

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

**VIRTUAL CONFERENCE**  
**October 29-30, 2020**



Co-provided by:



## PLANNING COMMITTEE

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

Cecily L. Betz, PhD, RN, FAAN  
Amanda Garey, MSN, RNC-OB, C-EFM  
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Luis Valdez, MPH

Sherry Vinson, MD  
Gail Vozzella, MSN, RN, NEA-BC  
Laura Warren  
Chava White, LMSW-AP  
Audrey Young, MPH

## ACTIVITY FACULTY

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

### Laura Alter, MS, CPRP

Manager, Employment Services  
Jewish Family Service

### Cecily L. Betz, PhD, RN, FAAN

Professor of Clinical Pediatrics  
USC Keck School of Medicine, Department of Pediatrics  
Nursing Director and Research Director  
USC Center of Excellence in Developmental Disabilities  
Children's Hospital Los Angeles  
Los Angeles, CA  
Editor-in-Chief, *Journal of Pediatric Nursing*

### Dakota Bramble, MPH

Type I Diabetes Transition Patient  
Texas Children's Hospital and Baylor College of Medicine

### Jennifer Disabato, DNP, CPNP-PC, AC

Assistant Professor  
Pediatric Nurse Practitioner  
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### Daniel DeSalvo, MD

Assistant Professor  
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### Kimberly Espinoza, DDS, MPH

Clinical Associate Professor  
Director of Dental Education in the Care of Persons with  
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University of Washington School of Dentistry  
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### Susan Fernbach, RN, BSN

Assistant Professor  
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### Al Freedman, PhD

Clinical Psychologist, Private Practice

### Beth Garland, PhD

Associate Professor  
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Section of Adolescent Medicine and Sports Medicine  
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### Jordan Kemere, MD

Assistant Professor  
Internal Medicine Section, Transition Medicine  
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### Mark Lawley, PhD

TEES Research Professor  
Deputy Director, Center for Remote Health  
Technologies and Systems,  
Department of Biomedical Engineering,  
Department of Epidemiology and Biostatistics,  
Texas A&M University  
College Station, TX

### Nelly Miranda, BS, RN, CDE

Coordinator for the Young Adult Diabetes Program  
Baylor College of Medicine

### Philip Moons, PhD, RN

Professor of Healthcare and Nursing Science  
Department of Public Health and Primary Care  
KU Leuven Belgium, Germany  
Research Leader, Health Care Transition Research Group,  
Institute of Health and Care Sciences  
University of Gothenburg, Sweden

### Beth Sufian, JD

Partner  
Sufian & Passamano

### Huda Zoghbi, MD

Investigator, Howard Hughes Medical Institute  
Director, Jan and Dan Neurological Research Institute  
Ralph D. Feigin Professor, Baylor College of Medicine

## 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:

- Identify strategies for setting up and evaluating a transition program as well as describe models of care for transitioning youth with a variety of chronic illnesses and disabilities.
- Identifying strategies for helping caregivers cope with the stress of caring for and then planning for the transition to adult-based care for their adolescents and young adults with special health care needs (AYASHCN).
- List the interdisciplinary aspects of care, such as formal planning related to HCT for families of AYASHCN, performed by many members of the provider team, especially nurses.
- Explain the legal issues associated with transition from pediatric to adult-based care.

## EDUCATIONAL METHODS

Lectures • Breakout Sessions • Question and Answer Sessions

## 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 11.75 *AMA PRA Category 1 Credits*<sup>™</sup>. 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 0.75 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, 11.75 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 11.75 contact hours.

This nursing continuing professional development activity awards up to 11.75 contact hours.

This includes 0.75 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 11.75 CCUs for PTs and PTAs.

Continuing Competency Units (CCU) have been applied for this conference through Texas Occupational Therapy Association (TOTA) 11.75 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/chronic2020](http://cpd.education.bcm.edu/chronic2020) 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 CYSHCN and their parents or guardians. For complete details, please contact Lauren Warren at [laura@txp2p.org](mailto: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/chronic2020](http://cpd.education.bcm.edu/chronic2020).

## **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.

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

## AGENDA

### THURSDAY, OCTOBER 29, 2020

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

**8:10 Inspirational video**

*Albert C. Hergenroeder, MD*

**8:00 Welcome and Announcements**

**8:15 Neurologic Research Institute Welcome and Update on Genetic Neurologic Disease and the Implications for Transition From Pediatric to Adult-Based Care**

*Huda Zoghbi, MD*

Investigator, Howard Hughes Medical Institute  
Ralph D. Feigin Professor, Baylor College of Medicine  
Director, Jan and Dan Duncan Neurological Research Institute

**Goal:** The audience will understand the dramatic changes of therapeutics in neurologic diseases.

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

- The future of therapeutics in genetic neurologic diseases.
- How those treatments are affecting providers', patients' and families' expectations of life expectancy and the expectation of moving from pediatric to adult-based care.
- The speaker's perspective on what we should start to build as an infrastructure for facilitating this eventual transition from pediatric to adult-based care, when appropriate, for some of these patients.

**8:45 Q&A**

**8:55 Houston City Council Proclamation**

*David Robinson*, Houston City Council, Proclamation  
*Gabe Cazares*, Director, Office for People with Disabilities

**9:05 Health Care Transition: 2020 and Beyond**

*Cecily L. Betz, PhD, RN, FAAN*

Associate Professor of Clinical Pediatrics,  
USC Keck School of Medicine, Department of Pediatrics  
Nursing Director and Research Director,  
USC University Center of Excellence in Developmental Disabilities at Children's Hospital  
Los Angeles

**Goal:** The audience will understand the state of HCT in 2020.

**Objectives:** At the end of this presentation, the participant 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 affecting improved outcomes for adolescents and emerging adults with SHCN and disabilities.

**9:50 Dental Care for Young Adults with Chronic Illness and Disability**

*Kimberly Espinoza, DDS*

Clinical Associate Professor,  
Director of the Dental Education in the Care of Persons with Disabilities (DECOD) Program at the University of Washington School of Dentistry; MCHB-funded Leadership Education in Neurodevelopmental Disabilities Discipline Leader (AUCD speaker)

**Goal:** The audience will understand 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 in the U.S. and worldwide.
- The special needs of those with intellectual, emotional and developmental disabilities.
- Barriers to receiving dental care during the transition years (age 18-25).
- Programs to deliver this care and train the next workforce of dental providers.

**10:35 Q&A**

**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 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.

11:45 Q&A

11:55 Break

12:10 p.m. **Meet-the-Faculty Lunch**

- Kimberly Espinoza, DDS
- Dakota Bramble, MPH
- Beth Sufian, JD
- Al Freedman, PhD
- Mark Lawley, PhD
- Got Transition

1:05 End lunch sessions

1:20 **Breakout Sessions I, with Faculty**

Attendees, please choose from one of the following:

### **Self-advocacy and Self-disclosure in Obtaining Employment**

**Laura Alter, CPRP**

Manager, Employment Services, Jewish Family Service

**Goal:** The audience would understand the importance of self-advocacy and self-disclosure in obtaining employment.

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

- Techniques of job interviewing that promote self-advocacy.
- How to handle questions from prospective employers about the applicant's chronic illness or disability.

### **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 describe:

- 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.

### **Operational and Administrative Aspects of a Dental Clinic for Adolescents and Young Adults with Medical Complexity**

**Kimberly Espinoza, DDS**

Clinical Associate Professor,  
Director of the Dental Education in the Care of Persons with Disabilities (DECOD) Program,  
University of Washington School of Dentistry MCHB-funded Leadership Education in Neurodevelopmental Disabilities Discipline Leader (AUCD speaker)  
Seattle, WA

### **From Stress to Strength**

**Susan Fernbach, RN, BSN**

Director, Office of Community Engagement and Diversity,  
Assistant Professor, Department of Molecular and Human Genetics,  
Baylor College of Medicine/Texas Children's Hospital

**Jordan Kemere, MD**

Assistant Professor, Internal Medicine,  
Section of Transition Medicine, Baylor College of Medicine

**Goal:** Provide the audience with 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 which will include specific tips gathered from one session.

This session includes a brief overview of the "From Stress to Strength" program model, qualitative results from the program as well as specific discussion from one session of Positive Adult Development curriculum: "From Conflict to Collaboration."

### **Technology to Improve No-Show Rates and Clinic Flow**

**Mark Lawley, PhD**

TEES Research Professor,  
Deputy Director, Center for Remote Health Technologies and Systems, Department of Biomedical Engineering,  
Department of Epidemiology and Biostatistics,  
Texas A&M University  
College Station, TX

**Goal:** The audience will understand the potential roles of technology in improving no-show rates and clinic operations in clinics that serve patients with special health care needs.

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

- An engineer's perspective on the no-show rate problem.
- Methods to improve no-show rates for patients with chronic illnesses.

### **What specialized training is needed for nurses who want to do health care transition planning?**

**Cecily L. Betz, PhD, RN, FAAN**

Associate Professor of Clinical Pediatrics,  
USC Keck School of Medicine, Department of Pediatrics  
Nursing Director and Research Director,  
USC University Center of Excellence  
in Developmental Disabilities at Children's Hospital  
Los Angeles

**Jennifer Disabato, DNP, CPNP-PC, AC**

Assistant Professor  
Pediatric Nurse Practitioner  
Children's Hospital Colorado  
Denver, CO

**Goal:** The audience will understand the knowledge, skills and attitudes (KSA) that are important for HCT planning for AYA with special health care needs (AYASHCN).

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

- KSA that are important for nurses who do HCT planning for AYASHCN.
- Nursing competencies that distinguish a nurse who, for example, does HCT planning in complex care, compared to a nurse who provides complex care but is not trained in HCT planning for AYASHCN.
- Whether nurses are receiving this specialized training.

**2:20 p.m. Breakout Sessions II, with Faculty Attendees, please choose from one of the sessions offered from Breakout Sessions I.**

**3:05 Break**

**3:20 Nursing Roles in Transition Planning**

**Cecily L. Betz, PhD, RN, FAAN**

Associate Professor of Clinical Pediatrics,  
USC Keck School of Medicine, Department of Pediatrics  
Nursing Director and Research Director,  
USC University Center of Excellence  
in Developmental Disabilities at Children's Hospital  
Los Angeles

**Jennifer Disabato, DNP, CPNP-PC, AC**

Assistant Professor  
Pediatric Nurse Practitioner  
Children's Hospital Colorado  
Denver, CO

**Nelly Miranda, BS, RN, CDE**

Coordinator for the Young Adult Diabetes Program,  
Baylor College of Medicine

**Goal:** The audience will understand the various roles that nurses play in HCT, in the outpatient setting.

**Objectives:** The audience will be able to describe the roles of nurses in the outpatient setting.

**4:05 Q&A and Evaluation**

**4:15 Adjournment**

# AGENDA

**FRIDAY, OCTOBER 30, 2020**

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

**8:00 Announcements**

**Albert C. Hergenroeder, MD**

**8:15 Addressing Patient Adherence with Motivational Interviewing (MI)**

**Beth Garland, PhD**

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

**Daniel DeSalvo, MD**, as patient in character.

**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 AYASHCN in transition.

**9:05 Q&A**

**9:20 Young Adult Perspective**

**Dakota Bramble, MPH**

Type I Diabetes Transition Patient,  
Texas Children's Hospital and Baylor College of Medicine

**Goal:** The audience will understand the perspective of a young adult with a chronic illness who has successfully navigated the transition to adult-based care and adulthood.

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

- Challenges this speaker faced during transition to adulthood and adult based care.
- Some specific coping strategies to facilitate successful transition.
- This speaker's use of digital technology in self-management.

**10:20 Q&A**

**10:35 Break**

**10:50 A Parent's Perspective on Transition**

**Al Freedman, PhD**

Clinical Psychologist, Private Practice

**Goal:** The audience will understand a parent's perspective on the process of transition from adolescence through young adulthood for their adolescent/young adult with a chronic illness or disability.

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

- How a parent supports their youth to develop self-management skills.
- How a parent supports autonomy while supporting their teen.
- Lessons learned.

**11:30 Q&A**

**11:45 Exhibitors**

**1:00 p.m. Remote Monitoring in Chronic Illness**

**Mark Lawley, PhD**

TEES Research Professor,  
Deputy Director, Center for Remote Health Technologies and Systems, Department of Biomedical Engineering, Department of Epidemiology and Biostatistics, Texas A&M University  
College Station, TX

**Goal:** The audience will understand the role of remote monitoring in managing chronic illness.

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

- Myths about how technology can improve chronic illness management.
- Principles of remote monitoring and how they interface with human behavior.
- Outcome data in adults with chronic disease as a function of their ability to adhere to remote monitoring.

**1:45 Break**

**2:00 Process Outcomes and Interventions in Improving Health Care Transition in Youth with Congenital Heart Disease**

**Philip Moons, PhD, RN**

Professor of Healthcare and Nursing Science,  
Department of Public Health and Primary Care,  
KU Leuven, Belgium  
Researcher/Scientific leader,  
Health Care Transition Research Group,  
Institute of Health and Care Sciences,  
University of Gothenburg, Sweden

**Goal:** The audience will understand the mixed methods used to evaluate the process outcomes of and intervention to improve healthcare transition in patients with CHD.

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

- The methods used to evaluate the process outcomes.
- Lessons learned in this evaluation process.
- Preliminary process outcome data.

**2:45 Q&A**

**3:00 Closing Comments/Evaluation**