Blue Ribbon Commission to Study the Organization of and Service Delivery
by the Department of Health and Human Services
Resolve 2023, chapter 98
Wednesday June 12, 9:30am
Room 216 (Environmental and Natural Resources Committee room)
Cross State Office Building, Augusta ME

AGENDA

- Welcome, *Chairs Senator Duson and Representative Craven*

- Commission member introductions (membership list)

- Dr. Amy Houtrow, MD, PhD, MPH
  - Title V Maternal and Child Health Services Block Grant
  - Child and Youth with Special Health Care Needs (CYSHN)
  - *Blueprint for Change: Guiding Principles for a System of Services for CYSHCN and Their Families,* Health Resources and Services Administration

- Eileen Forlenza, Senior Public and Population Health Consultant
  - Elevating Family Voices

- Stacey LaFlamme, Maine CDC
  - Children with special health needs
  - Maine's Blueprint

- Department of Health and Human Services Case Study Presentations
  - Case study #1: Child with medical diagnoses who is receiving IDEA Part C, needs SLP, PT, OT, neurologist and intensive early intervention treatments. Family needs child care

  - Case study #2: Low-income family facing homelessness with two children with special needs: a teenager with ADHD who needs medication management; and a younger child with autism who receives Sec. 28 services from provider(s) that are understaffed

- Commission discussions on presentations

- Next steps

Future meeting dates: July 10, September 17, October 9, October 30.

Blue Ribbon Commission to Study the Organization of and Service Delivery by the Department of Health and Human Services

Resolve 2023, chapter 98

Membership List

Name	**Representation**
Senator Jill Duson – Chair	Member of the Senate, appointed by the President of the Senate
Representative Margaret Craven – Chair	Member of the House, appointed by the Speaker of the House of Representatives
Senator Joseph Baldacci	Member of the Senate, appointed by the President of the Senate
Senator Marianne Moore	Member of the Senate, appointed by the President of the Senate
Representative Daniel Shagoury	Member of the House, appointed by the Speaker of the House of Representatives
Representative Kathy Javner	Member of the House, appointed by the Speaker of the House of Representatives
Rob Moran	Member representing interests of those with intellectual disabilities, behavioral health disorders, poverty, elderly or children receiving child welfare services or early childhood services
Allina Diaz	Member representing interests of those with intellectual disabilities, behavioral health disorders, poverty, elderly or children receiving child welfare services or early childhood services
Nancy Cronin	Member representing interests of those with intellectual disabilities, behavioral health disorders, poverty, elderly or children receiving child welfare services or early childhood services
Sharon Moore	Member who has lived experience in caring for one with intellectual disabilities, behavioral health disorders, poverty, elderly or children receiving child welfare services or early childhood services
Beth Hamm	Deputy Commissioner, Department of Health & Human Services
Ian Yaffe	Director of an office within the Department of Health & Human Services
Bill Montejo	Director of an office within the Department of Health & Human Services

Title V

Children and Youth with Special Health Care Needs

Amy J. Houtrow, MD, PhD, MPH
Professor of PM&R and Pediatrics
University of Pittsburgh

University of Pittsburgh

Funding Disclosures

- PCORI
- CDC
- NIH
- HRSA -LEND
- PA Dept of Health –care coordination
- FISA— Disability JEDI training
- FISA –Access to care
- LPFCH- DIVERSE Collective
- AAP –Health equity advisor for National Center for Systems of Services for CYSHCN

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Optimizing the health, functioning, well-being and belonging of children with disabilities

University of Pittsburgh

Understanding the Population of Children with Special Health Care Needs

CYSHCN have a chronic physical, developmental, behavioral or emotional condition AND require health and related services of a type or amount beyond that required by children generally

~73 million
Children in the United States

~58.5 million
Children do not have special health care needs

20% or ~14.5 million have special health care needs

9.7% or ~7 million have disabilities (a health condition that consistently and often a great deal affects their daily activities)

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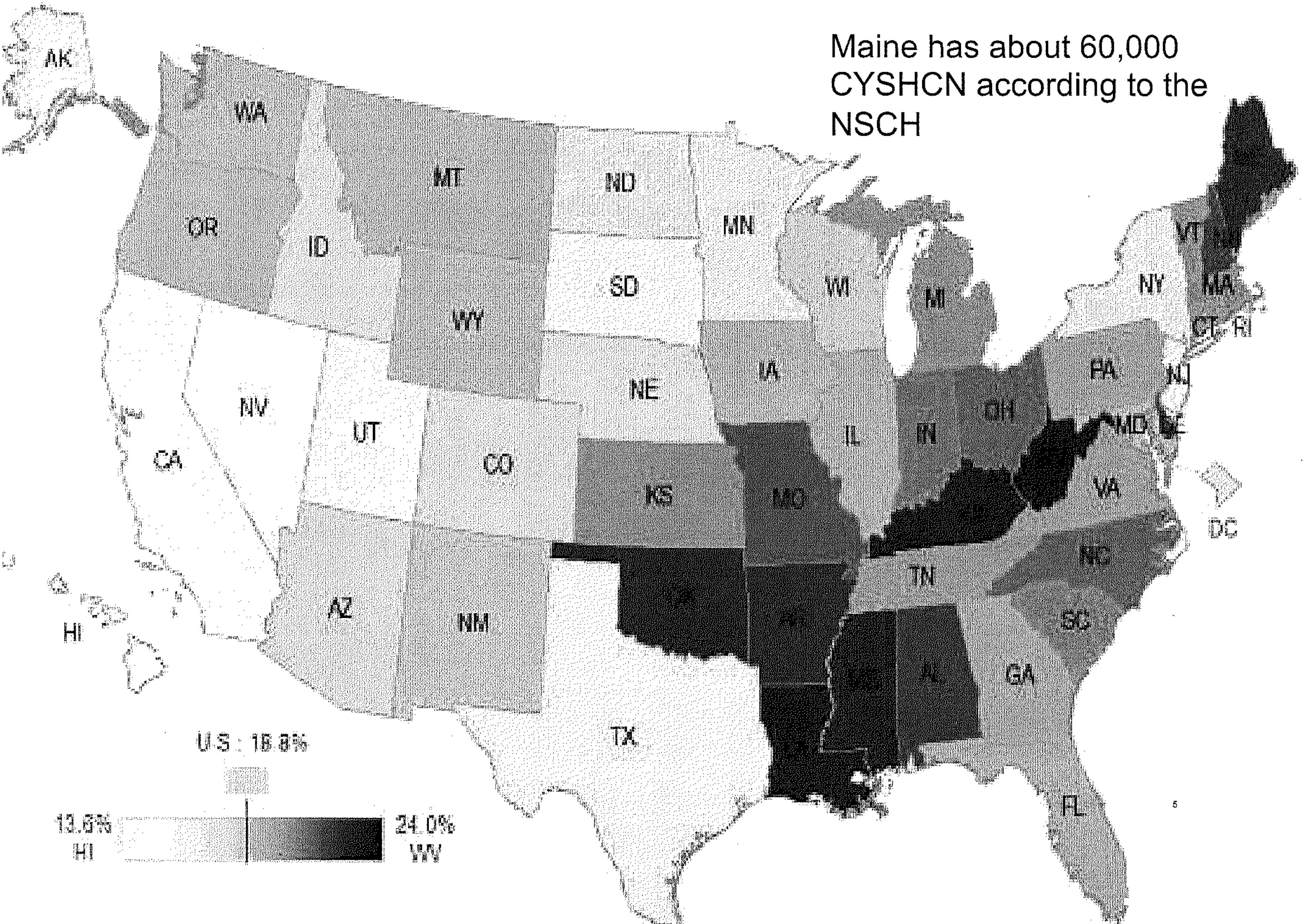
National Survey of Children's Health 2021-2 data available at www.childhealthdata.org

Maine has about 60,000 CYSHCN according to the NSCH



rom Ghandour et al. CYSHCN: A Profile. Pe trics 2022

A Quick History Lesson

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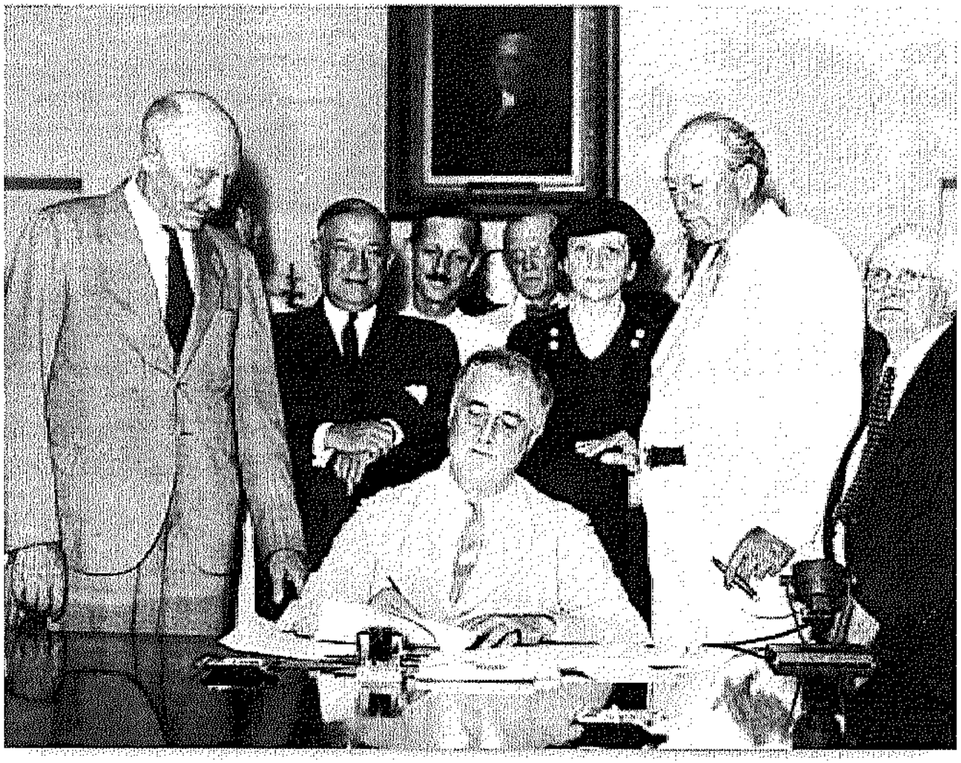
Background on Title V and CYSHCN



AUGUST 14, 1935

TITLE V OF THE SOCIAL SECURITY ACT

BACKGROUND

As a result of the Great Depression, cutbacks in federal health programs, and the declining health of mothers and babies, the Social Security Act was signed into law in August 1935 by President Franklin Delano Roosevelt. Secretary of Labor Frances Perkins enrolled Katharine Lenroot, then Children's Bureau Chief, to work with her to ensure that children were considered by the Committee on Economic Security, which drafted the legislation.

Title IV of the legislation also provided funding for federal-state partnerships to help the blind, the elderly, and children, the latter of which became the first incarnation of the Aid to Dependent Children welfare program. Funding was initially provided strictly for needy, dependent children, and it was not until the 1950s that funding was also given to caretakers. This was reflected in a name change to Aid to Families of Dependent Children (AFDC).

https://mchb.hrsa.gov/about-us/timeline

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1967

MEDICAID AND EPSDT

BACKGROUND

The Medicaid statute (Title XIX) was amended in 1967 under President Lyndon B. Johnson to create the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program for needy children, although regulations for EPSDT were not published until 1972. Much of the language of EPSDT came from the Crippled Children's legislation of 1935. The purpose of EPSDT was to identify and diagnose health problems of low-income children through the provision of periodic physical and developmental examinations. The program also provided funds for the treatment of illnesses and other health conditions.

IMPACT

As a required program in every state, EPSDT aims to improve the health of low-income children by financing appropriate and necessary pediatric services for infants, children, and youth under age 21 who are enrolled in Medicaid

1970

DEVELOPMENTAL DISABILITIES SERVICES AND FACILITIES CONSTRUCTION AMENDMENTS

BACKGROUND

The Developmental Disabilities Services and Facilities Construction Amendments created Developmental Disabilities (DD) Councils in each state. Members of DD Councils included people with disabilities and representatives of state and social service agencies, such as Title V and the Department of Education.

IMPACT

The Developmental Disabilities legislation initiated a multifaceted mandate to organize services for people with developmental disabilities. By 1978, developmental disabilities were functionally defined and DD Councils had developed comprehensive state plans identifying the needs

EDUCATION OF ALL HANDICAPPED CHILDREN ACT (P.L.94-142)

BACKGROUND

By 1975, it was discovered that more than half of children with disabilities in the United States were not receiving adequate educational services. This Congressional finding triggered the enactment of the Education for All Handicapped Children Act, which required that all handicapped children and youth (three years of age and beyond) be provided with free, appropriate education in the least restrictive environment. The Act was renamed the Individuals with Disabilities Education Act (IDEA) in 1990.

IMPACT

The passage of Public Law 94-142, also known as the Education of All Handicapped Children Act, was a major development in addressing the needs of children and youth with disabilities. New collaborations were formed among teachers and healthcare professionals to better serve the interests of children with disabilities.

1976

THE SUPPLEMENTAL SECURITY INCOME DISABLED CHILDREN'S PROGRAM

BACKGROUND

In 1976, the Supplemental Security Income Disabled Children's Program (SSI/DCP) provided cash payments to low-income children with disabilities (under the age of seven) to help defray family costs in caring for children with special health care needs. Through the program, a child was referred to the state's Title V agency and was ensured Medicaid services and benefits under the state's Crippled Children's Services (CCS) program.

IMPACT

Federal laws, such as Title V, IDEA, and SSI, demonstrated the shift in mentality from identifying disabilities as diseases/conditions to focusing on meeting the special needs of children with disabilities.

1981

OMNIBUS BUDGET RECONCILIATION ACT OF 1981

BACKGROUND

Title V of the Social Security Act was amended drastically in 1981 through the Omnibus Budget Reconciliation Act of 1981 (OBRA) (P.L. 97-35).

IMPACT

Although the Act did not change the program's focus on services to high-risk mothers and children, it modified the method of supplying the money to states through block grants, as well as the role of the federal government. The change resulted in the consolidation of seven categorical programs into a single block grant.

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1986

CRIPPLED CHILDREN'S SERVICES RENAMED CHILDREN WITH SPECIAL HEALTH CARE NEEDS

BACKGROUND

In 1986, Surgeon General C. Everett Koop coined the phrase 'Children with Special Health Care Needs' to replace Crippled Children's Services.

IMPACT

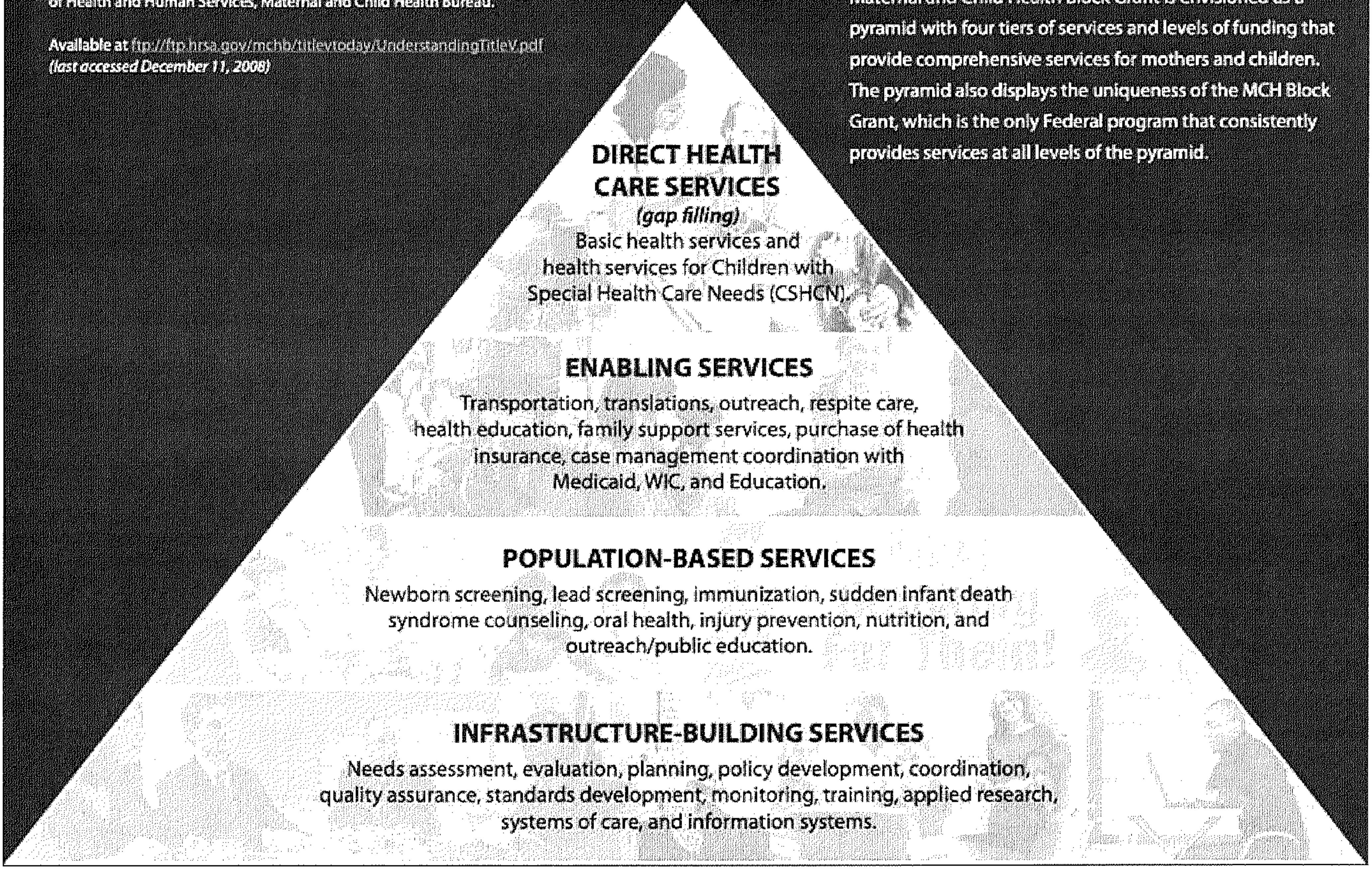
MCHB's Division of Services for Children with Special Health Needs works to make an impact on the nearly 20 percent of U.S. children under age 18 who have a special health care need. It seeks to give assistance to the one in five U.S. families who have a child with a special health care need, and to coordinate services from multiple systems to assist children and youth with special health care needs.

Maternal and Child Health Pyramid of Health Services

Reprinted from Understanding Title V of the Social Security Act, US Department of Health and Human Services, Maternal and Child Health Bureau.

Available at ftp://ftp.hrsa.gov/mchb/titlevtoday/UnderstandingTitleV.pdf
(last accessed December 11, 2008)

The conceptual framework for the services of the Title V Maternal and Child Health Block Grant is envisioned as a pyramid with four tiers of services and levels of funding that provide comprehensive services for mothers and children. The pyramid also displays the uniqueness of the MCH Block Grant, which is the only Federal program that consistently provides services at all levels of the pyramid.



DIRECT HEALTH CARE SERVICES
(gap filling)
Basic health services and health services for Children with Special Health Care Needs (CSHCN).

ENABLING SERVICES
Transportation, translations, outreach, respite care, health education, family support services, purchase of health insurance, case management coordination with Medicaid, WIC, and Education.

POPULATION-BASED SERVICES
Newborn screening, lead screening, immunization, sudden infant death syndrome counseling, oral health, injury prevention, nutrition, and outreach/public education.

INFRASTRUCTURE-BUILDING SERVICES
Needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, systems of care, and information systems.

TITLE V MATERNAL AND CHILD HEALTH SERVICES BLOCK GRANT TO STATES PROGRAM

A. Maternal and Child Health Services Block Grant (Title V)

Under Title V, MCHB administers a Block Grant and competitive Discretionary Grants. The purpose of the MCH Block Grant is to create federal/state partnerships in 59 states and jurisdictions for developing service systems that address MCH challenges, such as:

- Reducing infant mortality;
- Providing comprehensive care for all women before, during, and after pregnancy and childbirth;
- Providing preventive and primary care services for infants, children, and adolescents;
- Providing comprehensive care for children and adolescents with special health care needs;
- Increasing immunization for all children;
- Assuring access to care for all mothers and children; and
- Providing and promoting family-centered, community-based, coordinated care (including care coordination services for children with special health care needs) and facilitating the development of community-based systems of services for such children and their families.

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https://mchb.tvisdata.hrsa.gov/Admin/FileUpload/DownloadContent?fileName=BlockGrantGuidanceAppendix.pdf&isForDownload=False

System of Care Goals
Maternal and Child Health Bureau

Individuals & Families

Community-based Services
Ensure community services are organized for easy use by families.

Early Continuous Screening
Ensure children are screened early and continuously for special health care needs.

Access to Medical Home
The number of children with special health care needs who have a medical home that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.

Transition to Adulthood
The percent of adolescents with special health care needs who have received the services necessary to transition to all aspects of adult life, including adult health care, work, and independence.

Adequate Insurance
The number of children who are adequately insured.

Families as Partners
Ensure families are partners in decision making.

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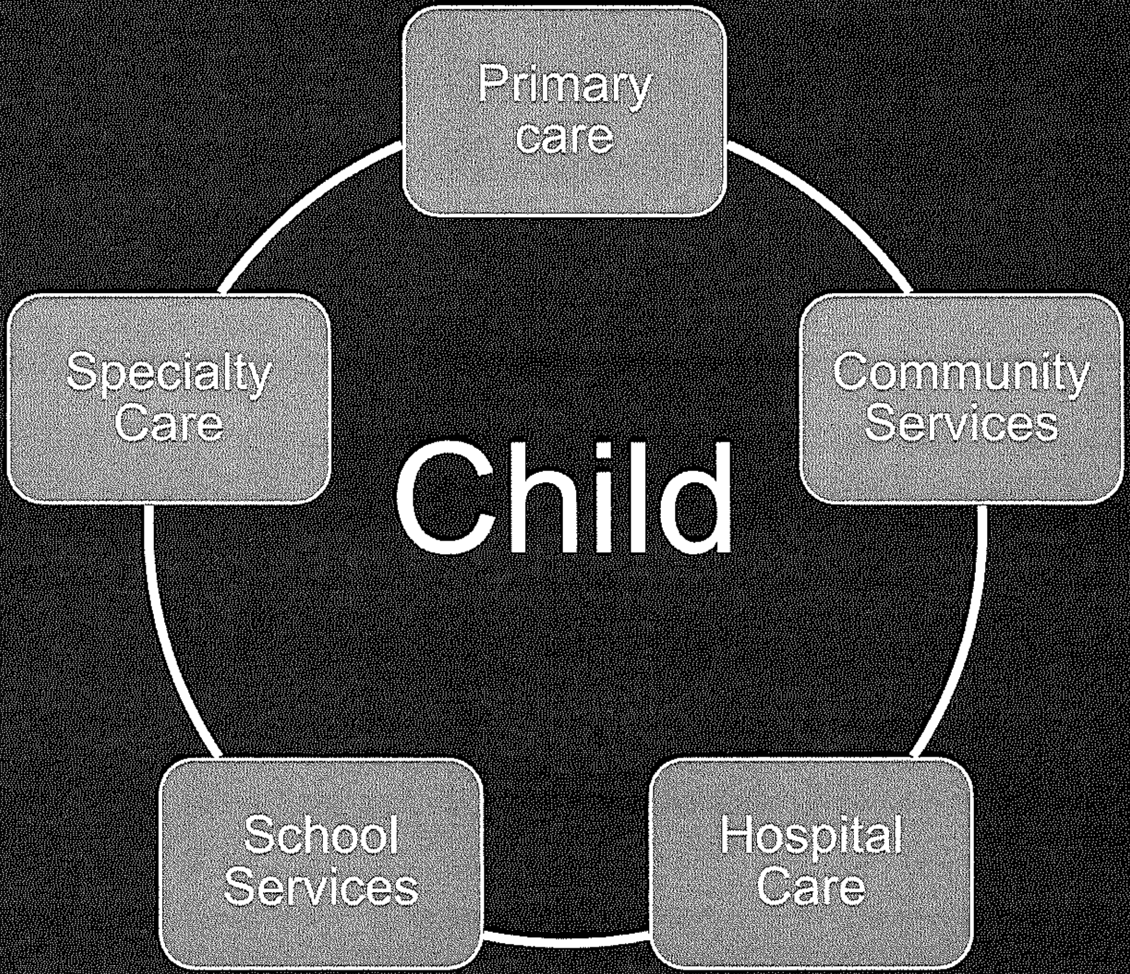
Source: https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs

System of health services for CYSHCN



Primary care

Community Services

Hospital Care

School Services

Specialty Care

Child

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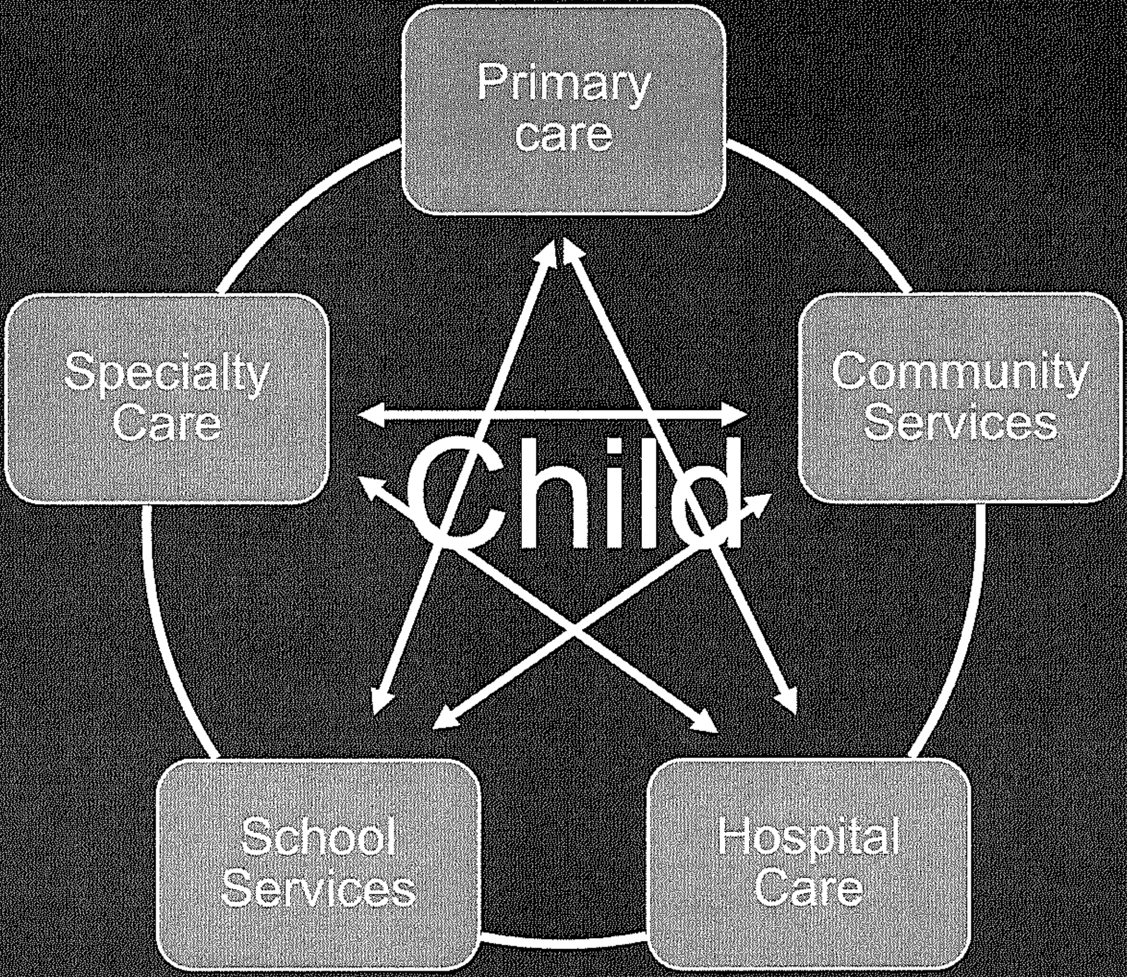
System of health services for CYSHCN



Primary care

Specialty Care

Community Services

Child

School Services

Hospital Care

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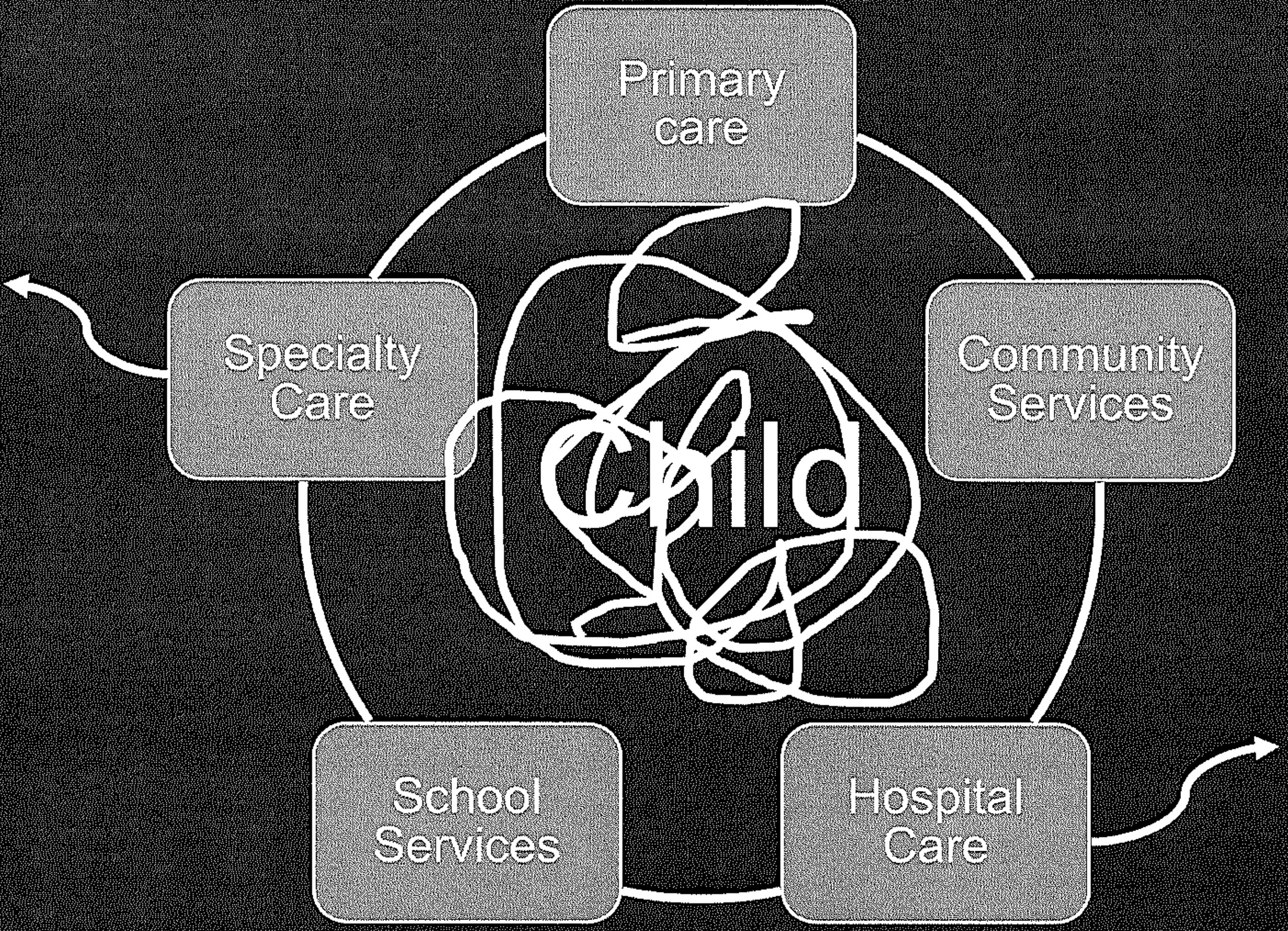
System of health services for CYSHCN



Primary care

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Child

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System of Care Goals
Maternal and Child Health Bureau

Individuals & Families

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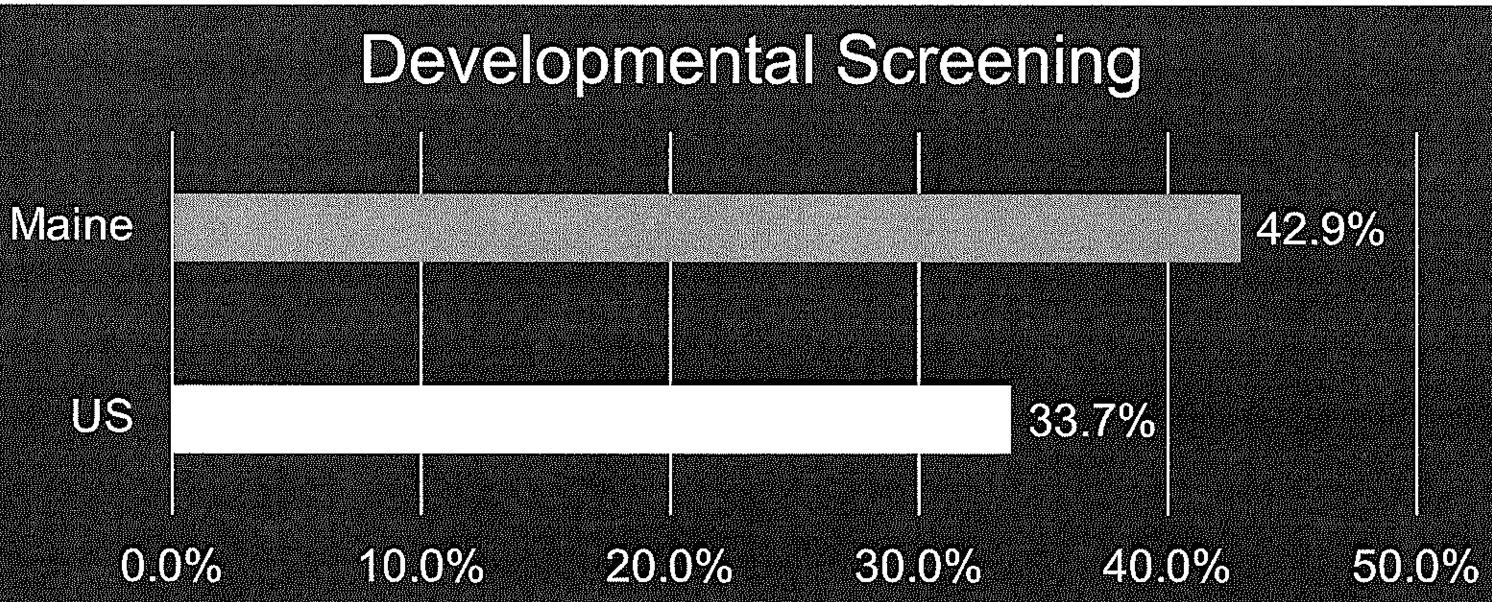
Source: https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs

MCHB Core Indicators (2021-22)

- Children and youth are screened early and continuously
- CYSHCN receive a medical home model of care that is patient-centered, coordinated, comprehensive, and ongoing
- Community-based services are organized so families can use them easily
- CYSHCN receive services necessary to make transitions to adult life, including healthcare
- Families have adequate insurance and funding to pay for services they need
- Families of CYSHCN are partners in decision-making at all levels of care, from direct care to the organizations that serve them.

https://www.childhealthdata.org/browse/survey/results?q=10759&r=1



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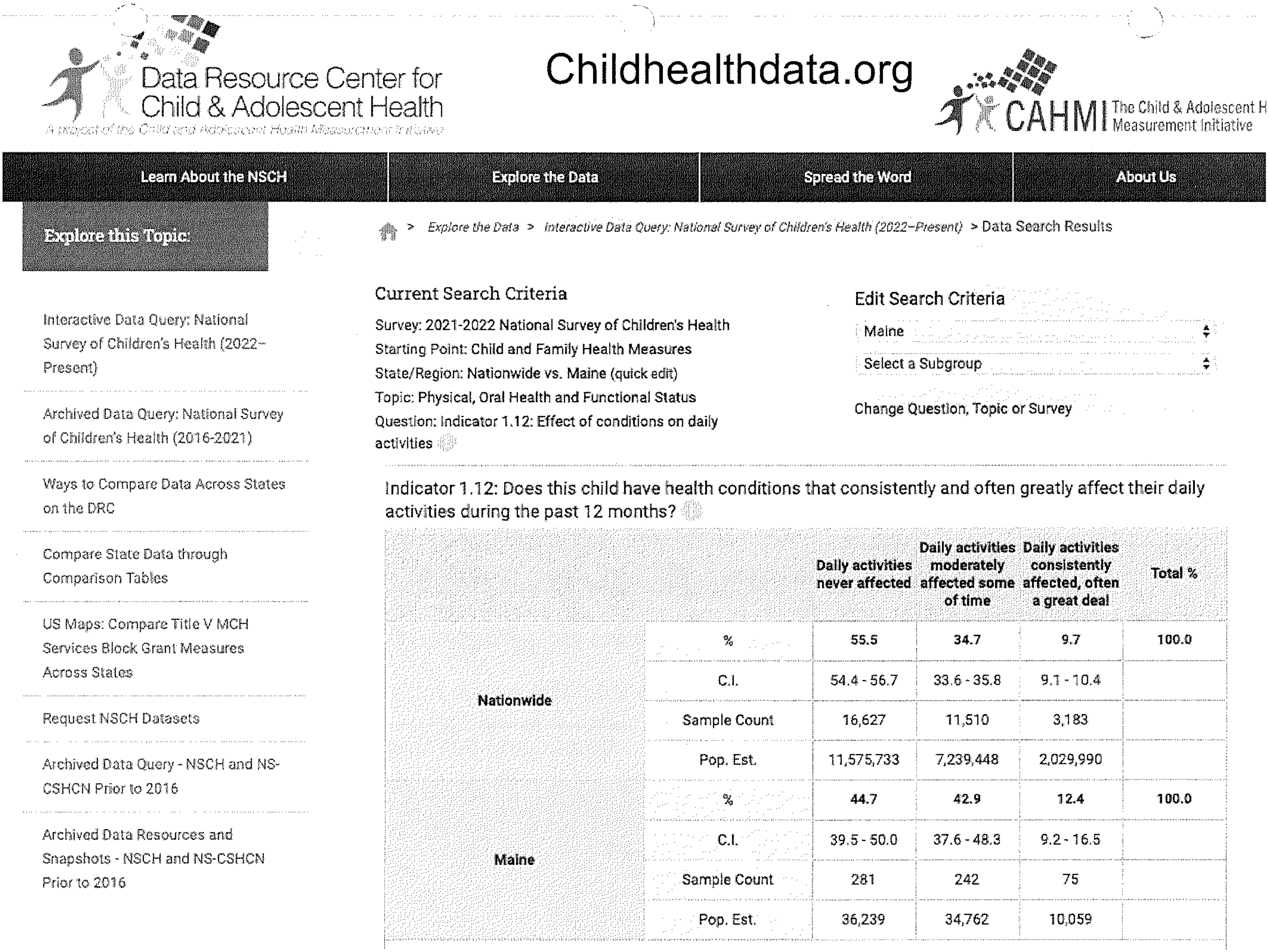

Current Search Criteria

Survey: 2021-2022 National Survey of Children's Health
Starting Point: Child and Family Health Measures
State/Region: Nationwide vs. Maine (quick edit)
Topic: Physical, Oral Health and Functional Status
Question: Indicator 1.12: Effect of conditions on daily activities

Indicator 1.12: Does this child have health conditions that consistently and often greatly affect their daily activities during the past 12 months?

		Daily activities never affected	**Daily activities moderately affected some of time**	**Daily activities consistently affected, often a great deal**	**Total %**
Nationwide	%	**55.5**	**34.7**	**9.7**	**100.0**
	C.I.	54.4 - 56.7	33.6 - 35.8	9.1 - 10.4	
	Sample Count	16,627	11,510	3,183	
	Pop. Est.	11,575,733	7,239,448	2,029,990	
Maine	%	**44.7**	**42.9**	**12.4**	**100.0**
	C.I.	39.5 - 50.0	37.6 - 48.3	9.2 - 16.5	
	Sample Count	281	242	75	
	Pop. Est.	36,239	34,762	10,059	

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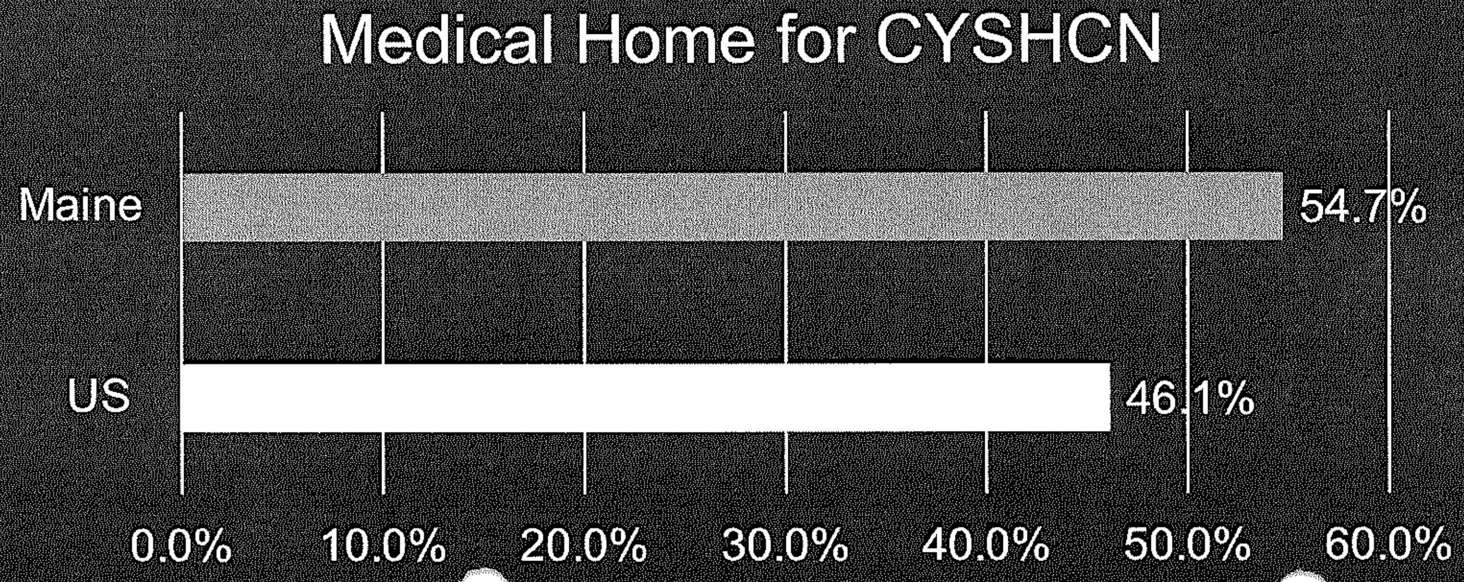
https://www.childhealthdata.org/browse/survey/results?q=10776&r=1



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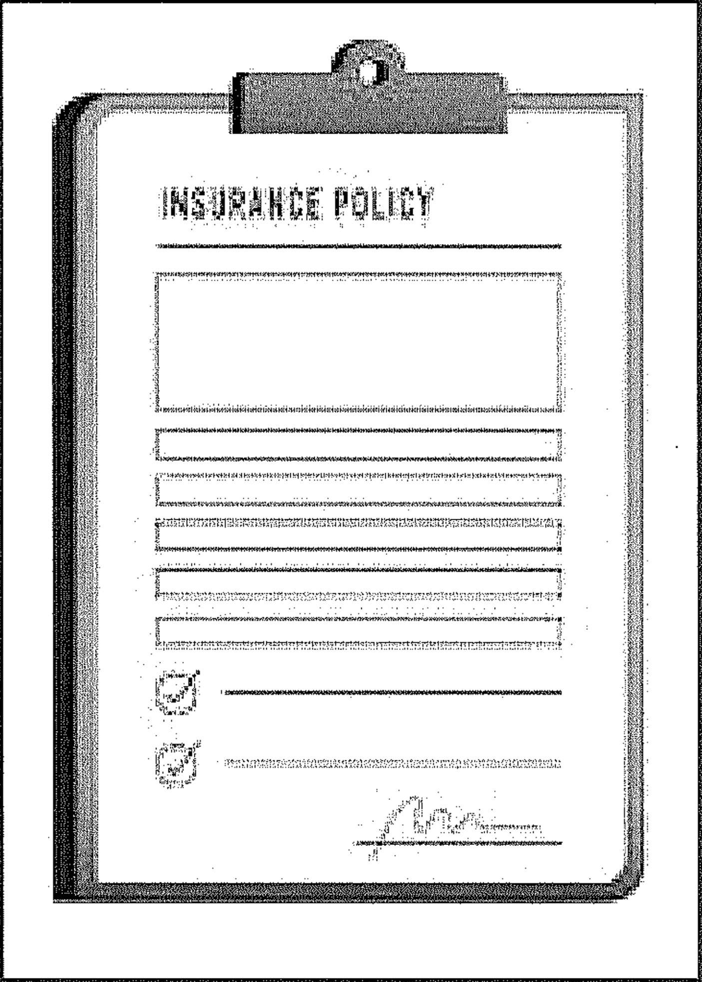
Adequate and continuous insurance

- Continuous: for the prior 12 months
- Adequate:
  - Usually or always met the child's needs
  - Usually or always allowed the child to see needed providers
  - No out-of-pocket expenses or the expenses were usually or always reasonable



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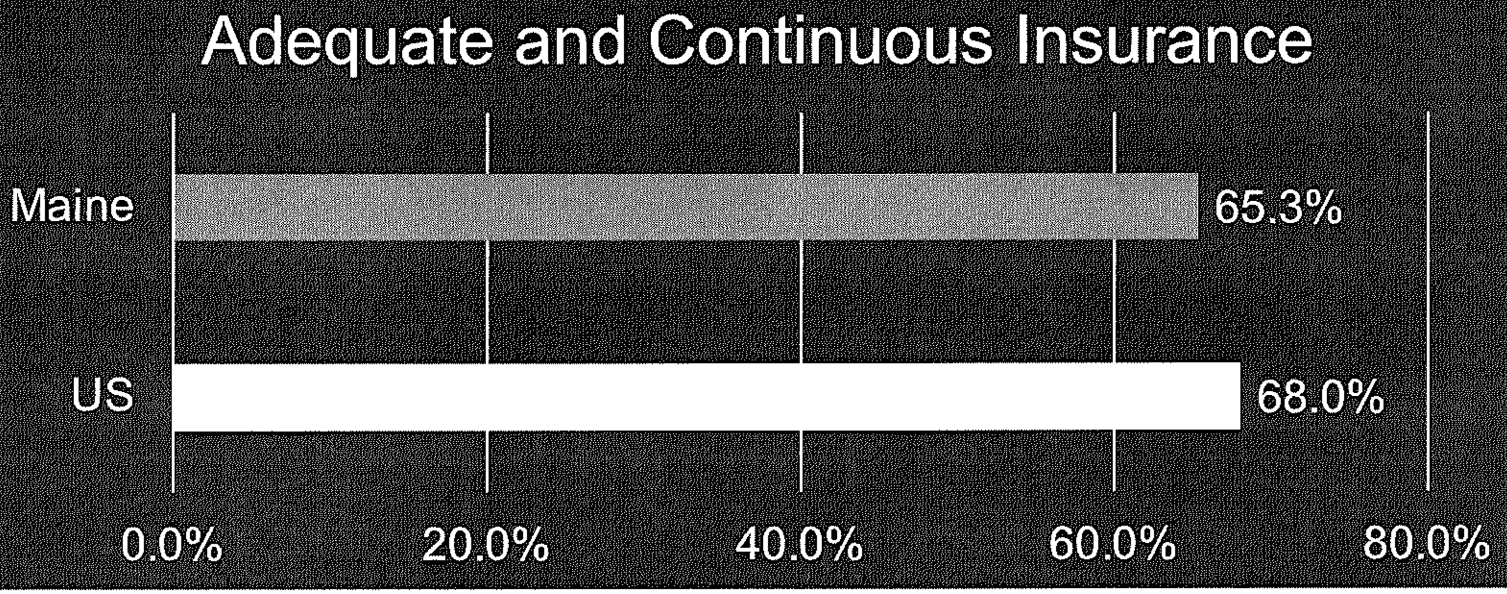

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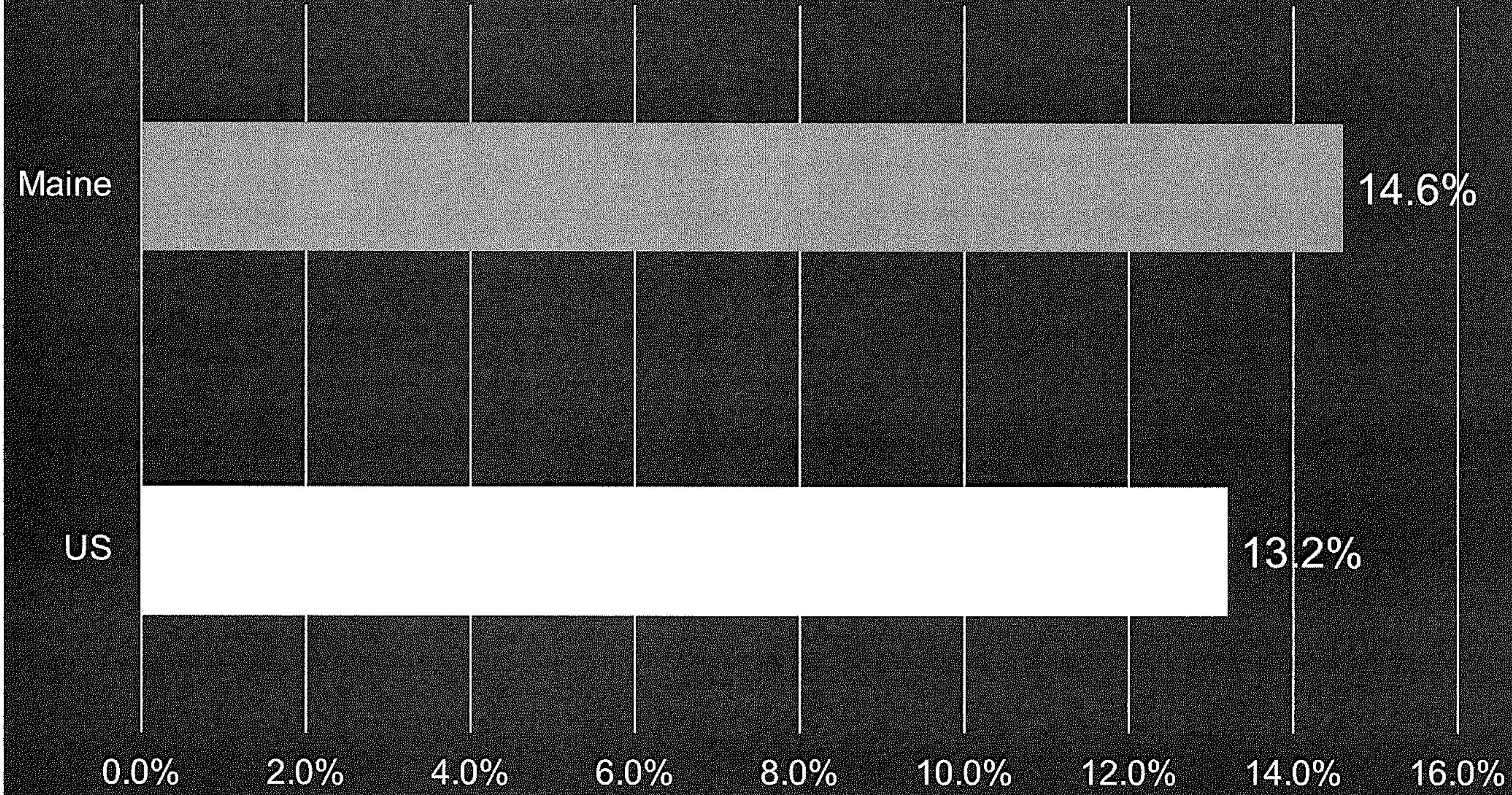
System of Care



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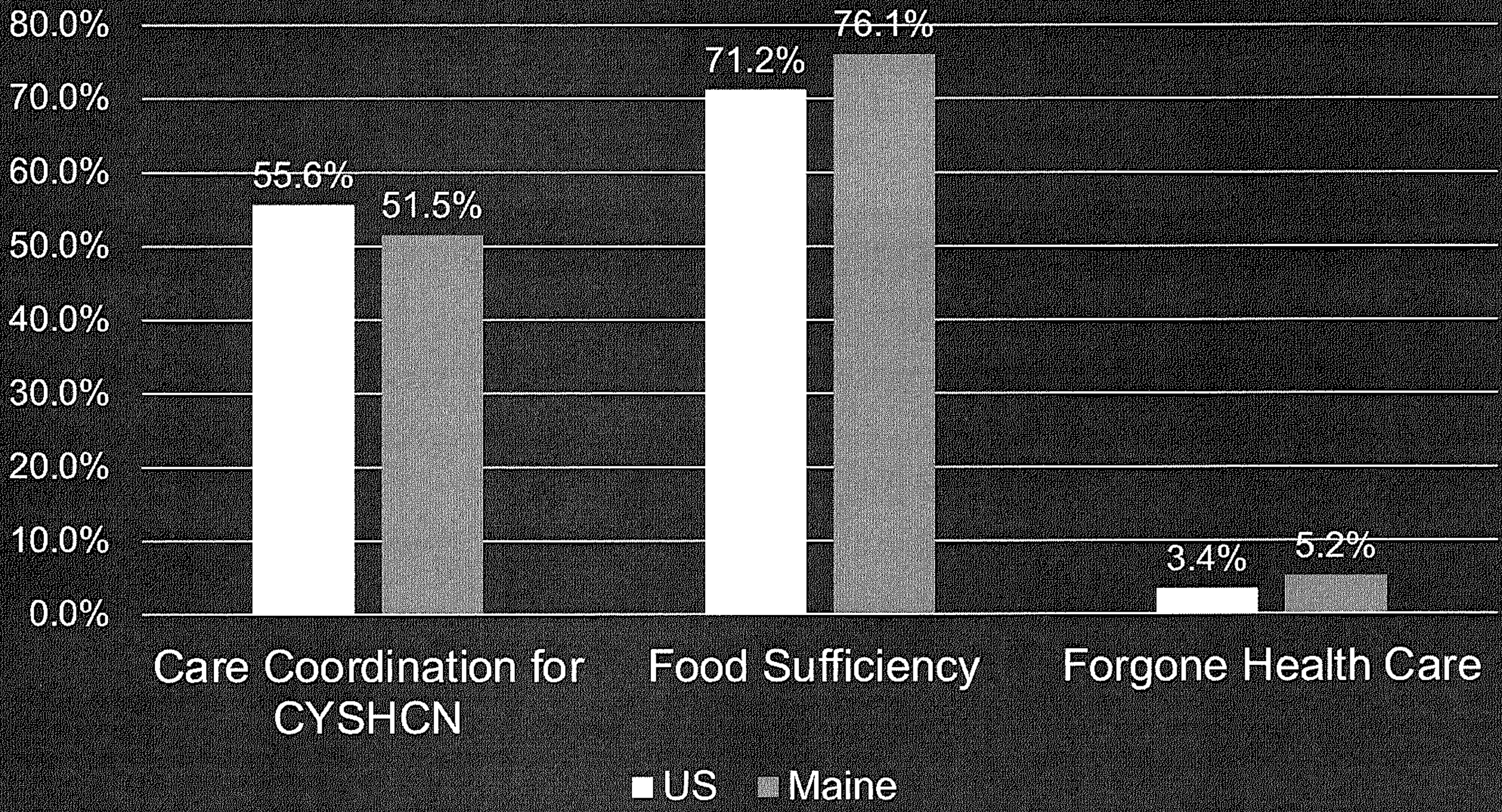
Maine v US (2022-3)



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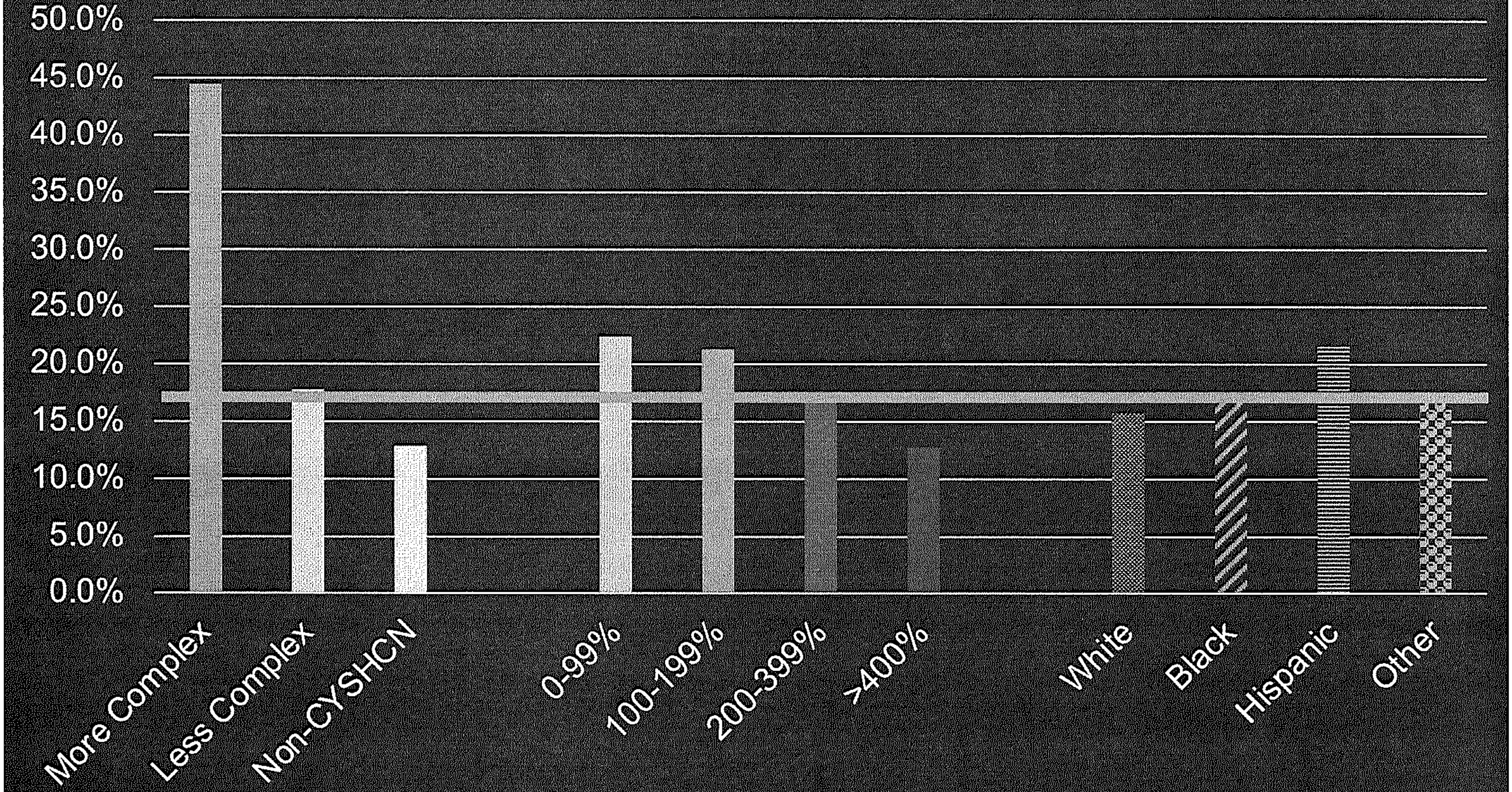
Frustration getting care (NSCH 2019-2020)



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HRSA
Maternal & Child Health

National Maternal Mental Health Hotline Sitemap

Home Funding Programs & Impact Data & Research Capacity Building Resources About Us

Home » Programs & Impact » Focus Areas » Children and Youth with Special Health Care Needs (CYSHCN) » Blueprint for Change

Blueprint for Change

A national framework for a system of services for children and youth with special health care needs (CYSHCN) where they enjoy a full life and thrive in their community from childhood through adulthood

Families of CYSHCN tell us that the current system of services is not working for their children. According to the National Survey

ARTICLES

https://publications.aap.org/pediatrics/issue/149/Supplement%207

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JUNE 2022 • VOLUME 149 • SUPPLEMENT 7
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A SUPPLEMENT TO PEDIATRICS

Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs

Treeby W. Brown, MA, Sarah E. McLellan, MPH, Marie Y. Mann, MD, MPH, FAAP, and Joan A. Scott, MS, CGC, Guest Editors

Funding for the publication of this article, including editorial support (review for formatting and consistency) for this article was funded by the US Department of Health and Human Services, Health Resources and Services Administration under contract number 75R60219D00014.

The views expressed in this publication are solely the opinions of the authors and do not necessarily reflect the official policies of the US Department of Health and Human Services or the Health Resources and Services Administration, nor does mention of the department or agency names imply endorsement by the US Government.

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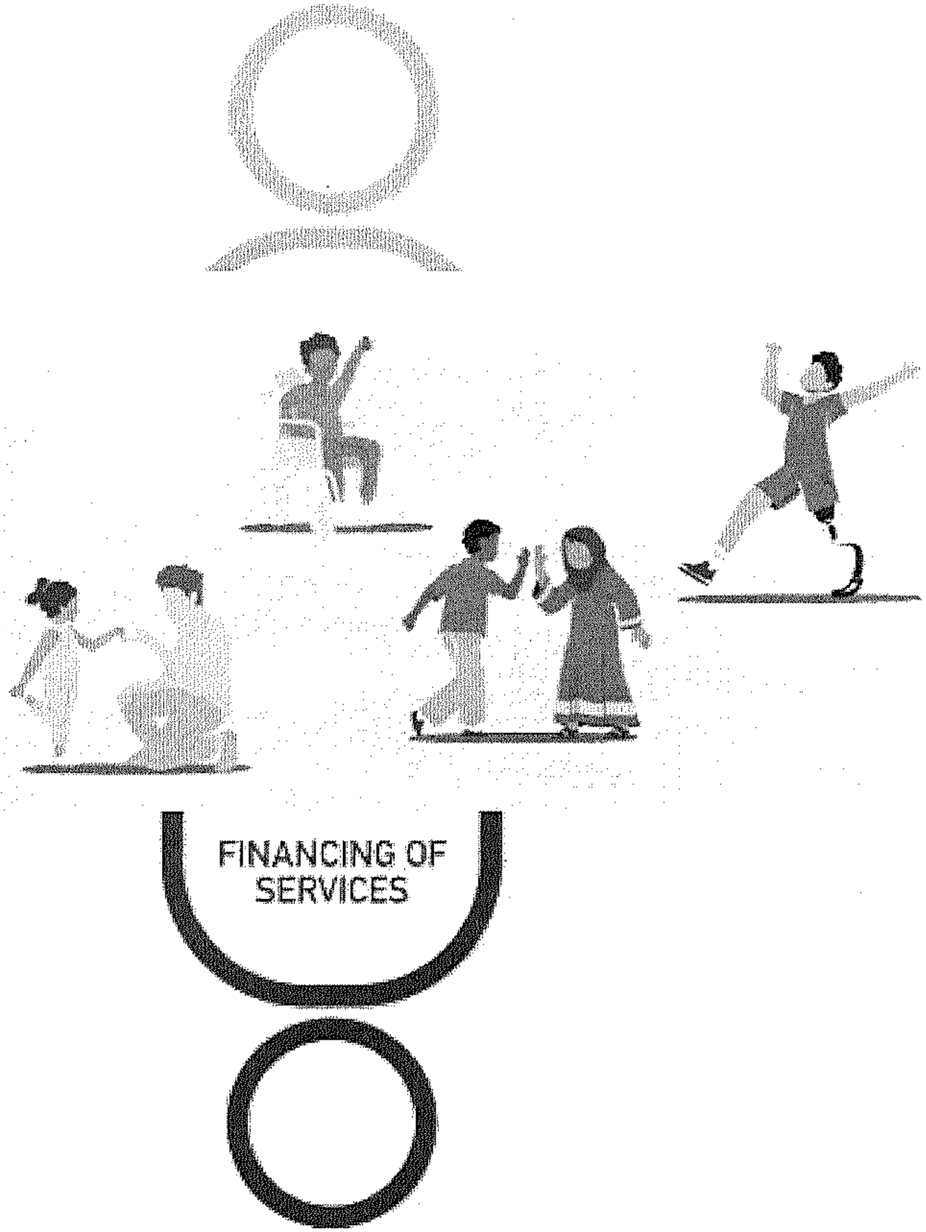
Critical Areas for a Well-Functioning System

Our goal

We want every family to get what their child needs so that they can play, go to school, and grow up to become a healthy adult. We want parents and siblings to thrive too.



adulthood

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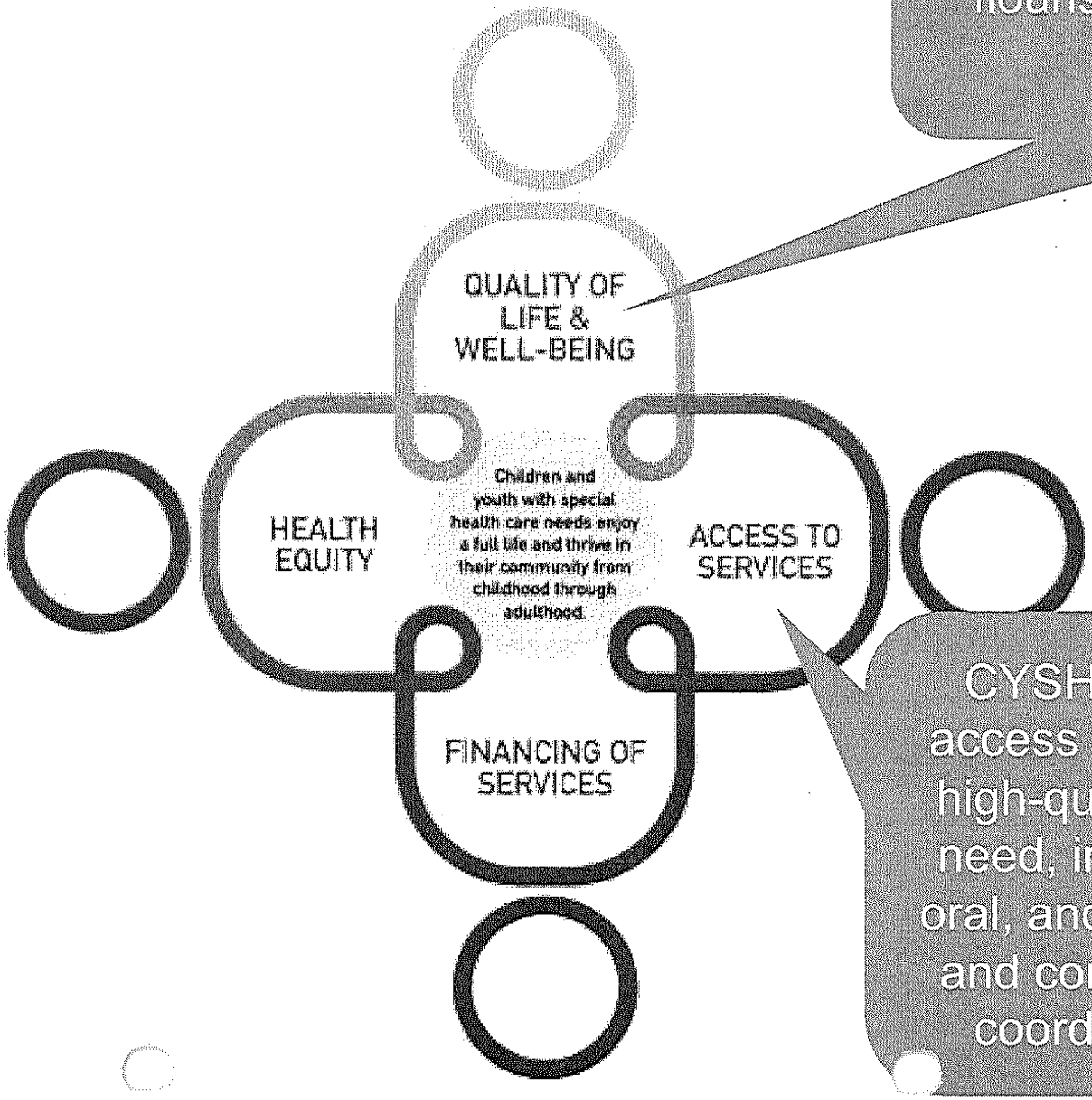
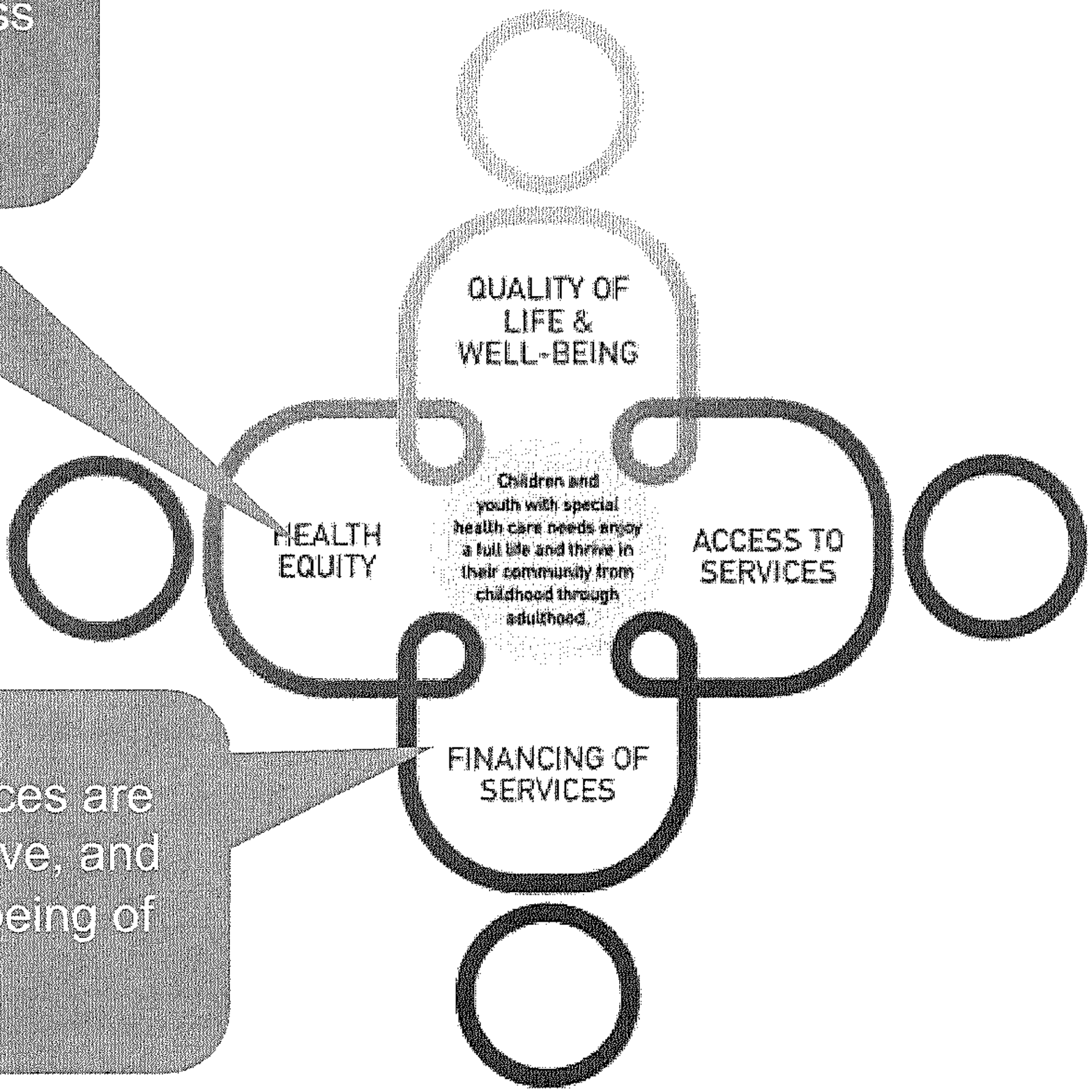


The service system prioritizes quality of life, well-being, and supports flourishing for CYSHCN and their families.

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

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.

National Center for a System of Services for Children and Youth with Special Health Care Needs

Home / Patient Care / National Center for a System of Services for Children and Youth with Special Health Care Needs

Feedback Form

1 in 5 children in the United States have a special health care need. This National Center for a System of Services for Children and Youth with Special Health Care Needs (CYSHCN) is here to support these children, their families/caregivers and the professionals who care for them.

Learn More About the National Center and the Blueprint for Change

What We Do

The goal of the National Center for a System of Services for Children and Youth with Special Health Care Needs (CYSHCN) is to advance and strengthen the system of services for CYSHCN, their families and caregivers at the community, state and national levels.

The work of the National Center is grounded in the **Blueprint For Change: A National Framework for a System of Services for CYSHCN**. The Blueprint for Change presents a vision for how to improve the system of services for CYSHCN through improved equity, access, quality of life and family well-being and financing.

To accomplish this goal, the National Center will:

- Convene families/caregivers, youth, public health professionals, clinicians and others to guide all project activities.
- Develop and disseminate a Roadmap to support implementation of the Blueprint for Change.
- Convene state teams co-led by Title V and families/caregivers to test Blueprint implementation strategies.
- Provide technical assistance, training, and support on Blueprint Implementation.
- Evaluate all project activities.

National Center for a System of Services for CYSHCN

Goal: Advance systems of services for CYSHCN through Blueprint implementation.

What We Do

- One-on-one technical assistance
- Tools
- Training
- Strategies
- Connections to peers and experts

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https://downloads.aap.org/AAP/PDF/Medical_home_FINAL_PPT_Slides_2023 _Dec.pdf

Blueprint for Change Strategies: At-a-Glance Overview

Home / Patient Care / National Center for a System of Services for Children and Youth with Special Health Care Needs / Blueprint for Change Strategies: At-a-Glance Overview

These are the 40 strategies outlined in the Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs (CYSHCN). The strategies are categorized by the 4 critical areas of focus: health equity, family & child well-being and quality of life, access to services, and financing of services.

Overall Vision: Children and youth with special health care needs enjoy a full life, from childhood through adulthood, and thrive in a system that supports their social, health, and emotional needs, ensuring dignity, autonomy, independence and active participation in their communities.

Aligning Your Work With the Blueprint for Change for CYSHCN

Home / Patient Care / National Center for a System of Services for Children and Youth with Special Health Care Needs / Aligning Your Work With the Blueprint for Change for CYSHCN

The National Center for a Systems of Services for Children and Youth with Special Health Care Needs (CYSHCN) developed a worksheet and an accompanying crosswalk to support Title V programs in aligning their work and priorities with the **Blueprint for Change: Guiding Principles for a System of Services for Children and Youth with Special Health Care Needs (CYSHCN) and Their Families**.

The worksheet presents a starting point for states to identify their current work that aligns with the Blueprint and begin to consider how they can build on it to improve the system of services for CYSHCN. This tool may support Title V programs in completing their Title V needs assessment and informing future Block Grant application information related to Blueprint activities. When thinking about future activities and priorities, consider how

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National Center for a System of Services for Children and Youth with special health care needs

About the National Center Join Our Listserv

Population Health and Medical Home: Strategies to Support Title V Programs

Home / Patient Care / National Center for a System of Services for Children and Youth with Special Health Care Needs / Population Health and Medical Home: Strategies to Support Title V Programs

Looking to learn more about the medical home national performance measure? This short 15 minute presentation and accompanying slide deck provides an overview of how Title V programs measure access to medical home and presents examples of medical home population health approaches.

The National Center for a System of Services for CYSHCN is available to support your Title V programs with additional medical home technical assistance, including understanding your state/jurisdiction medical home data and identifying population health medical home approaches.

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https://www.aap.org/en/patient-care/national-center-for-a-system-of-services-for-children-and-youth-with-special-health-care-needs/population-health-and-medical-home-strategies-to-support-title-v-programs

Committed to improving the health and well-being of all people across every state.

REPORT / 10-16-20

National Care Coordination Standards for Children and Youth with Special Health Care Needs

The National Care Coordination Standards for Children and Youth with Special Health Care ds (CYSHCN) outline the core, system-level components of high-quality care coordination YSHCN. These standards are designed to help state officials and other stakeholders

RELATED CONTENT

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https://nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs

Foundational Standards for Care Coordination

The National Care Coordination Standards for CYSHCN are guided by the following foundational standards. These seven standards are the foundation for all standards in each domain, and are critical to ensure comprehensive, high-quality care coordination for CYSHCN.

1. Care coordination for CYSHCN is based on the premise of health equity, that all children and families should have an equal opportunity to attain their full health potential, and no barriers should exist to prevent children and their families from achieving this potential.
2. Care coordination addresses the full range of social, behavioral, environmental, and health care needs of CYSHCN.
3. Families are co-creators of care coordination processes and are active, core partners in decision making as members of the care team. CYSHCN, families, and care coordinators work together to build trusting relationships.
4. Care coordination is evidence based where possible, and evidence informed and/or based on promising practices where evidence-based approaches do not exist.

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5. Care coordination is implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner to best serve CYSHCN and their families.

6. Insurance coverage of care coordination for CYSHCN allows for it to be accessible, affordable, and comprehensive.

7. Performance of care coordination activities is assessed with outcome measures that evaluate areas including:
    a. process of care coordination (e.g., number of families with a shared plan of care);
    b. Family experience with integration of care across medical, behavioral, social and other sectors and systems;
    c. Quality of life for CYSHCN and families; and
    d. Reduction in duplicative and/or preventable health care utilization.

BLOG / 04-1

Black
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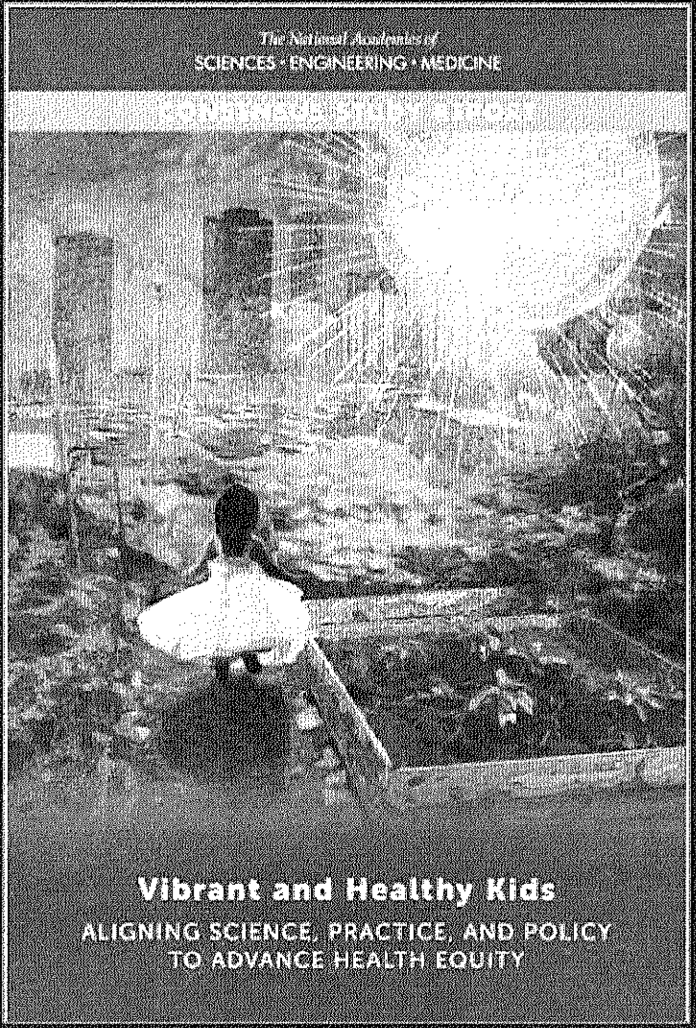
Leveraging the Health Care System



The National Academies of
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CONSENSUS STUDY REPORT

Vibrant and Healthy Kids

ALIGNING SCIENCE, PRACTICE, AND POLICY
TO ADVANCE HEALTH EQUITY

- Integration of behavioral health services with medical services
- Placing health care in communities of need
- Addressing adversity
- Workforce diversity and education
- Use new technologies to improve access

https://nap.nationalacademies.org/catalog/25466/vibrant-and-healthy-kids-aligning-science-practice-and-policy-to

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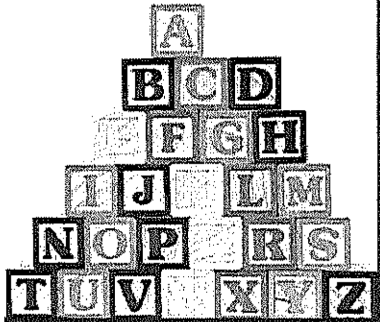
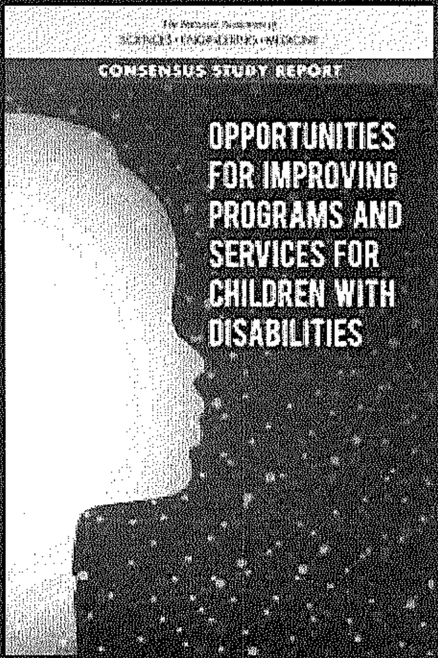


Effective Programs for Children with Disabilities



CONSENSUS STUDY REPORT

OPPORTUNITIES FOR IMPROVING PROGRAMS AND SERVICES FOR CHILDREN WITH DISABILITIES

- **A**ccessible
- **B**ased on individual needs and goals
- **C**oordinated
- **D**evelopmentally appropriate
- **E**vidence based
- **F**ocused on the children in the context of their family
- **G**oal directed –short-term and long-term goals are aligned
- **H**as scalability

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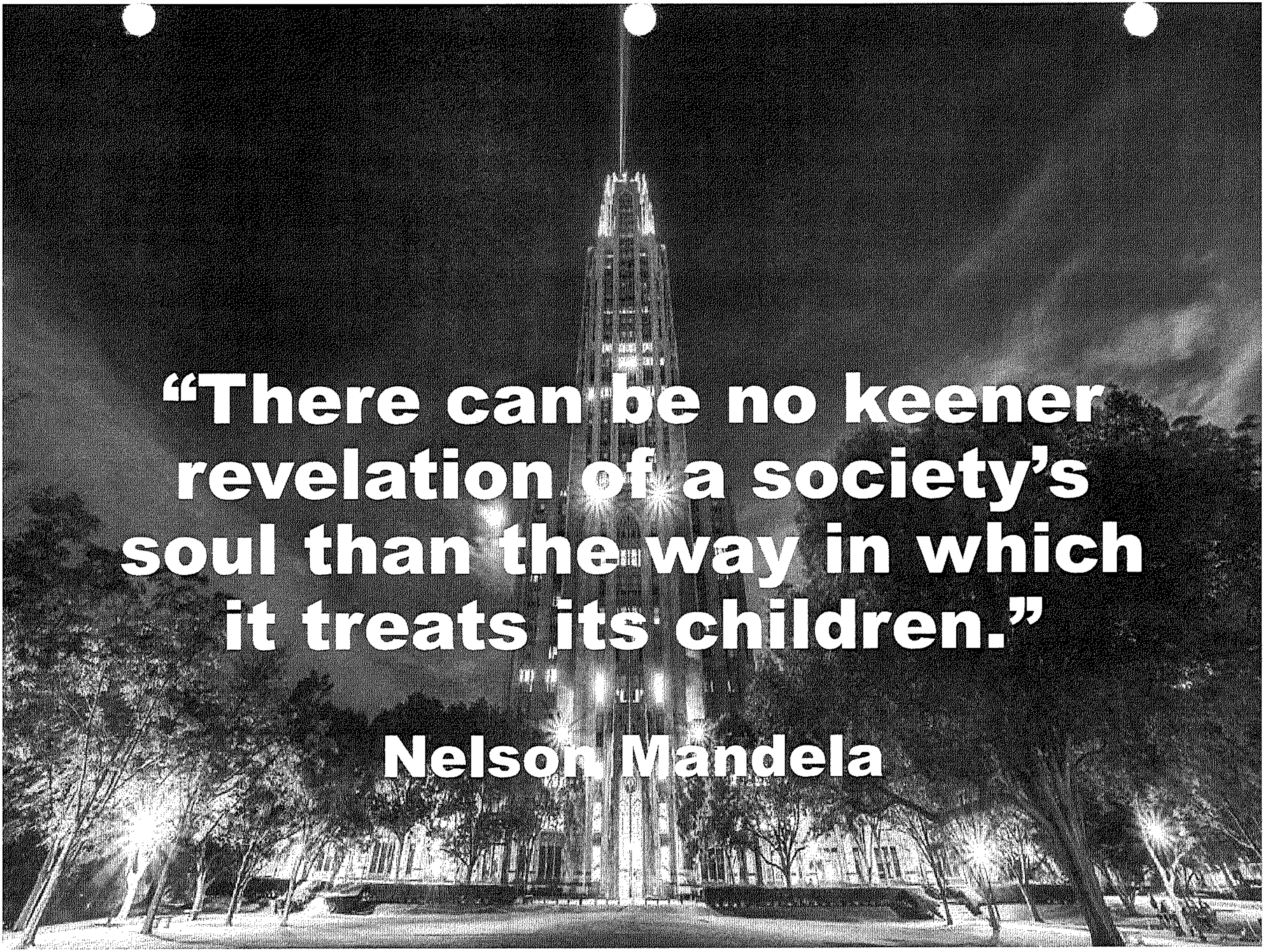
https://nap.nationalacademies.org/catalog/25028/opportunities-for-improving-programs-and-services-for-children-with-disabilities



“There can be no keener revelation of a society’s soul than the way in which it treats its children.”

Nelson Mandela

Leadership With Purpose

Partnering with Families

An imperative for CYSHCN

Eileen Forlenza

Activating Causal Leadership™

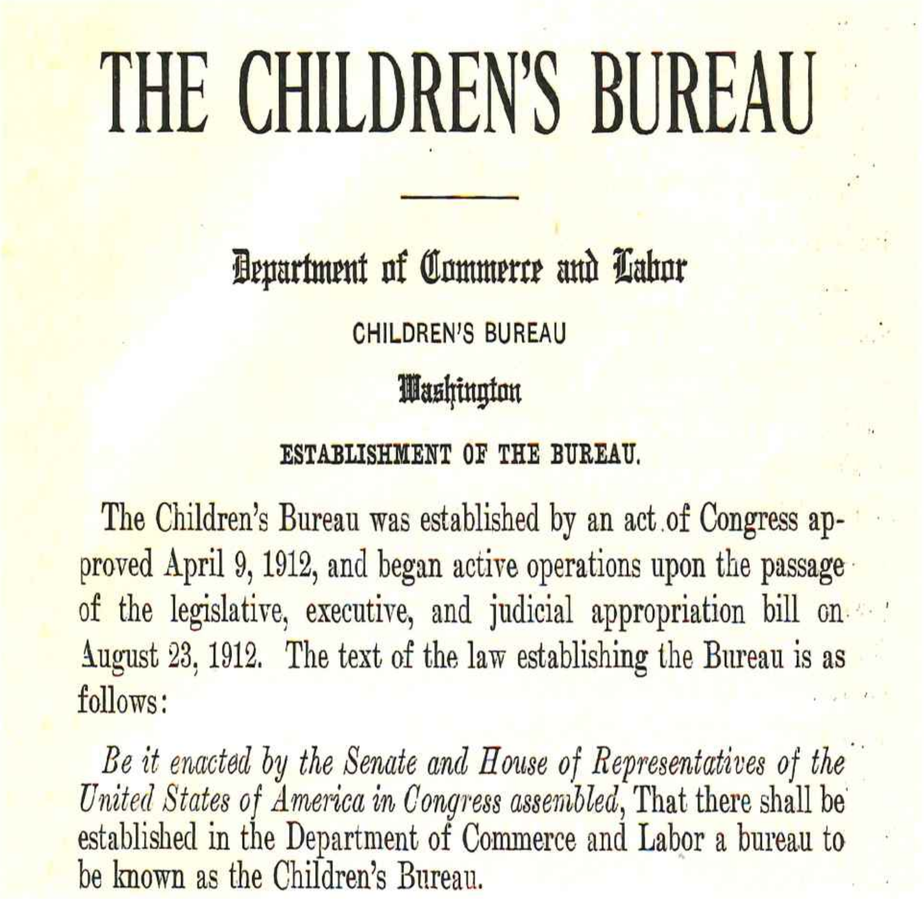
720-404-7444
EileenForlenza@comcast.net
www.EileenForlenza.com

From Challenges to Changes

1874: Mary Ellen Wilson, Society for the Prevention of Cruelty to Children. The first reported case of child abuse, leading to national and federal efforts to protect children and monitor their wellbeing.

Federal Oversight

The Children's Bureau became the first national government office in the world that focused solely on the well-being of children and their mothers.



THE CHILDREN'S BUREAU

Department of Commerce and Labor

CHILDREN'S BUREAU

Washington

ESTABLISHMENT OF THE BUREAU.

The Children's Bureau was established by an act of Congress approved April 9, 1912, and began active operations upon the passage of the legislative, executive, and judicial appropriation bill on August 23, 1912. The text of the law establishing the Bureau is as follows:

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That there shall be established in the Department of Commerce and Labor a bureau to be known as the Children's Bureau.

"Clearly, if economic waste is reprehensible, waste of child life, whether viewed economically or in terms of common and universal betterment, is more deplorable than war."

Herbert Hoover
1929

Title V of the Social Security Act of 1935, established grants to states requiring state leaders to monitor health and wellbeing of women and children, including "crippled" children.

Title V is the longest-standing public health legislation in American history, and it continues to work to improve the health of women and children.

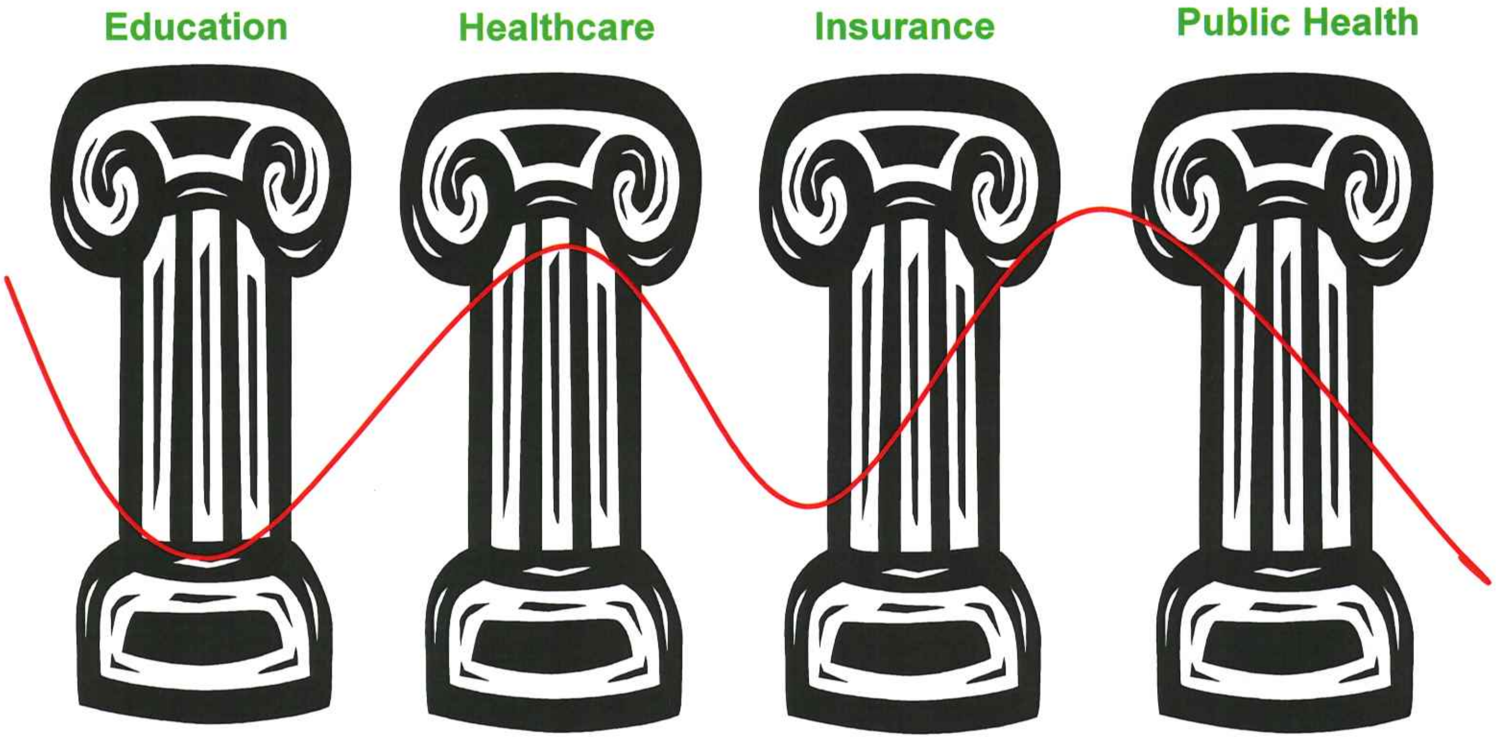
Children and Youth with Special Health Care Needs - CYSHCN

States are required to spend **30%** of their Title V funds from the Maternal and Child Health Services block grant on CYSHCN and to take specific steps toward **improving the service system** for these children and their families.

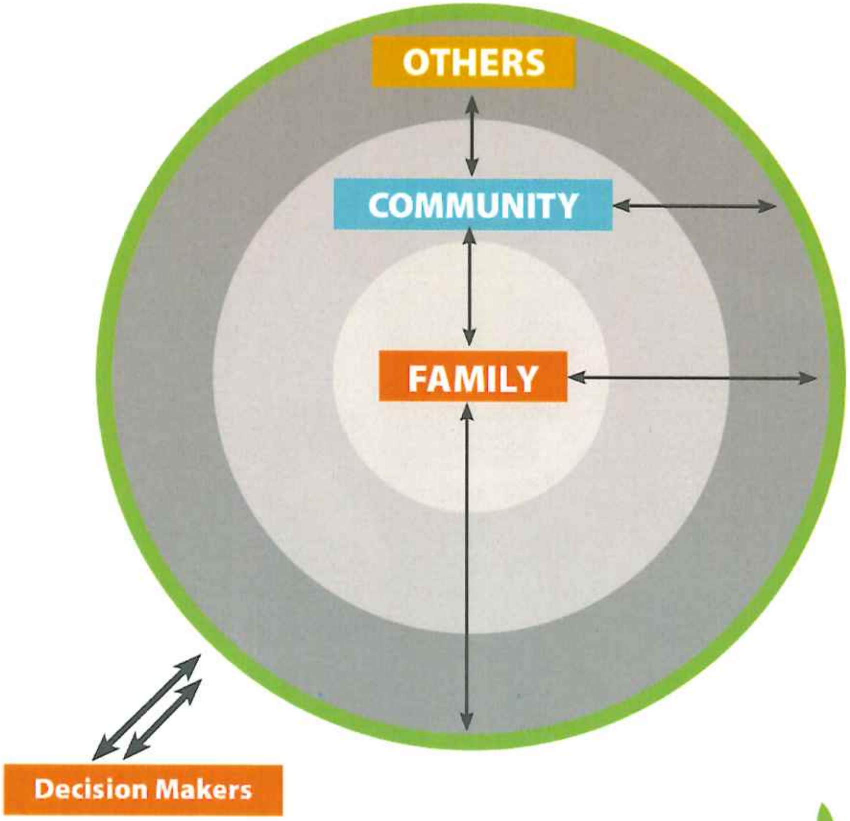
This is *the* national health policy for children and youth with special health care needs.

The Title V program is the only federally mandated program that establishes the grantee as the **guardian for CYSHCN**.

Families are a horizontal thread across vertical systems.



Progression of Family Leadership



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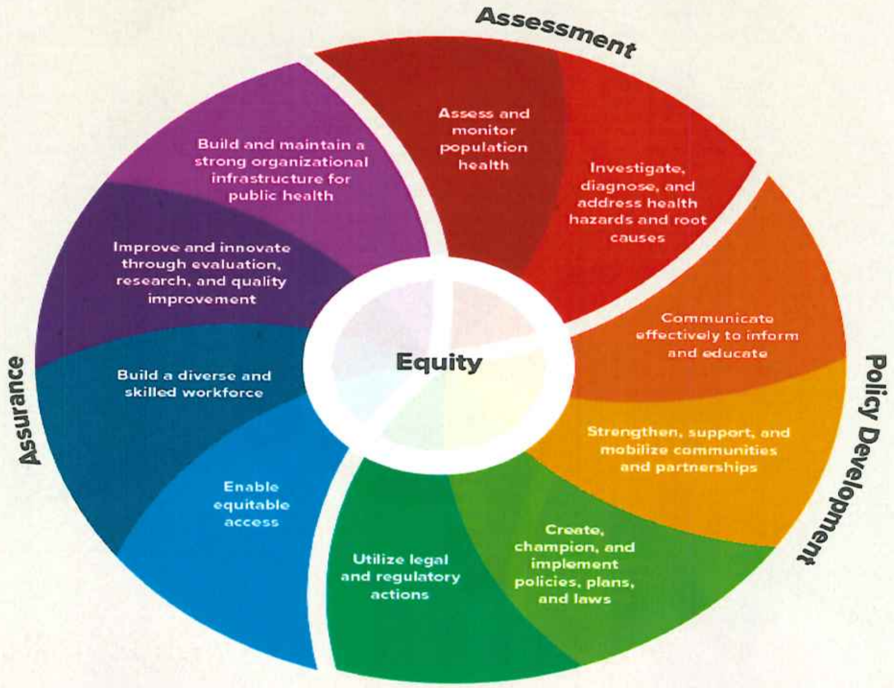
THE 10 ESSENTIAL PUBLIC HEALTH SERVICES



Assessment

Assess and monitor population health

Investigate, diagnose, and address health hazards and root causes

Policy Development

Communicate effectively to inform and educate

Strengthen, support, and mobilize communities and partnerships

Create, champion, and implement policies, plans, and laws

Utilize legal and regulatory actions

Assurance

Enable equitable access

Build a diverse and skilled workforce

Improve and innovate through evaluation, research, and quality improvement

Build and maintain a strong organizational infrastructure for public health

Equity

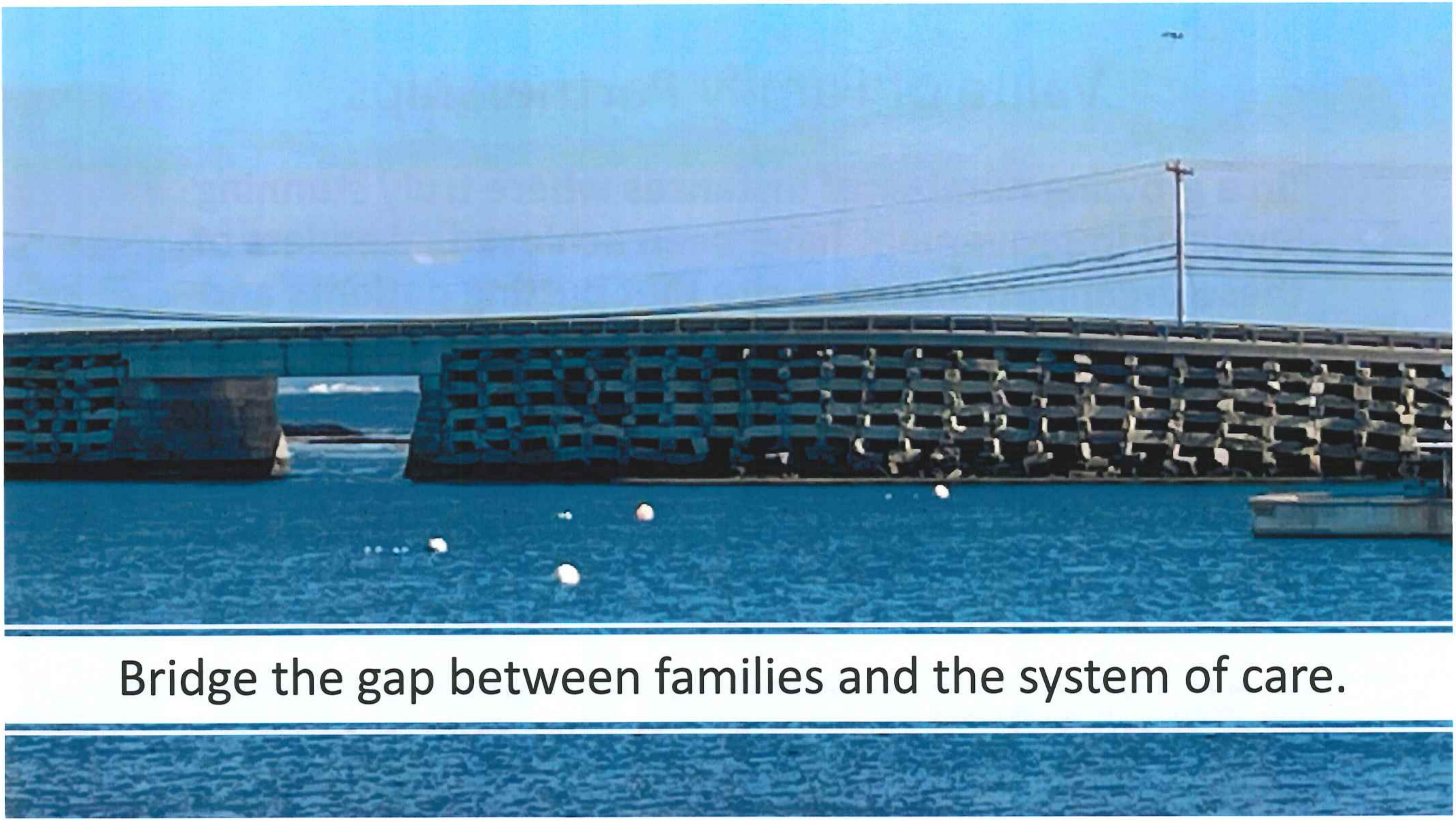
Capturing the Ripple Effect: Theory of Change

Henderson & Gill Kressley, 2016

Value of Family Partnerships

"In a growing number of instances where truly stunning levels of improvement have been achieved....Leaders of these organizations often cite that putting patients and families in a position of real power and influence, using their wisdom and experience to redesign and improve care systems – as being the single most powerful transformational change in history."

Reinertsen, J.L., Bisagnano, M & Pugh, M. Seven Leadership Leverage Points for Organizational Level Improvement in Health Care. 2nd Edition, IHI InnovationSeries, 2008.



Bridge the gap between families and the system of care.

Thank You!

EileenForlenza@comcast.net

720-404-7444

Department of Health and Human Services

Maine’s Children and Youth with Special Health Care Needs

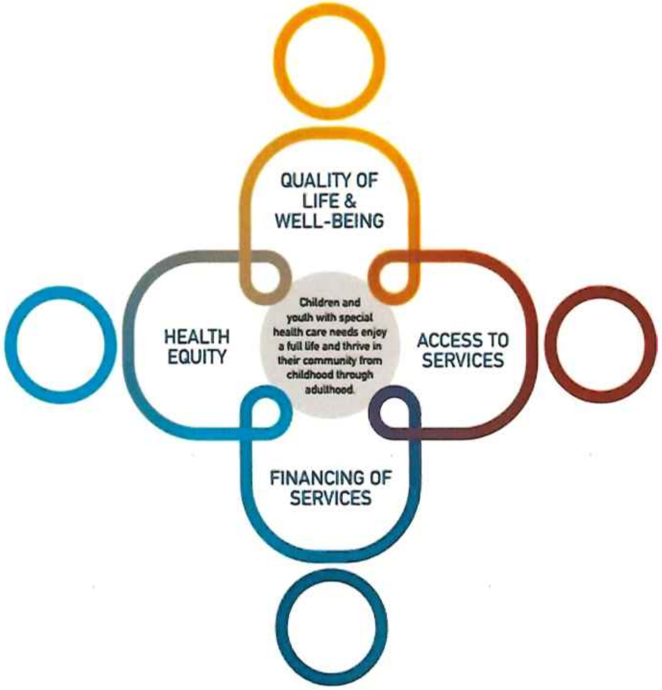
Blue Ribbon Commission
June 12, 2024

Stacey LaFlamme, Maternal & Child Health Program Manager

Children and Youth With Special Health Care Needs

- Maine's Children and Youth with Special Health Care Needs program sits at the Center for Disease Control, Division of Disease Prevention and is part of the Title V Maternal and Child Health Services Block Grant.

- Maine's Children and Youth with Special Health Care Needs services aims to provide and promote family-centered, coordinated care, and facilitate the development of community-based systems for children and families.



Blueprint for Change

[Standards for Systems of Care for Children and Youth with Special Health Care Needs]

VISION

We envision a State where all Children and Youth with Special Health Care Needs will:

Enjoy	Enjoy a full life, from childhood through adulthood.
Experience	Experience systems that support their social, emotional, physical health and wellbeing.
Have	Have dignity, autonomy, independence, and active participation in their communities.
Engage in	Engage in a system that supports families as partners in care and shared decision making.

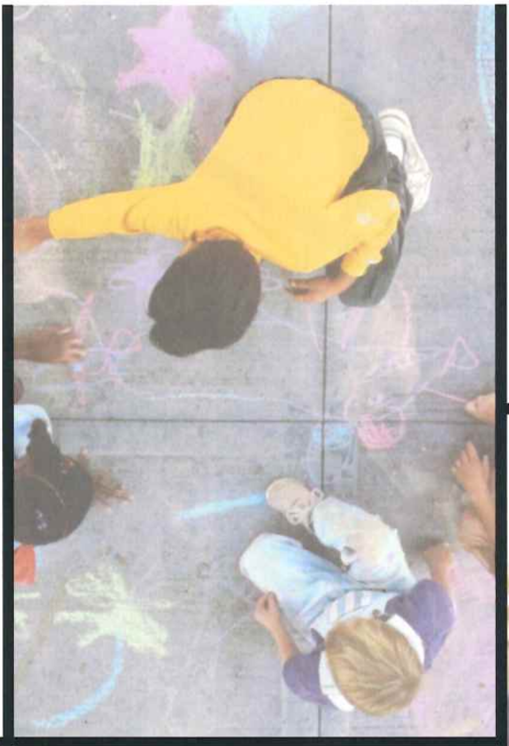
Our Goals

All Children and Youth with Special Health Care Needs will:

- * Be screened early and continuously for special health care needs.
- * Have access to appropriate referral resources.
- * Have adequate private and/or public insurance to pay for the services they need.
- * Have geographic and timely access to primary and specialty services.
- * Will receive coordinated ongoing comprehensive care within a medical home.
- * Have access to comprehensive home and community-based supports.
- * Will receive the services necessary to make appropriate transition into adulthood, including health care, education, work force, and independence.

Initiatives

1) Blueprint for Change:
Systems Asset & Gap Analysis



3) Medical Homes

2) Healthcare Coordination

4) Elevating Family
Voice & Partnership

5) CYSHCN Registry

Maine Children and Youth with Special Health Care Needs
2024 Primary Reason of Contact

Envision a system that...

- ✓ That meets the needs of CYSHCN and their families.
- ✓ That is based on the 10 Essential Public Health Services that is proactive rather than reactive by design.
- ✓ That is based on NEED rather than diagnosis or ICD-10 Codes
- ✓ That is based on relationships rather than transactions
- ✓ That is multigenerational in its approach
- ✓ Families are partners and are shared decision makers
- ✓ That allows for seamless transition from pediatric care to adult care
- ✓ That develops and implements care coordination curriculum that focuses on meeting the needs of the most vulnerable.
- ✓ That develops a payment mechanism and service that allows for multidisciplinary coordinated care / team approach.

Maine's Children and Youth with Special Health Care Needs (CYSHCN)

Department of Health and Human Services

Stacey LaFlamme, MCH Program Manager
Stacey.laflamme@maine.gov
207-441-5324

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Share Bulletin

MaineCare in Education: New Resources and Updated MaineCare in Education 2023 Guide

Maine Department of Health & Human Services sent this bulletin at 08/18/2023 11:00 AM EDT

STATE OF MAINE
Department of
Health and Human Services

Office of MaineCare Services

Having trouble viewing this email? View it as a Web page.

SHARE

You are subscribed to MaineCare - School Health Related Services for Maine Department of Health & Human Services. This information has recently been updated, and is now available.

MaineCare in Education: New Resources and Updated MaineCare in Education 2023 Guide

MaineCare in Education: New Resources and Updated MaineCare in Education 2023 Guide
Aug 18, 2023

The Office of MaineCare Services has updated the MaineCare in Education web page.

You are invited to:

- Sign up for MaineCare's E-Messages and Bulletins.
- Review the newly updated 2023 MaineCare in Education Billing Guide- Revised August, 2023.
- Access Joint Resources Developed by MaineCare and the Maine Department of Education.
- Sign Up for Virtual Meetings and Trainings.
- Participate in New MaineCare in Education Courses developed specifically for Parents, Guardians, MaineCare Providers, School Administrators, and other stakeholders.

For Parents and Guardians

My Student and MaineCare

For School Administrators and MaineCare Providers

MaineCare 100: Introduction to MaineCare

MaineCare 101: Introduction to School Health-Related Services

MaineCare 102: Advanced School Health-Related Services for Providers

As a reminder, all providers who deliver services pursuant to the Individuals with Disabilities Education Act (IDEA) must ensure all services are documented in accordance with the Department of Health and Human Services/Maine Department of Education Joint Guidance on Individualized Education Plan (IEP) documentation.

For technical assistance regarding the billing and processing of MaineCare claims, please email MaineCareinEducation.DHHS@maine.gov or Pamela.Grotton@maine.gov.

For all other questions related to the provision of School Health-Related Services, please email Trista.Collins@maine.gov.

Case Studies: June 12, 2024

Discussion with the Blue Ribbon Commission to Study the Organization of and Service Delivery by DHHS

June 12, 2024

Department of Health and Human Services

Agenda & Approach

- **Approach to the presentation**
- **Participants from DHHS**
- **Case 1: Child with Complex Medical Needs**
  - "A child with medical diagnoses, receiving IDEA Part C who needs SLP, PT, OT, neurologist, intensive early intervention treatment, as well as child care"
- **Case 2: Low-Income Family with Complex Needs**
  - "A low income family facing homelessness with two children with special needs. The teenager experiences ADHD and requires medication management, the younger child has autism and receives Sec. 28 services"

Case Study: Child with Complex Medical Needs

Commission Request: A child with medical diagnoses, receiving IDEA Part C who needs SLP, PT, OT, neurologist, intensive early intervention treatment, as well as child care

Definitions and Acronyms:

- **IDEA Part C**: the Individuals with Disabilities Education Act (IDEA) Part C is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities and their families.
- **SLP**: Speech Language Pathology
- **PT**: Physical Therapy
- **OT**: Occupational Therapy

Case Study: Child with Complex Medical Needs

Commission Request: A child with medical diagnoses, receiving IDEA Part C who needs SLP, PT, OT, neurologist, intensive early intervention treatment, as well as child care

Coverage for Care:

- MaineCare (Medicaid)
- Katie Beckett provides children under age 19, with serious health conditions who are over the income level for free MaineCare
- If not eligible for coverage through MaineCare, CoverME.org can connect families to affordable health care coverage through the state marketplace

Accessing Coverage

- Apply for coverage online through My Maine Connection, mail, fax, or email an application or visit a DHHS district office to apply in person

Covered Services

- General primary care and preventative services coverage under MaineCare
- Physical therapy, occupational therapy, and speech therapy
- Outpatient behavioral health services, including outpatient therapy, and rehabilitative and community support services
- Early and Periodic Screening, Diagnostic, and Treatment Program (EPSDT)

Case Study: Child with Complex Medical Needs

Commission Request: A child with medical diagnoses, receiving IDEA Part C who needs SLP, PT, OT, neurologist, intensive early intervention treatment, as well as child care

Coordination of Care

- Child Development Services (CDS) Early Intervention for ME can assist in arranging services, this is supported through Department of Education
- Case management support through various programs (OMS, OCFS, OBH, CSHN)
- Medical providers can also refer to SLP, PT, OT, neurologist through the medical model which are covered services under MaineCare
- Help Me Grow can assist families with access and finding the supports and resources that they need from prenatal to age 8. This includes a new Help Me Grow cultural broker/family resource specialist to work directly with New Mainer families with children from birth-8.
- The Preschool Development Grant (PDG) is funding four Grants to Community Based Organizations to support Community Health Workers to connect New Mainer families with young children with early intervention services, health care services and other basic needs. The goal is to provide tools for New Mainer parents to support their young children to grow and thrive.
- Children and Youth with Special Health Care Needs Program at the MCDC has a Healthcare coordinator to assist families and contracts with Maine Parent Federation to provide peer support to families to assist with navigating health, social service and education systems.

Case Study: Child with Complex Medical Needs

Commission Request: A child with medical diagnoses, receiving IDEA Part C who needs SLP, PT, OT, neurologist, intensive early intervention treatment, as well as child care

Child Care

- Child Care Affordability Program can assist the family in applying for child care assistance.
- Child Care Choices is a website that staff share with families. The site supports families in learning about child care options and finding child care.

Additional Services

- Public Health Nursing and Cradle ME
- Maine Families Home Visiting
- WIC Nutrition Program
- Early Intervention for ME and Child Development Services - DOE
- Early Head Start and Head Start

Case Study: Low Income Family with Complex Needs

Commission Request: A low income family facing homelessness with two children with special needs. The teenager experiences ADHD and requires medication management, the younger child has autism and receives Sec. 28 services.

Definitions and Acronyms:

- **ADHD**: Attention-deficit/hyperactivity disorder
- **Section 28**: Services for Children with Cognitive Impairments and Functional Limitations. Rehabilitative and Community Services (RCS) is for children or youth up to the age of 21 who have a developmental disability that affects their everyday functioning (Ex. Autism Spectrum Disorders & Intellectual Disability). Services include skill building in activities of daily living and behavior management.

*Types of medical coverage are the same or similar to the first case – see slide 4 for more information

Case Study: Low Income Family with Complex Needs

Commission Request: A low income family facing homelessness with two children with special needs. The teenager experiences ADHD and requires medication management, the younger child has autism and receives Sec. 28 services.

Meeting Basic Needs

- Housing supports:
    - Maine Housing programming including Stability through Engagement Program (STEP), housing navigation services, subsidized housing, voucher programs
    - Municipal General Assistance (GA) Programs can provide financial support for housing, food, utilities, and more. Each municipality has a GA program.
    - McKinney-Vento Homeless Assistance Act services through Maine Department of Education and local schools. Each school is required to have a liaison that can support
    - Local Community Action Programs offer a variety of services and supports including housing, nutrition, child care and youth development, and more
- Other needs:
    - Supplemental Nutrition Assistance Program (SNAP) for food insecurity
    - Temporary Assistance for Needy Families (TANF) provides cash assistance and programming and case management to support job training and education
    - OFI supports Whole Family Programs - many are through the Community Action Programs (CAP) agencies

Case Study: Low Income Family with Complex Needs

Commission Request: A low income family facing homelessness with two children with special needs. The teenager experiences ADHD and requires medication management, the younger child has autism and receives Sec. 28 services.

Coordination of Care

- *Targeted Case Management, Community Care Teams, or Behavioral Health Homes:* when eligible, child/family is assessed for needs across a variety of domains including: physical and social environment, health and medical status, educational and developmental status, behavioral health, skills (social, daily living, habilitative), individualized needs and strengths, existing support systems, etc.
  - Behavioral Health Homes are team-based services that include nurse care managers, family and youth peer support specialists, and psychiatric/medical consultants.
- Providers can identify any potential resources in their communities, link the family to them, then monitor effectiveness, following up as needed (e.g. Primary Care Plus)
- *Medication management* for teenager diagnosed with ADHD would most likely be done by their primary care provider. If their provider needs assistance on how to treat, they can receive psychiatric consultation through the Maine Pediatric and Behavioral Health Partnership. Connections can be made with a primary care provider, including a local Federally Qualified Health Center (FQHC) or School Based Health Center (SBHC), or to a psychiatric prescriber delivering services under Section 65 Medication Management services.

Case Study: Low Income Family with Complex Needs

Commission Request: A low income family facing homelessness with two children with special needs. The teenager experiences ADHD and requires medication management, the younger child has autism and receives Sec. 28 services.

Additional Coordination of Care Resources

- Depending on the age of the younger child, OCFS has the Help Me Grow program (up to age 8), that can be a resource for families to get connected to a variety of resources as well.
- Children's Behavioral Health Services (CBHS) Family Information Specialist works directly with families as well to help them navigate to potential resources and understand how to meet their child's behavioral health needs, including identifying a provider.
- Children and Youth with Special Health Care Needs program has a Healthcare Coordinator that can assist families and providers.
- Additional supportive resources for parents and families include:
    - GEAR Parent Network
    - Maine Parent Federation
    - Maine Autism Society
    - Maine Developmental Disabilities Council

Discussion

Caswell, Lynne

From: Broome, Anna
Sent: Monday, May 13, 2024 12:37 PM
To: Cronin, Nancy E
Cc: Duson, Jill; Craven, Margaret; Lazure, Luke; Caswell, Lynne
Subject: RE: Maine Blueprint and Care Coordination Speaker Request Confirmed

Hi Nancy,
That's great. I have let the chairs know that the intent for the June meeting is to take up the case studies with children's services and that there is a plan to talk about Title 5. I'm copying them here so that they know that this presentation is in the offing for June 12 and that it will be first up on the agenda.

We can do the zoom invite later on but you can go ahead and confirm the presentation in the meantime. These are busy folks so getting on their agenda ahead of time is key.

Thank you! By the way, I'm going to be gone for the next week and a half but Luke and Lynne are around – I've put their emails in the cc line. We'll talk about Title 5 and what you and I need to do when I get back. Thanks for slotting this piece into place.
Anna

From: Cronin, Nancy E <Nancy.E.Cronin@maine.gov>
Sent: Thursday, May 9, 2024 5:53 PM
To: Broome, Anna <Anna.Broome@legislature.maine.gov>
Subject: FW: Maine Blueprint and Care Coordination Speaker Request Confirmed

This message originates from outside the Maine Legislature.

Wow, Dr. Houtrow, MD, PhD, PPH is willing to speak about how critical the Title V Blueprint that they are asking States to implement is willing to speak.

Wow!

Nancy

Thank you for sharing additional details about the meeting. We have identified a speaker, Amy Houtrow, MD, PhD, MPH for this virtual presentation on 6/12/24 at 10am ET. Dr. Houtrow is the lead author on the Blueprint Health Equity article, and she serves on the Steering Committee for the Blueprint National Center. She is a pediatric rehabilitation medicine physician at UPMC Children's Hospital of Pittsburgh.

I've copied Dr. Houtrow on this email - she is looking forward to this presentation and I know she has some questions so if you're able to put her in touch with the appropriate person that would be great.

Thank you, both!

Janine Salameh, MPH (she/her)
Manager, System of Services for CYSHCN
American Academy of Pediatrics
Email: jsalameh@aap.org

Phone: 630-626-6427

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Dee A. Kerry, Executive Director
she/her

American Academy of Pediatrics, Maine Chapter
'Maine AAP'
Physical Address: 30 Association Drive
Mailing Address: PO Box 190
Manchester, ME 04351
cell: 207-620-0806
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