

Introduction to Transitions in the Life Course of Autism and Other Developmental Disabilities

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abstract

The Health Care Transitions Research Network for Autism Spectrum Disorder and other Developmental Disabilities and the Life Course Research Network, both funded by the Maternal and Child Health Bureau, invited articles for this Supplement. Our goal in this Supplement is to highlight and explore developmental and transition-related challenges over the life course of individuals on the autism spectrum and other neurodevelopmental disabilities, discuss the clinical and practice implications of these issues, highlight gaps in knowledge, and identify directions for future research.

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Autism spectrum disorder (ASD) is characterized by persistent social communication and interaction deficits, restricted and repetitive patterns of behavior and/or interests, and significant impairments that adversely affect daily functioning.¹ The degree of disability that an individual experiences due to ASD is thought to be a joint product of impairment severity and societal accommodation (or lack thereof).^{2,3} The degree of disability may also fluctuate as individuals progress through the life course, which consists of an ever-evolving set of social roles.⁴ Researchers from diverse fields have highlighted the emergent, continuously developing, complex, and interactive nature of health as it develops over the life course. Specifically, health may be influenced by multiple determinants that operate in nested genetic, biological, social, and economic contexts that are subject to change, and different health trajectories develop as a product of cumulative risk and protective factors that accumulate from preconception to death.⁵ Understanding critical factors and pivotal periods during the life course is imperative if we are to develop policies and practices to support optimal health.

The Life Course Research Network was thus developed and funded in 2010 by the Health Resources and Services Administration's Maternal and Child Health Bureau to bring together expertise from a diverse virtual collaborative network of researchers, service providers, and thought leaders to examine the origins and development of health and inform meaningful and evidence-based changes in practice, systems, and policies affecting children and families toward the ultimate goal of improving health and reducing disease.

A major pivotal period requiring attention is the transition to adulthood, which is a critical turning

point in the life course when youth begin to take on adult roles and responsibilities. Transition (from adolescence to young adulthood) can frequently be complex and fraught with risks that can lead to poor outcomes for all children and youth.⁶⁻⁹ These complexities and risks are compounded for youth on the autism spectrum who are especially vulnerable because of difficulties with communication and social interaction, challenging behaviors,¹⁰ high rates of comorbid health and mental health problems,¹¹ and complex service needs as they age out of eligibility for special education and attempt to access adult systems of care.¹² Over 50% of young adults on the autism spectrum are completely disconnected from any employment or education opportunities during the first 2 years after high school, a rate significantly higher than their peers with other disability types even after adjusting for disability severity and family income.¹³ Across recent studies, young adults with autism from low-income households and those who are African American were often more likely to experience services disconnections and poorer outcomes.¹⁴⁻¹⁶

With ~60 000 youth on the autism spectrum turning 18 years old in 2016 based on projections from the 2015 Census Bureau estimate of the number of 17-year-olds in the United States and recent estimates of the prevalence of ASD in the United States,¹⁷ it is imperative that we understand the needs of youth and young adults on the autism spectrum so that we may develop and implement appropriate policies and practices to support their optimal transition to adulthood.

Recognizing the magnitude of these challenges facing this population of youth and emerging adults on the autism spectrum, through a cooperative agreement in 2014, the Maternal and Child Health

Bureau funded and supported the establishment of the Health Care Transitions Research Network (HCT-RN) for Autism Spectrum Disorder and other Developmental Disabilities (coprincipal investigators Kuo and Shattuck), which was designed as an interdisciplinary, multi-center research forum for scientific collaboration and infrastructure-building, with a focus on research designed to improve health care transitions and promote an optimal transition to adulthood among youth and young adults with ASD and which includes both adolescent and adult researchers across a range of disciplines reflecting attention to the health and development of the whole person. Stipulated goals of the HCT-RN include the development of a national research agenda on the transition to support the attainment of better physical, social, and vocational outcomes among youth and young adults with ASD; establishing transition services guidelines; piloting quality improvement approaches to improve transition outcomes; disseminating findings and information relevant to transition and autism; and commencing the work of building a national network of stakeholders and infrastructure to improve our nation's capacity to conduct transition research.

The work of the HCT-RN is anchored in the life course perspective promoted by both the Life Course Research Network and Shattuck's Life Course Outcomes research program at the A.J. Drexel Autism Institute. This comprehensive, holistic perspective understands human development in terms of social roles and transitions, relationships, and the contextual understanding of people's lives as rooted in specific historical times and social settings.^{4,18,19} However, despite evidence of poor outcomes in young adulthood, research on autism anchored in a life course framework

is relatively rare²⁰ and receives little funding relative to topics like neuroscience and genetics.²¹

HCT-RN GUIDING PRINCIPLES

To effectively address the multisector challenges youth on the autism spectrum experience as they transition into adulthood and varying levels of need, the HCT-RN has adopted 5 guiding principles as the foundation of all network activities. These 5 guiding principles include the following: neurodiversity and inclusion, ecological perspective, life course development, social determinants, and systems perspective.

Neurodiversity and Inclusion: All Activities of the Network Will Be Informed by Individuals on the Autism Spectrum and Their Families

In recent years, a growing autism self-advocacy movement has challenged the deficits-oriented *Diagnostic and Statistical Manual of Mental Disorders* description of ASD and offered an alternative interpretive framework emphasizing autistic differences (some of which might be framed as strengths in the right social context) as aspects of neurologic variation (also known as neurodiversity) that are often inextricably linked to identity.²² Consistent with the World Health Organization's International Classification of Functioning, Disability, and Health framework for understanding disability, it is suggested in this counter narrative that the degree of disablement experienced by any given person is jointly a product of impairment severity and societal accommodation (or lack thereof).^{2,3}

Ecological Perspective: Individuals With ASD Live in Family, Social, and Community Contexts That All Impact the Individual's Life Course Trajectory and Adult Outcomes

Authors of life course and ecological health development models

emphasize the importance of social and environmental determinants of health.^{23–25} In addition to health outcomes, a life course framework is used to emphasize the understanding of development in terms of social roles and transitions, social participation and relationships, the contextual understanding of people's lives as rooted in specific historical times and social settings, and the timing of events.^{4,18,19}

Life Course Development: The Ability of Individuals With ASD To Reach Their Full Potential in Adulthood Is Influenced by a Changing Mix of Resilience and Risk Factors Throughout Life

Authors of life course models emphasize a longitudinal perspective on individual development and recognize that early life events have a subsequent impact on later life course outcomes and trajectories.^{4,7,26,27}

Social Determinants: Adult Outcomes for Individuals With ASD Are Dependent on the Social (Political and Cultural Expectations, Beliefs, and Ideologies) and Economic Environments in Addition to Individuals' Characteristics

For the first time, Healthy People 2020 has included a separate goal for social determinants, that of "creating social and physical environments that promote good health for all."²⁸ Social determinants are broadly defined as "the conditions in the environments in which people are born, live, learn, work, play, worship, and age."²⁸ Specific measures include factors such as family socioeconomic status, social networks and supports, social norms and attitudes, access to health and social care, culture, and exposure to mass media, among others.²⁸ These factors in turn appear to affect health development both directly and indirectly, frequently cluster, may initiate future chains of risk, and can have different effects at different phases of the life course.

Improving understanding of these social and environmental influences on health is now understood to be a priority for the Maternal and Child Health Bureau.

Systems Perspective: To Improve Population-Level Outcomes for Adults on the Autism Spectrum, Researchers Should Focus on Discovering Strategies To Build Communities' Capacities To Create Opportunities for Success and Measure Results at the Population Level. Researchers Should Not Solely Focus on Modifying Individual Abilities or Symptoms

A defining feature of the lives of many people on the autism spectrum is a lifetime of engagement with service systems that provide health and therapeutic interventions, material support, education and training, and direct care. Getting diagnosed with an autism spectrum disorder is not just a medical event or service encounter. It is a doorway into a social role as a lifelong service user. Thus, understanding and intervening at the level of service systems are seen as essential strategies in the quest to improve outcomes. A unique feature of our approach to the HCT-RN will be the incorporation of systems theory so as to be equipped to address this facet of the autism experience.

This *Pediatrics* Supplement is an outgrowth of the work of the HCT-RN. To engage a diverse, interdisciplinary group of the experts in the fields of autism and childhood systems as well as the important perspectives of self-advocates and family members, we solicited article submissions from HCT-RN members via e-mail invitation. Our challenge to authors was to highlight and explore developmental and transition-related challenges over the life course of individuals on the autism spectrum and other developmental disabilities, discuss the clinical and practice implications of these issues, highlight gaps in knowledge,

and identify directions for future research. In addition, we include 3 commentaries, 2 from self-advocates and 1 from a parent advocate, to include the perspectives of those living most closely with the issues discussed in the research articles. We believe these articles are equally as important, if not more so, with

respect to defining a research agenda for the population of emerging adults on the spectrum. Collectively, the articles in this Supplement represent a dynamic blend of multidisciplinary perspectives and innovative methodologies. Our hope is that readers will be challenged to think about health and development in new

ways that can improve policies and practices.

ABBREVIATIONS

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

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