

***A Blueprint for Change:* The National Roadmap for Children and Youth with Special Health Care Needs**

Dennis Z. Kuo, MD, MHS
Professor of Pediatrics
Chief, Developmental and Behavioral Pediatrics

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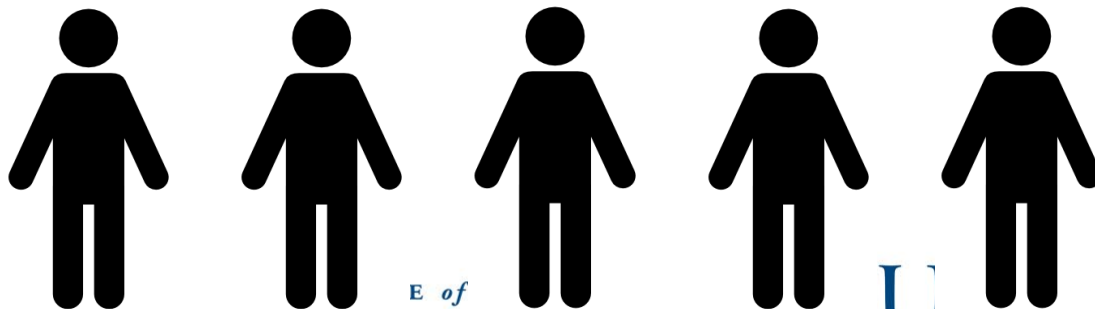
Acknowledgements

- Treeby Brown, HRSA
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Children and Youth with Special Health Care Needs (CYSHCN)

Who are CYSHCN?

Children or youth *who 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 for children generally.



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Autism

- Children with autism have special health care needs
- Children with autism require health and related services beyond that required for children generally
 - Subspecialty care: developmental/behavioral pediatrics, others
 - Often require therapies and educational services
 - Some have additional subspecialty care and medication needs
- Higher caregiver needs and health care costs

Maternal and Child Health Bureau Strategic Plan

Mission

To improve the health and well-being of America's mothers, children, and families.

Vision

Our vision is an America where all mothers, children, and families thrive and reach their full potential.

MCHB Goals

ACCESS

Assure access to high-quality and equitable health services to optimize health and well-being for all MCH populations.

EQUITY

Achieve health equity for MCH populations.

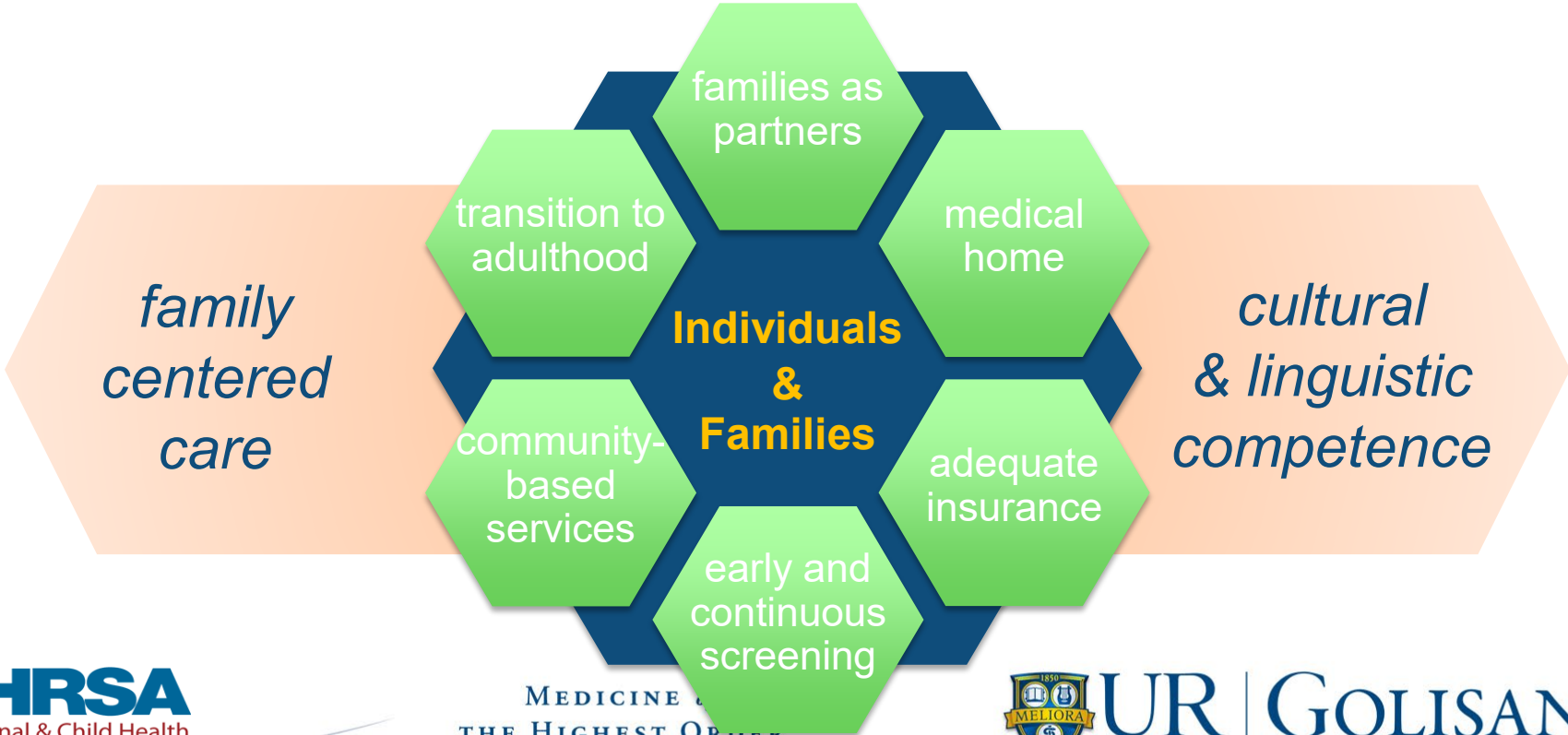
CAPACITY

Strengthen public health capacity and workforce for MCH.

IMPACT

Maximize impact through leadership, partnership, and stewardship.

Six Indicators of a Well-Functioning System



Autism: components of system of services

Primary care / medical home

Developmental pediatrician / DBP services

Education

Insurance

Therapies

Medications

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The journey through the system

- Identification often occurs in the medical system
- Treatment may be through the medical, education, mental health systems, which are supported by different laws and financing
- *Lack of a roadmap*
 - *The system is widely acknowledged to be fragmented and unpredictable*
 - *Families often feel they have to figure out how to navigate the system*

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Background on the *Blueprint*

- Over 20 years since last strategic planning for CYSHCN system
- Families and recent NSCH data tell us the current system of services is not working well for CYSHCN
- Nearly 14 million (1 in 5) children have a special healthcare need, yet **85% of CYSHCN still do not receive care in a well-functioning system**
- COVID-19, recent natural disasters, and social/economic unrest have had disproportionate impacts on CYSHCN

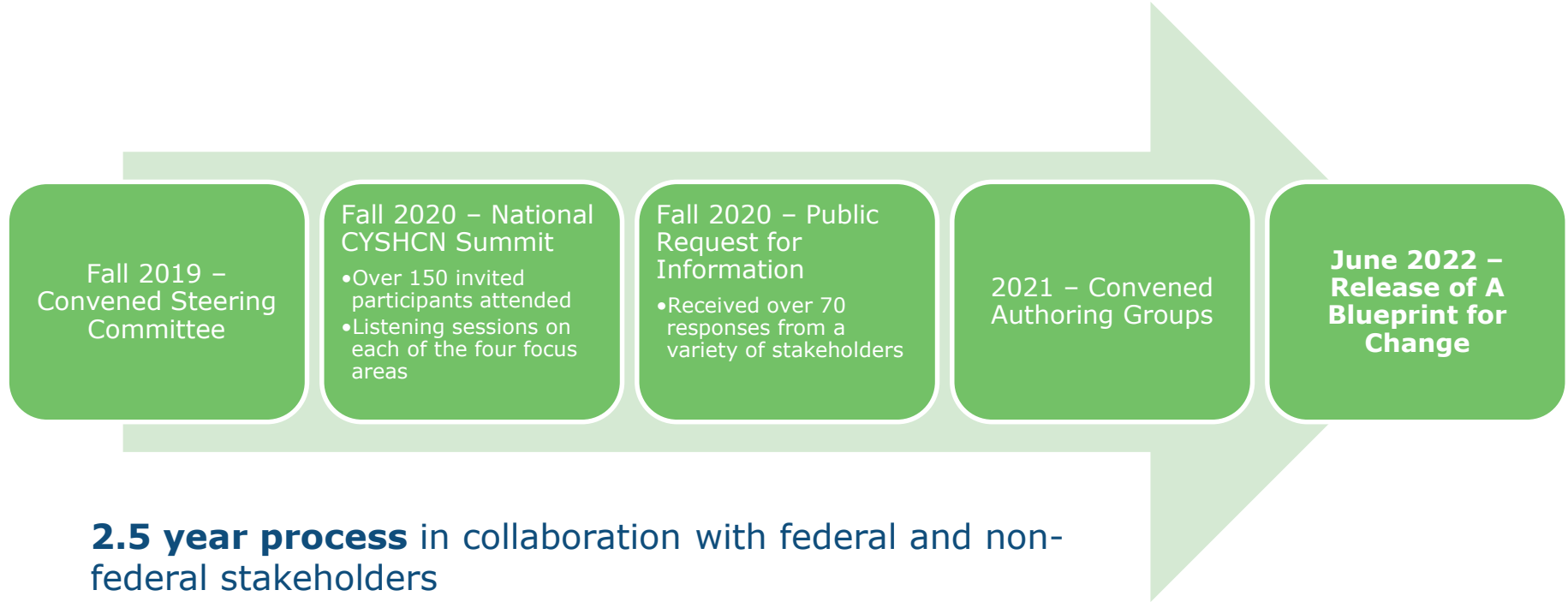
Autism: disparities

	Currently has Autism	No Autism
Does not receive care in well functioning system	89%	83%
Does not have medical home	64%	53%
Does not have adequate and continuous insurance	33%	32%
Does not demonstrate family resiliency	22%	15%

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Development of the *Blueprint for Change*



2.5 year process in collaboration with federal and non-federal stakeholders

Importance of the *Blueprint* for the Field

Aligns with the Six Indicators framework

- Provides a new lens of equity, access, and quality of life to the framework

Provides principles and recommendations for the field in several areas including:

- Families, researchers, providers, policy makers, and programs at the local, state, and federal levels

Guiding Assumptions

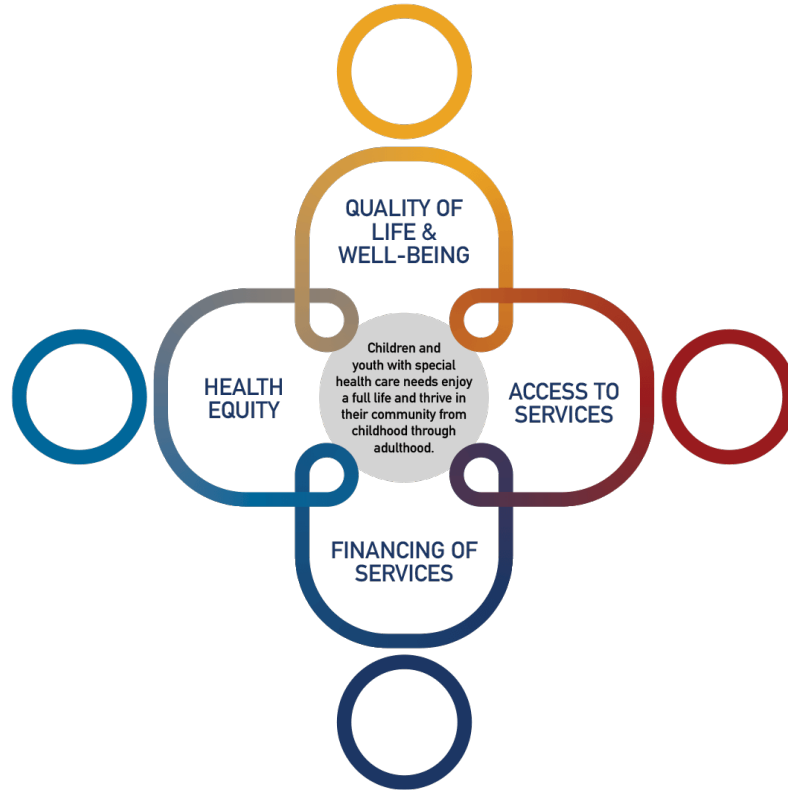
Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society.

Racism is a social risk factor that has a profound impact on the health status of children, adolescents, young adults, and their families.

CYSHCN require more and different types of services than those for typically developing children and youth, yet the current system is not ensuring access to these services, particularly for CYSHCN impacted by poverty and discrimination.

CYSHCN are more severely impacted by the adverse effects of social determinants of health and inequities.

Focus Areas



Health Equity

Vision

- All CYSHCN have a **fair and just opportunity to be as healthy as possible and thrive throughout their lives** (e.g. from school to the workforce), without discrimination, and regardless of the circumstances in which they were born or live.

Principles

- Structural and systemic causal barriers to health equity are eliminated, including discrimination, poverty, and other social risk factors.
- Sectors, systems, and programs that fund, deliver, and monitor services and supports for CYSHCN are designed and implemented to reduce health disparities and improve health outcomes for all CYSHCN.

Family/Child Well-Being and Quality of Life

Vision

- The service system **prioritizes quality of life, well-being, and supports flourishing** for CYSHCN and their families

Principles

- Families, regardless of circumstance, can access high-quality, affordable, community-based services that support the medical, behavioral, social, and emotional well-being of the child or youth and whole family.
- Health systems place value on the measurement and use of both child/family well-being and quality-of-life outcomes and health outcomes

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

Financing of Services

Vision

- Health care and other related services are **accessible, affordable, comprehensive, and continuous**; they prioritize the well-being of CYSHCN and families

Principles

- Health care and other related services for CYSHCN and families are financed and paid for in ways that support and maximize an individual's values and choice in meeting needs.
- Health and social service sector investments address social determinants of health to increase family well-being and flourishing.
- Payers and service sectors adopt value-based payment strategies that support families, advance equity, and incorporate continuous quality improvement by enhancing team-based integrated care.

What's New?

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

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

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


How the Blueprint influences the field

- Sets the expectation for initiatives, programs, policies
- What this looks like:
 - Integrated family partners at all levels
 - Equity addressed up front
 - Emphasis on lived experience, journeys, and design
- The four areas of the Blueprint are intertwined: equity, family/child well-being, access to services, financing of services


Reflection Questions



What can we learn from the *Blueprint* and its applicability for autism?



What does health equity look like for children with autism and their families?



What does a roadmap look like for a child with autism and their families?

What does equity look like for autism?

- Predictable journey through services – screening, follow up, service delivery, transition through sectors
- Office design and staff training to accommodate and welcome every child and family
- Inclusion of family partners and individuals with lived experience at all sectors of services
- **A roadmap of services and resources**

What's next?

- Children with autism enjoy a full life and thrive in systems that ensure dignity, autonomy, and independence in their communities
- The Blueprint is just being rolled out; expect the four sectors to influence programming over the next 15 years, not just HRSA, but other federal and state initiatives
- Take action, using the Blueprint as the lens
- More information here: <https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn/blueprint-change>



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