HEALTH WEALTH CAREER

CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS AND TRANSITION AGE YOUTH

TECHNICAL ASSISTANCE SESSION #2

AUGUST 2, 2018

OUTLINE

- Welcome and Introductions
- Today's Purpose
- Children and Youth with Special Health Care Needs
- Transition Age Youth
- Resources
- Questions

TECHNICAL ASSISTANCE
TODAY'S PURPOSE

- Today's presentation is the **second** of four technical assistance sessions in 2018:
  - **TA Session #1:** Reporting Template (held during Provider Informational Session)
  - **TA Session #2:** CYSHCN and TAY (today's presentation)
  - **TA Session #3:** Shared Savings (October 4th)
  - **TA Session #4:** Panel Presentation — Engaging Members in Care Coordination (December 6th)

- **CYSHCN and TAY:**
  - Overview of how these populations are defined
  - A review of national and state practices
  - Suggested tools and strategies

TECHNICAL ASSISTANCE TEST

DEER PHYSICALS

CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)
WHO ARE THEY?

Maternal Child and Health Bureau's (MCHB) definition:
"Have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."

- Typically defined as age 0-21 years
- Conditions are expected to last for at least 12 months
- 28 states use diagnosis as eligibility for CYSHCN programming (27 currently use the MCHB definition)
- Income and age also used as eligibility criteria in conjunction with diagnoses

CYSHCN
WHO ARE THEY?

SIMONE

- Age 5
- Diagnoses: Cerebral palsy, gastrostomy tube, visual impairment, spasticity
- Durable medical equipment: Wheelchair, gastrostomy feeding supplies, stander, oscillating mattress
- Services: Occupational, physical and speech therapy, IEP
- Living situation: Lives in a second floor apartment with mother and two older siblings; housing is subsidized and family receives SNAP

ALEX

- Age 11
- Diagnoses: Type I diabetes
- Durable medical equipment: Diabetic supplies (glucose meter, test strips, lancets)
- Services: Diabetic education for child and family
- Living situation: Lives with mother, father and 1 younger sibling; father has behavioral health challenges and receives SSI
- Multiple visits to ER over last year for blood sugar issues

HARLEY

- Age 16
- Diagnoses: Depression, anxiety, ADHD, asthma
- Durable medical equipment: SVN machine
- Services: Counseling, medication management and psychiatric services, 504 plan
- Living situation: Lives in a group home (in foster care), no contact with biological parents, has a biological brother age 17 who is in another group home

CYSHCN
WHO ARE THEY?

19.8% of US children have special health care needs

14.7% of CYSHCN have been diagnosed with developmental delay

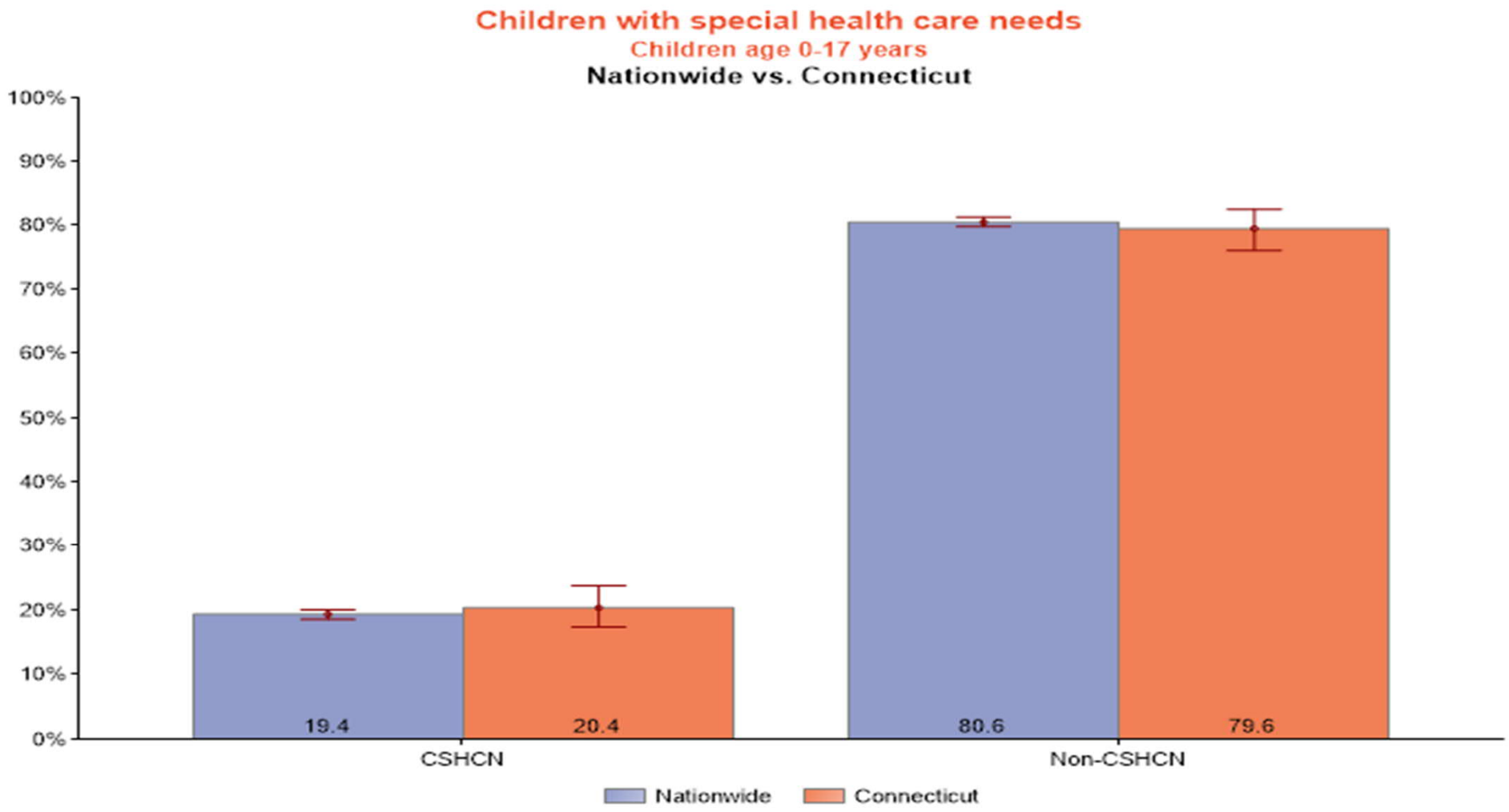
27.2% of CYSHCN have been diagnosed with a learning disability

32.2% of CYSHCN have been diagnosed with ADD/ADHD

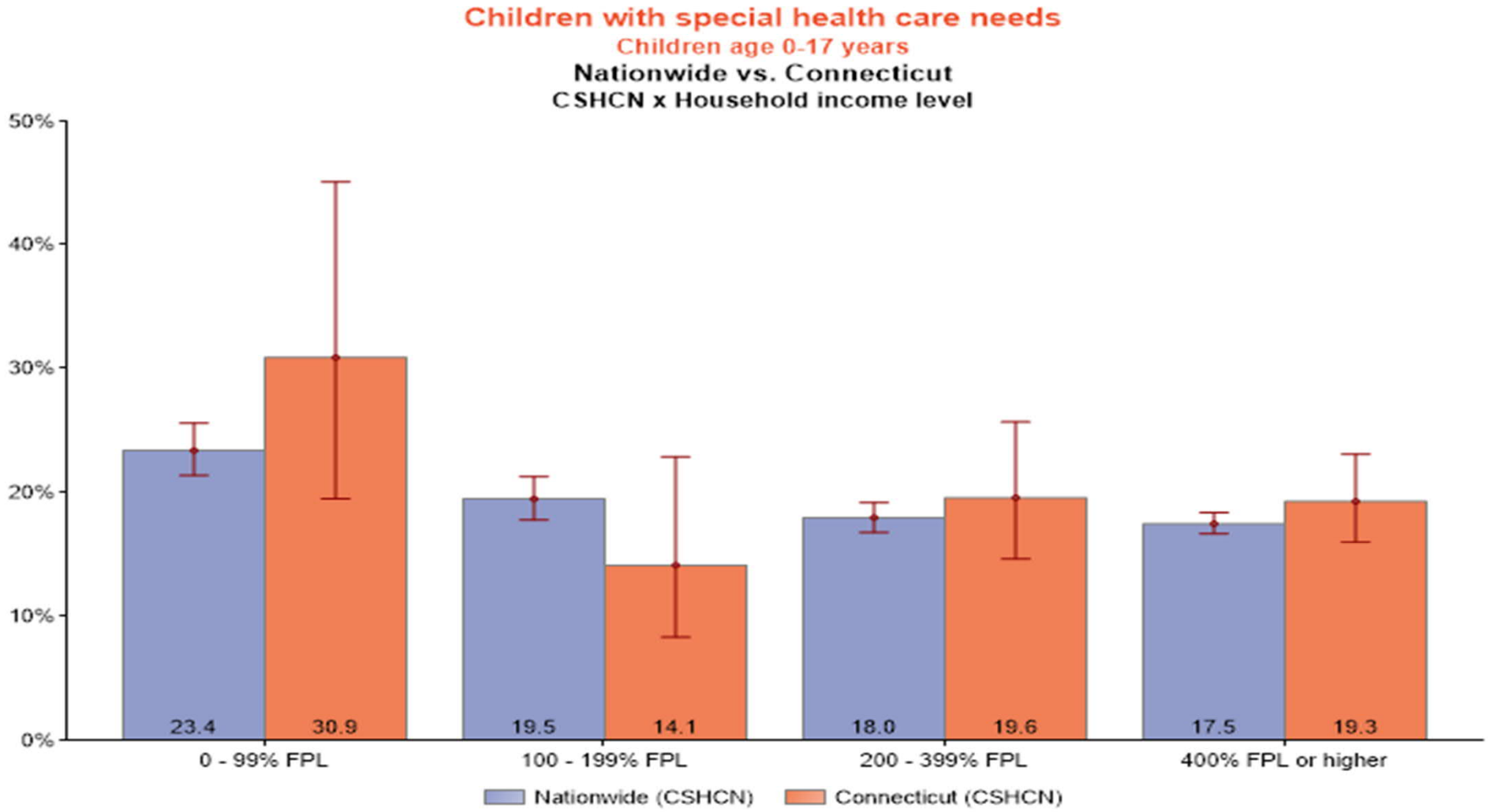
30.2% of CYSHCN been diagnosed with asthma

13.6% of CYSHCN have been diagnosed with behavioral problems

CYSHCN
WHO ARE THEY?

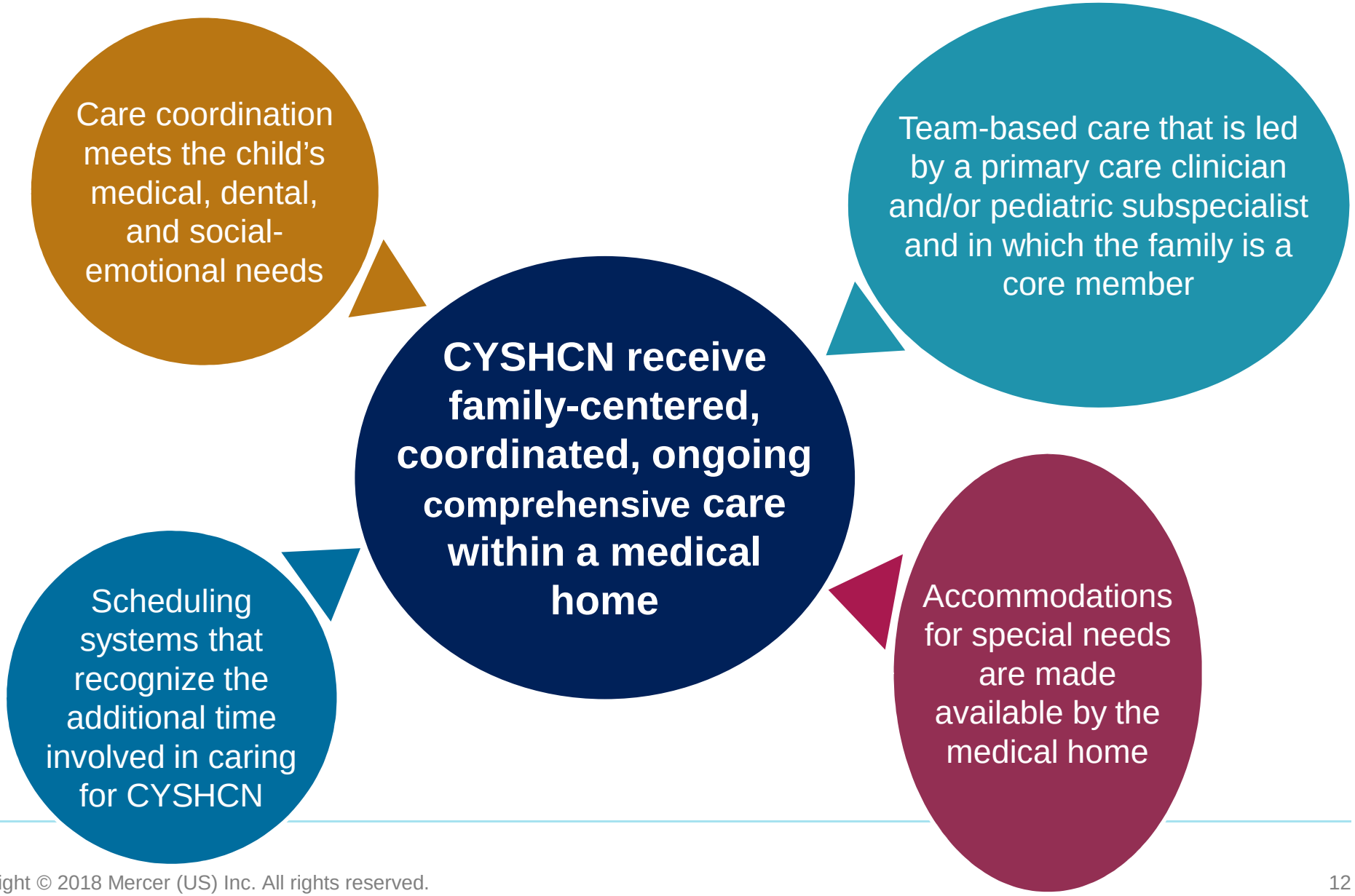


CYSHCN
WHO ARE THEY?

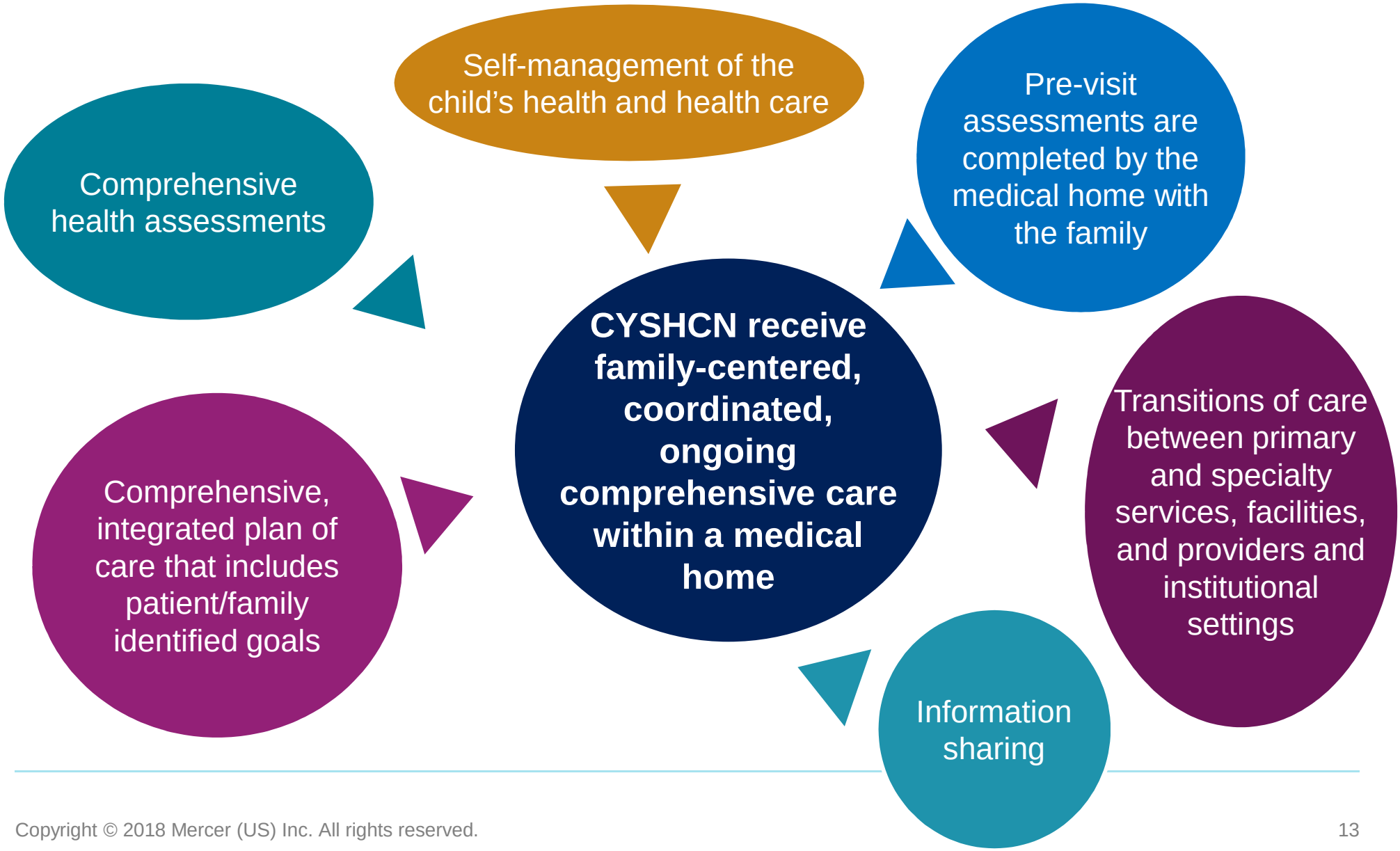


CYSHCN
SUGGESTED PRACTICES

CYSHCN
CORE DOMAIN: MEDICAL HOME

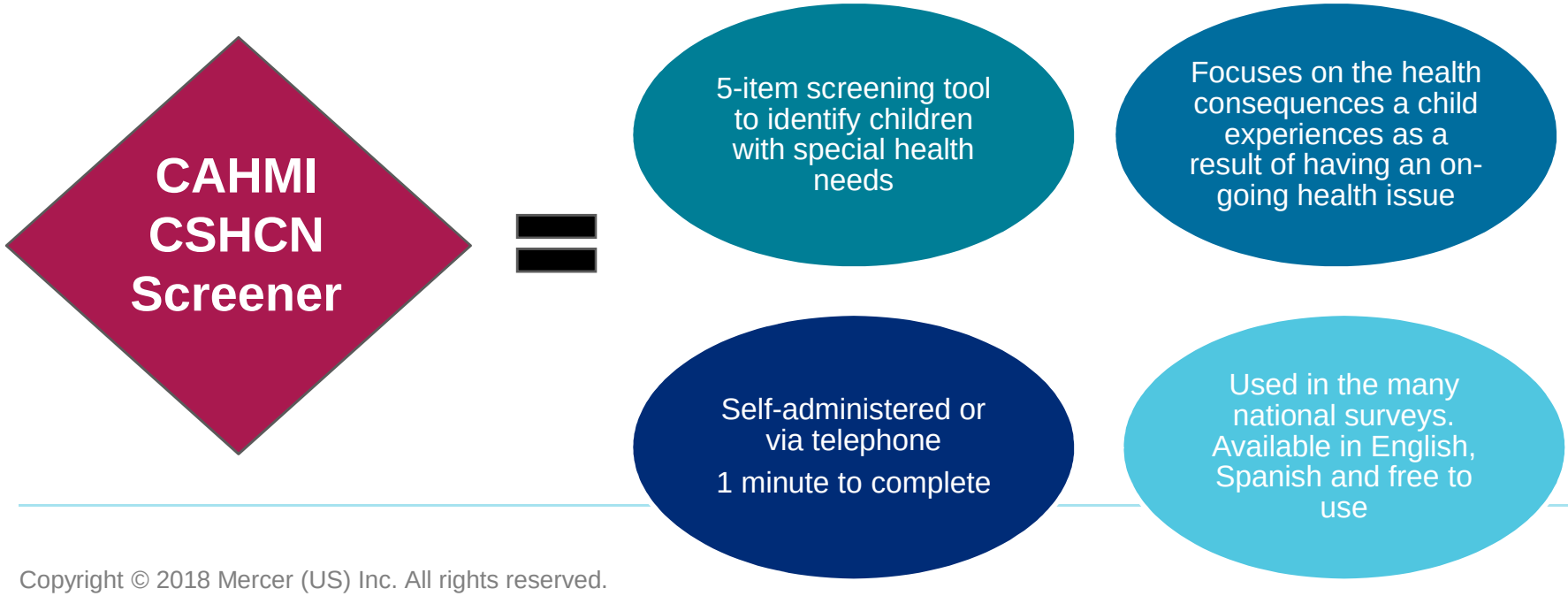


CYSHCN
CORE DOMAIN: MEDICAL HOME (CONT'D)



CYSHCN
IDENTIFICATION AND SCREENING

- Children who are eligible for CYSHCN program services are identified using a CYSHCN screening tool in 10 states, using the national screening tool in four of these states, and with other methods in 35 states.
- Other methods include assessment process, self-identification or application process, referral, Medicaid eligibility, list of diagnosis.
- Child and Adolescent Health Measurement Initiative (CAHMI) CSHCN Screener.



CAHMI CSHCN SCREENER

Children with Special Health Care Needs (CSHCN) Screener©
(mail or telephone)

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
   - ☐ Yes → Go to Question 1a
   - ☐ No → Go to Question 2

   1a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 1b
   - ☐ No → Go to Question 2

   1b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

2. Does your child need or use more **medical care, mental health or educational services** than is usual for most children of the same age?
   - ☐ Yes → Go to Question 2a
   - ☐ No → Go to Question 3

   2a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 2b
   - ☐ No → Go to Question 3

   2b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
   - ☐ Yes → Go to Question 3a
   - ☐ No → Go to Question 4

   3a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 3b
   - ☐ No → Go to Question 4

   3b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
   - ☐ Yes → Go to Question 4a
   - ☐ No → Go to Question 5

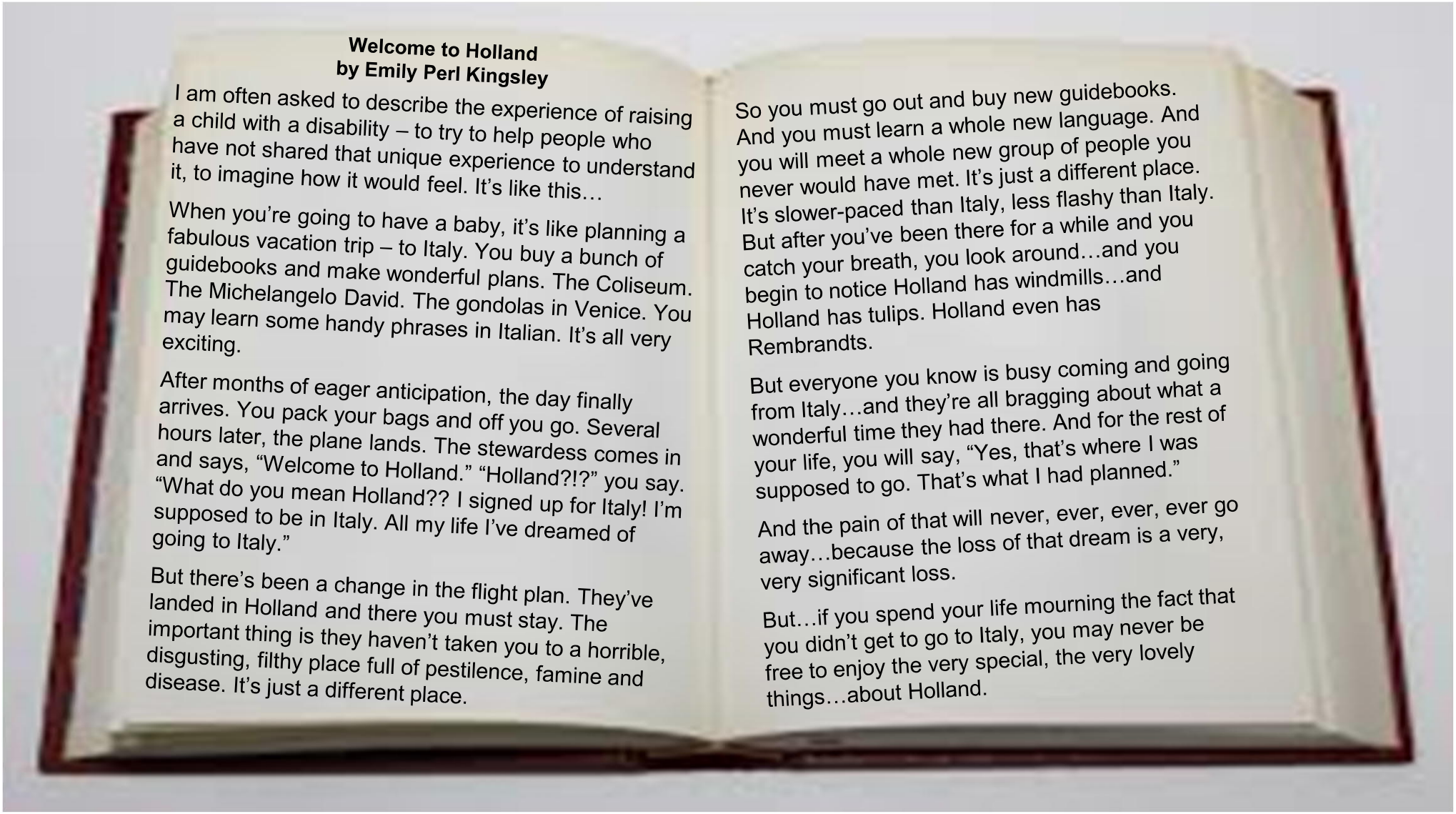
   4a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 4b
   - ☐ No → Go to Question 5

   4b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
   - ☐ Yes → Go to Question 5a
   - ☐ No

   5a. Has this problem lasted or is it expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

GRIEF AND LOSS



Welcome to Holland
by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this…

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met. It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around…and you begin to notice Holland has windmills…and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy…and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

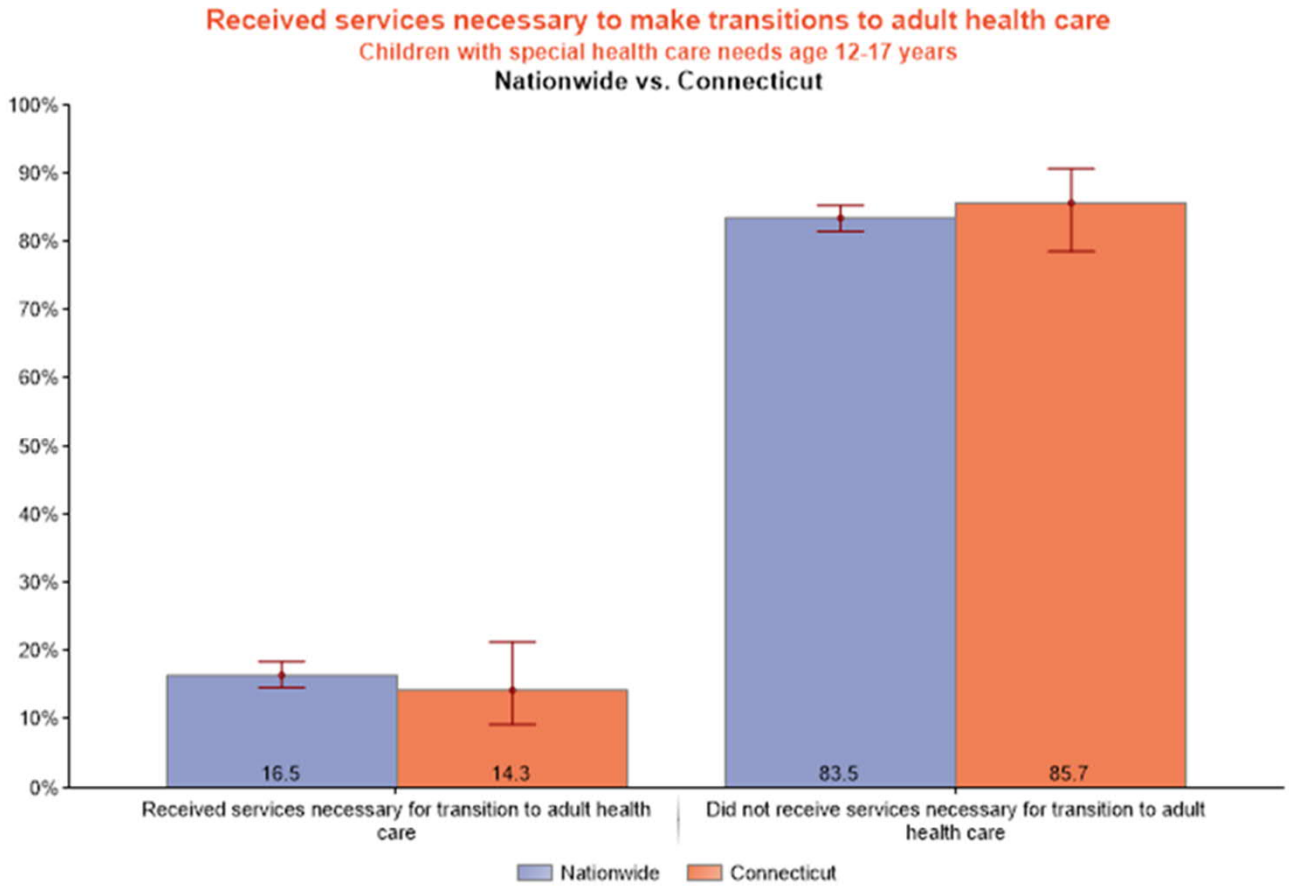
And the pain of that will never, ever, ever, ever go away…because the loss of that dream is a very, very significant loss.

But…if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very special, the very lovely things…about Holland.

TRANSITION AGE YOUTH

TAY
WHO ARE THEY?

- Commonly defined as individuals between the ages of 16 and 25 years. The age range for TAY can vary to include children as young as 12 years of age. Depending on the needs of the youth served, providers may choose to expand the upper and lower age range for TAY.
- 500,000 to 750,000 youth with special health care needs transition to adulthood annually.



TAY
TRANSITION DEFINITION

"Transition is defined as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems"

– The Society of Adolescent Medicine

TAY
PROMOTING TRANSITION

Promoting transition is supported by multiple organizations:

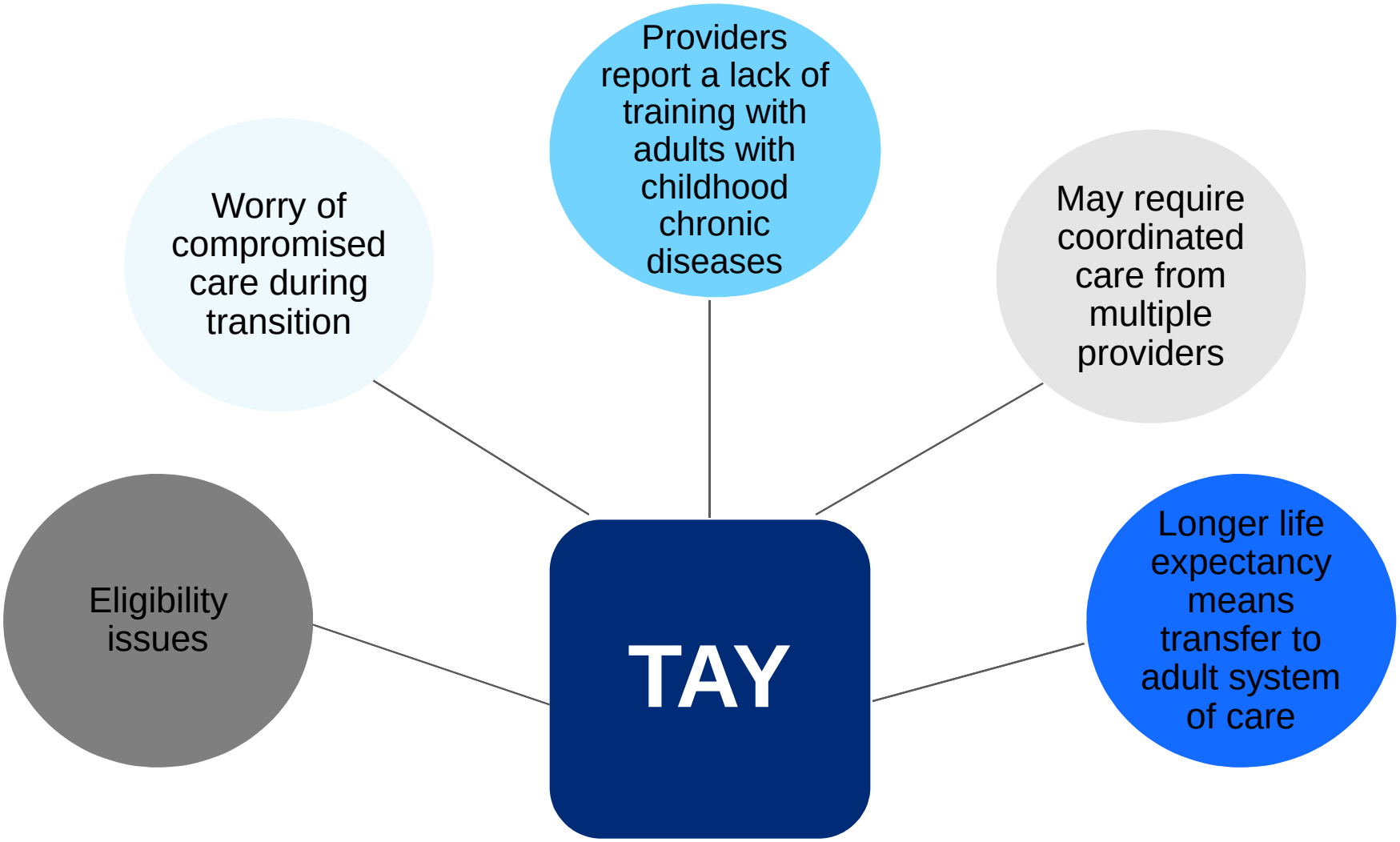
- Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs from American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP)-American Society of Internal Medicine (2002)
- Clinical report from American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians-American (2011)
- Healthy People 2020 goals
- Title V Transition Performance Measure
- NCQA Medical Home standard on transition

TAY
WHY IS TRANSITION PLANNING IMPORTANT?

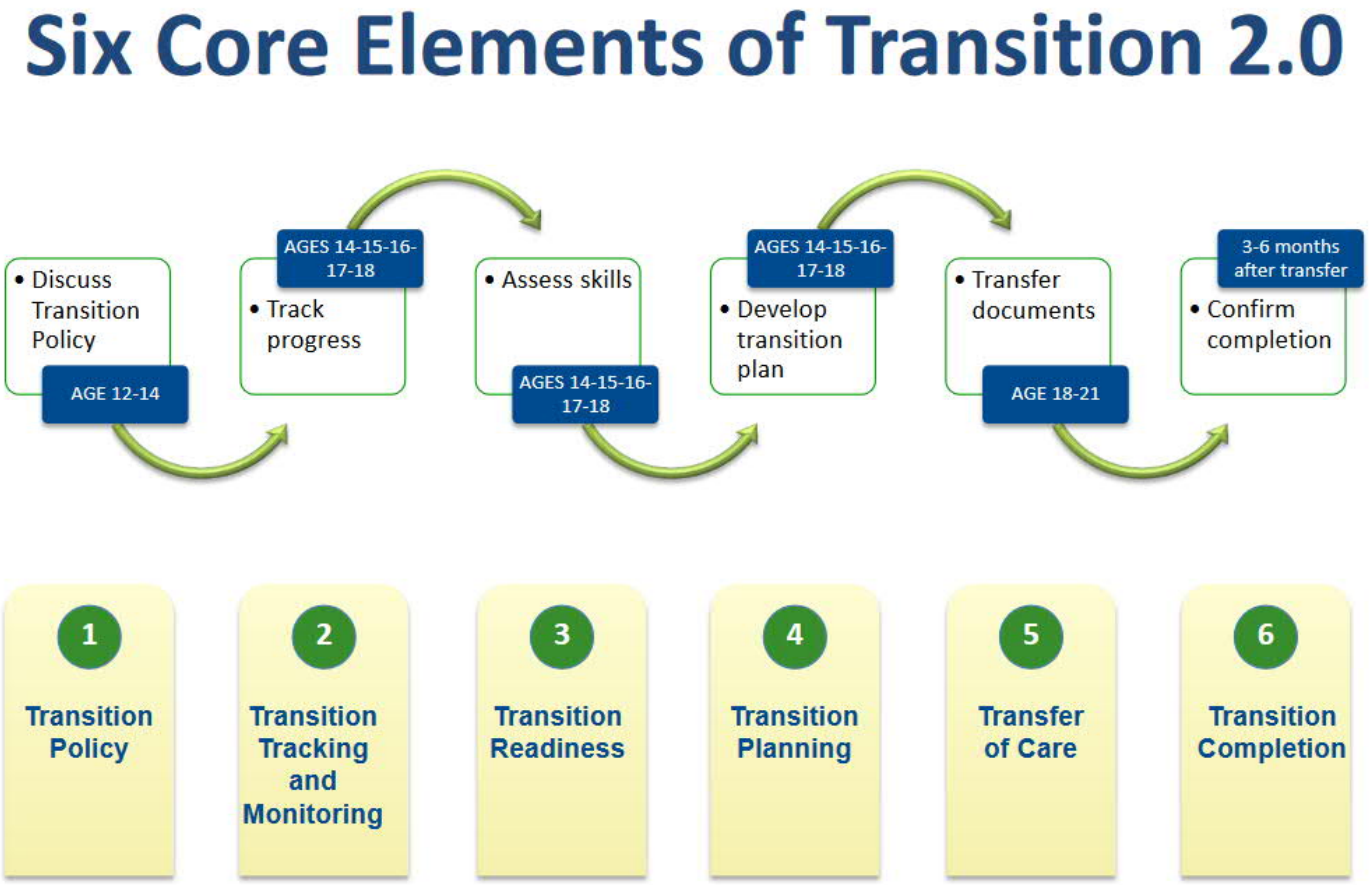
Positive outcomes result from health care transition:

- Adherence to care
- Improved patient-reported health and quality of life
- Development of self care skills
- Increased ambulatory visits
- Less time between the last pediatric and initial adult visit
- Lower emergency room and hospital use

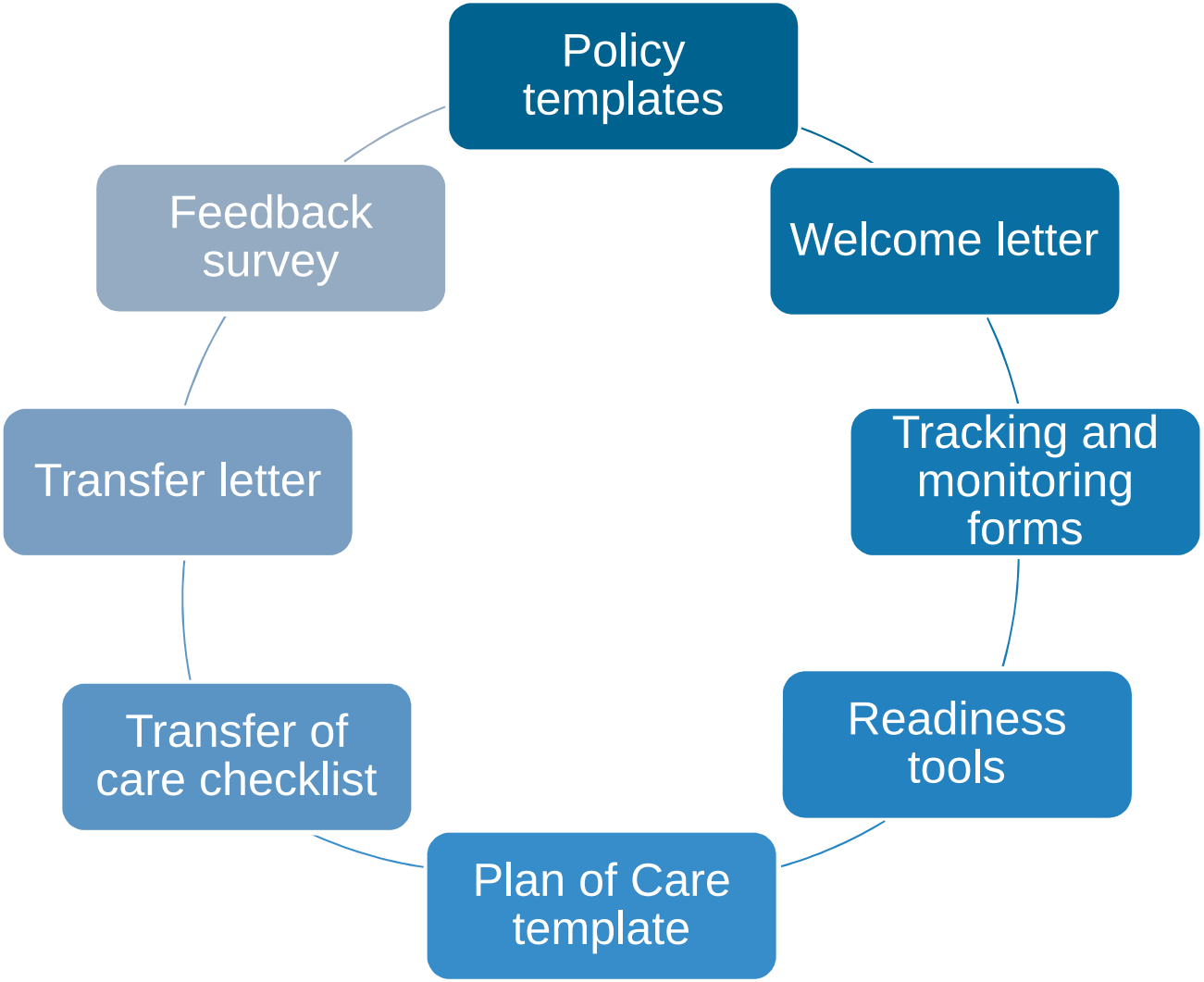
TAY
SPECIAL ISSUES FOR TAY



TAY
SIX CORE ELEMENTS OF HEALTH CARE TRANSITION



TAY
TOOLS FOR PROVIDERS



TAY
SUGGESTED TIPS AND PRACTICES FOR TAY

- Electronic health system programmed to have a pop-up reminder to do a readiness assessment for transition (every year or every few years)
- Face time warm handoff patient to the adult provider to introduce patient to the adult provider
- Healthcare app on phone with basic health information such as patient's name, emergency contact number, condition(s), allergies, medication, physician's name and number
- Parent navigators

TAY
WHO ARE THEY?

KARL

- Age 12
- Diagnoses: Cystic fibrosis
- Durable medical equipment: Suction machine, hospital bed
- Services: None
- Living situation: Lives with mother, grandmother and two older siblings
- **Transition Goals:**
  - Begin discussions regarding transition to adult care from pediatric; including specialist care
  - Begin reviewing medications with youth

JAVION

- Age 15
- Diagnoses: Spina bifida
- Durable medical equipment: Wheelchair, hospital bed, Foley catheters
- Services: 504 Plan, attendant care
- Living situation: Lives with mother, father and 1 younger sibling. Housing is subsidized but not accessible for a wheelchair.
- **Transition Goals:**
  - Start to identify potential adult care providers
  - Can identify his medications

LYLAH

- Age 19
- Diagnoses: Depression, anxiety
- Durable medical equipment: None
- Services: Counseling, medication management and psychiatric services
- Living situation: Lives in a college dormitory
- **Transition Goals:**
  - Can identify her medication and calls for refills
  - Schedules own appointments with providers

CYSHCN RESOURCES

- Association of Maternal and Child Health Programs (includes Standards for Systems of Care for CYSHCN Version 2.0): http://www.amchp.org/programsandtopics/CYSHCN/Pages/default.aspx
- Interactive Standards for Systems of Care for CYSHCN: http://cyshcnstandards.amchp.org/app-national-standards/#/
- The Child and Adolescent Health Measurement Initiative: www.cahmi.org
- Family Voices of Wisconsin (includes trainings/handouts for providers to distribute to families): http://www.familyvoicesofwisconsin.com/care-coordination/
- National Center for Medical Home Implementation: https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Practices.aspx
- Seattle Children's Hospital Program Center for Children with Special Needs: http://cshcn.org/
- Data Resource Center for Child and Adolescent Health: http://www.childhealthdata.org/browse/medicalhome

TAY RESOURCES

- State of Connecticut's website with transition information for adolescents with and without special health care needs: https://portal.ct.gov/DPH/Family-Health/Children-and-Youth/Youth-with-Special-Health-Care-Needs
- Got Transition – dedicated to improving transition from pediatric to adult health care through the use of innovative strategies for health professionals and youth and families: www.GotTransition.org
- The National Adolescent and Young Adult Health Information Center (NAHIC) – supports state efforts to improve care for adolescents and young adults. The website includes printable materials, journal articles, reports, toolkits, webinars, and guidelines/recommendations: http://nahic.ucsf.edu/
- Pathways RTC (Research and Training Center for Pathways to Positive Futures) – focused on improving the lives of youth and young adults with serious mental health conditions: https://www.pathwaysrtc.pdx.edu/