

Social-Ecological Correlates in Adult Autism Outcome Studies: A Scoping Review

Kristy A. Anderson, MSW,^a Anne M. Roux, MPH,^a Alice Kuo, MD, PhD,^b Paul T. Shattuck, PhD^a

abstract The transition into adulthood is a critical period in the life course that shapes later outcomes. Many adults on the autism spectrum fare poorly across a wide range of quality of life indicators. Understanding the multilevel factors that influence transition outcomes is necessary to develop strategies that promote better outcomes. In this scoping review, we characterize the use of social-ecological factors in adult autism outcome studies, identify understudied areas of research, and provide recommendations for future research. We conducted a literature search for studies in which the relationship between social-ecological factors and transition outcomes among transition-age youth with autism was assessed. We organized variables used in studies across 5 levels of influence: family-, interpersonal-, institutional-, community-, and policy-level factors. Our findings reveal that both breadth and depth of social-ecological factors usage in autism outcomes studies is limited because of the narrow inclusion of variables across social-ecological levels, the overreliance on a limited number of national data sets, and the overall lack of variation in research design. We propose 9 recommendations to inform the development of multilevel studies.

^aLife Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, Philadelphia, Pennsylvania; and ^bCenter for Healthier Children, Families and Communities, University of California, Los Angeles, Los Angeles, California

Ms Anderson conceptualized and designed the review, conducted the initial literature search, and drafted the initial manuscript; Ms Roux helped with the conceptualization and design of the review, established interrater reliability in the inclusion of the reviewed studies, and participated heavily in the interpretation and revision of the manuscript; Dr Shattuck participated in the conceptualization and interpretation of the manuscript and critically reviewed each iteration of the manuscript; Dr Kuo advised in the development of the manuscript's research question and direction, and critically reviewed the manuscript in its final form; and all authors approved the final manuscript as submitted.

DOI: <https://doi.org/10.1542/peds.2016-4300H>

Accepted for publication Sep 26, 2017

Address correspondence to Kristy A. Anderson, MSW, A.J. Drexel Autism Institute, 3020 Market St, Suite 560, Philadelphia, PA 19104. E-mail: kaa92@drexel.edu

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2018 by the American Academy of Pediatrics

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Supported by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS) under the grant UAGMC27364 and title Health Care Transitions Research Network for Youth and Young Adults with Autism Spectrum Disorders for the grant amount of \$900 000. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the US Government.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

Autism spectrum disorder (ASD) is a developmental disability characterized by social and communication impairments.¹ Each year, nearly 50 000 adolescents with autism turn 18 in the United States.² Many of these young adults will require continued supports as they transition out of special education and into community-based care; however, there are few evidence-based interventions, transition models, and adult services for them to transfer into.^{3,4} Developing innovative, effective practices requires a holistic understanding of the factors that impact transition outcomes.

Policy and practice recommendations often reveal a need for multilevel approaches to achieving positive transition outcomes.^{5–8} However, most transition interventions for youth on the autism spectrum focus primarily on altering individual-level behaviors and skills.^{3,9} Little research has been conducted to examine the social-ecological factors that may influence outcomes during and after the transition period.¹⁰ Social-ecological factors refer to a wide range of environmental influences, ranging from peer relationships and family structure to societal norms and policies, that can have a direct or distal impact on individual development.¹¹ Some researchers have conceptualized the dynamic intersection between individual behaviors and social-ecological influences during the transition into adulthood.^{5,7,12–14} Consistent with the World Health Organization's International Classification of Functioning, Disability and Health framework for understanding disability, in these models, it is recognized that outcomes are a function of the interrelationships among individual characteristics and their surrounding sociocultural environments.¹⁵ In this scoping review, we aimed to identify the ways in which researchers have used

social-ecological factors in research about young adult outcomes.

METHODS

We followed Cochrane and Arksey and O'Malley¹⁶ guidelines for conducting scoping reviews. Scoping reviews are preliminary assessments of the size and scope of available research. Their aim is to identify the nature and extent of a body of research to inform later reviews and research priorities. Unlike systematic reviews, scoping reviews typically do not have a process for assessing the quality of the included literature.

Literature Search Strategy

We searched studies published from January 1, 2005, to January 31, 2016. We considered a study to be correlational if its authors examined the relationship between 2 or more quantifiable variables.¹⁷ To be included in our review, the study had to be published in a peer-reviewed, English-speaking journal; be based on a US sample; have ASD as the primary focus or main comparison group; and have observed outcomes among transition-age youth (TAY) between the ages of 14 and 26 years. We excluded studies in which individual-level life skills (eg, vocational skills or independent living skills) or behaviors (eg, social communication and executive functioning) were the only dependent variables. All included studies had at least 1 social-ecological independent variable (defined below).

Conceptual Framework

We organized social-ecological factors into 5 levels of influence: (1) family-level factors include characteristics of households or family systems (eg, household income, parental expectations, and involvement in transition planning), (2) interpersonal-level factors describe the relationships TAY have

with nonfamily members (eg, peers, teachers, and service providers), (3) institutional-level factors refer to the nature of, participation in, and the characteristics of institutions or organizations that TAY interact with (eg, schools, health care and vocational services), (4) community-level factors describe sociodemographic features of a person's locale (eg, economic indicators and the availability of services), and (5) policy-level factors refer to rules, regulations, and laws that influence the design, availability, and delivery of services, supports, and assistance.

RESULTS

Twenty articles met inclusion criteria for this review.^{18–37} Table 1 describes sample characteristics and methodological attributes across studies. Table 2 describes the social-ecological correlates included in the reviewed research.

Sample Characteristics and Methodological Attributes

In the 20 studies reported in Table 1, 6 sources of data were used. Most were reliant on large secondary data sets. The authors of 15 studies drew from the National Longitudinal Transition Study–2,* the authors of 2 studies used the National Survey of Children with Special Health Care Needs,^{20,30} and the authors of 1 study used the Rehabilitation Services Administrative Case Services Report.²³ The authors of the remaining 2 studies directly recruited families of adults with autism.^{34,35} Sample sizes ranged from 39 to 17 818 people. The age of participants with autism ranged from 12 to 26 years, and the mean proportion of sample members who were male was 85%. The percentage of each study's participants who

* Refs 18, 19, 21, 22, 24–29, 31–33, 36, and 37.

TABLE 1 Sample and Methodological Characteristics of Correlation Studies (*n* = 20)

Author (Date)	ASD Sample, <i>N</i>	Sample Inclusion Criteria	Characteristics of Individuals With ASD			Data Set	Analytic Methods	Theory or Framework
			Age, y	% Male	% White			
Anderson et al ¹⁸ (2014)	620	Young adults who received special education services under the autism category	21–25	85	70	NLTS2 ^a	Logistic regression	NR
Bouck and Joshi ¹⁹ (2015)	Weighted, 4995	Students who had autism as a primary disability category on their IEP	14–20	95	62	NLTS2 ^a	Logistic regression	NR
Cheak-Zamora et al ²⁰ (2012)	806	Youth with ASD	12–17	78	67	2005–2006 NS-USHCN ^b	Logistic regression	NR
Chiang et al ²¹ (2012)	430	High school leavers who received special education services under the autism category	19–23	84	70	NLTS2 ^a	χ^2 ; logistic regression	NR
Chiang et al ²² (2013)	Weighted, 4116	High school leavers who received special education services under the autism category	Mean: 21	85	85	NLTS2 ^a	χ^2 ; logistic regression	NR
Cimera et al ²³ (2013)	906	Young adults with a primary or secondary diagnosis of autism who received vocational rehabilitation services and had a high school IEP	Mean: 20	84–86 (strata)	81–83	RSA-911 ^c	Trend analysis; group comparisons <i>t</i> test	NR
Griffin et al ²⁴ (2013)	320	Students with ASD who received special education services	16–20	NR	67	NLTS2 ^a	Logistic regression	NR
Kirby ²⁵ (2016)	770	Students with ASD with a district-provided diagnosis of autism and/or a parent confirmation of an autism diagnosis	13–17, first wave	83	56	NLTS2 ^a	Correlation; structural equation modeling	Expectancy-value theory of achievement motivation

TABLE 1 Continued

Author (Date)	ASD Sample, N	Sample Inclusion Criteria	Characteristics of Individuals With ASD				Data Set	Analytic Methods	Theory or Framework
			Age, y	% Male	% White	Communication Ability			
Liptak et al ²⁶ (2011)	725	Students with ASD who received special education services	17–21	82	75	Thirteen percent had no trouble, 34% had little trouble, and 39% had much trouble conversing. Fourteen percent did not converse at all.	NLTS ^{2a}	Logistic regression; structural equation modeling	World Health Organization ICF framework
Myers et al ²⁷ (2015)	Weighted, 17 818	High school leavers who received special education services under the autism category	21–26	83	73	Forty percent had no trouble, 34% had little trouble, and 24% had a lot of trouble communicating. Seventeen percent did not communicate at all.	NLTS ^{2a}	Logistic regression	NR
Narendorf et al ²⁸ (2011)	920	Students with ASD who received special education services	Mean: 15	85	65	NR	NLTS ^{2a}	Logistic regression	Andersen's behavior model
Orsmond et al ²⁹ (2013)	660	High school leavers who received special education services under the autism category	21–25	85	70	Twelve percent had no trouble, 41% had little trouble, and 30% had a lot of trouble conversing. Fourteen percent did not communicate at all.	NLTS ^{2a}	Logistic regression	NR
Rast et al ³⁰ (under review)	1119	Children with a parent-reported ASD diagnosis	12–17	NR	75	NR	NS-CSHCN ^b	Logistic regression	Andersen's behavior model
Roux et al ³¹ (2013)	620	High school leavers who received special education services under the autism category	21–25	85	70	Twelve percent had no trouble, 41% had little trouble, and 50% had much trouble conversing. Seventeen percent did not converse at all.	NLTS ^{2a}	Logistic regression	NR
Shattuck et al ³² (2011)	410	Students with ASD who received special education services	19–23	86	75	Twenty-one percent were nonverbal.	NLTS ^{2a}	Logistic regression	Life course
Shattuck et al ³³ (2012)	500	Students with ASD who received special education services	19–23	87	74	Eighteen percent had no trouble, 43% had little trouble, and 26% had a lot of trouble conversing. Thirteen percent did not converse at all.	NLTS ^{2a}	Logistic regression	NR
Taylor and Seltzer ³⁸ (2011)	66	Youth who left high school between 2004 and 2008 with an autism diagnosis validated by ADI-R scores	19–26	80	90	Eighty percent were verbal.	Longitudinal study of adolescents and adults with ASD	χ^2 ; 1-way ANOVA	NR
Taylor and Henninger ³⁵ (2015)	39	Young adults in their last year of high school with an autism diagnosis by ADOS scores	17–22	80	90	NR	Sample of young adults with ASD	Spearman ρ correlation; ordinal regression	NR

TABLE 1 Continued

Author (Date)	ASD Sample, N	Sample Inclusion Criteria	Characteristics of Individuals With ASD			Data Set	Analytic Methods	Theory or Framework	
			Age, y	% Male	% White				Communication Ability
Wei et al ³⁶ (2015)	120	High school leavers who received special education services under the autism category	Within 6 y of high school exit	87	84	Eighty-four percent had little or no trouble carrying on a conversation.	NLTS2 ^a	Life course sequence analysis; logistic regression	NR
Wei et al ³⁷ (2014)	210	College students who received special education services under the autism category	13–17, first wave	85	81	Twenty-five percent had no trouble, 55% had little trouble, and 20% had a lot of trouble communicating or did not communicate at all.	NLTS2 ^a	Logistic regression	NR

ADI-R, Autism Diagnostic Interview, Revised; ADOS, Autism Diagnostic Observation Schedule; ANOVA, analysis of variance; ICF, International Classification of Functioning, Disability and Health; IEP, individualized education plan; NLTS2, National Longitudinal Transition Survey-2; NR, not reported; NS-CSHCN, National Survey of Children with Special Health Care Needs; RSA-911, Rehabilitation Service Administration Case Service Report.

^a The authors of the NLTS-2 manage a nationally representative sample of high school students who received special education services in 2000 over a 10-y period. Data were collected from 2001 to 2009.

^b NS-CSHCN is a national survey of parents of children, ages 0 to 17 y, with special health care needs.

^c The RSA-911 collects administrative data on all individuals who applied for and received vocational rehabilitation services in a given year.

were white ranged from 56% to 90% (mean = 74%).

The vast majority of study authors used logistic regression to examine the association of independent variables on transition outcomes. The authors of only 2 studies examined moderating or mediating mechanisms.^{25,26} The authors of 2 studies used structural equation modeling,^{25,26} and the authors of 1 study employed sequence analysis.³⁶ The authors of 2 studies observed individual transition outcomes across multiple time points.^{36,37} Although the authors of 6 studies referenced some theoretical orientation or conceptual framework,^{18,25,26,28,30,32} authors explicitly used that theory or framework to inform which factors to include in the analytical model in only 4 studies.^{25,26,28,30}

Social-Ecological Correlates

Family Level

The authors of 19 studies assessed family level variables, which included household and/or parent income ($n = 19$),^{18–22,24–37} parent education ($n = 6$),^{20–22,25,26,37} parent expectations ($n = 3$),^{21,22,25} parent satisfaction with services ($n = 2$),^{20,21} parent involvement ($n = 5$),^{20–22,24,28} family composition ($n = 3$),^{20,26,30} and family support ($n = 1$).²⁶ The relationship between family-level variables (such as household and/or parent income and parents' education) and transition outcomes varied across studies.

Parent income was the most common social-ecological correlate. Higher parent income was positively linked to living independently¹⁸ and youth participation in transition planning.²⁴ Some study authors found a positive relationship between parent income and postsecondary employment, educational attainment, and social engagement,^{19,21,22,25–27,31,33,36} whereas others found no significant association.^{19,27,29,34,36,37} Lower parent income was associated with decreased access to services.^{30,32}

TABLE 2 Social-Ecological Predictors of Postsecondary Outcomes in Correlation Studies (*n* = 20)

Author (Date)	Predictor Variables				Policy	Dependent Variables
	Family	Interpersonal	Institutional	Community		
Anderson et al ¹⁸ (2014)	Household income	—	—	—	—	Independent living
Bouck and Joshi ¹⁹ (2015)	Household income	—	High school urbanicity	—	—	PSE, employment
Cheak-Zamora et al ²⁰ (2012)	Family federal poverty level, highest education in family household, 2-parent household, family involvement and/or satisfaction in health care decision-making	—	—	—	—	Health care transition
Chiang et al ²¹ (2012)	Household income, parent education, parent expected child to participate in PSE, parent satisfaction with high school services, parent met with teachers to set the child's postgraduation goals, parent felt the child's transition goals were challenging and appropriate	—	Information about services after high school was available to parent, school contacted PSE institution, representative of PSE institution participated in transition planning, high school urbanicity	—	—	PSE
Chiang et al ²² (2013)	Household income, parent education, parent attended TP, parent expected child would participate in postsecondary employment, parent met with teachers to set the child's postgraduation goals	—	School contacted postsecondary vocational training programs or potential employers	—	—	Employment
Cimera et al ²³ (2013)	—	—	—	—	States require transition to be addressed by age 14 or 16 y	Employment
Griffin et al ²⁴ (2013)	Household income, discussion of transition at home, frequency of parent's school involvement	—	—	—	—	Transition planning
Kirby ²⁵ (2016)	Household income, mother's education, parent expected that youth will have a paid job in the future, parent expected that youth will live independently in the future	—	—	—	—	Employment, independent living, friendships
Liptak et al ²⁶ (2011)	Household above poverty level, education of head of household, 2-parent household, family support scale, parent involvement with school	Teased at school	—	—	—	Employment or PSE, friendships
Myers et al ²⁷ (2015)	Household income	—	High school urbanicity	—	—	Community engagement, friendships
Narendorf et al ²⁸ (2011)	Household income, parent attended transition planning	Youth was bullied, youth bullied others	—	—	—	Services

TABLE 2 Continued

Author (Date)	Predictor Variables				Dependent Variables	
	Family	Interpersonal	Institutional	Community		Policy
Orsmond et al ²⁹ (2013)	Household income	—	—	—	—	Friendships
Rast et al ³⁰ (under review)	Household income, primary language spoken at home, household composition, No. children in home, No. children with SHCNs in home	—	—	—	—	Health care transition
Roux et al ³¹ (2013)	Household income	—	—	—	—	Employment Services
Shattuck et al ³² (2011)	Household income	—	—	—	—	PSE and employment
Shattuck et al ³³ (2012)	Household income	—	—	—	—	Employment, PSE, services
Taylor and Seltzer ³⁴ (2011)	Household income	—	—	—	—	Services
Taylor and Henninger ³⁵ (2015)	Household income, parental health, parental depressive symptoms, parental anxiety	—	—	—	—	Employment, PSE
Wei et al ³⁶ (2015)	Household income	—	—	—	—	PSE
Wei et al ³⁷ (2014)	Household income, parent education	—	—	—	—	—

PSE, postsecondary education; SHCN, special health care need; TP, transition planning; —, not applicable.

Parental educational attainment was significantly associated with youth postsecondary education attendance^{21,37} and employment^{22,25} but not with independent living or friendships.²⁵

Parent expectations and involvement in transition planning were positively associated with postsecondary education attendance,^{21,25,26} employment,^{22,25,26} independent living,²⁵ and friendships.²⁵ The odds of receiving health care transition services were higher if parents were involved in decision-making and satisfied with their child's health care.²⁰

Interpersonal Level

Bullying was the only interpersonal factor assessed across studies. TAY who were bullied or teased in high school had higher odds of mental health service use²⁸ and lower odds of postsecondary employment than their peers who were not bullied.²⁶ None of the authors of studies included in this review examined the quality or nature of social interactions or social networks among TAY and nonfamily members.

Institutional Level

Institutional-level factors included high school urbanicity ($n = 3$),^{19,21,27} contact between the high school and postsecondary institution staff during transition planning ($n = 2$),^{21,22} and whether a student's high school provided families with information about postsecondary services ($n = 1$).²¹ Postsecondary outcomes did not vary by high school urbanicity.^{19,21,27} TAY had higher odds of postsecondary employment if their high school contacted a vocational rehabilitation representative during transition planning.²² However, contact between high schools and postsecondary education institutions (eg, a 2- or 4-year college or vocational and/or technical school) was not a significant predictor of postsecondary education attendance.²¹

Community and Policy Levels

No study authors examined community-level factors. The authors of 1 study examined the impact of policy on transition outcomes and found that postsecondary employment was higher among residents of states that mandated transition planning by age 14, as opposed to age 16.²³

DISCUSSION

In this study, we characterized the use of social-ecological factors in TAY autism outcome studies. Overall, the authors of few studies examined social-ecological factors and none examined community-level factors. The range of factors examined was limited, and the explicit use of theory or conceptual frameworks to inform study design and analyses was rare. Although most health and allied fields train researchers in social-ecological and systems theories of human development, few study authors actually employed ideas and measures that allowed us to understand the context for development and outcomes of TAY on the autism spectrum. As a result, most studies and recommendations focused on measuring and intervening on individual-level factors without regard to social-ecological context.

Research Recommendations

Family Level

Because of our findings, we suggest that TAY from high-income households have better transition outcomes and access to services. Families with more disposable income may be more likely to be able to pay for educational enrichment activities, services, and college,³⁹ without needing public funding.⁴⁰ Alternatively, more affluent families may also have more developed and effective social networks and greater social capital, which

can be associated with improved outcomes. Little work has examined the role of family advocacy or preparedness for transition may have on later outcomes. Our first research recommendation is to expand the range of modifiable family-level factors examined as possible predictors of outcomes and understand programs and policies that might strengthen family capacity, regardless of household income (a variable that is relatively immutable).

Parental involvement in transition planning had a positive effect on postsecondary outcomes. However, this relationship was only examined in high school settings. This is a critical gap in the literature considering that transition extends well into the post-high school years. Moreover, none of the study authors examined sources of support for families and caregivers. A review of qualitative research studies revealed that parents, TAY, and professionals had discrepant views regarding the role of parental involvement after high school.⁴¹ In recent decades, it has become more common for TAY (with and without disabilities) to rely on their parents for support in early adulthood. Indeed, continued parental support can increase one's chances for success.³⁹ However, overreliance on parents could also prevent TAY from attaining the skills that are necessary for independence in adulthood. Our second research recommendation is to examine the role of parents in the continued transition to adulthood period and identify the family supports needed to ensure a successful transition.

No study authors examined how interpersonal relationships within families affected transition outcomes. This is a noticeable gap in the literature, considering that parent criticism has been found to increase maladaptive behaviors among adults

with autism.^{42,43} Moreover, study authors have also shown that the quality of parent-child relationships can change during the transition into adulthood.^{38,44} Our third research recommendation is to examine the interrelationships among family context, family-systems, and adult outcomes.

Interpersonal Level

The studies included in this review were focused on the direct effects of peer rejection and social impairment on postsecondary outcomes. Little is known of the social support networks of TAY with autism or how those networks may contribute to positive transition outcomes. Nonfamily members (such as peers, service providers, and employers) offer support and resources that are critical during the transition into adulthood. Through these relationships, TAY receive emotional support, develop new skills, and build social capital.⁴⁵ Our fourth research recommendation is to examine the influence of peer relationships and social networks on postsecondary outcomes.

Institutional Level

Most study authors did not include institutional-level factors. Interagency communication and collaboration are often considered paramount to effective service delivery and transition planning.⁴⁶ None of the authors of the reviewed research examined how adult service systems interact with one another after high school exit. This is a critical gap in the literature, considering that parents often describe the adult service system as fragmented and inconsistent.⁴¹ Our fifth research recommendation is to characterize the quality of service delivery systems and their supports to identify modifiable targets for policy intervention.

No study authors examined the climate of relevant settings like

colleges, the workplace, and high school. TAY with autism have described several aspects of the college and working environment as important to transition success,⁴¹ including awareness and acceptance of disability, flexible scheduling, and the knowledgeable ability of employers and faculty.^{47,48} Our sixth research recommendation is to examine how the organizational climate and related characteristics are associated with outcomes and how implementation research and delivery science can be used to modify these features of organizations.

Community Level

The authors of studies on neighborhood effects have established that the area in which an individual lives, works, and plays shapes individual outcomes.⁴⁹ Researchers in child and adolescent development consistently show that neighborhood disadvantage negatively affects school readiness and achievement.⁵⁰ Parents of TAY with autism have also reported that many services were not provided in a geographic area or were not convenient or accessible.³⁵ Other factors (like the number of job openings and community views of disability) may also contribute to the experiences and outcomes of TAY. Including descriptive variables, such as those drawn from census tracts or through geocoding, or TAY's subjective appraisals of neighborhood quality may help to identify which neighborhood factors are important to transition success. Our seventh research recommendation is to adapt established methods from public health to examine the influence of neighborhood and community factors on TAY outcomes.

Policy Level

The authors of only 1 study examined the correlation between policy factors and transition outcomes.²³ This is a

critical gap in the autism literature, considering the United States spends roughly \$130 billion annually on services for people with autism.⁵¹ In addition to the reviewed study about state-mandated transition policies,²³ research on children with special health care needs⁵² has also revealed how we can learn policy-relevant lessons by comparing outcomes across states. Our eighth research recommendation is to examine how mutable policy factors are associated with variability in TAY outcomes.

Changing trends in the labor market also have important implications for people with autism. For example, many of the job losses during the 2007–2009 recession were in occupational classifications in which people with autism are most frequently employed,^{31,53} such as transportation and utilities and clerical occupations.⁵⁴ Over the past several decades, the labor market has also shifted from a production industry to a service-based industry. The greatest projected growth in job opportunities are either in occupations that require a college degree⁵⁵ or are low-paid service jobs.^{55,56} However, study authors suggest that many TAY with autism work in low-skilled, low-paying jobs.³¹ Our ninth research recommendation is to examine how occupational structures and other economic factors influence transition outcomes.

Methodological Considerations

Most study authors in this review failed to fully capture the dynamic intersections between individuals and their social-ecological environment because of a limited inclusion of variables across levels, an overreliance on a limited number of national data sets, and an overall lack of variation in research design. The design of future national surveys should include variables that allow for a rich understanding of social-ecological factors.

The use of social network analysis also has the potential to address several gaps in the research. Findings from other large data sets, such as the Adolescent Health Survey, include network questions in their survey instrument. Findings from these analyses were used to help characterize the size and quality of TAY social networks.⁵⁷

Finally, future researchers should emphasize longitudinal data collection. The authors of long-term studies of adults with autism have provided valuable insights into the trajectories of adult development,^{58,59} but few population-level studies have conducted long-term follow-up on postsecondary outcomes. The transition into adulthood is marked by rapid changes in social roles and participation in institutions. Many TAY cycle in and out of jobs, return home after living independently, and take time off school. Therefore, study authors who rely on a single observation period to determine the prevalence of postsecondary outcomes may produce biased estimates.

Additionally, some study authors used a dichotomous measure of having ever had a job, attended higher education, or lived independently since leaving high school. Although these measures can be used to help to capture the presence of outcomes across a longer period of time, they fall short when used to characterize issues like the fit among personal aspirations, abilities, and outcomes. A part-time job in the service industry might represent a winning outcome for 1 person but underemployment for someone with different abilities and aspirations.

Limitations

The goal of this article was to examine the breadth of available research on social-ecological

correlates. Therefore, we did not base our inclusion criteria on the quality or rigor of the research study. It is also important to acknowledge that correlation studies are not used to explain causal relationships. Some relationships among constructs may be bidirectional.

CONCLUSIONS

Overall, there is scant research about the social-ecological factors that affect transition outcomes for TAY with autism in correlation research. The majority of the social-ecological correlates included in this review operated at the family and institutional levels. Interpersonal, community, and policy factors were generally excluded in the research. Additionally, because of a limited range of analytic methods, the majority of studies focused on direct effects rather than intervening mechanisms, hindering the understanding of the interrelationships of factors across ecological levels.

ABBREVIATIONS

ASD: autism spectrum disorder
TAY: transition-age youth

REFERENCES

- American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: American Psychiatric Publishing; 2013
- Shattuck PT, Roux AM, Hudson LE, Taylor JL, Maenner MJ, Trani J-F. Services for adults with an autism spectrum disorder. *Can J Psychiatry*. 2012;57(5):284–291
- Taylor JL, Dove D, Veenstra-VanderWeele J, et al. *Interventions for Adolescents and Young Adults With Autism Spectrum Disorders*. Rockville, MD: Agency for Healthcare Research and Quality; 2012
- Rogers K, Zeni MB. Systematic review of medical home models to promote transitions to primary adult health care for adolescents living with autism spectrum disorder. *Worldviews Evid Based Nurs*. 2015;12(2):98–107
- Aspel N, Bettis G, Quinn P, Test DW, Wood WM. A collaborative process for planning transition services for all students with disabilities. *Career Dev Transit Except Individ*. 1999;22(1):21–42
- Schwartz LA, Tuchman LK, Hobbie WL, Ginsberg JP. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child Care Health Dev*. 2011;37(6):883–895
- Halpern AS. A systems change approach to improving secondary special education and transition programs at the community level. *Career Dev Transit Except Individ*. 1992;15(1):109–120
- King GA, Baldwin PJ, Currie M, Evans J. Planning successful transitions from school to adult roles for youth with disabilities. *Child Health Care*. 2005;34(3):193–216
- Taylor JL, McPheeters ML, Sathe NA, Dove D, Veenstra-Vanderweele J, Warren Z. A systematic review of vocational interventions for young adults with autism spectrum disorders. *Pediatrics*. 2012;130(3):531–538
- Hendricks DR, Wehman P. Transition from school to adulthood for youth with autism spectrum disorders: review and recommendations. *Focus Autism Other Dev Disabl*. 2009;24(2):77–88
- Bronfenbrenner U. *Ecological Systems Theory*. London, United Kingdom: Jessica Kingsley Publishers; 1992
- Dente CL, Coles KP. Ecological approaches to transition planning for students with autism and Asperger's syndrome. *Child Schools*. 2012;34(1):27–36
- Morgan RL, Schultz JC. Towards a multi-modal, ecological approach to increase employment for young adults with autism spectrum disorder. *J Appl Rehabil Counsel*. 2012;43(1):27–35
- Cobb RB, Alwell M. Transition planning/ coordinating interventions for youth with disabilities: a systematic review. *Career Dev Transit Except Individ*. 2009;32(2):70–81
- World Health Organization. *International Classification of Functioning, Disability and Health: ICF*. Geneva, Switzerland: World Health Organization; 2001
- Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005;8(1):19–32
- Gay LR, Mills GE, Airasian PW. *Educational Research: Competencies for Analysis and Applications*. London, United Kingdom: Pearson Higher Education; 2011
- Anderson KA, Shattuck PT, Cooper BP, Roux AM, Wagner M. Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism*. 2014;18(5):562–570
- Bouck EC, Joshi GS. Does curriculum matter for secondary students with autism spectrum disorders: analyzing the NLTS2. *J Autism Dev Disord*. 2015;45(5):1204–1212
- Cheak-Zamora NC, Yang X, Farmer JE, Clark M. Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics*. 2013;131(3):447–454
- Chiang H-M, Cheung YK, Hickson L, Xiang R, Tsai LY. Predictive factors of participation in postsecondary education for high school leavers with autism. *J Autism Dev Disord*. 2012;42(5):685–696
- Chiang H-M, Cheung YK, Li H, Tsai LY. Factors associated with participation in employment for high school leavers with autism. *J Autism Dev Disord*. 2013;43(8):1832–1842
- Cimera RE, Burgess S, Wiley A. Does providing transition services early enable students with ASD to achieve better vocational outcomes as adults? *Res Pract Persons Severe Disabl*. 2013;38(2):88–93
- Griffin MM, Taylor JL, Urbano RC, Hodapp RM. Involvement in transition planning meetings among high school students with autism spectrum disorders. *J Spec Educ*. 2013;47(4):256–264

25. Kirby AV. Parent expectations mediate outcomes for young adults with autism spectrum disorder. *J Autism Dev Disord*. 2016;46(5):1643–1655
26. Liptak GS, Kennedy JA, Dosa NP. Social participation in a nationally representative sample of older youth and young adults with autism. *J Dev Behav Pediatr*. 2011;32(4):277–283
27. Myers E, Davis BE, Stobbe G, Bjornson K. Community and social participation among individuals with autism spectrum disorder transitioning to adulthood. *J Autism Dev Disord*. 2015;45(8):2373–2381
28. Narendorf SC, Shattuck PT, Sterzing PR. Mental health service use among adolescents with an autism spectrum disorder. *Psychiatr Serv*. 2011;62(8):975–978
29. Orsmond GI, Shattuck PT, Cooper BP, Sterzing PR, Anderson KA. Social participation among young adults with an autism spectrum disorder. *J Autism Dev Disord*. 2013;43(11):2710–2719
30. Rast JE, Shattuck PT, Roux AM, Anderson KA, Kuo A. The medical home and health care transition for youth with autism. *Pediatrics*. 2018;141(s4):e20164300J
31. Roux AM, Shattuck PT, Cooper BP, Anderson KA, Wagner M, Narendorf SC. Postsecondary employment experiences among young adults with an autism spectrum disorder. *J Am Acad Child Adolesc Psychiatry*. 2013;52(9):931–939
32. Shattuck PT, Wagner M, Narendorf S, Sterzing P, Hensley M. Post-high school service use among young adults with an autism spectrum disorder. *Arch Pediatr Adolesc Med*. 2011;165(2):141–146
33. Shattuck PT, Narendorf SC, Cooper B, Sterzing PR, Wagner M, Taylor JL. Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*. 2012;129(6):1042–1049
34. Taylor JL, Seltzer MM. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *J Autism Dev Disord*. 2011;41(5):566–574
35. Taylor JL, Henninger NA. Frequency and correlates of service access among youth with autism transitioning to adulthood. *J Autism Dev Disord*. 2015;45(1):179–191
36. Wei X, Wagner M, Hudson L, Yu JW, Shattuck P. Transition to adulthood employment, education, and disengagement in individuals with autism spectrum disorders. *Emerg Adulthood*. 2015;3(1):37–45
37. Wei X, Christiano ER, Yu JW, Blackorby J, Shattuck P, Newman LA. Postsecondary pathways and persistence for STEM versus non-STEM majors: among college students with an autism spectrum disorder. *J Autism Dev Disord*. 2014;44(5):1159–1167
38. Taylor JL, Seltzer MM. Changes in the mother-child relationship during the transition to adulthood for youth with autism spectrum disorders. *J Autism Dev Disord*. 2011;41(10):1397–1410
39. Semyonov M, Lewin-Epstein N. The impact of parental transfers on living standards of married children. *Soc Indic Res*. 2001;54(2):115–137
40. Cooper ER. *Medicaid Residential Options for People With Autism and Other Developmental Disabilities*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services; 2012
41. Anderson KA, Sosnowy CD, Kuo A, Shattuck PT. Factors that shape the transition into adulthood: a review of qualitative studies in autism research. *Autism Treatment and Research*. In press.
42. Baker JK, Smith LE, Greenberg JS, Seltzer MM, Taylor JL. Change in maternal criticism and behavior problems in adolescents and adults with autism across a 7-year period. *J Abnorm Psychol*. 2011;120(2):465–475
43. Greenberg JS, Seltzer MM, Hong J, Orsmond GI. Bidirectional effects of expressed emotion and behavior problems and symptoms in adolescents and adults with autism. *Am J Ment Retard*. 2006;111(4):229–249
44. Lounds J, Seltzer MM, Greenberg JS, Shattuck PT. Transition and change in adolescents and young adults with autism: longitudinal effects on maternal well-being. *Am J Ment Retard*. 2007;112(6):401–417
45. Schall CM, McDonough JT. Autism spectrum disorders in adolescence and early adulthood: characteristics and issues. *J Vocat Rehabil*. 2010;32(2):81–88
46. Kohler PD. Best practices in transition: substantiated or implied? *Career Dev Transit Except Individ*. 1993;16(2):107–121
47. Giarelli E, Ruttenberg J, Segal A. Bridges and barriers to successful transitioning as perceived by adolescents and young adults with Asperger syndrome. *J Pediatr Nurs*. 2013;28(6):563–574
48. Camarena PM, Sarigiani PA. Postsecondary educational aspirations of high-functioning adolescents with autism spectrum disorders and their parents. *Focus Autism Other Dev Disabl*. 2009;24(2):115–128
49. Diez Roux AV. Neighborhoods and health: where are we and where do we go from here? *Rev Epidemiol Sante Publique*. 2007;55(1):13–21
50. Jones C, Jing S. Neighborhood social capital, neighborhood disadvantage, and change of neighborhood as predictors of school readiness. *Urban Stud Res*. 2014:204583
51. Buescher AV, Cidav Z, Knapp M, Mandell DS. Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatr*. 2014;168(8):721–728
52. Parish SL, Shattuck PT, Rose RA. Financial burden of raising CSHCN: association with state policy choices. *Pediatrics*. 2009;124(suppl 4):S435–S442
53. Fogg NP, Harrington PE, McMahon BT. The impact of the Great Recession upon the unemployment of Americans with disabilities. *J Vocat Rehabil*. 2010;33(3):193–202
54. Lockard CB, Wolf M. Occupational employment projections to 2020. *Mon Labor Rev*. 2012;135(1):85–108
55. Roberts K. Opportunity structures then and now. *J Educ Work*. 2009;22(5):355–368

56. Danziger S, Ratner D. Labor market outcomes and the transition to adulthood. *Future Child*. 2010;20(1):133–158
57. Carbonaro W, Workman J. Intermediate peer contexts and educational outcomes: do the friends of students' friends matter? *Soc Sci Res*. 2016;58:184–197
58. Seltzer MM, Shattuck P, Abbeduto L, Greenberg JS. Trajectory of development in adolescents and adults with autism. *Ment Retard Dev Disabil Res Rev*. 2004;10(4):234–247
59. Woodman AC, Smith LE, Greenberg JS, Mailick MR. Contextual factors predict patterns of change in functioning over 10 years among adolescents and adults with autism spectrum disorders. *J Autism Dev Disord*. 2016;46(1):176–189

Social-Ecological Correlates in Adult Autism Outcome Studies: A Scoping Review

Kristy A. Anderson, Anne M. Roux, Alice Kuo and Paul T. Shattuck

Pediatrics 2018;141;S306

DOI: 10.1542/peds.2016-4300H

Updated Information & Services

including high resolution figures, can be found at:
http://pediatrics.aappublications.org/content/141/Supplement_4/S306

References

This article cites 51 articles, 4 of which you can access for free at:
http://pediatrics.aappublications.org/content/141/Supplement_4/S306#BIBL

Permissions & Licensing

Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:
<http://www.aappublications.org/site/misc/Permissions.xhtml>

Reprints

Information about ordering reprints can be found online:
<http://www.aappublications.org/site/misc/reprints.xhtml>

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Social-Ecological Correlates in Adult Autism Outcome Studies: A Scoping Review

Kristy A. Anderson, Anne M. Roux, Alice Kuo and Paul T. Shattuck

Pediatrics 2018;141;S306

DOI: 10.1542/peds.2016-4300H

The online version of this article, along with updated information and services, is located on the World Wide Web at:

http://pediatrics.aappublications.org/content/141/Supplement_4/S306

Pediatrics is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. Pediatrics is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2018 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

