

CYSHCN Blueprint for Change: Implications for Newborn Screening

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Objectives

Discuss CYSHCN system of care and the context for newborn screening

Introduction to the Blueprint for CYSHCN

Discuss implications from the Blueprint on CYSHCN care

Review potential implications for newborn screening and the RUSP

Credit: Treeby Brown, Sarah Beth McLellan, HRSA for slides

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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.

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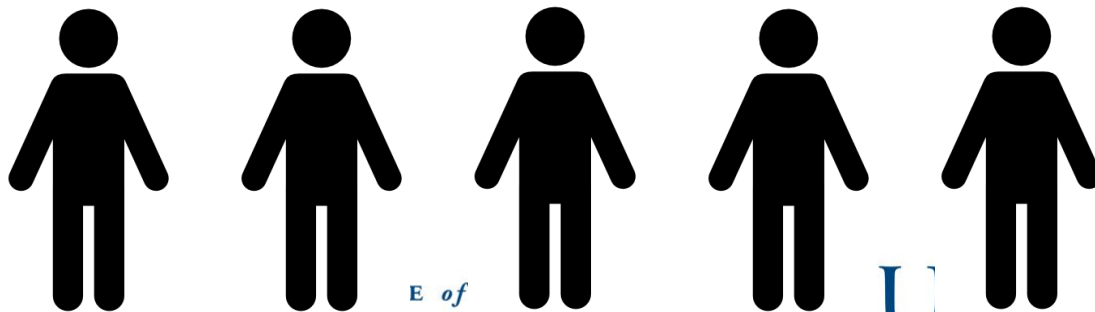
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Children and Youth with Special Health Care Needs (CYSHCN)

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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Examples of CYSHCN

Asthma

ADHD

Cerebral Palsy

Down syndrome

Juvenile arthritis

Spina bifida

RUSP examples

Metabolic disorders

Endocrine disorder – hypothyroid, CAH

Sickle cell disease

Critical congenital heart disease

Cystic fibrosis

Hearing loss

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RUSP

Conditions chosen based on potential net benefit of screening, ability of states to screen for disorder, and availability of effective treatments

- Testing goals: within 48 hours of life, and reported to “newborn’s health care provider” 5-7 days of life
- “follow-up activities, including those necessary to achieve best practices in rapid diagnosis and appropriate treatment in the short-term, and those that ascertain long term case management outcomes and appropriate access to related services” (Title 42 U.S.C. § 300b-10)



Almost all RUSP conditions result in special health care needs

- Chronic care and ongoing specialty care management
- Medications and formulas
- Therapies
- Early and continuous screening for co-morbidities, including learning difficulties
- Special health care needs are best served by a comprehensive **system of care** that addresses needs proactively and holistically

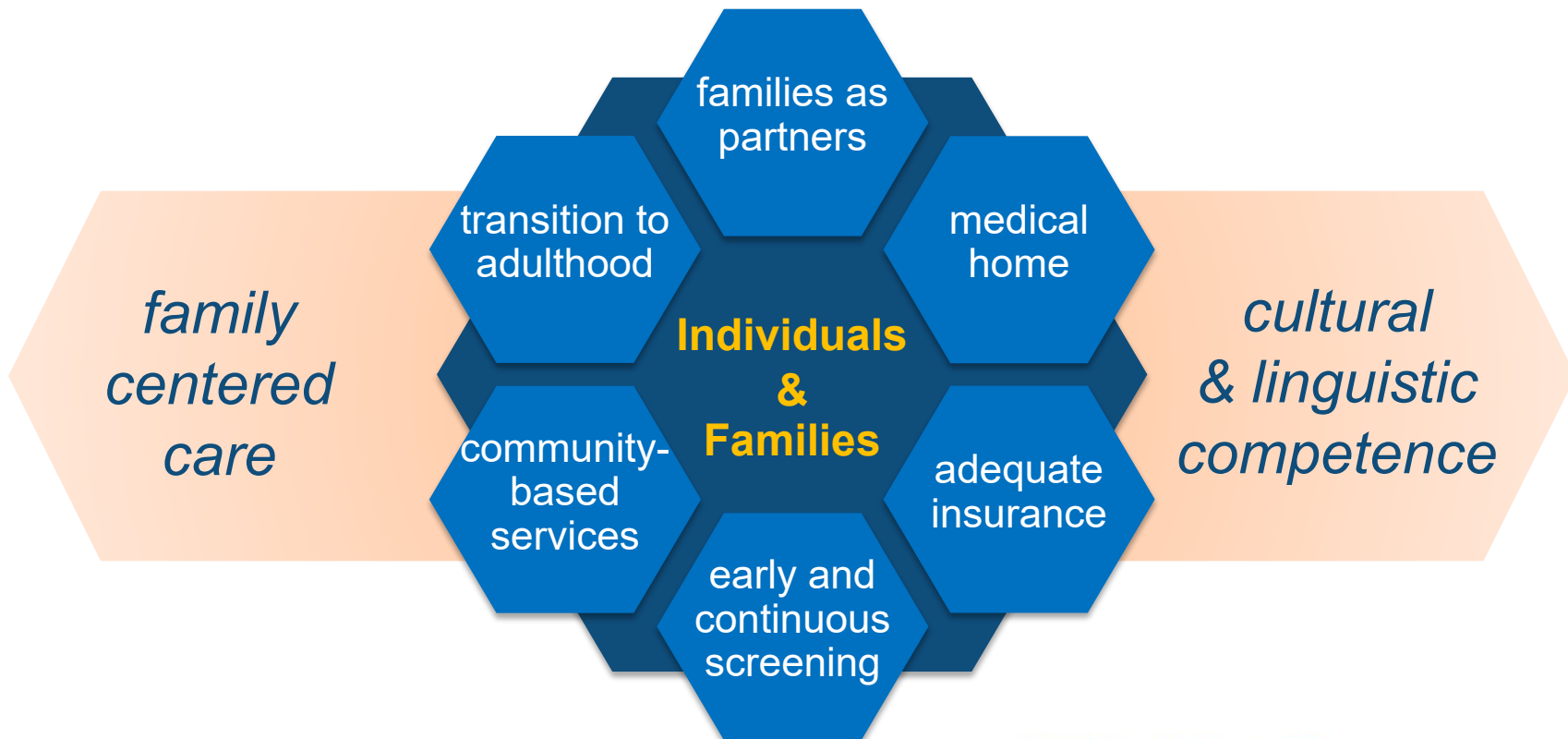
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Six Indicators of a Well-Functioning System



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Components of system

Families as partners in decision making at all levels

Medical Home, receiving coordinated, ongoing, comprehensive care

Adequate insurance

Early and continuous screening for special health care needs

Community based services that are organized

Transition to all aspects of adult life, including health care, work, independence

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Context of newborn screening system

Life course approach

- Process only begins when blood spot is taken
- Early diagnosis and intervention impacts life course (health, development, wellness, achievement of potential)

After the diagnosis

- Family education
- Medical home and specialty care
- Education (therapies are often handled in the education system)
- Financing for service access

Case example: sickle cell disease screening

Medical home

Comprehensive maintenance health care, typically subspecialist led

- Infection and vaso-occlusive event prevention
- Nutrition optimization
- Acute event management
- Screening and amelioration of psychological co-morbidities

Financing for service access

Transition to adult health care system and supports

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Case example: hearing screening

- Medical home
 - Follow-up timely testing
 - Subspecialty diagnosis and management
 - Routine screening and follow up for developmental delays,
 - Financing for service access
 - Transition to adult health care services and supports
- HRSA EHDI
 - support the development of state and territory programs and systems of care to ensure that children who are deaf or hard of hearing are identified through newborn, infant, and early childhood hearing screening
 - receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development

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Case example: SMA screening

Medical home

Multispecialty (complex) care: pulmonary, orthopedic, PM&R, GI, nutrition

Disease-modifying therapy

Genetic counseling

Educational evaluation, services, and accommodations

Community-based services

Financing for services

Transition to adult health care system

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Why the Blueprint for CYSHCN?

System hasn't moved enough

- 86% of CYSHCN still do not have access to a well-functioning system of services
- Services remain fragmented
- Inequities in access, particularly in under-resourced communities

Acknowledging the critical role of families in achieving the stated vision

Structural racism, ableism, and social/environmental factors impact health and well-being

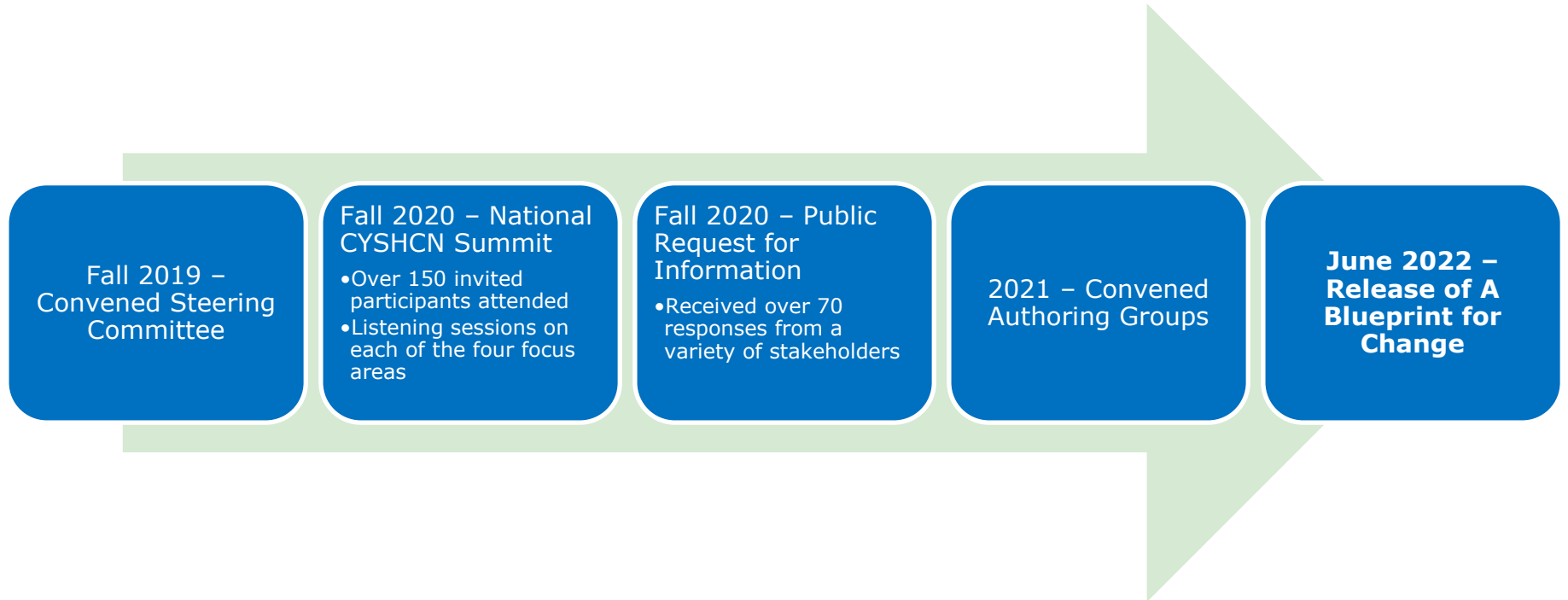
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Development of the Blueprint



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What's New in the Blueprint

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

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Blueprint Focus Areas and Vision

Children and youth with special health care needs enjoy full lives and thrive in their communities from childhood through adulthood



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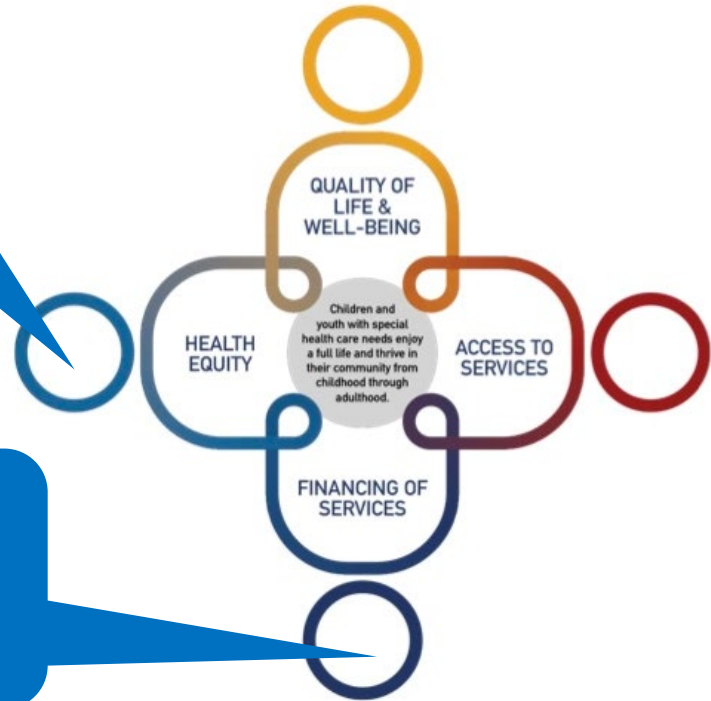
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Focus Area Visions

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

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



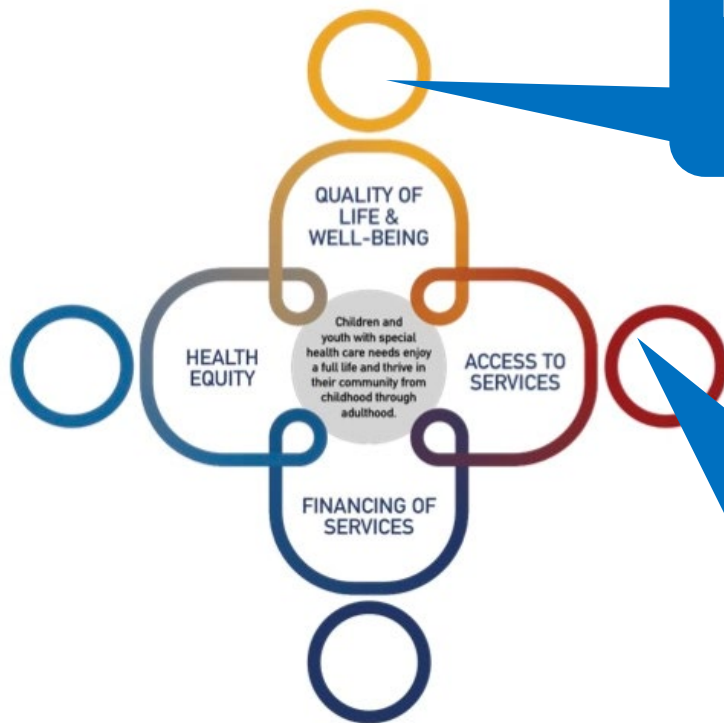
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Focus Area Visions



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

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.

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.

Quality of Life and Well-Being

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

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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.

Blueprint Summary

Blueprint informs research, policy, and programs for CYSHCN systems of care at the federal, state and community levels

- Emphasis on care integration, health equity, family-defined outcomes
- Human-centered design
- Messaging across bureaus, divisions, systems

How can we facilitate discussion?

- What can you do as a family
- What can you do as a provider
- What can you do as a state program
- What can you do as a health care or research institution

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Thoughts for discussion: Education & Training Workgroup

Broad system of service partners

Health equity / systemic barriers to services

Community and family partners for collaboration

- Family-to-Family Health Information Centers
- Education
- Departments of Health

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Thoughts for Discussion: Follow Up and Treatment Workgroup

Consider co-morbidities – continuous screening for (e.g.)

- Developmental delay
- Mental health

Address systemic barriers to service access

- Medical home
- Health equity / systemic barriers
- Telehealth

Importance of care navigation, care integration, and family support

Thoughts for Discussion: Laboratory Standards & Procedures Workgroup

Finance and payment

System access for false positives/negatives

- Training and resources for hospitals
- Learning collaboratives and data-driven outcomes
- Regional oversight, including hospitals and outpatient providers

Examine service access for follow up

- Health equity
- Family support / partners

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Personal experience: 22q11.2 deletion

Child diagnosed at 5 weeks with seizures due to low calcium level

- No cardiac disease identified when hospitalized
- Immune deficiencies identified

Service requirements: specialty care, feeding management, speech therapy, behavior management

Medical home provider: stay one step ahead of anticipated needs - minimize illnesses and access services to maximize health and wellness

Long-term follow up at her 18th birthday! "I want to thank you...[you] didn't sugar coat what was happening and assured me you'd be there..." "...[she] does not let a little missing piece of the 22 chromosome get in her way."

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Personal example continued

- Most prevalent microdeletion syndrome – at least 1 in 3,000
- 5/12 review: “No published studies are available to show the benefits or effectiveness of early treatment in mild cases, or in cases without life-threatening manifestations, if diagnosed early in life. Thus, there is a need for pilot studies of the proposed newborn screening test algorithm and treatment protocols to provide the data necessary to inform an evidence review”
- Blueprint for CYSHCN frames system and research initiatives – to make the journey more predictable and improve outcomes

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Thank you!

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