

AMCHP Family LEAD Committee The Blueprint for Change Part 1

March 29, 2023



Healthy Children. Healthy Families. Healthy Communities.

Agenda:

I. Brief Introductions

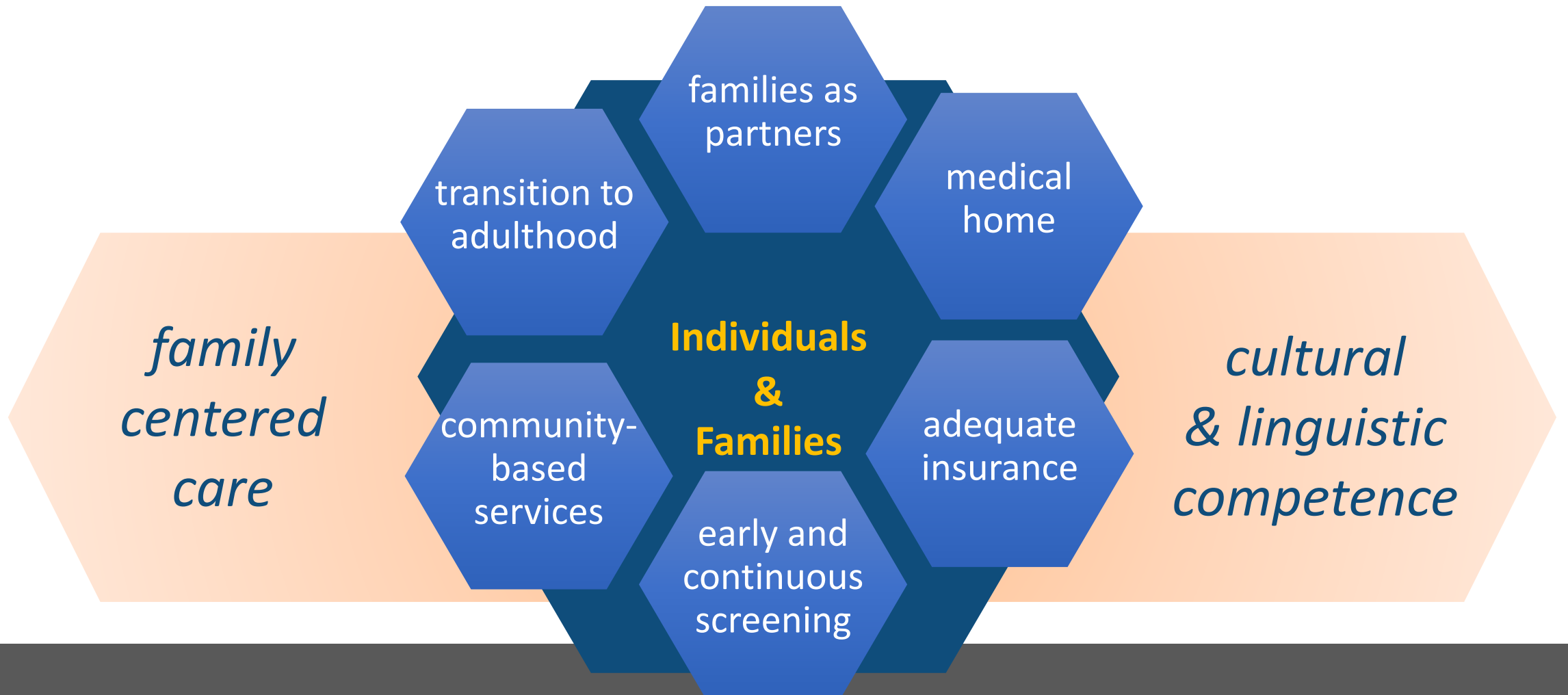
II. Family Perspective

III. Brainstorm how the Blueprint can be implemented with family engagement - breakouts

IV. Report out and Next Steps



85% of CYSHCN do not receive care in a well-functioning system





Why do we need a Blueprint? What's New?

Lots of questions during formation and even now- and that is GREAT!

A **call** for health care systems to measure outcomes that are **meaningful to children and families**

Four interdependent focus areas that **center around the issues families** consider most important to strengthen the system of care

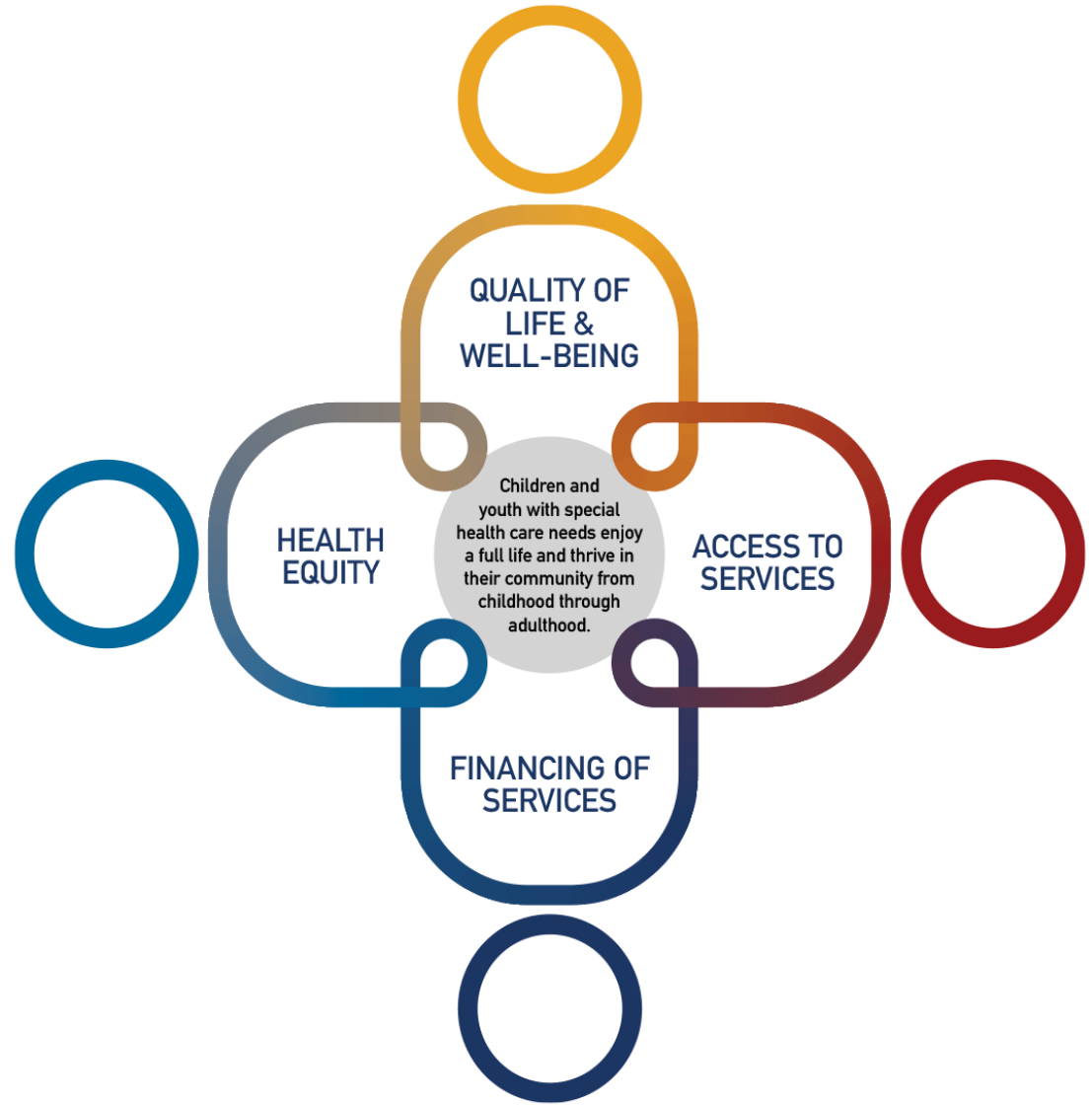
A **call** to address the upstream and downstream factors that prevent **CYSHCN** from a fair and just opportunity to be healthy

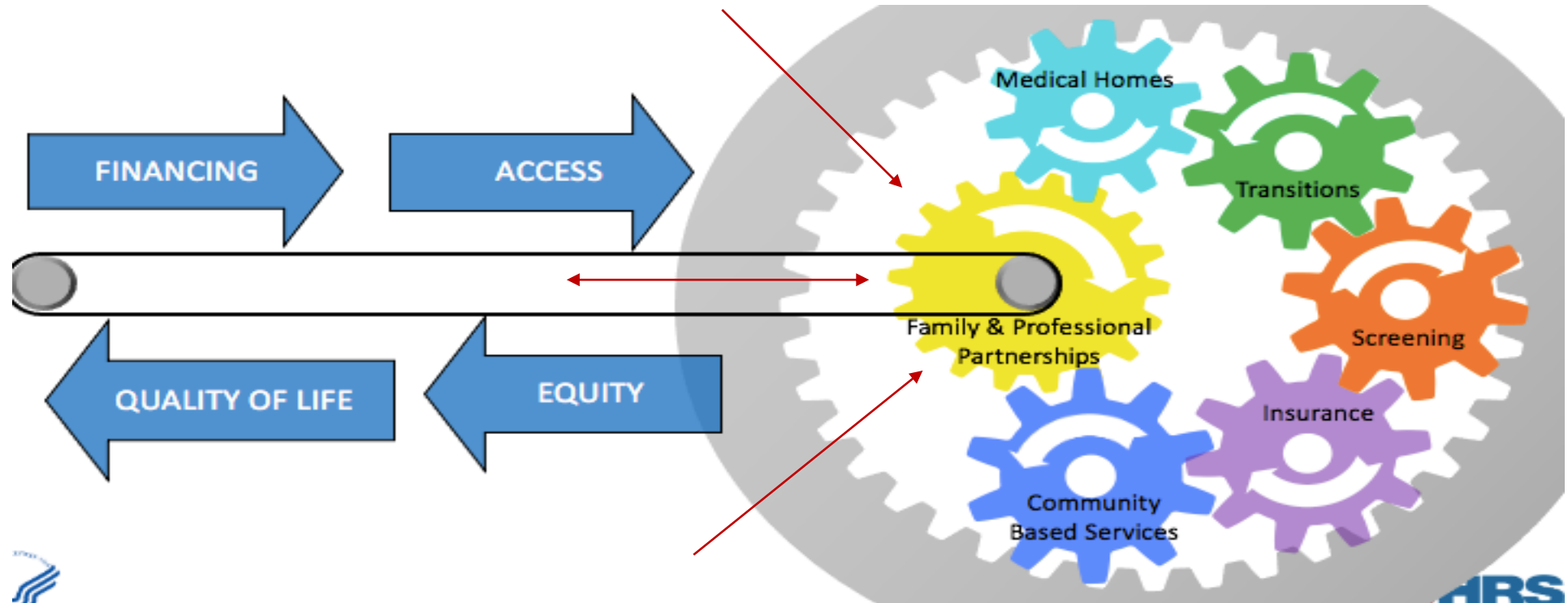
A **call** to design a system that is **built around the needs of children and families** not just a diagnosis or treatment protocol

A **call** to support a service system that supports access, equity and integration, and **eases the financial burden on families**

An understanding that if we improve the system of care for **CYSHCN**, all children will benefit

Justice Frameworks: conviction & enactment, vision & practice, nouns/ adjectives to verbs





Key to movement= Partnerships

- Meaningful and authentic
 - Systematic... not just a survey or RFI
 - Not just a one-off
 - Culture change- equity demands it
- Family-led, community-based
- Infrastructure and Compensation

Plain Language Version = Anything but “*Plain*”

Every child gets the services they need,
so that they can play, go to school,
and grow up to become a healthy adult.
(And so grown-ups and siblings can thrive too.)

= **Equity!!!!**

= **Child thriving aka Be a Kid/Teen- period!**

= **Transition aka dream, strive, arrive!**

= **well-being aka be a family, live life not just appointments, doing care/ coordination etc.**



Family as Partners & Leaders in Blueprint:

Measurement
and
Maps
(aka some tools and weapons))

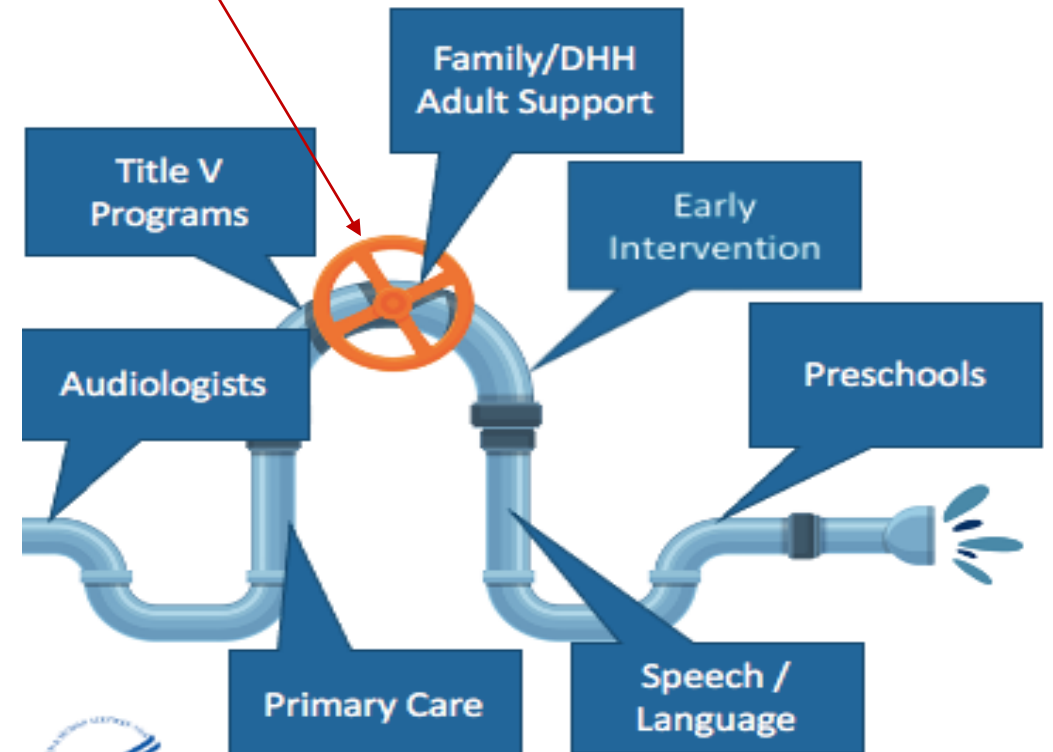
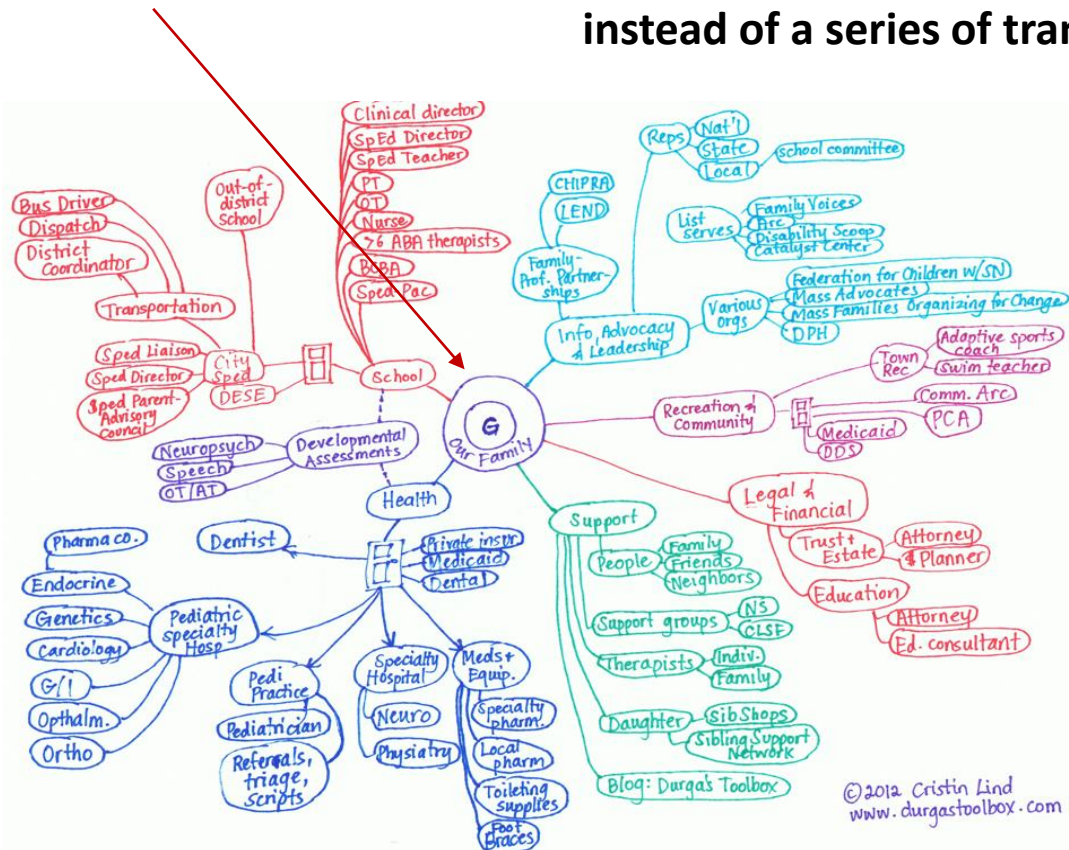


QOL Measurement:

Experience from the Collaborative for Innovation and Improvement Network (CoIIN) to Advance the Care of Children with Medical Complexity

Map the Change to Enact the Blueprint for Change

“For too long, the system of services for CYSHCN and families has been **designed around the services themselves**. . . . **Reimagining** the system around the life course of the CYSHCN entails thinking about a **proactive, human-centered** system that addresses health through all of its determinants, and views access as a **journey built on relationships** **instead of a series of transactions.**” (Access to Services, Kuo et al. 2022)



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Thank you!

Slides and recordings for both webinars in the series will be sent to participants.

