Executive Summary

This workshop brought together experts from various backgrounds and disciplines to explore high-priority research topics related to services and support for the transition from pediatric to adult care. The National Institutes of Health (NIH) is uniquely poised to coordinate health care transition research efforts as they relate to each Institute’s, Center’s, and Office’s (ICO) mission and vision. Thanks to various collaborations, this workshop synergized between disciplines to tackle transition across diseases and further leverage the research supported at NIH. NIH funding from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), Office of Behavioral and Social Sciences Research (OBSSR), the National Cancer Institute (NCI), and the NIH Helping to End Addiction Long Term℠ (HEAL) Initiative provided support for this Workshop.

Video recordings of the workshop are available at:

- Day 1: https://videocast.nih.gov/watch=38570 (as of December 15, 2020: 954 Total Views)

Introduction and Welcome Remarks

Sonia Lee, Ph.D., and Diana Bianchi, M.D., Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

Dr. Lee welcomed participants to this workshop. Dr. Bianchi described the Trans-NIH Pediatric Research Consortium, which had initiated this workshop and includes representatives from every NIH Institute and Center (IC) involved in child health research. Dr. Bianchi also described links between the research themes of the NICHD Strategic Plan 2020 and the theme of this workshop, as well as components of the NIH-Wide Strategic Plan for COVID-19 Research that pertain to children, adolescents, and young adults.

Background Context: NIH Portfolio Analysis and Goals for Meeting

Dara Blachman-Demner, Ph.D., Office of Behavioral and Social Sciences (OBSSR); and Samantha Calabrese, M.P.H., NICHD

Looking across NIH, both a NIH Portfolio and NIH-supported publication analysis were conducted. The Trans-NIH Pediatric Research Consortium working group found that 14 NIH ICs have supported 166 health care transition research grants, totaling $65 million. A total of 96 NIH-supported articles on transition were published between 2008 and 2020, including 69 empirical research reports. These analyses indicate health care transition research remains an emerging area of scholarship and will continue to contribute research outputs like publications and measures in the future.
Session 1: Overview of Transition Research and Practice

Health Care Transition Research Consortium and History of Transition Research
Cecily Betz, Ph.D., RN, University of Southern California Keck School of Medicine

The Health Care Transition Research Consortium brings together transition researchers, practitioners, advocates, and consumers. In addition to an annual research symposium, the consortium offers monthly conference calls and sponsors a special interest group, Health Care Transition and Self-Management, in the Pediatric Academic Societies. Dr. Betz also reviewed the history of health care transition research, which was first featured in a journal article in 1981.

Six Core Elements of Health Care Transition
Patience White, M.D., M.A., Co-Project Director, Got Transition and George Washington University

A 2011 report from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians led to the identification of the six core elements of health care transition for all youth.1 Got Transition, the federally funded national resource center on health care transition, offers customizable tools for different practice settings, including for youth who are making the transition to adult health care and clinicians. Got Transition also provides resources for health care transition measurement, including outcome feedback surveys for youth or young adults and their parents or guardians and for clinicians.

Ongoing Systematic Review: Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs
Kim Wittenberg, M.A., Agency for Healthcare Research and Quality (AHRQ)

The National Cancer Institute commissioned an AHRQ systematic review, Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs, in response to the Childhood Cancer Survivorship, Treatment, Access, and Research Act (STAR Act). The three draft key questions for this review are to address the effectiveness and harms of care interventions for children with special health care needs and their families and caregivers, provider-focused training and implementation strategies, and tools to facilitate communication between pediatric and adult providers. The draft report will be released for public comment in summer 2021, and the final report will be available in fall 2021.

Session 2: Participant Panel—Voices of Transition

Panel members included four adults ages 21 to 30 who had completed the transition to adult health care—Carlos Davis, Scottie Vogel, Kiara Howard, and Maurice Williams—as well as Robert Vogel, Mr. Scottie Vogel’s father; and Allison Agwu, M.D., the physician of Ms. Howard and Mr. Williams. This session consisted of questions from the workshop audience and responses from panel members. Topics discussed included the transition experiences of the four young adults, what they wished had happened differently to assist them with their transitions, and sources of support during the transition.

Session 3: Measures of Success: Defining and Measuring Transition Outcomes

Defining and Measuring Transition Outcomes
Maria Ferris, M.D., Ph.D., University of North Carolina

The STARx (Self-management and Transition to Adulthood with Rx=treatment) program develops and improves self-management skills and disease knowledge among adolescents and young adults with chronic health conditions. STARx has developed two transition readiness instruments for completion by providers and patients. Most studies that have used these and other questionnaires to measure health care transition readiness have collected cross-sectional data only, so longitudinal evidence is lacking. Dr. Ferris described theoretical models for health care transitions and findings from studies that used transition readiness measurement tools.

Measuring Patient-Reported Outcomes in Youth with Disabilities That Affect Cognition
Christina Nicolaidis, M.D., M.P.H., Portland State University

Most measurement tools use vocabulary that is difficult to understand or confusing for adults with disorders that affect cognition. These instruments can be adapted for use in this population by, for example, simplifying sentence structure or changing difficult words. A new Academic Autism Spectrum Partnership in Research and Education project will identify outcomes to measure when evaluating services for adults with autism and how to measure these outcomes. The project will also test a set of patient-reported outcome measures for adults with autism.

Pediatric Cancer Survivors Head to Adult Care: How Will We Know Whether It Works?
Christopher Recklitis, Ph.D., Harvard Medical School

Self-reported data from people who might have cognitive impairments have limited value. For example, these young adults might not remember whether they visited an emergency department. Some adult survivors of childhood cancer have cognitive impairments, so researchers often rely on proxy reports. Parents are sometimes asked to be sources of information on young adults’ transition readiness or experiences and sometimes to report on their own readiness, representing an area in transition research that could benefit from more clarity. Administrative data can overcome some of these limitations, but they can be difficult to obtain, because young people tend to move frequently.
Session 4: Examples of Success: Transition Interventions

Using the Positive Youth Development Framework to Guide Transition Interventions
Gary Maslow, M.D., Duke University

In the Positive Youth Development model, the ecological and internal assets of adolescents lead to positive developmental characteristics of competence, confidence, character, caring, and connection. The Peer i-Coaching for Activated Self-Management Optimization (PiCASO) (NCT03938324) intervention for people ages 16 to 22 with a chronic health condition uses a telephone- and text-based interface to offer access to knowledge, experience, and support from a trained peer coach. The intervention helps participants develop self-management skills, become actively engaged in their care, and navigate typical developmental transitions.

Targeting Engagement in Mental Health Treatment in Young Adults
Sarah Narendorf, Ph.D., M.S.W., University of Houston

The Just Do You program for young adults with serious mental illness (NCT03423212) is a brief engagement program in which a provider team of a licensed clinician and a peer addresses mistrust, lack of hope for the future, concerns about stigma, mental health literacy, and sense of efficacy. The aim is to increase young adult engagement in personalized recovery-oriented services.

Engaging Families and Communities in Planning for Transition Support
Roberta Rehm, Ph.D., RN, University of California, San Francisco

The transition-to-adulthood planning study in youth ages 14 to 26 with a disability and complex chronic conditions showed that support for transition planning from educators and health care providers was inconsistent and not coordinated. In one intervention, a transition facilitator assesses the needs of each youth and family, develops a family-centered transition plan, and provides education about the transition process. An ongoing study, Resilience in Action: Building Resilience and Appropriate Independence in Young Adults with Autism (NCT03842332), helps young adults with autism maintain and/or build skills that will enhance their health and quality of life after they leave the school system.

---

Day 2: Welcoming Remarks

*Christine Hunter, Ph.D., Deputy Director, OBSSR*

Behavioral and social sciences research is essential for filling many research gaps to promote a more successful transition from pediatric to adult care. Dr. Hunter described the three scientific priorities in the [OBSSR 2017–2021 Strategic Plan](https://obssr.nih.gov/wp-content/uploads/2018/01/StrategicPlan_2017_2021.pdf) that align well with the goals of this workshop.

Session 5: Identifying Key Transition Challenges and Opportunities for Implementation

**Challenges During the Transition to Adult Health Care in Youth with Spina Bifida**

*Grayson Holmbeck, Ph.D., Loyola University Chicago*

The [Chicago Healthy Adolescent Transition Study](https://www.chicagobaby.org/chats/) (CHATS) revealed that youth with spina bifida have significant social and neurological difficulties. CHATS-2, a longitudinal study in 140 children, is studying the transfer of medical self-management from parents to children during late childhood and adolescence and the transition from pediatric to adult health care. Measurement challenges in this population include that youth who are given new self-management responsibilities might not have the skills to take on these responsibilities or might have the skills but not the responsibilities. In addition, measures developed for other conditions must be adapted for use in people with spina bifida, and one-third of youth with spina bifida cannot complete these measures or acquire many self-management skills or adherence behaviors.

**Challenges in Transition to a Transitional Care Program for Patients with Urologic Disorders**

*Michael Hsieh, M.D., Ph.D., George Washington University and Children’s National Hospital*

The [Clinic for Adolescent and Adult Pediatric-Onset Urology](https://www.cnie.org/) (CAPITUL) is a joint venture between Children’s National and George Washington University Hospital. Dr. Hsieh has clinical privileges at both institutions, where he provides care to children, adolescents, and young adults. Patients who receive pediatric urological care at Children’s National are referred to CAPITUL at the appropriate age. A challenge for CAPITUL is that several insurance plans accepted at Children’s National are not accepted at George Washington.

**Integrating Digital Health into Care of Adolescents and Young Adults with Sickle Cell Disease**

*Jane Hankins, M.D., St. Jude Children’s Research Hospital*

The [Sickle Cell Transition E-Learning Program](https://www.sicklecelldisease.org/transition) helps adolescents with sickle cell disease (SCD) make a successful transition to adult medical care. Patients stay an extra hour after their appointment to learn self-care basics, including scheduling appointments, refilling prescriptions, and using insurance cards. The InCharge Health mobile app reminds adolescents by text message to take their hydroxyurea and offers educational information on the drug and the disease. A second mobile app for providers, Hydroxyurea Toolbox, provides SCD clinical guidelines adapted for pediatric and adult providers as well as guidance on prescribing hydroxyurea and monitoring its effects.

---


Health Literacy in Teens with Special Health Care Needs
Deena Chisolm, Ph.D., Nationwide Children’s Hospital

Children with special health care needs use more health care services than their healthy peers and continue to do so into adulthood. Once they become adults, approximately one-third have unmet medication needs. Half of adolescents do not have adequate health literacy to use health information to make decisions. Less-than-adequate health literacy is associated with a lower likelihood of perceiving that the provider spends enough time with them, that they received the information they needed from the provider, or that the provider was sensitive to their family’s values and customs. However, young people with adequate e-health literacy (ability to obtain, understand, appraise, and apply electronic health information) can schedule appointments, refill prescriptions, visit their health care providers, and track their health records online. Health care transition for adolescents with substance use disorder, including opioids, was discussed as well as challenges to ensuring these young people receive the treatment they need and make a successful transition to adult care.

Summary and Discussion
Session Chairs: Dara Blachman-Demner, Ph.D., OBSSR; and Sonia Lee, Ph.D., NICHD

Dr. Lee provided a brief recap of the workshop, including key messages from each session. She also listed several research gaps identified during the presentations and discussions as well as audience comments not addressed during the discussions. Examples of research gaps included the impact of structural racism and health disparities on health care transitions for underserved populations, policy implications of transition research, longitudinal cohorts or national registries for chronic conditions to better understand health care transitions, and applicability of research on health care transitions in youth with chronic conditions to typically developing adolescents.
Planning Committee:

- Sonia S. Lee, Ph.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)
- Samantha C. Calabrese, M.P.H., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)
- Dara R. Blachman-Demner, Ph.D., Office of Behavioral and Social Sciences (OBSSR)
- Michelle Mollica, Ph.D., National Cancer Institute (NCI)
- Lori Wiener, Ph.D., D.C.S.W., L.C.S.W.-C., National Cancer Institute (NCI)
- Marrah Lachowicz-Scroggins, Ph.D., National Heart, Lung, and Blood Institute (NHLBI)
- Aruna Natarajan, M.D., Ph.D., F.A.A.P., National Heart, Lung, and Blood Institute (NHLBI)
- Susan Mendley, M.D., National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
- Lynn Adams, Ph.D., National Institute of Nursing Research (NINR)
- Denise Juliano-Bult, M.S.W., National Institute of Mental Health (NIMH)

Acknowledgements:
The Planning Committee would like to acknowledge Debby Berlyne and Palladian Partners (8484 Georgia Avenue, Suite 400, Silver Spring, MD 20910) for their assistance preparing the Executive Summary.