

A National Research Agenda for the Transition of Youth With Autism

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abstract

In this article, we outline a national research agenda to improve the transition to adulthood among youth with autism. We synthesized the results from 5 interconnected sets of activities: (1) a scoping review of published autism research and research priority statements, (2) a series of key informant interviews with stakeholders, (3) a 2-day National Research Agenda meeting, (4) a modified Delphi survey of stakeholders, and (5) 2 formal reviews of published literature on autism and transition. We identified 2 overarching priorities to advance research about autism and transition: (1) increased focus on community- and systems-level factors that influence outcomes with population-level approaches to measuring outcomes and (2) greater involvement of people with autism in establishing research priorities, designing research studies, and producing study findings and recommendations. We discuss how the life course framework can guide future inquiry that addresses gaps in extant research.

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Autism spectrum disorder (ASD) is a developmental disability characterized by difficulties with social communication, restricted and repetitive behaviors and/or interests, and clinically significant impairments in important areas of daily functioning.¹ An estimated 1 in 68 American children has ASD, and nearly 50 000 of these individuals transition into adulthood each year.^{2,3} A large proportion of these young adults experience poor outcomes across multiple domains, including employment, education, social engagement, independent living, and access to health and social care.^{4,5} In addition to high societal costs in health care and loss of economic productivity, unsuccessful transitions can increase the risk for poor health and social outcomes in later life.⁶⁻⁸ As the number of young adults on the autism spectrum continues to rise, so too does the need for research aimed at improving the transition into adulthood.

The Health Care Transitions Research Network (HCT-RN) for Autism Spectrum Disorder and Other Developmental Disabilities was launched in 2014 through a cooperative agreement with the Maternal and Child Health Bureau of the Health Resources and Services Administration. The current overarching goal of the HCT-RN is to advocate for research that improves health care transitions and promotes an optimal transition into adulthood among youth and young adults with ASD.⁹ In this article, we describe the development of the HCT-RN National Research Agenda that is aimed at informing our nation's emerging priorities and growing investment in this area.

METHOD

The University of California, Los Angeles Office of the Human Research Protection Program approved this study. To develop

the agenda, we synthesized the results from 5 interconnected sets of activities: (1) a scoping review of published autism research and research priority statements from funding and advocacy organizations, (2) a series of key informant interviews with stakeholders recruited for their extensive knowledge of autism and transition issues, (3) a 2-day National Research Agenda meeting in Washington, DC, (4) a modified Delphi survey of HCT-RN stakeholders, and (5) 2 formal reviews of published literature on autism and transition.

Scoping Review

We conducted a scoping review¹⁰ of research about autism and transition to provide background to the National Research Agenda Meeting described below. The primary aim of this unpublished scoping review was to map the current state of knowledge about the transition into adulthood among youth with autism. Drawing from a wide range of resources (including journals, editorials, conference proceedings, and Web sites of governmental and advocacy organizations), we conducted a broad scan of the available literature of the prevalence and correlates of transition outcomes among youth on the autism spectrum. We also compiled published research priority recommendations from funders, advocacy groups, and research efforts from other countries. We limited our review to resources that were published from 2000 to 2015 and combined the search term "autism" in succession with the following transition topic descriptors: community, employment, families, health and health care transitions, independent living, postsecondary schooling, psychosocial outcomes, safety and risk in the community, services, social engagement, and transition planning. After compiling the available literature, we collated findings into 5 major categories:

(1) background, in which the concepts and definitions related to each transition topic were described; (2) outcomes, in which the prevalence and distribution transition outcomes of adults with autism relative to other peer groups were overviewed; (3) predictors, in which the correlates of transition outcomes identified in the literature were reported; (4) interventions, in which interventions aimed at improving transition outcomes were reviewed; and (5) gaps in current research, in which statements about knowledge gaps and recommendations for future research were summarized.

Key Informant Interviews

We conducted interviews with 13 stakeholders. Details of the procedures are available in another article in this supplement.¹¹ Briefly, the stakeholders were recruited from membership of the HCT-RN and included 1 self-advocate, 4 parents and/or family members, 5 researchers, and 3 service providers.

National Research Agenda Meeting

In May 2015, 30 stakeholders from around the United States participated in a 2-day meeting in Washington, DC, including 5 federal agency representatives, 2 young adults on the autism spectrum, 4 parents of individuals on the autism spectrum, and 19 practice and research professionals representing the fields of medicine, developmental pediatrics, developmental psychology, sociology, education, child health policy, occupational therapy, speech therapy, epidemiology, organizational management, law, public relations, public health, and the nonprofit sector.⁹ We identified participants by professional networking through national autism research, practice, and advocacy communities. Professional facilitators led the meeting and produced written and graphic summaries. The meeting's

TABLE 1 Number of Respondents, Mean Ratings, and Rankings of Specific Research Aims Provided to Participants in Delphi Survey Round 2

	Research Aim Text	<i>n</i>	Mean	Rank
Research about services and programs				
1A	The longitudinal patterns of service use and related outcomes. (For example, how do people cycle in and out of eligibility for SSI and vocational rehabilitation?)	14	3.6	1
1B	The changing phenomenology of autism and how it influences service needs as individuals transition into adulthood	13	3.3	6
1C	Development of assessment tools and measurement approaches for service needs of youth or emerging adults	14	3.1	8
1D	How variations in institutional settings, policies or practices influence individual outcomes. (For example, how and/or why vocational rehabilitation access and outcomes vary by state for people who have similar challenges and/or backgrounds?)	13	3.4	5
Research about the interaction and coordination among people and organizations				
2A	Development of conceptual typologies, frameworks, and measurement approaches for systems-level factors that might influence transition processes and outcomes. (For example, how does interagency collaboration [or lack thereof] influence the transition service handoff from special education to adult service agencies?)	13	3.5	2
2B	How programs that nominally focus on helping a defined group of participants may also yield system-level benefits in terms of interagency collaboration, practices, or policies. (For example, project SEARCH aims to help high school students have internships and find jobs. However, the interagency collaboration necessary to implement project SEARCH may also yield system-level benefits, like facilitating interagency collaboration.)	14	2.9	9
2C	Evaluation of programs that intervene at the level of organizations, communities, networks of providers, etc, rather than at the level of individuals. (For example, collective impact approaches [eg, Halfon's example using the EDI/TECCS approach].)	14	3.4	4
How QoL and functional outcomes change				
3A	Development of assessment tools and measurement approaches for QoL of youth or emerging adults	14	3.2	7
3B	How does variation in institutional settings, policies, and practices people are exposed to at an earlier stage during the life course impact the transition to adulthood?	13	3.5	3

EDI, Early Development Instrument; SSI, Supplemental Security Income; TECCS, Transforming Early Childhood Community Systems.

organizers and professional facilitators analyzed meeting minutes to extract key themes and summarize statements about priorities. The summary was shared back with participants to verify their accuracy and completeness.

Modified Delphi Survey

Iterative Delphi techniques are often used to reach consensus on a statement of priorities. We employed a modified Delphi technique in 2 rounds of online surveys. We used a list of potential priorities derived from the scoping review and the national meeting in the first round (rather than an open-ended question). In keeping with the HCT-RN's emphasis on the social ecological factors that influence outcomes,⁹ we excluded potential priorities that focused exclusively on clinical treatments (eg, individual-level behavioral or medical treatments for symptoms or behaviors). The round 1 survey asked

respondents to rate the importance of 26 potential research priorities on a 4-point scale (0: of little importance; 1: somewhat important; 2: important; 3: very important). Participants could also provide written comments for each item and suggest additional priorities that were not yet listed.

On the basis of a careful review of the written comments and ratings, we revised and combined potential priorities from round 1. We also revised our rating scale to a 5-point Likert scale (0: of little importance; 1: somewhat important; 2: neutral; 3: important; 4: very important). Because we wanted to inform the establishment of future research priorities with funders (eg, foundations and federal agencies), we framed round 2 priority statements using specific aims language commonly found in program announcements and requests for proposals (see Table 1).

In both rounds, participants rated research priorities in terms of its importance to the health, family, and social needs of youth on the spectrum as they transition into adulthood. We invited participants to complete the second round of surveys regardless of their participation in the first round.

Reviews of Published Literature

We wrote 2 literature reviews (included in this supplement) of factors related to the transition experiences and outcomes of young adults on the autism spectrum.^{12,13} We restricted our analyses to peer-reviewed studies published in the United States, had ASD as a primary focus or main comparison group, and were focused on the transition outcomes or experiences of transition-aged youth with autism. Please refer to these articles in this supplement for complete methodological details. In the first article, we reviewed

studies published from 2005 through 2016 to identify social ecological correlates of young adult outcomes.¹² In the second article, we reviewed qualitative studies published from 2000 through 2016 that examined the barriers and facilitators to supporting positive adult outcomes from the perspectives of young adults, their families, and professionals.¹²

RESULTS

Scoping Review

We identified 5 gaps in extant research on autism and transition: (1) the limited understanding of the social-ecological determinants of transition outcomes; (2) the poor understanding of the distribution of support needs among adults with autism; (3) few longitudinal studies of adults with autism, including the current generation of young adults; (4) outcome findings cannot be compared across studies because of small sample sizes, heterogeneous sampling approaches, and inconsistent approaches to measurement; and (5) frequently used conceptual frameworks of quality of life (QoL) are outdated and not in sync with contemporary understanding of development during emerging adulthood.

To stimulate discussion at the National Research Agenda Meeting, we provisionally identified the following 8 priorities for future research: (1) develop conceptual frameworks for organizing future investigation of life course and social-ecological determinants; (2) collect data at multiple ecological levels; (3) devise ways to measure and stratify the population by need for support to more directly inform policy and service system design; (4) launch population-based longitudinal studies that include transition-aged youth; (5) identify measures that can reliably and validly examine change over time; (6) include measures

also used in studies of other populations to enable comparative analyses; (7) develop measures that can characterize QoL across the heterogeneity of the autism spectrum and across the receipt of a wide array of services, program models, and outcomes; and (8) develop QoL indicators that are relevant and important to people on the autism spectrum and their families.

Key Informant Interviews

One prominent theme across stakeholders was the need for research to examine community-level characteristics, including financing of services, interagency coordination, service system dynamics, and policies. Stakeholders often noted the fragmented nature of postsecondary services as a major obstacle to achieving positive outcomes for individuals. This was typically observed in contrast to the fact most extant research is focused on modifying individual behavior rather than the community context of development. Refer to Crapnell and co-workers¹¹ for a detailed presentation of results.

National Research Agenda Meeting

Participants shared a wide range of ideas about needed research priorities reframing how we think about autism transition issues using an ecological model and life course perspective. The stakeholders' primary research agenda item that emerged was a need to increase examination of community- and systems-level factors and interventions that impact outcomes at an aggregate population level. In addition, participants agreed that future research should include a strengths-based ability perspective to counteract the predominant deficit-based disability framework used to organize most research on autism. Participants also affirmed the need for study designs that acknowledge individuals with autism as valued

members of the community and include their voices in the research process. Participants also discussed challenges related to providing and financing health and social care. For example, participants identified the lack of autism training among general internists as a prominent health care challenge.

Modified Delphi Survey

Nineteen stakeholders participated in round 1 and 14 participated in round 2. The mean ratings per item for both rounds are presented in Tables 1 and 2. Round 1 results revealed an emphasis on the importance of the availability and accessibility of adult services and the coordination and integration of health, mental health, and social service systems. These results and open-ended written comments highlighted the importance of 3 overarching priority areas that we used to organize round 2 questions:

1. Research about services and programs including issues of availability, access, client experiences, how need for types of services change across the lifespan, and how to individualize services to unique needs;
2. Research about the interaction and coordination among people and organizations involved in supports and services including autistic adults, family members, health and mental health organizations, developmental services systems, vocational rehabilitation, etc; and
3. How QoL and functional outcomes change over time and vary across individuals, groups, and populations.

Round 2 mean ratings clustered tightly in a range from 2.9 to 3.6, suggesting we had come close to consensus. The following items had the highest mean ratings: (1) the need for research about the longitudinal patterns of service

TABLE 2 Number of Respondents, Mean Ratings, and Rankings of Research Priorities Provided to Participants in Delphi Survey Round 1

	Topic	<i>n</i>	Mean	Rank
1	Individuals diagnosed as adults with ASD	18	1.6	25
2	Coordination and integration of health, mental health, and social service systems	19	2.8	1
3	Coordination across individuals, their families, and professionals	19	2.4	6
4	Availability and accessibility of adult services	19	2.8	2
5	Changing service needs across the lifespan	19	2.4	7
6	How to individualize and tailor services to meet an individual's unique needs	19	2.4	3
7	Essential components of a transition plan to promote quality adjustment to adulthood	19	2.2	12
8	Neurodiversity and inclusion of individuals with ASD	19	2.2	13
9	Stereotype threat: how individual, family, and/or professional perceptions shape transition and adjustment to adulthood	19	1.9	18
10	Measuring community capacity to support individuals with ASD	18	2.2	11
11	Conceptualization and measurement of QoL	18	2.0	15
12	QoL differences between individuals with and without ASD	19	1.2	26
13	Self-advocacy	18	2.1	14
14	Ongoing family burden	19	1.6	24
15	Factors resulting in health disparities for underserved populations	19	2.4	4
16	Health, safety, mortality risk, and reproductive health	19	1.8	22
17	Availability and efficacy of interventions for adults on the autism spectrum	19	2.3	9
18	Cost-effectiveness of interventions for individuals on the autism spectrum	18	2.0	16
19	Skills that should be targeted in childhood that are associated with better adult outcomes	18	2.4	5
20	How timing and receipt of services in childhood impact QoL in adulthood	19	1.9	19
21	Social networking and capital of individuals with ASD and their families	18	1.9	20
22	Barriers and facilitators to engaging and sustaining community engagement in supporting individuals on the autism spectrum	19	2.4	8
23	Training and support for employers	17	2.2	10
24	Transitions and adjustments across care settings and environments	18	2.0	17
25	Availability of residential options	16	1.9	21
26	Leadership development for youth on the autism spectrum	18	1.7	23

use and related outcomes; (2) research on the development of conceptual typologies, frameworks, and measurement approaches for systems-level factors that might influence transition processes and outcomes; and (3) research on the ways in which 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.

Reviews of Published Literature

Taken together, our literature reviews highlight the importance of establishing an evidence base for family-, community-, and population-level interventions to complement the field's more common focus on modifying the person with autism. In our review of correlational studies, we found that there is scant research about social ecological factors that may affect transition outcomes. When measured at all, the majority

of social ecological correlates found in studies were at the family level. We have little understanding of interpersonal, social capital, social network, community, service system, and policy factors that may impact transition outcomes. Our review of qualitative literature revealed that poor transition outcomes are a function of several factors, including poor person-environment fit, uncertainty about the roles of parents, and a lack of comprehensive or integrated services. Across many studies, stakeholders reported that individualized supports and environmental modifications, the diversification of supports, and information sharing between parents and providers may help to improve the transition outcomes of young adults.

CONCLUSIONS

A top research priority that emerged consistently across all efforts is the

need for more studies to combine a focus on community- and systems-level factors that influence outcomes with population-level approaches to measuring outcomes. There have been notable efforts in other fields to create and test collective impact approaches aimed at improving outcomes related to a specific transition. For example, the national Transforming Early Childhood Community Systems initiative helps to build the capacity of communities to improve school readiness among children entering kindergarten by using an aggregate measure of school readiness, the Early Development Instrument, to inform place-based interventions.^{14,15} The vast majority of autism research and research funding to date has been focused on understanding person-level correlates of outcomes and clinical interventions to modify the behavior and skills of individuals on the spectrum.^{3,16,17} Many people at the Agenda meeting and in key informant

interviews noted that postsecondary transition outcomes at a population level remain poor despite billions spent on research and interventions for modifying the development of young children. The importance of early intervention was repeatedly affirmed in the context of comments pointing out the need to also understand factors beyond clinical interventions that can influence young adult outcomes.

Another notable research agenda priority was more ethical in nature: the need for increased involvement of people on the autism spectrum in establishing research priorities, designing research studies, and the production of findings and recommendations from studies. This finding is consistent with autism research agenda setting efforts in the United Kingdom.¹⁸ In addition, no single methodological recommendation emerged as predominant. Agenda meeting participants and reviewed studies noted a wide range of approaches for greater involvement in research, including community-based participatory research, the use of advisory panels, and the hiring of autistic research staff members.

Our approach to establish a national research agenda on autism and transition had several notable strengths: a multimodal approach that drew from 5 strands of activity and mixed methods, as well as the inclusion of many stakeholder perspectives beyond researchers, including adults on the autism spectrum, parents, service providers, health care professionals, regulatory and government staffers, and members of advocacy groups. A limitation was the snowball sampling approach to recruit people known to the study team as leaders in the field who would likely have a high degree

of familiarity with the salient issues for both the key informant interviews and the Agenda meeting. This may have missed hearing from people with important alternative perspectives who have not yet had opportunities to emerge as leaders in the field.

ABBREVIATIONS

ASD: autism spectrum disorder
 HCT-RN: Health Care Transitions Research Network
 QoL: quality of life

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