AUTISM SPECTRUM DISORDERS (ES BRODKIN, SECTION EDITOR)



Disparities Based on Race, Ethnicity, and Socioeconomic Status Over the Transition to Adulthood Among Adolescents and Young Adults on the Autism Spectrum: a Systematic Review

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Abstract

Purpose of Review Few studies have examined disparities in autism services and functional outcomes over the life course. Transition to adulthood is an especially important developmental period, as it sets up trajectories of adult functioning. This systematic review summarizes patterns of service use and transition outcomes according to race, ethnicity, and socioeconomic characteristics over the transition to adulthood.

Recent Findings Forty studies were included. Low-income and racial/ethnic minority youth on the autism spectrum were less likely to participate in transition planning meetings, enroll in postsecondary education, find competitive employment after high school, live independently, participate in social activities, and receive health care transition services than their White and higher income peers on the autism spectrum.

Summary Racial/ethnic minority and low-income youth on the autism spectrum were more likely to be disconnected from educational, occupational, and social activities upon entering adulthood. Future research should explore the mechanisms underlying these disparities as a first step to addressing them.

Keywords Autism · Transition to adulthood · Disparities · Race/ethnicity · Socioeconomic status

Introduction

Autism spectrum disorder (ASD) is characterized by social and communication impairments and restricted and repetitive behaviors that persist across the lifespan [1]. ASD research has focused on early childhood and shown associations between early diagnosis and treatment initiation and better long-term outcomes, such as improvements in IQ and adaptive behavior [2–4]. Similarly, research has documented diagnostic and service use disparities in children with ASD [5] but has focused primarily on younger children. On average, racial/ethnic minority children are diagnosed a year and a half later

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than their White peers [6] and have decreased access to ASD services [7]. Similarly, ASD is less likely to be diagnosed among children from lower income families, and low-income children also have decreased access to health-related services [8]. Although these race/ethnicity- and income-based disparities are likely to continue into adulthood [9, 10], few studies have examined ASD service disparities over the life course.

The increasing prevalence of ASD has been accompanied by a growing interest in the transition into adulthood [11]. For all young people, this transition is a time of extended exploration, and decisions made during this period influence trajectories of adult functioning [12]. Youth who are neither working nor enrolled in postsecondary education in the 3 years following high school graduation have increased risk for poorer long-term outcomes, such as poverty, mental health problems, and unemployment [13–15]. This disconnection is more likely to occur in individuals on the autism spectrum, for whom navigating the transition into adulthood may be especially challenging due to ASD-related deficits in social communication and adaptive behaviors [16]. The marked change from school to adult activities that occurs during this



transitional time often exacerbates ASD symptoms and disruptive behavior [17]. Furthermore, many school-based ASD services and supports abruptly end in adulthood, requiring a profound shift toward managing daily life without assistance [18].

To successfully navigate these changes, young people on the autism spectrum benefit from intensive transition planning and skill building [19–22], in which individualized post-high school goals are articulated and addressed [23]. Transition planning is a multifaceted process that encompasses postsecondary education, employment, living arrangements, health services, and social activities. Early and thorough planning is essential because critical skills for navigating adult life, such as interpersonal communication and self-determination, can take time to develop [24]. The Individuals with Disabilities Education Improvement Act (IDEA) requires school-based transition planning to begin by age 16 [25], and many states recommend beginning transition planning by age 14 [26].

Over the last two decades, there has been increased research attention on understanding the needs of youth with disabilities during the transition to adulthood. In 2000, the US Department of Education funded the National Longitudinal Transition Study-2 (NLTS2) to assess the implementation of transition services mandated by IDEA. This longitudinal study enrolled a nationally representative sample of 11,270 youth enrolled in special education services in the USA, a subset of whom had ASD. Parents and youth provided information about school-based transition services and outcomes (e.g., post-graduation employment or education). Youth were enrolled at ages 13–16 years and followed for 10 years [27].

Despite this recent emphasis on the importance of transition to adulthood, research has rarely examined disparities in transition outcomes among youth on the autism spectrum. This is surprising given the likelihood that disparities based on race, ethnicity, or socioeconomic status (SES) will persist into adulthood [28]. Although few studies have focused exclusively on exploring disparities among transition-aged youth on the autism spectrum, race/ethnicity- and SES-focused analyses may be more frequently included as secondary aims of studies. This systematic review aims to (1) review and synthesize the extant literature regarding dimensions of transition to adulthood (i.e., education, employment, living arrangements, social participation, health and mental health, safety and risk, and family well-being) according to race, ethnicity, and socioeconomic characteristics by focusing on all study aims; (2) assess the overall methodological rigor and quality of examining and reporting on race, ethnicity, and culture in included studies; and (3) inform next steps for a research agenda to understand and address race/ethnicity- and SES-based disparities over the transition to adulthood among youth on the autism spectrum.



Procedure

This systematic review was registered in the International Prospective Register of Systematic Reviews (PROSPERO) and was conducted according to PRISMA guidelines [29]. The review process was managed using Covidence systematic review software [30]. Four reviewers (two PhD-level researchers and two doctoral-level graduate students) were involved in all aspects of the review process.

Search Strategy

Searches were conducted in PsycINFO, MEDLINE/PubMed, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Education Resources Information Center (ERIC) using the following search terms: (adult* OR postsecondary) AND (autism) AND (transition). Search terms were queried in abstracts, titles, and full-text articles. The search was limited to peer-reviewed articles published between January 1997 and January 2018, because the Individuals with Disabilities Education Act of 1997 significantly expanded the provisions regarding school-based transition planning for children with disabilities [31]. The search was not restricted by study location or language.

Study Selection

Articles were included if they (1) were empirical; (2) focused on transition-age youth (ages 14-25 years) with ASD; (3) included information about transition-related planning, service use, and/or young adult outcomes related to the following domains: education, employment, living arrangements, social participation, health and mental health, safety and risk, and family well-being; and (4) presented interpretable outcomes by race, ethnicity, and/or SES (Fig. 1). The lower age limit was based on the age at which IDEA recommends that transition planning begin. The upper age limit and the transition to adulthood domains mirrored the methods used in existing transition to adulthood literature [27]. SES indicators included family or per capita income, parent education, parent occupation, income eligibility for government benefits, free or reduced-price lunch, subjective SES, insurance status, and food insecurity. SES was operationalized by the authors of each individual study. Most papers that analyzed the NLTS2 dataset used the following family income categories: \leq \$25,000, \$25,001-\$50,000, \$50,001-\$75,000, and >\$75,000.

Each abstract was reviewed independently by two authors for potential inclusion. Those that were deemed potentially relevant were screened using the full text. Twenty percent of the full-text articles were reviewed independently by two



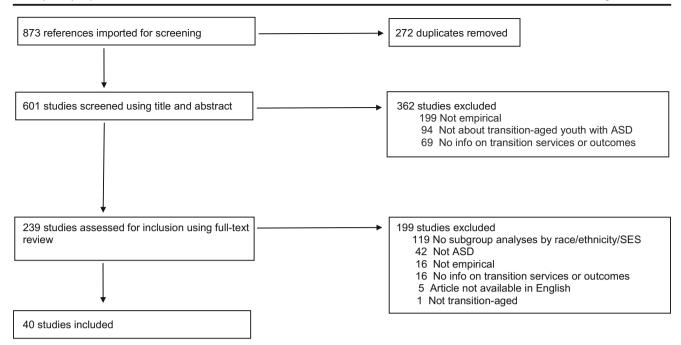


Fig. 1 PRISMA flow chart of literature search results and inclusion in the systematic review

authors to establish reliability of using the inclusion/exclusion criteria. Discrepancies in each step were resolved in discussion with the entire team.

Data Extraction and Quality Assessment

Key study characteristics, such as study location, dates of data collection, sample demographics, disability and/ or ASD characteristics, study purpose, methodology, and outcomes were extracted for each included article using a standardized extraction form. Studies were rated on 11 criteria previously used in the literature to evaluate scientific merit. These criteria assessed rationale, study design and statistical approach, measurement, internal and external validity, accuracy of conclusions and acknowledgment of limitations, and contribution to the evidence base [32–34]. Criterion scores ranged from 1 (no/little evidence of fulfilling this guideline or done poorly) to 3 (good evidence/high quality). The total scientific merit score was calculated by averaging scores across the 11 criteria (range 1-3). Initially, two quantitative papers and one qualitative paper were rated independently by all authors to establish consistency in applying the rating criteria. Subsequently, 20% of included papers were double rated. Intra-class correlations demonstrated high inter-rater reliability (ICC = 0.86). For each study, quality assessments were based on the analyses stratified by race, ethnicity, or SES, which were not always related to the primary study aims. Thus, a high-quality paper may have been rated low in methodological quality if the race/ethnicity/SES analyses were not well defined or implemented.

Given our aim of assessing the quality of reporting specifically regarding race/ethnicity and SES, an adapted version of the Group for the Advancement of Psychiatry's Race, Ethnicity, And Culture in Health checklist (GAP-REACH) [28] supplemented the overall scientific merit ratings. GAP-REACH is an empirically derived checklist of minimum standards for the consideration of race, ethnicity, and culture in psychiatric research publications [28]. Of the original 16 items in the checklist, the nine items corresponding to adequacy of reporting were used in the present study. Items corresponding to methodological rigor were omitted due to overlap with our more comprehensive ratings of scientific merit (see above). A second reviewer double-coded GAP-REACH criteria for 20% of included full-text articles. The inter-rater reliability was high (ICC = 0.91).

Data Synthesis

The first author used narrative synthesis to summarize findings for each transition to adulthood domain. An overview of the literature is provided, including assessment of methodological rigor and quality of reporting on race, ethnicity, and SES. Findings are then summarized across seven domains of transition to adulthood (education, employment, living arrangements, social participation, health and mental health, safety and risk, and family well-being) according to race, ethnicity, and/or SES.



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Results

Available Literature

The initial search yielded 873 citations, of which 601 were unique (Fig. 1). Of these, 362 papers were excluded because the title and abstract demonstrated that they did not meet inclusion criteria. The majority (55%) were excluded because they were not empirical (e.g., literature reviews, case studies, practice guidelines). After title/abstract review, the 239 remaining papers underwent full-text review. Of these, 199 did not meet inclusion criteria. The majority (60%) of these studies were excluded because outcomes related to race, ethnicity, or SES were not reported. The final review included 40 articles: 39 quantitative (97.5%) and 1 qualitative (2.5%). Twenty papers (50%) analyzed data from the NLTS2 and five papers (12.5%) analyzed data from the Research Services Administration database (RSA-911).

Scientific Merit

Scientific merit ratings ranged from 1.36-2.82 (M=2.27, SD=0.30). Papers that scored 1 standard deviation below the mean (<1.97) were designated as low quality (n=6, 15%; Table 1). Common reasons for studies to be designated as low quality included using measures that had limited psychometric support, lacking a representative sample, conducting poorly controlled or inappropriate analyses, and/or not contributing significant new knowledge to the field. The scientific merit of specific studies is referenced throughout this "Results" section, and low-quality studies are identified in Table 1.

Quality of Reporting on Race, Ethnicity, and Socioeconomic Status

GAP-REACH ratings ranged from 4 to 9 (M = 6.75, SD = 1.23). Papers that scored 1 standard deviation below the mean (< 5.52) were considered low quality regarding reporting on sociodemographic factors (n = 7, 17.5%; Table 1). Due to our inclusion criteria, all studies described their samples in terms of sociodemographic characteristics, and a majority (87.5%) of studies referred to sociodemographic characteristics in their interpretation of results. Common reasons for lower GAP-REACH ratings included lack of discussion about the rationale for the study design in terms of sociocultural factors (32.5%), lack of discussion about sociocultural factors in the study limitations (57.5%), and not using race/ethnicity/SES terms in the article title or abstract (50%). Together, this suggests that analyses related to race, ethnicity, or SES were not a primary aim of most included studies. Studies with low GAP-REACH ratings are identified in Table 1.



Education

Thirteen papers examined outcomes related to education, including transition planning during high school (n = 3 studies) and postsecondary education involvement (n = 10 studies). The majority of studies found significant racial, ethnic, and socioeconomic disparities in educational outcomes. Two articles that used NLTS2 data reported that low-income students on the autism spectrum were significantly less likely to participate in transition planning meetings than their higher income peers on the autism spectrum [35, 36]. Of the eight papers that examined associations between household income and postsecondary education, six analyzed NLTS2 data and showed that lower household income was significantly associated with lower rates of attending 2- or 4-year colleges [37, 38•, 39, 40•, 41, 42]. Two studies (one rated low in scientific merit) that analyzed data from the same non-representative sample found no significant associations between household income and college participation [43, 44].

Two articles that used NLTS2 data reported that African American students were significantly less likely to participate in transition planning meetings than their White peers on the autism spectrum [35, 36]. In addition, African American students on the autism spectrum were more likely than White students to endorse the goal of attending college, yet they were less likely to participate in college preparatory activities, such as participating in mainstream classes, passing graduation tests, and completing career and technical education [45]. Similarly, Hispanic students on the autism spectrum were also less likely to participate in mainstream coursework and passed fewer graduation tests than non-Hispanic White students on the autism spectrum [45]. Three papers, all of which used NLTS2 data, examined associations between racial/ethnic minority background and participation in postsecondary education. Hispanic and African American young adults on the autism spectrum were less likely to enroll in postsecondary education compared to their White peers on the autism spectrum [38•]. However, minority students on the autism spectrum who enrolled in college were more likely to persist in college than their White peers [46]. With regard to racial/ ethnic gaps in Science, Technology, Engineering, and Math (STEM) education, White students on the autism spectrum were significantly more likely to major in STEM-related fields than racial/ethnic minority peers [47].

Employment

Fifteen papers examined employment-related outcomes. Findings were mixed. Of the seven papers that used NLTS2 data, five found that youth on the autism spectrum from lower income households were less likely to engage in paid employment than their higher income peers [38•, 42, 48, 49, 50••]. Similarly, an analysis of the RSA-911 dataset found that

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Study	Participants	Sample size	% of sample with ASD	Primary outcomes	Main results by race/ethnicity	Main results by SES ^a
Baer, Daviso III, Queen, and Flexer (2011)	Young adults who graduated or aged out of special education	4572	$1\% \ (n = 66)$	Participation in transition services during high school	Compared to the study population as a whole: African American students were more likely to report college as a transition goal; African American and Hispanic students were less likely to participate in mainstream curricula and passed fewer graduation tests; African American students were less likely to report full-time work socals.	
Griffin, Taylor, Urbano, and Hodapp (2014)	NLTS2 dataset; participants with an ASD diagnosis with transition planning data available	320	100%	Participation in transition planning		Individuals who came from families making more than \$50,000 a year were significantly more likely to be involved in transition planning
Wei, Wagner, Hudson, Yu, and Javitz (2016)	NLTS2 dataset; participants with an ASD diagnosis	920	100%	Participation in transition planning	Students with ASD who participated in transition planning were less likely to be African American	Students with ASD who participated in transition planning were less likely to come from low-income families (household income ≤ \$25,000/year)
Chiang, Cheung, Hickson, Xiang, and Tsai (2012)	NLTS2 dataset; participants with an ASD diagnosis who had exited high school	430	200%	Participation in postsecondary education	1	Compared to annual household income of > \$50,000, annual household income of ≤ \$25,000 significantly predicted lower likelihood of enrollment in postsecondary education
Wei, Christiano, Yu, Blackorby, Shattuck, and Newman (2014)	NLTS2 dataset; participants with an ASD diagnosis who were enrolled in college and provided information about college major	190	100%	College STEM major	Minority college students with an ASD had significantly higher odds of persisting in college than their white peers	
Wei, Yu, Shattuck, and Blackorby (2017)	lataset; participants n ASD diagnosis vere enrolled in e and provided	150	100%	College STEM major	Minority students with an ASD had significantly lower odds of majoring in STEM fields than White students with an ASD	
Shattuck, Narendorf, Cooper, Sterzing, Wagner, and Taylor (2012)	ataset; participants n ASD diagnosis rovided data during 4	089	200%	Participation in postsecondary education; paid employment	Involvement in postsecondary education and paid employment was lower for Hispanic and African American youth with ASD (vs. Caucasian youth with ASD)	Involvement in postsecondary education and paid employment was lower for those with lower income (income measured in \$10,000 increments)



Table 1 (continued)	(pai					
Study	Participants	Sample size	% of sample with ASD	Primary outcomes	Main results by race/ethnicity	Main results by SES ^a
Roux, Shattuck, Rast, Rava, Edwards, Wei, et al. (2015)	NLTS2 dataset; participants with an ASD diagnosis who provided data during Wave 5	620	100%	Participation in postsecondary education	I	Significantly fewer youth with ASD who attended 2-year colleges came from homes with incomes \$25,000, compared to those who never participated in postsecondary education
Taylor and Seltzer (2011) ^b	Caregivers with a son or daughter with ASD ages 10 or older	99	100%	Participation in postsecondary education; employment outcomes	ſ	No significant differences in family income (family income categories ranged from 1 = less than \$10,000/year to 14 = \$160,000/year or more) based on postsecondary education/employment outcome
Wei, Yu, Shaftuck, McCracken, and Blackorby (2013)	NLTS2 dataset; participants with an ASD diagnosis who provided data during Wave 5	099	100%	Participation in postsecondary education; College STEM major	No significant demographic predictors of STEM major	Young adults from lower income households (≤\$75,000/year) were significantly less likely to enroll in a 2-year or 4-year college even after controlling for severity of functional impairment
Wei, Wagner, Hudson, Yu, and Shattuck (2015)	NLTS2 dataset; participants with an ASD diagnosis who were out of high school at or before the third wave of data collection	120	%001	Participation in postsecondary education; employment outcomes	1	Compared with youth with ASD who were continuously or increasingly disengaged, youth primarily focused on postsecondary education had significantly higher odds of coming from a higher income family (>\$75,000/year); no significant group differences in employment outcomes
Taylor and Mailick (2014)	Caregivers with a son or daughter with ASD ages 10 or older	161	100%	The Vocational Index (composite measure of vocational and educational activities of adults with ASD at a given time point)	1	No significant differences in Vocational Index scores by family income (family income categories ranged from 1 = less than \$5000 to 13 = over \$70,000)
Liptak, Kennedy, and Dosa (2011)	Liptak, Kennedy, NLTS2 dataset; and Dosa participants with (2011) an ASD diagnosis	1020 at Wave 1 (2001), 725 at Wave 3 (2003)	%001	Participation in postsecondary education; employment outcomes; obtained driver's license or permit; social participation with friends	White (vs. racial/ethnic minority) youth with ASD were significantly more likely to have their driver's license or permit. African American (vs. Caucasian) youth with ASD were significantly less likely to have spent time with friends in the past year	Those who were above the poverty level (vs. those below poverty level) were significantly more likely to have a driver's license or permit and more likely to be enrolled in postsecondary education or employed



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Table 1

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Study	Participants	Sample size	% of sample with ASD	Primary outcomes	Main results by race/ethnicity	Main results by SES ^a
Sung, Sánchez, Kuo, Wang, and Leahy (2015)°	RSA-911 dataset; youth ages 16–25 with an ASD diagnosis who had received vocational rehabilitation (VR) services	5344	100%	Employment status at VR closure	No significant differences in competitive employment outcome between White and non-White youth	I
Roux, Shattuck, Cooper, Anderson, Wagner, and Narendorf (2013)	NLTS2 dataset; participants with an ASD diagnosis who provided data during Wave 5	620	100%	Employment outcomes	I	Young adults with an ASD had higher odds of ever having had a paid job if they were from higher income households (income measured in \$10,000 increments)
Alverson and Yamamoto (2017) ^c	RSA-911 dataset; young adults with ASD who had received vocational rehabilitation services from 2003 to 2012	49,623	100%	Employment outcomes	In 8 of 10 years, White clients with ASD were significantly more likely than non-White clients with ASD to achieve an employment outcome	I
Chiang, Cheung, Hickson, Xiang, and Tsai (2013)	NLTS2 dataset; participants ages 13–16 with primary diagnosis of ASD	830	%001	Employment outcomes	I	Those whose parents have a high school degree or lower are significantly less likely to be employed after leaving high school than those whose parents have a bachelor's degree or higher. Compared to high school leavers with ASD from low-income families (≤\$25,000), students with ASD from high income families (>\$50,000) are more likely to participate in employment
Carter, Austin, and Trainor (2012)	NLTS2 dataset; participants with severe disabilities	450	36% $(n = 160)$	Post school employment outcomes	Race/ethnicity not associated with employment	Family factors, including parental education and family income (measured by poverty level), not significantly associated with employment in the 2 years after leaving high school
Kirby (2016)	NLTS2 dataset; participants with a diagnosis of ASD who provided data during Wave 1	1170	%001	Employment outcomes; independent living	White race was associated with higher rates of paid employment and independent living	Higher household income (family income categories included <\$25,000, \$25,001-\$50,000, and > \$50,000) was significantly associated with higher rates of paid employment, independent living, and social participation



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Study	Participants	Sample size	% of sample with ASD	Primary outcomes	Main results by race/ethnicity	Main results by SES ^a
Taylor and Da Walt (2017) ^b	Participants with an ASD diagnosis who were scheduled to leave high school within the next 12 months	36	100%	Employment outcomes	1	Family income (family income categories ranged from 1 = less than \$10,000 to 14 = \$160,000 or more) not significantly associated with work, vocational activities, or postsecondary education
Kaya, Chan, Rumrill, Hartman, Wehman, Iwanaga, et al. (2016) ^c	RSA-911 dataset; participants ages 16–25 with a primary diagnosis of ASD	4322	100%	Employment outcomes	Non-white clients were less likely to obtain competitive employment than white clients	I
Chen, Sung, and Pi (2015) ^c	RSA-911 dataset; participants with ASD as primary or secondary diagnosis	5681	100%	Competitive employment status	Black/African American (vs. European American) young adults with ASD were significantly less likely to be competitively employed at VR exit	Youth who received work disincentives (SSI/SSDI or Medicaid/Medicare) were significantly less likely to competitively employed at VR exit
Wehman, Chan, Ditchman, and Kang (2014)	RSA-911 dataset; participants ages 16–25 receiving VR services	23,298	13% $(n = 3131)$	Receipt of supported employment services; competitive employment status	I	Effect of supported employment on competitive employment outcomes was strongest for youth who received social security benefits
Anderson, Shattuck, Cooper, Roux, and Wagner (2014)	NLTS2 dataset; participants with a diagnosis of ASD	620	%001	Living arrangements	African American (vs. White) youth with ASD were significantly less likely to have ever lived independently since leaving high school; Hispanic (vs. Non-Hispanic) youth with ASD were significantly more likely to have lived with parents since leaving high school	Adults with an ASD from higher income families (income measured in \$10,000 increments) had higher odds of living independently
Rueda, Monzo, Shapiro, Gomez, and Blacher (2005)	Mothers of children ages 14–31 with severe developmental disabilities	16	25% (n = 4)	Beliefs and experiences related to transition to adulthood	Key themes from focus groups with Latina mothers: 1. Fear of world outside family 2. Expectation for adult with disability to live in the family home 3. Lack of information about transition services, mistrust of and poor communication with service providers 4. Lack of information in Spanish 5. Concern about young adult's interest in sexual relationshins	1
Myers, Davis, Stobbe, and	NLTS2 dataset; participants with a diagnosis of ASD	Only reported weighted	100%	Community participation and social participation		Higher household income (>\$25,000) predicted greater community involvement in early adulthood



(continued)
Table 1

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Study	Participants	Sample size	% of sample with ASD	Primary outcomes	Main results by race/ethnicity	Main results by SES ^a
Bjornson (2015) Huang, Kao, Curry, and Durbin (2012) ^b	who completed all five waves of data collection Participants ages 15–18 with a diagnosis of ASD without intellectual disability	sample size 297	100%	Participation in driving	No significant association between race/ethnicity and driver's license	No significant association between household income (family income categories were ≤\$100,000 and >\$100,000) and driver's license
Orsmond, Shattuck, Cooper, Sterzing, and Anderson (2013)	NLTS2 dataset; participants with a diagnosis of ASD who were no longer in high school	620	100%	Social participation	No significant association between race/ethnicity and social participation	No significant association between income (family income categories included \leq \$25,000, \$25,001–\$50,000, \$50,001–\$75,000, and >\$75,000) and social participation
McCollum, LaVesser, and Berg (2016) ^c	Young adults with diagnosis of high functioning ASD or Asperger's disorder	24	%001	Participation in daily activities (e.g. chores, leisure activities)	I	A trend for participating in more leisure activities among participants who reported an income level greater than \$75,000
Walsh, Jones, and Schonwald (2017)	Adolescents ages 12–17 with a diagnosis of ASD	1125	200%	Overall transition core outcome (discussed the following with pediatric provider: transition to an adult health care provider, changing health care needs, and maintaining health insurance coverage)	Youth who were non-Hispanic Black were significantly less likely to have met the national transition core outcome than non-Hispanic white youth	Parents who reported a family income less than the federal poverty level were less likely to have met the national transition core outcome
Cheak-Zamora, Yang, Farmer, and Clark (2013)	NS-CSHCN dataset; participants ages 12–17 with a diagnosis of ASD	908	100%	Health care transition services	Hispanic (vs. non-Hispanic white) youth with ASD were significantly less likely to receive health care transition services	Family income (based on poverty level) was not significantly associated with receipt of health care transition services
Beal, Riddle, Kichler, Duncan, Houchen, Casnellie, et al. (2016) ^c	Adolescents and young adults with type 1 diabetes, Turner syndrome, ASD, spina bifida, and a sample of youth without any chronic conditions	163	21% ($N = 35$)	Health care transition readiness	1	Lower maternal education level was significantly associated with less readiness of youth to manage medications independently
Biggs and Carter (2016) ^b	Caregivers with a son or daughter ages 13–21 with ASD or ID and lived in the state of Tennessee	389	60% $(n = 232)$	Quality of life	Based on data from the whole sample, higher physical well-being scores were predicted by minority status	ı
Taylor and Henninger (2015) ^b	Caregivers with a son or daughter with ASD who was currently within 12 months of high school exit	39	100%	Service access (e.g., speech/language services, psychological/mental health services or counseling)	More unmet service needs were associated with racial/ethnic minority status	I



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Study	Participants	Sample size	% wi	of sample Primary outcomes th ASD	Main results by race/ethnicity	Main results by SES ^a
Rava, Shattuck, Rast, and Roux (2017)	NLTS2 dataset; participants with a diagnosis of ASD who had no missing data at Wave 1	920	100%	Criminal justice system involvement (i.e., ever being stopped or questioned by police)	I	No significant association between household income (income measured in \$10,000 increments) and criminal justice involvement
Bamard-Brak, Schmidt, Chesnut, Wei, and Richman (2014)	NLTS2 dataset; participants who had provided data about intellectual functioning	5070	11% $(n = 540)$	Receipt of sex education in high school	1	For students with moderate to severe intellectual disability (with or without ASD), higher household income (family income categories included <\$25,000, \$25,001-\$50,000, and >\$50,000) significantly predicted greater likelihood of receiving sex education in high school
Shattuck, Steinberg, Yu, Wei, Cooper, Newman, et al. (2014)	NLTS2 dataset; participants with a primary diagnosis of ASD who attended college	120	100%	Disability identification; self-efficacy	African American (vs. White) youth with ASD had a lower likelihood of seeing themselves as disabled and a lower self-efficacy rating related to getting others to listen	I
Boehm, Carter, and Taylor (2015)	Youth ages 13–21 who lived in Tennessee and had a diagnosis of ID or ASD	425	42.8% $(n = 182)$	Quality of life among families of transition-aged youth	No significant association between race/ethnicity and family quality of life	Eligibility for free or reduced-price meals associated with lower family quality of life scores
Taylor and Seltzer (2011)	Youth with ASD age 10 or older who were in high school at Time 2	170	%001	Changes in the mother-child relationship; caregiver burden		Income (family income categories ranged from 1 = < \$5000 to 13 = > \$70,000) was not significantly related to change in mother-child positive affect over time, nor to mothers' subjective burden over time
McKenzie, Ouellette-Ku- ntz, Blinkhorn, and Démoré (2016) ^{b. c}	Adolescents 16 and older with intellectual and developmental disabilities	31	48% (n = 15)	48% ($n = 15$) Parental distress during post school transition		Based on data from the whole sample, working parents reported more distress post-transition than non-working parents

^a Definitions of low and high SES were determined by the authors of each included study and therefore vary across included studies



 $^{^{\}rm b}$ Low scientific merit score (≤ 1 SD below mean)

^cLow GAP-REACH score (≤1 SD below mean)

young adults on the autism spectrum who were eligible for government benefits like Supplemental Security Income (a proxy for income) were less likely to achieve competitive employment than those who were not eligible for government benefits [51]. Vocational rehabilitation services (e.g., supported employment) have the strongest impact on employment outcomes for young adults with disabilities who received social security benefits [52]. Two NLTS2 studies that analyzed smaller subsets of the data and three studies that used a nonnationally representative dataset (one low in scientific merit) found no significant associations between household income and paid employment [40•, 43, 44, 53, 54].

Five papers found that racial/ethnic minority youth on the autism spectrum were less likely to secure competitive employment than White youth on the autism spectrum [38•, 50••, 51, 55, 56]. In addition, fewer African American students with disabilities endorsed full-time work as a transition goal than White students [45]. Another paper, which analyzed a subset of youth with severe disabilities (with and without ASD) in the NLTS2 dataset, found no association between race/ethnicity and paid employment after high school [53]. Similarly, an analysis of the RSA-911 dataset found that race/ethnicity was not a significant predictor of competitive employment among youth on the autism spectrum who had received vocational rehabilitation services [57].

Living Arrangements

Two quantitative papers and one qualitative paper examined living arrangements. Both quantitative papers used NLTS2 data and reported that low-income and racial/ ethnic minority young adults on the autism spectrum were less likely to live independently and more likely to live with parents or guardians after high school than their White and higher income peers [50., 58.]. This result was mediated by parent expectations about independent living (i.e., parents from low-income and/or racial/ethnic minority backgrounds were less likely to expect that their child would live independently, and these parental expectations were associated with lower rates of independent living in adulthood) [50...]. The one qualitative study further elucidated cultural factors that may affect parents' beliefs about independent living. Specifically, Latina mothers of adults with disabilities reported the belief that leaving home is associated with marriage, rather than a milestone connected to age. It is therefore less expected that Latino young adults with disabilities will move outside of the family home after high school graduation [59].

Social Participation

Seven papers examined social participation. Three of these papers reported that youth on the autism spectrum from lower income households were less likely to participate in social activities, such as spending time with friends and participating in leisure activities in the community [50••, 60, 61]. One paper reported that African American youth on the autism spectrum were less likely to spend time with friends than their White peers [42]. One examination of the NLTS2 dataset found no significant associations between sociodemographic characteristics and social isolation [62]. When measured qualitatively, Latina mothers expressed strong worries about their children's growing interest in dating and sexual relationships and their ability to express these feelings appropriately [59].

Two studies reported characteristics associated with driving (which is related to independent participation in community and social activities). One paper, which used NLTS2 data, found that those who were White or above the poverty level were significantly more likely to have a driver's license than their peers [42]. A survey-based cross-sectional study of high functioning youth on the autism spectrum revealed no significant demographic differences between youth who had learned to drive and youth who were not driving [63]. This study sample was largely White and well educated and was rated low in scientific merit.

Health and Mental Health

Six papers examined outcomes related to health. Two papers, which analyzed data from a nationally representative sample, found that racial/ethnic minority and lowincome youth on the autism spectrum were significantly less likely to receive health care transition services (i.e., planning for adult providers) than their White and higher income peers on the autism spectrum [64, 65]. Racial/ethnic minority youth on the autism spectrum also reported more unmet healthcare service needs than their White peers [66]. Due to a sample size and lack of representativeness, this study was rated low in scientific merit. In contrast, a study rated low in scientific merit found that minority status was associated with significantly higher physical well-being as rated by parents of youth with ASD or intellectual disability (ID) [67]. Another study found no significant demographic differences in overall self-reported health-related transition readiness, although lower maternal education level (proxy for SES) was significantly associated with less readiness to manage medications independently [68]. Of note, only 3% of the ASD sample in this study identified as a racial/ethnic minority. In a qualitative study of Latina mothers of young adults with disabilities, lack of resources in Spanish and incongruity between health care providers' advice and families' wishes were identified as barriers to achieving health care transition goals [59]. No studies reported on transition-related disparities in mental health.



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Safety and Risk

Three papers examined outcomes related to safety and risk. In terms of prevention of risk behaviors, an analysis of the NLTS2 data showed that students with ID (with or without ASD) from lower income households were less likely than their higher income peers to receive sex education during high school [69]. Regarding involvement with the criminal justice system, another analysis of the NLTS2 data found no significant association between household income and probability of being stopped or questioned by police [70]. When measured qualitatively, Latina mothers reported safety concerns related to discrimination in the workplace and explained that protections that had been present in the school setting were no longer afforded to people with disabilities in employment settings [59].

Family Well-Being

Four papers examined family well-being. None of the papers examined data from nationally representative samples, and findings were mixed. One study found that eligibility for free or reduced lunch (a proxy for income) independently predicted reduced family quality of life scores [71]. Additionally, parents who were employed reported greater distress after the child's transition out of high school than parents who were unemployed [72]. This study was rated low in scientific merit. Another study found no significant associations between SES and change in the mother-child relationship or caregiver burden over the transition to adulthood [73]. In a qualitative study, Latina mothers reported an unequivocal lifelong responsibility to care for a child with a disability and the responsibility of another family member in the event that she is no longer able to provide care [59]. Within this cultural context, caring for a person with a disability is a family affair rather than the responsibility of the larger service system or society.

Discussion

The current systematic review examined how race, ethnicity, and/or SES relate to transition-related planning, service use, and/or outcomes in transition-aged youth on the autism spectrum. Overall, the literature indicates that there are disparities based on race, ethnicity, and SES across education, employment, living arrangements, social participation, health, safety and risk, and family well-being domains. Racial/ethnic minority and low-income youth on the autism spectrum are more likely to be disconnected from opportunities and services after high school than their White and higher income peers. Given findings that disconnection in the years following high school graduation increases risk for poverty, mental health problems, and unemployment in the general population [13–15, 74],

these disparities are also likely to set up longer-lasting negative trajectories for adults on the autism spectrum.

Although the majority of studies point to the existence of race/ethnicity- and SES-based disparities in transition-related outcomes, somewhat mixed results were found in every domain except independent living. Our findings suggest that a primary reason underlying mixed findings regarding such disparities is the use of non-representative samples. Indeed, a majority (56%) of the studies that reported no differences in transition outcomes based on race, ethnicity, or SES used samples that were not nationally representative [43, 44, 54, 63, 73]. Non-representative samples introduce an increased likelihood of drawing erroneous conclusions about the role of sociodemographic factors and other variables that systematically differ across subgroups. They also limit the generalizability of findings, which is particularly problematic in the context of research on health disparities (e.g., nonrepresentative samples have insufficient power to conduct subgroup analyses by race, ethnicity, and SES). In addition to non-representative samples limiting generalizability to specific sociodemographic groups, two additional studies had limited generalizability in other ways. Specifically, Sung et al. analyzed a sample of youth who had received vocational rehabilitation services (i.e., these youth were already connected to at least some transition-related services) [57] and Carter et al. analyzed a subset of youth from the NLTS2 dataset with severe disabilities (including but not limited to ASD) [53].

Half of the studies in this review used data from the NLTS2 dataset (data collected from 2000 to 2009). Therefore, much of our current knowledge is limited to this cohort of youth and young adults on the autism spectrum. Given the resources required to conduct a large nationally representative prospective cohort study, this pattern of publishing is not surprising. Of the papers that analyzed NLTS2 data, none received low GAP-REACH or scientific merit ratings. This demonstrates the methodological rigor of the dataset and associated analyses, and the attention paid to differences in outcomes based on sociodemographic characteristics. On the other hand, 17.5% of overall studies in this review received a low GAP-REACH score, demonstrating that group differences related to race, ethnicity, and SES were often not a primary aim of included studies. For some studies, this secondary focus of race, ethnicity, and SES also resulted in a lower scientific merit rating for these specific analyses.

Given that disparities have been documented consistently, a crucial next step for future research is to explore the mechanisms of these disparities to inform interventions and/or policy to reduce systematic differences in service access and transition outcomes [75]. Possible mechanisms of transition-related disparities for youth on the autism spectrum include system-level factors (e.g., differential access to care or systematic differences in expectations for achievement), cultural factors (e.g., preferences for education or independent living),



and individual characteristics (e.g., individual transition goals). In spite of research emphasizing the importance of examining mechanisms contributing to disparities in order to reduce inequalities [75], only one study examined mechanisms of transition-related disparities empirically. Kirby found that family background (including race/ethnicity and SES) and adaptive skills of the youth on the autism spectrum predict transition-related outcomes in the domains of employment, independent living, and social participation and that these relationships are mediated by parent expectations. In other words, sociodemographic factors interact with a youth's functional skills to shape a parent's expectation for the child's future. These parental expectations then influence the outcomes of the individual on the autism spectrum in adulthood [50••]. Given the importance of understanding mechanisms of disparities in order to effectively address them [75], mechanisms underlying disparities across the transition to adulthood in youth on the autism spectrum is a promising area for future research. A first step toward understanding mechanisms of disparities is often to employ qualitative methods. Yet, only one qualitative study was included in this review. Given the strong potential for qualitative data to contextualize quantitative findings and deepen our understanding of the processes underlying disparities, qualitative work is another important future direction.

Despite the many strengths of this review such as a comprehensive time frame based on the promulgation of federal requirements to include transition planning in school-based services for students with disabilities, integration of findings from many domains of transition to adulthood, and rigorous quality assessment, findings should be considered in light of some limitations. First, transition-related outcomes and sociodemographic predictors were operationalized in different ways across studies, which can make it difficult to combine findings. However, results were generally consistent with a conceptualization of race-, ethnicity-, and SES-based disparities regardless of how the outcomes were operationalized. This suggests that our main finding regarding transition-related disparities is even more robust. Second, to increase feasibility, our review did not include culture-specific search terms (e.g., familism). However, inclusion of broad search terms suggests that papers focused on culture in transition-aged youth likely would have been identified through full-text review. Future research should consider expanding the definition of culture to capture a broader range of group differences. Third, nine studies in this review presented outcomes for a mixed-disability sample. The same pattern of results emerged regardless of whether the samples were limited to ASD or included other disability groups but future research would benefit from specifically examining ASD samples given the unique challenges this population experiences during transition. Fourth, this review could not tease apart the distinct roles of SES and race/ethnicity (which are often correlated) in predicting various transition-related outcomes. Finally, many included studies did not contain indicators of ASD severity and/or comorbid ID, so we were not able to determine the role of these factors in predicting disparities in transition-related outcomes. Individuals with lower intellectual and adaptive functioning have a higher risk of low SES in adulthood [76], so the combined risk of sociodemographic disparities and disability-related risk is important to consider in future research.

Conclusions

In conclusion, minority racial/ethnic groups and lower income groups of transition-age youth on the autism spectrum are less likely to access and participate in transition-related services and activities than their White and higher income peers. Although some of the research is mixed in this area, the majority of evidence points to the existence of these disparities. More recent research is needed to characterize underlying mechanisms that lead to these disparities. These steps may help inform the development of interventions and/or policy that reduce these differences and lead to more equitable access to services among all groups of youth on the autism spectrum [75]. As transition to adulthood is a critical period for setting up positive life trajectories for youth on the autism spectrum that persist across the lifespan, reducing disparities during this period should be a priority for researchers and policymakers. This review provides a starting point by characterizing the nature of sociodemographic disparities in transition-related outcomes among the increasing population of youth and young adults on the autism spectrum.

Compliance with Ethical Standards

Conflict of Interest Jenna Sandler Eilenberg, Madison Paff, Ashley Johnson Harrison, and Kristin A. Long each declare that they have no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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