

**23<sup>rd</sup> Annual**  
**Chronic Illness and Disability Conference:**  
***Transition from Pediatric to Adult-Based Care***

**VIRTUAL CONFERENCE**  
**October 26-28, 2022**



*Co-provided by:*



## PLANNING COMMITTEE

### **Albert C. Hergenroeder, MD – Activity Director**

Cecily L. Betz, PhD, RN, FAAN  
Jackie Czyzia, MPH  
Amanda Garey, PhD, RN, NPD-BC,  
NPDA-BC  
Scott Garner, MBA

Ivy Goldstein  
Cynda Green  
Albert C. Hergenroeder, MD  
Elaine Hime  
Sripoom McKay, MD  
Peggy McManus, MHS

Diane Murrell, LMSW  
Diane Scardino, MBA, MHA, FACHE  
Shelley Townsend, MSW  
Chava White, LMSW-AP  
Audrey Young, MPH

## ACTIVITY FACULTY

All faculty are located in Houston, Texas, unless otherwise noted.

### **Amy Bragman, LCSW**

Clinical Program Coordinator, Rheumatology Service  
Texas Children's Hospital  
Baylor College of Medicine

### **Treeby Brown, MA**

Deputy Director, Division of Services for Children  
with Special Health,  
HRSA, Washington, DC

### **Bethany Coyne, PhD**

Associate Professor, School of Nursing  
University of Virginia  
Charlottesville, VA

### **Sneha Dave, BA**

Founder, Executive Director, Generation Patient  
Indianapolis, IN

### **Mary Ferguson, LMSW**

Medical Social Worker, Rheumatology Service  
Texas Children's Hospital  
Baylor College of Medicine

### **Beth Garland, PhD**

Associate Professor of Pediatrics,  
Division of Adolescent Medicine and Sports Medicine,  
Baylor College of Medicine, Department of Pediatrics

### **Dennis Kuo, MD**

Associate Professor,  
Chief of the Division of General Pediatrics,  
University of Buffalo | Buffalo, NY

### **Gary Maslow, MD**

Associate Professor of Psychiatry and Behavioral Sciences,  
Associate Professor of Pediatrics,  
Associate Clinical Professor, School of Nursing  
Duke University | Durham, NC

### **Peggy McManus, MHS**

Co-Project Director, Got Transition  
Washington, DC

### **Kylee Phalen**

Transition Coordinator, Title X Coordinator,  
Department of Pediatrics, Adolescent and Young Adult Clinic  
East Tennessee State University  
Johnson City, TN

### **Lauren Ramos, MPH**

Director, Division of MCH Workforce Development,  
HRSA, Washington, DC

### **David Robinson**

Member, Houston City Council

### **Rylin Rodgers**

Disability Policy Advisor, Microsoft Accessibility  
Washington, DC

### **Dawn Rowe, PhD**

Associate Professor, School of Medicine,  
National Technical Assistance Center on Transition (NTACT-C),  
East Tennessee State University,  
Johnson City, TN

### **Beth Sufian, JD**

Partner, Sufian & Passamano

### **Patience White, MD**

Co-Project Director, Got Transition  
Washington, DC

### **Stephen Williams, MEd, MPA**

Director, Health and Human Services  
City of Houston Health Department

### **David Wood, MD**

Professor, Department of Pediatrics,  
Director, Adolescent and Young Adult Clinic  
East Tennessee State University,  
Johnson City, TN

### **Jason Woodward, MD**

Associate Professor, School of Medicine,  
Director, Transition Medicine;  
Director, Spina Bifida Clinic and the  
Division of Adolescent and Transition Medicine  
University of Cincinnati  
Cincinnati Children's Hospital  
Cincinnati, OH

## NEEDS STATEMENT

Skill preparation and planning for healthcare transition for children and youth with special healthcare needs is inadequate. Less than fifty percent of families nationwide indicate that their children with special healthcare needs have received the services necessary to make appropriate transitions to adult healthcare, work, and independence. One of the major hurdles to receiving this care is the lack of a workforce, including physicians, nurses, social workers, mental health providers and all who provide services to youth and young adults with special healthcare needs trained to provide the services necessary to make the healthcare transition. There is a strong need for physicians to have the knowledge and skills to provide the services needed to facilitate a successful transition from pediatric to adult-based care and services.

Because of increased awareness of transitioning to adult-based care, clinicians are required to update their knowledge of the changing strategies for integrating emerging adult-based care into practice.

For all conference participants, there will be a discussion of the legal issues involved in healthcare transition, as well as time to meet and talk with faculty in small groups, to exchange ideas among participants, and to share knowledge and information about how best to plan for a successful transition to adulthood.

## TARGET AUDIENCE

Physicians in internal medicine, family practice, pediatrics, psychiatry, and physiatry; other healthcare providers including psychologists, social workers, nurses, dietitians, case managers, counselors, and primary care providers; and youth and young adults who have a chronic illness or disability and their parents or guardians.

## LEARNING OBJECTIVES

At the conclusion of the conference, participants should be able to:

- Describe the legal and ethical issues involved in HCT for adolescents and young adults with special health care needs AYASHCN
- Discuss the HRSA/ MCHB's Blueprint for Change framework for AYASHCN
- Discuss considerations of when is the best time to transition to adult-based care
- Discuss training and education for secondary and out-of-school youth with special health care needs
- Implement motivational interviewing in the clinical setting
- Discuss positive youth development in the context of health care transition
- Describe how successful health care transition is defined
- Outline example of a sub-specialty transition program based in a large children's hospital; and joint telehealth med-peds transition clinics

## EDUCATIONAL METHODS

Lectures • Small Group Breakout Sessions • Question and Answer Sessions • Audience Response System • Role Play

## ACTIVITY EVALUATION

Evaluation by questionnaire will address program content, presentation, and possible bias.

## ACCREDITATION/CREDIT DESIGNATION

### **Physicians**

Baylor College of Medicine is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

Baylor College of Medicine designates this live activity for a maximum of 12.50 *AMA PRA Category 1 Credits™*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

The presentation, **Legal Issues in the Transition from Pediatric to Adult-Based Care**, has been designated by Baylor College of Medicine for 1.0 credit of education in medical ethics and/ or professional responsibility.

### ***Social Work***

Texas Children's Hospital is an approved continuing education provider for Social Workers through the Texas State Board of Social Worker Examiners. Social work continuing education units provided, 12.50 hours of continuing education including 0.75 hour of ethics.

### ***Nursing***

Texas Children's Hospital is accredited with distinction as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation. This continuing nursing education activity awards up to 12.50 contact hours.

This nursing continuing professional development activity awards up to 12.50 contact hours.

This includes 1.0 out of the 2.0 contact hours required for Nursing Jurisprudence and Ethics Continuing Nursing Education Requirement.

### ***Occupational Therapy and Physical Therapy***

This activity has been approved by the Texas Board of Physical Therapy Examiners for 12.50 CCUs for PTs and PTAs.

Continuing Competency Units (CCU) have been applied for this conference through Texas Occupational Therapy Association (TOTA) 12.50 hours credit. Texas Children's Hospital is an Approved Provider for the Texas Occupational Therapy Association. The assignment of TOTA CE hours does not imply endorsement of a specific course, content, products, or clinical procedures by TOTA.

## **FEE, REGISTRATION AND CONFIRMATION INFORMATION**

Refer to the online registration form at [cpd.education.bcm.edu/chronic2021](http://cpd.education.bcm.edu/chronic2021) for the fee schedule. Your registration will not be processed until payment is received. Your registration will be confirmed. If you have not received confirmation at least 5 business days before the activity start date, contact the Baylor College of Medicine (BCM) Division of Continuing Professional Development (DCPD) immediately.

A limited number of scholarships are available for adolescents and young adults with special health care needs and their parents or guardians. For complete details, please contact Cynda Green at [cynda.green@txp2p.org](mailto:cynda.green@txp2p.org).

The DCPD reserves the right to limit the number of participants in an activity and will not be responsible for any expenses incurred by an individual whose registration is not confirmed and for whom space is not available.

To register/ pay for the conference, visit our website at [cpd.education.bcm.edu/chronic2021](http://cpd.education.bcm.edu/chronic2021).

## **CANCELLATION/REFUND POLICY**

Requests for registration refunds must be in writing and received by the DCPD at least 10 business days before the activity begins. The date the request is received by the DCPD will be considered the cancellation date. Requests received after the refund deadline will not be processed. Cancellations are subject to a \$50 administrative fee to be deducted from the paid registration fee to cover guarantees and other expenses. Requests should be emailed to [cpd@bcm.edu](mailto:cpd@bcm.edu).

The DCPD reserves the right to cancel activities, not less than 10 business days before the scheduled date, if extenuating circumstances make it necessary. Registrants will be notified at the contact number indicated on the registration form and again in writing. If an activity is cancelled, the DCPD's liability is limited to the paid registration fee. Note: If the registration payment was made by check, a Social Security number is required to process the refund.



# 23<sup>rd</sup> Annual Chronic Illness and Disability Conference: *Transition from Pediatric to Adult-Based Care*

## AGENDA

**THURSDAY, OCTOBER 27, 2022**

**7:50 a.m. Waiting Room (Zoom) and Registration**

**8:00 Welcome and Announcements**

**Albert C. Hergenroeder, MD**

**8:10 Introduction and Welcome**

**8:15 Inspirational Video: "I'll Push You"**

**8:25 Houston City Council Proclamation**

**David Robinson**, Houston City Council

**Stephen Williams**, MEd, MPA,

Director, Houston Health Department

**8:35 Health Care Transition as a Federal Priority**

**Treeby Brown, MA**

Deputy Director, Division of Services for Children with Special Health

**Lauren Ramos, MPH**

Director, Division of MCH Workforce Development, HRSA

**Goal:** The audience will understand the commitment of HRSA and the MCHB to improving the lives and wellbeing of CYSHCN including the transition from pediatric to adult-based care.

**Objectives:** The audience will be able to describe HRSA-MCHB's

*Blueprint for Change: A national Framework for a System of Services for Children and Youth with Special Health Care Needs*

Specifically, to address the four critical areas to strengthen the system of care:

- Health equity
- Access to service
- Quality of life
- Financing

And to address workforce development through interdisciplinary training in HCT and CYSHCN to help improve the system of care.

**9:20 When is the right time to transition?**

**Jason Woodward, MD**

Associate Professor, University of Cincinnati School of Medicine, Director, Transition Medicine; Director, Spina Bifida Clinic and the Division of Adolescent and Transition Medicine, Cincinnati Children's Hospital

**Goal:** The audience will understand the importance of making the decision of when is the best time to transition a patient from pediatric to adult-based care.

**Objectives:** At the end of this presentation, the participant will be able to discuss:

- Models of transition decision-making: age based, vs. disease specific vs. policy driven
- The effect of public vs. commercial insurance on the decision
- Outcomes in countries with mandatory transition age, e.g. Canada, European countries, compared to the U.S
- Evidence in favor of the different models

**10:00 Q&A**

**10:15 Break**

**10:30 The History and Current Status of the Transition Readiness Assessment Questionnaire (TRAQ)**

**David Wood, MD**

Professor, Department of Pediatrics, East Tennessee State University, Director, Adolescent and Young Adult Clinic

**Goal:** The audience will understand the role of the TRAQ in the field of health care transition

**Objectives:** The audience will be able to describe, with respect to the TRAQ:

- Its history
- Its validation
- Its impact in the health care transition field: how many other centers have used and its appearance in published research.

**11:15 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:

- Government benefit changes that occur at the time of the health care transition in the context of the current eligibility review landscape.
- Social Security Continuing Disability Reviews and ensuring eligible individuals continue benefits.
- Health insurance options when certain coverage is lost due to age.

**Noon Q&A**

12:15 p.m. Lunch

### 12:30 Meet-the-Faculty Lunch

- Dawn Rowe, PhD
- Bethany Coyne, PhD
- David Woods, MD
- Beth Sufian, JD
- Jason Woodward, MD
- Got Transition

1:15 Conclusion of lunch sessions

### 1:35 BREAKOUT SESSIONS I, WITH FACULTY

*Attendees: please select one at 1:35 p.m. and a different one at 2:35 p.m.*

#### Measuring Success in Training and Education

**Dawn Rowe, PhD**

Associate Professor, East Tennessee State School of Medicine and the National Technical Assistance Center on Transition (NTACT-C)

**Goal:** The audience will understand the importance of evaluating interventions to improve education and training.

**Objectives:** The audience will be able to describe, in the context of secondary school education and training, how success is measured in terms of the following outcomes:

- Enrollment
- Graduation
- Credential attainment
- Competitive integrated employment
- Community engagement

#### Legal Issues

**Beth Sufian, JD**

Partner, Sufian & Passamano

**Goal:** The audience will be able to understand guardianship and power of attorney and SSI non-eligibility as a teenager transitions into adulthood.

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

- Guardianship decisions
- Insurance options

#### Practical Use of the TRAQ in Research and Clinical Care

**Kylee Phalen**

Transition Coordinator, Title X Coordinator, East Tennessee State University School of Medicine, Department of Pediatrics, Adolescent and Young Adult Clinic

**Goal:** The audience will be able to understand the TRAQ as a research and clinical tool.

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

- How the TRAQ has been implemented in research
- How the TRAQ has been implemented to assist in health care transition planning and assessment readiness

#### Access to Services for CYSHCN and Their Families

**Dennis Kuo, MD**

Associate Professor, Chief, Division of General Pediatrics, University of Buffalo; Kylin Rodgers, Disability Policy Advisor, Microsoft Accessibility, Washington, D.C.

**Goal:** The audience will understand the presence of barriers to access to care for CYSHCN and their families and opportunities for innovation.

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

- The current state of access of services, the workforce, health equity and financing of services, especially in the transition from pediatric to adult-based care.
- Opportunities for innovation in each of the above areas.

#### Positive Youth Development and Transition

**Gary Maslow, MD**

Duke University School of Medicine

**Goal:** The audience will understand positive youth development (PYD) in the context of health care transition for AYASHCN.

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

- Examples of PYD programs
- The evidence of the effects of PYD programs on outcomes for AYASHCN

#### The Nursing Perspective on Transition and Transition Research

**Bethany Coyne, PhD**

University of Virginia

**Goal:** The audience will understand the roles of nursing in health care transition.

**Objective:** The audience will be able to describe the various roles of nurses in the clinical, administrative, research, advocacy, and teaching of health care transition.

### 2:35 p.m. BREAKOUT SESSIONS II, WITH FACULTY

*Attendees: please select one at 1:35 p.m. and a different one at 2:35 p.m.*

3:20 Break

### 3:40 Training and Education for Secondary and Out-of-School Youth with Special Health Care Needs

**Dawn Rowe, PhD**

Licensed Psychologist

Associate Director, The Center for START Services, University of New Hampshire Institute on Disability

**Goal:** The audience will understand the importance of effective services and instruction for secondary school youth and out-of-school youth.

**Objectives:** The audience will be able to describe, in the context of adolescents and young adults with special health care needs (AYASHCN):

- The scope of the problem of lack of educational and training
- Evidence-based strategies for effective learning in high school
- Model programs of interagency partnership
- Developing sustainable partnerships

4:20 Q&A

4:30 Evaluation and Adjournment

## AGENDA

**FRIDAY, OCTOBER 28, 2022**

7:30 a.m. Waiting Room (Zoom) and Registration

8:00 **Announcements**

*Albert C. Hergenroeder, MD*

8:15 **Motivational Interviewing About Insurance**

*Beth Garland, PhD*

Baylor College of Medicine, Division of Adolescent Medicine and Sports Medicine

**Goal:** Audience will understand the motivational interviewing techniques in the context of a clinic interview.

**Objective:** The audience will be able to describe specific questions to use in a clinical interview to promote a MI approach to patient care.

9:00 Q&A

9:10 **Young Adult Perspective**

*Sneha Dave, BA*

Executive Director, Generation Patient

**Goal:** The audience will understand the speaker's challenges with her illness through adolescence and adulthood and how she coped with those challenges; and her role with Generation Patient.

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

- How Generation Patient was founded
- The methods used in their successful advocacy
- Their focus on drug affordability

9:40 Q&A

9:55 Break

10:05 **Positive Youth Development and Transition**

*Gary Maslow, MD*

Associate Professor of Psychiatry and Behavioral Sciences, Associate Professor of Pediatrics, Associate Clinical Professor, School of Nursing, Duke University

**Goal:** The audience will understand the importance of positive youth development as it relates to transition from pediatric to adult-based care for youth and young adults with chronic illness or disability.

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

- The key components of Positive Youth development (PYD).
- PYD in AYASHCN compared to those without identified SHCH.
- How PYD translates into policy for improving outcomes for AYASHCN as they transition to adulthood.

10:50 **How to Define Successful Transition**

*Bethany Coyne, PhD*

University of Virginia School of Nursing

**Goal:** The audience will understand the importance of defining successful transition.

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

- Previous definitions of successful transition
- Medical and non-medical metrics to define successful transition
- Considerations in standardizing a definition of successful transition.

11:35 Q&A

11:45 Lunch

1:00 p.m. **Integrating IEPs Transition Plans and Health Care Plans**

*NTACT-C*

**Goal:** The audience will be able to understand the importance of aligning the health care plan with the IEP.

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

- How to structure and build processes to bring the IEP and health care plan in alignment.
- Examples of successful integration.
- Barriers to communication and successful solutions.

1:45 Q&A

1:55 Break

## **2:05 Setting Up a Disease Specific Transition Programs**

**Mary Ferguson, LMSW, Medical Social Worker and  
Amy Bragman, LCSW, Clinical Program Coordinator**  
Clinical Program Coordinator, Rheumatology Service,  
Texas Children's Hospital

**Goal:** The audience will understand how the staff at one subspecialty clinic established a method of tracking patients who are in the health care transition planning phase.

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

- Why this project was started
- The chronology of setting up the tracking system
- How the tracking system was set up in the EMR and as an Excel spreadsheet
- Infrastructure for peds-medicine transition
- Barriers to setting up this system
- Data entry and tracking
- Percent time on this project
- Process and outcome data for the AYASHCN in this system

## **2:45 Joint Telehealth Pediatrics-Medicine Transition Clinic Visits**

**Patience White, MD and Peggy McManus, MHS,  
Got Transition**

Rheumatology Transition Program, Texas Children's Hospital

**Goal:** The audience will be able to understand the content and arrangement of a joint visit to transfer to adult care.

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

- The rationale for developing a Joint Telehealth Visit for your HCT process from pediatric to adult health care.
- A new Got Transition Joint Telehealth Visit tool kit:  
The role of families, young adults and clinicians.
- Pilot evaluation results of Joint Telehealth visits from a Medicaid HCT pilot project with youth with ID/ D  
Lessons learned.

## **3:30 Q&A**

## **3:40 Closing Comments/Evaluation**