



25th Annual Chronic Illness and Disability Conference:

Transition from Pediatric
to Adult-Based Care

OCTOBER 10-11, 2024
IN-PERSON LIVE/VIRTUAL CONFERENCE



**Texas Children's
Hospital®**

Co-presented by:



ADVISORY BOARD MEMBERS

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Division of Adolescent Medicine and Sports Medicine

Professor of Pediatrics

Baylor College of Medicine

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Transition Conference

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Co-Director of Got Transition

Kristi Miller, BSR

Director

Department of State Health Services

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Texas Children's Hospital

Kate Thompson, MSW

Senior Program Manager, MCH Engagement

Association of University Centers on Disabilities

Shelly Townsend, MSW

Program Director and Family Support Partner

University of Houston

ACTIVITY FACULTY

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Baylor College of Medicine
Transition Clinic

Shamera Beckham

Director
Texas Children's Project Search

Christina Boothby, MPA

Senior Director
Children and Youth with Special Health
Care Needs Initiatives
American Academy of Pediatrics

Jarred Bolt

Project Search Alumnus
Current TCH employee as a mentor

Kim Brown, JD

Executive Director
Belong Kitchen

Tom Davis, MD

Geisinger Medical Center

Ellen Fremion, MD

Baylor College of Medicine
Transition Clinic

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Kristi Miller, QIDP

Director
Children & Youth with Special Health Care Needs
(CYSHCN)
Group Manager
CYSHCN Systems Development

Diane Murrell, MSW (Moderator)

Licensed Clinical Social Worker
Texas Children's Hospital

Drew Scoggins, MSFS

Houston Professional
Parents of a Child with a Disability
Franchise Owners
Bitty & Beau's Coffee Houston

Kelly Scoggins, MBA
Houston Professional
Parents of a Child with a Disability
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Swaran Singh, MD
Professor
Social and Community Psychiatry
Warwick University, UK

Deborah Sukin, Ph.D
President
Texas Children's Hospital

Beth Sufian, JD
Partner
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Kate Thompson, LMSW
Senior Program Manager
MCH Engagement
Association of University Centers on Disabilities

Allysa Ware, PhD, MSW
Executive Director
Family Voices

Patience White, MD, MA
Co-Director of Got Transition
Center for Health Care Transition

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



NEEDS STATEMENT

Skill preparation and planning for healthcare transition for youth and young adults with special healthcare needs is inadequate. Less than 50 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 trained 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 and all healthcare providers 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, healthcare providers 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 primary and subspecialty care medical care during the transition years; discussions of models of transition programs and data to support their processes; the legal issues involved in healthcare transition; family and young adult perspectives in a plenary format 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 this activity, the participants should be able to:

- Discuss critical referrals for all families with Adolescents/Young Adults with Special Health Care Needs (AYASHCN) undergoing transition
- Discuss improving self-efficacy for AYASHCN during transition
- Discuss the role of families from different cultures during transition
- Discuss the importance of advocacy and self-advocacy
- Describe the legal and ethical issues involved in Health Care Transition (HCT) for AYASHCN
- Discuss strategies for addressing bullying in AYASHCN
- Discuss building a transition program between a large children's hospital and a large county hospital system
- Discuss the importance of treatment adherence during the transition to adult-based care
- Summarize how pediatricians and adult providers can collaborate
- Outline the demographic differences in HCT planning

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

Physician

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 11.25 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Ethics

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.

Nursing

Texas Children's Hospital is accredited with distinction as a provider of nursing continuing professional development by the American Credentialing Center's Commission on Accreditation. This nursing continuing professional development activity awards up to 11.25 contact hours.

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, 11.25 hours of continuing education including 0.75 hour of ethics.

Occupational Therapy

May be eligible for 11.25 hours of OT education. Please see event organizers for supporting documentation.

Physical Therapy

This activity is provided by the Texas Board of Physical Therapy Examiners Accredited Provider #2604051TX and meets continuing competence requirements for physical therapists and physical therapist assistants licensure renewal in Texas for 11.25 CCUs.



AGENDA

THURSDAY, OCTOBER 10, 2024

7:15 AM

Coffee and bagels in the lobby

8:00 AM

Welcome and Announcements

Albert C. Hergenroeder, MD

Chief

Division of Adolescent Medicine and Sports Medicine

Professor of Pediatrics

Baylor College of Medicine

Founding Program Director

Transition Conference

8:15 AM

The Importance of Successful Transition

Deborah Sukin, PhD

President

Texas Children's Hospital

8:25 AM

Reflections on the 25 years of the Conference

Albert Hergenroeder, MD

Chief

Division of Adolescent Medicine and Sports Medicine

Professor of Pediatrics

Baylor College of Medicine

Founding Program Director

Transition Conference

Goal: The audience will understand the history of the conference

Objective: The audience will be able to discuss

- Notable events for the conference
- Trends seen in health care transition over these 25 years and future considerations

9:05 AM

The Current State of Health Care Transition: An International Perspective

Swaran Singh, MD

Professor

Social and Community Psychiatry

Warwick University, UK

Goal: The audience will the current state of health care transition with an emphasis on mental health in Europe

Objective: The audience will be able to discuss

- The clinical and research implications of this work

9:50 AM

Pediatric and Medicine Collaboration: Building Strong Collaboration

Ellen Fremion, MD

Baylor College of Medicine, Transition Clinic

Tom Davis, MD

Geisinger Medical Center

Goal: The audience will understand the importance of functional pediatric-adult medicine collaboration in successful health care transition

Objective: The audience will be able to discuss

- The structure and processes that have worked in successful pediatric-adult medicine health care transition programs
- Common barriers to successful pediatric-adult medicine collaborations and solutions to overcome these barriers

10:30 AM

Questions and Answers

10:40 AM

Break

AGENDA

11:10 AM

Complexity of Health Care Transition
Across Systems

Allysa Ware, PhD, MSW
Executive Director
Family Voices

Goal: The audience will understand the complexity of health care transition across systems

Objective: The audience will be able to discuss

- Critical referrals for all families
- Potential barriers for AYASHCN with medical complexity
- Meeting the needs of AYASHCN with intersectional identities
- The role of families from different cultures in health care transition

11:55 AM

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

Objective: 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.
- The most significant legal issues affecting health care transition in the past 25 years.

12:35 PM

Questions and Answers

12:45 PM

Meet the Faculty Luncheon (meal provided)

Swaren Singh, MD

Beth Sufian, JD

Peggy McManus, MHS

Kristi Miller, QIDP

Patience White, MD, MA

Christina Boothby

Ellen Fremion, MD

Tom Davis, MD

1:45 PM

End lunch sessions

2:00 PM

Breakout Sessions I with Faculty

35 minute session followed by 10 minute Q&A

Attendees: please select one at 2:00pm and a different one at 3:00pm

ADVOCACY

Allysa Ware, PhD, MSW
Executive Director
Family Voices

Goal: The audience will understand the importance of advocacy and self-advocacy for AYASHCN in successful health care transition

Objective: The audience will be able to discuss

- Self-advocacy and self-efficacy as learned behaviors
- Improving knowledge of strategies to address bullying in AYASHCN

AGENDA

KNOWN KNOWNS, KNOWN UNKNOWNNS AND UNKNOWN UNKNOWNNS' IN TRANSITION RESEARCH

Swaran Singh, MD

Professor

Social and Community Psychiatry
Warwick University, UK

Goal: This breakout session will summarize state of the art evidence on international research in transition from pediatric to adult healthcare, focusing on important questions that have been answered, others that remain under-researched, and areas yet unexplored. In a participatory manner with active engagement, attendees will have a chance to explore the research landscape of transitional care, primarily in Anglophone and European settings but also in global health

Objective: By attending the session, participants will

- Understand the nature and magnitude of problems in transitional care
- Explore models of managed transition which have evidence of effectiveness
- Identify areas of uncertainty or lack of evidence and discuss possible research designs to fill this gap
- Have an opportunity to network and collaborate with like-minded clinicians and academics

GOT TRANSITION®

Peggy McManus, MHS

President

The National Alliance to Advance
Adolescent Health

Co-Director of Got Transition

Center for Health Care Transition

Patience White, MD, MA

Co-Director of Got Transition

Center for Health Care Transition

Goal: The audience will understand current Got Transition activities

Objective: The audience will be able to describe

- Current Got Transition initiatives

EMPLOYMENT FOR YOUNG ADULTS WITH CHRONIC ILLNESS

Kelly Scoggins, MBA

Houston Professional

Parents of a Child with a Disability

Franchise Owners

Bitty & Beau's Coffee Houston

Drew Scoggins, MSFS

Houston Professional

Parents of a Child with a Disability

Franchise Owners

Bitty & Beau's Coffee Houston

Kim Brown, JD

Executive Director

Belong Kitchen

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

Objective: The audience will be able to describe

- The structure and processes for employment for AYASHCN
- What the speakers have learned in the process of setting up employment opportunities
- The national perspective on employment opportunities for young adults with intellectual disabilities in the U.S.
- Success stories

AGENDA

BUILDING PEDIATRIC-MEDICINE PARTNERSHIPS FOR COMPLEX CARE IN AYASHCN AND EDUCATING THE NEXT GENERATION OF PROVIDERS IN HCT

Ellen Fremion, MD

Baylor College of Medicine
Transition Clinic

Elisha Acosta MD

Baylor College of Medicine
Transition Clinic

Tom Davis, MD

Geisinger Medical Center

(This session will not be repeated, rather it is over the 2 breakout periods.)

Goal: The audience will understand the importance of structure and processes in establishing complex care clinics for young adults with special health care needs in an adult care system

Objective: The audience will be able to describe how two complex care programs

- Set up their structure and processes
- Work with their hospital leadership to support these programs
- Build partnerships between the pediatric and adult providers
- Are training the future health care transition workforce

IMPLEMENTATION SCIENCE APPLIED TO HEALTH CARE TRANSITION: PRACTICAL STRATEGIES.

Sharon Hudson, PhD

Director

Implementation Science and Evaluation
AltaMed Institute for Health Equity

Goal: The audience will understand the importance of implementation science in health care transition

Objective: The audience will be able to discuss

- The operational aspects of implementation sciences

3:00 PM

Breakout Sessions II with Faculty

35 minute session followed by 10 minute Q&A

Attendees: please select one at 2:00pm and a different one at 3:00pm

3:45 PM

Break

4:10 PM

Evidence-based and HCT Methods and a Look to the Future

Kate Thompson, LMSW

Association of University Centers on Disabilities

Goal: The audience will understand the intersections of interdisciplinary approaches in health care transition and AUCD's role in promoting meaningful transition outcomes

Objective: The audience will be able to discuss

- AUCD's initiatives to improve HCT for AYASHCN in the future
- The evidence base for interdisciplinary approaches for HCT from pediatric to adult-based care
- The importance of self-determination and inclusion in decisions around HCT

4:50 PM

Questions and Answers

5:00 PM

Evaluation and adjourn

AGENDA

FRIDAY, OCTOBER 11, 2024

7:15 AM

Registration, coffee and bagels

8:00 AM

Announcements

Albert C. Hergenroeder, MD

Chief

Division of Adolescent Medicine and Sports Medicine

Professor of Pediatrics

Baylor College of Medicine

Founding Program Director

Transition Conference

8:15 AM

Young Adult/Youth Panel

Shamera Beckham (Facilitator)

Director

Texas Children's Hospital Project Search

Jarred Bolt

Project Search Alumnus

Current TCH employee as a mentor

Julio Grajeda

Former Project Search Intern

Current Target Employee

Diane Murrell, MSW (Moderator)

Licensed Clinical Social Worker

Texas Children's Hospital

Goal: The audience will understand the importance youth and young adult voice in advocating for improved health care transition

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 AM

Questions and Answers

9:10 AM

Parent Panel

Kristi Miller, QIDP

Director

Children & Youth with Special Health Care Needs (CYSHCN)

Group Manager

CYSHCN Systems Development

Allysa Ware, PhD, MSW

Executive Director

Family Voices

Albert C. Hergenroeder, MD (Facilitator)

Chief

Division of Adolescent Medicine and Sports Medicine

Professor of Pediatrics

Baylor College of Medicine

Founding Program Director

Transition Conference

Goal: The audience will understand the parents' perspective on HCT from a global perspective

Objective: The audience will be able to describe parents'/caregivers perspectives on their AYASHCN's Trauma Informed journey through transition to adulthood and lessons learned

9:40 AM

Questions and Answers

9:55 AM

Break

AGENDA

10:15 AM

Medication Adherence and Motivational Interviewing

Beth Garland, PhD

Division of Adolescent Medicine and Sports Medicine
Division of Psychology
Department of Pediatrics
Baylor College of Medicine

Goal: The audience will understand the importance of medication adherence and adherence to other aspects of the treatment plan in maintaining health during the transition to adult-based care

Objective: The audience will be able to discuss

- The extent of the problem of medication non-adherence in outcomes for AYASHCN
- Evidence-based methods to improve medication adherence

11:00 AM

Implementation Science and Health Care Transition

Sharon Hudson, PhD

Director of Implementation Science and Evaluation

The Alta Med Institute for Health Equity

Goal: The audience will be understand the principles of implementation science

Objective: The audience will be able to describe

- The structure and processes of implantation science
- Specific examples of successful implementation science strategies

11:45 AM

Questions and Answers

11:55 AM

Lunch (provided)

1:00 PM

Health Care Transition for CYSHCN:
An Overview of AAP Initiatives

Christina Boothby, MPA

Senior Director

Children and Youth with Special Health Care Needs Initiatives
American Academy of Pediatrics

Goal: The audience will be able to describe AAP initiatives to improve HCT for CYSHCN

Objective: The audience will be able to

- Describe AAP's health care transition initiatives for CYSHCN and how they align with the Blueprint for Change
- Identify at least 2 key learnings or lessons learned based on project/activity outcomes
- Identify at least 2 health care transition resources that can be utilized within your own practice or organization

1:45 PM

Questions and Answers

1:55 PM

Break

2:15 PM

Aging Out of Medicaid, CHIP, SSI, and Title V Programs: Impacts, Inequities, and Recommendations

AGENDA

Peggy McManus MHS

President

The National Alliance to Advance
Adolescent Health

Co-Director of Got Transition

Center for Health Care Transition

Objective: The participants will be able to

- Discuss the racial disparities in insurance and poverty status among adolescents and young adults with disabilities
- Review the unique roles that these four programs play in supporting low income adolescents and young adults with disabilities
- Describe the challenges and inequities commonly experienced by adolescents and young adults with disabilities and their families when they lose their childhood eligibility for public programs
- Discuss recommendations for program and policy reforms, outreach and education, and research and evaluation

2:55 PM

Building a transition program between a children's hospital and a large public health county system for patients aging out of Medicaid

Albert Hergenroeder, MD

Chief

Division of Adolescent Medicine and
Sports Medicine

Professor of Pediatrics

Center for Health Care Transition

Goal: The audience will understand the importance of using a quality improvement framework in building a health care transition program between a children's hospital and a large, public county health system for young adults aging out of Medicaid

Objective: The audience will be able to describe

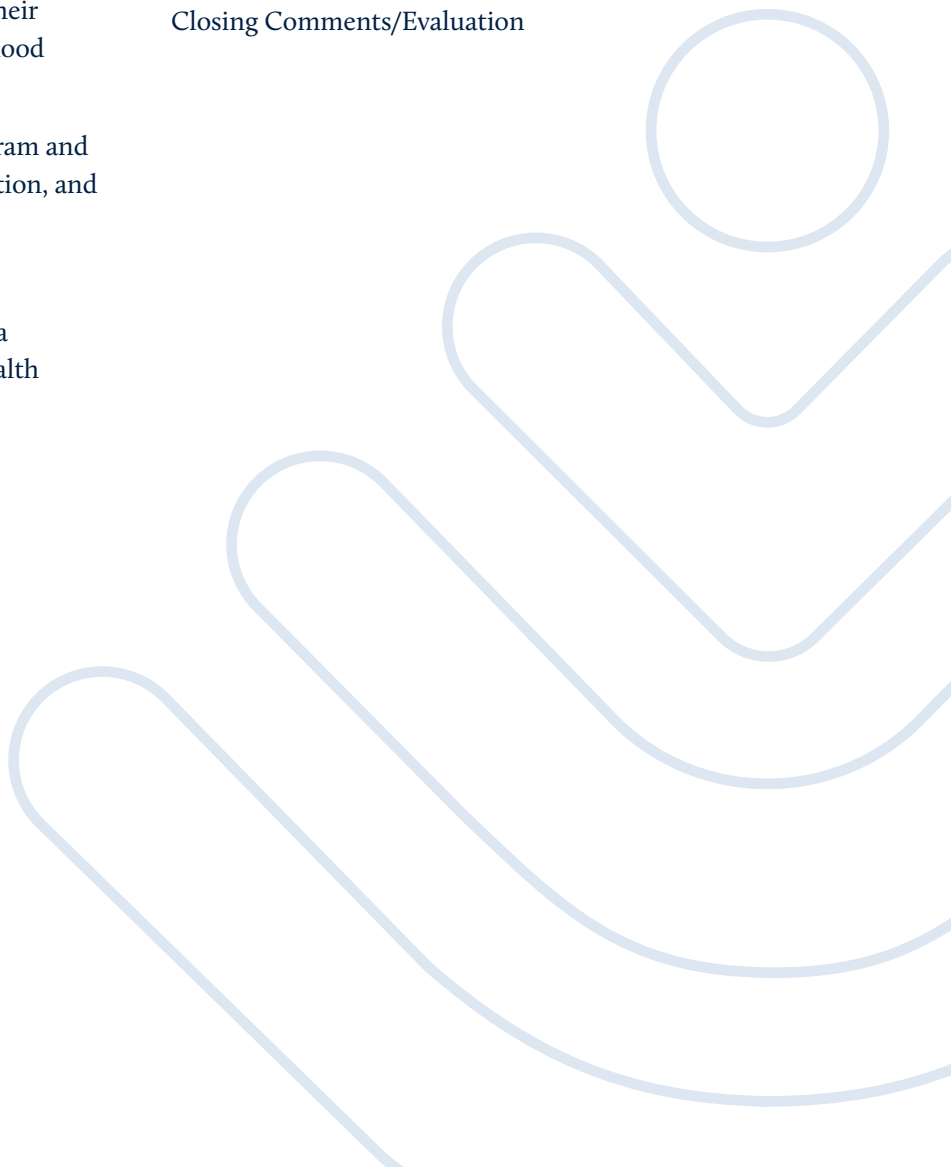
- The structure and process of the Texas Children's Hospital – Harris Health Transition Program
- Outcome data of patients successfully transitioned

3:40 PM

Questions and Answers

3:50 PM

Closing Comments/Evaluation





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