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Need for Care Integration for Children with Special Health Care Needs: Focus on Children with Medical Complexity

November 2, 2021

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Maternal and Child Health Bureau (MCHB)

Vision: Healthy Communities, Healthy People

Outline

- Maternal and Child Health Bureau Overview
- Division of Services for Children with Special Health Needs (DSCSHN)
- Guiding Frameworks
- DSCSHN programs: Spotlight on Children with Medical Complexity
- Moving towards Care Integration: Care Coordination, Telehealth
- Wrap up

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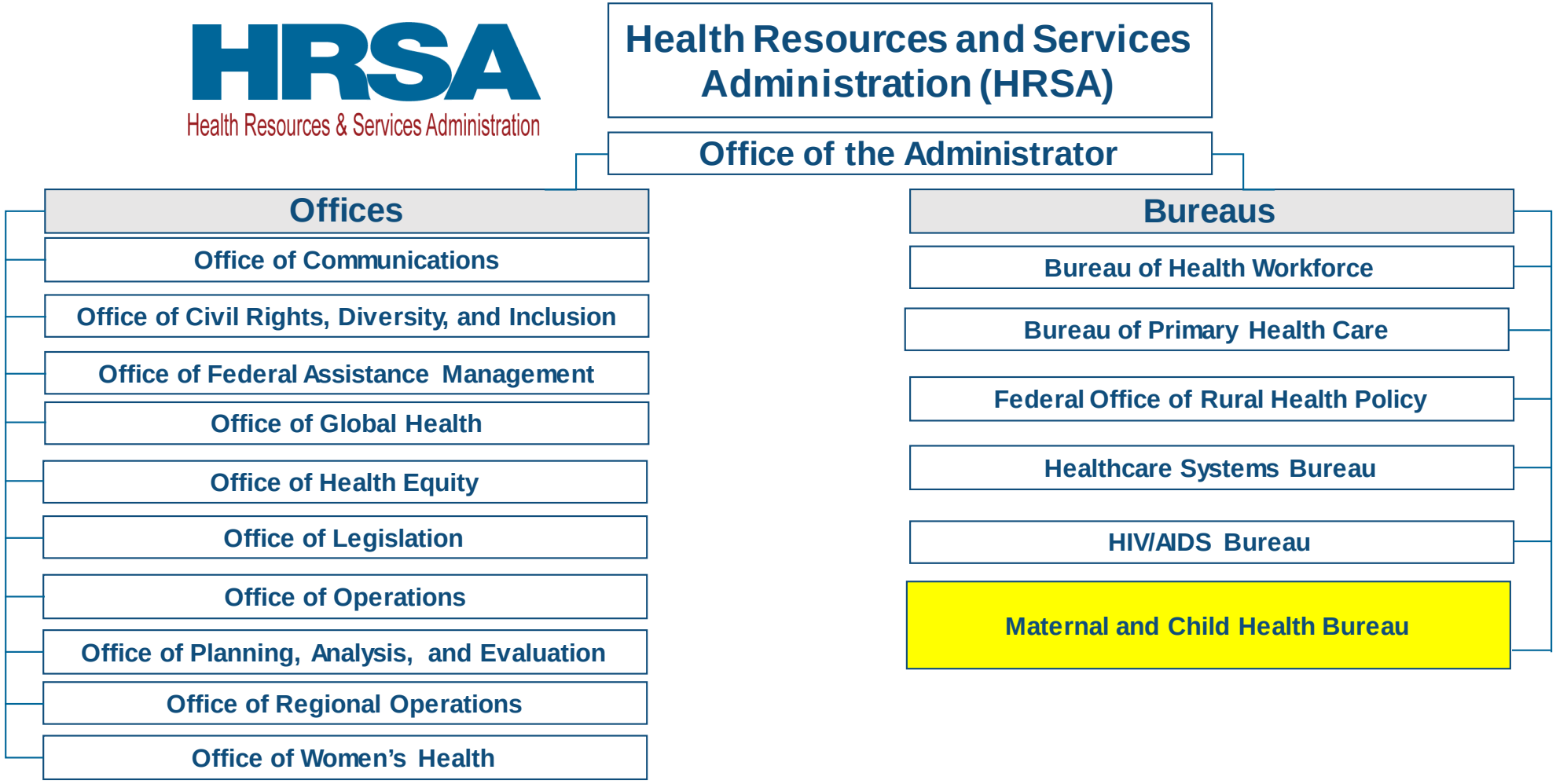

HRSA Maternal & Child Health

HRSA's Maternal and Child Health Bureau

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

- **Vision:** An America where all mothers, children, and families are thriving and reach their full potential.

Maternal and Child Health Bureau Strategic Plan

MCHB MISSION

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MCHB VISION

An America where all mothers, children, and families are thriving and reach their full potential.

GOAL 1 Assure **access** to high-quality and equitable health services to optimize health and well-being for all MCH populations.

GOAL 2 Achieve **health equity** for MCH populations.

GOAL 3 Strengthen **public health capacity and workforce** for MCH.

GOAL 4 Maximize **impact** through leadership, partnership, and stewardship.

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- **Objective 1.1.** Monitor and improve equitable **access to a continuum** of high-quality prevention, early intervention, and treatment services that address medical and social determinants of health across the life course.
- **Objective 1.2.** Strengthen state- and community-based comprehensive **systems of care** for MCH populations that equitably improve well-being.
- **Objective 1.3.** Ensure **family and consumer leadership** and partnership in efforts to improve health and strengthen MCH systems of care.
- **Objective 1.4.** Accelerate implementation and adoption of **preventive services** in medical homes and other settings for MCH populations.
- **Objective 1.5.** Support access to medical homes with **team-based, coordinated approaches to primary care** for MCH populations.

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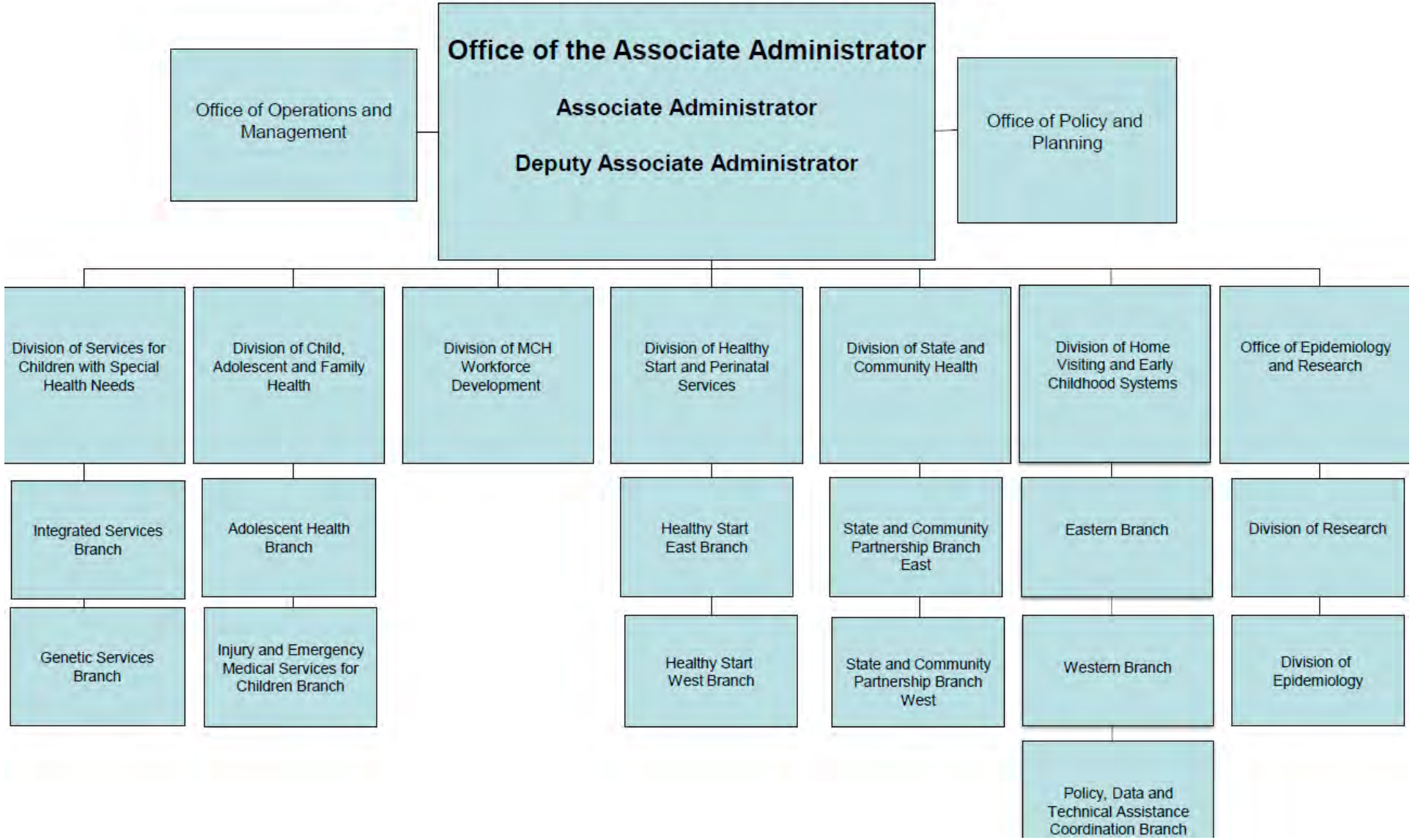

DSCSHN: Who are we?

- Mission: To improve access to systems of services for children and youth with special health care needs (CYSHCN) and their families across the life course
- Vision: Optimal health and quality of life for all CYSHCN and their families
- Purpose: To provide national leadership and resources to expand, strengthen, and improve the quality and equity of systems of care for CYSHCN and their families

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DSCSHN: Who do we serve?

Children or youth who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services or a type or amount beyond that required for children generally.

- Nearly 20% of U.S. children under age 18 years have a special health care need
- One in five U.S. families has a child or youth with a special health care need
- Services needed from multiple systems: health care, public health, education, mental health, and social services

DSCSHN Program Snapshot

Systems

- Advancing systems of services
- Family/Professional partnership
- Children with medical complexity
- Research network

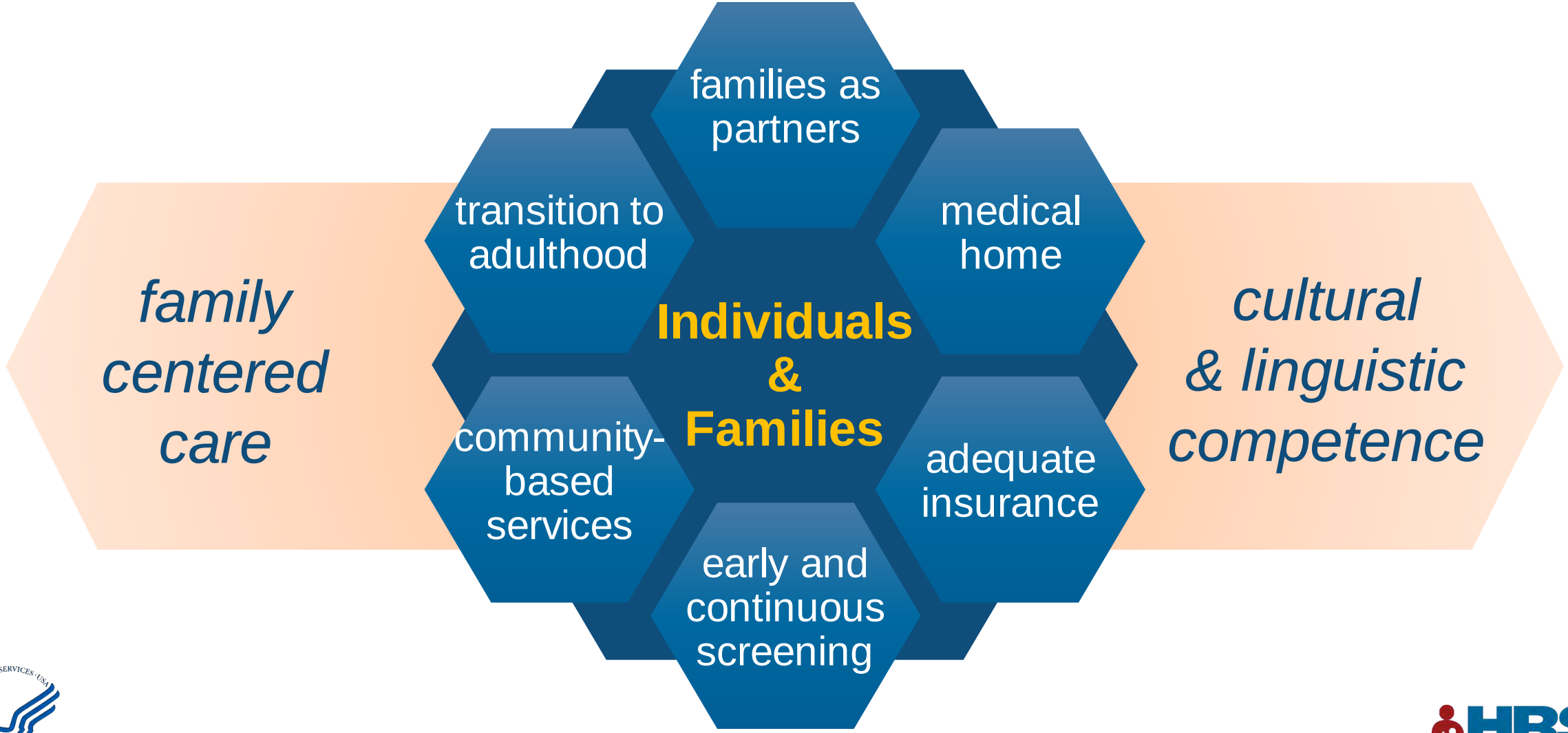
Screening

- Newborn hearing screen
- Newborn screening
- Genetics
- Environmental health
- Vision Screening

Condition-specific

- Hemophilia
- Sickle Cell
- Thalassemia
- Epilepsy
- Autism

DSCSHN: Six Core Systems Outcomes



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DSCSHN: Why we need to better serve CYSHCN

- 2017-2018 National Survey of Children's Health estimates only 13.9% of CYSHCN received all six components of a well-functioning system of care.
- While nearly all CYSHCN (95.8%) were insured at the time of the survey, only 62.3% were reported to be adequately and continuously insured throughout the year.
- Less than half of CYSHCN (42.7%) had a medical home.
- One in three CYSHCN needed health care provided at home and/or health care coordinated on a weekly basis.

Children with Special Health Care Needs NSCH Data Brief July 2020

DSCSHN: How can we better serve CYSHCN?

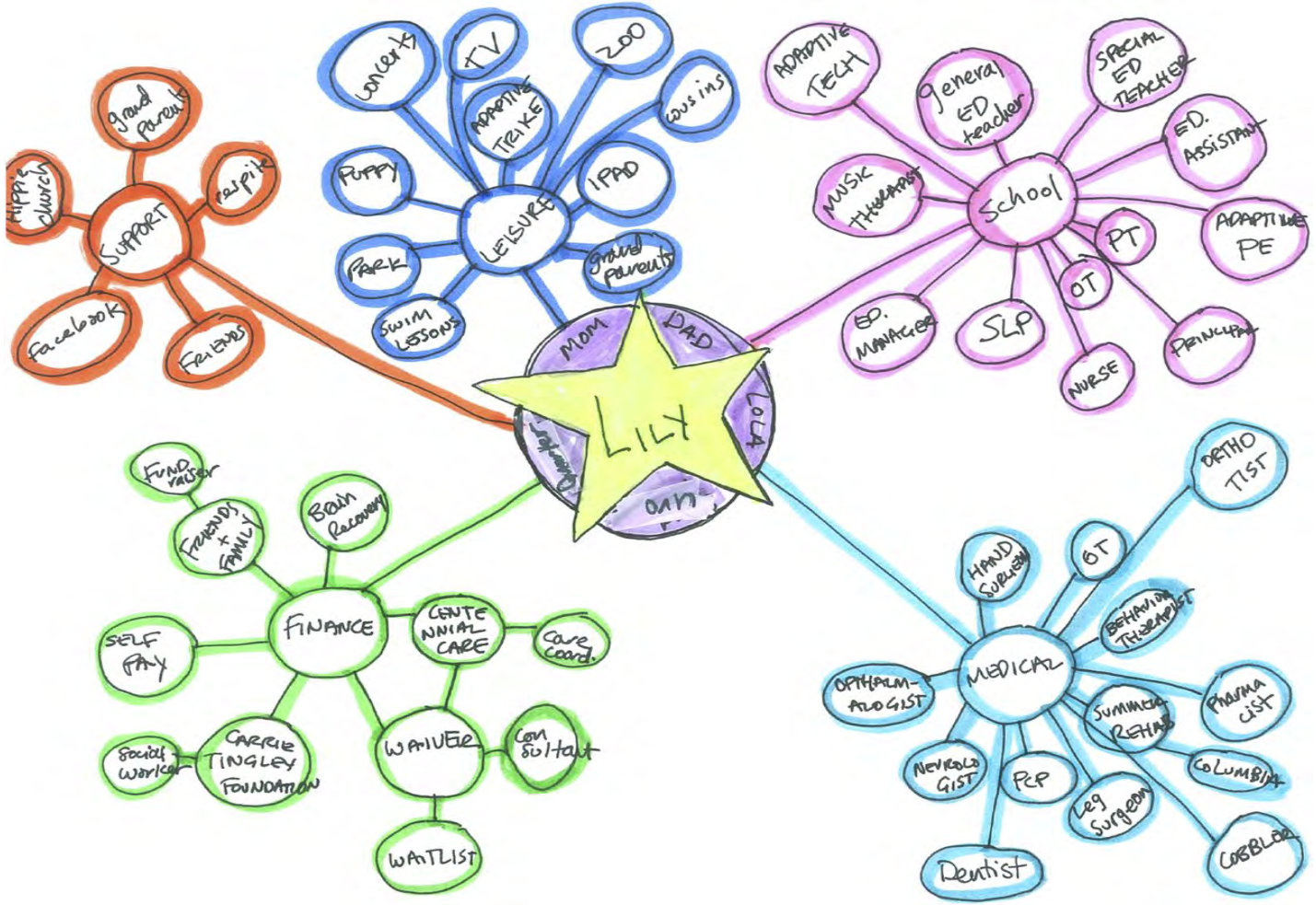
- *A Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs (CYSHCN) and Families* (final version estimated release: Spring/Summer 2022)
- Guide strategic direction for the field over the next 10-15 years
- Develop actionable vision and goals at the community, state, and federal level:
  - Health Equity
  - Family Well-being and Quality of Life
  - Access to Services
  - Financing of Services

DSCSHN: How can we better serve CYSHCN?

- Care Integration – The seamless provision of health care services across the care continuum[1]
- Who should be engaged
  - Health care providers, including primary and specialty care (pediatric and adult), behavioral health, oral health, palliative care, educators, social services, home care support, therapists, etc.
- Why should we integrate care
  - Improve the quality of life and well being of CYSHCN and their families
  - Time and cost effectiveness for families and providers
  - CYSHCN are living longer
  - System of care is fragmented, especially for children with medical complexity (CMC)

1 Kuo DZ, McAllister JW, Rossignol L, Turchi RM, Stille CJ. Care Coordination for Children With Medical Complexity: Whose Care Is It, Anyway? Pediatrics. 2018 Mar;141(Suppl 3):S224-S232. doi: 10.1542/peds.2017-1284G. PMID: 29496973.

Need for Care Integration: Care Map



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Need for Care Integration: COVID-19 Pandemic

- Home care support
  - Home care providers – availability and capability
  - Access to supplies
  - Payment/reimbursement of services
- Access to Therapy
  - Equipment is in the schools
  - Therapy via telehealth

Care Integration vs Care Coordination

- Care Integration
  - Provision of health care services across the care continuum
  - System level
  - Difficult to achieve
- Care Coordination[2]
  - Patient and family-centered
  - Assessment-driven
  - Team-based
  - Enhance the care giving capabilities of families
  - Family partnership
  - Needs to be effective to achieve care integration

2 Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems COUNCIL ON CHILDREN WITH DISABILITIES and MEDICAL HOME IMPLEMENTATION PROJECT ADVISORY COMMITTEE Pediatrics May 2014, 133 (5) e1451-e1460; DOI: 10.1542/peds.2014-0318

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Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity

- Goal: improve the quality of life for children with medical complexity, the well-being of their families, and the cost effectiveness of their care
- CMC CoIIN partners include Title V, Medicaid, families/caregivers of CMC, pediatric primary and specialty care providers, leaders of health care delivery systems/children's hospitals
- Ten state teams (AL, CO, IN, KY, MA, MN, OR, TX, WA, WI)
- Project focus areas include care coordination, supporting rural care with telemedicine and virtual care teams, transition, innovative partnerships, and testing of innovative payment models
- Family partnership is at the center

CMC CoIIN Care Coordination

- Examples of care coordination
  - Family Engagement/Partnership at all levels of the CMC CoIIN
  - Get to Know Me Forms and Goal Cards
  - Pediatric to Adult Care Transition (PACT) Workbook
  - Per member per month agreement with an Managed Care Organization to provide service coordination
  - Care Coordination Academy

CMC CoIIN Care Coordination

- Lessons Learned/Challenges
  - Payment/reimbursement for care coordinators
  - Compensating families for providing home care support
  - Workforce development and training to support care coordinators
  - Transition from pediatric to adult providers
  - Incorporating telehealth as a means to provide care

Telehealth as a Strategy for Care Coordination

- Provide care/support during the COVID-19 pandemic
- Strengthen family/provider partnerships
- Support care in rural or underserved areas, or areas where there is a shortage of CYSHCN/CMC specialists
- Support CYSHCN/CMC home caregivers

Incorporating Telehealth to care for CYSHCN: CMC CoIIN

- Lessons Learned
  - Opportunity to see CYSHCN/CMC in their home environment
  - Less travel time for the families
  - Ability to gather multiple providers from different systems at one time
- Barriers/Challenges
  - Equipment required and bandwidth of families and/or providers
  - Payments/reimbursement for using telehealth vs in-person visits
  - Knowing when a child should come into the office and when a telehealth visit will be sufficient

Questions?

Resources

- MCHB/Division of Services for Children with Special Health Needs https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs
- Children with Special Health Care Needs NSCH Data Brief July 2020 https://mchb.hrsa.gov/sites/default/files/mchb/Data/NSCH/nsch-cshcn-data-brief.pdf
- CoIIN to Advance Care for CMC https://ciswh.org/project/coiin-cmc
- Pediatric to Adult Care Transition (PACT) Workbook https://ciswh.org/wp-content/uploads/2021/08/Transition_workbook_revised_v4_pdf.pdf
- National Resource Center for Patient/Family-Centered Medical Home https://medicalhomeinfo.aap.org/Pages/default.aspx
- Title V Block Grant https://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program

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