Transition: Access to Services for CYSHCN and Their Families

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Goals and objectives

Goal: The audience will understand the presence of barriers to access to care for CYSHCN and their families and opportunities for innovation.

Objectives: The audience will be able to describe:
- The current state of **access of services**, the workforce, health equity and financing or services, especially in the transition from pediatric to adult-based care.
- Opportunities for innovation in each of the above areas.

Who we are – Rylin

- Parent to 22/ 25 year old young adults with chronic conditions first diagnosed at birth
  - Multiple specialty visits
  - Expensive medications
  - Mobility and DME
- Health care transition journey

22	25
Out of state for college another state post college	Stayed in state did not complete college
Currently setting up new set of providers	Joined work force
On parent insurance (also changed)	Currently seeking primary care co-management
Still seeking next job	Preparing to transition to own insurance

Who we are - Dennis

- Parent to (almost) 23 year old college graduate with a chronic condition first diagnosed at age 5
  - Multiple specialty visits
  - Expensive injectable medications
- Health care transition journey
  - Moved out of state for college, then even farther away for first job
  - Remains on parent health insurance (which has also changed)
  - Currently setting up new team of specialists

Existing transition guidelines

- Planned, prepared health care transition
  - Start discussion between ages 12-14 with shared plan of care
  - Transition locus of care between 18-21 years of age
- Health care transition
  - Locus of care and health care services, including medical home and specialty services
  - Families generally don’t compartmentalize services into sectors - other services to consider include education, work, medication, financing

White PH, Cooley WC, et al. *Pediatrics* (2018) 142 (5): e20182587.

Definition of Access to Services

- Coverage – that service is paid for
- Service – that transaction/good meets the need of the child/family
- Timeliness – service is provided when needed
- Capable – workforce is effective, qualified, and culturally responsive

Kuo DZ, Rylin RC, et al. *Pediatrics* (2022) 149 (Supplement 7): e2021056150H.

Current state of access

- Families report services are disorganized
  - <50% report medical home
  - Less than one-third report receiving needed care coordination
  - Disparities by race/ethnicity
  - Workforce limitations
  - No roadmap on how to access services
- Transition services (2020-21 National Survey of Children's Health)
  - 20.5% of caregivers 12-17 reported services necessary for transition
  - 18 and up: ????

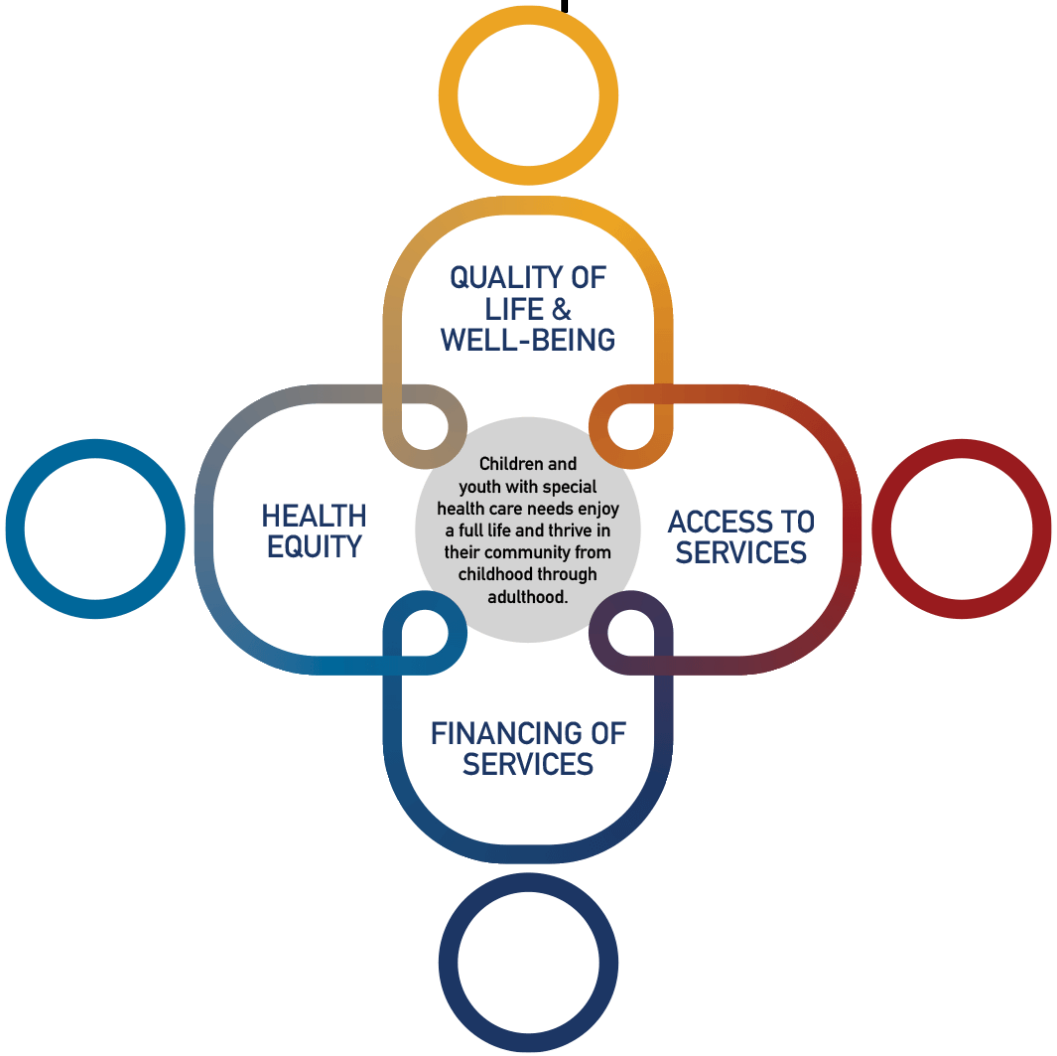
Lived Experience

- Rylin
  - Pre-college: self management, self access port for infusion, manage loss of Medicaid
  - College: campus accessibility, airline wheelchair, blockers to internships and study aboard
  - Post- college: new medical team, ventilation access
- Dennis
  - Pre-college: insurance costs, medications, self-management
  - College: advocacy for accommodations, scheduling visits around vacations, shipping medication snafus
  - Post-college: insurance, new medical team, more medication snafus

COVID-19 Impacts

- Personal health risk
- Accessibility in online/virtual classes and employment
- Access to vaccine
- Differing public health policy by institution, state, and jurisdiction

Transition and the Blueprint for Change



Access to Services

Vision

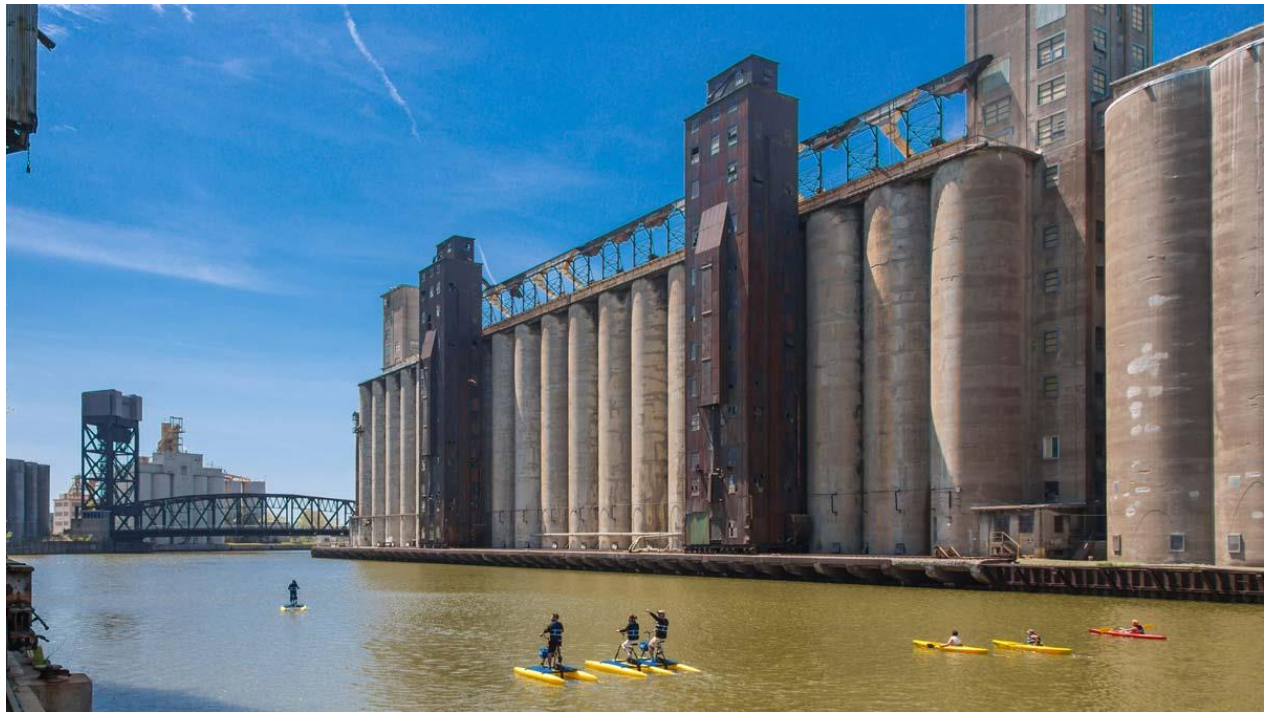
- CYSHCN and their families have **timely access to the integrated, easy-to-navigate, high-quality health care and supports they need**, including but not limited to physical, oral, and behavioral health providers; home and community-based supports; and care coordination throughout the life course

Principles

- All services and supports at the individual, family, community, and provider levels are easy for families and professionals to navigate when, where, and how they need them
- The workforce is trained to meet the needs of CYSHCN and their families, reflects the families and communities they serve, and is culturally responsive
- Service sectors increase the ability of CYSHCN and their families to access services by addressing administrative and other processes that hinder access

“Concepts and Considerations for an Integrated Systems Redesign”

- Silos are not just a good tourist attraction in Buffalo, NY
- Integration = work across silos
- Systems = how components interact with each other, guided by a philosophy of care



Fry-Bowers, E. K., et al. (2014) e JAMA Pediatr **168**(6): 505-506.
Edwards, S. T., et al. (2014). J Gen Intern Med.

https://www.visitbuffaloniagara.com/seven-ways-enjoy-silo-city/

Other Blueprint areas are also intertwined

- Equity – address structural and systemic causal barriers to service access
- Finance - ensure adequate and comprehensive coverage that support service access
- Quality of Life / Well-Being – ensure that service access supports meaningful outcomes where youth/young adults are flourishing (e.g. work, school, community)

Access to services: flipping the script

- Start with the outcomes – the end goal
  - Health and wellness
  - The exact service may not be the right answer – what if the service is in a different town? State? A waiting room full of screaming toddlers?
- Emphasize the journey (not just the components)
- Understand that services are intertwined – behavior, social, medical, transportation, community, financing
- Be planned and proactive

Human-centered design: designing the experience

- An approach that puts human needs, capabilities, and behavior first
- The process that ensures the design matches the needs and capabilities of the people for whom intended
  - Encompasses an understanding of psychology and technology
  - Provides a pleasurable experience
- Starts with a good understanding of people and the needs that the design is intended to meet

Norman, D. The Design of Everyday Things. Rev. New York, NY: Basic Books, 2013
http://www.designkit.org/human-centered-design

Consider the lived experience

- School – what happens when the young adult enters college?
- Work – what happens if young adult stays on parent's insurance but moves out of town?
- Equity – what are systemic factors (racism, ableism) that young adults need to self-advocate for when accessing services?

How might this look?

- Timing of transition of locus of services
  - Focus services on where youth needs them
  - Telemedicine offers new options for access
- Consider entry and continuity of services
  - When counseling – consider all services needed, including home health, family peer, telehealth
  - Careful about “coordinating the coordinators”
- Advocacy
  - Workforce accommodations
  - School accommodations

Innovations

- Consider a “roadmap” approach
  - Single point of service entry
  - Proactive – what does access look like in the future?
- Services based on need, not diagnosis
- Continuity, transition, placed-based approach
  - Telehealth
  - Co-management
  - Utilize care navigators when available

Equity

- Structural factors including race, poverty, ableism
  - First generation college students
  - Different costs of living
- Culturally responsive care
  - Understand demographic shifts and local population needs
  - Recognize increasing levels of chronic care and mental health needs

Take-home messages

- Be aware of research, policy, and program directions
- Innovations for access to services may include:
  - Navigation – follow the journey across sectors, including education, finance, workplace
  - Training/workforce – community-based, telehealth, co-management
  - Equitable – focused on youth and communities that are under resourced. Also consider the newly diagnosed