

24th Annual
Chronic Illness and Disability Conference:
Transition from Pediatric to Adult-Based Care

OCTOBER 26-27, 2023

*Resuming the in-person meeting format
for the first time since 2019*



Co-provided by:



PLANNING COMMITTEE

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ACTIVITY FACULTY

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

William Anderson, MD

Associate Professor, Pediatric Allergy & Immunology,
Director, Multidisciplinary Asthma Clinic,
Co-Director, CHICO Improving Pediatric to
Adult Care Transition (ImPACT) Program,
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Ellen Fremion, MD, FAAP, FACP

Associate Professor of Internal Medicine and Pediatrics,
Baylor Transition Medicine Clinic,
Clinical Director at the Center for Pursuit,
Texas Children's Hospital Spina Bifida Transition
Clinic Director

Angelo Giardino, MD, PhD

Chair, Department of Pediatrics,
University of Utah's School of Medicine,
Chief Medical Officer,
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Peter Hotez, MD, PhD, DSc (hon), FASTMH, FAAP

Dean, National School of Tropical Medicine,
Professor, Departments of Pediatrics,
Molecular Virology & Microbiology;
Endowed Chair of Tropical Pediatrics/Co-director,
Texas Children's Hospital Center for Vaccine Development

Raghuveer Puttagunta, MD

Associate Chief Medical Informatics Officer,
Hospitalist, Internal Medicine – Pediatrics,
Pediatric Complex Care Clinic/Comprehensive Care Clinic,
Geisinger Health System
Danville, PA

David Robinson

Member, Houston City Counsel and/or
Director City of Houston Health Department

Jane N.T. Sattoe, PhD

Senior Researcher,
Research Centre Innovations in Care,
Rotterdam University of Applied Sciences
Rotterdam, The Netherlands

Drew and Kelly Scoggins

Owners of Houston's Bitty and Beau's Coffee Shop

Beth Sufian, JD

Partner, Sufian & Passamano

Peggy Turner, BS, CTRS

Athletics Community Liaison,
Adapted Sports & Recreation Community Programs
Coordinator, Texas Institute for Rehabilitation and Research
(TIRR) Memorial Hermann

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 evidence for using interventions to promote self-management in AYASHCN
- Discuss the current state of EMR-based transition planning tools
- Discuss the importance and evidence for improving self-management for AYASHCN during transition
- Be able to implement person-centered and patient activating techniques in the provider-patient clinical visit
- Incorporate the patient and parent perspectives into health care transition programs
- Discuss issues in information transfer and confidentiality in the process of transitioning patients from pediatric to adult-based care and the impact of the 21st Century Cures Act
- Be able to incorporate techniques to improve HCT for AYASHCN with IDD
- Discuss establishing a transition planning program in a primary care practice

EDUCATIONAL METHODS

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

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 11.50 *AMA PRA Category 1 Credits*TM. 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, 11.5 hours of continuing education including 1.0 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 11.5 contact hours.

This includes 1.0 out of 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 11.5 CCUs for PTs and PTAs.

Continuing Competency Units (CCU) have been applied for this conference through Texas Occupational Therapy Association (TOTA) 11.5 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/content/chronic2023 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.

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/content/chronic2023.

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.

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 canceled, 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.

24th Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care

AGENDA

THURSDAY, OCTOBER 26, 2023

7:15 a.m. Registration, coffee and bagels in the lobby

8:00 **Welcome and Announcements**

Albert C. Hergenroeder, MD

8:15 **Inspirational Video: TBD**

8:25 **Houston City Council Proclamation** **David**

Robinson, Houston City Council at-Large

8:35 **Self-Management Interventions for Young People Growing Up with Chronic Conditions**

Jane N.T. Sattoe, PhD

Senior Researcher, Research Centre Innovations in Care, Rotterdam University of Applied Sciences
Rotterdam, The Netherlands

Goal: The audience will be able to understand the importance of self-management and self-management support in successful transition.

Objectives: The audience will be able to describe:

- The components of self-management
- The relationship between self-management and transition of care
- The measurement of self-management
- Evidence of interventions to improve self-management

9:20 **Building EMR-based Transition Planning Tools: Overview**

William Anderson, MD

Associate Professor, Pediatric Allergy & Immunology, Director, Multidisciplinary Asthma Clinic, Co-Director, CHICO Improving Pediatric to Adult Care Transition (ImPACT) Program, Children's Hospital Colorado Denver, CO

Goal: The audience will be able to understand the implementation of an EMR-based transition planning tool to promote transition preparation.

Objectives: The audience will be able to describe:

- The evidence base for using transition planning tools in HCT
- The role of an EMR-based planning tool to direct and standardize self-management education
- The role of an EMR-based planning tool to facilitate communication regarding transition between care teams/specialties
- Barriers to and successes in the use of transition planning tools in clinical practice

10:00 Q&A

10:15 Break

10:30 **Issues in Information Transfer and Confidentiality in the Process of Transition**

Raghuveer Puttagunta, MD

Associate Chief Medical Informatics Officer, Hospitalist, Internal Medicine – Pediatrics, Pediatric Complex Care Clinic/Comprehensive Care Clinic, Geisinger Health System Danville, PA

Goal: The audience would be able to talk about the various methods through which HIPPA-protected information is transferred from pediatric to adult-based care institutions.

Objectives: The audience will be able to discuss, with respect to information transfer between pediatric and adult institutions at the time of transition:

- Best practices
- The effect of the 21st Century Cures Act
- Barriers
- Confidentiality

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. **Meet-the-Faculty Luncheon**

- Beth Sufian, JD
- Got Transition
- Raghu Puttagunta, MD
- William Anderson, MD
- Peggy Turner
- Jane N.T. Sattoe, PhD

1:15 Conclusion of Luncheon sessions

1:35 **BREAKOUT SESSION I, WITH FACULTY**

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

Transition for Young Adults with Intellectual/Developmental Disabilities (YIADD)

Ellen Fremion, MD, FAAP, FACP

Associate Professor of Internal Medicine and Pediatrics,
Baylor Transition Medicine Clinic,
Clinical Director at the Center for Pursuit,
Texas Children's Hospital Spina Bifida Transition
Clinic Director

Goal: The audience would be able to talk about state of transition care for YIADD nationally.

Objectives: The audience will be able to describe:

- The state of transition care for YAIDD in the U.S.
- Evidence-based guidelines for care for YAIDD in transition.

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

Issues in Information Transfer and Confidentiality in the Process of Transition – Operational Issues

Raghuveer Puttagunta, MD

Associate Chief Medical Informatics Officer, Hospitalist, Internal Medicine – Pediatrics, Pediatric Complex Care Clinic/Comprehensive Care Clinic, Geisinger Health System Danville, PA

Goal: The audience will understand unanticipated consequences and potential remedies.

Objectives: The audience will be able to describe:

- Operational issues in managing the transfer of information.
- Structure and processes of transition planning in the speaker's institution.

Building the Transition Planning Tool (TPT) 2.0

William Anderson, MD

Associate Professor, Pediatric Allergy & Immunology,
Director, Multidisciplinary Asthma Clinic,
Co-Director, CHICO Improving Pediatric to Adult Care
Transition (ImpACT) Program,
Children's Hospital Colorado
Denver, CO

Goal: The audience will be able to understand the current state of the Transition Planning Tool 2.0 in Epic at Children's Hospital Colorado.

Objectives: The audience will be able to describe, with respect to the TPT 2.0.

- Care team identified gaps in transition planning documentation
- Modifications made to the original TPT to meet users' needs
- Strategies to promote implementation and track utilization of the TPT 2.0

Employment for Young Adults with IDD

Drew and Kelly Scoggins

Owners of Houston's Bitty and Beau's Coffee Shop

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

Objectives: The audience will be able to describe:

- The structure and processes of the Bitty and Beau's Coffee shop in Houston
- What the speakers have learned in the process of setting up this employment opportunity
- The national perspective on employment opportunities for young adults with intellectual disabilities in the U.S.
- Success stories from the employees at the coffee shop

Methods of Promoting Self-management at the Patient-provider Level

Jane N.T. Sattoe, PhD

Senior Researcher, Research Centre Innovations in Care,
Rotterdam University of Applied Sciences
Rotterdam, The Netherlands

Goal: The audience will be able to understand methods to promote self-management (including active involvement) of the patient during the patient-provider encounter.

Objectives: The audience will be able to discuss:

- Adopting a person-centered approach
- Interventions to promote active involvement of patients

2:35 p.m. **BREAKOUT SESSION 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 **Transition in Primary Care**
Lynn F. Davidson, MD, FAAP

Associate Professor of Pediatrics,
Division of Academic General Pediatrics, Children's Hospital,
Albert Einstein College of Medicine
Bronx, NY

Goal: The audience will understand the importance of transition planning in primary care.

Objectives: The audience will be able implement strategies to:

- Establish the structure and processes of a transition planning program in a primary care setting
- Discuss information transfer techniques from pediatric to adult-based primary care

4:20 Q&A

4:30 Evaluation and Adjournment

AGENDA

FRIDAY, OCTOBER 27, 2023

7:15 a.m. Registration, coffee and bagels in the lobby

8:00 **Announcements**

Albert C. Hergenroeder, MD

8:15 **How to Become a Batman**
Michelle Colvard

Director, Research Administration,
University of Texas MD Anderson Research Center

Goal: The audience will understand medical, personal and professional transition from the perspective of an adult with a chronic disability who is now a parent.

Objective: The audience will be able to describe:

- Challenges with youth and young adults with disabilities during transition to adulthood and adult based care
- Challenges from a parent's in supporting normal child development

9:00 Q&A

9:10 **Parental Perspective: Transitioning a Daughter With Autism**

Peter Hotez, MD, PhD, DSc (hon), FASTMH, FAAP

Dean, National School of Tropical Medicine,
Professor, Departments of Pediatrics,
Molecular Virology & Microbiology;
Endowed Chair of Tropical Pediatrics/Co-director,
Texas Children's Hospital Center for Vaccine Development

Goal: The audience will understand the speaker's challenges the speaker, his wife and daughter have encountered in transitioning her care to the adult health care system.

Objectives: The audience will be able to describe barriers in transition related to:

- Insurance
- Finding a provider
- Home care
- Mental health issues
- How the speaker incorporated autism into his professional development

9:40 Q&A

9:55 Break

10:10 **Dental Care for Adolescents and Young Adults with Chronic Illness and Disability**

David Fray, MBA, DDS

Professor, Department of General Practice and Dental Public Health, University of Texas School of Dentistry, Faculty in Transitional Care Clinic and Hospital, Baylor Medical Center

Goal: The audience will understand the challenges for delivering dental care to adolescents and young adults with special health care needs.

Objectives: The audience will be able to describe:

- The dental needs of youth and young adults with special health care needs
- The special needs of those with intellectual, developmental and emotional disabilities
- Barriers to receiving dental care during the transition years
- Programs to deliver this care

10:55 **Financing HCT**

Angelo Giardino, MD, PhD

Chair, Department of Pediatrics,
University of Utah's School of Medicine,
Chief Medical Officer Intermountain Primary
Children's Hospital
Salt Lake City, UT

Goal: The audience would be able to understand the complexity of financing health care transition and how it applies to their health care setting.

Objectives: The audience would be able to discuss, in the context of financing health care transition from pediatric to adult-based care (HCT):

- Value-based care
- Managed care
- Structural elements to payments (e.g. contractual language)
- Process outcomes in a successful HCT payment plan
- A model of a successful payment program in HCT

11:35 Q&A

11:45 Lunch

1:00 p.m. **Adaptive Sports**

Peggy Turner, BS, CTRS

Athletics Community Liaison, Adapted Sports & Recreation
Community Programs Coordinator,
TIRR Memorial Hermann

Goal: The audience will be have a framework for establishing an adaptive sports program in their institution.

Objectives: The audience will be able to describe:

- The history of how the speaker's program was established
- The structure and processes of the current program
- Other adaptive sports programs

1:45 Q&A

1:55 Break

2:05 **The Transition Program at Children's Hospital Colorado**

William Anderson, MD

Associate Professor, Pediatric Allergy & Immunology,
Director, Multidisciplinary Asthma Clinic,
Co-Director, CHICO Improving Pediatric to Adult Care
Transition (ImpACT) Program,
Children's Hospital Colorado,
Denver, CO

Jennifer Disabato, DNP, CPNP-PC, AC

Associate Professor, Pediatrics School of Medicine
Associate Professor, College of Nursing
University of Colorado Anschutz Medical Campus
Co-Director, Improving Pediatric to Adult Care Transition
(ImpACT) Program
Children's Hospital Colorado
Denver, CO

Goal: The audience will understand the transition program at Children's Hospital Colorado.

Objectives: The audience will be able to describe:

- Development of a hospital-wide pediatric to adult transition program that incorporates evidence-based best practices
- Utilization of a central resource hub to provide both consultative and coaching services
- Incorporation of tools into the EMR to promote transition education, team communication, and adult provider engagement
- Evaluation utilizing metrics obtained from a reporting dashboard

2:45 **Improved Health Care Transition for Young Adults with Developmental at Texas Children's Hospital**

Ellen Fremion, MD, FAAP, FACP

Associate Professor of Internal Medicine and Pediatrics,
Baylor Transition Medicine Clinic,
Clinical Director at the Center for Pursuit,
Texas Children's Hospital Spina Bifida Transition
Clinic Director

Goal: audience would be able to talk about the structure, processes and outcomes of the clinic serving young adults with intellectual disabilities (YAIDD) and potentially be able to apply some of these structure and processes to improve outcomes at their institution.

Objectives: The audience will be able to describe:

- The state of transition for YAIDD in the U.S.
- Evidence-based guidelines for care for YAIDD in transition
- The structure and processes for the clinic
- Outcome data

3:30 Q&A

3:40 Closing Comments/Evaluation