeli University Adult ASD Sample (KAAS), an ongoing longitudinal cohort. To establish the KAAS sample, the records of patients presenting to the outpatient clinic of the Department of Child and Adolescent Psychiatry at Kocaeli University Faculty of Medicine were retrospectively reviewed. Individuals who had received a diagnosis of autism (Pervasive Developmental Disorder according to DSM-IV, excluding Rett syndrome) during outpatient follow-up and had reached the age of 18 years were identified, and their parents were contacted to provide information about the study. Cases were excluded if the parent had a severe mental disorder (psychotic disorder or mood disorder in the acute phase, or moderate to severe intellectual disability), severe hearing or speech-related difficulties affecting communication, was illiterate, or could not be reached.

Eighty-seven patients who met the inclusion and exclusion criteria, and who consented to participate together with their parents, were interviewed by a child and adolescent psychiatrist. Following the interviews, the evaluating psychiatrist completed the sociodemographic data form, the Childhood Autism Rating Scale (CARS), and the Clinician-Rated Severity of Autism Spectrum and Social Communication Disorder Scale based on direct clinical observation and a structured interview with the participant and their parent.

Information regarding developmental and clinical history during childhood and adolescence (e.g., age at first words and sentences, developmental regression history, age at diagnosis, special education and treatment history, and childhood co-occurring psychiatric conditions) as well as results of any standardized cognitive assessments conducted in childhood, was obtained through retrospective review of medical and educational records. Information obtained from past records was reviewed and verified during the adulthood interview with both the participant and their parent to ensure accuracy and consistency across time points. Current clinical and functional characteristics (e.g., outcome classification, current co-occurring psychiatric conditions, co-occurring physical health conditions, speech pattern, and educational status) were assessed during the adulthood clinical interview conducted by the child and

adolescent psychiatrist with both the participant and their parent. Evaluation results regarding social functioning and daily living activities in this cohort have been published previously (Erarkadaş et al. 2025a), and psychiatric symptoms in a subset of their parents have been reported in a separate study (Erarkadaş et al. 2025b). The present study examines distinct outcomes and variables, providing novel insights not reported elsewhere. All procedures were approved by the Kocaeli University Faculty of Medicine Ethics Committee, and written informed consent was obtained.

Determination of Autism Subtypes and Loss of Autism Diagnosis

Autism subtypes were classified according to DSM-IV criteria as AD, PDD-NOS, and AS to maintain consistency with participants' childhood diagnoses and prior longitudinal studies on diagnostic stability and loss of autism diagnosis. Participants were initially diagnosed in childhood based on these criteria, and all follow-up assessments were anchored to the original diagnoses, enabling longitudinal tracking of diagnostic stability and identification of individuals who no longer met criteria for ASD, even though DSM-5 criteria have since replaced these subtypes. Accordingly, while childhood diagnoses and subtype classifications were anchored to DSM-IV criteria, current diagnostic status in adulthood was evaluated using DSM-5 criteria, in line with contemporary diagnostic standards. Studies addressing diagnostic stability in ASD have used concepts such as 'loss of autism diagnosis,' 'recovery,' or 'optimal outcome' (Eigsti et al., 2023). In the present study, the term 'loss of autism diagnosis (LAD)' was adopted to refer to individuals who were diagnosed with ASD in childhood but no longer meet diagnostic criteria in current evaluations. Consistent with prior research on optimal outcome, the LAD group was defined according to criteria first described by Helt et al. (2008) and subsequently used in later studies (e.g., Fein et al., 2013; Mukaddes et al., 2014; Orinstein et al., 2014; Troyb et al., 2014; Orinstein et al., 2015; Sevin et al., 2025). This approach was used to ensure consistency with and comparability to the existing optimal outcome literature. According to these criteria, inclusion required that participants had initially met the diagnostic criteria for autism according to DSM-IV, exhibited early speech delay (absence of a word by 18 months or absence of word combinations by 24 months), and had a CARS score above 25.5 at the time of the childhood diagnosis. At the current adulthood assessment, conducted by child and adolescent psychiatrists, participants were required not to meet the DSM-5 diagnostic criteria for ASD, show no current need for autism-specific special education or rehabilitative support for core autism characteristics, score below the ASD cutoff on the CARS based on the adulthood evaluation, and demonstrate intellectual functioning in the borderline or higher range based on the clinical evaluation. Apart from the individuals classified as having LAD, all remaining participants continued to meet DSM-5 diagnostic criteria for ASD in adulthood. Childhood diagnoses were established clinically according to DSM-IV criteria. Childhood CARS scores were reviewed retrospectively to document the presence of clinically meaningful autistic features, and the 25.5 cut-off was applied solely as a pragmatic inclusion threshold for the LAD group, consistent with prior optimal outcome studies.

Assessment of Outcome

The outcomes of participants were evaluated using the criteria developed by Howlin et al. (2004), as applied in many studies assessing adults. This outcome classification framework was applied uniformly to all participants, irrespective of their adult diagnostic status (LAD or ongoing ASD). Based on the sum of scores in the domains of employment status, friendships, and independent living skills, individuals were classified into five levels (very good, good, fair, poor, very poor). Evaluations were based on medical records and interviews conducted with the patients and their parents.

Measures

(a) Sociodemographic data form was used to collect information regarding the demographic and clinical characteristics of the patients and their families. The form was developed by the research team based on variables commonly assessed in previous ASD outcome studies (Howlin et al., 2004; Farley et al., 2009; Fein et al., 2013; Magiati et al., 2014; Steinhausen et al., 2016; Mason et al., 2021) and routinely collected information in our clinic. To ensure content validity, the form was reviewed by three child and adolescent psychiatry specialists with clinical experience in ASD diagnosis and follow-up, and item wording was refined for clarity and clinical utility. Because the form functioned as a structured clinical data extraction tool rather than a psychometric scale, pilot testing and internal consistency analyses were not applicable. The form included items assessing the patient's age, gender, educational background, previous diagnoses and treatments, history of developmental regression (language, social interaction, and motor domains), and socioeconomic status. For socioeconomic status assessment, household income was categorized based on the minimum wage at the time of data collection (5,500 Turkish Lira (TRY) into

three groups: (1)≤5,500 TRY, (2) 5,501–10,999 TRY, and (3)≥11,000 TRY.

(b) Childhood Autism Rating Scale (CARS) was used to assess autism characteristics. The CARS was developed by Schopler et al. (1980), adapted into Turkish by Sucuoğlu et al. (1996), and validated in Turkish by İncekaş (2009). A total CARS score of 15–29.5 indicates absence of autism characteristics, 30–36.5 indicates mild-to-moderate ASD, and 37–60 indicates severe ASD. For adolescents and adults, a cutoff score of 28 is recommended for autistic symptoms, and 35 for severe autistic symptoms (Schopler et al., 2007; İncekaş, 2009). The CARS has been reported to be valid and reliable for adults and is useful for classifying ASD severity (Schopler et al., 1980; Mesibov et al., 1989). The CARS was administered during both the childhood diagnostic evaluation and the adulthood reassessment for all participants, and the childhood CARS scores were extracted directly from the original clinical records. In the present study, CARS severity ranges were used to describe symptom severity at the time of the adulthood assessment, whereas childhood CARS scores were reviewed retrospectively to document the presence of clinically significant autistic features in individuals already diagnosed with ASD.

(c) Clinician-Rated Severity of Autism Spectrum and Social Communication Disorders Scale was used to assess the severity of social communication difficulties and restricted, repetitive behaviors. The Turkish validity and reliability study was conducted by Aydın and Çökmüş (2017). This two-item, four-point Likert-type scale (0: None/No support required, 1: Mild/Support required, 2: Moderate/Substantial support required, 3: Severe/Very substantial support required) aligns with the DSM-5 severity levels for ASD (APA, 2013). The scale is rated by the interviewer. The first item measures functional difficulties and the level of support needed due to social communication difficulties, while second item evaluates the severity of restricted interests and repetitive behaviors, along with the support needs (Aydın & Çökmüş, 2017).

(d) Intellectual functioning: In line with previous studies in the literature, patients' intellectual functioning was assessed using the results of prior standardized intelligence assessments together with the current clinical evaluation during adulthood (Farley et al., 2009; Nguefack et al., 2021; Rerkmoung et al., 2022). Retrospective review of patient files revealed that 22 patients had been assessed with the Denver-II Developmental Screening Test, 25 with the Wechsler Intelligence Scale for Children – Revised (WISC-R), 1 with the Stanford-Binet Intelligence Test, and 1 with the Porteus Maze Test. In cases where multiple tests had been administered, the WISC-R result was used if available; otherwise, the developmental test administered closest to the school-entry age of six years was used. For the Denver-II, total cognitive capacity scores (developmental quotients; DQ) were calculated using the formula: "developmental age/chronological age ×100" as in similar studies (Nguefack et al., 2021; Rerkmoung et al., 2022). DQ calculations were feasible only for participants assessed with Denver-II, as age-equivalent scores required for DQ computation were not available from WISC-R or from participants without any childhood developmental testing. In 38 patients without prior developmental or cognitive testing due to inability to comply with or complete formal assessments, intellectual functioning was estimated based on the clinical evaluation during the adult interview, conducted by an experienced child and adolescent psychiatrist. This clinical assessment considered expressive and receptive language abilities, problem-solving demonstrated in interaction, independence in daily living skills, educational and occupational history, and caregiver report. This approach is consistent with DSM-5, which defines intellectual disability primarily in terms of adaptive functioning rather than IQ test scores alone (APA, 2013). Intellectual functioning was categorized according to DSM-5 as average (IQ≥90), borderline/low average (IQ 70–89), mild intellectual disability (IQ 50–69), moderate intellectual disability (IQ 35–49), and severe intellectual disability (IQ≤34) (APA, 2013).

Statistical Analysis

Statistical analyses were performed using IBM SPSS 26.0. The normality of data distribution was assessed with the Shapiro-Wilk test. Numerical variables were reported as mean ± standard deviation, or median (IQR: 25th–75th percentile), and categorical variables as frequency (percentages). All group comparisons were performed for the three main diagnostic categories (Autistic disorder, PDD-NOS, Asperger's syndrome). The loss of autism diagnosis (LAD) subgroup was excluded from p value calculations due to small sample size. Percentages are presented within each group. For numerical variables, between-group differences were analyzed using one-way ANOVA for normally distributed data and the Mann–Whitney U test or Kruskal–Wallis test for non-normally distributed data. Differences between categorical variables were analyzed using the chi-square test and Fisher's Exact test. Effect sizes were reported for significant group comparisons. η^2 was calculated for ANOVA tests, ε^2 for Kruskal–Wallis tests, and Cramer's V for chi-square analyses. Because case distribution across the

Table 1 Developmental, diagnostic, and educational characteristics of participants across diagnostic sungroups

Variable		Autistic disorder	PDD-NOS	Asperger's syndrome	Loss of autism diagnosis	Total	*p*
Age[a]		21.0 (19.0–22.0)	21.0 (19.0–24.0)	23.0 (20.0–24.0)	21.0 (19.0–25.5.0.5)	21.0 (20.0–23.0)	0.462
Sex	Male	38 (88.4)	15 (83.3)	19 (90.5)	4 (80.0)	76 (87.4)	0.865
	Female	5 (11.6)	3 (16.7)	2 (9.5)	1 (20.0)	11 (12.6)	
Place of residence	Provincial center	13 (30.2)	10 (55.6)	9 (42.9)	0 (0.0)	32 (36.8)	0.08
	District/Town	30 (69.8)	8 (44.4)	12 (57.1)	5 (100.0)	55 (63.2)	
Family income	≤5,500 TRY	2 (4.6)	0 (0.0)	1 (4.8)	0 (0.0)	3 (3.4)	0.211
	5,501–10,999 TRY	15 (34.9)	3 (16.7)	1 (4.8)	0 (0.0)	19 (21.8)	
	≥11,000 TRY	26 (60.5)	15 (83.3)	19 (90.5)	5 (100.0)	65 (74.7)	
Age at first word, months[a]		18.0 (12.0–48.0)	30.0 (18.0–49.5.0.5)	18.0 (12.0–30.0)	36.0 (21.0–45.0)	24.0 (16.0–36.0)	0.160
Age at first sentence, months[b]		74.0±44.57	58.59±33.04	34.86±11.79	49.2±7.82	54.2±34.06	**0.001***
Developmental regression[c]		27 (62.8)	7 (33.3)	2 (9.5)	2 (40.0)	37 (42.5)	**<0.001***
Age at regression, months[a]		24.0 (18.0–42.0)	39.0 (24.0–63.0)	54.00 (48.0-.)	18.00 (12.0-.)	24.0 (24.0–51.0)	0.211
Age at diagnosis, months[a]		36.0 (30.0–48.0)	30.0 (24.0–63.0)	120.0 (57.0–144.0.0.0)	30.0 (24.0–31.0)	36.0 (30.0–72.0)	**<0.001***
Age at initiation of special education, months[a]		36.0 (36.0–60.0)	36.0 (28.5–63.0)	84.0 (40.5–138.0)	30.0 (22.0–31.0)	36.0 (30.0–60.0)	**0.008***
Duration of special education, years[a]		16.0 (15.0–18.0)	15.0 (12.75–16.0.75.0)	8.0 (4.0–13.0)	5.0 (4.0–13.0)	15.0 (11.0–17.0)	**<0.001***
Currently receiving special education[c]		25 (58.1)	5 (27.8)	3 (14.3)	0 (0.0)	33 (37.9)	**0.001***
Received speech therapy[c]		19 (44.2)	6 (33.3)	5 (23.8)	4 (80.0)	34 (39.1)	0.288
Attended nursery school[c]		15 (34.9)	10 (55.6)	5 (23.8)	4 (80.0)	34 (39.1)	0.115
Attended kindergarten[c]		24 (55.8)	12 (66.7)	18 (85.7)	5 (100.0)	59 (67.8)	0.058
Educational status[c]							
Did not attend school		4 (9.3)	0 (0.0)	0 (0.0)	0 (0.0)	4 (4.6)	**<0.001*,x**
Primary school graduate		1 (2.3)	3 (16.7)	0 (0.0)	0 (0.0)	4 (4.6)	
Secondary school graduate		4 (9.3)	0 (0.0)	2 (9.5)	0 (0.0)	6 (6.9)	
Currently attending high school		6 (14.0)	1 (5.6)	0 (0.0)	0 (0.0)	7 (8.0)	
High school graduate		28 (65.1)	14 (77.8)	11 (52.4)	1 (20.0)	54 (62.1)	
Currently attending university		0 (0.0)	0 (0.0)	5 (23.8)	2 (40.0)	7 (8.0)	
University graduate		0 (0.0)	0 (0.0)	3 (14.3)	2 (40.0)	5 (5.7)	
Type of education[c]							
Regular classroom		0 (0.0)	1 (5.6)	14 (66.7)	4 (80.0)	19 (21.8)	
Inclusive education		0 (0.0)	6 (33.3)	5 (23.8)	1 (20.0)	12 (13.8)	**<0.001*,y**
Special sub-class/Autistic children education center		11 (25.6)	3 (16.7)	0 (0.0)	0 (0.0)	14 (16.1)	
Vocational application school		28 (65.1)	8 (44.4)	2 (9.5)	0 (0.0)	38 (43.7)	
Did not attend school		4 (9.3)	0 (0.0)	0 (0.0)	0 (0.0)	4 (4.6)	
Current speech pattern[c]							
Non-speaking		13 (30.2)	1 (5.6)	0 (0.0)	0 (0.0)	14 (16.1)	**<0.001***
Single words		12 (27.9)	0 (0.0)	0 (0.0)	0 (0.0)	12 (13.8)	
2–3-word sentences		16 (37.2)	3 (16.7)	0 (0.0)	0 (0.0)	19 (21.8)	
Spontaneous speech with disruptions		2 (4.7)	12 (66.7)	6 (28.6)	0 (0.0)	20 (23.0)	
Fluent speech		0 (0.0)	2 (11.1)	15 (71.4)	5 (100.0)	22 (25.3)	

Table 1 (continued)

Variable	Autistic disorder	PDD-NOS	Asperger's syndrome	Loss of autism diagnosis	Total	*p*
Intellectual functioning[c]						
Average	0 (0.0)	0 (0.0)	10 (47.6)	2 (40.0)	12 (13.8)	**<0.001**[*,z]
Borderline/low average	1 (2.3)	3 (16.7)	11 (52.4)	3 (60.0)	18 (20.7)	
Mild ID	9 (20.9)	10 (55.6)	0 (0.0)	0 (0.0)	19 (21.8)	
Moderate ID	22 (51.2)	4 (22.2)	0 (0.0)	0 (0.0)	26 (29.9)	
Severe ID	11 (25.6)	1 (5.6)	0 (0.0)	0 (0.0)	12 (13.8)	

[a]Median (25th–75th percentile); Kruskal-Wallis test was used

[b]Mean ±SD; one-way ANOVA was used. [c]n (%); Chi-square test or Fisher's Exact Test was used where appropriate

[x]For statistical testing, educational status was grouped into three categories (Below high school, high school, and university); the original detailed categories are presented descriptively, [y]The category "Did not attend school" was not included in statistical testing

[z]For statistical testing, intellectual functioning was grouped into three categories (Average/borderline, mild ID, and moderate/severe ID)

*$p < 0.05$

ASD: Autism spectrum disorder, *ID:* Intellectual disability, *PDD-NOS:* Pervasive developmental disorder not otherwise specified

Statistical comparisons (p values) were conducted only among the autistic disorder, PDD-NOS, and Asperger's syndrome groups

The loss of autism diagnosis group is shown descriptively and was not included in statistical testing due to its small sample size ($n = 5$)

Percentages represent within-group proportions

five outcome levels was highly uneven, resulting in sparse cell counts that would compromise the proportional odds assumption and model stability in ordinal logistic regression, outcome ratings were dichotomized into two clinically meaningful categories (poor/very poor vs. fair/good/very good) for regression analyses. Variables entered into the regression models were selected based on their theoretical and empirical relevance to ASD outcomes in prior literature and their significant associations with the outcome in preliminary analyses, in order to maintain a parsimonious and stable model. Logistic regression analysis was conducted to identify variables predicting the outcome and LAD. Given the small cell counts in some subgroups, Firth's penalized likelihood logistic regression was used to reduce bias in parameter estimates. A p-value < 0.05 was considered statistically significant.

Results

Participants' Clinical Characteristics

Based on retrospective review of patients' medical records and current clinical evaluation, the 87 cases included in the study were classified into four groups: AD ($n = 43$, 49.4%), PDD-NOS ($n = 18$, 20.7%), AS ($n = 21$, 24.7%), and LAD ($n = 5$, 5.7%). Participants were aged 18–39 years (minimum–maximum), with a median age of 21.0 (IQR = 20.0–23.0) and 87.4% were male. No statistically significant differences were observed between the groups in terms of age, sex, place of residence, or family income (all $p > 0.05$) (Table 1).

The age at first spoken word did not differ significantly between groups ($p = 0.160$). However, a significant difference emerged for age at first sentence, with individuals with AS producing their first sentences earlier than those with AD ($p = 0.001$; $\eta^2 = 0.22$). A history of developmental regression was reported in 42.5% of participants and was most frequent in the AD group (62.8%) ($p < 0.001$; Cramer's V = 0.46), with language being the most commonly affected domain across all groups (Table 1).

Significant group differences were observed in age at diagnosis ($p < 0.001$, $\varepsilon^2 = 0.28$), with participants in the AS group being diagnosed at a later age compared to the other groups. All participants had received special education services for at least part of their childhood. Group differences were also found in age at initiation of special education ($p = 0.008$, $\varepsilon^2 = 0.10$), and duration of special education ($p < 0.001$; $\varepsilon^2 = 0.26$), and whether special education was still ongoing at the time of assessment ($p = 0.001$; Cramer's V = 0.4). Participants with AS began special education later, while the duration of special education was significantly

longer in the AD group compared to the AS. Attendance in regular classrooms ($p<0.001$) and participation in university education ($p<0.001$) were most frequent among individuals with AS compared to the other groups (Table 1).

There was a significant difference in speech pattern distribution among the AD, PDD-NOS and AS groups ($p<0.001$; Cramer's V = 0.72). In the AD group, 30.2% of participants were non-speaking and none demonstrated fluent speech. Most individuals with PDD-NOS could engage in reciprocal conversation (66.7%), whereas fluent speech was observed in 71.4% of individuals with AS. All individuals in the LAD group were fluent speakers. Intellectual functioning also differed significantly between groups ($p<0.001$; Cramer's V = 0.69). IQ scores below 70 were observed in 65.5% of the total sample, including 97.7% of the AD group and 83.3% of the PDD-NOS group, while all individuals in the AS and LAD groups scored at or above 70 (Table 1). Detailed individual-level childhood and adulthood characteristics for all LAD participants are presented in Supplemental Table 1.

Overall, 92% of all participants had at least one co-occurring psychiatric condition during childhood and adolescence. Attention deficit hyperactivity disorder (ADHD) ($p=0.007$) and behavioral problems ($p<0.001$) were significantly more common in the AD and PDD-NOS groups, whereas anxiety disorders ($p=0.019$) and specific learning disorders ($p=0.001$) were more frequent in the AS group (Fig. 1A). In adulthood, co-occurring psychiatric conditions remained common, with 74.7% of participants presenting at least one condition. Behavioral problems remained significantly more frequent in the AD and PDD-NOS groups compared to the AS group ($p<0.001$) (Fig. 1B).

Self-injurious behavior was observed in 56.3% of participants during childhood and adolescence, and persisted into adulthood in 46%. The frequency and severity of self-injurious behavior were significantly higher in the AD group ($p<0.001$) (Fig. 2). Aggressive behavior towards others or property damage was reported in 67.8% of participants during childhood and adolescence, with 57.5% continuing to display in adulthood. Similarly, aggressive behavior was most frequent and severe in the AD group ($p<0.001$) (Fig. 2).

The clinical and medical characteristics of participants are presented in Table 2. In adulthood, co-occurring physical health conditions did not differ between groups ($p=0.199$). The most common conditions were obesity and epilepsy. Emergency department visits due to self-injurious or aggressive behavior ($p=0.001$) and inappropriate sexualized behaviors such as masturbation or touching in public ($p=0.021$) were significantly more frequent in the AD group. Although overall psychotropic medication rates did not differ, the rate of antipsychotic use ($p=0.001$), the number of different antipsychotics used ($p<0.001$), and the use of injectable antipsychotics ($p<0.001$) were highest in the AD group, followed by the PDD-NOS group. The most commonly used medications were antipsychotics, mood stabilizers, and antidepressants in the AD and PDD-NOS groups; antipsychotics, antidepressants, and methylphenidate in the AS group. In the LAD group, no psychotropic use was observed except for methylphenidate.

Results of Autism Assessment Tools

CARS scores differed significantly between groups, with the highest scores in the AD group, followed by the PDD-NOS and AS groups ($p<0.001$; $\varepsilon^2 = 0.71$). All individuals in the LAD group scored below the autism diagnostic cutoff. Consistently, ASD severity classifications indicated that, all participants in the AD group were rated as having severe levels of autism characteristics, whereas in the PDD-NOS group 55.6% were classified as severe and 44.4% as mild–moderate. All individuals in the AS group were classified in the mild–moderate severity range ($p<0.001$) (Fig. 3).

According to the Clinician-Rated Severity of Autism Spectrum and Social Communication Disorder Scale, social communication difficulties ($p<0.001$; Cramer's V = 0.71) and restricted interests and repetitive behaviors showed significant group differences ($p<0.001$; Cramer's V = 0.65). These autism characteristics were most pronounced in the AD group, moderate in the PDD-NOS group, mild in the AS group. No participants in the LAD group showed social communication difficulties or restricted/repetitive behaviors (Fig. 3).

Assessment of Outcome

The overall outcome distribution was as follows: very poor in 5.7% ($n=5$), poor in 55.2% ($n=48$), fair in 24.2% ($n=21$), good in 8% ($n=7$), and very good in 6.9% ($n=6$) of all participants, with a significant difference between groups ($p<0.001$) (Fig. 4). Notably, all individuals in the LAD group had been diagnosed with PDD-NOS in childhood.

For further analysis, outcomes were dichotomized into poor/very poor ($n=53$) versus fair/good/very good ($n=34$), and variables considered likely to influence the outcome were compared between the groups (Table 3). Compared to the fair/good/very good outcome group, the poor/very poor group had a significantly higher proportion of individuals with IQ < 70, developmental regression, and co-occurring psychiatric conditions in both childhood/adolescence and adulthood, as well as a higher median age at first sentence and a younger age at diagnosis ($p<0.05$). No significant differences were found in age at initiation of special education or age at first spoken word ($p>0.05$).

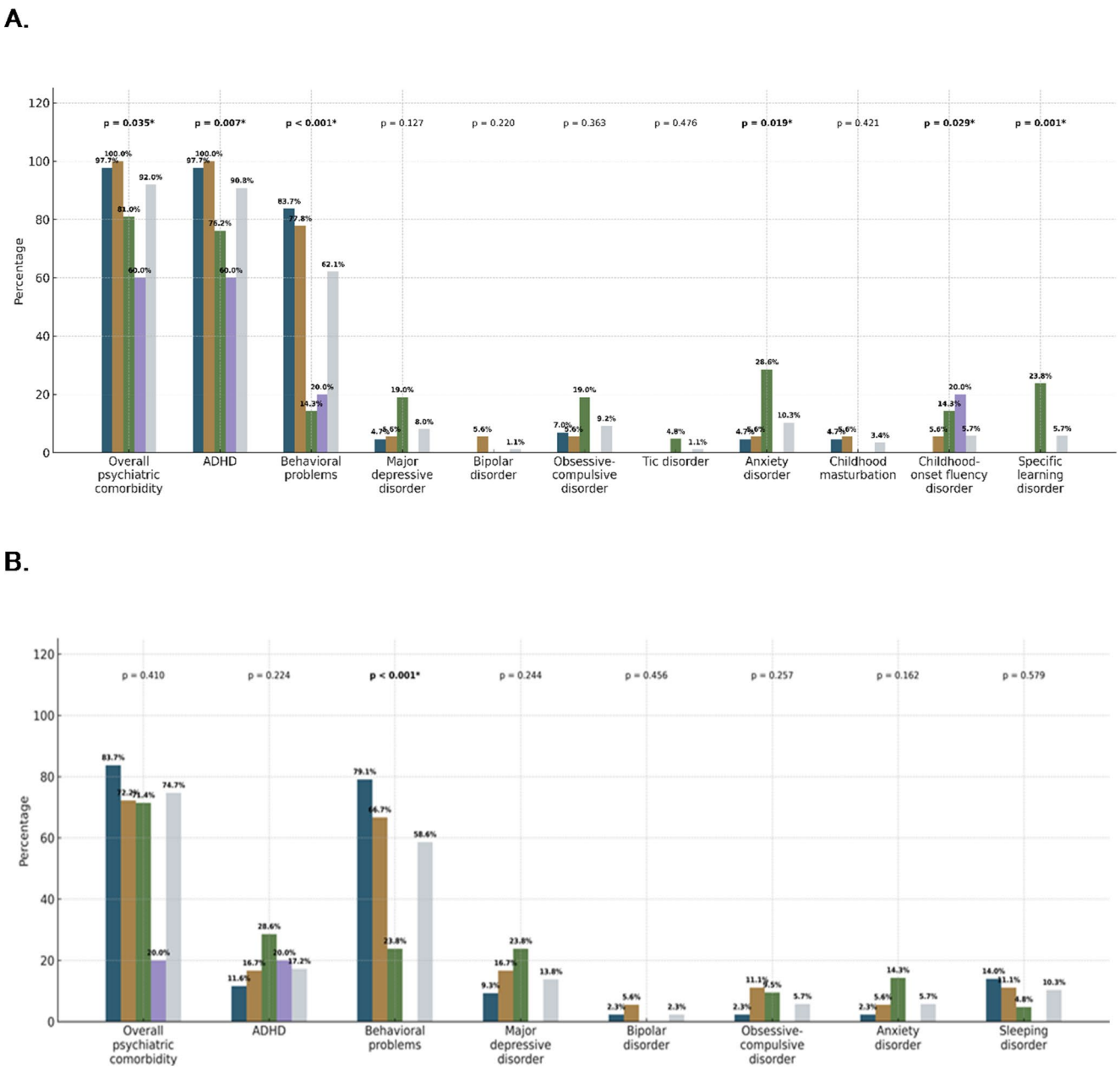

Fig. 1 Psychiatric co-occurring conditions in childhood/adolescence (**A**) and adulthood (**B**). From left to right, bars represent individuals with autistic disorder (dark blue), PDD-NOS (brown), Asperger's syndrome (green), loss of autism diagnosis (purple), and the total sample (gray), respectively. Chi-square test or Fisher's exact test was used where appropriate. *$p<0.05$. PDD-NOS: pervasive developmental disorder not otherwise specified. Statistical comparisons (p values) were conducted only among the autistic disorder, PDD-NOS, and Asperger's syndrome groups. The loss of autism diagnosis group is shown descriptively and was not included in statistical testing due to its small sample size ($n=5$). Percentages represent within-group proportions

Logistic regression analysis was performed by including the variables found to be statistically significant in Table 3. The analysis revealed that having an IQ≥70 (B = −4.369; $p=0.001$) was a strong protective factor against a poor/very poor outcome, whereas a history of regression (B=2.763; $p=0.048$) significantly increased the likelihood of a poor/very poor outcome (Table 4).

To identify predictors of LAD, variables previously reported in the literature to be associated with LAD were entered into a logistic regression model. Intellectual level was the only significant predictor of LAD, with IQ≥70 strongly associated with LAD status (B=2.862; $p=0.041$) (Table 5).

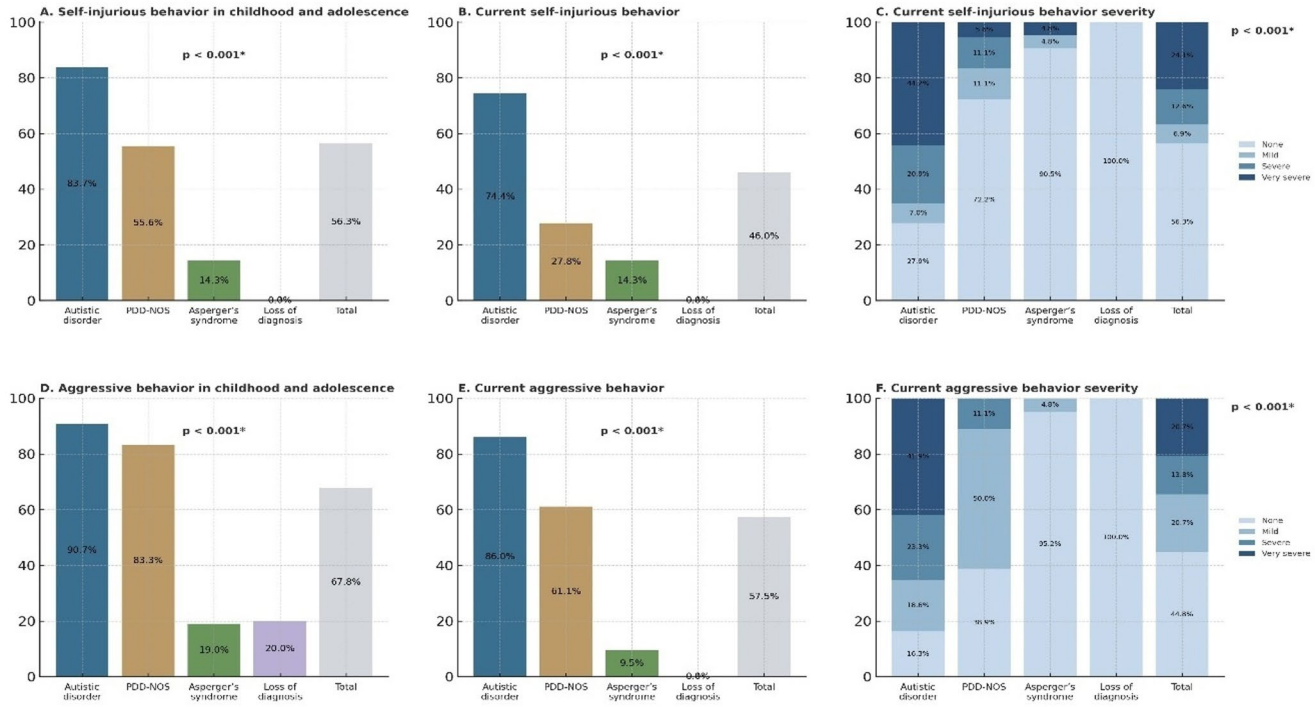

Fig. 2 Self-injurious behavior and aggressive behaviors in childhood/adolescence and adulthood. **A**–**C** present self-injurious behaviors; **D**–**F** present aggressive behaviors. Chi-square test or Fisher's exact test was used where appropriate. *$p<0.05$. PDD-NOS: pervasive developmental disorder not otherwise specified. Aggressive behavior refers to aggressive acts directed toward others or property damage. Statistical comparisons (p values) were conducted only among the autistic disorder, PDD-NOS, and Asperger's syndrome groups. The loss of autism diagnosis group is shown descriptively and was not included in statistical testing due to its small sample size ($n=5$). Percentages represent within-group proportions

Discussion

In recent years, research on adult outcomes in ASD has increased; nevertheless, findings remain inconsistent, and the factors influencing long-term trajectories are not fully understood. In this context, we assessed the adult clinical features of individuals diagnosed with ASD in childhood and examined predictors of both overall outcome and LAD. Our findings indicate that the developmental trajectory of ASD is not fixed; while a minority of individuals no longer meet diagnostic criteria, many continue to experience substantial support needs, reflecting marked interindividual variability. The absence of intellectual disability significantly predicted a more adaptive outcome and LAD, whereas developmental regression was associated with an unfavorable outcome; initial diagnostic subtype was also associated with differences in adult outcomes. Viewed from a neurodiversity-informed perspective, these findings underscore that adult outcomes reflect diverse developmental pathways, rather than immutable diagnostic categories.

Given the well-established heterogeneity of ASD across sex, developmental stage, and socioeconomic context (Rai et al., 2012; Werling & Geschwind, 2013; Magiati et al., 2014; Matos et al., 2022), it is notable that the diagnostic subgroups in our sample did not differ in age, sex, residence, or family income. This comparability reduces the likelihood of demographic confounding, suggesting that the variability in adult outcomes observed here more plausibly reflects differences in developmental profiles rather than background characteristics.

Adult Outcomes and Symptom Trajectories

ASD is generally characterized as a lifelong neurodevelopmental disorder, although the manifestation of core autistic traits may change across development. Previous research suggests that autism characteristics generally lessen from adolescence into adulthood, with more pronounced improvement in restricted and repetitive behaviors than in social communication (Seltzer et al., 2003; Shattuck et al., 2007; Howlin et al., 2014; Pickles et al., 2020). Our findings align with this pattern: although a minority of participants no longer met diagnostic criteria, the majority continued to exhibit autism characteristics at varying levels, with many requiring ongoing support. Social communication difficulties were markedly more common than restricted interests and repetitive behaviors, consistent with evidence that

Table 2 Clinical and medical characteristics of participants

Variable	Group	Autistic disorder	PDD-NOS	Asperger's syndrome	Loss of autism diagnosis	Total	p^a
		n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	
Co-occurring physical health conditions		29 (67.4)	12 (66.7)	10 (47.6)	0 (0.0)	51 (58.6)	0.199
Emergency department visit due to SIB or AB		17 (39.5)	7 (38.9)	0 (0.0)	0 (0.0)	24 (27.6)	**0.001***
Inappropriate sexualized behaviors (e.g., public masturbation or touching)		15 (34.9)	3 (16.7)	1 (4.8)	0 (0.0)	19 (21.8)	**0.021***
Use of psychotropic medication		37 (86.0)	14 (77.8)	16 (76.2)	1 (20.0)	68 (78.2)	0.559
Use of complementary or alternative treatments		21 (48.8)	12 (72.2)	4 (19.0)	2 (20.0)	40 (46.0)	**0.004***
Suicide attempt		0 (0.0)	0 (0.0)	0 (0.0)	1 (14.3)	1 (1.1)	—
Hospitalization		30 (69.8)	11 (61.1)	11 (52.4)	5 (100.0)	57 (65.5)	0.425
Reason for hospitalization	Organic	28 (90.3)	8 (72.7)	2 (18.2)	5 (100.0)	43 (74.1)	**<0.001***
	Psychiatric	3 (9.7)	3 (27.3)	9 (81.8)	0 (0.0)	15 (12.1)	
Psychiatric hospitalization setting	Inpatient	2 (66.7)	3 (100.0)	3 (33.3)	0 (0.0)	7 (46.7)	—
	Day clinic	1 (33.3)	0 (0.0)	6 (66.7)	0 (0.0)	8 (53.3)	
Tobacco use		1 (2.3)	1 (5.6)	2 (9.5)	0 (0.0)	4 (4.6)	—
Alcohol use		0 (0.0)	0 (0.0)	2 (9.5)	2 (40.0)	4 (4.6)	—
Substance use		0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	—
Frequency of psychiatric follow-up visits	None	6 (14.0)	5 (27.8)	5 (23.8)	5 (100.0)	21 (24.1)	0.832
	Irregular	11 (25.6)	3 (16.7)	3 (14.3)	0 (0.0)	17 (19.5)	
	1–2 times/year	6 (14.0)	2 (11.1)	2 (9.5)	0 (0.0)	10 (11.5)	
	3–4 times/year	20 (46.5)	8 (44.4)	11 (52.4)	0 (0.0)	39 (44.8)	

[a]Statistical testing was omitted for variables with very small cell counts; these values are presented descriptively only

Chi-square test or Fisher's Exact Test was used where appropriate

*$p<0.05$

PDD-NOS: Pervasive developmental disorder not otherwise specified, *AB:* Aggressive behaviors, *SIB:* Self-injurious behavior

Statistical comparisons (p values) were conducted only among the autistic disorder, PDD-NOS, and Asperger's syndrome groups

The loss of autism diagnosis group is shown descriptively and was not included in statistical testing due to its small sample size ($n=5$)

Percentages represent within-group proportions

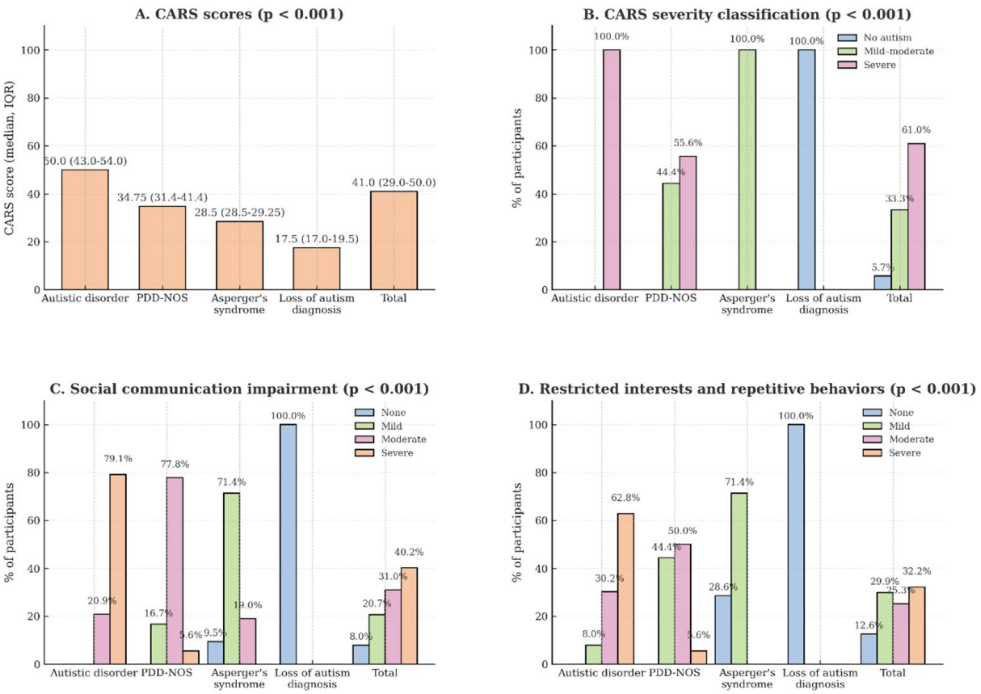

Fig. 3 Autism characteristics across diagnostic subgroups—adult assessment. **A** presents CARS scores as median (25th–75th percentile); between-group comparisons were performed using the Kruskal–Wallis test. **B**–**D** present categorical percentage distributions; statistical comparisons were conducted using the chi-square test or Fisher's exact test where appropriate. CARS: Childhood Autism Rating Scale; PDD-NOS: Pervasive developmental disorder–not otherwise specified. Statistical comparisons (p values) were conducted only among the autistic disorder, PDD-NOS, and Asperger's syndrome groups. The loss of autism diagnosis group is shown descriptively and was not included in statistical testing due to its small sample size ($n=5$). Percentages represent within-group proportions

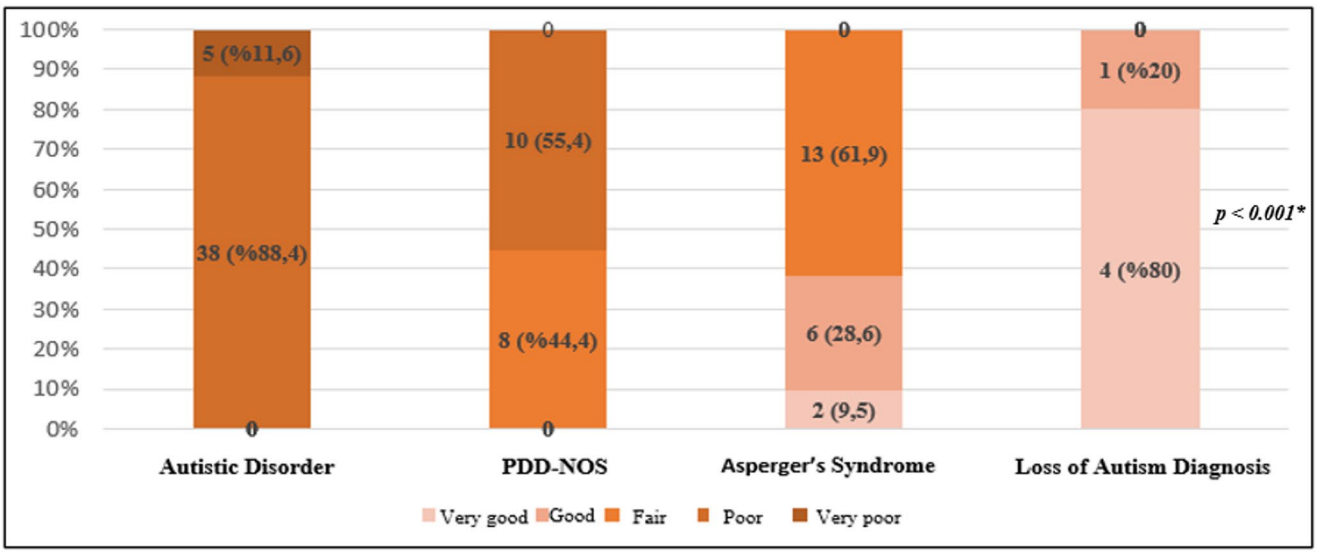

Fig. 4 Distribution of adult outcomes across diagnostic subgroups. Fisher's exact test was used. *$p<0.05$; PDD-NOS: Pervasive developmental disorder not otherwise specified. Statistical comparisons (p values) were conducted only among the autistic disorder, PDD-NOS, and Asperger's syndrome groups. The loss of autism diagnosis group is shown descriptively and was not included in statistical testing due to its small sample size ($n=5$). Percentages represent within-group proportions

Table 3 Evaluation of variables associated with poor/very poor outcome and fair/good/very good outcome

Variables		Poor/Very Poor ($n=53$)	Fair/Good/Very Good ($n=34$)	χ^2	p^a
		n (%)	*n* (%)		
Intellectual functioning	<70	52 (98.1)	5 (14.7)	63.780	**<0.001***
	≥70	1 (1.9)	29 (85.3)		
Childhood and adolescence co-occurring psychiatric conditions	Absent	1 (1.9)	6 (17.6)	6.954	**0.008***
	Present	52 (98.1)	28 (82.4)		
Adulthood co-occurring psychiatric conditions	Absent	9 (17.0)	13 (38.2)	4.953	**0.026***
	Present	44 (83.0)	21 (61.0)		
Co-occurring physical health conditions	Absent	26 (49.1)	24 (70.6)	3.929	**0.047***
	Present	27 (50.9)	10 (29.4)		
History of developmental regression	Absent	20 (37.7)	30 (88.2)	21.611	**<0.001***
	Present	33 (62.3)	4 (11.8)		
	Median (25th–75th percentile)		Median (25th–75th percentile)	Z	p^b
Age at diagnosis (months)	36.0 (30.0–48.0)		60.0 (30.0–130.5.0.5)	2.483	**0.013***
Age at initiation of special education (months)	36.0 (30.0–60.0)		48.0 (30.0–84.0)	0.957	0.399
Age at first spoken word (months)	18.0 (12.0–48.0)		24.0 (18.0–36.0)	−0.145	0.885
Age at first sentence (months)	60.0 (36.0–108.0.0.0)		39.0 (30.0–49.5.0.5)	−2.935	**0.003***

[a]Chi-square test or Fisher's Exact Test was used

[b]Mann–Whitney U test was used where appropriate

*$p<0.05$

social interaction challenges often persist even when other domains improve over time.

Across diagnostic subtypes, we observed a graded pattern in both restricted/repetitive behaviors and social communication, with the most pronounced difficulties in AD and the least in AS. This gradient parallels previous reports indicating more pronounced repetitive behaviors in AD than in AS or PDD-NOS (Szatmari et al., 2003) and likely reflects differences in developmental profiles and support needs rather than fixed severity levels. Clinically, recognizing these heterogeneous trajectories is crucial for planning individualized supports in adulthood, particularly in domains such as social participation, daily living skills, and autonomy.

LAD occurred in a small minority (5.7%) of our sample, indicating that, for a minority of individuals, autism

Table 4 Logistic regression analysis of variables predicting poor/very poor outcome

Variable	B	*p*	Odds Ratio	95% Confidence Interval
Age at first sentence	−0.019	0.318	0.981	0.945–1.019
Age at diagnosis	0.012	0.578	1.012	0.971–1.054
Intellectual level (0: <70, 1: ≥70)	−4.369	**0.001***	0.013	0.001–0.168
Childhood and adolescence co-occurring psychiatric conditions (0: absent, 1: present)	0.430	0.856	1.537	0.015–161.949
Adulthood co-occurring psychiatric conditions (0: absent, 1: present)	0.668	0.605	1.951	0.155–24.613
Co-occurring physical health conditions (0: absent, 1: present)	1.050	0.357	2.858	0.306–26.670
Developmental regression (0: absent, 1: present)	2.763	**0.048***	15.849	1.031–243.735

Model fit: Nagelkerke $R^2 = 0.802$; Hosmer-Lemeshow test: $X^2 = 2.268$, df = 8, $p = 0.972$

*$p < 0.05$

Table 5 Logistic regression analysis of variables predicting loss of diagnosis

Variable	B	*p*	Odds Ratio	95% Confidence Interval
Age at first word	0.008	0.768	1.008	0.956–1.062
Age at diagnosis	−0.014	0.878	0.986	0.825–1.178
Age at initiation of special education	−0.041	0.658	0.960	0.799–1.152
Intellectual level (0: <70, 1: ≥70)	2.862	**0.041***	17.498	1.118–273.955
Childhood and adolescence co-occurring psychiatric conditions (0: absent, 1: present)	−0.549	0.707	0.577	0.033–10.117

Model fit: Nagelkerke $R^2 = 0.400$; Hosmer-Lemeshow test: $X^2 = 6.567$, df = 8, $p = 0.584$

*$p < 0.05$

characteristics may diminish over development to the point that diagnostic thresholds are no longer met. Consistent with this, prior longitudinal studies report LAD rates ranging from 3% to 25%, reflecting substantial heterogeneity across samples and methodologies (Helt et al., 2008; Fein et al., 2013; Helles et al., 2015; Anderson et al., 2014; Blumberg et al., 2016; Rattaz et al., 2018; Eigsti et al., 2023). In line with previous work, individuals who no longer met diagnostic criteria often continued to experience co-occurring conditions such as ADHD (Helt et al., 2008; Farley et al., 2009; Orinstein et al., 2014; Sevin et al., 2025). Thus, LAD should not be interpreted as an absence of support needs; rather, it reflects a shift in diagnostic status within an ongoing neurodevelopmental trajectory that still requires monitoring and access to flexible, developmentally appropriate services.

ASD, with its heterogeneous clinical presentation and developmental course, is associated with a broad range of adult outcomes, from substantial functional challenges to relatively independent functioning (Eaves & Ho, 2008; Howlin & Magiati, 2017). Variation in reported outcomes across studies likely reflects differences in diagnostic criteria, follow-up duration, and sample characteristics. Meta-analytic studies indicate that favorable outcomes are relatively uncommon, with approximately 15–20% of adults showing good outcomes, 25–30% fair outcomes, and nearly half showing poor outcomes (Steinhausen et al., 2016; Mason et al., 2021). In our study, the outcome distribution closely paralleled these estimates (14.9% good, 24.2% fair, and 60.9% poor). This close concordance likely reflects the inclusion of individuals across the full autism spectrum, encompassing a wide range of cognitive and adaptive profiles, which enhances comparability with meta-analytic data.

Developmental Predictors of Long-Term Outcome

Initial diagnostic subtype has been shown to influence developmental trajectories, with individuals diagnosed with AS often demonstrating more adaptive outcomes than those with AD or PDD-NOS (Cederlund et al., 2008; Farley et al., 2009; Osada et al., 2012; Steinhausen et al., 2016; Chamak & Bonniau, 2016; Mason et al., 2021). Consistent with this pattern, all individuals with AD in our sample had poor outcomes, whereas those with PDD-NOS showed predominantly poor to fair outcomes, and individuals with AS demonstrated comparatively more adaptive developmental trajectories. Moreover, all LAD cases had been initially diagnosed with PDD-NOS, consistent with previous findings that LAD is more frequently observed in individuals with this diagnostic subtype (Helt et al., 2008; Blumberg et al., 2016).

In our study, the median age at ASD diagnosis was 36.0 (30.0–72.0) months. Prior reports indicate mean ages of 51 months in the 2016 CDC report (Maenner et al., 2020) and 52.6 months in high-income versus 60.38 months in lower-middle-income countries (Matos et al., 2022). In the LAD group, the median age at diagnosis was 30.0 (24.0–31.0) months, comparable to the previously reported 2.35 years from our country (Mukaddes et al., 2014). While some studies suggest that earlier diagnosis is a favorable indicator for LAD (Helt et al., 2008; Orinstein et al., 2014), others find no

direct association with changes in core autism characteristics (Szatmari et al., 2015; Kim et al., 2016). In our sample, age at diagnosis was not a predictive factor. Individuals with AS were diagnosed at a later age than those in the AD and PDD-NOS groups. This was also reflected in the outcome distribution, as the fair/good outcome group included a higher proportion of individuals with AS, contributing to the higher average age at diagnosis in this subgroup. Given that individuals with AS often have average or near-average intellectual functioning and that their primary difficulties lie in social communication, early autism characteristics may be less noticeable and may become clinically apparent only when social demands increase. In addition, co-occurring symptoms and variability in early developmental presentation can complicate differential diagnosis, contributing to delayed recognition. Thus, the later age at diagnosis in AS is likely to reflect the timing at which social communication difficulties become observable, rather than representing a factor that directly influences prognosis.

Early intervention in ASD has been associated with reduced behavioral difficulties, improved language development, and lower levels of autism characteristics (Warren et al., 2011). Studies of individuals achieving optimal outcomes similarly report earlier clinical identification and earlier initiation of intervention services (Helt et al., 2008; Orinstein et al., 2014; Sevin et al., 2025). However, recent meta-analytic findings indicate that although early intervention is associated with developmental gains, it is not a standalone predictor of long-term outcome (Towle et al., 2020). In our sample as well, age at initiation of special education did not predict either LAD or outcome. Indeed, the poor-outcome group began special education at a younger age than the good-outcome group, although the difference was not statistically significant. The poor-outcome group primarily consisted of individuals with AD and PDD-NOS, who entered intervention earlier due to more pronounced autism characteristics, whereas the good-outcome group more frequently included individuals with AS, who typically show milder autistic traits and therefore start special education later. This pattern indicates that differences in outcome reflect heterogeneity in developmental profiles within ASD, rather than differences in treatment timing alone. Accordingly, intervention timing should not be interpreted in isolation when considering prognosis; long-term outcomes appear more closely linked to the individual's broader developmental trajectories over time.

Early language development is among the most robust predictors of long-term outcomes in ASD (Shattuck et al., 2007; Eaves & Ho, 2008; Farley et al., 2009; Howlin et al., 2014; Magiati et al., 2014; Mason et al., 2021). Consistent with this, individuals with fair/good outcomes in our sample had a significantly earlier age at first sentence than those with poor outcomes. Individuals with AS demonstrated the earliest sentence formation, aligning with literature describing relatively preserved early language development in this subgroup (Szatmari et al., 2003), a profile that likely contributes to their comparatively more adaptive trajectories. Although early language development has been associated with LAD in several studies (Helt et al., 2008; Mukaddes et al., 2014; Sevin et al., 2025), in our regression model early language milestones did not independently predict LAD, suggesting that early language ability contributes to—but does not solely determine—developmental pathways.

Overall, while a portion of individuals achieved conversational or fluent speech, a sizeable subgroup continued to exhibit restricted expressive language, consistent with variability reported in previous adult ASD samples (Magiati et al., 2014; Howlin et al., 2014; Rattaz et al., 2018; Wise et al., 2020; Kutuk et al., 2023). Non-speaking communication was most common in AD, limited reciprocal conversation in PDD-NOS, and fluent speech in AS, whereas all individuals in the LAD group spoke fluently. Clinically, these findings highlight that expressive language follows distinct developmental pathways across subgroups, underscoring the importance of early and ongoing language-focused supports that are responsive to each individual's developmental profile. Such individualized approaches may help maximize communicative competence and functional independence across adulthood.

In our sample, individuals with IQ < 70 had significantly poorer outcomes. Logistic regression further indicated that having an IQ ≥ 70 was the only significant predictor of LAD. These findings are consistent with previous systematic reviews and meta-analyses showing that intellectual functioning is one of the strongest predictors of adult outcome in ASD (Magiati et al., 2014; Mason et al., 2021), and with studies reporting that individuals who lose the diagnosis typically have higher cognitive abilities (Helt et al., 2008; Fein et al., 2013; Mukaddes et al., 2014; Sevin et al., 2025). Nevertheless, these findings should be interpreted with caution, because standardized childhood cognitive test data were not available for all participants, and intellectual functioning was estimated clinically in adulthood for a subset of cases. Given evidence that intellectual functioning in autistic individuals may increase over time (Prigge et al., 2022), the lack of comprehensive childhood IQ measurements represents a methodological limitation. Despite this constraint, the overall pattern in our data suggests that intellectual functioning continues to play a central role in shaping developmental trajectories and should be a core consideration in intervention planning and longitudinal follow-up.

Developmental regression was observed in a substantial proportion of individuals in our sample (42.5%) and was more frequent among those initially diagnosed with AD,

most commonly involving loss of previously acquired language. The prognostic significance of regression remains debated, with some studies associating regression with greater levels of autism characteristics and poorer cognitive and language outcomes (Thompson et al., 2019; Hu et al., 2024), whereas others have reported no consistent link with long-term outcomes (Rogers, 2004; Lord et al., 2012). In our study, however, regression was significantly more frequent in the poor/very poor outcome group and independently predicted poorer adult outcomes. This suggests that regression may indicate a developmental pathway characterized by increased neurodevelopmental vulnerability, rather than representing a transient fluctuation in early skills. Recognizing regression early may therefore help anticipate longer-term support needs and guide proactive, individualized intervention planning across development.

Educational Pathways Across Development

Early participation in inclusive preschool settings can support social communication and peer modeling in children with ASD (Campbell et al., 2005). However, previous research indicates that children with ASD in inclusive classrooms often experience social exclusion and limited teacher support (Metin et al., 2015; Yazıcı et al., 2018), and early exclusion from peer contexts has been associated with later social participation challenges (Shattuck et al., 2011). Extending these findings, parents in our study described obstacles to preschool inclusion: some reported difficulty securing enrollment, while others noted that although their children attended preschool, they were not fully accepted or meaningfully included by teachers and peers. In our sample, among the three diagnostic subgroups compared, preschool participation was lowest in individuals with AD, moderate in those with PDD-NOS, and highest in those with AS. All individuals in the LAD group had attended kindergarten, consistent with reports that individuals with LAD tend to receive preschool education for longer periods than others on the spectrum (Orinstein et al., 2014; Sevin et al., 2025). This pattern likely reflects variation in adaptive and communicative abilities across subgroups, with greater social-communication and behavioral challenges in AD and PDD-NOS contributing to reduced participation. These findings are consistent with broader evidence that stronger adaptive and communicative abilities are associated with more successful adjustment in social and educational contexts (Magiati et al., 2014; Howlin et al., 2014). Overall, these results highlight that the central issue is not merely access to preschool but the quality and continuity of engagement. Physical inclusion alone does not ensure social engagement, communicative opportunities, or supportive teacher interaction. Fostering classroom environments that actively promote participation—rather than simply accommodating presence—is therefore essential for developmental growth. Given the established benefits of early education and the legal guarantee of every child's right to schooling, ensuring equitable access to inclusive preschool settings that support developmentally appropriate participation should remain a central policy and clinical priority.

Academic status represents a key domain of adult outcome. As shown in previous research, the heterogeneous nature of ASD extends to educational outcomes (Keen et al., 2016), and this diversity was also evident in our findings. Individuals with AS were most likely to attend regular classes and continue into higher education, while those with AD and PDD-NOS predominantly remained in special education settings, a pattern consistent with previous longitudinal evidence (Cederlund et al., 2008). Although the LAD group was not included in the statistical comparison due to its small size, most individuals in this group had either completed or were pursuing university education, indicating a more favorable trajectory. The relatively better academic outcomes in the AS and LAD groups align with their higher cognitive abilities and earlier language-development profiles—characteristics that have been linked to greater academic participation in previous research (Farley et al., 2009; Kim et al., 2018; Espeloer et al., 2023). Moreover, overall participation in higher education remained low in our sample, consistent with prior reports showing that only a minority of autistic young adults pursue postsecondary education (Rattaz et al., 2018). Collectively, these results highlight the wide heterogeneity of educational pathways in autism and emphasize the importance of considering individual learning profiles, cognitive strengths, and contextual supports. From a neurodiversity-informed perspective, such variation reflects diverse developmental routes and environmental fit rather than deficits. Strengthening inclusive educational practices and supporting transitions to higher education are critical to promoting autonomy and meaningful participation in adulthood.

Co-occurring Psychiatric, Behavioral, and Physical Health Conditions

Nearly all participants had at least one co-occurring psychiatric condition in childhood, and three-quarters continued to exhibit co-occurring conditions in adulthood. Co-occurring condition rates were significantly greater among individuals with poor outcomes across childhood and adulthood, reinforcing evidence that co-occurring conditions contribute to less favorable functional trajectories (Helt et al., 2008; Farley et al., 2009). In addition, consistent with longitudinal evidence, self-injurious and aggressive behaviors declined over time but often persisted into adulthood, particularly in

AD and, to a lesser extent, PDD-NOS. In these subgroups, emergency visits due to behavioral crises and inappropriate sexualized behaviors were also more common, reflecting greater clinical severity and persistent difficulties in impulse control and social cognition that extend into adulthood. Reflecting this elevated psychiatric and behavioral burden, overall psychotropic medication use was high, consistent with international evidence of substantial treatment needs and polypharmacy in autistic adults (Pandina et al., 2020). The AD and PDD-NOS groups showed the greatest burden, including more frequent use of multiple agents and long-acting injectable formulations. These subgroups, characterized by lower intellectual functioning and higher co-occurring psychiatric conditions, also showed the poorest adult outcomes, indicating that persistent behavioral and regulatory difficulties may both reflect and contribute to less favorable long-term trajectories (Farley et al., 2009; Rattaz et al., 2018).

Despite this high prevalence of co-occurring conditions and associated medication use, nearly half of our participants were not receiving regular psychiatric follow-up. Parents frequently reported a marked reduction in service availability after age 18, including loss of access to specialized autism clinics. This discontinuity of care during the transition to adulthood—often referred to as the "services cliff"—creates a critical gap in support, particularly given the chronic nature of co-occurring conditions and their adverse impact on adaptive functioning and quality of life (Roux et al., 2015; Lai et al., 2019). As individuals with ASD spend most of their lives in adulthood, our findings highlight the need to expand autism-informed adult psychiatric services, including specialized centers and continuous outpatient programs, to ensure equitable and sustainable care across the lifespan.

Beyond psychiatric and behavioral co-occurring conditions, physical health conditions were also common and significantly associated with poorer outcomes in our sample, highlighting the contribution of broader medical burden to long-term functioning. Among these conditions, obesity was most prominent, echoing prior work in autistic adults (Kutuk et al., 2023). Nearly all individuals with obesity (92.6%) were receiving psychotropic medication and many exhibited predominantly sedentary and socially isolated lifestyles, reflecting multifactorial and potentially preventable risk patterns (Kahathuduwa et al., 2019). These findings underscore the need for integrative, lifespan-oriented care models that combine psychiatric treatment with systematic monitoring of metabolic parameters and proactive lifestyle interventions (e.g., structured physical activity, nutritional counseling, and support for community engagement).

Limitations and Future Perspectives

The study was conducted cross-sectionally, and the sample consisted of adults previously followed in a single university clinic, resulting in a selected group that may not represent the broader autistic population. The small overall sample, and particularly the limited size of some subgroups, reduces the robustness of subgroup comparisons; therefore, these findings should be considered preliminary. In addition, participants were predominantly young adults, preventing conclusions about outcomes in midlife or older age.

A standardized cognitive test was not re-administered in adulthood, and intellectual functioning was estimated using clinical evaluation supported by childhood test scores. However, for some participants, childhood cognitive data were unavailable due to difficulties completing standardized testing—a common occurrence in ASD, where limited verbal communication, attention regulation difficulties, and challenges complying with test procedures can affect performance. In these cases, intellectual functioning was evaluated through clinical assessment of adaptive functioning and developmental history, consistent with DSM-5 guidelines, which emphasize adaptive functioning across conceptual, social, and practical domains rather than IQ scores alone. Although this approach reflects real-world clinical practice and has been used in prior longitudinal ASD studies, it may reduce the precision of cognitive classification and highlights the need for assessment tools that can more accurately capture the diverse cognitive and communication profiles observed in autistic adults.

In our study, variables related to childhood and adult co-occurring conditions were obtained from medical records and family reports. The heterogeneity of information sources and reliance on retrospective recall for part of the data may limit the reliability of the findings and the accuracy of comparisons across life periods. Similarly, expressive language in adulthood was evaluated through clinical observation and parental report due to the lack of validated ASD-specific language measures for adults in Turkish. Although gold-standard diagnostic instruments such as the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS) provide comprehensive assessment of features of autism, neither instrument has been adapted or validated for use in Turkish populations, limiting the standardization and precision of adult assessments.

Diagnostic subgroups were defined using DSM-IV criteria. While these categories allowed comparison across previously established ASD subtypes (AD, PDD-NOS, AS), they may not fully reflect current DSM-5 conceptualizations, and some distinctions may be less relevant under newer diagnostic frameworks. Nevertheless, using DSM-IV

categories ensured continuity with earlier longitudinal outcome studies and facilitated comparison with prior literature. Furthermore, including comparison groups drawn from other neurodevelopmental or psychiatric conditions in future research would also provide a valuable contextual benchmark, helping to clarify the specificity of developmental trajectories and outcome predictors in ASD.

LAD and outcome classifications were based on criteria commonly used in longitudinal ASD studies. Although the absence of universally standardized definitions is a limitation across the field, applying established criteria ensured methodological consistency with prior research and improved comparability with existing findings. Continued efforts to develop internationally agreed-upon standards will further strengthen future studies and support more consistent evaluation of diagnostic stability and developmental change across cohorts.

Despite these limitations, this study contributes rare adulthood follow-up data from a non-Western clinical context, addressing an internationally recognized gap in the ASD outcome literature. Future research based on large, multicenter, community-based cohorts with longitudinal follow-up will be essential for clarifying developmental pathways and strengthening adult services for autistic individuals.

Conclusions

This study demonstrates that ASD diagnosis is not developmentally static; while some individuals continue to experience significant challenges, others show substantial improvement, and a small subset no longer meet diagnostic criteria in adulthood. The absence of intellectual disability emerged as the strongest predictor of both favorable outcome and loss of diagnosis, underscoring the protective role of higher cognitive functioning. Conversely, developmental regression predicted poorer outcomes, suggesting a subgroup with heightened neurodevelopmental vulnerability. Diagnostic subtype also influenced adult trajectories, indicating that early categorical distinctions—although all conditions are now grouped under a single spectrum in the DSM-5 classification—may still hold prognostic value. Nearly all individuals who are now adults were initially diagnosed under DSM-IV, which distinguished subtypes and shaped early evaluations, intervention planning, and clinical follow-up. This historical diagnostic context underscores the continuing relevance of subgroup-specific analyses for understanding long-term outcomes. Accordingly, our comparative examination of adult outcomes across diagnostic subgroups and varying levels of autism characteristics provides novel evidence to a still underexplored section of the literature.

Viewed through a neurodiversity-informed lens, these findings indicate that adult outcome heterogeneity in ASD reflects diverse and multifactorial developmental pathways rather than fixed deficits or a simple better–worse continuum. This perspective highlights individual strengths, adaptive capacities, and varied support needs, and underscores the importance of enhancing environmental fit through autism-informed adult services, inclusive educational and vocational opportunities, and supports that promote autonomy and meaningful participation across adulthood.

Despite the fact that individuals with ASD spend most of their lives as adults, only about 2% of autism research funding is devoted to adulthood (Office of Autism Research Coordination, 2017). There remains a pressing need for longitudinal and cross-cultural research to clarify the developmental course, clinical characteristics, and evolving support needs of autistic adults. Such studies are essential to inform clinicians, educators, and service providers—who will increasingly encounter autistic adults across diverse contexts—and to guide service models that bridge the gap between child- and adult-focused systems of care. Strengthening adulthood-focused research is therefore crucial to building a more robust evidence base that can guide clinical practice, service planning, and policy development for autistic individuals throughout adulthood.

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Declarations

Competing Interests The authors have no competing interests to declare that are relevant to the content of this article.

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