

# Challenges and Opportunities in Transitioning Autistic Individuals Into Adulthood

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**BACKGROUND AND OBJECTIVES:** Approximately 1.2 million autistic youth will reach the legal age of adulthood over the next decade. Given dynamic changes in the socioecological context of the transition to adulthood, we produced an updated transitions research agenda reflecting the perspectives of autistic young adults, care partners (parents), and professionals who use autism research.

**METHODS:** We conducted 9 focus groups: 4 young adult, 4 care partner, and 1 professional, with 59 total participants. Young adults were grouped by self-reported identity: (1) racial and ethnic minority, (2) lesbian, gay, bisexual, transgender, queer, intersex, asexual, and other identities, and (3) nonspeaking, in addition to a general group. We selected care partners who supported youth with varying intensity of support needs. We used rapid qualitative inquiry methods to extract key points from answers to semistructured interview questions.

**RESULTS:** Delays in diagnosis and transition processes, and placement on wait lists resulted in significant obstacles to successful transitions. Parents assumed a dominant role by coordinating services, navigating systems and identifying opportunities for community participation, and providing direct supports. There was an overarching need for inclusion of autistic people in transitions research and consideration of cultural differences in priorities and values. Participants prioritized investigation of variation in transitions among autistic youth with intersecting identities, navigation support (eg, peer mentors), efficacy of services and supports (eg, transition and employment services), differences in available services by location, and problems within specific benefits programs.

**CONCLUSIONS:** Research should focus on understanding population-level factors of system performance on outcomes and support needs, service delivery among marginalized groups, and transformation of complex service ecosystems.

abstract



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**WHAT'S KNOWN ON THIS SUBJECT:** Research regarding autistic transition-age youth has moved beyond homogenous characterizations of their needs, experiences, and outcomes. However, fewer studies have included diverse study samples, involved autistic research participants, or considered the multisectoral nature of transition service delivery.

**WHAT THIS STUDY ADDS:** This study builds upon recent autism services research recommendations by generating community-informed guidance for research priorities to support successful transitions to adulthood for autistic youth and young adults. Findings reflected research priorities of autistic young adults, care partners, and professionals.

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The estimated prevalence of autism nearly doubled between 2010 and 2020, from 1 in 68 children in the United States to 1 in 36.<sup>1</sup> Approximately 1 173 000 autistic youth will reach the legal age of adulthood (18 years) over the next decade.<sup>2</sup> For these youth and young adults, the transition to adulthood is neither a linear nor singular process, but rather, multiple overlapping transitions across different service systems. These changes require independent and/or supported decisions about employment, continued education, living arrangements, transportation, health care, social life and relationships, and well-being. During the transition years (defined here as 14–29 years), autistic youth may also experience: Emergence of psychiatric conditions,<sup>3</sup> developing understanding of their gender identity and sexual orientation,<sup>4</sup> aging out of foster care,<sup>5</sup> interactions with the justice system,<sup>6</sup> and other nuanced changes that add complexity within an already challenging period of life. Further vulnerability may stem from financial hardship among households of autistic youth,<sup>7</sup> implementation of policies that compound limited access to reproductive health services and gender affirming care,<sup>8</sup> and exposure to institutional bias, structural ableism and racism, trans/homophobia, and antiimmigrant sentiment.<sup>9–13</sup> These factors, in isolation or in combination, may contribute to adult outcomes that are different than what youth and their families expected. It is critical that the continued evolution of autism research reflects these complicated realities which have long existed, but have only recently been explored, as factors of proximal and distal outcomes of autistic youth.

The Health Care Transitions Research Network published the first national research agenda regarding autistic transition-age youth in 2017.<sup>14</sup> Subsequent iterations of recommendations to guide research on transitions among autistic youth are shown in Table 1. These recommendations focused on community- and systems-level factors, improving the performance and coordination of service systems, developing frameworks and measurement, addressing disparities in service access and care, and building capacity to serve autistic youth. Other researchers have recommended: Prioritizing a diverse array of perspectives in improving the transition to adulthood,<sup>15–17</sup> including minimally-verbal and nonspeaking individuals;<sup>16</sup> increasing interagency communication and coordination within transition services;<sup>18</sup> identifying facilitators of successful transitions to adulthood, such as use of peer mentors;<sup>19</sup> and improving health care to better support autistic transition-age patients.<sup>20</sup> The federal Interagency Autism Coordinating Committee (IACC) recently expressed the importance of understanding the service needs of individuals at the intersection of autism and minoritized race, ethnicity, gender, and sexuality through qualitative research.<sup>21</sup> Black and Brown youth have historically been especially underrepresented in autism transitions research.<sup>9</sup> Academic researchers and community advocates have also called for research that attends

to the needs and lived experiences of lesbian, gay, bisexual, transgender, queer, intersex, asexual, and other identities (LGBTQIA+) autistic youth and adults,<sup>22–24</sup> given that a large proportion of autistic individuals report sexual orientations beyond heterosexuality,<sup>25–27</sup> and are more likely than their cisgender peers to identify as transgender, non-binary, and/or gender nonconforming.<sup>4,28</sup>

Given dynamic changes in the social-ecological context of the transition to adulthood, we aimed to produce an updated agenda reflecting input from autistic young adults, care partners, and others who use autism research. Social-ecological levels of influence include: Family (eg, parental expectations) and interpersonal (eg, peer relationships), institutional (eg, how services are accessed and organized), community (eg, opportunities in one's community, ease of navigation), and sociopolitical (eg, laws and regulations).<sup>29</sup> This study builds upon recent autism services research recommendations,<sup>30</sup> by generating community-informed guidance for research activity in the United States to facilitate equitable transitions to adulthood for autistic youth.

## METHODS

We conducted qualitative focus groups to gather a diverse range of perspectives on priorities for the next generation of autism transitions research. The Drexel University institutional research review board approved this study.

### Recruitment and Participation

We used purposive sampling of transition-age autistic young adults, their care partners, and professionals who use research regarding transition-age autistic youth. We primarily recruited by e-mail within closed groups, such as individuals known to our community partners as autistic adults or their care partners, and a flyer distributed through social media. We employed a multistep ratings e-process of each participant (with exception of nonspeaking young adults and Latino care partners) by 2 researchers to avoid recruitment of fraudulent participants.<sup>31</sup> We also separately recruited a professional focus group through advertisement at a national, autism-related meeting. We recruited 9 focus groups comprising 59 participants representing all 4 regions of the United States: 4 autistic young adult groups ( $n = 17$ ), 4 care partner groups ( $n = 12$ ), and 1 group of professionals ( $n = 30$ ). Young adults and care partners were recruited independently and were unrelated. Participants received a \$40 gift card for participation in the study.

We included autistic young adults who were: (1) 18 to 29 years, (2) out of high school, (3) able to communicate (spoken or written) about their experiences with leaving high school and becoming an adult, (4) their own legal guardian, and (5) able to answer comprehension questions about study consent information. No participants were aged <20 years, and most were in their mid to late 20s. Self-reported demographic characteristics are detailed in Table 2.

| TABLE 1 Historical Recommendations Regarding Autism Transitions Research                                   |                                                                                                                                                                                                                                                                                                                                                            |
|------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Report Themes                                                                                              | Specific Research Recommendations                                                                                                                                                                                                                                                                                                                          |
| <b>Health Care Transitions Research Network<sup>14</sup></b>                                               | "Increased focus on community- and systems-level factors that influence outcomes with population-level approaches to measuring outcomes"                                                                                                                                                                                                                   |
| Community- and systems-level factors                                                                       | Longitudinal research on patterns of service use and outcomes;                                                                                                                                                                                                                                                                                             |
| Involvement of autistic people                                                                             | "development of conceptual typologies, frameworks, and measurement approaches for systems-level factors" of transition processes and outcomes; and                                                                                                                                                                                                         |
|                                                                                                            | how "variations in institutional settings, policies, and practices that individuals are exposed to at an earlier stage during the life course may impact the transition to adulthood"                                                                                                                                                                      |
|                                                                                                            | "Greater involvement of people with autism in establishing research priorities, designing research studies, and producing study findings and recommendations"                                                                                                                                                                                              |
| <b>Report to Congress: Young Adults and Transitioning Youth with Autism Spectrum Disorder<sup>45</sup></b> | "Efficacy of transition-oriented programming in achieving positive outcomes in education, daily life and social skills training, vocational training, employment, residential placement, and community integration"                                                                                                                                        |
| Outcomes research                                                                                          | Tailoring outcome goals to address individualized needs                                                                                                                                                                                                                                                                                                    |
| Program development and evaluation                                                                         | Development of program models for individualized, coordinated, comprehensive services, and supports for transition-age youth and young adults; evaluation of the effectiveness of these programs                                                                                                                                                           |
| Measurement                                                                                                | Determining which "services and supports are effective across different autism phenotypes, genders, race/ethnicity/cultural groups, and cognitive abilities, as well as of functioning, circumstances of social, economic, and institutional support"                                                                                                      |
| Service research and translation                                                                           | Translation of service delivery research into practice with strategies to ensure access across groups of service users                                                                                                                                                                                                                                     |
| Family and social system support for transition                                                            | "Understand how caregivers, and especially parents, can best support youth and young adults with ASD through the transition process," and parallel examination of "the extent to which fostering social support systems for individuals with ASD may serve to increase independence and decrease the reliance on families as the single source of support" |
| <b>Review of Autism Transitions Research Project Evidence and Research Recommendations<sup>30</sup></b>    | Continued analysis of population-level data, and "need for further examination of variability of youth and family experiences across different service systems, user characteristics, and across time/age"                                                                                                                                                 |
| Analysis of population-level data to examine variation in outcomes                                         | Identification of modifiable state policy factors as social determinants of adult outcomes including variation in service access and utilization among Medicaid-enrolled autistic youth, and young adults on waitlists for Medicaid home- and community-based services waivers                                                                             |
| Service delivery methods and programs targeting marginalized groups                                        | "Examination of outcome domains at the population level" using multisectoral data and data linkages, when possible                                                                                                                                                                                                                                         |
| Complex service system ecosystems                                                                          | Examination of "service access and delivery to marginalized groups and the feasibility, effectiveness, dissemination, and implementation of promising programs"                                                                                                                                                                                            |
| Involvement of autistic people                                                                             | Adapting existing programs                                                                                                                                                                                                                                                                                                                                 |
|                                                                                                            | Use of existing federal programs to foster equity                                                                                                                                                                                                                                                                                                          |
|                                                                                                            | Expanded research "to inform improvements in the performance and coordination of complex service ecosystems to build capacity within and across programs that address the needs of autistic youth;" increased understanding of the transition services ecosystem                                                                                           |
|                                                                                                            | "Prioritize methods for bolstering the roles of autistic youth and their family members within the research process, as members of autism research advisory boards, and across the research process"                                                                                                                                                       |

ASD, autism spectrum disorder.

Young adults were assigned to 1 of 4 types of focus groups on the basis of self-reported identity: (1) racial and ethnic minorities ( $n = 2$ ), (2) LGBTQIA+ ( $n = 8$ ), (3) non-speaking ( $n = 3$ ), or (4) a general group of youth who did not identify in groups 1 to 3 or who chose this group on the basis of scheduling preferences ( $n = 4$ ). We recognized that differences in culture and lived experiences were likely across group participants. Our objective was to establish safe environments for constructive discourse and to ensure that findings had broader applicability beyond specific minoritized groups. Those who endorsed multiple identities were given the option to select 1 focus group.

All 12 care partner participants, including 4 English-speaking Latino parents, were parents of autistic young adults who had left high school and required some assistance during the transition to adulthood. Two of the 12 parents endorsed round-the-clock care and 3 said their young adult needed support "most of the time."

We recruited 1 group of professionals from attendees at a national meeting of Autism Collaboration Accountability Research Education and Support research grantees by advertising this opportunity for participation in a focus group at the conference. We accepted all volunteers; 30 professionals consented to participate. Participants self-

| TABLE 2 Self-Identity of Autistic Young Adults in Focus Groups |          |            |
|----------------------------------------------------------------|----------|------------|
|                                                                | <i>n</i> | Percentage |
| Total                                                          | 17       |            |
| Gender                                                         |          |            |
| Male                                                           | 5        | 29.4       |
| Female                                                         | 3        | 17.6       |
| Nonbinary                                                      | 3        | 17.6       |
| Nonbinary female                                               | 2        | 11.8       |
| Transmasculine                                                 | 1        | 5.9        |
| Agender                                                        | 1        | 5.9        |
| Not provided                                                   | 2        | 11.8       |
| LGBTQIA+                                                       | 10       | 58.7       |
| Racial or ethnic minority                                      | 3        | 17.6       |
| Nonspeaking                                                    | 3        | 17.6       |
| Geographic region of high school                               |          |            |
| Midwest                                                        | 2        | 11.8       |
| North                                                          | 6        | 35.3       |
| South                                                          | 4        | 23.5       |
| West                                                           | 2        | 11.8       |
| Not provided                                                   | 3        | 17.6       |
| Lived in a high poverty area during high school                | 3        | 17.6       |
| At least some college education                                | 13       | 76.5       |
| Diagnosed as a teen or adult                                   | 9        | 52.8       |

identified as researchers, educators, LEND program directors and trainees, and program leaders from the Health Resources and Services Administration and the Association of University Centers on Disability. Several were parent-professionals or also identified as autistic.

## Design

We conducted 9 1-hour focus groups using Zoom, 1 in-person professional group, and collected written answers to focus group questions from nonspeaking individuals. Participants in Zoom and in-person groups first viewed a 3-minute animated video with voiceover by a young adult, that explained the transition to adulthood (eg, leaving high school, finding a job, transitioning to an adult primary care doctor), services some youth receive during this period (eg, vocational rehabilitation [VR]), and issues that youth may encounter (eg, difficulty qualifying for services or benefits). This video was produced by our team for this project, to provide an overview of what the transition to adulthood might encompass, as a starting point for discussion of transition experiences.

We used a semistructured focus group guide to query participants about their transition experiences, things that helped during the transition, important questions researchers should explore, and other priority needs. See Table 3. We also used written comments on Post-it notes, and an interactive exercise to prioritize comments, to facilitate the larger professionals group. We accommodated individual needs by permitting off-camera participation after initial verification of identity and written responses in the chat.

One team member facilitated each focus group, whereas 1 to 2 others took notes off camera. We selected facilitators to best match group characteristics (eg, age, sexuality,

| TABLE 3 Focus Group Guide                                                        |                                                                                                              |
|----------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|
| Topic                                                                            | Potential Questions                                                                                          |
| Introduction                                                                     |                                                                                                              |
| Introductions                                                                    | Tell us your first name and what brings you here today.                                                      |
| Opening question                                                                 | What are a couple words that come to mind when you hear the words transitioning to adulthood?                |
| Feedback on the transition video                                                 |                                                                                                              |
| How well does this story match your own experiences with transition?             | What was your experience like?                                                                               |
|                                                                                  | What do you think it looks like to become an adult?                                                          |
| What would you add, take out, or correct?                                        | What would you change about this video?                                                                      |
|                                                                                  | Where did we get the story wrong?                                                                            |
| What else do you think people should know about transition?                      |                                                                                                              |
| Barriers/facilitators                                                            | What was easy about transition?                                                                              |
|                                                                                  | What was difficult about transition?                                                                         |
|                                                                                  | What would help autistic people as they're becoming adults?                                                  |
| Research priorities                                                              |                                                                                                              |
| What would you like researchers to study about transition?                       | What do you think researchers need to be looking at to make the transition to adulthood easier?              |
|                                                                                  | What questions should researchers ask about transition?                                                      |
|                                                                                  | What would you like to learn about transition?                                                               |
| Recommendations                                                                  |                                                                                                              |
| Research funding                                                                 | If you had a million dollars to spend on helping autistic youth with transition, what would you spend it on? |
| Summary                                                                          |                                                                                                              |
| How well did I capture what we talked about? Is there anything you would change? | What else should we have asked you about?                                                                    |
|                                                                                  | Is there anything else you need us to know?                                                                  |

gender, race/ethnicity, autistic individual, or care partner) between 4 team members (A.R., K.C., K.M., M.C.). A Latino researcher (K.L.) conducted the Latino parent groups. At the end of each focus group, a notetaker summarized the discussion and asked participants to offer clarification. Focus groups were recorded and transcribed, and chat box messages were captured. Immediately after each focus group, 2 members of the research team wrote memos documenting group characteristics, discussion themes, insights, and notable emotions or contradictions within the group. The facilitator and notetakers then reviewed the recording and took notes for key questions from the focus group guide.

## Analysis

We used rapid qualitative inquiry (RQI) methods, which are a team-based approach to analyzing qualitative data,<sup>32</sup> by organized key points into matrices for exploring data in an efficient and systematic manner, useful in decision-making.<sup>33</sup> RQI is appropriate for analyzing semistructured data to inform ongoing research, including health-related data.<sup>34,35</sup> We applied RQI to help make decisions about topics to prioritize in a research agenda.

We extracted main themes and notable quotes from transcripts, memos, and notes. The lead researcher transferred themes and quotes for each group into a matrix with columns corresponding to topics from the focus group guide. Key points from each summary matrix were summarized in a final matrix representing collective input sorted by group. We compared themes from across focus groups to identify points of convergence and divergence in perspectives across groups. At least 1 other researcher reviewed matrices, and discrepancies were discussed, at each step of the process. We also returned the themes and extracted quotations to participants at the end of the process for verification.

The research team drafted research agenda recommendations on the basis of themes identified across focus groups. These recommendations were reviewed and approved by focus group members, the research team and external professional advisors for this work, and our community advisory group composed of autistic adults, professionals, and family members.

## RESULTS

We present themes and quotes related to overall transition experiences and recommended research topics.

### Experiences With Transitioning Into Adulthood

#### System Failure

Both parents and young adults described transitions as “scary,” given confusion and limited information across “multiple transitions” at ages 14, 18, and 21 years and older. One parent said, “It’s like having no directions, like

someone hijacked your Google maps.” Parents, therefore, assumed a dominant role during the transition into adulthood. They assisted in coordinating services, navigating systems and identifying opportunities for community participation, and providing direct support to young adults with high-intensity needs. Recognizing the need for improved policy, a parent said, “They [school] will not do anything they are not absolutely 100% required to do.” Two parents referenced the federal Individuals with Disabilities in Education Act, explaining:

“One of the biggest issues with transition is that parents are not being educated about what transition is, about what it looks like. And the Individuals with Disabilities in Education Act has a mandate that students are prepared for transition. And if the parents don’t know ... it means the students don’t know.”

“I cannot tell you how many parents of 18- or 22-year-olds I’ve talked to who don’t know what a transition plan is, who never applied for supplemental security income [SSI], who never connected with their VR agency, whose child has academic capability but ... has no friends. And I have to explain to them your school district failed your child because they did not provide the functional, social-emotional, and other supports that were required.”

### Delays in Diagnosis/Navigating Supports

Delays in diagnosis, late starts to transition, and delays in placement on wait lists presented significant obstacles to successful transitions. Young adults felt conflicted about the focus on “functionally eliminating the autism” within school-age interventions, which created confusion. One explained:

“You’ve put all your eggs in that basket, and then 18 happens, and you’re (out of luck). So, trying to pick up the pieces in adulthood is not the most effective way to do that. It’s very much a medical model, fix the broken thing ... And that makes it much more difficult to set up successful autistic adults, when you’re not even having that conversation or acknowledging that, ‘Yeah, we become autistic adults when we turn 18, and we’re still gonna be autistic.’ So, I guess they need to start earlier and with more intention of how to help the person be part of society, rather than just like slapping patchwork on it afterwards.”

The LGBTQIA+ focus group expressed difficulty accessing diagnoses and navigating supports, because they tended to be estranged from family members to support them. Racially and ethnically minoritized young adults experienced racism and differences in how independence was valued across generations and cultures. Nonspeaking young adults felt disenfranchised, misunderstood, underestimated, and disempowered during their transition experiences.

## Focus Group Recommendations

Table 4 illustrates focus group recommendations for autism transitions research categorized by whether the suggested focus concerned individual versus social-ecological levels. One young adult asked, “What does a healthy adult life look like for us, and how can we facilitate and support that?” Another suggested developing a better understanding of “what the transition to adulthood looks like ... for autistic people, as far as living independently, possibly living with a partner, getting a job.”

## Understanding Variations

At the individual level, questions emerged about how multiple, intersecting identities influence transition experiences. These identities included undiagnosed and self-diagnosed

adults who face challenges accessing diagnosis because of financial hardship, and limited access to diagnosticians with expertise in differential diagnosis of adults. Others expressed the need to research sensory issues; and motor control issues contributing to dyspraxia among nonspeaking individuals.

Across social-ecological levels, recommended research concerned: Noninstitutional and non-familial relationships for navigation support (eg, peer mentors), efficacy of various services and supports (eg, transition and employment services), differences in services available across states and localities, and problems with specific benefits programs like SSI. Two participants questioned how to interrupt cycles of accumulating and progressing problems (eg, decreased income > reliance on SSI > inability to exceed

| <b>TABLE 4</b> Themes That Address a Need for Research, Categorized by Individual Versus Social-Ecological Level Factors (Family and Interpersonal, Institutional, Community, Sociopolitical) From Young Adult, Parent, and Professional Focus Groups |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Individual Factors</b>                                                                                                                                                                                                                             | <b>Exemplary Quotes</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Diagnostic variation                                                                                                                                                                                                                                  | “There should be more research done on different presentations of autism. I feel like the model right now is young boys essentially ... that kind of presentation. So, if you present differently, like if you're masking, or if you have different social expectations, then it might not be noticed because you don't fit that typical model.” (YA)                                                                                                                                                                                                                                                            |
| Independent living                                                                                                                                                                                                                                    | “There are many autistic people on the spectrum who would not be able to live independently. ... I used to live with roommates and that just caused so much anxiety for me, cause I was just constantly drained all the time. ... so now I do live in independently and that has been helpful.” (YA)                                                                                                                                                                                                                                                                                                             |
| Sensory needs                                                                                                                                                                                                                                         | “Sensory issues create more problems that we don't have a way of explaining without speech.” (YA, nonspeaking)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
|                                                                                                                                                                                                                                                       | “And like the bus is also overstimulating, so often I'm biking. But I'd bike with my headphones on, which is apparently illegal, and I've gotten in trouble.” (YA)                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| Special interests                                                                                                                                                                                                                                     | “I feel like some special interests kind of have more prevalence than others. And I take interest in that, because I don't think it all has to be about suffering. I think some of it can be about joy. One thing, I guess, that's about autism is just being so passionate.” (YA)                                                                                                                                                                                                                                                                                                                               |
| Variation in experiences                                                                                                                                                                                                                              | “Understanding the transition experience for autistic individuals compared with other disabilities, particularly in terms of mental health.” (Professionals)                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Cultural identity, language, gender identity, race/ethnicity, etc                                                                                                                                                                                     | [In regard to] “...families who are trying to define their needs in terms of ‘profound autism,’ research should not contribute to blurring support needs. Levels of support should be a cross-cutting issue.” (Professionals)                                                                                                                                                                                                                                                                                                                                                                                    |
|                                                                                                                                                                                                                                                       | “Gender differences in outcomes” (Professionals)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Family and Interpersonal Factors</b>                                                                                                                                                                                                               | <b>Exemplary Quotes</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Family roles                                                                                                                                                                                                                                          | “When I make a choice, it is the problem of my mom to figure out how to finance it, staff it, plan the d for it, make it possible when everyone says no and doesn't treat me like an intelligent man, and then give everything to help me. Next, they don't offer her any help, and then work to make it more difficult to do a job she has done for no money ... Study how government has put all the burden on families, made them give up every single resource they have for their entire life, and then put extra burdens on them that those who don't have a disabled child don't have.” (YA, nonspeaking) |
|                                                                                                                                                                                                                                                       | “I think it would be really great if researchers specifically look at how the transition from adulthood impacts changes in daily routines. Because that'll look at how you know autistic adults are being supported by their parents, versus how they might not be supported in their transition to adulthood ... How to teach autistic youth to navigate household tasks and schoolwork, social things, without the support of parents.” (YA)                                                                                                                                                                   |
| Friendships and relationships                                                                                                                                                                                                                         | “I think it would be interesting to see how many autistic people feel lonely both figuratively and literally ... Do they ever want to share finances with someone, but they struggle to find a romantic partner? Maybe you should think about platonic partnerships.” (YA)                                                                                                                                                                                                                                                                                                                                       |
| Loneliness, reliance on nonparental relationships for support into adulthood                                                                                                                                                                          | “I'm really curious as to how autistic people can rely on nonparental or nonfamilial relationships to get support, because so many of us LGBT folk are estranged from our families.” (YA)                                                                                                                                                                                                                                                                                                                                                                                                                        |

| TABLE 4 Continued                       |                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|-----------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Family and Interpersonal Factors        | Exemplary Quotes                                                                                                                                                                                                                                                                                                                                                                                                                      |
| Masking                                 | "I'm still learning to unmask, especially when it comes to realization that there was any point, before realizing I had autism, at which I wasn't masking. That was when people hated me the most, so that's like it became a learned behavior to do it before." (YA)                                                                                                                                                                 |
|                                         | "I definitely resonate with the isolation, especially as an adult who sort of came to terms with my autism diagnosis as an adult ... sort of looking back onto how well I was able to mask it and fit in with others for so long ... as a woman especially." (YA)                                                                                                                                                                     |
| Transition                              | "Go back to where the problem is happening (beginning of middle school) and address issues there. Because the outcome could be different at transition time if the base is stronger." (YA)                                                                                                                                                                                                                                            |
|                                         | "How does the availability of direct service providers impact the transition?" (YA)                                                                                                                                                                                                                                                                                                                                                   |
|                                         | "Identifying the shortcomings of schools in preparing autistic young adults for successful transitions." (Professionals)                                                                                                                                                                                                                                                                                                              |
|                                         | "Fluctuation is an important concept. Young adults may spend 3 – 4 mo in higher education and then bomb because of executive functioning. We may not be preparing them well." (Professionals)                                                                                                                                                                                                                                         |
|                                         | "Lack of longitudinal studies tracking transition experiences over the lifespan. Things start off good and then trail off later." (Professionals)                                                                                                                                                                                                                                                                                     |
| Institutional Factors                   | Exemplary Quotes                                                                                                                                                                                                                                                                                                                                                                                                                      |
| Diagnostic variation                    | [Understanding] "Why people some people, especially like medical professionals, seem to not be on the same page in regard to autism and how it's different for everyone." (YA)                                                                                                                                                                                                                                                        |
| Professional training                   |                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Health care                             | "Inadequate health care and research into medical issues in adulthood" (YA)                                                                                                                                                                                                                                                                                                                                                           |
|                                         | "More longitudinal about the transition to adult medical care from child care, particularly for females. I'm thinking like with OB/GYN and breast checks and all the things that in everyday life that we all have to do. And do those all get done? Can you find a practitioner who can do that in a way that is comfortable for the individual?" (Parent)                                                                           |
| Services and supports                   | "Maybe consequences of being unable to get support. Maybe even things like substance problems and issues, cause there's a lot of pressure I feel put on people like me. Like an autistic individual to do a bunch of stuff like paperwork, medical stuff and insurance things, and I feel like there's a lot of pressure." (YA)                                                                                                       |
| Access                                  | "Examining crises triggered by the loss of support services" (Professionals)                                                                                                                                                                                                                                                                                                                                                          |
|                                         | "Or how they struggle to get support ... like that I haven't even told my therapist because it's too much pressure on me to try think of, talk about that yet. But I plan to, even though it could be causing me lots of difficulty, just some of the social issues of wanting to speak to someone or a doctor is just overwhelming." (YA)                                                                                            |
|                                         | "There's a lot of trauma that goes into growing up autistic, even diagnosed or undiagnosed, and there needs to be some sort of avenue to unpack a lot of that." (YA)                                                                                                                                                                                                                                                                  |
| Impacts of systemic issues in adulthood | "We're having a lot of trouble with Social Security, and it's been going on almost 10 mo. But then that affects every else ... So, then he doesn't have access to the psychiatrists, the counselors. One thing affects another thing." (Parent)                                                                                                                                                                                       |
|                                         | "They're always at home, and they have no education. And maybe they get their Social Security check, right? But then that gives them more anxiety, because they don't get out. That gives them more self-doubt. That gives them less confidence in themselves." (Parent)                                                                                                                                                              |
|                                         | "Adulthood has no options... And if you are seen as more challenging, even the d programs don't want you. No support staff will work with you. I have 25- and 26-y-old peers sitting at home with parents, because literally no d program will take them. A support staff watches a peer from outside his home, so his mom can run grocery errands. No staff is willing to work hands-on with him. What kind of a life is this?" (YA) |
| Services and supports                   | "Programmatic factors of success" (Professionals)                                                                                                                                                                                                                                                                                                                                                                                     |
| Efficacy                                | "Understanding the impact of mental health presentations and treatment options. What treatments are people using, and what works?" (Professionals)                                                                                                                                                                                                                                                                                    |
|                                         | "Developing and testing college support models;" "exploring college systems that effectively support autistic young adults;" "what do autistic students need within the college environment?" (Professionals)                                                                                                                                                                                                                         |
|                                         | "Is there some way to look at best outcomes from services? ... either by satisfaction from adults with autism, and the parents, or best outcomes from 10 y down the road?" (Parents)                                                                                                                                                                                                                                                  |
|                                         | "Nobody is taught how to emotionally regulate, and it's so hard to learn when you're always overstimulated." (YA)                                                                                                                                                                                                                                                                                                                     |
|                                         | "Evaluation of voc rehab services that they provide ... What's happening to them once they let go of them, you know, close the voc rehab case? I want to know after 6 mo.. after a y..?" (Parents)                                                                                                                                                                                                                                    |

| TABLE 4 Continued                                                             |                                                                                                                                                                                                                                                                                                                                                                                                    |
|-------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Institutional Factors                                                         | Exemplary Quotes                                                                                                                                                                                                                                                                                                                                                                                   |
| Supporting autistic transgendered adults                                      | "I was in mental health systems for so long... but this [autism] wasn't something that was noticed. And being a trans person, it's been kind of confusing navigating those systems." (YA)                                                                                                                                                                                                          |
| Transition services and navigation                                            | "When is transition starting for nonspeaking autistic people? If it's commonly starting later, why is that?" (YA)                                                                                                                                                                                                                                                                                  |
|                                                                               | "What supports stop? And could they feasibly continue through to adulthood?" (YA)                                                                                                                                                                                                                                                                                                                  |
|                                                                               | "What are the services that are mandated that apply to transition? And how do the different states and agencies acknowledge and provide said services, breaking those services down into the classic categories: Housing, employment, health care, to include psychiatric services, as well. And what agencies are required to provide those mandated services?" (Parents)                         |
|                                                                               | "I think it's a confusing system to get Social Security or SSI. I think guardianship is also confusing and it's expensive and families don't know to plan for that." (Parents)                                                                                                                                                                                                                     |
|                                                                               | "What research is about the steps to being able to get a job, and keep a job? And what does that job need to be starting out, and then when they're 22, 25, 28, 33? ... What is best practices in terms of that? Because we kind of just have it in our head like, oh, they're 18, they're going to graduate from high school, then maybe take some classes and then they'll get a job." (Parents) |
| Variation in experiences                                                      | "Culturally responsive and culturally relevant approaches to transition meetings with IEP teams;" "culturally competent outreach and communication methods, including languages other than English." (Professionals)                                                                                                                                                                               |
| Cultural identity, language, gender identity, race/ethnicity, and backgrounds | [They should study] "autistic people in prisons." (YA)                                                                                                                                                                                                                                                                                                                                             |
| Community Factors                                                             | Exemplary Quotes                                                                                                                                                                                                                                                                                                                                                                                   |
| Driving and Transportation                                                    | "Driving is very important, because driving and housing are often barriers to employment." (YA)                                                                                                                                                                                                                                                                                                    |
|                                                                               | "How autistic adults navigate outside environments like grocery stores and public transit." (YA) "... The transportation thing gets to me a lot because I do get overstimulated with noise. But it's not like I can afford to take an Uber everywhere." (YA)                                                                                                                                       |
| Employment                                                                    | "How about barriers to hiring people with autism for the employers? ... Is it that they're unaware of what these disabilities bring? Or is it that they can't recognize the good stuff that comes from our kids, too?" (Parents)                                                                                                                                                                   |
|                                                                               | I think it is well-researched that autistic people are more likely to be unemployed, but people don't really say why. So, I think there should be more research on why aren't autistic people being hired." (YA)                                                                                                                                                                                   |
|                                                                               | "Who is employing autistic young adults ... besides the programs for geniuses like Microsoft?" (Parents)                                                                                                                                                                                                                                                                                           |
| Impact of moving                                                              | "How does moving from 1 county to the next, or like exiting one's space of origin if they lived in the same home for a long time, impact autistics. And then, I was specifically thinking that, in terms of autistic folk of color, if they're moving from 1 predominant like cultural space to another." (YA)                                                                                     |
| Nonspeaking autistic adults                                                   | "Stratifying the lived experience, based on level of support needs." (YA, nonspeaking)                                                                                                                                                                                                                                                                                                             |
| Community participation                                                       | "Study what happens when a person loses all hope and all their hope is taken from them, and they are locked up with no opportunity to ever speak on their own behalf. Find out how many nonspeaking autistics have been put in homes and had all their rights taken. Also, study the death rate of how many have died in these homes." (YA)                                                        |
| Variation in experiences                                                      | "... people feel different ways about autism. People from different regions. [Researchers should study] anything that could impact how they feel about cultural identity. I think there's so many things that really influence how one sees it [autism]. ... I think that's like a common misconception that everyone feels really the same way about it." (YA)                                    |
| Cultural identity, language, gender identity, race/ethnicity, and backgrounds | "Researching the best ways to support trans folk in the community" (YA)                                                                                                                                                                                                                                                                                                                            |
| Sociopolitical Factors                                                        | Exemplary Quotes                                                                                                                                                                                                                                                                                                                                                                                   |
| Discrimination                                                                | "The other issue that there's not so much out there is the intersection of ableism and racism. Because I do wonder to what extent my son's experience with trying to secure employment also has to do with racism." (Parent)                                                                                                                                                                       |
| Financial accessibility                                                       | "Because I get [paid], I no longer qualify for SSI benefits, even though I have all the challenges and needs of a higher support-needs person, I have been kicked off all state benefits. My family picks up the tab for all supports now, which seems very unfair and how long can they keep supporting me?" (YA)                                                                                 |
|                                                                               | "So, our son, he did get a college degree and he got his first job, but this first job doesn't pay enough to live, you know?" (Parents)                                                                                                                                                                                                                                                            |

| TABLE 4 Continued                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Sociopolitical Factors                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | Exemplary Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | "Getting on some type of insurance is an obstacle for many folks, especially if you don't have any means to pay a premium..." (YA)                                                                                                                                                                                                                                                                                                                                     |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | "Study how if you can't be given a way to earn a decent income, you are condemned to poverty simply because of motor impairments." (YA)                                                                                                                                                                                                                                                                                                                                |
| Self-determination                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | "Guardianship is a loss of rights for a severe nonspeaker with autism like myself.... Supported decision-making is the only acceptable choice for free adults in an independent society like ours. Independence should never be dependent on the ability to control your body...Those with disabilities like me have had their rights taken away simply because they couldn't say stop." (YA, nonspeaking)                                                             |
| Services                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | "Raising awareness and providing support for crisis prevention and intervention;" and "crisis intervention and support, including the risk of losing support and services." (Professionals)                                                                                                                                                                                                                                                                            |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | "Identifying ways to reduce waiting lists for housing" (Professionals)                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | "My daughter went to school through 21. Literally, the d she turned 21, all of her in-home services stopped. So that was awful because it just cut off, and then she finished school for the y." (Parents)                                                                                                                                                                                                                                                             |
| State and local variation in services                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | "One of the things that I notice is that it's locally different. The policies are different from state to state. They're different from city to city. And even the culture of voc rehabs can be different. Even if the policies are the same, they can be different from city to city. So, you never know what's available and what you're gonna get per those silos and the barriers of the silos, so to speak. It's difficult, very difficult to navigate" (Parents) |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | "How many did go to voc rehab? And what voc rehab did they go to? And what was provided, is it regionally different? And what were those outcomes? (Parents)                                                                                                                                                                                                                                                                                                           |
| <p>Social–ecological levels are defined as follows. Family and interpersonal-level factors, characteristics of households or family systems and relationships with nonfamily members; institutional level factors, nature of, participation in, and the characteristics of institutions or organizations that people interact with; community-level factors, sociodemographic features of a person's location (eg, regional economics and services availability). Sociopolitical level factors, societal norms and policies (rules, regulations, and laws) that influence the design, availability, and delivery of services, supports, and assistance.<sup>29</sup> IEP, individualized educational program; OB/GYN, obstetrician gynecologist; voc, vocational; YA, young adult.</p> |                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |

income levels without losing benefits > anxiety and depression about quality of life).

Need for Information and Resources

Overwhelmingly, focus group participants expressed desperate needs for information and resources for navigating transitions into adulthood, adult diagnosis, and services. These topics are noted as practical recommendations in Supplemental Table 6 to reflect the need for information dissemination as a necessary component of healthy transitions, along with the need to create community-informed, user-friendly products that reflect the needs of subgroups of the autism population at local, state, and national levels.

DISCUSSION

This study built upon previous autism transitions research recommendations (see Table 1), further delineating specific priorities (see Table 4). Focus group data confirmed 3 critical areas of research, and Table 5 provides examples of expressed topics within these themes. Although some topics transcended the transition period, they represent the need for investigation into issues that cause enhanced vulnerability, which may compound across the life course if positive redirection, through supportive systems responses, is not achieved. Across all areas of services research, our understanding of what is needed to advance systems-level reform must be driven by the intentional and meaningful involvement of neurodiverse service system

users and those who support them, along with thoughtful consideration of how transitions into adulthood are defined, prioritized, and valued across cultural groups.

- 1. Analysis of population-level indicators of system performance to better understand factors of outcomes and support needs during transitions into adulthood.
- 2. Service delivery methods and programs to wrap around specific and diverse cultural needs during the transition to adulthood among marginalized groups.
- 3. Transformation of complex service ecosystems to broker connectedness across pediatric and adult systems, and to invoke and sustain systems change needed to forge integrated supports across adolescence and adulthood.

Additional focus group recommendations for systems and policy change included:

- 1. training health care professionals about variations in autism presentation in transition-age youth and how this variation contributes to individual service needs as youth age and move between and within systems;
- 2. building capacity to provide consistent, connected, and navigable care that is neurodiversity-affirming and culturally-responsive as autistic youth transition from child to adult-serving systems;
- 3. simplifying and streamlining application processes when moving from child to adult eligibility status (in

| <b>TABLE 5</b> Updated Autism Transitions Research Recommendations and Exemplary Topics |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              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| Cross-cutting Themes                                                                    | Cross-cutting: Our understanding of what is needed to advance systems-level reform must be driven by the intentional and meaningful involvement of neurodiverse service system users and those who support them. Research should prioritize collaboration with historically underresearched populations including nonspeaking autistic persons, gender and sexual minorities, people of color, and representatives of people with high levels of complex needs                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| Priority Areas of Investigation                                                         | <p>1. Analysis of population-level indicators of system performance to better understand factors of outcomes and support needs during transitions into adulthood. We need population-level data collection and reporting to track performance of service systems and identify targets for improvement to better meet the needs of autistic transition-age youth and young adults, and their care partners. Research priorities include understanding of variation in transition outcomes related to:</p> <ul style="list-style-type: none"> <li>○ Intersectionality: Identity (race/ethnicity, gender, sexual orientation, socioeconomic position), geographic location, and disability characteristics (including levels of support need and cooccurring diagnoses)</li> <li>○ Diagnostic processes: Experiences of people who were late diagnosed, undiagnosed, self-diagnosed, or misdiagnosed, and the impact of this experience on healthy transitions <ul style="list-style-type: none"> <li>■ Individual, family, and community-level impacts of limited, delayed, inadequate, or culturally incompetent support services</li> </ul> </li> <li>○ Service needs: Understanding service needs to support achievement of healthy life outcomes, as determined by youth (and/or their care partners), including: <ul style="list-style-type: none"> <li>■ integration of early and ongoing transition planning in schools and health care systems</li> <li>■ better supports for cooccurring behavioral and emotional concerns among autistic transition-age youth</li> <li>■ Mapping transition preparation onto anticipated changes in daily routines based on youth and family priorities for types of living arrangements</li> <li>■ Understanding the impact of sensory issues on multiple domains and identifying necessary accommodations</li> <li>■ Understanding implications of masking on functioning and access to care</li> <li>■ Transportation, including models for teaching driving and navigation within the community <ul style="list-style-type: none"> <li>○ Family supports, including understanding healthy roles of families in transition and functioning in supporting young adults. For example: <ul style="list-style-type: none"> <li>○ Understanding the experiences of family care partners and their support needs, given limited supply of direct support workers and limited family support options</li> <li>○ Understanding the economics of family care partners providing support for autistic transition-age youth and young adults</li> </ul> </li> </ul> </li> <li>■ Impact of guardianship (and its alternatives) on supportive decision-making during the transition years <ul style="list-style-type: none"> <li>○ Healthy life goals, including understanding what a healthy adult life looks like for different autistic people, and models of how to support transitioning toward healthy adult lifestyles</li> </ul> </li> </ul> </li> </ul> <p>2. Service delivery methods, and programs to wrap around specific and diverse cultural needs during the transition to adulthood among marginalized groups.<br/>We need research that examines the feasibility, effectiveness, dissemination, and implementation of promising programs and strategies for service delivery for marginalized groups of autistic transition-age youth. Research priorities include understanding of:</p> <ul style="list-style-type: none"> <li>○ Service delivery methods and programs that can meet the individualized and changing needs of marginalized autistic youth with intentional consideration of the needs of historically underresearched populations including nonspeaking autistic persons, gender and sexual minorities, people of color, immigrants and/or households where English is a second language, and representatives of people with high levels of complex needs.</li> <li>○ Intensive study of interventions for dyspraxia to better meet the expressed needs of nonspeaking persons</li> <li>○ Use of nonfamilial relationships for support (eg, peer mentorship models) during the transition to adulthood</li> <li>○ Trauma- and violence-informed service delivery methods to better meet the needs of multiply marginalized autistic transition-age youth</li> </ul> <p>3. Transformation of complex service ecosystems to broker connectedness across pediatric and adult systems, and to invoke and sustain systems change needed to forge integrated supports across adolescence and adulthood. We need research regarding the performance and coordination of complex service ecosystems to inform the system transformations necessary to address the needs of autistic transition-age youth and young adults, and their care partners. Research priorities include understanding of:</p> <ul style="list-style-type: none"> <li>○ Implications of service disconnections and development of service system interventions (via systems and policy improvements) to promote continuity of care, and to avoid the effects of accumulating disconnection and disengagement during the transition years</li> <li>○ Multisystem collaboration and integration to facilitate continuity of services and supports between high school and adulthood, and between child and adult serving systems of care</li> <li>○ Policy reforms needed to dismantle the “poverty traps” of public benefits and their unintended consequences</li> <li>○ Improvements needed to support successful employment and career development</li> </ul> |

programs like SSI and Medicaid) to avoid redundancy and maximize opportunities to transfer information about service and support needs across systems and over time; and

4. immediately increasing publicly available information on public benefits and services across jurisdictions (eg Medicaid, VR) to guide people seeking to move; and eventually increasing consistency and portability of these benefits and services, to facilitate equity in access to services within and across states.

Our research recommendations concur with priorities identified in recently published service research recommendations,<sup>30</sup> and current recommendations of the IACC.<sup>21</sup> The IACC prioritized adolescent and adult research regarding:

1. services: Improving equity of services access, culturally competent service provision, and need for systems navigation and caregiver supports;
2. lifespan needs: Improving approaches to adult autism diagnosis, services integration and coordination during the transition to adulthood, and opportunities to participate in community-engaged research;
3. infrastructure: Intentional diversity of sampling to enable a focus on variation in experiences and outcomes; and
4. cross-cutting needs: Consideration of service and support needs by sex, gender, and sexual orientation.

Our recommendations diverge by calling for attention to fragmented service system ecosystems which give rise to service disconnections, inefficiency, and ineffectiveness in achieving targeted outcomes, and inequities.

Our recommendations add specificity to previous transitions research recommendations in Table 1 by addressing emerging research issues such as variation in experiences related to diagnosis (eg, late-diagnosed, self-diagnosed), intersectionality, differing levels of support needed from family care partners, development of trauma and violence-informed service delivery methods for multiply marginalized youth, integration of supports across systems, and the need to address poverty as an unintended consequence of maintaining eligibility for public benefits.

### A Call to Rethink Transitions for Marginalized Groups

The dominant American conceptualizations of the transition to adulthood have focused on expectations among white populations that youth exhibit independence by moving away from one's home of origin and family, graduating from high school, getting married, having children, and developing financial stability.<sup>36,37</sup> Such conceptualizations do not align with all cultures or the perspectives of modern American youth. For example, Latine families report the importance of the family and interdependence

over independence, home life, and worries about the world outside of the home.<sup>38–40</sup> In a study of Black, Latine, Native American, and white parents of youth with developmental disabilities ages 13 to 22 years, Latine parents valued the involvement of extended family in the transition to adulthood process, rather than solely relying on formal service providers.<sup>38</sup> Latine families also valued self-sufficiency and desired youth to develop skills to grow independence at home rather than solely depend on family members which had been previously suggested by other studies. Thus, it is necessary to widen the conceptual scope of transition to include self-sufficiency and incorporate family support throughout the transition process,<sup>39</sup> when researching how a diverse group of autistic transition-age youth are moving through various systems.

Previous research on the Latine population highlights the need to conduct qualitative research to reconceptualize the transition to adulthood. For example, in discussions of transition, there are instances in which phrases may not be possible to directly translate from English to Spanish.<sup>41</sup> Active listening to Latine autistic youth and their families is needed to understand their experiences and needs, followed by working with them to build culturally informed interventions.<sup>42</sup> This will further require researchers to value the lived experience of the participants and facilitate the development of culturally adapted autism transition planning interventions.<sup>43</sup> These insights are equally applicable to research on any marginalized group of autistic youth and their family members. In summary, the results of this study, enhanced by intentional inclusion of autistic people with diverse identities, reinforce the need for cultural humility,<sup>44</sup> to inform research and solutions that are sensitive to the needs of autistic youth who are increasingly diverse in their intersectional identities.

### Limitations

Although focus groups were the unit of analysis in this study, individual participants likely influenced group topics via their perspectives and statements. Video content may have also influenced topics. Young adult groups were skewed toward college-educated and/or late-diagnosed individuals who were able to comprehend and communicate conversation-level discourse and discussion of topics related to their experiences. We attempted to balance this dynamic by intentionally recruiting parents of young adults with more intensive needs.

### CONCLUSIONS

Approximately 1.2 million autistic youth will reach the legal age of adulthood over the next decade. Our understanding of the needs of this complex and diverse group of youth remains underdeveloped, particularly regarding factors

contributing to inequities in service receipt and outcomes. Focus group data illustrated 4 priorities for future research regarding autistic transition-age youth. The updated transitions research agenda builds on previous recommendations by explicitly focusing on investigating and transforming the performance of complex service systems that are the basis of complicated and difficult-to-navigate transitions, and by illuminating the need to address cultural differences when planning transitions and service delivery.

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## ABBREVIATIONS

IACC: Interagency Autism Coordinating Committee  
LGBTQIA+: Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, and other identities  
RQI: rapid qualitative inquiry  
SSI: Supplemental Security Income  
VR: Vocational Rehabilitation

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