

**22nd Annual
Chronic Illness and Disability Conference:
*Transition from Pediatric to Adult-Based Care***

VIRTUAL CONFERENCE
October 28-29, 2021



Co-provided by:



PLANNING COMMITTEE

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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.
- Discuss payment challenges and options for HCT services.
- Implement advances in HCT services for adolescents and young adults with psychiatric illness.
- Outline an example of the structure, processes, evaluation and outcomes of a sub-specialty transition program based in a large children's hospital.

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 I 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.

22nd Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care

AGENDA

THURSDAY, OCTOBER 28, 2021

7:50 a.m. Waiting Room (Zoom)

8:00 Welcome and Announcements
Albert C. Hergenroeder, MD

8:10 Introduction and Welcome
Catherine Gordon, MD
Chair, Department of Pediatrics, Baylor College of Medicine

8:15 Inspirational Video

8:25 Houston City Council Proclamation
David Robinson, Houston City Council
Stephen Williams, Director, Houston Health Department

8:35 The State of Health Care Transition (HCT) in 2021
Mary Ciccarelli, MD
University of Indiana School of Medicine

Goal: The audience will understand the state of health care transition in 2021.

Objectives: The audience will:

- Appreciate the advances that have been made in the field pertaining to health care transition science and practice.
- Gain awareness of the successful strategies that have contributed to the development of health care transition science and practice.
- Understand the future challenges that confront the widespread implementation of health care transition service models.
- Recognize the unique features of health care transition field of science and practice and its potential for effecting improved outcomes for adolescents and emerging adults with Special Healthcare Needs (SHCN) and disabilities.

9:20 Paying for Transition
Peggy McManus, MHS
Got Transition

Goal: The audience will understand the importance of current payment options for HCT services.

Objectives: The audience will be able to describe:

- Current fee-for-service and value-based payment strategies that can be used to support HCT.
- Quality performance options to align with payment.
- Applying payment and quality innovations to support a successful transfer of care.

10:00 Advocacy for Adolescent Access to Care
Mark Del Monte, JD
CEO, American Academy of Pediatrics

Goal: (TBD)
Objective: (TBD)

10:45 Break

11:00 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 guardianship and supportive decision making; and, practical methods of ensuring legally mandated insurance coverage during the health care transition.

Objective: The audience will be able to discuss health care transition in the context of the current health care landscape.

- Guardianship/supportive decision making/power of attorney.
- Health insurance and supplemental security income (SSI) non-medical eligibility.

11:50 Q&A

Noon Lunch

12:15 Meet-the-Faculty Lunch

- Karen Weigle, PhD
- Mary Ciccarelli, MD
- Beth Sufian, JD
- Susan Fernbach, RN, BSN (family speaker)
- Got Transition

1:00 Conclusion of lunch sessions

(Continued)

1:20 **BREAKOUT SESSIONS I, WITH FACULTY**

Attendees, please choose from one of the following six sessions:

IDD, Trauma, and Mental Health: Addressing the Mental Health and Wellness of Adolescents and Young Adults with IDD

Colleen Horton, MPAff

Director of Policy, Hogg Foundation for Mental Health
The University of Texas at Austin, Division of Diversity and
Community Engagement

Goal: To increase our capacity to support individuals with
IDD who experience mental health conditions and/or the
impact of trauma.

Objectives: The audience will be able to discuss:

- The need to recognize mental health conditions in individuals with IDD – it's not always about "behavior!"
- The impact of trauma and the importance of creating trauma-informed environments.
- The barriers that exist for individuals with IDD who need mental health treatment.
- Additional resources to further explore the mental health of individuals with IDD.

Legal Issues

Beth Sufian, JD

Partner, Sufian & Passamano

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

Objectives: The audience will be able to discuss:

- The difference between guardianship and power of attorney.
- The pros and cons of guardianship and power of attorney from the perspective of the patient and guardian.
- Health insurances and SSI non-medical eligibility.

Targeted Programs to Improve Transition Outcomes for YA with Psychiatric Illness

Kristin Cleverly, RN, PhD

CAMH Chair, Mental Health Nursing
Assistant Professor, University of Toronto
Toronto, Ontario

Goal: (TBD)

Objective: (TBD)

Social Security Insurance

Andy Hardwick

Public Affairs Specialist, Social Security Administration,
Area III

Goal: The audience will understand the importance of successful application for supplemental security income (SSI) and supplemental security disability insurance (SSDI) benefits as the young adult transitions into adult-based care.

Objective: The audience will be able to describe:

- The process of applying for these benefits.
- The timeline for preparing the application.
- Common reasons why people are turned down in their application.
- The types of services these benefits cover.

Health Disparities and Health Care Transition

Deena Chisolm, PhD

Director, Center for Child Health Equity and Outcomes
Research; Abigail Wexner Research Institute,
Nationwide Children's Hospital; Associate Professor of
Pediatrics, Ohio State University College of Medicine and
Public Health

Goal: The audience will understand the health disparities that exist in the transition from pediatric to adult-based care for youth and young adults with special health care need.

Objectives: The audience will be able to discuss:

- The evidence of health disparities during the transition period.
- Potential solutions to address these health care disparities.

Operation of the START Program

Karen Weigle, PhD

Licensed Psychologist
Associate Director, The Center for START Services (Skills,
Trauma, Anxiety, Rehabilitation, and Treatment (START),
University of New Hampshire Institute on Disability

Goal: The audience will understand an overview of the START model's role in systems change, crisis prevention, and crisis intervention.

Objectives: The audience will be able to discuss:

- Values of the START model.
- Structure of a START program.
- Outcomes so far.

2:20 p.m. **BREAKOUT SESSIONS II,
WITH FACULTY**

Attendees: please choose from one of the six sessions offered from Breakout Sessions I (see previous page).

3:05 Break

3:20 **Improving Mental Health Outcomes for
Individuals with Intellectual Disabilities: What Works**

Karen Weigle, PhD

Licensed Psychologist

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

Goal: The audience will understand the diagnosis and treatment of mental health conditions in transitioning adults with IDD.

Objective: The audience will be able to:

- Describe vulnerabilities/common issues associated with transition from youth to adult mental health care for people with IDD in North America and U.K.
- Describe the START model in the U.S., research associated with the model, outcomes, and recommendations.
- Describe a guide to promote an integrated approach to adult mental health care available to all participants.

4:05 Q&A

4:15 Evaluation

4:20 Adjournment

AGENDA

FRIDAY, OCTOBER 29, 2021

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

8:00 **Announcements**

Albert C. Hergenroeder, MD

8:15 **Addressing Patient Adherence with Motivational
Interviewing Maybe as a Mental Health Transition
Problem**

Beth Garland, PhD

Associate Professor of Pediatrics,

Section of Adolescent Medicine and Sports Medicine,
Department of Pediatrics, Baylor College of Medicine

Goal: The audience will understand MI techniques as a way of addressing non-adherence.

Objectives: The audience will be able to discuss:

- MI techniques they could implement in their practice.
- How MI could be used to address non-adherence in self-management for Adolescent/Young Adult with special health care needs (AYASHCN) in transition.

9:00 Q&A

9:10 **Young Adult Perspective**

Brynne Willis, M.Sc.

Research Assistant, Case Western Reserve School of Law,
Cleveland, Ohio

Goal: The audience would understand how social stigma and chronic grief impact young adults with chronic medical illness transitioning from adolescence to young adulthood.

Objective: The audience will be able to describe:

- How social stigma impacts mental health and behaviors in adolescents and young adults during transition
- The process of chronic grief.
- How these dynamics are addressed by the medical community.

9:40 Q&A

9:55 Break

(Continued)

10:05 Anxiety and Depression in the Transition – A Clinical Perspective

Chadi Calarge, MD

Professor of Psychiatry, Baylor College of Medicine

Goal: The audience will be able to understand the clinical course of anxiety disorders and major depressive disorder between adolescence and young adulthood.

Objective: The audience will be able to describe:

- Evidence-based treatments for Generalized Anxiety Disorder (GAD) and Major Depressive Disorder (MDD) adolescents and young adults.
- The natural history of GAD and MDD in patients successfully treated with medication and psychotherapy.
- The interface of anxiety and depressive disorders and other chronic medical illnesses in adolescents and young adults.

10:50 Transition Advances in the Mental Health Field

Kristin Cleverly, PhD

Senior Scientist, Margaret and Wallace McCain Centre for Child, Youth & Family, Mental Health Division; Assistant Professor, Lawrence Bloomberg Faculty of Nursing and Department of Psychiatry, University of Toronto

Goal: The audience will understand the current state of transition from pediatric to adult-based care for adolescents and young adults with psychiatric illness.

Objectives: The audience will be able to describe:

- The state of transition to adult-based care for youth and young adults with psychiatric illness in the United States (international and in U.S.)
- Models for transition, with outcome data.
- Educational and career outcomes for patients after they transition.

11:35 Q&A

11:45 Exhibitors and lunch

1:00 p.m. Health Literacy and Transition

Deena Chisolm, PhD

Director, Center for Child Health Equity and Outcomes Research; Abigail Wexner Research Institute, Nationwide Children's Hospital

Associate Professor of Pediatrics, Ohio State University, College of Medicine and Public Health

Goal: The audience will be able to understand the importance of health literacy in developing transition readiness.

Objectives: The audience would be able to describe:

- Methods to assess health literacy.
- Relationship between health literacy and transition readiness.
- Epidemiology of health illiteracy and its health and economic consequences.
- Methods to improve health literacy.

1:45 Q&A

1:55 Break

2:05 From Stress to Strength

Susan Fernbach, RN, BSN

Assistant Professor, Department of Molecular and Human Genetics, Baylor College of Medicine

Goal: Provide the audience methods to improve self-care for Caregivers of teens/young adults with IDD as they transition to adult care.

Objective: The audience will be able to describe a program for improving self-care for caregivers, including specific tips gathered from one session. This session includes a brief overview of the From Stress to Strength program model and qualitative results from the program, as well as specific discussion from one session of Positive Adult Development curriculum: "From Conflict to Collaboration."

2:45 The Rheumatology Transition Program at Texas Children's Hospital: Structure, Processes and Outcomes

Tiphonie Vogel, MD, PhD

Rheumatology Transition Program, Texas Children's Hospital

Goal: The audience will be able to understand the structure, process and outcomes of this transition program.

Objectives: The audience will be able to describe the following elements to this transition program and how they have developed over several years:

- The structure
- The processes
- The outcomes
- How data for these metrics were collected

3:30 Q&A

3:40 Closing Comments/Evaluation