Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies

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abstract   Many young adults with autism spectrum disorder experience poor transition outcomes in key areas, including postsecondary employment, higher education, health care, social connectedness, and independent living, yet we lack a clear understanding of the specific factors that impact these outcomes. We reviewed qualitative research in which the perspectives of youth and young adults with autism spectrum disorder, parents, services providers, and other stakeholders were gathered to identify barriers and facilitators to optimal outcomes. Findings revealed that poor transition outcomes are influenced by several factors, including poor person-environment fit, uncertainty about the roles of parents, and the lack of comprehensive or integrated services. These findings also revealed the aspects of familial, organizational, and policy contexts that may be targeted for interventions. Finally, stakeholders emphasized that supports should be individualized and focused on the changing aspects of the young adult's social and physical environment rather than behavior change. We discuss implications for policy and practice and provide recommendations for further research.

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An estimated 1 in 68 children in the United States meet diagnostic criteria for autism spectrum disorder (ASD), a lifelong neurodevelopmental condition characterized by difficulties in social communication and the presence of repetitive or restrictive behavior patterns.[1] Approximately 50 000 people with ASD age into adulthood each year,[2] and a majority experience poor postsecondary outcomes across multiple domains, including employment, education, health care, social engagement, and independent living.[3] Although poor outcomes after high school are a concern themselves, they also increase the risk for poor individual outcomes in later life.[4,5]

The growing prevalence of young adults with ASD has lent urgency to efforts to improve transition programs and supports.[6] Researchers in quantitative studies have established an evidence base documenting poor outcomes and identified a range of contributing factors, including a lack of financial resources,[7] low parent expectations and involvement,[8,9] and poor interagency collaboration between high schools and adult service providers.[9] A more in-depth understanding of the needs of transitioning youth and their families, the strategies they employ to achieve desired outcomes, and the availability and efficacy of supports and services can inform program development. Qualitative research in which the perspectives of stakeholders are directly solicited is uniquely suited to understanding the mechanisms contributing to poor outcomes. In this scoping review, we synthesize findings from published qualitative research about the transition to adulthood to discuss implications for practice and provide recommendations for future research.

METHODS

In this scoping review, we synthesized original qualitative research studies aimed at describing the transition experiences of youth and young adults with ASD. The scoping review is a useful approach to mapping research evidence about a broad or emerging topic area. Unlike systematic reviews, scoping reviews typically do not use quality-assessment tools to exclude research studies.[10] The lead author searched electronic databases for articles published between January 2000 and December 2015 that met the following criteria: (1) a primary focus on youth or young adults with an ASD; (2) used qualitative methods to understand the perspectives of stakeholders (youth or young adults with autism, families, and support professionals, such as college faculty and health care providers); and (3) a primary aim of describing supports, services, or policies for youth or young adults with ASD in the areas of postsecondary education, employment, independent living, social engagement, and health care. We included only peer-reviewed studies conducted in the United States and excluded reviews of research. We chose to limit our review to studies conducted in the United States because the transition experiences of youth and their families, services, and policies may vary significantly across contexts. Seventeen articles met the criteria for inclusion.

We employed thematic analysis techniques to synthesize and analyze this body of research. Thematic analysis is a method for identifying, analyzing, and reporting patterns within data[11] qualitative research. Concurrent with our appraisal, we extracted the following information: (1) sampling, including sample characteristics, the sampling frame, and sampling approach; (2) data collection, including the mode of administration and instrument development; and (3) analysis, including analytical approach, rigor, and reporting (Table 1).[12,13]

RESULTS

Study Characteristics

Studies were focused on several areas related to transition, including high school transition planning,[22,24] postsecondary education,[14,15,20,26,28,29] employment,[21,23,27] health care delivery,[16,25,30] and the general transition to adulthood.[17–19] Some studies were specifically focused on the challenges of transition for young adults with autism,[15,17,19] whereas others examined the transition experiences of young adults and their families more broadly.[16,18,23,27,28] Five studies were focused on service transitions and used stakeholders' perspectives to help inform the development of a specific intervention[22,24] or describe the quality and availability of existing services in colleges.[14,26,29] Researchers in other studies asked employers,[21] health care professionals,[25,30] and college faculty[20] to describe the promising strategies they use to help facilitate optimal outcomes for young adults with autism.

The total sample across all 17 research studies included 121 individuals with autism, 186 parents or caregivers, and 192 professionals. Two studies were focused exclusively on the views of parents,[26,28] 2 studies were focused on adolescents or young adults on the autism spectrum,[14,19] and 4 studies included the perspectives of both parents and their children on the autism spectrum.[15–17,23] Researchers in 3 studies elicited the views of all 3 stakeholder groups.[18,22,24] Researchers in the remaining 6 studies collected the views of college faculty,[20] college disability student services staff,[29] employers,[21] vocational service providers,[27] or health care professionals.[25,30] Across the 12 studies in which youth or young adults with autism were sampled, the mean proportion of

TABLE 1 Aims, Methodological Characteristics, and Key Findings of Qualitative Views Studies

Author (Date)	Aims	Recruitment and Sample Characteristics	Data Collection and Analysis	Key Findings
Briel and Getzel[14] (2014)	To describe college students' experiences in career planning and preparation, the use of campus services and supports, and their satisfaction with these services	Seventeen matriculating postsecondary-level students with ASD who were receiving supports and services related to their disability, ages 18–43 y	Structured face-to-face interview and short-answer questionnaire; analysis plan not reported	College career centers were the least likely source for information and support. Students were acutely aware of their limitations in social situations and the impact of their limitations in the work environment. Students expressed a need for more experiential learning opportunities and a desire to gain a better understanding of what accommodations they could request.
Camarena and Sarigiani[15] (2009)	To assess the postsecondary educational aspirations and thoughts concerning obstacles and resources that shape educational achievement	Recruited through a network of contacts provided by special education administrators and community support groups: 21 youth with ASD or AS, ages 12–19 y; 20 mothers; and 13 fathers	Face-to-face interviews with open- and close-ended questions: content analysis	Both adolescents and their parents have clear postsecondary educational goals but have significant concerns about the readiness of postsecondary institutions to meet the adolescents' needs. Key members must be trained and clearly identified as a resource for students. Specific social supports need to be built into the lives of students with ASD.
Cheak-Zamora and Teti[16] (2015)	To examine the health care transition experiences of youth with ASD and their caregivers	Flyers posted in clinics and mailers were sent to addresses from clinic participant listservs: 13 youth with ASD, ages 15–22 y, and 19 caregivers	Semistructured focus groups: thematic analysis	Parents' discussion emphasized the loss of the relationship with providers, the lack of support in transitioning from pediatric to adult care, providers' lack of knowledge about ASD, and concerns about losing guardianship. Youth emphasized their confusion and anxiety around medical providers' role, especially in the transition to adulthood, and managing their medical lives independently.
Cheak-Zamora et al[17] (2015)	To examine the social, educational, and vocational needs of youth with ASD during their transition into adulthood	Flyers posted in clinics and mailers were sent to addresses from clinic participant listservs: 13 youth with ASD, ages 15–22 y, and 19 caregivers	Semistructured focus groups: grounded theory	Both caregivers and youth experienced fear and anxiety about transitioning. Unmet service needs were high, leaving caregivers struggling to fill gaps. Most caregivers and youth reported lacking individualized services. Caregivers faced difficulty in motivating youth and creating opportunities for education and employment. Although youth have future goals, they were unaware of the steps needed to accomplish them and were hesitant to talk to caregivers.
Giarelli and Fisher[18] (2013)	To describe the movement out of secondary school to independent living or higher education	Thirteen youth with AS, ages 18–23 y; 13 parents; 5 high school teachers; 5 high school teachers who instructed someone with ASD; and 5 employers who have hired or supervised individuals in a company or business in the area	Audiotaped interviews: constant comparison, grounded theory, and symbolic interactionism	The core psychosocial problem of transitioning to the community is the need to have a steady lifestyle. Adolescents, with the support of parents, teachers, and sympathetic employers, solved this problem using 3 psychosocial processes: structuring (ie, the planned reorganization of situational factors to positively influence the adolescent's ability to transition), anchoring (ie, the attachment to another person as the source of security, stability, and personal connection), and embarking (ie, moving under one's own power in the direction of a self-identified, realistic goal).
Giarelli et al[19] (2013)	To examine the expectations, facilitators of, and barriers to attending college, vocational training, or finding paid employment	Recruited through 2 major support networks that served people with AS: 16 youth with AS, ages 18–23 y	In-depth, semistructured, telephone interviews with a demographic questionnaire: thematic content analysis	Perceived barriers were as follows: self-assessed behavioral problems (ie, the inability to socialize comfortably, "getting stuck," and the inability to make casual conversation); self-assessed, associated features (ie, limited attention span and focus, anxiety, and unstable mood and meltdowns); other personal factors (ie, perceived low self-image, difficulties in motor control, and lack of motivation); and institutional factors (ie, inflexibility of the environment, inadequate orientation for an experience, and co-worker negativity). Bridges to facilitate the transition were as follows: accommodations in the community, cognitive abilities, personal qualities and/or strengths, and mentor qualities.
Gobbo and Shmulsky[20] (2014)	To identify faculty viewpoints on the academic strengths and weaknesses of college students with ASD and effective instructional practices for them	Faculty recruited through a university that serves people with ASD: 18 faculty who have taught at least 1–2 students with ASD	Seven focus groups: analysis plan not reported	Results were grouped into 3 broad categories: academic challenges for students with ASD (ie, social skill deficits, critical-thinking challenges, and anxiety), academic strengths (ie, passionate interests, desire to be right, and adherence to rules), and promising instructional approaches (ie, provide structure and attend to the emotional climate).

TABLE 1 Continued

Author (Date)	Aims	Recruitment and Sample Characteristics	Data Collection and Analysis	Key Findings
Hagner and Cooney[21] (2005)	To locate individuals with autism who were successfully employed at jobs in the community and begin to identify factors that contributed to their success	Community rehabilitation service provider organizations and parent support groups for people with ASD identified successful cases for the researchers: 14 supervisors, 11 co-workers, and 9 job coaches or disability agency staff person.	Semistructured interviews and 10 participant observations: analytic induction	Supervisors evaluated their employees highly. Supervisory accommodation strategies that were commonly associated with successful supervision included maintaining a consistent schedule and set of job responsibilities, using organizers to structure the job, reducing idle or unstructured time, being direct when communicating with the employee, and providing reminders and reassurances. Supervisors believed that the assistance that the individual received from a rehabilitation agency was critical to successful employment.
Hedges et al[22] (2014)	To analyze multiple stakeholder perspectives on challenges impacting the success of students with ASD in high school	E-mails to listservs of community organizations and university education and related departments, distribution of flyers to local businesses, and snowball sampling through targeted contact with school autism specialists in area high schools: 5 adults with ASD, ages 15–40 y; 10 parents; and 26 school personnel	Focus groups: analysis plan not reported	Three themes demonstrate the misalignment that exists between the nature of high school and the needs of students with ASD as they prepare for success in postsecondary environments: (1) inconsistencies, many of which are intrinsic to the secondary environment; (2) difficulties with interpersonal connections; and (3) knowledge and/or process breakdowns.
Hillier and Galizzi[23] (2014)	To conduct an initial investigation into the employment outcomes and experiences of young adults on the autism spectrum	Flyers sent to targeted referrals made from organizations serving people with ASD and their families:19 parents and/or guardians of young adults, mean age 23 y, on the autism spectrum; and 17 young adults, ages 19–28 y, on the autism spectrum	Mail survey with open- and close-ended questions: analysis plan not reported	Findings demonstrate that those with ASD have difficulty finding employment, typically find employment through people they know, are paid low wages, and are likely to work in part-time, entry-level positions. Generally, however, people with ASD comment favorably on their work environments. Many also receive considerable support from their families.
Kucharczyk et al[24] (2015)	To explore the contexts, considerations, and complexities associated with delivering interventions to meet the needs of high school students with ASD from the vantage point of practitioners, parents, and other key stakeholders	Flyers and e-mails sent to ASD advocacy groups, service providers, schools, and e-mailing lists for the universities and ASD-specific groups, direct contacts and flyers placed in community locations: 47 parents or caregivers of youth ages 10–29 y; 6 individuals with ASD ages, 18–40 y; 45 educators; 30 administrators; and 24 service providers	Twenty-eight focus groups across 4 states: constant-comparative approach	Participants emphasized the inadequacy of prevailing intervention approaches in secondary schools, underscored the importance of attending to the feasibility of and alignment with the diverse needs of students with ASD, and stressed the need for broader awareness and training efforts surrounding autism.
Kuhlthau et al[25] (2014)	To identify the current strategies that ASD-expert pediatric providers are using or designing to help facilitate the transition to adult care	Sixteen sites were recruited through autism treatment networks in the United States and Canada. The person who was the most knowledgeable about transition and autism was asked to complete the interview: 5 physicians, 5 psychologists, 7 social workers and/or care coordinators, and 2 registered nurses and/or nurse practitioners.	Telephone interview: framework approach	Intervention strategies that are currently being used include the following: providing families with written medical summaries to give to adult providers, compiling lists of available adult providers or community resources, coordinating care and communication between individual pediatric and adult providers, making transition-specific appointments, and using checklists to track transition process. Other intervention strategies that were identified as needed but not currently in practice were focused on education and training (eg, informational workshops to train families and youth about transitioning) and a transition center where all services could be coordinated in 1 place.

TABLE 1 Continued

Author (Date)	Aims	Recruitment and Sample Characteristics	Data Collection and Analysis	Key Findings
Morrison et al[26] (2009)	To explore parent perceptions of the supports and accommodations that college-bound students with AS need at the postsecondary level to be successful	Recruited through a network of professionals associated with a local chapter of the Autism Society of America: 4 parents of young adults with AS, ages 8–16 y	Focus groups: analysis plan not reported	Parents recommended that colleges match students with accommodating professors and provide a professional in the college student services program to advocate for their children. Parents discussed the possibility that alternative routes to a 4-y college (eg, community college) may be the best avenue for their children. Parents agreed that their children would continue to require higher levels of parental involvement and support in college, particularly with daily living skills.
Nuehring and Sitlington[27] (2003)	To see how the transition process in place was working and whether it was doing all that it could for adolescents with autism	Four young adults with ASD ages 19–22 y and 3 vocational service providers	Audio-recorded interviews and classroom observations in by a teacher; interviews at 3 adult service providers' facilities: analysis plan not reported	Successful aspects of adult providers included the following: the employment of knowledgeable transition specialists, the variety of choices that students and their families had in a geographic area, and the use of assessment data in 1 of the agencies. Areas of improvement included the following: increased education of high school teachers and staff about the adult vocational service providers; the use of assessment data throughout the transition; increased communication among the student, his or her family, the school, and the adult vocational service provider; and aligned programming between high school and the student's future environments.
Peña and Kocur[28] (2013)	To explore the experiences of parents as their students with ASD transitioned to a community college	Recruitment e-mail sent to university support services offices, clinicians who work with clients with ASD, in addition to autism support groups and social networking sites: 18 parents of young adults with AS, autism, or PDD-NOS who attended community college	Audio-recorded interviews: constant-comparison analysis method	Parents reported playing 2 predominant roles: (1) coaching students to navigate campus services and (2) encouraging students to participate in college more independently. Two major challenges emerged from parent reports: (1) navigating the Federal Educational Rights and Privacy Act and (2) finding supportive faculty.
Smith[29] (2007)	To examine the needs of students with AS and the availability of postsecondary services and accommodations	Mailed surveys to staff of postsecondary disability services offices who are members of the Association on Higher Education and Disability: 29 staff members in disability services offices in secondary institutions	Web-based survey with close- and open-ended questions: analysis plan not reported	Accommodations at the postsecondary level do not take into consideration the specific needs of students with AS. Respondents reported a need for assistance in the areas of social skills, interviewing skills, work ethic, and social behavior.
Warfield et al[30] (2015)	To understand professional health providers' experiences in providing primary medical care to people with ASD, the training they received, the training they lacked, and recommendations for encouraging more physicians to serve this population	Recruited through the Autism Treatment Network and New England Index: 9 physicians and 1 nurse who actively provide medical care to adults with ASD	Telephone-based, structured interview guide: framework approach	Challenges at providing care were identified at the system level (eg, the availability of services and/or providers), the practice and provision levels (eg, organizing patient care, the physical environment, and family involvement), and the training and education levels (eg, physician knowledge of ASD). Systems-level solutions included financial incentives for physicians. Practice- and provision-level solutions included improving communication among physicians and providing localized lists of service providers. Teaching- and education-level solutions included training providers and office staff and connecting physicians to existing programs and services.

AS, Asperger syndrome; PDD-NOS, pervasive developmental disorder not otherwise specified.

male participants was 86%. Although the ages of the 121 participants with autism ranged from 12 to 43 years, roughly 89% of them were ≤26 years old. Race was reported in only 5 of these studies,[14,18,19,22,24] and the mean proportion of white participants with autism was 81%.

Qualitative data consisted primarily of interviews* or focus groups[16,17,20,22,24,26] with participants. The approach and/or methods used to analyze the data, which included grounded theory,[17,18] analytic induction,[21] content analysis,[15] thematic analysis,[16,19] the framework approach,[25,30] and the constant-comparative method, were explicitly named in 10 studies.[15,24,28]

Key Findings

We organized our analysis to identify the major barriers to and facilitators of supporting optimal postsecondary outcomes.

Barrier 1: Poor Person-Environment Fit

Person-environment fit refers to the match between the developmental needs of individuals and the opportunities afforded to them by their surrounding environments, including high school, workplace, college, and community service systems.[31] Findings from this review reveal that postsecondary settings often do not address the unique needs of individuals on the autism spectrum. Although many young adults,[14,15] their parents,[16,17,22] and professionals,[20,24,29,30] emphasized the need for settings to appropriately tailor supports and accommodate the social needs of young adults with autism, many felt this was lacking.[14–17,24,29] For example, parents described the formal accommodations offered in postsecondary education as less individualized and more limited than

those provided in high school.[15,26,28] Parents[15,28] and young adults[15] were concerned that college faculty and staff had limited understanding about autism and were unaware of the unique challenges faced by students on the spectrum.

Stakeholders in 4 studies described a mismatch between individual skills and employment.[17,19,23,27] Parents and young adults believed that negative social views about autism led employers to underestimate employees' capabilities.[17] Although employers described people with autism as dependable, punctual, conscientious, and consistent,[21] some parents felt that their children were steered toward jobs that were underpaid, uninteresting, and for which they may be overqualified.[17,23] Young adults also felt that there was a mismatch between their individual skills and work demands, reporting that they had jobs rather than careers, and were unable to find work related to their college degrees.[23] They felt they would fare better at work if their individual talents matched employer needs.[19]

Facilitator 1: Individualized Supports and Environmental Modifications

Researchers in several studies recommended that young adults be matched with supportive people in high school,[17] college,[15] and the workplace.[21,23] For example, parents recommended that colleges could make efforts to pair individuals with understanding roommates[15] and faculty[26] who might serve as supportive advocates and help them navigate social and academic challenges. Parents also recommended that colleges provide opportunities for young adults to meet other people with autism.[15] Supervisors of employees with autism reported that having 1 or 2 designated co-workers to help the young adult learn tasks and social rules helped with their success in

the workplace.[21] The supervisors also suggested that employers could improve the awareness of autism in the workplace by encouraging co-workers to initiate conversations with employees who are on the autism spectrum.[21]

Young adults reported that they are likely to be more successful in working environments that accommodate their individual needs and foster a supportive culture.[19,23] They preferred management styles that practiced clear communication (ie, explaining responsibilities and offering constructive feedback), provided individual accommodations (ie, flexible scheduling, extra time to learn and complete tasks, and additional training), and offered emotional support.[19] A young adult described the importance of feeling accepted by employers and co-workers, stating, "They have to know that everybody has a place in this world and that being different does not mean [people with autism] are not good people."[19] Parents also expressed a preference for managers who had previous experience working with people with ASD, were tolerant, applied strengths-based management, and considered the needs of the employee.[23]

College faculty[20] and employers and/or supervisors[18,21] also provided examples of the types of accommodations they could make to facilitate person-environment fit. College professors reported the benefits of allowing students to focus on their specific interests, work individually rather than in groups, clearly communicate their expectations, and provide direct feedback to students.[20] Supervisors of employees on the autism spectrum recommended that employers give specific directions and ask the employees to repeat back what they said to verify that they understood.[21] One employer stated, "I have learned to step back and allow my workers who have special needs to do things

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* Refs 16, 17, 20, 22, 24, 26, 27, 29, 30

their own way, whenever possible, then we're both more likely to be pleased with the outcomes."[18] Parents also described several strategies that were employed in their children's workplaces, such as structuring an individual's routine on the basis of their preferences and needs, having a private space to go to when feeling overwhelmed, or reducing the length of unstructured time.[23]

Parents and young adults also recommended modifying the physical environment (ie, lighting, sound, and the distance of chairs and desks) to better accommodate the sensory challenges of people with autism.[18] A health care professional acknowledged the importance of lessening patients' waiting time, stating, "The most important thing is to try to create a comfortable environment [and] to move things along more efficiently; it makes a big difference that folks don't have to wait because they don't always understand why they are waiting."[30]

Barrier 2: Uncertainty About Changing Parent Roles

Many parents reported having difficulty navigating their role in their children's transition. Many parents of young adults with autism wanted their children to gain independence and adopt adult roles and responsibilities[15,16] yet were aware that the social and functional challenges of autism may hinder that process.[15,28] Therefore, parents often continued to perform daily living tasks, such as cooking, managing finances, and making appointments, for their children.[16,17,23,26,28]

Although parents reported feeling overwhelmed by the number of responsibilities they had,[15,17,23,28] many felt that their close involve-ment was necessary, especially given the lack of available supports.[26,28] In 5 studies, parents described feeling a responsibility to educate support professionals about their children and ASD more

broadly.[15–17,22,28] High school personnel,[22] college staff,[29] and adult health care providers[15,25] also reported a lack of professionals who have experience teaching and caring for adults on the autism spectrum.

In contrast to parental beliefs that a high level of involvement is sometimes necessary, some professionals argued that parental involvement hindered young adults in developing life skills and greater independence. Some parents reported feeling pushback from college administrators to play a smaller role in their children's daily lives at college.[28] One parent of a college student with autism said, "The professors don't want to talk to me. And I understand all the privacy issues and all that stuff. But even if [my son] signs off, they don't want to deal with you."[28]

Facilitator 2: Gradual Transition to Diverse Supports

Parents reported using a variety of strategies to gradually increase their children's independence in college, such as asking the directors of college disability programs to include them on e-mails or attending their children's meetings with college counselors but purposefully taking a less active role.[28] In 5 studies, parents and young adults reported that sharing some responsibilities with other members of the community, such as peer mentors,[17,19,26] teachers,[18] or key personnel within organizations,[15] allowed parents to assume a smaller role and facilitate their children's independence without removing all sources of support. For example, some parents suggested that colleges provide their children with a counselor or someone to "check in" on them to help ease the transition and build a sense of security.[15] Similarly, other parents suggested that colleges appoint an advocate within their student support services program to act as the "advisor and go-between" for young adults and their professors.[26]

Some parents recommended that job coaches teach life skills in addition to employment skills.[28]

Structured supports, such as vocational services (and job coaches in particular), played a critical role in improving young adults' employment experiences. For example, parents reported that job coaches provided a sense of familiarity until the employer and young adult got to know one another.[16] Employers reported that job coaches helped them supervise their employees by sharing relevant information about their employees' medical needs.[21] Some supervisors also said they would be unable to support their employees with autism if the community vocational provider was not there to help supervise them.[21]

Barrier 3: Lack of Comprehensive or Integrated Services

Studies revealed the need for services to help families and young adults prepare for and understand the transition process. The drastic decline in the availability of services after high school was a primary concern of parents and young adults.[15–17] Many were not sure which resources were available in adulthood or where they could turn to for guidance.[14–16] For example, young adults often have to switch from a pediatrician to an adult health care provider after they turn 18 years old. This change may be abrupt, with little time for the young adult to adjust to a new provider.[16] Although some young adults felt that it was important to understand how their medical care would impact them in adulthood,[16] findings reveal that parents and young adults have little access to formal health care transition planning and have difficulty finding adult health care professionals with experience treating patients with ASD.[16,25,30]

The need for training and professional development in ASD was

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mentioned in 7 studies.[15,19,22,24–26,30] However, high school teachers[22,24] and health care professionals[25] felt they did not have the needed support from their respective institutions to learn about autism. For example, both reported feeling overworked and did not have the time to attend autism-specific training.[22,25] Health care professionals felt that they were hindered in their efforts to facilitate a successful transition because health care providers are not reimbursed for the additional time it takes to care for patients with complex health needs because of insurance reimbursement policies.[30]

Facilitator 3: Information Sharing and Collaboration

Health care professionals recommended educational resources for families, such as family workshops[25] or classes[30] and lists of adult physicians in the community who are knowledgeable about ASD.[30] To help orient young adults to postsecondary settings, parents and health care professionals recommended that young adults meet with college faculty[15] and adult physicians[16] before making the transition. Young adults also suggested that experiential learning opportunities, such as internships or attending a college lecture, could help ease their anxiety around transitioning.[14,15,19]

According to high school educators[22] and adult health care providers,[25] documentation that describes the young adult's history, needs, and strengths can assist adult service providers in better addressing the young adult's needs.[22,25] Health care providers recommended teleconferencing between pediatric and adult physicians and using checklists to help patients manage their own health care and better communicate with providers.[25] Stakeholders also suggested that formal training for college faculty,[15,29]

co-workers and/or employers,[19] and medical students and residents[30] can also raise awareness of working with individuals with ASD.

IMPLICATIONS FOR POLICY AND PRACTICE

Existing interventions are often focused exclusively on teaching skills for independence. Findings from many of the studies in this review reveal that practitioners should also consider changing aspects of their social and physical environments[32,33] to accommodate young adults' needs and lessen some of their challenges. These strategies typically involve modifying the social or physical environment at either the individual level (eg, professionals could change the ways in which they communicate with young adults) or the organizational level (eg, colleges could facilitate efforts to increase campus awareness and acceptance of autism). Stakeholders also endorsed efforts to match young adults to understanding people and settings through individualized mentorship programs.[15,17,21,26,28]

Although these strategies may help improve the transition experiences of young adults, there are few established social policies or practice guidelines to guide their implementation. Decisions about where to intervene are often based on professionals' subjective appraisal of need rather than formal assessments, but other factors could be incorporated into protocols. For example, existing employment assessments examine the fit between an individual's abilities and interests and the requirements of a particular job, but they could also be used to evaluate aspects of the workplace that are not matched well with the sensory needs of young adults with ASD.[34,35]

Although stakeholders agreed that young adults with ASD would fare better in flexible and tolerant

environments, existing services are rarely customized to fit the individuals' unique goals and challenges. Incorporating principles of person-centered planning in adult services and programs may help practitioners tailor supports to the needs of individuals. Person-centered planning is an approach to supporting people with disabilities that emphasizes individual choice and community engagement.[36,37] It is also an interactive process in which young adults, families, service providers, and community members develop solutions to mutually agreed on problems. In addition to facilitating a better fit between the individuals and their environments, person-centered programs also have the potential to increase the capacity for interagency collaboration.[38]

Policies must also consider the needs of organizations in addition to those of the youth and their families. Specifically, we need to consider systems capacity in relation to coordinating service transitions and sharing information among providers and institutions. The evidence in this review reveals that the delivery of individualized programs is often constrained by the larger systems in which the programs operate. For example, throughout the life course, people with autism are embedded in a network of services that aim to promote stable housing, employment, and education. The structure of these service networks change drastically during transition because the social policies that govern the adult service system are far less comprehensive than those offered in high school.[26] Therefore, these policies and practices need to be expanded to adapt to the needs of transition-aged youth and young adults.

LIMITATIONS OF THE REVIEWED RESEARCH STUDIES

We found several limitations to analyzing this set of studies.

First, there was not enough information about participants, making comparisons among studies difficult. Few researchers clearly described the characteristics of their samples. Among the few studies in which demographic information was reported, it was clear that overall, samples lacked demographic and socioeconomic diversity. Only 5 studies included indicators of cognition, social skills, or communication ability,[14–17,27] and researchers in 13 studies did not report how participants' autism diagnoses were verified. Sampling biases may also result in a skewed understanding of the issues we examined. For example, young adults who did not use words to communicate were excluded from the research. Therefore, findings may only be characteristic of the segments of the population represented.

Second, researchers in only 3 studies tailored their methods to fit the unique needs of young adults on the autism spectrum by allowing the young adults to bring an advocate with them to the interview and provided photographs to supplement the questions.[14,16,17] This could be important because people with ASD may have difficulty linking past experiences to current consequences and processing auditory input.[39] As a result, respondents with autism may interpret the interview questions differently from the researcher's intended meaning. Nicolaidis et al[40] have collaborated with people on the autism spectrum to modify consent forms and interview protocols so that they ask present information and ask questions more clearly. These modifications included eliminating ambiguous terms, adding specific examples, and providing definitions for potentially confusing terms. To create more consistency in this line of qualitative research, we recommend that researchers in future studies clearly describe the characteristics of their samples,

document their strategies for verifying diagnoses and eligibility, and report data collection procedures in detail.

CONCLUSIONS

In this review of qualitative studies about young adult transition, we describe efforts to understand the perspectives of stakeholders about the factors that facilitate or impede transition. Many of the strategies described in this review emphasized interventions that change the environment and foster collaborative relationships among professionals, parents, and young adults rather than being focused on modifying individual behavior, which is more typical. These findings reveal the need for and importance of programs that are used to target aspects of familial, organizational, and policy contexts. However, questions remain concerning the feasibility and implementation of such interventions in postsecondary settings.

We identified several factors that may hinder the development of effective interventions, including the large variability of individual support needs, the lack of available support outside the family system, and asynchrony in the goals and expectations among stakeholders. Future researchers should work toward establishing an evidence base that can be used to inform the development of interventions and improve team communication and functioning.

ABBREVIATION

ASD: autism spectrum disorder

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