

# 25th Annual Chronic Illness and Disability: Transition from Pediatric to Adult-based Care October 10 – 11, 2024

## Thursday, October 10, 2024

- 7:15a.m.**      **Registration, Coffee, and Bagels in the Lobby**
- 8:00**            **Welcome and Announcements**  
**Albert C. Hergenroeder, MD**
- 8:15**            **The Importance of Successful Transition**  
**Deborah Sukin, PhD** | President, Texas Children's Hospital
- 8:25**            **Reflections on the 25 years of the Conference**  
**Albert C. Hergenroeder, MD** | Baylor College of Medicine, Founding Program Director, Transition Conference  
*Goal:* The audience will understand the history of the conference.  
*Objective:* The audience will be able to discuss:  
1) Notable events for the conference.  
2) Trends seen in health care transition over these 25 years and future considerations.
- 8:55**            **The Current State of Health Care Transition: An International Perspective**  
**Swaran Singh, MD** | Professor, Social and Community Psychiatry, Warwick University, UK  
*Goal:* The audience will the current state of health care transition with an emphasis on mental health in Europe.  
*Objectives:* The audience will be able to discuss:  
1) The clinical and research implications of this work.
- 9:40**            **Pediatric and Medicine Collaboration: Building Strong Collaboration**  
**Ellen Fremion, MD** | Baylor College of Medicine, Transition Clinic  
**Tom Davis, MD** | Geisinger Medical Center  
*Goal:* The audience will understand the importance of functional pediatric-adult medicine collaboration in successful health care transition.  
*Objectives:* The audience will be able to describe:  
1) The structure and processes that have worked in successful pediatric-adult medicine health care transition programs.  
2) Common barriers to successful pediatric-adult medicine collaborations and solutions to overcome these barriers.
- 10:20**         **Questions and Answers**

- 10:35**      **Break**
- 11:05**      **Complexity of Health Care Transition Across Systems**  
**Allysa Ware, PhD, MSW** | Executive Director, Family Voices  
*Goal:* The audience will understand the complexity of health care transition across systems.  
*Objectives:* The audience will be able to discuss:
- 1) Critical referrals for all families.
  - 2) Potential barriers for AYASHCN with medical complexity.
  - 3) Meeting the needs of AYASHCN with intersectional identities.
  - 4) The role of families from different cultures in health care transition.
- 11:50**      **Legal Issues in the Transition from Pediatric to Adult-Based Care**  
**Beth Sufian, JD** | Partner, Sufian & Passamano  
*Goal:* The audience will be able to understand the significance of the Social Security Continuing Review Process and the impact of medical records on eligibility.  
*Objectives:* The audience will be able to discuss:
- 1) Government benefit changes that occur at the time of the health care transition in the context of the current eligibility review landscape.
  - 2) Social Security Continuing Disability Reviews and ensuring eligible individuals continue benefits.
  - 3) Health insurance options when certain coverage is lost due to age.
  - 4) The most significant legal issues affecting health care transition in the past 25 years.
- 12:30p.m.**      **Questions and Answers**
- 12:35**      **Meet the Faculty Luncheon (meal provided)**  
**Swaren Singh, MD**  
**Alyssa Ware, PhD, MSW**  
**Beth Sufian, JD**  
**Peggy McManus, MHS and Patience White, MD, MA**  
**Christina Boothby**  
**Ellen Fremion, MD and Tom Davis, MD**
- 1:35**      **End lunch sessions**
- 1:55**      **Breakout Sessions with Faculty (attendees select one at 1:55 pm and a different one at 2:55 pm)**
- 1) Advocacy**  
**Allysa Ware, PhD, MSW** | Executive Director, Family Voices  
*Goal:* The audience will understand the importance of advocacy and self-advocacy for AYASHCN in successful health care transition.  
*Objectives:* The audience will be able to describe:
- 1) Self-advocacy and self-efficacy as learned behaviors.

2) Improving knowledge of strategies to address bullying in AYASHCN.

## 2) **Known Knowns, Known Unknowns and Unknown Unknowns' in Transition Research**

**Swaran Singh, MD** | Professor, Social and Community Psychiatry, Warwick University, UK

*Goal:* This breakout session will summarize state of the art evidence on international research in transition from pediatric to adult healthcare, focusing on important questions that have been answered, others that remain under-researched, and areas yet unexplored. In a participatory manner with active engagement, attendees will have a chance to explore the research landscape of transitional care, primarily in Anglophone and European settings but also in global health.

*Objectives:* By attending the session, participants will:

- 1) Understand the nature and magnitude of problems in transitional care.
- 2) Explore models of managed transition which have evidence of effectiveness.
- 3) Identify areas of uncertainty or lack of evidence and discuss possible research designs to fill this gap.
- 4) Have an opportunity to network and collaborate with like-minded clinicians and academics.

## 3) **Got Transition®**

**Peggy McManus, MHS** | President, The National Alliance to Advance Adolescent Health, Co-Director of Got Transition: Center for Health Care Transition

**Patience White, MD, MA** | Co-Director of Got Transition: Center for Health Care Transition

*Goal:* The audience will understand current Got Transition activities.

*Objectives:* The audience will be able to describe:

- 1) Current Got Transition initiatives.

## 4) **Employment for Young Adults with Chronic Illness**

**Kelly Scoggins, MBA** | Houston Professional, Parents of a Child with a Disability, Franchise Owners, Bitty & Beau's Coffee Houston

**Drew Scoggins, MSFS** | Houston Professional, Parents of a Child with a Disability, Franchise Owners, Bitty & Beau's Coffee Houston

**Kim Brown, JD** | Executive Director, Belong Kitchen

*Goal:* The audience will understand the importance of employment for a young adult with chronic illness or disability from a business owner's perspective.

*Objectives:* The audience will be able to describe:

- 1) The structure and processes for employment for AYASHCN.
- 2) What the speakers have learned in the process of setting up employment opportunities.
- 3) The national perspective on employment opportunities for young adults with intellectual disabilities in the U.S.

4) Success stories.

**5) Building Pediatric-Medicine Partnerships for Complex Care in AYASHCN and Educating the Next Generation of Providers in HCT**

(This session will not be repeated, rather it is over the 2 breakout periods)

**Ellen Fremion, MD** | Baylor College of Medicine, Transition Clinic

**Elisha Acosta, MD** | Baylor College of Medicine, Transition Clinic

**Tom Davis, MD** | Geisinger Medical Center

*Goal:* The audience will understand the importance of structure and processes in establishing complex care clinics for young adults with special health care needs in an adult care system.

*Objectives:* The audience will be able to describe how two complex care programs:

- 1) Set up their structure and processes.
- 2) Work with their hospital leadership to support these programs.
- 3) Build partnerships between the pediatric and adult providers.
- 4) Are training the future health care transition workforce.

**6) Implementation Science Applied to Health Care Transition: Practical Strategies**

**Sharon Hudson, PhD** | Director, Implementation Science and Evaluation, AltaMed Institute for Health Equity

*Goal:* The audience will understand the importance of implementation science in health care transition.

*Objectives:* The audience will be able to discuss:

- 1) The operational aspects of implementation science.

**2:55 Breakout Sessions II with Faculty**

**3:40 Break**

**4:10 Training Tomorrow's Leaders for Successful Transition - How LEND and DBP Networks are Shaping the Future of HCT**

**Kate Thompson, LMSW** | Association of University Centers on Disabilities

*Goal:* The audience will understand the intersections of interdisciplinary approaches in health care transition and AUCD's role in promoting meaningful transition outcomes.

*Objectives:* The audience will be able to discuss:

- 1) AUCD's initiatives to improve HCT for AYASHCN in the future.
- 2) The evidence base for interdisciplinary approaches for HCT from pediatric to adult-based care.
- 3) The importance of self-determination and inclusion in decisions around HCT.

**4:50 Questions and Answers**

**5:00 Evaluation and Adjourn**

## Friday, October 11, 2024

**7:15a.m.**      **Registration, Coffee, and Bagels**

**8:00**            **Announcements**  
**Albert C. Hergenroeder, MD**

**8:15**            **Young Adult/Youth Panel**  
**Jarred Bolt** | Project Search Alumnus, Current TCH employee as a mentor  
**Julio Grajeda** | Former Project Search intern, Current Target Employee  
**Diane Murrell, MSW (Moderator)** | Licensed Clinical Social Worker, Texas Children's Hospital  
*Goal:* The audience will understand the importance youth and young adult voice in advocating for improved health care transition.  
*Objectives:* The audience will be able to describe:  
1) Challenges with youth and young adults with disabilities during transition to adulthood and adult based care.  
2) Challenges from a parent's in supporting normal child development.

**9:00**            **Questions and Answers**

**9:10**            **Parent Panel**  
**Allysa Ware, PhD, MSW** | Executive Director, Family Voices  
**TBD**  
*Goal:* The audience will understand the parents' perspective on HCT from a global perspective.  
*Objectives:* The audience will be able to describe parents'/caregivers perspectives on their AYASHCN's Trauma Informed journey through transition to adulthood and lessons learned.

**9:40**            **Questions and Answers**

**9:55**            **Break**

**10:15**          **Medication Adherence and Motivational Interviewing**  
**Beth Garland, PhD** | Division of Adolescent Medicine and Sports Medicine, Division of Psychology, Department of Pediatrics, Baylor College of Medicine  
*Goal:* The audience will understand the importance of medication adherence and adherence to other aspects of the treatment plan in maintaining health during the transition to adult-based care.  
*Objectives:* The audience will be able to discuss:  
1) The extent of the problem of medication non-adherence in outcomes for AYASHCN.  
2) Evidence-based methods to improve medication adherence.

- 11:00**      **Implementation Science and Health Care Transition**  
**Sharon Hudson, PhD** | Director of Implementation Science and Evaluation, The Alta Med Institute for Health Equity  
*Goal:* The audience will be understand the principles of implementation science  
*Objectives:* The audience will be able to describe:  
1) The structure and processes of implantation science.  
2) Specific examples of successful implementation science strategies.
- 11:45**      **Questions and Answers**
- 11:55**      **Lunch (provided)**
- 1:00p.m.**      **Health Care Transition for CYSHCN: An Overview of AAP Initiatives**  
**Christina Boothby, MPA** | Senior Director, Children and Youth with Special Health Care Needs Initiatives, American Academy of Pediatrics  
*Goal:* The audience will be able to describe AAP initiatives to improve HCT for CYSHCN.  
*Objectives:* The audience will be able to:  
1) Describe AAP’s health care transition initiatives for CYSHCN and how they align with the Blueprint for Change.  
2) Identify at least 2 key learnings or lessons learned based on project/activity outcomes.  
3) Identify at least 2 health care transition resources that can be utilized within your own practice or organization.
- 1:45**      **Questions and Answers**
- 1:55**      **Break**
- 2:15**      **Ageing Out of Medicaid, CHIP, SSI, and Title V Programs: Impacts, Inequities, and Recommendations**  
**Peggy McManus, MHS** | President, The National Alliance to Advance Adolescent Health, Co-Director of Got Transition: Center for Health Care Transition  
*Objectives:* The participants will be able to:  
1) Discuss the racial disparities in insurance and poverty status among adolescents and young adults with disabilities.  
2) Review the unique roles that these four programs play in supporting low-income adolescents and young adults with disabilities.  
3) Describe the challenges and inequities commonly experienced by adolescents and young adults with disabilities and their families when they lose their childhood eligibility for public programs.  
4) Discuss recommendations for program and policy reforms, outreach and education, and research and evaluation.

**2:55 Building a transition program between a children’s hospital and a Large Public Health County System for Patients Aging Out of Medicaid**

**Albert C. Hergenroeder, MD** | Professor of Pediatrics, Baylor College of Medicine, Chief, Division of Adolescent Medicine and Sports Medicine

*Goal:* The audience will understand the importance of using a quality improvement framework in building a health care transition program between a children’s hospital and a large, public county health system for young adults aging out of Medicaid.

*Objectives:* The audience will be able to describe:

- 1) The structure and process of the Texas Children's Hospital – Harris Health Transition Program.
- 2) Outcome data of patients successfully transitioned.

**3:40 Questions and Answers**

**3:50 Closing Comments/Evaluation**