

# Minding the Gap in Severe Asthma

Let's transition and let's do it right!

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Assistant Professor, Harvard Medical School



**Boston  
Children's  
Hospital**

BRIDGES Adult Transition Program

**BRIGHAM HEALTH**



**BRIGHAM AND WOMEN'S**  
Department of Medicine



**Harvard**  
Medical School

# Disclosures

- None for our discussion on transition

# Objectives

- Understand the need for adult providers to be involved in the care of burgeoning adult with asthma, severe asthma in particular
- Recognize challenges and barriers to transitioning from a pediatric to an adult medical home
- Discuss BCH BRIDGES Program and strategies for continuing care for complex pediatric patients as they become adults

# Survivors of Chronic Disease of Childhood - Asking the right questions

- **Who** are we talking about?
- **Why** is this important?
- **What** is transition?
  - Developmental process and patient and family centered
- **When** should we be thinking about transition and transfer?
- Does it matter **where** you are (free standing pediatric hospital vs. combined adult/peds setting e.g. MGH)?
- **How** should we go about, or not go about, transition?



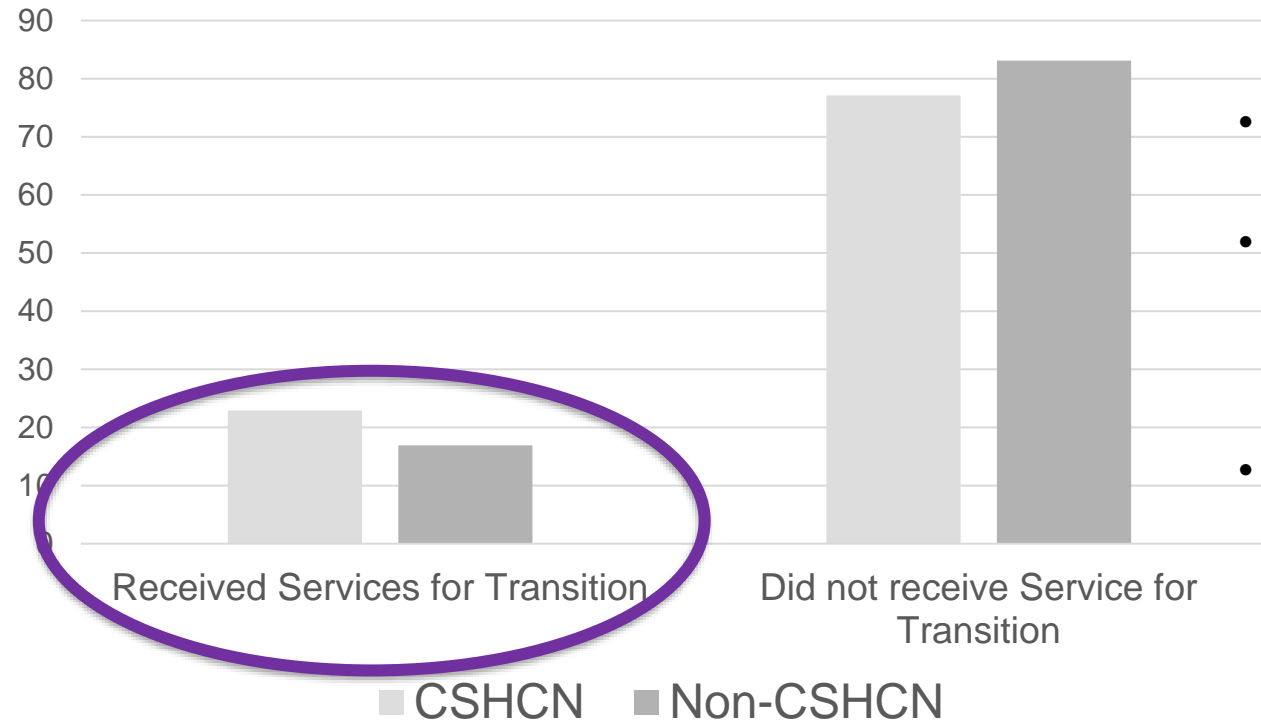
Pai & Schwartz, 2011  
Mazzucato et al., 2018  
Wijlaars et al., 2016



Lotstein, 2005



## Youth Received necessary services for transition to adult health care (%)



- HCP discussed shift to adult provider (41%)
- HCP actively worked to gain skills or understand changes in health care during transition (68.6%)
- HCP spent time alone with youth with SHCN at last check up (44.4%)

Data Resource Center for Child & Adolescent Health. National Survey of Children with Special Health Care Needs. <http://childhealthdata.org>

Lebrun-Harris, et al., 2018  
<http://childhealthdata.org>

# Cystic Fibrosis - A Story of Progress

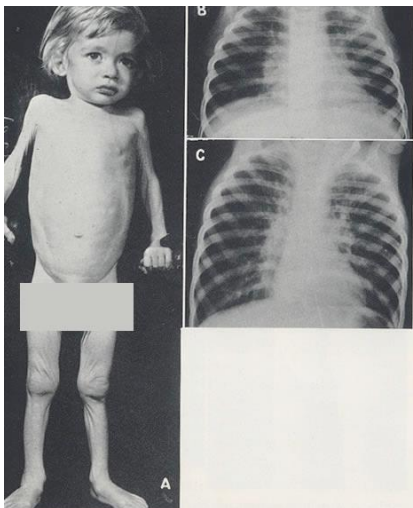
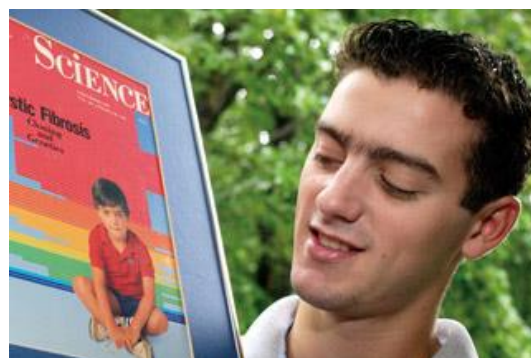
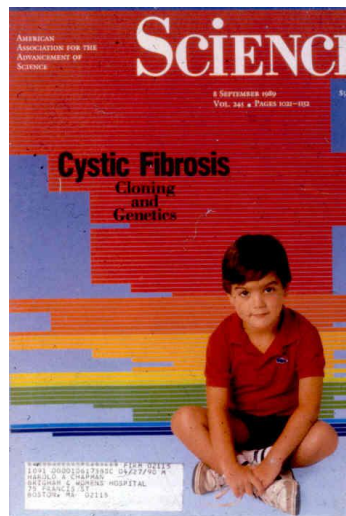
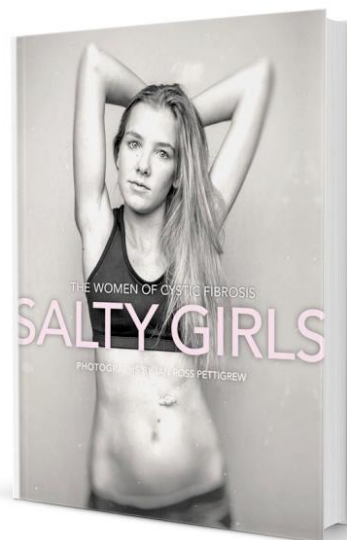


Figure 7. A. Patient with Cystic Fibrosis of the Pancreas at two years, five months. B. Lungs at one year, two months. C. Lungs at two years, five months. When infection becomes established in the viscid secretion of the bronchioles at an early age, and persists, the lungs show progressive development of peribronchial infiltration and emphysema. The nutritional state deteriorates with advance of the infection. (Reproduced from Plate V, May, C. D. and Lowe, C. U., Fibrosis of the pancreas in Infants and Children, *J. Pediat.*, 34:663 (1949) with permission of C. V. Mosby, St. Louis.)

1950



1989



2015



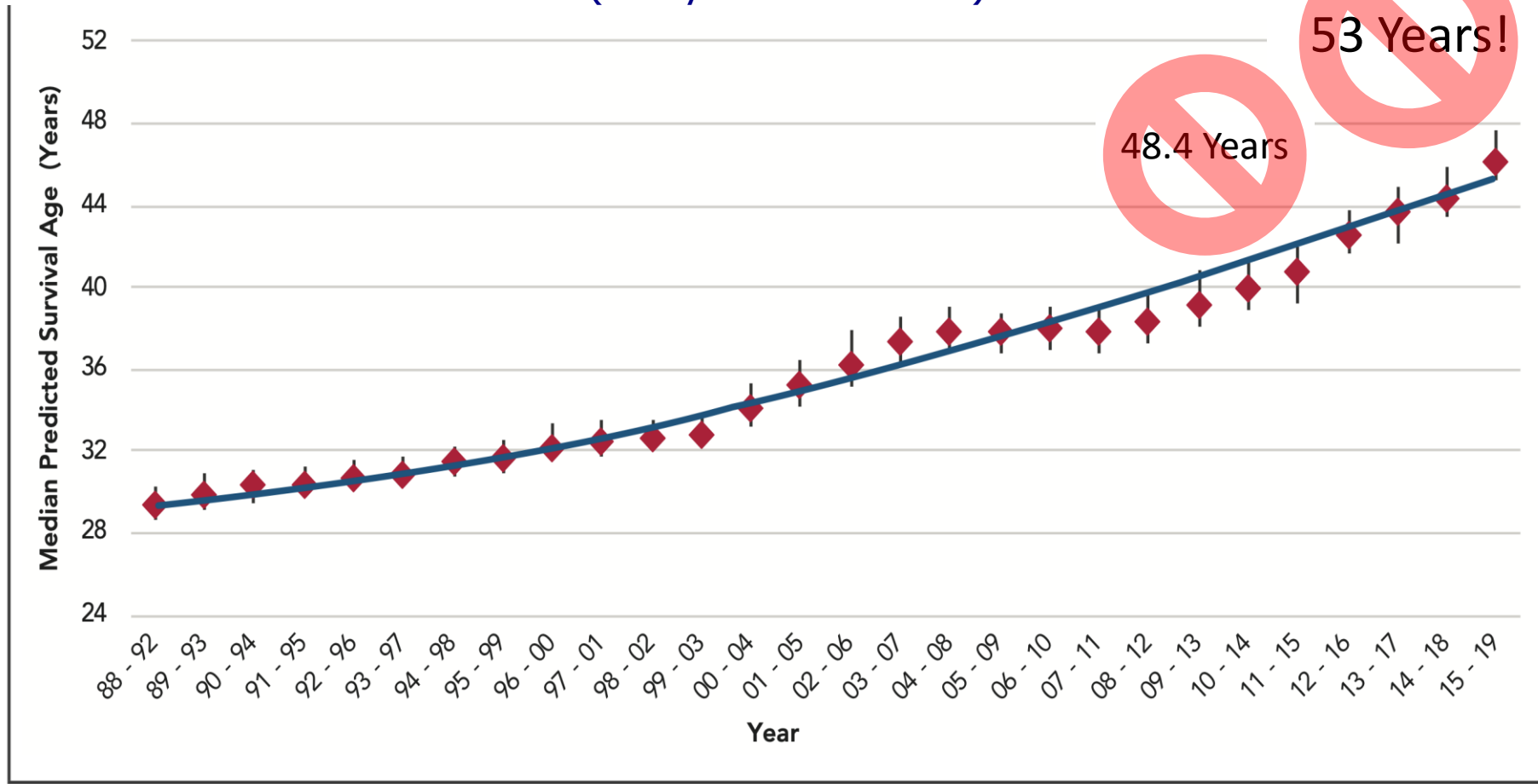
2021

TIME



# Improving Survival in Cystic Fibrosis

Median Predicted Survival Age, 1988-2020  
(in 5 year increments)

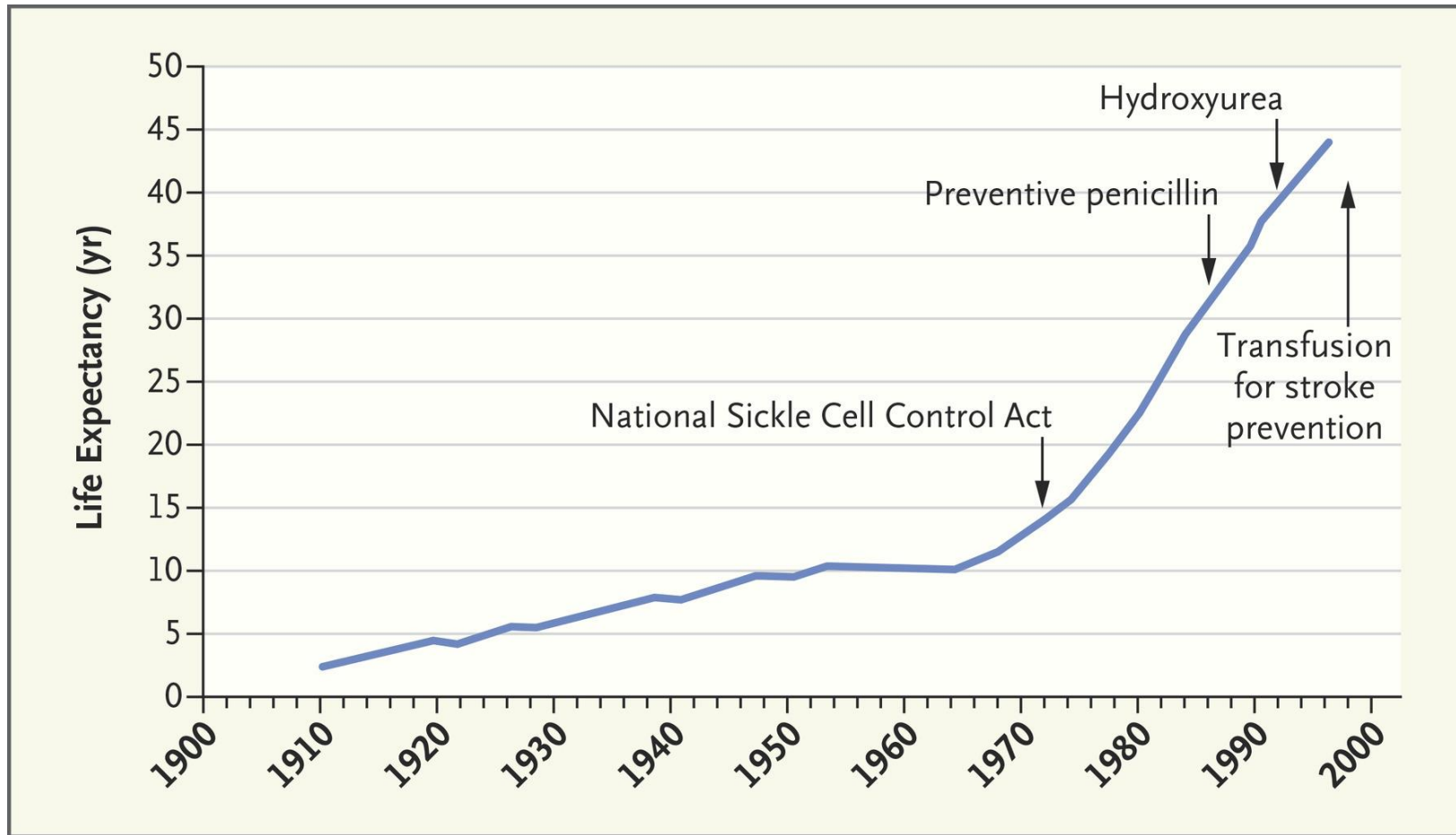


68+!

53 Years!

48.4 Years

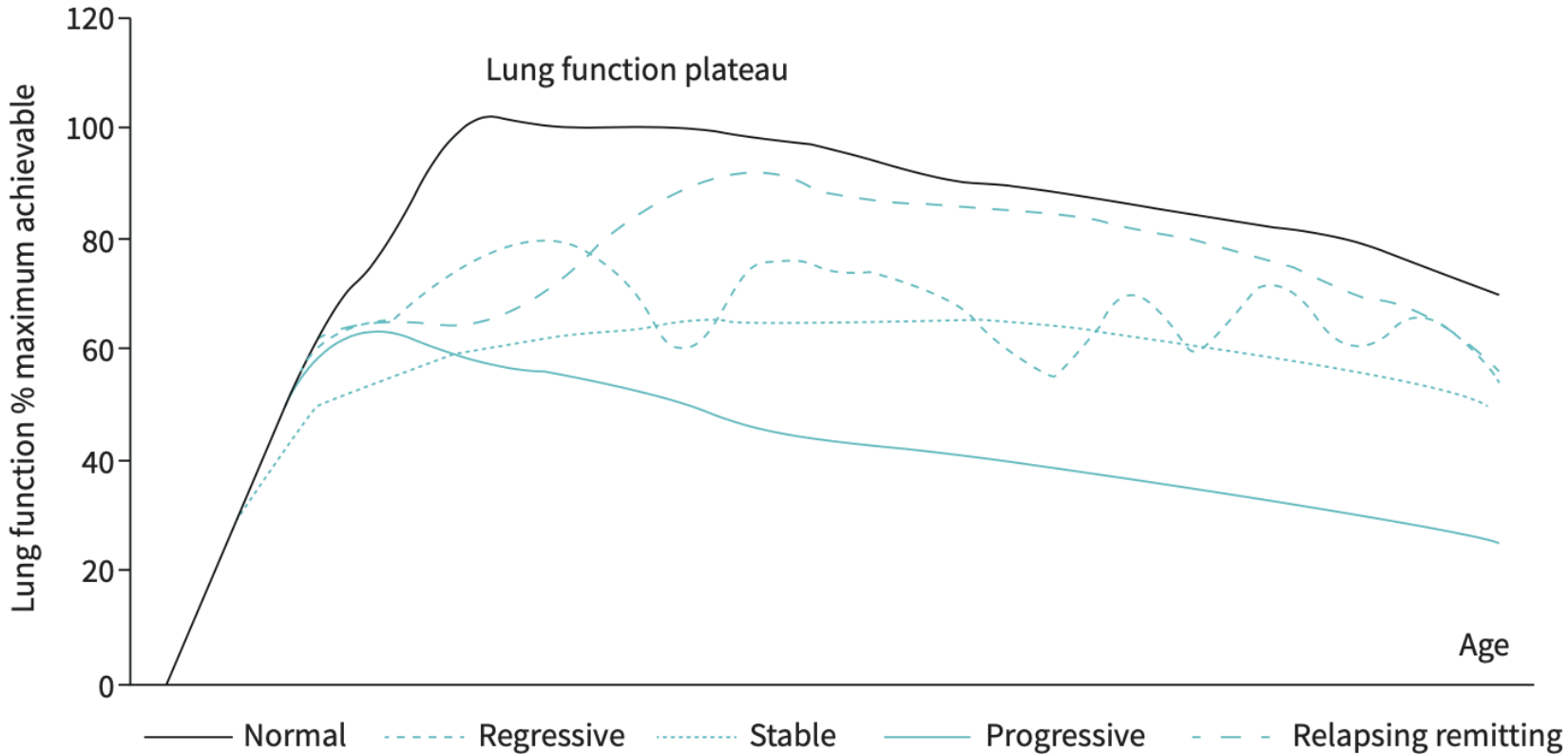
# Improving Survival in Sickle Cell Disease



52.6 Years!

Wailoo K. NEJM 2017

# Pediatric to Adult ILD Transition



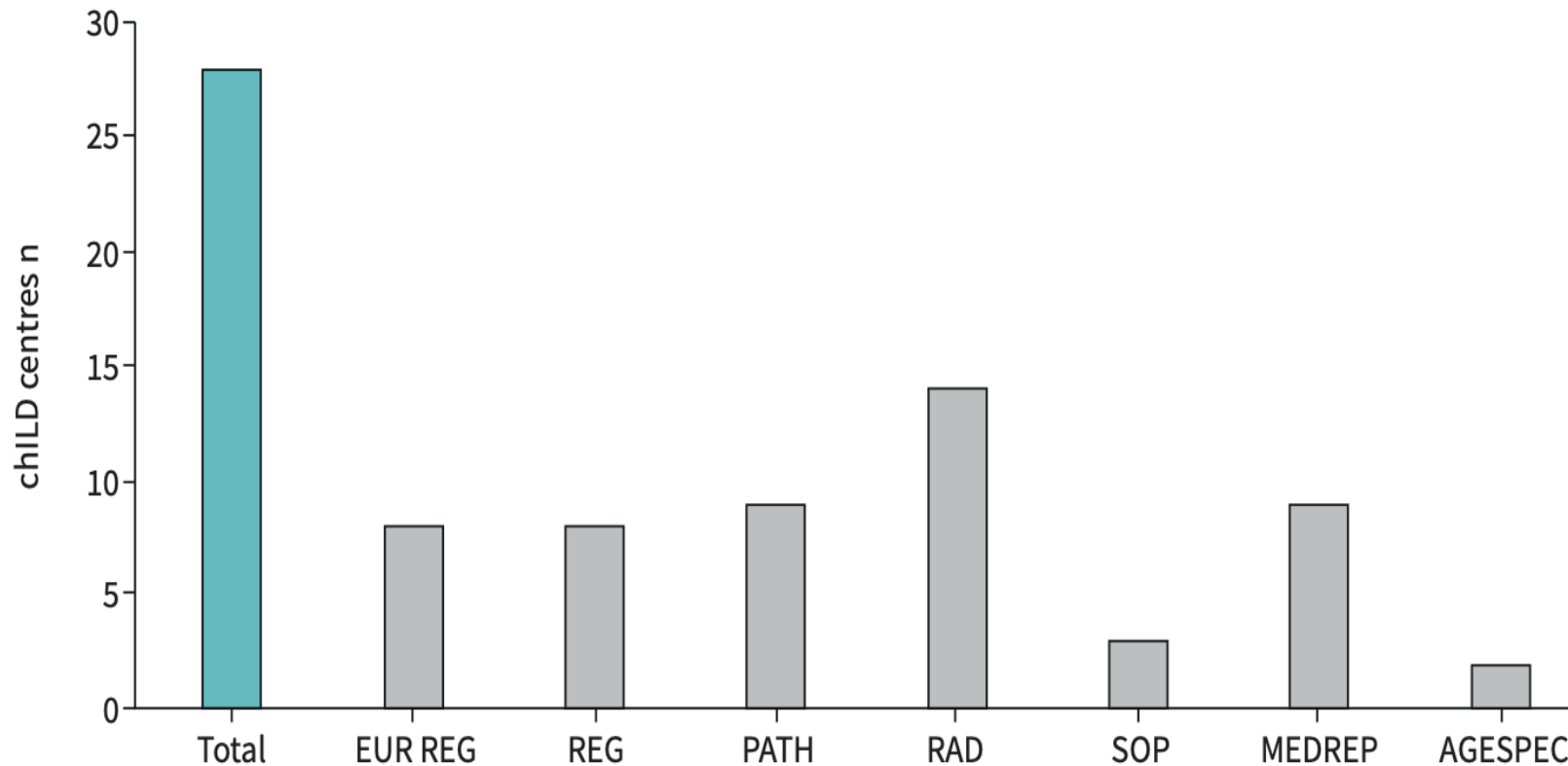
**683 patients representing a heterogenous group of disorders (US chILD registry)**

- Alveolar Growth Disorder (4.8%)
- Surfactant Dysfunction (12.0%)
- NEHI (22.7%)
- Bronchiolitis Obliterans (11.0%)
- Alveolar Hemorrhage (9.2%)
- Connective tissue / immune-mediated (16.5%)
- Others\* (12.7%)
- Unclassified (11.0%)

Koucky V, et al. ERJ Open Res 2021

# Pediatric to Adult ILD Transition

Survey – Funded by European Cooperation in Science and Technology (COST)



**39 centers from 21 countries**

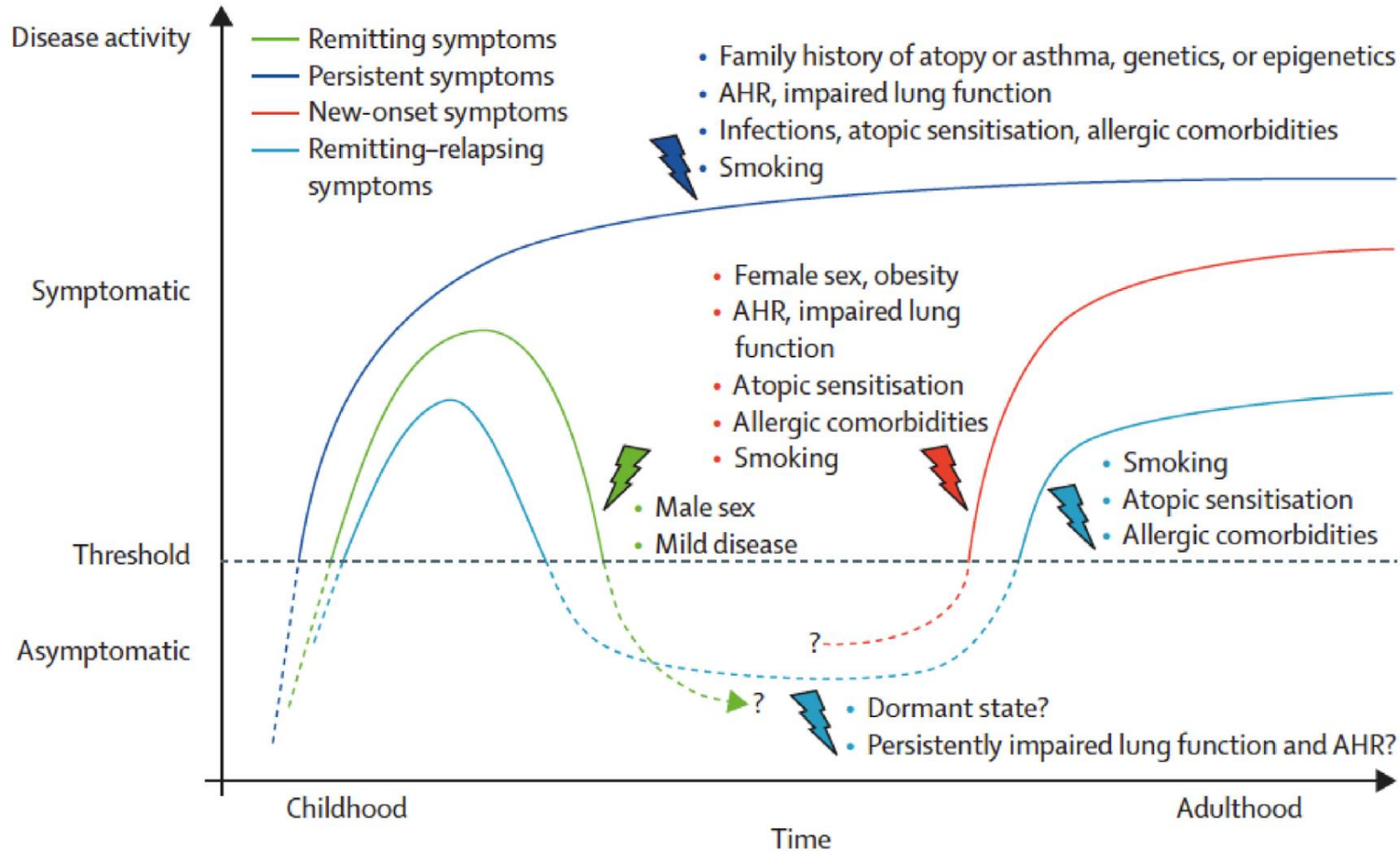
- 51% had a MDT (pulm, rad, path)
- RN, Dietitian less common

## **Transition related**

- 11% peds centers with SOP for transition
- 32% created med report
- 14% pre-transition meeting with all involved
- 32% without patients/parents
- 18% adult centers (2 centers) long-term follow-up with child

Koucky V, et al. ERJ Open Res 2021

# Pediatric to Adult Asthma Transition



## Life expectancy decline:

- Danish Study
  - **3.3 years** for asthma and otherwise healthy
  - **9.3 – 12.8 years** for asthma-COPD overlap
  - **10.1 years** for COPD
- Iranian Study
  - **18.6 years** lost compared to placebo

# WHO - Four Adult Patient “Tracks” Seen at BCH

“Easier” to transition

Hardest to transition

	Healthy Population	Non-Complex Chronic	Congenital/ Rare Diseases Requiring Shared Expertise	Special Healthcare Needs
Description	Adults who come through our ED, college kids who have not changed PCP yet, etc. Small percentage of cases seen at BCH	Legacy patients with chronic conditions who have a level of comfort with BCH providers	Patients with congenital conditions who are now living into adulthood. Many of these patients but could benefit from greater shared care.	Patients with cognitive and developmental challenges, trach and/or ventilator dependent
Sample disease areas	<ul style="list-style-type: none"> <li>• Opportunity to transition these patients to BWH primary care from Children’s affiliated primary care centers</li> </ul>	<ul style="list-style-type: none"> <li>• Asthma</li> <li>• Endocrine - Diabetes</li> <li>• GI - IBD</li> <li>• Neurology (less complex)                             <ul style="list-style-type: none"> <li>• Headache</li> <li>• Epilepsy</li> </ul> </li> <li>• Rheumatology</li> <li>• Psych</li> </ul>	<ul style="list-style-type: none"> <li>• Cystic Fibrosis (inpatient specialty care at BWH, clinic at BCH)</li> <li>• Spina Bifida</li> <li>• Congenital Heart</li> <li>• Endocrine-Thyroid nodules/carcinomas</li> <li>• Metabolism</li> <li>• Vascular</li> <li>• Blood Disorders</li> </ul>	<ul style="list-style-type: none"> <li>• CCS</li> <li>• These patients touch multiple departments/ specialties (e.g., Neuro, ORL, Pulm)</li> </ul>

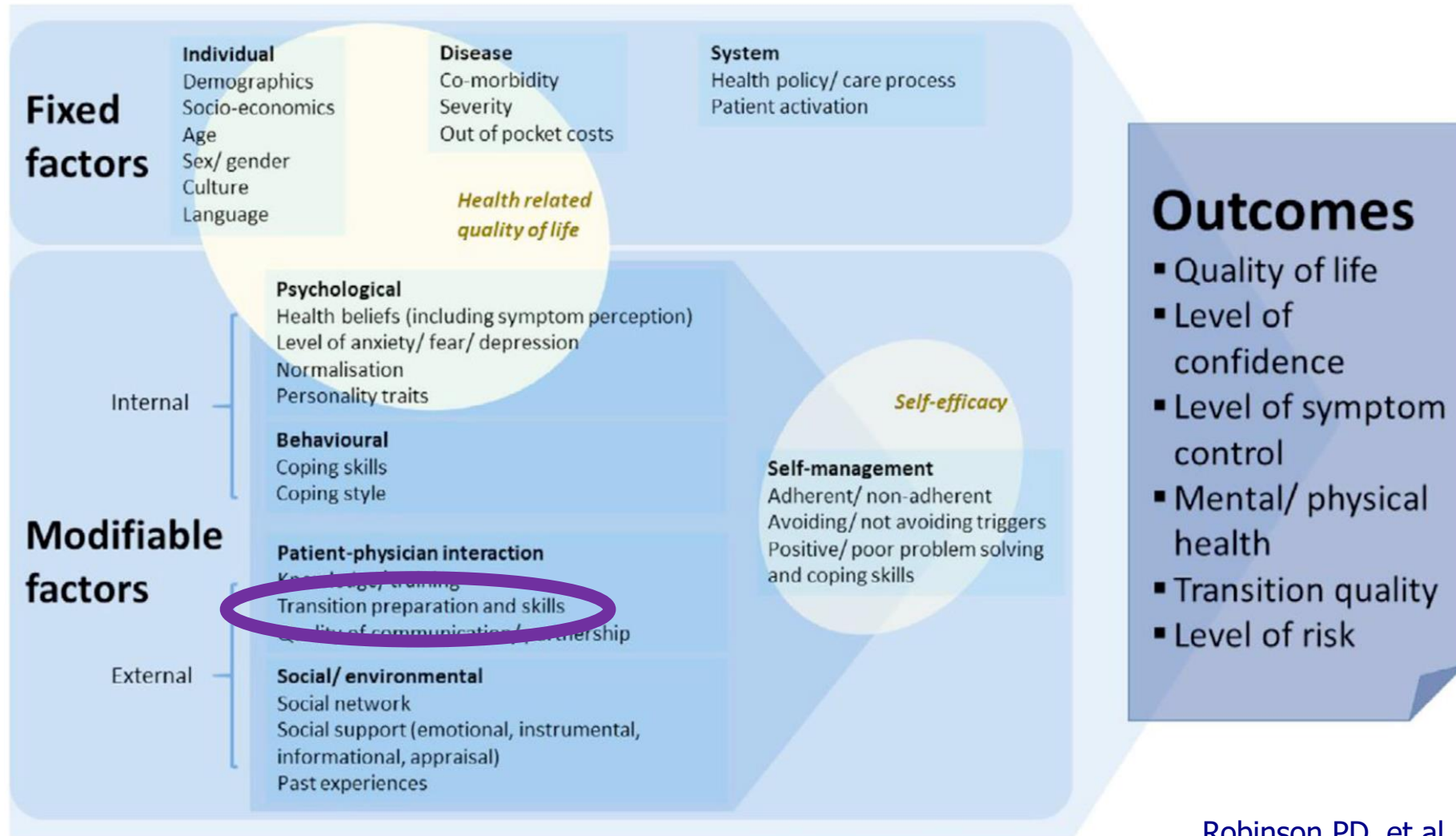
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# Improving Asthma Care into Adulthood



Robinson PD, et al. Ped Resp Rev. 2022

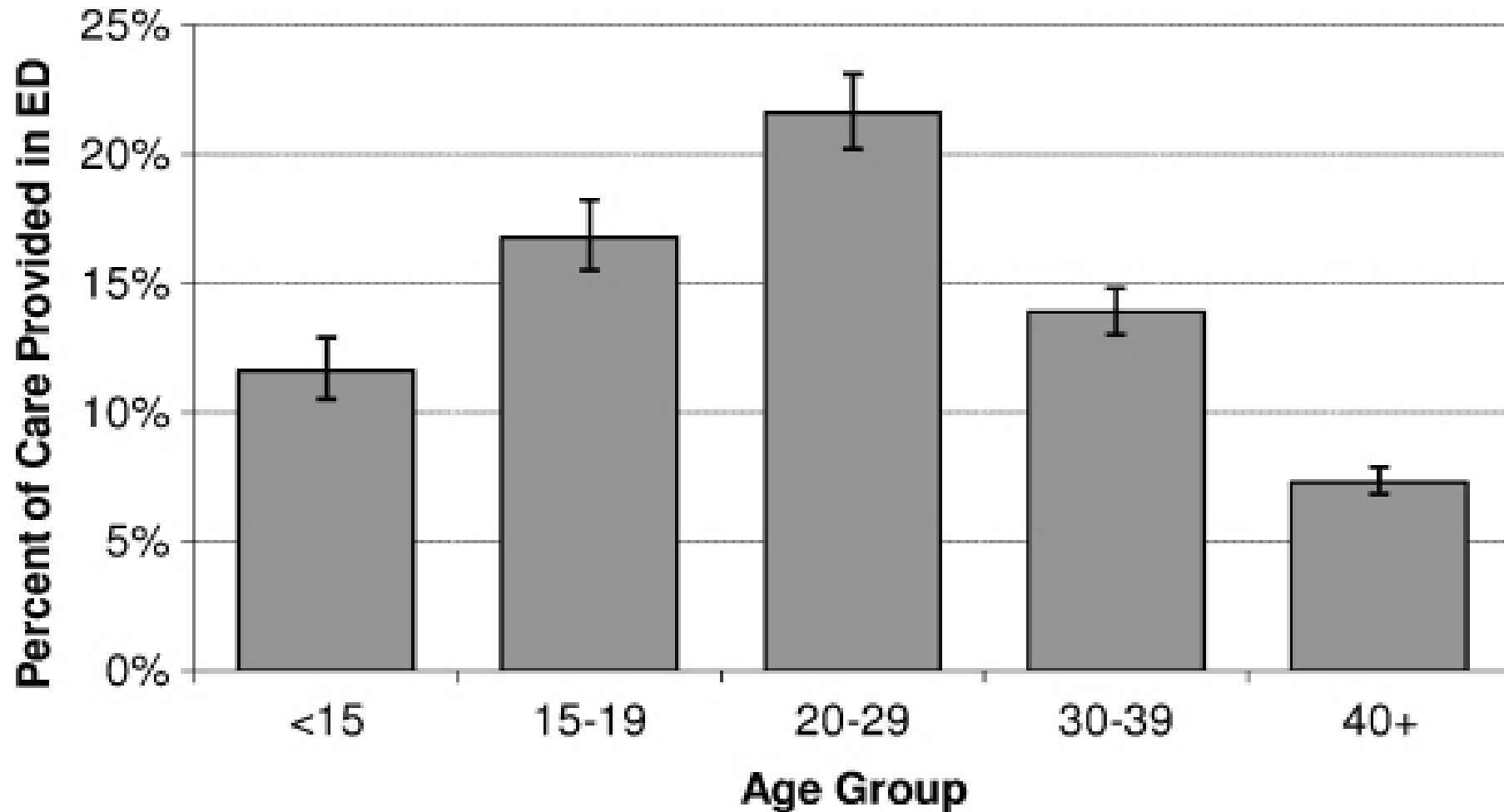


# WHY it's important?

**Transition is inevitable** but doesn't need to be uncomfortable

- Hopeful message to patients and parents
- Self-esteem and enhanced decision making
- Development of self advocacy skills
- Aging parents also benefit from knowing their adult child is in good hands, including those with development disabilities

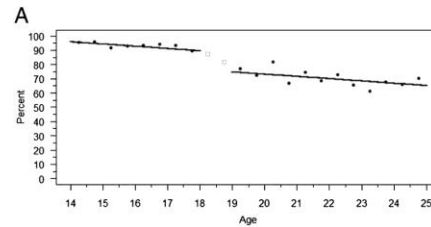
# Emergency Room Utilization



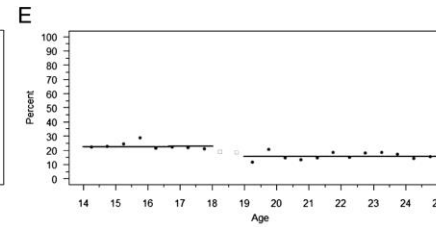
Fortuna JGIM 2010

# Asthma: Health care access and utilization among older adolescents and young adults

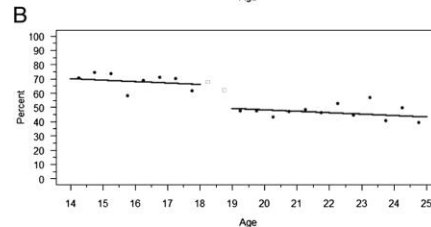
Usual Source of Care



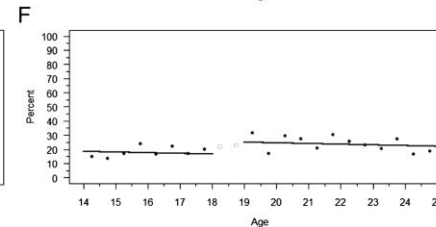
Fill of asthma controller



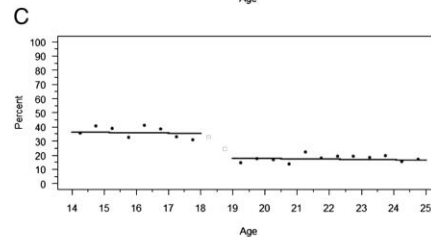
Primary Care Visit



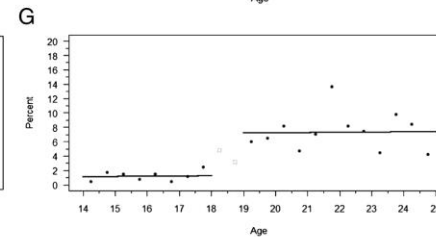
ED visit



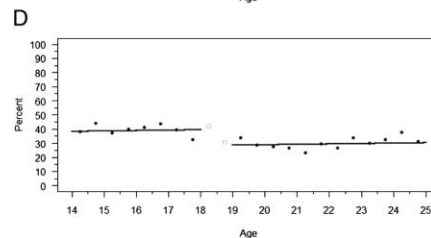
Preventive Visit



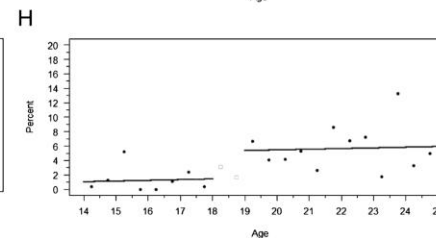
Access Issue for Medical Care



Fill of a SABA



Access Issue for Meds



Chua K et al. Pediatrics 2013;131:892-901

# WHAT is the Definition of Transition

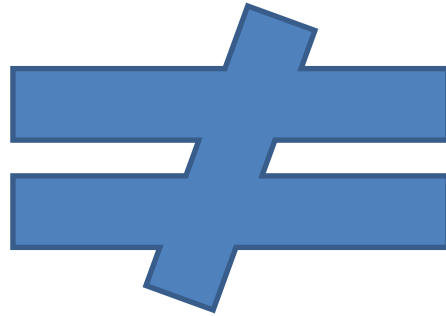
“Health care transition is the process of changing from a pediatric to an adult model of health care. The goals of health care transition are to improve the ability of youth and young adults to manage their own health care and effectively use health services, and to ensure an organized clinical process in pediatric and adult practices to facilitate transition preparation, transfer of care, and integration into adult-centered care.”

- [www.gottransition.org](http://www.gottransition.org)

# TRANSITION



**Preparation** over  
time (toward  
independence)

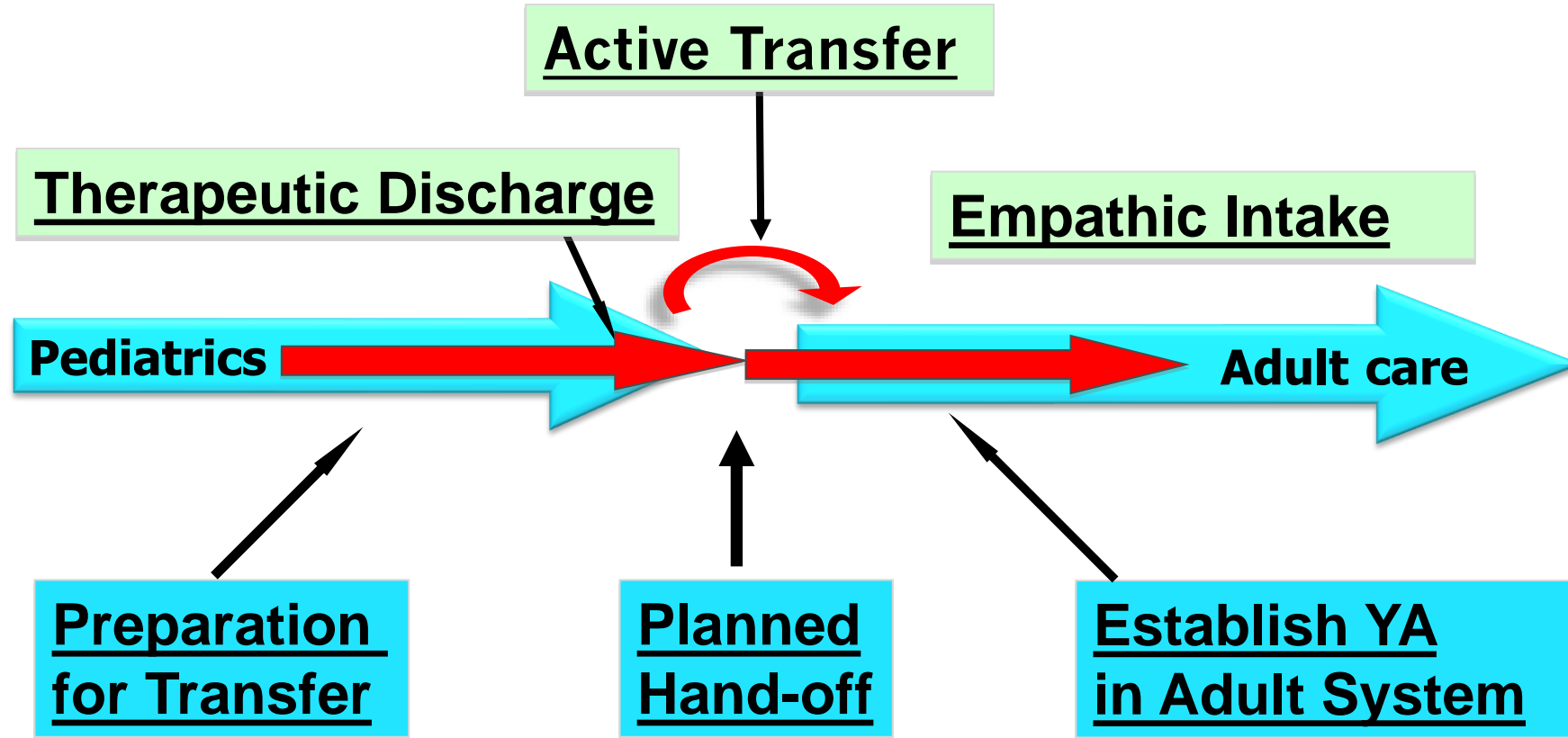


# TRANSFER



Handoff/one moment in time

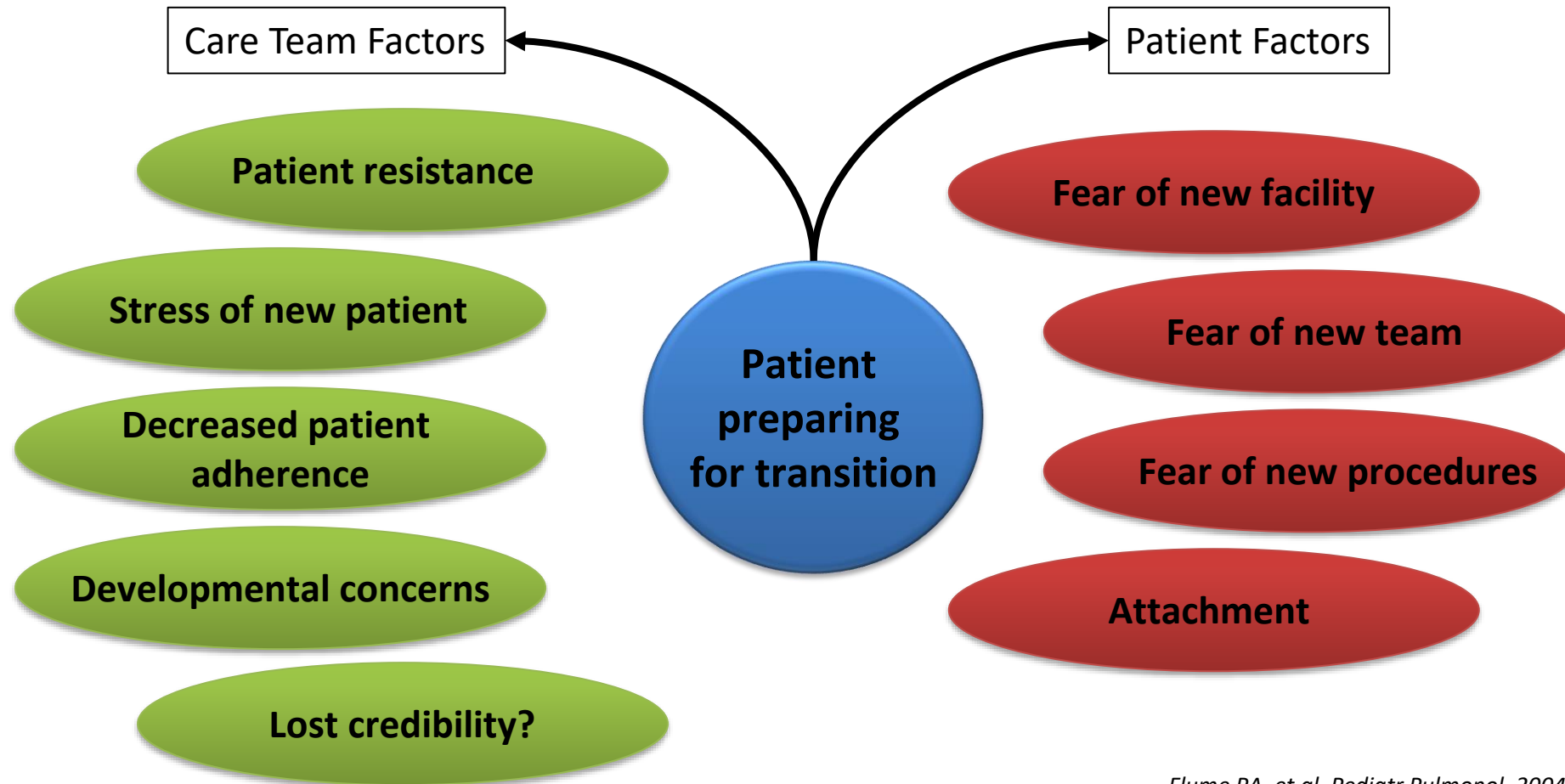
# Goal: A Comprehensive Process



# WHAT are other common obstacles we run into

- Waiting to Start the Conversation
- Much more to Healthcare Transition than Transfer
  - e.g. guardianship/HCP, school/education, living arrangements, insurance
- Need more provider connections and increase provider preparedness, both pediatric and adult

# Perceived Barriers to Transition



*Flume PA, et al. Pediatr Pulmonol. 2004*



# WHEN - Transition Consensus Evolution

## 2002: Consensus document approved

by the boards of the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine

(American Academy of Pediatrics, et al., 2002)

## 2011: Clinical Guidelines developed

(AAP, AAFP, ACP, Transitions Clinical Report Authoring Group, 2011)

## 2018: Update with practice-based QI guidance

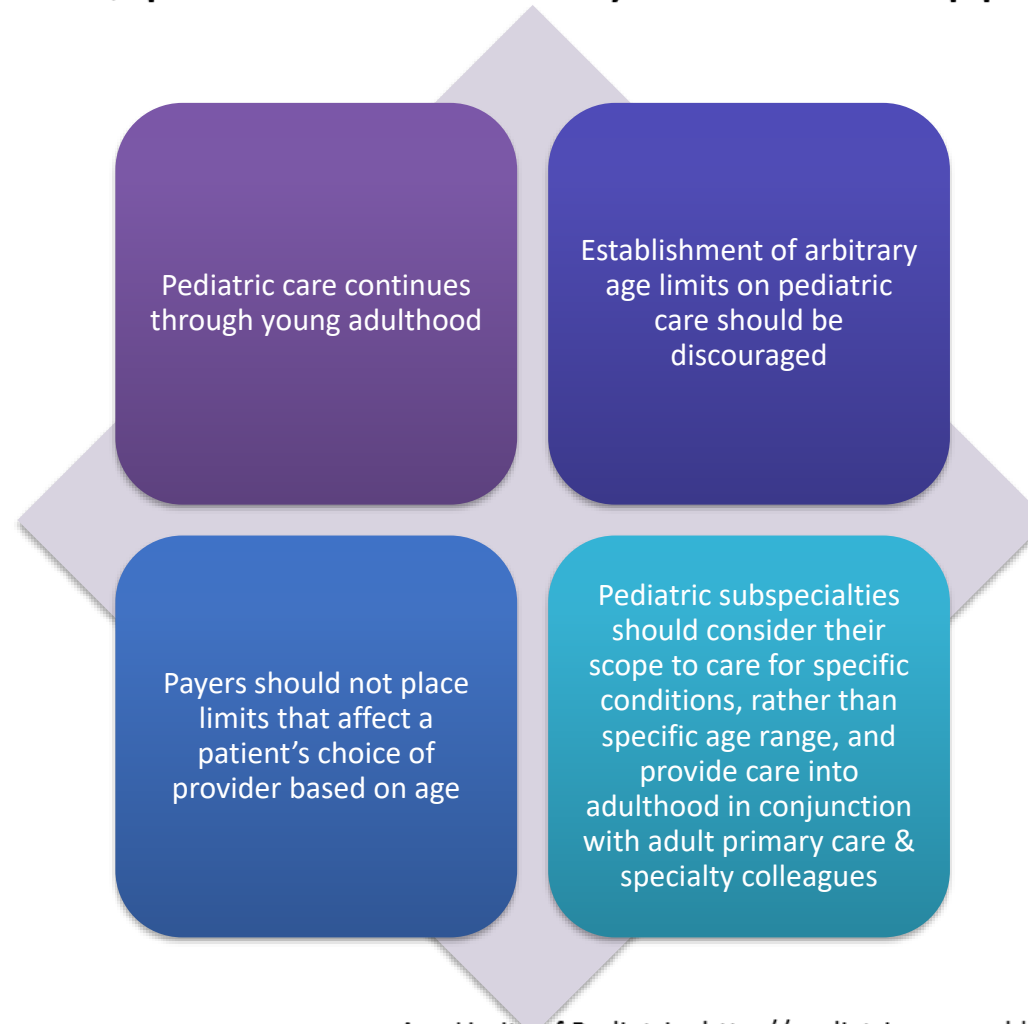
(White et al., 2018)

2023: Updated and Reaffirmed



# 2017 American Academy of Pediatrics Guidelines

flexible, patient- and family- centered approach



Comments: O'Hare, Sharma, Shanske, Uluer

Age Limits of Pediatrics <http://pediatrics.aappublications.org/content/early/2017/08/17/peds.2017-2151>

# WHEN should we begin thinking about transition?

## SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE

### 1 POLICY/GUIDE

Develop, discuss, and share transition and care policy/guide

AGE 12-14

### 2 TRACKING & MONITORING

Track progress using a flow sheet registry

AGE 14-18

### 3 READINESS

Assess self-care skills and offer education on identified needs

AGE 14-18

### 4 PLANNING

Develop HCT plan with medical summary

AGE 14-18

### 5 TRANSFER OF CARE

Transfer to adult-centered care and to an adult practice

AGE 18-21

### 6 TRANSITION COMPLETION

Confirm transfer completion and elicit consumer feedback

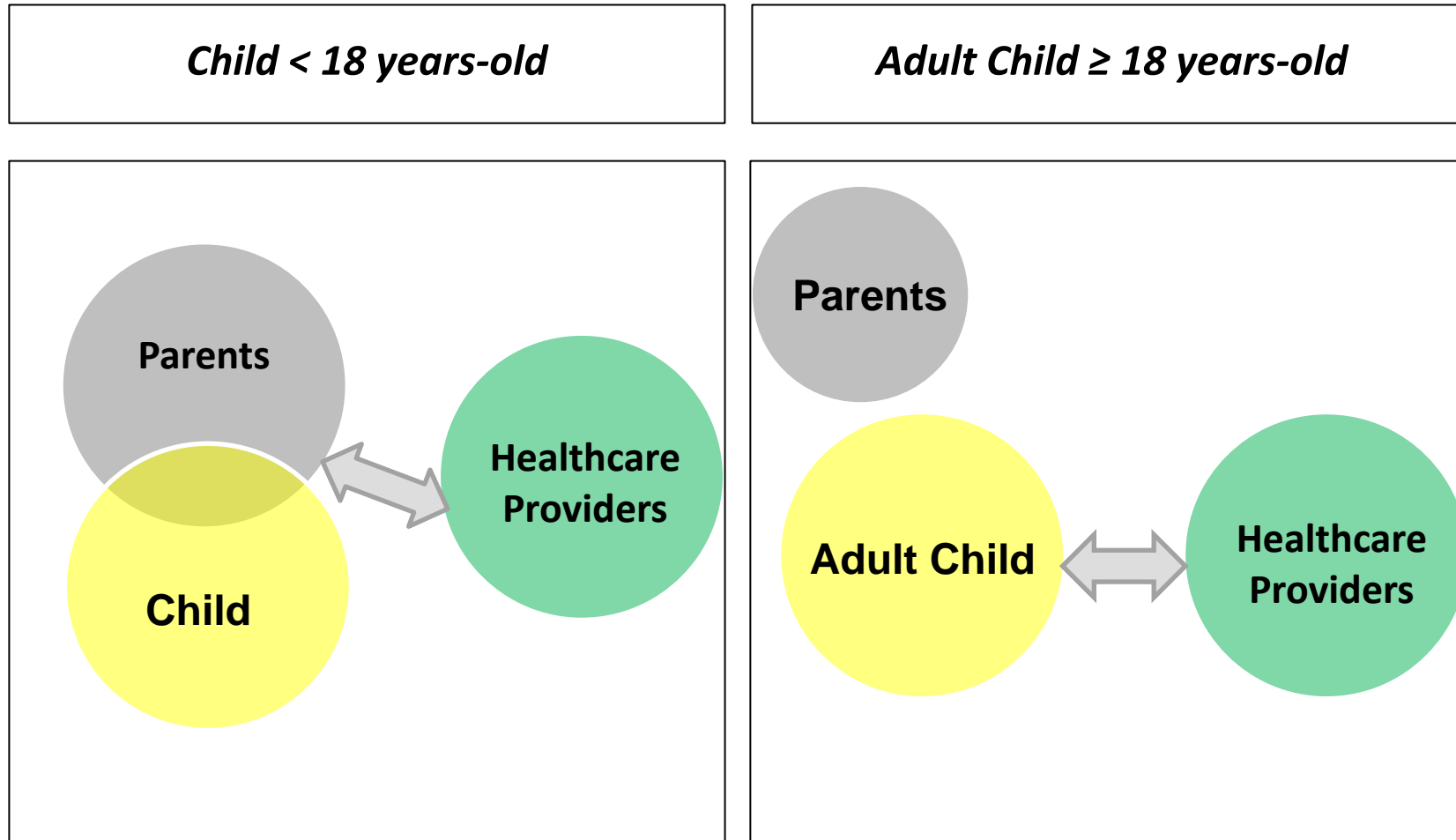
AGE 18-23

[www.gottransition.org](http://www.gottransition.org)

# Family Centered Care and Autonomy

- Do you have a release on file?
- Have you given time to the patient, alone, to address more sensitive topics?
- Does the patient understand what a Health Care Proxy is (and is not)?
  - Have they had a discussion with the identified person?

# Communication in Healthcare



# At the age of 18

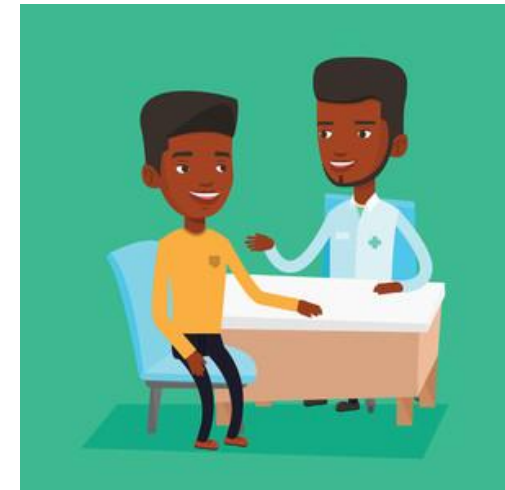
***Legally, your patient assumes all responsibility for decision making, which includes:***

- Medical decision making (e.g., procedures, compliance, admissions, treatment consents, results)
- Educational decisions (e.g., IEP, remaining in school, consenting to assessments, limited communication with parents allowed-even re: grades)
- Social decisions (e.g., where to live, to get married, have a child, who to associate with)
- Financial decisions (e.g., managing their own money, budgeting, pay bills, etc.)
- Unless you need Guardianship (unable to make decisions or communicate needs) or HCP (if temporarily unable due to medical state)



# For Providers

- Relationship abandonment
- Acknowledge patient growing up
- Discuss policy and specific needs/goals of patient
- Encourage and empower self management
- Address legal requirements



# How to monitor/measure transition?

- Remember the [childhealthdata.org](http://childhealthdata.org) metrics
  - Discuss transition, alone at appt, work on a skill
- Determine number of people who may need guardianship
  - How many of your 18 and up have HCP/ROI on file?
- Pre-transfer
  - Readiness assessment (TRAQ, STARX)? Medical summary? Education?
- Post Transfer
  - ED utilization, satisfaction survey, joint clinic appt?
- Do you have a program/division/department specific Transition Policy?



# BRIDGES Adult Transition (BAT) Program and Changes starting July 2023



- **Mission:** Establish a comprehensive program to support the medical/surgical needs of young adults with congenital or acquired pediatric diseases, improve quality of life by empowering and educating all stakeholders, with an emphasis on their individual needs to ensure a seamless transition from pediatric to adult care
- **Important components:**
  1. ~~Medical inpatient units (support for surgical unit) focused on age-appropriate care for young adults~~
  2. **Consult Service** with medical expertise provided by internal medicine trained clinicians
  3. **Ambulatory care partnerships** with local clinics with **transitional care support** for all departments across Boston Children's Hospital

# July 2023: BRIDGES Adult Transition (BAT) Program

([transition@childrens.harvard.edu](mailto:transition@childrens.harvard.edu) or pager 1382)

## Preoperative Clearance

- Inpatient or outpatient basis, in collaboration with the anesthesia team

## Medical Co-Management

- “Follow along” with a primary medical or surgical service during admission to provide additional perspective on overall care
- Management of specific chronic medical conditions in adult patients (e.g. HTN, CHF, CKD)

## Fertility, Reproductive and Sexual Health

- Expertise on fertility preservation and sexual health among young adults with Special Health Care Needs

## Workup and Treatment of Acute Problems

- Chest pain, respiratory distress, suspected or documented VTE, acute kidney injury, arrhythmias, etc

## Assistance with Transition of Care

- Can work with patients and their BCH care teams to assess appropriateness and readiness for transition to an adult care setting
- Assist with connecting patients with new adult primary care physicians or adult subspecialists, as needed



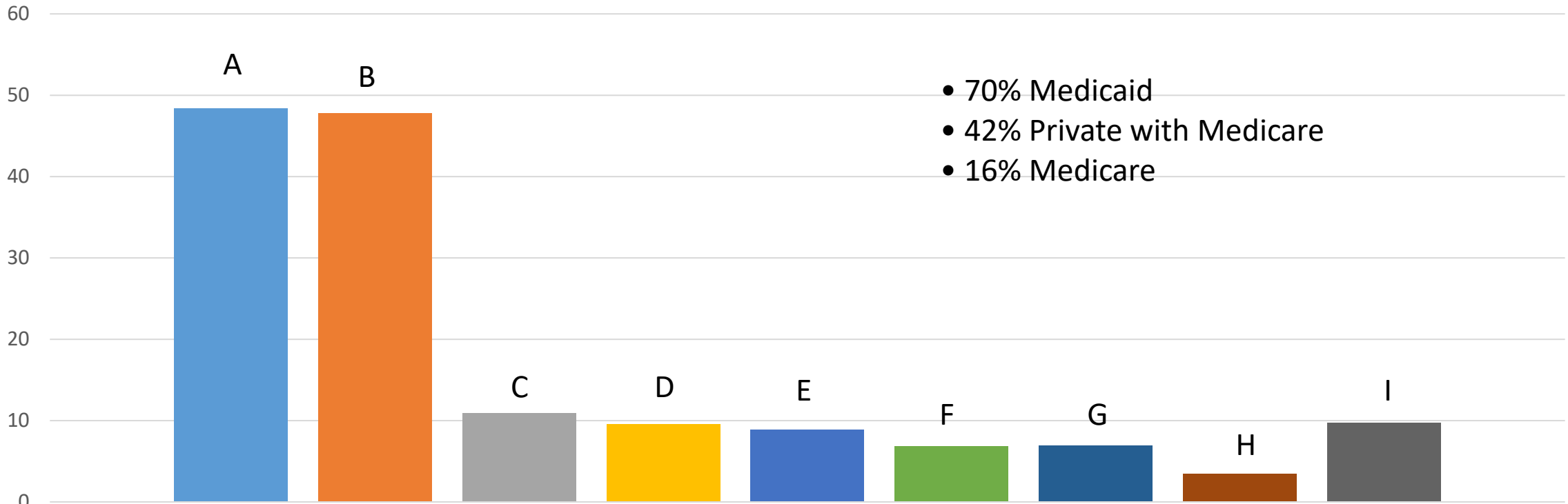
# BRIDGES Multidisciplinary Virtual Visits

- Visits provide comprehensive support to young adults with congenital or acquired pediatric diseases
- They aim to meet their individual needs ensuring a seamless transition from pediatric to adult care
- 45-minute visits with a multi-disciplinary team
  - Team includes Transition Nurse Coordinator, physician, and social worker



# Type of Consults at Boston Children's Hospital from 2017 - 2022

## 1,566 Consults



- 70% Medicaid
- 42% Private with Medicare
- 16% Medicare

BRIDGES Consults

- |                                 |                                  |                             |
|---------------------------------|----------------------------------|-----------------------------|
| ■ Identifyin PCP/Specialist (A) | ■ Transition Assistance (B)      | ■ Medical Co-Management (C) |
| ■ Pre-Op Clearance (D)          | ■ Community Resources (E)        | ■ Guardianship (F)          |
| ■ Health Care Proxy (G)         | ■ Reproductive/Sexual Health (H) | ■ Other (I)                 |

# Consults at Adult Hospital (BWH)

## Pediatric Disease Expertise

- Metabolic patient with urea cycle disorder with specific dietary needs

## Behavioral Support

- Patient with Autism on oncology service receiving chemotherapy

## Referral to Virtual Clinic

- Patient with poorly controlled diabetes who benefitted from learning transition related skills

## Newly Transitioned Patient Assistance

- Prevented patient leaving AMA and updated chart with details missing in chart, including preferences while hospitalized, medication intolerances, updated team

## Pediatric Sized Adult (or pediatric patient)

- Arranged for supplies to accommodate a patient admitted with LVAD awaiting heart transplant, needed smaller French G-tube and BiPAP mask

# Internal and External Websites

The screenshot shows the top navigation bar of the Boston Children's Today website. It includes the logo 'Boston Children's Today' on the left, the Boston Children's Hospital logo with the tagline 'Where the world comes for answers' in the center, and a search bar on the right. Below the logo is the date 'Sunday, April 11, 2021'. The navigation menu includes links for Home, Human Resources, Depts & Programs (highlighted in pink), Policies & Tools, Clinical, Nursing, Research, and About Us.

## The Weitzman Family BRIDGES Adult Transition Program

[External Website](#)

[Meet the Team](#)

[Transition to Adult Care Conference](#)

[Resources and Tip Sheets](#)

[BRIDGES Toolkit](#)

[FAQs](#)

[Helpful Links](#)

[Contact Us](#)

## The Weitzman Family BRIDGES Adult Transition Program

### Welcome to the Weitzman Family BRIDGES Adult Transition Program!

Boston Children's Hospital is a pediatric hospital. That does not mean our patients stop being patients the moment they become legal adults. The young adult patients seen at Boston Children's may have a specific set of needs that may not be immediately recognizable by pediatric and medical staff. The Weitzman Family BRIDGES Adult Transition Program focuses on how to best serve this population and their unique set of needs. The program is comprised of a multi-disciplinary team of physicians, case managers, social workers, nurse practitioners, and administrative staff who are all dedicated to improving the experience of young adult patients and their families as they transition from pediatric to adult healthcare.

This site provides information on the program, our mission, our services, the team, and some helpful links and resources.

[View our feature on BCH's Facebook Live!](#)

Please feel free to contact us at [transition@childrens.harvard.edu!](mailto:transition@childrens.harvard.edu)

Our Mission	Our Services
<p>Our mission is to provide a comprehensive program to support the medical/surgical needs of young adults with congenital or acquired pediatric diseases, improve the quality of life by empowering and educating all stakeholders, with an emphasis on their individual needs to ensure a seamless transition from pediatric to adult care.</p>	
<p>Three important components</p> <ul style="list-style-type: none"><li>» Medical and surgical inpatient units focused on age-appropriate care for young adults</li><li>» Consult service with expertise provided by internal medicine trained clinicians</li><li>» Ambulatory care partnerships with local clinics and transitional care support for all departments across Boston Children's Hospital</li></ul>	

The screenshot shows the top navigation bar of the Boston Children's Hospital website. It includes the Boston Children's Hospital logo on the left and navigation links for International Visitors, Ways to Help, Careers, and a Donate button on the right.

The screenshot shows the header of the Weitzman Family BRIDGES Young Adult Transition Program page. It features a navigation menu with links for For Patients, For Health Care Professionals, Programs & Services, Conditions & Treatments, Research, and Innovation. Below the menu is a large image of a young girl's face with the text 'Weitzman Family BRIDGES Young Adult Transition Program' overlaid.

[Overview](#)

[Meet our Team](#)

## Weitzman Family BRIDGES Young Adult Transition Program

The Weitzman Family BRIDGES Young Adult Transition Program (a.k.a. BRIDGES Program) is a resource for providers, patients, and families at Boston Children's Hospital. Patients and families with pediatric-to-adult transition-related concerns are encouraged to ask a member of their care team to consult with us to help provide guidance on adult related medical management, transition readiness, and transfer planning. Care teams are welcome to reach out from Boston Children's Hospital, Mass. General Brigham, and/or community sites that are not affiliated. Reach the program by email at [transition@childrens.harvard.edu](mailto:transition@childrens.harvard.edu).

### Why Do We Exist?

Children with special health care needs (SHCN), including those with formerly life-limiting congenital and pediatric acquired conditions, are living longer and requiring specialized care well into adulthood. Advancement in medicine and surgical techniques allow our patients to survive and thrive as adults. Our service strives to ensure that patients' adult medical and psychosocial needs are addressed during this time. Together, we are working to strengthen the system by empowering providers, patients, and families to advocate and navigate the "bridge" to an adult medical home.

### Multi-disciplinary BRIDGES Service

Members of team include:

- medicine-pediatrics trained physician
- nurse practitioner
- nurse transition coordinator
- social work
- program manager

- Weitzman Family Bridges Adult Transition Program**
- About Us
- Our Mission
- Meet the Team
- What Do We Do?
- Helpful Links
- BRIDGES Toolkit
- Transition to Adult Care Conference 2018-2019 Schedule**
- Transition to Adult Care Conference 2017-2018 Schedule
- Contact Us
- FAQs

## Weitzman Family Bridges Adult Transition Program

Welcome to the Weitzman Family Bridges Adult Transition Program! This site provides information on the program, our mission, team, and some helpful links and resources.

Please view our feature on BCH's Facebook Live! <https://www.facebook.com/BostonChildrensHospital/videos/10160248558945333/>

Please feel free to contact us at [transition@childrens.harvard.edu](mailto:transition@childrens.harvard.edu)!

 Report a broken link on this page.

Bridges  
Internal  
website

Weitzman Family Bridges Adult Transition Program
About Us
Our Mission
Meet the Team
What Do We Do?
Helpful Links
<b>BRIDGES Toolkit</b>
Transition to Adult Care Conference 2018-2019 Schedule
Transition to Adult Care Conference 2017-2018 Schedule
Contact Us
FAQs

## BRIDGES Toolkit

### **Transition Policy**

- » [Sample Got Transition policy](#)
- » [Metabolism Transition to Adult Healthcare \(for clinicians\)](#)
- » [Metabolism Transition to Adult Healthcare \(for adolescents, young adults, and families\)](#)
- » [Primary Care at Longwood policy](#)
- » [Endocrine policy](#)

### **Transition Tracking and Monitoring**

- » [Sample Got Transition registry](#)
- » [CF clinic schedule \(example\)](#)
- » [CP program registry \(example\)](#)
- » [Martha Elliot tracking sheet \(example\)](#)
- » [Sample Got Transition transition flow sheet](#)
- » [Transition action plan](#)

### **Transition Readiness**

- » [TRAQ 5.0](#)
- » [My Children's Portal FAQ for providers](#)
- » [One Step at a Time booklet](#)
- » [My Patients Flyer 2018](#)
- » [My Patients Guide 2018](#)
- » [Specialist FAQ](#)
- » [Medical ID on iPhone](#)
- » [What Happens When I Turn 18](#)

### **Transition Planning**

- » [Advanced Directives and Health Care Proxy family education sheet](#)
- » [Mass Health Care Proxy information](#)
- » [Mass Health Care Proxy form](#)
- » [Authorization for release and collection of patient information](#)
- » [Guardianship brochure \(Spanish version\)](#)
- » [A Parent's Guide to Health Insurance brochure](#)
- » [A Young Adult's Guide to Health Insurance brochure](#)
- » [Transition Planning for Caregivers](#)
  - » [Intellectual Disability](#)
  - » [Healthcare Needs](#)
- » [Questions to Ask Your Doctor - Youth](#)
- » [Questions to Ask Your Doctor - Parents](#)

### **Transfer of Care**

- » [Sample Got Transition medical summary and emergency care plan](#)
- » [Sample Got Transition transfer letter](#)
- » [For parents](#)

### **Transfer Completion**

- » [ADAPT instructions](#)
- » [ADAPT survey](#)

Bridges -  
Internal website




## AUGUST 2013:

Baseline survey to assess the state of transition policy and practice across the hospital, completed by division (17 responses)

## SUMMER/FALL 2020:

Updated survey sent to compare to 2017 (86 responses)

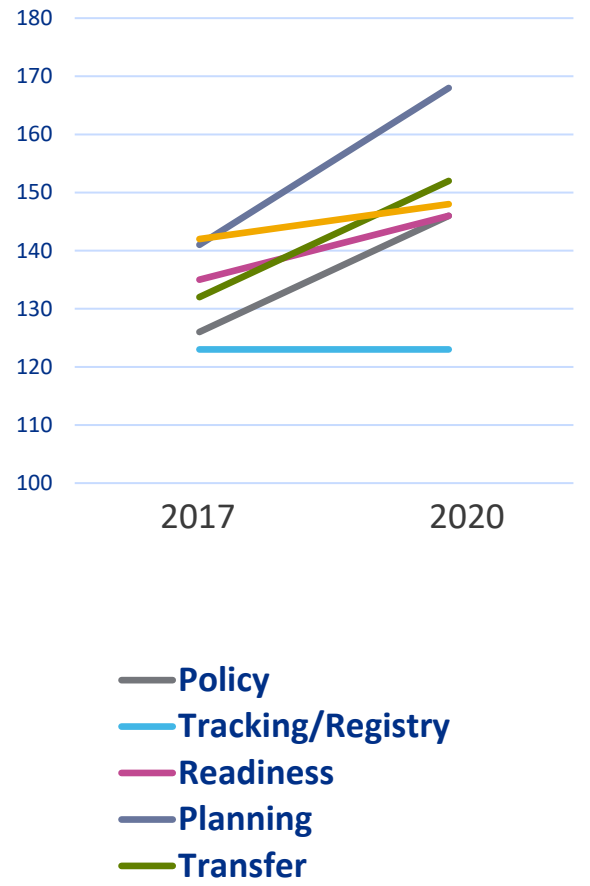
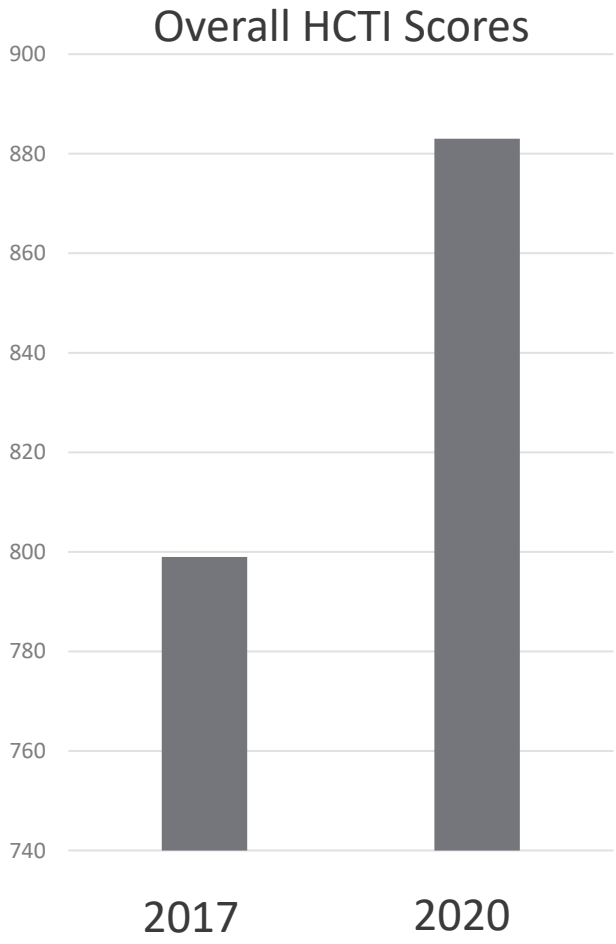
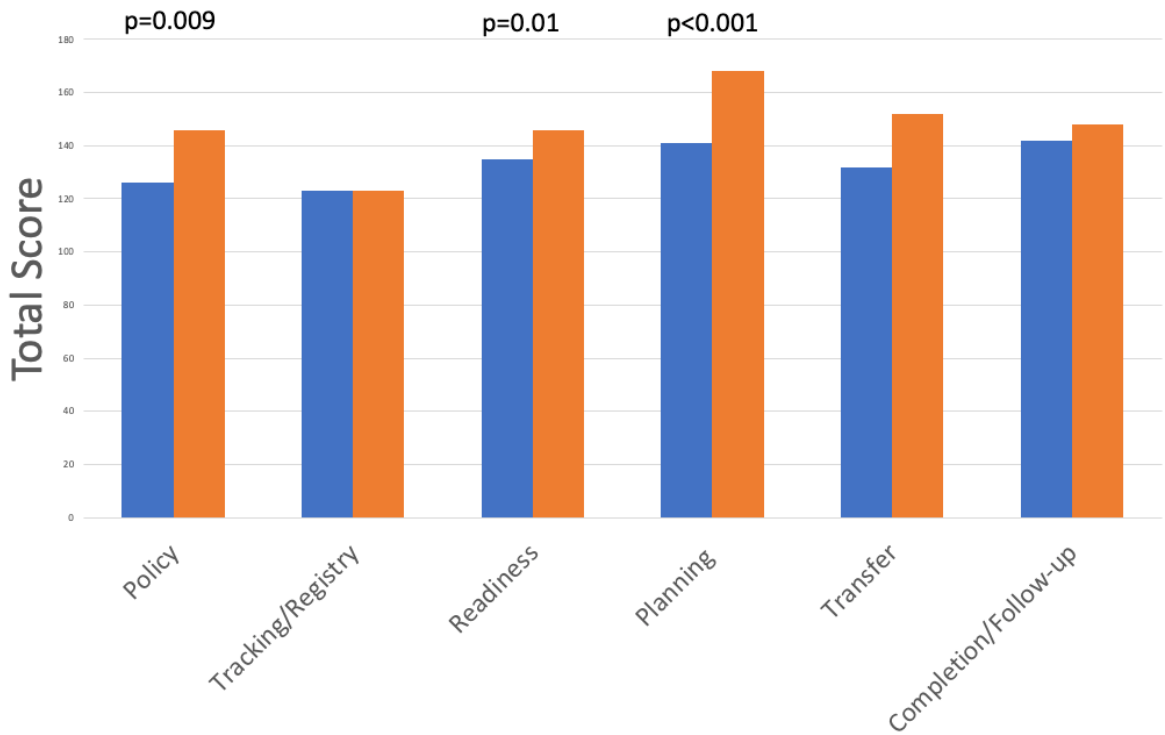


Fall 2023  
Surveys Sent

## JANUARY 2017:

Requested updated data, this time at the program level (106 responses)

# Change in HCTI Scores following BRIDGES Program Access (2017 vs 2020)



# Severe Asthma Program - Transition Working Group

Partnership between BCH and BWH

- Creating a policy statement for transition/transfer
- Registry of patients aged 16 and older

# Severe Asthma Program - Transition Working Group

## Partnership between BCH and BWH

- Creating a policy statement for transition/transfer
- Registry of patients aged 16 and older
- Readiness and Preparation
  - Severe Asthma Transition Education Sheet

### Severe Asthma Transition Education Sheet

Transitioning to the Severe Asthma Program at Brigham and Women's Hospital from Boston Children's Hospital.

#### Overview

The Severe Asthma Program at Boston Children's Hospital (BCH) is committed to helping you transition as you take the next step in your medical care journey. You've been under the care of our dedicated team at Boston Children's Hospital, and now, as you step into adulthood, we're here to guide you through the transition to the Severe Asthma Program at Brigham and Women's Hospital (BWH).

This education sheet is given to patients ages 16+ to explain the steps involved in graduating to adult Asthma care in the future.

#### Summary

<b>Getting you ready to be involved in your care</b>	When you're in pediatric care, your parents or guardians make most of your healthcare decisions. In adult care, you make most and or all of the decisions. When you are about 16 years old, during your appointments we may begin to speak with you without your parent or guardian present, if appropriate. We'll begin to discuss how to get ready to transition to adult care. This may mean helping you learn more about your condition, and teaching you how to use your patient portal to manage your medications.
<b>What does it mean you are a legal adult?</b>	When you turn 18 years old, you have legally become an adult. This changes what information is shared with your parents/caregivers and means we need your permission to speak with your parents/caregivers about your care. There will also be changes to decision-making. For example, at age 18, you will have a chance to re-consent to the Severe Asthma Registry consent form and the Communication Consent Addendum during your clinic visit at BCH. Some patients may have conditions that prevent them from fully understanding their health condition or making health care decisions. In these situations, we'll help you and your parent/caregivers consider options for decision-making support before your 18th birthday. We respect and encourage a family-centered approach to your care so long as you permit us to involve your parents/caregivers. To give your parents/caregivers permission to be included in your care decisions, you will need to complete a "Release of Information" see QR code below.
<b>Next steps</b>	By the age of 22, you'll transition from Boston Children's Hospital to an adult-care team at Brigham and Women's Hospital. If you are interested, a nurse transition coordinator at Boston Children's Hospital will work with you to ensure a smooth transition. They will assist you in finding your new healthcare provider and will be available to address any questions or concerns you may have along the way. If you have any medical questions or concerns, please contact your Boston Children's provider.

#### Contact Information

<b>Kristina Taylor</b> (Nurse Transition Coordinator, BRIDGES Adult Transition Program)	Phone: 617-355-5029 Email: Kristina.Taylor@childrens.harvard.edu
<b>Meron Power</b> (Coordinator for Severe Asthma Program, Boston Children's Hospital)	Phone: 617-919-1317 Email: Meron.Power@childrens.harvard.edu

#### More Information

Release of Information Form



# Severe Asthma Program - Transition Working Group

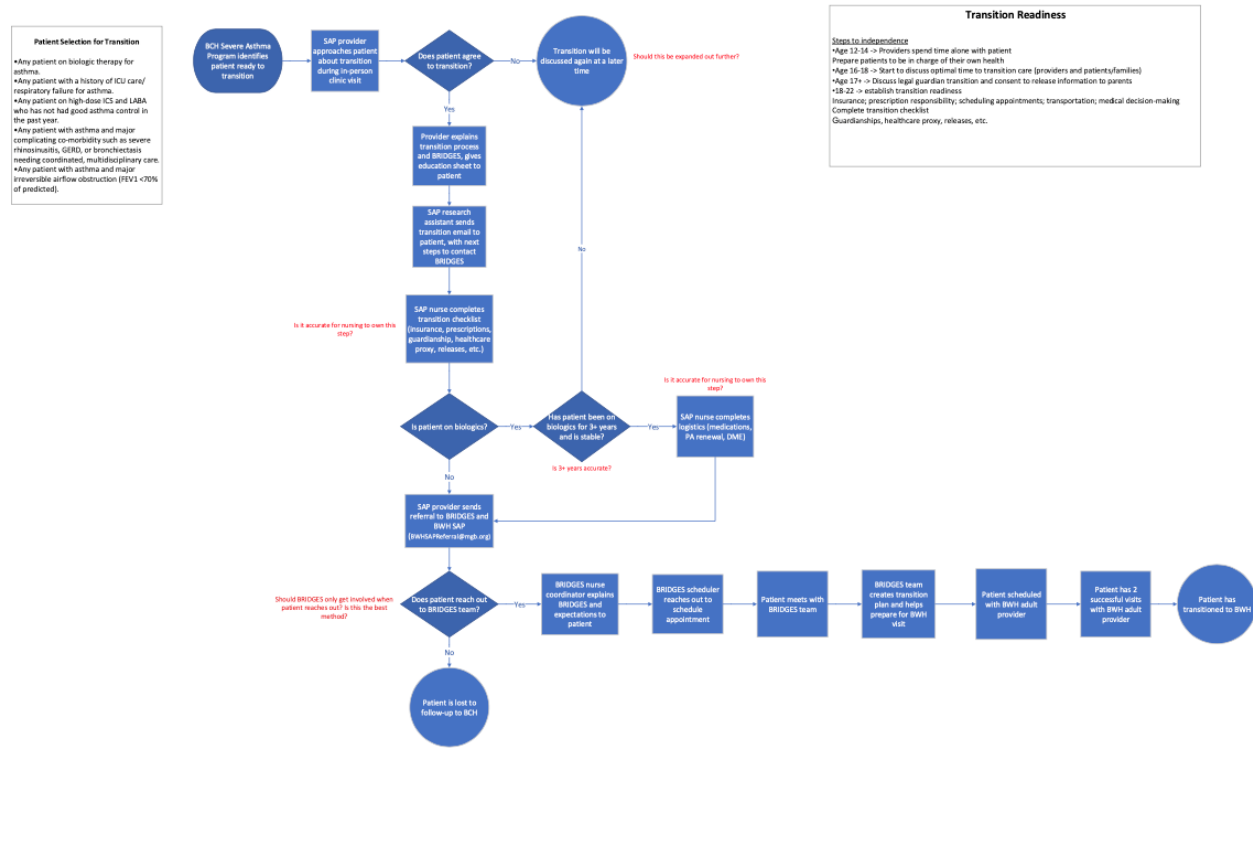
Partnership between BCH and BWH

- Creating a policy statement for transition/transfer
- Registry of patients aged 16 and older
- Readiness and Preparation
  - Severe Asthma Transition Education Sheet
- Planning
  - Develop process map

# Severe Asthma Program - Transition Working Group

## Partnership between BCH and BWH

### Severe Asthma Transition Process Map - BCH



**Transition Readiness**

**Steps to Independence**

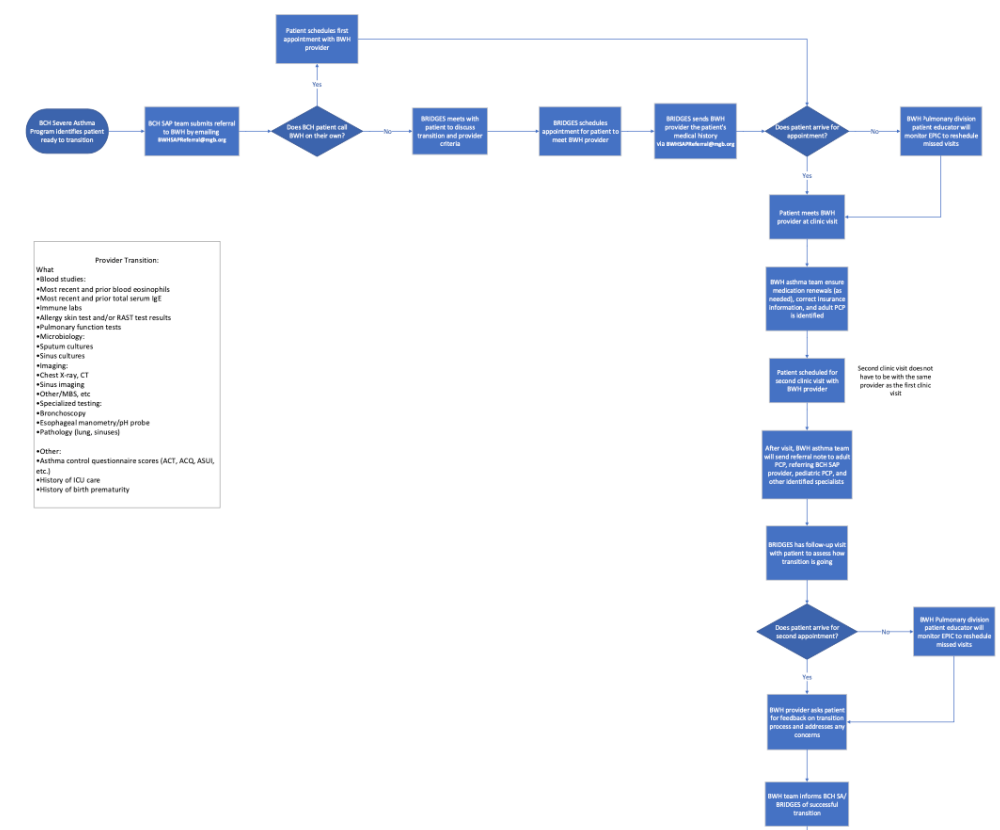
- Age 12-18 -> Providers spend time alone with patient
- Prepare patients to be in charge of their own health
- Age 16-18 -> Start to discuss optimal time to transition care (providers and patient/families)
- Age 17+ -> Discuss legal guardian transition and consent to release information to parents
- 18-22 -> establish transition readiness

Insurance, prescription responsibility; scheduling appointments; transportation; medical decision making

Complete transition checklist

Guardianship, healthcare proxy, releases, etc.

### Severe Asthma Transition Process Map - BWH



**Provider Transition:**

**What:**

- Blood studies:
- Most recent and prior blood eosinophils
- Most recent and prior total serum IgE
- Immune labs
- Allergy skin test and/or RAST test results
- Microbiology:
- Sputum cultures
- Sinus cultures
- Imaging:
- Chest X-ray, CT
- Sinus imaging
- Other/MMS, etc
- Specialized testing:
- Bronchoscopy
- Lung biopsy/manometry/CPAP probe
- Pathology (lung, sinus)

**Other:**

- Asthma control questionnaire scores (ACT, ACQ, ASU, etc)
- History of ICU care
- History of birth prematurity

# Severe Asthma Program - Transition Working Group

## Partnership between BCH and BWH

- Creating a policy statement for transition/transfer
- Registry of patients aged 16 and older
- Readiness and Preparation
  - Severe Asthma Transition Education Sheet
- Planning
  - Develop process map
- Transfer to empathic group of program
  - Developed Welcome Letter and created SAP transition email
- Measure outcomes
  - No gaps in biologic prescriptions, no change in ED visits, etc.

Severe Asthma: BCH to BWH transition

BWH Severe Asthma Program Welcome

We, the team of providers at the Severe Asthma Program and Brigham and Women's Hospital, are pleased to have the opportunity to provide you with care for your asthma as you transition from Boston Children's Hospital to an adult care setting at Brigham and Women's Hospital. We look forward to getting to know you, to helping you achieve good asthma control, and to being available when you are having difficulty with your asthma.

Below is some information that may be useful to you (and we hope not overwhelming). It is not meant as a substitute for the one-on-one relationships that we are hoping to build with you. Rather, it is simply meant as a brief summary of some details about our Program that may be of use.

**Our philosophy:** Though it cannot (yet) be cured, asthma can be controlled. We strive to achieve good asthma control in all patients through a co-management strategy – doctor and patient collaborating to achieve a life not limited by asthma symptoms and free from asthma attacks. Medications are part of this strategy; we strive to minimize cost, side effects, and inconvenience associated with asthma treatments. Our goal: breathe free, be fully active, and “stay forever young.”

**Our resources:** Pulmonary function testing, including exhaled nitric oxide, airway oscillometry, and bronchial challenges (including methacholine, exercise, and aspirin)  
Allergy skin testing  
Cardiopulmonary exercise testing  
Educational materials  
Access to biologic therapies, bronchial thermoplasty, and asthma research  
Multi-specialty consultative expertise as needed

**Who:**

Pulmonary: Elliot Israel, M.D., Bruce Levy, M.D., Nancy Lange-Vaidya, M.D., M.P.H., Justin Saliccioli, M.D., Carrie Pistenmaa, M.D.; Kathleen Haley, M.D., Victoria Forth, PA; Kim McCarty, P.A.

Allergy: Nora Barrett, M.D., Dinah Foer, M.D., Ayobami Akenroye, M.D., Ph.D., David Sloane, M.D., Ed.M., Tanya Laidlaw, M.D.; Margee Louisias, M.D., M.P.H.; Camellia Hernandez, M.D.

GI/reflux disease: Walter Chan, M.D., M.P.H.

ENT/Voice Program: Thomas Carroll, M.D.; Christopher Dwyer, M.D.

ENT/Sinusitis: Alice Maxfield, M.D., Regan Bergmark, M.D., Rachel Roditi, M.D., Stella Lee, M.D.

Patient Educator: Jackie Rodriguez-Louis, MPH, MEd

Psychiatric Social Worker: pending

Navigator: Sheryl Chicoine, RPSGT

**Where:**

# BRIDGES Program Educational Opportunities



BWH

Young Adults with Chronic Conditions: Optimizing Treatment and Transition from Pediatric to Adult Care Conference

BWH

Transition to Adult Care Conference Series

Health Care Transition Index Program Outreach

Young Adult/Adult Medical Education and Journal Club

Transition Planning for Caregivers

Community Education

Bedside Nursing



# Caregiver and Bridges Provider Training

## Social Work Transition committee

- Creating forms and resources for Patients and Families (Lead: Susan Shanske and SW Committee)
- Caregiver Training offered multiple times a year

## Provider Training

- Joint effort with the SW Transition Committee (CME event)
- Presentation, Expert Panel, Discussion with a patient
- Great reviews and feedback!

**Considering the Road Ahead**  
Transition Planning for Caregivers of Children with Healthcare Needs

- Do you have an adolescent who is or will be transitioning to adulthood in the next few years?
- Would you like to hear more about topics including insurance benefits, education, and transition milestones?
- Join us for our FREE half-day workshop! Recurrent throughout the year!

**Location:**  
Boston Children's Hospital  
Longwood & Waltham

**Featuring:**

- Overview of transition basics
- Professional panel
- Lunch with peers
- Family Stories

**Sponsored by:**  
BCH Social Work Department with the support of the Weitzman Family BRIDGES Adult Transition Program.

**For more information please send us an email at:**  
SWTransition@childrens.harvard.edu

Or ask to speak with your child's provider

This recurrent event is for caregivers of children treated at Boston Children's Hospital

**Considering the Road Ahead**  
Transition Planning for Caregivers of Children with Intellectual Disability

- Do you have an adolescent who is or will be transitioning to adulthood in the next few years?
- Would you like to hear more about topics including guardianship, insurance benefits, education, and transition milestones?
- Join us for our FREE half-day workshop! Recurrent throughout the year!

**Location:**  
Boston Children's Hospital  
Longwood & Waltham

**Featuring:**

- Overview of transition basics
- Professional panel
- Lunch with peers
- Family Stories

**Sponsored by:**  
BCH Social Work Department with the support of the Weitzman Family BRIDGES Adult Transition Program

**For more information please send us an email at:**  
SWTransition@childrens.harvard.edu

Or ask to speak with your child's provider

This recurrent event is for caregivers of children treated at Boston Children's Hospital

**SPONSORED BY THE WEITZMAN FAMILY BRIDGES ADULT TRANSITION PROGRAM, THE BWH/BCH MEDICINE PEDIATRIC RESIDENTRY PROGRAM, AND THE SOCIAL WORK TRANSITION COMMITTEE**

**JUNE 11TH, 2019**  
**TRANSITION TO ADULT CARE:**  
**WHY IT IS IMPORTANT TO PROVIDERS**

**TUESDAY, JUNE 11th, 2019**  
**8:00AM – 10:00AM**  
**(LIGHT REFRESHMENTS AT 7:30AM)**  
**BOSTON CHILDREN'S HOSPITAL**  
**PATIENT ENTERTAINMENT CENTER**

**CME AND CEU CREDITS PROVIDED!**

- **PHYSICIAN** BOSTON CHILDREN'S HOSPITAL DESIGNATES THIS LIVE ACTIVITY FOR A MAXIMUM OF 2.0 AMA-PRA CATEGORY 2 CREDITS. PHYSICIANS SHOULD CLAIM ONLY CREDIT COMMENSURATE WITH THE EXTENT OF THEIR PARTICIPATION.
- **NURSE, PHARMACY** BOSTON CHILDREN'S HOSPITAL DESIGNATES THIS ACTIVITY FOR 2.0 CONTACT HOURS FOR NURSES. NURSES SHOULD ONLY CLAIM CREDIT COMMENSURATE WITH THE EXTENT OF THEIR PARTICIPATION IN THE ACTIVITY.
- **SOCIAL WORK** THE COLLABORATIVE OF NASW-MA CHAPTER AND THE BOSTON COLLEGE AND SIMMONS COLLEGE SCHOOLS OF SOCIAL WORK APPROVED THIS ACTIVITY FOR 2.0 CEU CREDITS.

**PARTICIPANTS WILL LEARN ABOUT...**

- THE DISTINCTION BETWEEN TRANSITION AND TRANSFER
- DEVELOPMENTAL CONSIDERATIONS FOR PROVIDERS TO ASSESS
- HOW TO MANAGE RELATIONSHIPS WITH PARENTS, CAREGIVERS, AND OTHER PROVIDERS
- SUPPORTED DECISION MAKING, INCLUDING GUARDIANSHIP
- ENCOURAGING SELF-MANAGEMENT/SKILL MASTERY
- RESOURCES FOR FAMILIES
- PATIENT PERSPECTIVE

**FEATURING A MULTIDISCIPLINARY EXPERT PANEL & PERSONAL REFLECTIONS FROM BOSTON CHILDREN'S HOSPITAL PATIENTS AND CAREGIVERS**

**\*FREE TO ATTEND\***  
SPACE IS LIMITED. REGISTER BY JUNE 3RD  
TRANSITION@CHILDRENS.HARVARD.EDU

# Upcoming CME Conferences

- Optimizing Transition from Pediatric to Adult Care
  - Live Streaming May 1-3, 2024
  - <https://transition.hmscme.com>

# The Transition Process



*Courtesy of Dr. Laurie Fishman*

# BRIDGES Adult Transition (BAT) Program

## **BRiDGEs**

**B**uilding **R**elationships and **D**eveloping **G**oals with **E**merging adults**S**

Email: [transition@childrens.harvard.edu](mailto:transition@childrens.harvard.edu)

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[ahmet.uluer@childrens.harvard.edu](mailto:ahmet.uluer@childrens.harvard.edu)

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