Navigating Pediatric to Adult Health Care: Lost in Transition Workshop
September 30, 2020 - October 1, 2020

AGENDA

Workshop Overview:

The purpose of this workshop is to bring together experts from various backgrounds and disciplines to explore research areas of high priority for youth regarding needed transition services/support as part of routine care. Given increasing coordination efforts on the topic of health care transition across the United States Department of Health and Human Services (HHS), 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.

With improved rates of survival in childhood illnesses in the United States and globally, individuals are living longer with one or more chronic conditions.[i] To meet the needs of diverse populations with chronic physical/medical conditions or intellectual/developmental disabilities as they transition from pediatric to adult centric services, barriers to successful health care transition (HCT), methods and measures for defining HCT, and the identification of promising practices must be better understood. Additionally, health care transition should consider the context of typical developmental processes during the transition to adulthood and the multiple domains of functioning that are critical to life success (e.g., schooling, work, housing).[ii]

Workshop Goals:
- Bring together researchers and clinicians representing a broad range of pediatric diseases and conditions to learn from each other and define the current state of health care transition research
- Use this knowledge and experience from a broad range of conditions to:
    o Identify common themes and highlight shared research gaps and opportunities that can complement ongoing disease-specific work across NIH ICOs and collaborating organizations
    o Further define the needs of youth with chronic physical/medical conditions or intellectual/ developmental disabilities in the context of health care transitions

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[i] Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2016 (GBD 2016) All-cause Under-5 Mortality, Adult Mortality, and Life Expectancy 1970-2016. Seattle, United States: Institute for Health Metrics and Evaluation (IHME), 2017.

[ii] Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper of the Society for Adolescent Medicine.*Journal of Adolescent Health*,*14*(7), 570-576

Day 1: September 30, 2020

Introduction and Welcome Remarks

9:00 - 9:30

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

Background Context: NIH Portfolio Analysis and Goals for Meeting

- **Dara Blachman-Demner**, Ph.D., Office of Behavioral and Social Sciences (OBSSR)
- **Samantha Calabrese**, M.P.H., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)

Session 1: Overview of Transition Research and Practice
Session Chair: Michelle Mollica, Ph.D., M.P.H., R.N., O.C.N., National Cancer Institute (NCI)

9:30 - 10:45

- **Patience White**, M.D., M.A., Co-Project Director Got Transition®
- **Cecily Betz**, Ph.D., R.N., F.A.A.N., University of Southern California (USC) Keck School of Medicine
- **Kim Wittenberg**, M.A., Agency for Healthcare Research and Quality (AHRQ)

Break: 10:45 AM - 11 AM

Session 2: Participant Panel – Voices of Transition
Session Chair: Denise Juliano-Bult, M.S.W., National Institute of Mental Health (NIMH)

11:00 - 12:30

Participants: Patient, Parent, Loved One, Caregiver: The Voices of Transition Session will amplify the personal experiences, needs, and challenges of diverse populations with chronic physical/medical conditions or intellectual/developmental disabilities as they transition from pediatric to adult centric services.

Lunch Break: 12:30 PM - 1:30 PM

Session 3: Measures of Success: Defining and Measuring Transition Outcomes
Session Chair: Lori Wiener, PhD, DCSW, LCSW-C, National Cancer Institute (NCI)

1:30 - 2:45

- **Christopher Recklitis**, Ph.D., Harvard Medical School
- **Christina Nicolaidis**, M.D., Portland State University
- **Maria Ferris**, M.D., Ph.D., University of North Carolina

Break: 2:45 PM - 3:00 PM

Session 4: Examples of Success: Transition Interventions
Session Chair: Lynn Adams, Ph.D., National Institute of Nursing Research (NINR)

3:00 - 4:15

- **Sarah Narendorf**, Ph.D., M.S.W., University of Houston
- **Gary Maslow**, M.D., Duke University
- **Roberta Rehm**, R.N., Ph.D., University of California San Francisco

4:15 – 4:45

Facilitated Discussion: Emerging Themes and Remaining Questions
- Dara Blachman-Demner (OBSSR), Sonia Lee (NICHD), and Samantha Calabrese (NICHD)

4:45   Adjourn

Day 2: October 1, 2020

Welcome Back and Recap of Day One

- **Dara Blachman-Demner**, Ph.D., OBSSR
- **Sonia Lee**, Ph.D., and **Samantha Calabrese**, M.P.H., NICHD

9:00-9:30

Welcome Remarks

- **Christine Hunter**, Ph.D., Deputy Director, Office of Behavioral and Social Sciences (OBSSR)

Session 5: Identifying Key Transition Challenges and Opportunities for Implementation

Session Chair: Marrah Lachowicz-Scroggins, PhD, National Heart, Lung, and Blood Institute (NHLBI)

9:30-11:00

- **Michael Hseih**, M.D., Ph.D., George Washington University and Children's National
- **Grayson Holmbeck**, Ph.D., Loyola University Chicago
- **Jane Hankins**, M.D., St. Jude's Children's Research Hospital
- **Deena Chisolm**, Ph.D., Nationwide Children's Hospital

Break: 11 AM – 11:15 AM

Discussion and Next Steps

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

11:15 – 12:45

- Identify Research Gaps
- Future Scientific Opportunities and Collaborations

12:45   **Adjourn**