

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

VIRTUAL CONFERENCE

October 26-28, 2022



Co-provided by:



PLANNING COMMITTEE

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ACTIVITY FACULTY

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

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Deputy Director, Division of Services for Children
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Bethany Coyne, PhD

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Beth Garland, PhD

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Dennis Kuo, MD

Associate Professor,
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Gary Maslow, MD

Associate Professor of Psychiatry and Behavioral Sciences,
Associate Professor of Pediatrics,
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David Robinson

Member, Houston City Council

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Dawn Rowe, PhD

Associate Professor, School of Medicine,
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Beth Sufian, JD

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Patience White, MD

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Stephen Williams, MEd, MPA

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David Wood, MD

Professor, Department of Pediatrics,
Director, Adolescent and Young Adult Clinic
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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 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 Lauren Warren at laura@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.

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 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.

23rd 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