

Stakeholder Perspectives on Research and Practice in Autism and Transition

Alice A. Kuo, MD, PhD, MBA,^{a,b} Tara Crapnell, OTD, OTR/L,^a Lynette Lau, PhD,^a Kristy A. Anderson, MA,^c Paul Shattuck, PhD^c

abstract

OBJECTIVES: Individuals with autism spectrum disorder (ASD) are reported to experience significant challenges during the transition to adulthood. Although recent evidence indicates that individuals with ASD experience poor outcomes in adulthood, little is understood about the contributing factors. In this qualitative study, we investigated the barriers to and needs in research and practice in the transition to adulthood among individuals with ASD.

METHODS: Thirteen researchers, including service providers, family members, and an individual with ASD participated in 30- to 60-minute, semistructured, open-ended telephone interviews. Interviews were transcribed, and data were analyzed by using an inductive approach to identify themes related to barriers to and needs in the transition to adulthood for youth with ASD.

RESULTS: Stakeholders identified the need for transition planning and preparation to begin earlier and for systems to better accommodate the interests and varying abilities of individuals with ASD. Stakeholders also felt that parent and service provider expectations and perceptions influence early opportunities and experiences offered throughout the transition process.

CONCLUSIONS: This study reveals the multilevel barriers to and needs in the transition to adulthood and the need for interagency and multidisciplinary collaboration and research to address the varying levels of needs, abilities, and multisector challenges.

Departments of ^aInternal Medicine and Pediatrics, and ^bCenter for Healthier Children, Families and Communities, University of California, Los Angeles, Los Angeles, California; and ^cA.J. Drexel Autism Institute, Drexel University, Philadelphia, Pennsylvania

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Address correspondence to Alice A. Kuo, MD, PhD, MBA Department of Medicine, Section on Medicine-Pediatrics, University of California, Los Angeles, 757 Westwood Plaza, Los Angeles, CA 90095. E-mail: akuo@mednet.ucla.edu

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More than 50 000 teenagers with autism spectrum disorder (ASD) will reach their 18th birthday annually in the United States.¹ The transition into adulthood (typically, between 18 and 25 years of age) is often challenging and stressful as individuals navigate and adjust to the new expectations and increasing demands that are associated with adulthood.² This transition may be particularly challenging for individuals with ASD because of the loss of school-based services (eg, special instruction, occupational therapy, and speech therapy) provided through their Individualized Educational Program and challenges associated with accessing supports in the community after leaving the K-12 school system. This transitional process is further complicated by the concurrent transition from a pediatric to adult health care system, the latter of which may often be comprised of care providers who are inadequately prepared to optimally meet the needs of individuals with ASD. Recent federal initiatives, including those by the Interagency Autism Coordinating Committee and the Maternal and Child Health Bureau, have revealed the need for multidisciplinary collaboration to tackle these complex issues and address the dearth of knowledge around factors that impact outcomes for adults with ASD.^{3,4}

Although the transition to adulthood for individuals with autism (autism transition) is a relatively new area of research, the literature reveals that the experiences of individuals with ASD before and during their transition to adulthood may impact their life course development by shaping their continued engagement with communities and use of health care and ancillary support services.⁵⁻⁸ Individuals with ASD experience a multitude of poor outcomes, including high rates of societal disconnection and disparities in access to health care transition

services. Nationally, only 58% of young adults with ASD ever work for pay outside of the home, 36% attend postsecondary education, and 24% suffer social isolation from the time they graduate from high school through their early 20s.⁵ Similarly, only 14% of young adults with ASD have ever had a discussion with their pediatrician about transitioning to an adult provider, and 45% ever have discussions about taking appropriate responsibility for their health care needs.⁹ In this qualitative study, we address the lack of knowledge about the barriers and needs as well as the services and models of care that yield improved outcomes for adults with ASD by presenting a multidisciplinary overview of key stakeholder perspectives to identify current barriers to and needs in the transition to adulthood.

METHODS

Participants

Thirteen stakeholders, including autism researchers, service providers, advocates, and family members, were recruited from the membership of the Health Care Transitions Research Network for Youth and Young Adults with Autism Spectrum Disorders and Other Developmental Disabilities. The Health Care Transitions Research Network (HCT-RN) was formed to support the creation of an interdisciplinary, multicenter research forum for scientific collaboration and infrastructure building with a focus on research designed to improve all aspects of the transition into adulthood for individuals with ASD and developmental disabilities, including physical, psychosocial, educational, and vocational outcomes. At the time of this study, the HCT-RN was comprised of 22 experts in the fields of autism and childhood systems (representing the fields of medicine, developmental pediatrics,

developmental psychology, sociology, education, child health policy, occupational therapy, speech therapy, epidemiology, organizational management, law, public relations, public health, and the nonprofit sector), young adults on the autism spectrum, and family members.

The 13 stakeholders who indicated interest in study participation (59%) were comprised of 1 self-advocate (8%), 4 parent(s) and/or family member(s) (31%), 5 researchers (39%), and 3 service providers (23%). Seven stakeholders (54%) identified as having >1 relationship to individuals with ASD (ie, parent and/or family member and researcher).

Procedures

The University of California, Los Angeles Office of the Human Research Protection Program approved this study and waived written consent. Recruitment e-mails were sent to HCT-RN members. Stakeholders who indicated interest in participating provided consent through e-mail and again verbally when they were contacted via telephone for participation in one 30- to 60-minute, semistructured interview. Participants were asked questions related to barriers to and needs in research and practice for youth with ASD as they transition into adulthood. Participants were further asked to envision and describe an ideal transition, explain why they believe some youth remain disconnected from services on leaving the school system, and what is needed to accomplish the ideal transition at the individual, community, and national levels. All interviews were recorded for transcription purposes.

Data Analysis

Two senior research staff (ie, postdoctoral level) members of the HCT-RN separately reviewed and

used an inductive approach based on content analysis to identify codes around the themes of needs and barriers. The 2 research staff then met over the course of 4 sessions to compare agreement regarding these codes. Thematic saturation was reached by the third session, after which no new themes emerged. With analyst triangulation, they sought to use differing perspectives to explore the themes as opposed to reaching a consensus. After discussion and comparison of the preliminary codes, the research staff revised and finalized themes after thorough exploration and discussion.

RESULTS

Stakeholders identified a number of barriers to and needs for youth on the autism spectrum and their families in postsecondary and health care transitions. Participants described these barriers and needs at the individual, family, community, and systems levels. Common themes for each of the levels are described in detail as follows. Although we recognize that in qualitative analysis, every theme is valid regardless of the number of times mentioned, we provide quantitative information regarding the frequency of the occurrence of each theme to give relative weights to those who seek this comparison.

We Need to Know More

Ten participants (80%) discussed the current lack of information and research being conducted on individuals with ASD in adulthood and the need to know more to make better-informed decisions. Examples included the need to know more about skills that should be targeted in childhood that would lead to better outcomes in adulthood, interventions and models that should be duplicated, and the types of adult programs that should be developed. One participant stated the following:

We don't have a good evidence base about what works about transition; what are the most important elements to connecting people [about] where they need to go, what are the services that are most effective, what models work for people, and what types of programs [should we] be creating?

Most participants acknowledged that individuals with ASD have varying levels of needs, strengths, and abilities and experience transition challenges at various levels. Interviewees discussed that to better address these challenges, more research should target system-level differences across states, including the systems that prepare individuals for transition (ie, public school system) and the systems to which they are transitioning (ie, vocational and adult developmental disabilities systems) after high school. This would include research focused on identifying how funds are distributed and services are initiated and delivered. One participant mentioned the following:

I would say that research is strongly needed in this area [systems-level differences], and the systems-level and the environmental-level kinds of examinations of what is going on would be very helpful rather than specific randomized control trials of this versus that. I think that if we could understand some of the environments and systems that are successful, we could do a much better job, as well as understanding the needs of people with autism spectrum disorders and a bit more...I think that might yield some information (sic).

The Earlier the Better

A recurrent theme was that transition planning and preparation does not start early enough. Twelve participants (92%) described transition planning and preparation as a dynamic process that should start as early as birth and continue through adulthood, with a large focus on functional skills that will lead to independence, including daily living skills, self-determination and self-advocacy skills, communication, and following instruction. In addition to addressing individual skills,

participants identified limited experiences and opportunities to explore the different possibilities in adulthood as a barrier to a successful transition and reaching optimal outcomes in adulthood. One participant stated the following:

Transition begins at birth....It should be a period of experimenting and seeing what fits, and I think we need to give transition-aged youth with autism those same opportunities to explore....We tend to funnel people into 1 route and not give them a lot of chances to explore and find good matches for their skills and their needs.

Participants also stated that opportunities should be based on the interests and desires of the individual and family and that these opportunities should change as new interests emerge. Participants also acknowledged that because there is a range of abilities among individuals on the autism spectrum, transition plans should be individualized:

I think [transition planning] needs to start with a discussion with the parents when the kids are younger, with the idea that kids have skills, they have desires, and just like any other [children], children with autism also have those skills and desires. We should focus on those positive skills and help translate them into nonacademic goals that can be functionally related.

Families and Service Providers Play an Important Role

All interviewees recognized the need to better support the individual as well as the family in both postsecondary and health care transitions. Participants commonly brought up the need to better educate individuals and families about the options available to them within their community. One participant stated the following:

...the average family in the Midwest or in rural areas does not know that the sky is really the limit and that there are resources available into adulthood for their individual. When [does the individual] first get to dream big of, "Hey, what do you want to do in adulthood?" That is a very big question that people even without a disability have difficulty answering...

Participants also speculated that high rates of societal and occupational disconnection after high school among individuals on the autism spectrum may be due to the lack of family resources (ie, financial and social). To overcome this significant barrier, participants identified the need to better support individuals and families in navigating the system and expanding their social networks by connecting them to their communities. One participant (of many) stated the following when asked why they believe some youth are disconnected after high school:

I venture that it is families with social networks and connections [who] can find someone who will hire their student or plug them into a volunteer opportunity or help them connect to something because their social network is wide enough that they can find people who are willing to do that and people [who] have something to offer that are in the interest area of that student. People that are more disadvantaged or have less social capital or smaller networks, I would think that it would be much more difficult to find places to plug your child into, and you are also talking about having to have the time to do this, too.

Participants felt that service providers play an important role in supporting individuals and families through postsecondary and health care transitions. Although the role of service providers in the school system was a prominent point of discussion, the unique role of physicians in all aspects of transition was also discussed:

The role of a pediatrician, developmental or primary, is often one of helping a family navigate the systems of care, helping them with advocacy with other systems (like school systems and so on), and making sure they are getting access to services. I think physicians can be pretty influential in these areas if they know how to do it.

Participants also felt service providers' knowledge of the resources available in their communities and their perceived role in assisting in the transition process was an important factor in successful

transition. In addition, participants discussed the importance of provider and parent expectations and perceptions of individuals on the autism spectrum (ie, capable of being independent or working after high school) and how this can negatively or positively impact the trajectory of transition planning and preparation. In addition, some felt as if expectations for individuals on the autism spectrum are much lower in comparison with other disability groups:

...there are very low expectations for folks with autism. I think that our perceptions and our expectations need to change. I think we need to assume, like someone with any other disability, that they may very well be able to do what others can with appropriate accommodations for their disability. I think that in the educational realm, most of the educators see the disability and don't see the ability and don't properly set expectations and goals...

Community Receptivity is Key

All participants identified improving community capacity for supporting individuals with ASD and overall receptivity to these individuals as crucial, at some level, in improving the transition and outcomes in adulthood. Another significant barrier to successfully transitioning into adulthood that was noted was the lack of community options, opportunities, and services available to adults on the autism spectrum. Although participants acknowledged the need for more services for adults with ASD, some also felt that creating niche services for these individuals was not a viable or a sustainable long-term option and that we should instead be leveraging what is already available in our local communities:

...I believe we can't build things just for people with autism but need to leverage what is in our own respective communities and allow [community members] to help encourage [individuals with ASD] to integrate with those communities, whether it is the library, the zoo, or volunteer opportunities, or work opportunities, or health care. It is that...[pause]...how do we help condition and make aware

or condition the community to be more understanding, accepting, and recognize that our adults can add a lot of value and bring out goodness in people? ...And they do.

Another participant expressed the need for creativity to find jobs that match the interests and unique abilities of people on the autism spectrum:

As a society, I think we need to find ways to create some flexibility so people can in fact be used for the things that they are really good at, that they enjoy, that match their special interests, that match their abilities. That is going to take a lot of creativity. That is not going to be something we just make a policy about, and it is not going to be covered by following ADA [Americans with Disabilities Act] laws and making sure that people have reasonable accommodations because I think it goes beyond reasonable accommodations to actual job carving and creating these little niches.

We Need Systems That Accommodate the Varying Levels of Needs, Abilities, and Interests

A significant, recurrent theme mentioned by all participants was system-level barriers to and needs in postsecondary as well as health care transition. Participants commonly described the postsecondary systems (ie, the Department of Vocational Rehabilitation and the Department of Developmental Services) as "rigid," "disconnected," and "a fractured system where no one talks to each other." Participants felt that current policies do not support or accommodate the unique social needs and ongoing support required for some individuals on the autism spectrum. In addition, many felt that there was a lack of communication and continuity of care from pediatric to adult systems. When asked what needs to be in place to assist with transition, 1 participant responded with the following:

So, there should be integration [in] the adult system of benefits and supports years before kids leave school, and they should be forced to work hand in glove. The adult system [ie, the Department of Vocational

Rehabilitation and the Department of Developmental Services] should help inform the educational system [and/or] the childhood system about what is needed so that they can be working on it, and the childhood system should be accountable for helping achieve what the adult system needs as well.

When discussing health care transitions, participants described similar challenges to those observed in postsecondary transition. Although policy and lack of care coordination between pediatric and adult health care was a prominent barrier, participants also discussed that the adult health care system in general was not accommodating to the needs of individuals on the autism spectrum, particularly when it came to sensory sensitivities, facilitating social interactions, fostering self-determination skills, and connecting people to community resources.

DISCUSSION

The themes identified in this study indicate a wide range of barriers and needs in research and practice in autism transition at multiple levels. One of the most prominent themes identified in the current study was the lack of research on ASD in adulthood and the limited evidence base for services for adults with ASD. The population of adults with ASD is growing, and recent evidence reveals high rates of disconnection from any jobs or education after high school and poorer outcomes in adulthood in comparison with those in other disability groups.^{5,10} Although it is known that individuals with ASD have less optimal outcomes in education, vocation, and access to health care, little is understood about the factors that may lead to poorer outcomes for individuals.^{5,10} As a result, several reviews on transition services and outcomes on adults with ASD have suggested a need for more research and a strengthened evidence base on services for adults on the autism spectrum.^{1,3,11}

Findings from the current study further confirm the growing need for research in adulthood to make better-informed decisions about practice and policy for individuals on the autism spectrum.

Another identified theme was the need for transition planning to start earlier and for preparation to focus on developing functional skills. Deficits in the ability to socially interact and communicate is a hallmark of ASD.¹² Research has shown that individuals on the autism spectrum often experience deficits in daily living skills.^{13,14} The ability to perform these skills has been significantly predictive of later outcomes, including social participation and future employment.^{15,16} Fostering self-management and self-determination skills may help increase managing their choices in life, such as their own health care or transition plans. Participants also discussed the need for transition preparation to include job exploration and volunteer opportunities that are individualized to their strengths and interests. These types of opportunities have been shown to have a positive influence on self-esteem, motivation, the application of skills, and expanding career opportunities and interests.¹⁷⁻¹⁹ These studies further validate our findings, indicating the importance of targeting these skills early in school settings.

A theme that also emerged was the important role that family and service providers play in shaping transition plans and opportunities for youth and young adults on the autism spectrum. Previous researchers have found that family and service provider expectations play a large role in shaping opportunities and outcomes for youth with ASD and those in other disability groups.^{18,20,21} The influence of expectations was a common discussion point for participants in the current study.

Additionally, participants also identified the lack of knowledge of available supports and benefits as a significant barrier to a successful transition. Without proper knowledge, families may not know what opportunities to pursue. Furthermore, service providers may not know what services to connect individuals to, the types of goals to develop, or how to foster skills that lead to independence.¹⁷ Therefore, service providers (ie, physicians, therapists, and educators) need to be more knowledgeable about the availability of resources in their communities to not only connect families and individuals but to help them make better-informed decisions during the transition process.

Primary care physicians have a unique opportunity to be able to guide families in this transition process. After completion of K-12 education, health care providers may be the only source of continual, regular follow-up for many of these individuals. More training during residency is needed to equip primary care physicians with the knowledge and skills to support families through the transition process.

Our study reveals the importance of having higher expectations of individuals on the autism spectrum and not limiting their experiences on the basis of personal ideas and beliefs of what an individual is or is not capable of achieving. In addition, this study also reveals the importance of better educating families and service providers about the available resources available to them within their communities to assist all those involved in the transition process in envisioning a more positive, productive, and hopeful future for individuals with ASD.

One of the most significant findings from the current study was the collective agreement on the need to improve community- and systems-level supports for both postsecondary and health care

transitions. Over the past few years, awareness of the need for more research in adulthood for individuals on the autism spectrum has grown. Although several federal initiatives have made it a priority to conduct more research on adults, research that is aimed at better understanding the impact of nonprofit and government services on outcomes in adulthood is urgently needed.^{3,4} Currently, robust research and practice guidelines exist related to improving transition outcomes and preventing postsecondary disconnection in other populations, including youth exiting foster care and youth from disadvantaged families and communities.^{6,22,23} The field of autism research should consider whether lessons learned in these other arenas might be fruitfully adapted.

A major limitation to this study was that it included a small sample size with only 1 self-advocate with ASD. Furthermore, participants were only recruited from within

the HCT-RN. Key stakeholders were recruited because of their personal experiences with individuals on the autism spectrum and expertise in research and practice in transition. Although we were able to interview people with diverse professional and personal backgrounds in ASD, their perspectives and beliefs regarding barriers to and needs in transition may be different from the general population, which may be less connected to academia, research, and services. Although there is the limitation that findings cannot be used to define the prevalence of any opinion or attitude, which is an inherent limitation to qualitative analysis, it should be noted that the experiences and knowledge of these participants do have applicability and benefits to the larger population of individuals and families.

transition for youth with ASD. We found that although focusing on individual skills is necessary and has implications for later outcomes, the community becomes increasingly more important as individuals on the autism spectrum transition to adulthood. In addition, this study reveals the influence of families and providers and the unique role they can have in transition planning and the opportunities provided throughout the process. To address the varying levels of need and multisector challenges, future researchers should aim to improve support at all levels, including the individual, family, community, and systems levels. In this study, we provide further evidence of the need for more research in adulthood.

ABBREVIATIONS

ASD: autism spectrum disorder
HCT-RN: Health Care Transitions Research Network

CONCLUSIONS

This study reveals the multilevel needs in and complexity of

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