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Individualized Education Programs and Transition Planning for Adolescents With Autism

Michelle M. Hughes, PhD^a, Anne V. Kirby, PhD^b, John Davis, PhD^c, Deborah A. Bilder, MD^b, Mary Patrick, MPH^a, Maya Lopez, MD^d, Leann S. DaWalt, PhD^e, Elise T. Pas, PhD^f, Amanda V. Bakian, PhD^b, Kelly A. Shaw, PhD^a, Monica DiRienzo, MA^a, Allison Hudson, BS^d, Yvette D. Schwenk, MS^d, Thayer M. Baroud, MHSA^d, Anita Washington, MPH^a, Matthew J. Maenner, PhD^a

^aNational Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia

^bUniversity of Utah, Salt Lake City, Utah

^cUniversity of Texas at San Antonio, San Antonio, Texas

^dUniversity of Arkansas for Medical Sciences, Little Rock, Arkansas

^eUniversity of Wisconsin, Madison, Wisconsin

^fJohns Hopkins Bloomberg School of Public Health, Baltimore, Maryland

Abstract

OBJECTIVES: The study objectives were to examine the contents of individualized education programs (IEPs) of adolescents with autism spectrum disorder (ASD), including postsecondary transition goals, services, and changes in special education classification over time.

METHODS: This study involved a longitudinal population-based surveillance cohort from the Autism Developmental Disabilities Monitoring Network from 2002 to 2018 in 3 catchment areas in the United States. The sample included 322 adolescents who were born in 2002, identified with ASD, and had an IEP available for review at ages 15–16 years.

RESULTS: We found that 297 (92%) adolescents with ASD had an IEP including a transition plan. Those without intellectual disability (ID) were more likely to have postsecondary education and employment goals and have those goals be to pursue higher education or competitive employment compared with those with ID. Forty-one percent of adolescents with ASD had a postsecondary living arrangement goal. Although 28% of adolescents with ASD received school-based mental health services, none of these adolescents were Black; additionally, 15% of those

Address correspondence to Michelle M. Hughes, PhD, National Center on Birth Defects and Developmental Disabilities, US Centers for Disease Control and Prevention (CDC), 4770 Buford Hwy, Atlanta, GA 30341. mhughes7@cdc.gov.

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with ID received mental health services compared with 34% without ID. The percentage of adolescents with ASD served under an autism classification increased from 44% at age 8 years to 62% by age 16.

CONCLUSIONS: We identified gaps and disparities in school-based postsecondary transition planning. Working with education partners, families, and adolescents will be important to identify what challenges contribute to these findings and what supports are needed to improve the equity and quality of the transition planning process for adolescents with ASD so they are prepared for adulthood.

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disability characterized by impairments in social communication and interaction and restricted and repetitive behaviors.¹ Young adults with ASD are less likely to attend college, participate in paid employment, and live independently compared with those without ASD.²⁻⁴

The transition from adolescence to adulthood necessitates planning to ensure that those with ASD receive the supports and services they will need as adults.^{5,6} Transition planning for people with ASD primarily occurs in health care and educational settings.^{7,8} Individualized education programs (IEPs) are created for children eligible for special education to tailor services and supports to meet a student's needs.⁹ Children are placed into a primary eligibility category (eg, ASD, intellectual disability) to reflect the area with their greatest needs for services; eligibility categories may change over time to reflect increasing or changing needs. IEPs typically include the current level of educational performance, measurable annual goals for the child, and special education services and accommodations needed to meet those goals. Since 1990, federal education policy, through the Individuals with Disabilities Education Act, has acknowledged the importance of transition services as part of IEPs.¹⁰ Studies have revealed that higher-quality transition planning for adolescents with disabilities improves transition progress and post-school outcomes.^{11,12}

Despite the challenges people with ASD may face after high school exit and the importance of educational transition planning, the process of transition planning for adolescents with ASD is less well-understood. Self-reported survey data from the seminal National Longitudinal Transition Study-2 (NLTS-2) are now >10 years old and were restricted to those with an autism special education classification who agreed to participate.¹³ The authors of 2 recent studies with limited sample sizes reported on IEPs for transition-age adolescents with ASD, finding wide variation in transition plan quality.^{14,15} Although states monitor postsecondary transition planning to report annually to the US Department of Education¹⁶ and report a range of compliance¹⁷ for postsecondary transition planning, there are additional factors associated with transition planning quality that are not specifically captured in this monitoring including adaptive skills instruction.¹¹

In 2018, the Autism and Developmental Disabilities Monitoring (ADDM) Network conducted its first ASD surveillance among children aged 9 to 16 years.¹⁸ The initial report described changes in the ASD population during this period including their complex health needs and briefly summarized transition planning. The authors of this surveillance report aim to describe the IEPs of transition-age youth with ASD in detail, associated individual factors, and changes in special education classification over time.

METHODS

Population and Data Collection

The ADDM Network conducts population-based surveillance for children with ASD using the methods previously described.¹⁹ Our study is focused on children born in 2002 whose health and education records were reviewed and abstracted for ASD surveillance in the 2010 ADDM Network surveillance year (SY2010) at age 8 years and were followed up during the 2018 ADDM Network surveillance year (SY2018) at age 16 years at select sites. Records were abstracted in SY2010 on the basis of the presence of ASD-associated behavioral characteristics within health or education records from 2002 through 2010. We reviewed education and health records from 2011 to 2018 for these children and linked these follow-up data to SY2010 data. The 3 participating sites (Arkansas, Georgia, and Utah) had access to annual IEP data in SY2018.^{19,20}

Case Ascertainment

As previously described,¹⁸ children were determined as an ASD case if they lived in the study area in 2010 and ever had a written statement from a medical professional diagnosing ASD on a comprehensive evaluation, a special education classification of autism in a public school, or an ASD *International Classification of Diseases* code²¹ obtained from administrative or billing information.¹⁹

Variable Definitions: Data Collected in 2010 (Age 8 Years)

Demographic data from 2002 to 2010 included sex and race/ethnicity (non-Hispanic white [white], non-Hispanic Black or African American [Black], Hispanic, or other). Scores from the most recent IQ test were used to classify children as either having or not having an intellectual disability (ID), by using a cutoff of 70 as having an ID.²² Eligibility categories were determined on the basis of the most recent category for children with IEPs and included autism, developmental delay, emotional disorder, intellectual disability, speech or language impairments, specific learning disabilities, traumatic brain injury, multiple disabilities, other health impairment, other, and unknown (if no eligibility found).

Variable Definitions: Data Collected in 2018 (Age 16 Years)

In 2004, the Individuals with Disabilities Education Improvement Act was passed,¹⁰ requiring that, by age 16 years, the IEP must include postsecondary goals related to training/education, employment, and, if applicable, living arrangements (independent living skills).²³ Data elements were collected from IEPs children received from ages 15–16 years, including whether a transition plan section was included in the records (transition plan completion) and free-text responses describing postsecondary goals for education/training, employment/career, and independent living skills/daily living skills/community participation. Transition plans did not have to have all elements completed to be included in this study. Additional IEP components collected included primary special education eligibility category, whether an adolescent participated in standardized assessments, anticipated year of high school exit (categorized as on-time [2020–2021] or delayed [2022–2025]), and school services provided (speech, special instruction, occupational therapy, adaptive physical education, social skills

instruction, physical therapy, mental health, and extended school year). Anticipated job positions for adolescents listed by IEP teams based on an assessment or knowledge of the adolescent's goals or interests were also collected.

Analytic Methods

Among individuals with ASD, the most recent IEP that included a transition plan (created when the adolescent was 15 years old) was analyzed. Free-text responses for postsecondary goals were coded by 2 independent coauthor researchers to allow examination of more specific details about postsecondary plans and preparation. Coding logic was informed by post-school activity data collection required by the Office of Special Education Programs²⁴ and the US Department of Education's NLTS-2 (Supplemental Table 1).²⁵ Free-text responses from the independent living skills/daily living skills/community participation were used to inform coding for the postsecondary living arrangement goals and the adaptive skills. Interrater agreement and κ statistics were calculated on the entire set; all differences were reconciled via consensus.

The percentage of adolescents with each IEP and transition plan component (Supplemental Table 1) was calculated overall and stratified by individual characteristics including site, sex, race/ethnicity, and ID status at age 8 years. The statistical significance of differences in IEP components by each of the individual characteristics was tested by using Fischer's exact tests because of some cells with sample sizes <5 . Using an overall type I error rate of 5%, a P value adjustment due to multiple comparisons was made by using the Benjamini-Yekutieli method.²⁶ Anticipated job positions were grouped into similar coauthor-defined employment type categories (eg, "computer technology" and "entertainment"). Individuals could have multiple job types present. Fischer's exact tests were also used to test differences in employment types by ID status. Stata SE/17.0 and R version 4.1.1 were used for data management and analyses.

RESULTS

Overall

Of the 980 ASD cases identified, 322 lived in the study area and had an IEP available for review at ages 15–16 years; the other 658 ASD cases did not live in the study area or did not have educational records available for review. Of these 322, 92% ($n = 297$) had an associated transition plan. For postsecondary planning among these 297 adolescents, 89% had educational goals, 93% had employment goals, and 41% had living arrangement goals (Fig 1A). Goals related to conceptual (26%), social (14%), and practical (20%) adaptive skills were infrequently noted. Ten percent had a goal related to securing at least 1 form of identification (eg, driver's license).

Site Differences

Although overall transition plan completion was high (92%) among adolescents with IEPs, more adolescents in Utah had a transition plan completed (96%) compared with those in Arkansas (86%); transition plan completion was 94% in Georgia. There was substantial variability across sites except for the presence of postsecondary education and employment

goals. Documentation of post-high school living arrangement goals was completed for 78% of adolescents in Arkansas versus 18% in Utah (Supplemental Table 2). The percentage of adolescents with specific adaptive skills noted, participating in standardized assessments, and with specific services also varied by site with the exceptions of extended school year and speech services (Supplemental Table 2).

Cooccurring Intellectual Disability Differences

Compared with those without ID, a lower percentage of adolescents with ID had an educational goal or a goal to pursue a college education (Fig 1B; Supplemental Table 3). Similarly, a lower percentage of those with ID had a goal to pursue competitive employment compared with those without ID. A higher percentage of those with ID had any mention of a post-high school living plan; those without ID had a higher percentage with a goal to live independently compared with those with ID.

Those with ID were more likely to not participate in standardized assessments and to have an anticipated delayed high school exit. Adolescents with ID were more likely to receive services for speech, occupational therapy, adaptive physical education, and physical therapy, but less likely to receive mental health services than adolescents with ID (Fig 2; Supplemental Table 3).

Demographic Differences (Sex and Race/Ethnicity)

There were no differences identified by sex across all outcomes (Supplemental Table 4). Black adolescents were more likely than those of other races/ethnicities to have at least 1 practical adaptive skill goal noted (Supplemental Table 5). No Black adolescents were identified as receiving school-based mental health services compared with 33% ($n = 83$) receiving these services among all other adolescents. These findings were consistent when stratified by ID status (data not shown).

Anticipated Employment Types

The most common employment types were related to computer technology and entertainment (~10% each; Supplemental Table 6). Adolescents with ID were more likely to have employment types related to personal care/customer service, retail/sales, factory/workshop/manufacturing, and cleaning/maintenance compared with those without ID. Those without ID were more likely to have an engineering-related employment type. Specific examples of responses assigned to each of the 29 employment types are provided (in Supplemental Table 7).

Changes in Special Education Classifications From 2010 to 2018

The percentage of adolescents identified with ASD with a special education classification of autism increased from 44% in 2010 (age 8) to 62% in 2018 (age 16; Fig 3). More than one-half (55%) of those who moved to a 2018 autism eligibility were previously categorized as either developmental delay/preschool or had unknown or no eligibility.

DISCUSSION

Developing and implementing individualized transition planning that meets adolescents' abilities and personal goals is challenging given the diversity of the needs of those with ASD.^{27,28} Data are needed to understand current practices to identify how transition planning teams can best support a successful transition to adulthood.¹¹ This study contributes recent data from several US communities to describe educational transition planning. Some adolescents' IEPs did not have goals related to education or employment, particularly adolescents with ID, as seen in previous studies.^{13,14} The fact that the collected IEPs represented a snapshot in time during the earliest phases of transition planning may have influenced the findings. Transition plans may evolve over time with increasing specificity as the adolescent progresses toward school exit/graduation, which was more likely to be delayed for adolescents with ID. Beginning transition planning at younger ages may also contribute to transition plan completeness. Utah required transition planning to begin at the age of 14 years, 2 years earlier than the federally required age, and had the highest percentage of adolescents (96%) with a transition plan.¹⁶ Starting the transition planning process at earlier ages may improve the likelihood of schools engaging in needed practices to help adolescents achieve their postsecondary goals.²⁹ The higher percentage of those with ASD with a transition plan (92%) compared with previous studies warrants further study to understand if the increase is due to differences in measurement, temporal changes, or other factors.¹³

Although postsecondary living arrangement goals are not required components of transition planning, a minority of young adults with ASD live independently without supports.^{30,31} Thus, planning for the anticipated living situation post-high school is important to consider for those with ASD during transition planning. We found that 41% had a living arrangement goal, a finding similar to previous studies.^{13,15} Fewer than 1 in 5 adolescents had this goal in Utah, reflecting geographical differences in completion of this optional IEP component, similar to variation in other IEP practices seen across sites. Almost one-half of adolescents with ID had a living arrangement goal to live at home or in a supported environment, indicating a future need for these services that include families and caregivers. Fewer adolescents without ID had a living arrangement goal, possibly reflecting an expectation that many will live independently. However, providing a process to plan postsecondary living arrangements for youth without ID could still promote clearer planning and opportunities to support their transition into an independent living arrangement.

Almost one-half of adolescents with ASD had goals indicating a plan for higher education and 70% indicated a plan for competitive employment, in contrast to existing data on post-high school outcomes in which fewer people with ASD than in our study achieve these goals in early adulthood.^{2,3,31,32} In addition, the inclusion of adaptive skills in postsecondary goal setting was uncommon despite their importance in postsecondary success. Adaptive skills training may have been missed in the coding for this study if not listed within the goals on the IEP.³³ Active student, family, and interagency adult services collaboration in school transition planning, including the opportunity for paid employment or internships during high school and instruction in adaptive functioning skills are examples of practices shown to improve post-school outcomes that could be captured in future studies.^{8,10,12,34}

Although having high expectations can be beneficial,³⁵ matching postsecondary goals to adolescents' abilities with appropriate transition services and planning could also improve outcomes. Supporting families, teachers, and schools so they have the training and resources necessary may be important so they can collaboratively help adolescents with ASD achieve their desired postsecondary goals.³⁶⁻³⁹

The most common services used by those with ASD were special instruction (83%) and speech (80%), as previous studies have revealed.⁴⁰ Social skills instruction was noted only for 24% of adolescents, similar to a recent study,¹⁵ despite deficits in social communication and social interaction being a core feature for those with ASD.^{1,41} Similarly, mental health services were noted only for 28% of adolescents despite estimates that more than 60% have 1 or more mental health diagnoses.⁴²

We observed striking racial disparities in school-based mental health services, with no mental health services noted for Black adolescents. Although recent data on racial disparities in school-based receipt of mental health services are not available,⁴³ this finding mirrors disparities in mental health service use observed in the general population.^{44,45} This could point to issues with the equitable provision of school-based mental health services for Black adolescents with ASD. For adaptive skills, the higher percentage of Black adolescents with practical adaptive skills noted may reflect differences in expectations by school teams or differences in student or parental expectations.

Most service use was higher for those with ID; however, a lower percentage of those with ID used mental health services, despite high mental health needs recognized for those with ASD and ID.⁴⁶ This lower service use may be due to the difficulty in diagnosing mental health conditions, such as depression and anxiety, in individuals with limited expressive language abilities.

Service needs and use may increase or become more focused over time as adolescents were more likely to move from no or other special education classifications to autism by age 16; this finding was associated with time-period effects⁴⁷: 5.8% of adolescents aged 3 to 21 years in the United States were served under an autism classification from 2009 to 2010 compared with 10.2% from 2017 to 2018.⁴⁸ Changes in special education classification over time may be due to increased identification of ASD after age 8 years, increased community awareness of ASD, and changing service and support needs.

This report is subject to several limitations. First, the study population may not be representative or generalizable to the United States. Second, our sample is not representative of all people with an ASD special education classification by age 16 years because only people who had contact with health or educational developmental specialists by age 8 years were included. Third, when transition goals were vague, this report's categorization may have misinterpreted the school team's intent when creating the IEP; however, each categorization was independently reviewed by 2 researchers. Moreover, our analysis looked at the presence and types of postsecondary goals but did not specifically examine the quality, including the measurability and appropriateness of the goals, of IEP transition planning. Lastly, there is no comparable method to capture the transition process in medical records,

which inherently limits this study to the postsecondary transition process within public education settings.

Expanding ages in the ADDM Network to include transition-aged youth allowed for an in-depth examination of educational practices and postsecondary transition planning for adolescents with ASD. The broad range of goals set for adolescents with ASD highlights the diverse interests, abilities, and needs of this population. Special education within the public school system plays a central role in preparing many adolescents with ASD for adulthood. To better understand the association between high school transition planning and postsecondary outcomes, future surveillance efforts could link these data to span the late adolescence and early adulthood period. Moreover, gaps and disparities in postsecondary transition planning identified in the current population-based surveillance study warrant further evaluation. Working with education partners, families, and adolescents is an essential step to identifying challenges and needed support to improve equity and quality of the transition planning process for adolescents with ASD so they are well prepared for adulthood.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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ABBREVIATIONS

ADDM	Autism and Developmental Disabilities Monitoring
ASD	autism spectrum disorder
ID	intellectual disability
IEP	Individualized Education Program
NLTS-2	National Longitudinal Transition Survey-2
SY	surveillance year

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WHAT’S KNOWN ON THIS SUBJECT:

The contents of school-based post-high school transition planning are poorly understood among adolescents with autism spectrum disorder.

WHAT THIS STUDY ADDS:

This study identified potential gaps and disparities in educational services and transition planning among adolescents with autism, helping to guide support for schools and families.

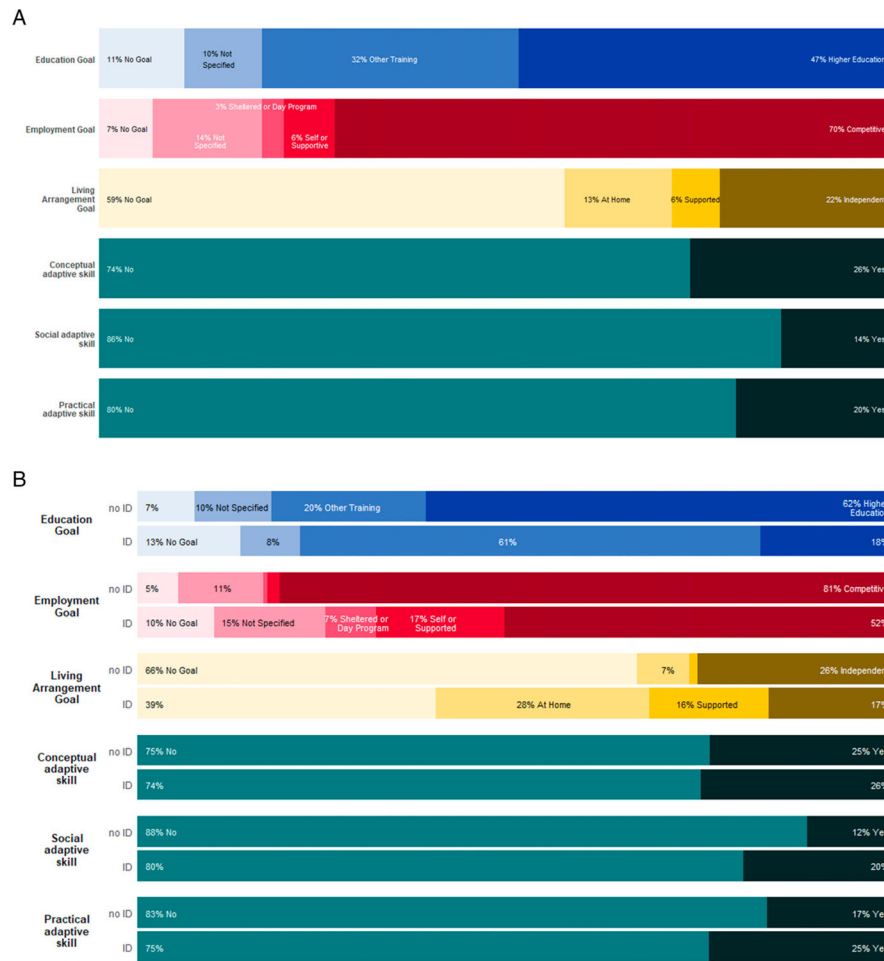


FIGURE 1. (A) IEP postsecondary transition planning and (B) IEP postsecondary transition planning by ID status.

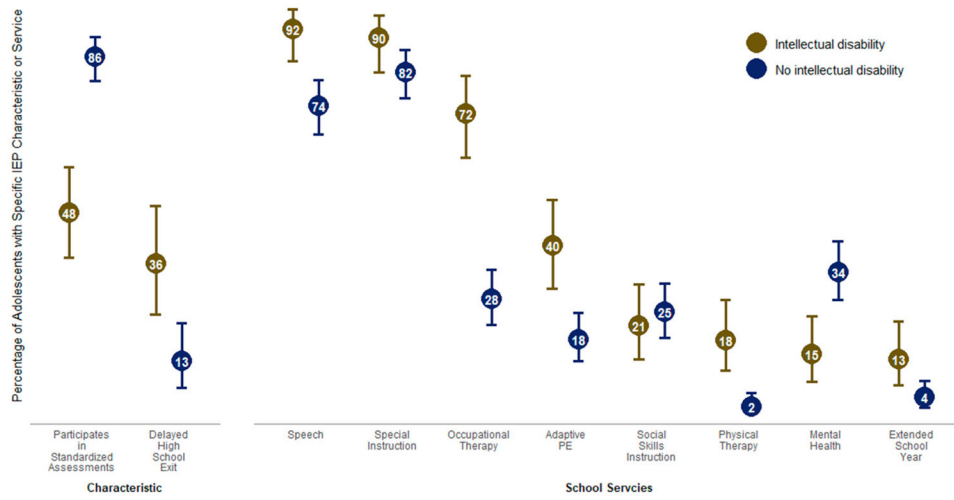


FIGURE 2. Percentage of adolescents with ASD with specific IEP components and services by ID status footnote: bars represent 95% confidence intervals.

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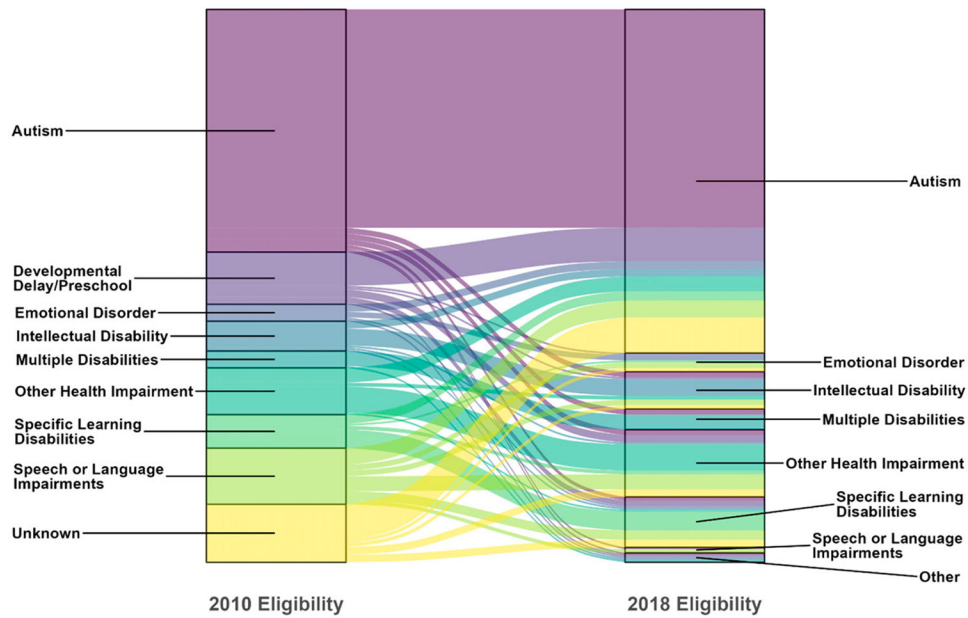


FIGURE 3.

Changes in special education classifications from 2010 to 2018. The alluvial diagram represents the change in special education classifications (eligibilities) from 2010 (age 8 years) to 2018 (age 16 years). The height of each eligibility category is proportional to the number of adolescents represented in that category. In 2018, color patterns within a current 2018 eligibility represent the prior eligibility in 2010. The percentage of adolescents with autism eligibility increased from 44% in 2010 and 62% in 2018. The figure excludes 1 adolescent with a traumatic brain injury eligibility in 2010 and in 2018.