National Conference of State Legislatures: NC Children and Youth with Special Health Care Needs and Families

January 2023

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NC DEPARTMENT OF HEALTH AND HUMAN SERVICES

Objectives

- **CYSHCN**: Children and Definitions
- **Guiding principles/framework**: Blueprint for Change

- **Leadership & Structure**
  - Prioritizing children and families
  - Breaking down siloes for CYSHCN in state government
  - Commission on CSHCN

- **Q&A**

ABBREVIATIONS

CYSHCN: Children & Youth with Special Health Care Needs
CMARC: Care Management for At-Risk Children
DCFW: Division of Child and Family Well-Being
EI: Early Intervention
LHD: Local Health Department
NC InCK: NC Integrated Care for Kids

Children and Youth with Special Health Care Needs

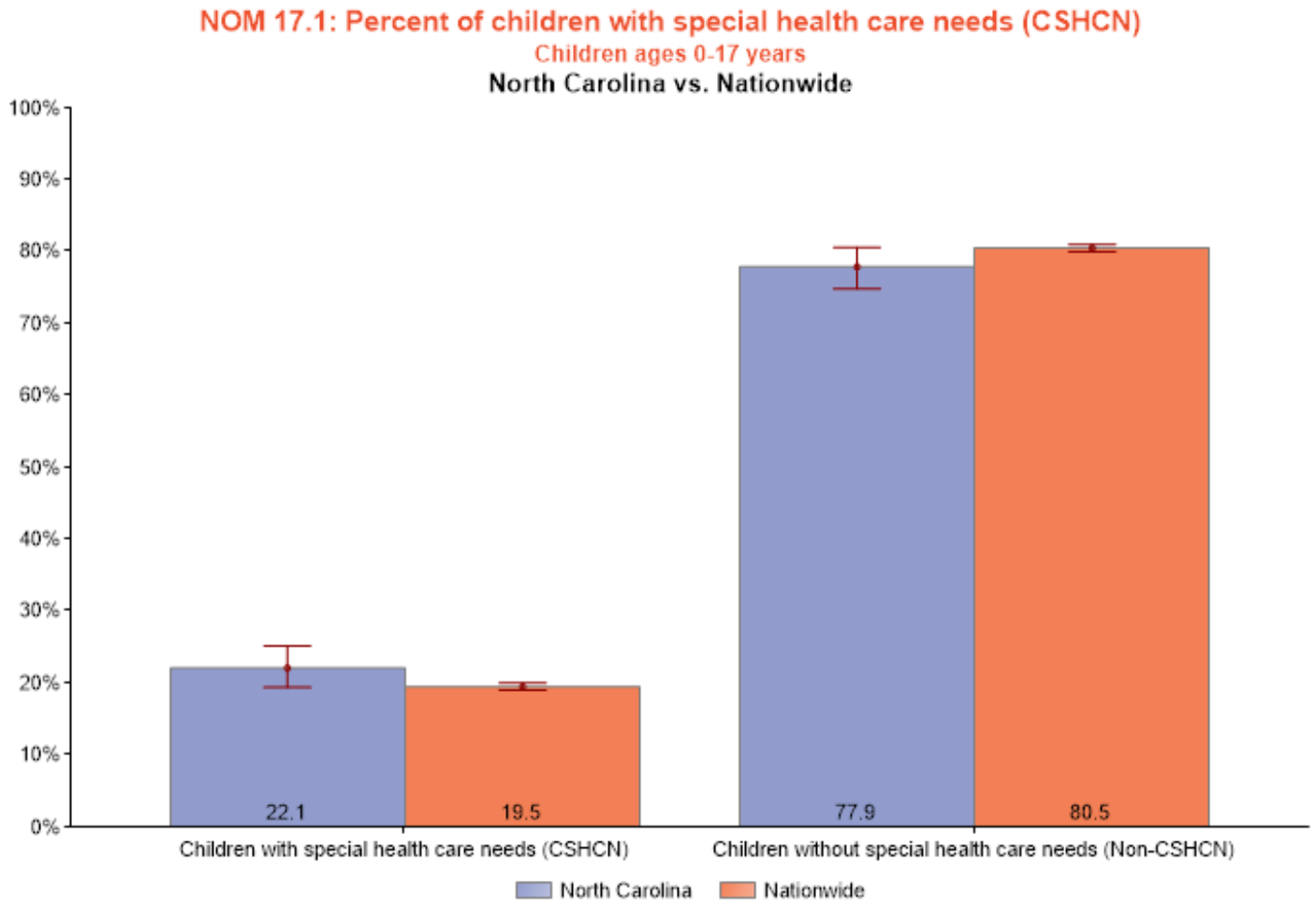
Photo by Anne Geddes

Children and Youth with Special Health Care Needs (CYSHCN)

- **CYSHCN are** "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."
  - **14 million** children in the US (aka ~20% of all children)
  - **68%** have 2 or more health conditions
  - **45.5%** have health conditions that affect their daily activities
  - **37.5%** require specialized medical care
- Examples of concerns or conditions include but are not limited to: prematurity, placement in foster care, maternal depression, anxiety, asthma, sickle cell, long COVID, autism, genetic and metabolic conditions, hearing loss, untreated congenital syphilis

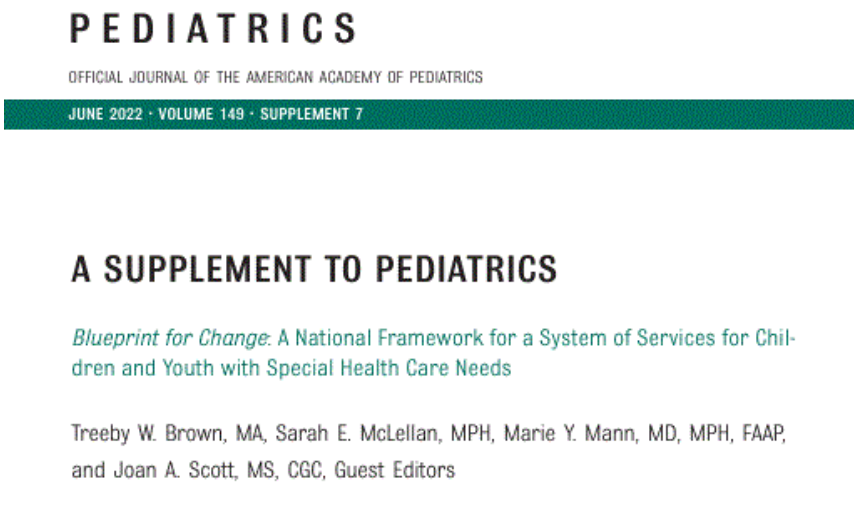
85% of CYSHCN still do not receive services in a well-coordinated system

Children and Youth with Special Health Care Needs (CYSHCN)



https://www.childhealthdata.org/browse/survey/results?q=9611&r=35&r2=1

A Blueprint for Change: Guiding Principles for a System of Services for CYSHCN and Their Families


PEDIATRICS

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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

VISION: CYSHCN 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.

https://publications.aap.org/pediatrics/article/149/Supplement%207/e2021056150C/188225/A-Blueprint-for-Change-Guiding-Principles-for-a

A Blueprint for Change: Guiding Principles for a System of Services for CYSHCN and Their Families

- NC was invited to participate in multiple work groups to inform the development of a national resource for state Title V staff focused on the Blueprint

- Four critical areas drive the Blueprint for Change:
  - **Health equity**
  - **Family and child well-being and quality of life**
  - **Access to services**
  - **Financing of services**

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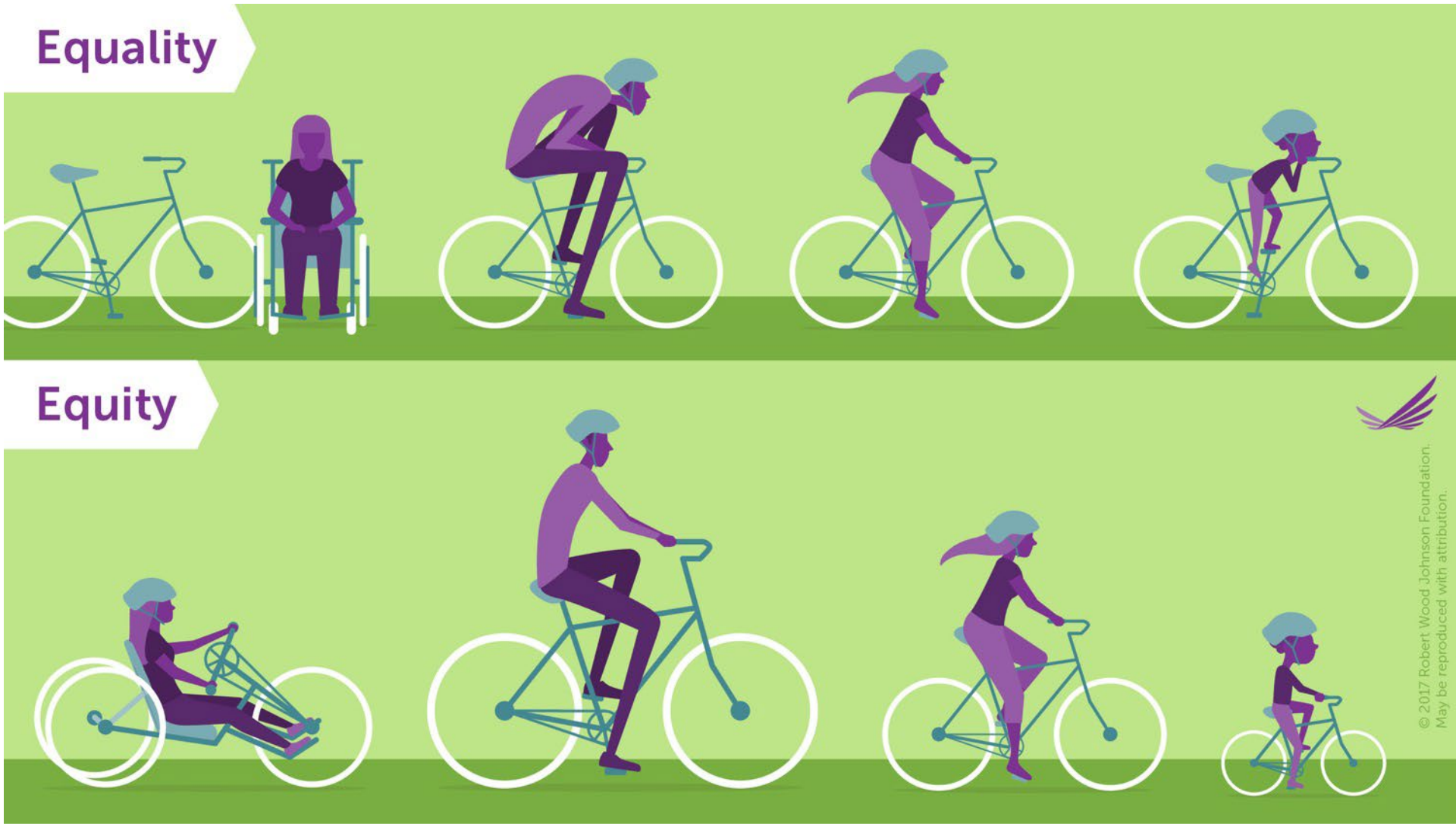

https://www.rwjf.org/en/library/infographics/visualizing-health-equity.html

Blueprint for Change: 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.
- **NC Examples**
  - **Data tracking**: Enrollment in programs by race/ethnicity, geography
  - **Staff training**: Recommendations on EHR documentation, DEI trainings
  - **Diverse workforce**: Representation in hires
    - Native Spanish-speaker is minority outreach coordinator for Medicaid and SCHIP
    - ADA assessments for LHDs and practices is a person with lived disability experience in a wheelchair

Neutral	Stigmatizing
He still has pain rated 10/10. His girlfriend is by his side but will need to go home soon.	He is insisting that his pain is "still a 10." His girlfriend is lying on the bed with her shoes on and requests a bus token to go home.

https://publications.aap.org/pediatrics/article/149/Supplement%207/e2021056150C/188225/A-Blueprint-for-Change-Guiding-Principles-for-a

Blueprint for Change: Family and 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. Families of CYSHCN are equal partners in developing services and supports designed for their benefit.

NC Examples

- **Family partner steering committee**: Feedback on programs and requests of DHHS team (e.g., training on sexual health for CYSHCN), meet quarterly
- **Youth Health Advisors**: Recruited members who are CYSHCN, informed COVID-19 communications, meet monthly
- **Supporting family & youth participation**
  - Youth and families paid for time & contributions
  - Families supported to attend/present at national and state conferences

https://publications.aap.org/pediatrics/article/149/Supplement%207/e2021056150C/188225/A-Blueprint-for-Change-Guiding-Principles-for-a

Blueprint for Change: 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.
  - 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.
- **NC Examples**
  - **Help Line for CYSHCN**: Partnership between Title V and Medicaid, accessible by phone or email, resource and referral assistance (e.g., Medicaid eligibility, how to access specific services)
  - **Commission on CSHCN**
  - **Care Management for CYSHCN**: Care Management for At Risk Children in NC

https://publications.aap.org/pediatrics/article/149/Supplement%207/e2021056150C/188225/A-Blueprint-for-Change-Guiding-Principles-for-a

Children and Youth with Special Health Care Needs Help Line

1-800-737-3028
CYSHCN.Helpline@dhhs.nc.gov

Web site for families of CYSHCN:
https://publichealth.nc.gov/wch/families/cyshcn.htm

Program Spotlight: CMARC

- CMARC is a **care management program for at-risk young children** birth to age five
- **Broad eligibility that includes 'at risk' children**: CSHCN, experienced an adverse childhood event, medical home referral, Medicaid and non-Medicaid insured children
- **Coordination** between healthcare providers, linkages and referrals to other community, family and social supports
- **Partnership program**: LHDs, Managed Care Organizations, Medicaid, Medical home, Family

Program Spotlight: Early Intervention (EI)

- Provides supports to children **birth to three who have special needs**
- 16 Children's Developmental Service Agencies (CDSAs) work with local service providers to help families across the state
- **NC Focus**: EI policies and processes allow more infants and children with **social emotional concerns** and conditions to be eligible for services
  - **A continuum of services**: Pyramid Model Framework pilots for evidence-based practices that promote young children's healthy social-emotional development
  - **Expert partners**: Connecting with the NC Infant Mental Health (IMH) Association.

Blueprint for Change: Financing of Services

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

- **NC Examples**
  - **EPSDT**: Medicaid must provide all medically necessary health care services to Medicaid-eligible children
  - **Integrated Care for Kids**

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Program Spotlight: NC Integrated Care for Kids (NC InCK)

The **Integrated Care for Kids (InCK) Model** is a child-centered local service delivery and state payment model, aimed at **reducing expenditures** and **improving the quality of care** for children in Medicaid and CHIP, especially those with or at-risk for developing significant health needs.

Improve priority outcomes of child health and wellbeing

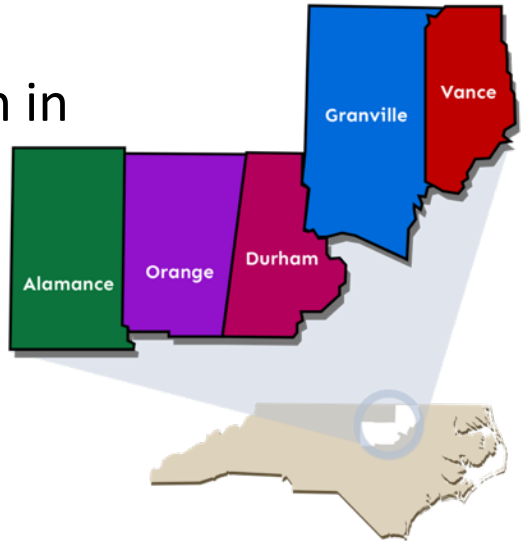
Reduce avoidable inpatient stays and out-of-home placements

Create sustainable, alternative ways of paying for care
(Also called Alternative Payment Models)

www.ncinck.org | @nc_inck

Program Spotlight: NC Integrated Care for Kids (NC InCK)

- **Population:** All Medicaid and CHIP-insured children in this 5-county area in central NC
  - Birth to age 20
  - Regardless of where they receive medical care
  - ~95,000 children



- **Funding:** A 7-year, $16M grant from CMS to the following lead organizations

Duke UNIVERSITY

THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL

NC DEPARTMENT OF HEALTH AND HUMAN SERVICES

- **Launched in January 2022** after a 2-yr planning period

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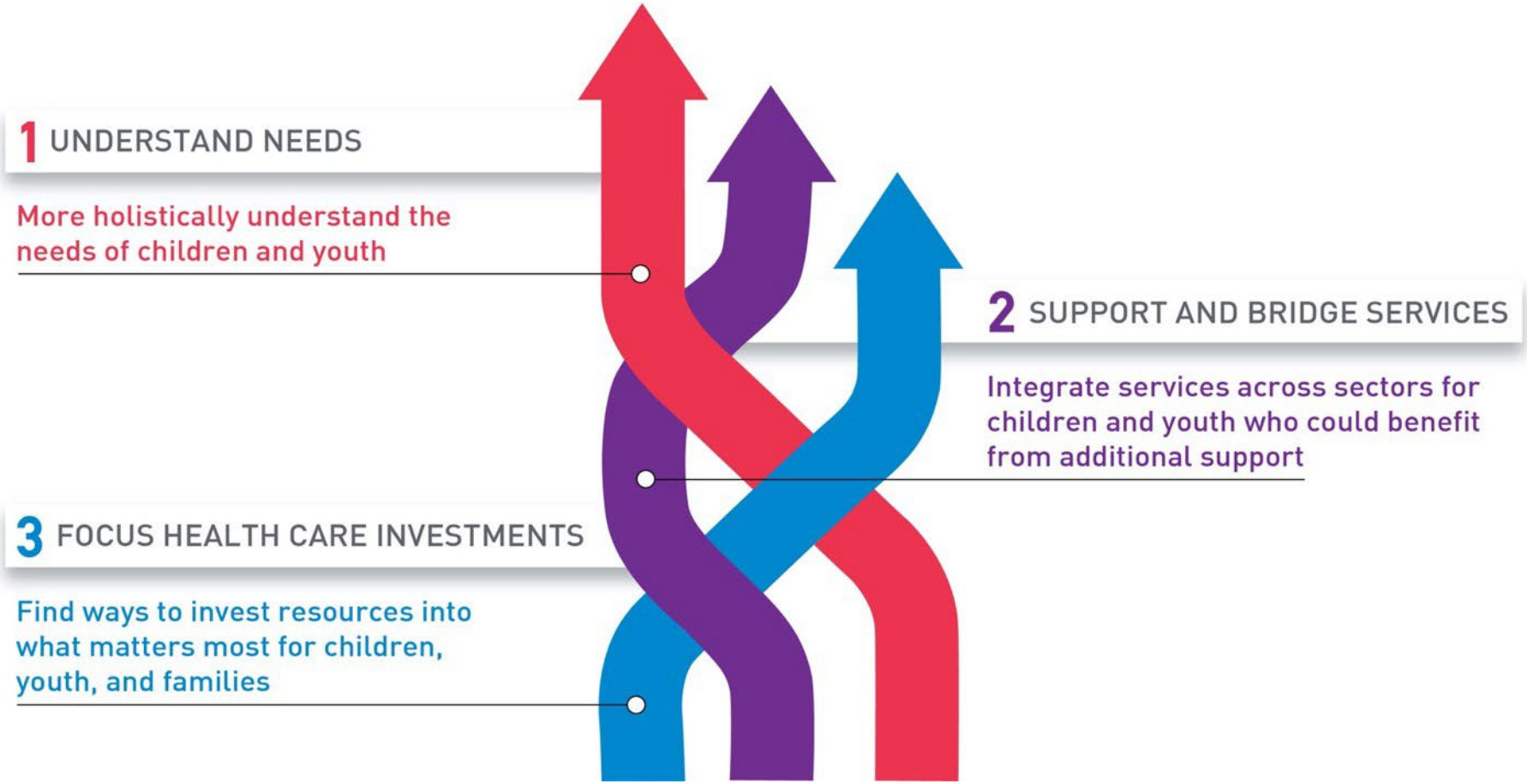
Program Spotlight: NC Integrated Care for Kids (NC InCK)



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Program Spotlight: NC Integrated Care for Kids (NC InCK)

NC InCK is integrating statewide data beyond administrative healthcare data in a pediatric-focused risk model

Category	Examples of Data used to Assess Needs
SDOH Needs	• Food, housing, transportation needs from Care Needs Screen • Social Deprivation Index for member address
Education	• # of school absences and suspensions
Juvenile Justice	• Placement in detention or development center • Probation status
Child Welfare	• Current foster care placement • Recently returned home from foster placement
Guardian	• Casehead substance use during pregnancy • Casehead qualifies for Tailored Plan
Medical Complexity	• Pediatric Medical Complexity Algorithm, Level 3

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Program Spotlight: NC Integrated Care for Kids (NC InCK)

NC InCK Integrates Across These Ten Core Child Services:

1. Schools
2. Early Care and Education
3. Food – SNAP, WIC, Food banks
4. Housing
5. Physical & Behavioral Healthcare
6. Maternal & Child Services – Title V
7. Social Services – Child Welfare
8. Mobile Crisis Response
9. Juvenile Justice
10. Legal Aid

Example Innovations

- **NC InCK Consent Form**: Allows integrated care team members (e.g., PCP, therapists, school personnel) to communicate about a child's well-being needs

- **NC InCK Asthma Intervention**
  - School nurses identify & assess children with asthma
  - Pediatric pulmonary teams do allergy testing related to the home environment
  - Local community-based organizations remediate the home environment

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Program Spotlight: NC Integrated Care for Kids (NC InCK)

NC InCK Early Childhood Innovation Committee chose interventions that primary care practices can take to promote kindergarten readiness from birth to age 6


Well visit


Office-Based Literacy Promotion


Developmental screening


Social emotional screening

PreK referral


Parenting support programs


Early intervention referral


Early childhood mental health services


Community-based literacy programs

Goal: Encourage and give providers credit for taking these actions

Incentive: Bundle documentation via a new Medicaid administrative code will be linked to an incentive payment in the NC InCK alternative payment model

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Discussion Question

How can you envision applying the Blueprint for Change principles (health equity, family and child well-being and quality of life, access to services, financing of services) to support the health and well-being of CYSHCN in your state?

NCDHHS Priorities

*These priorities and our work across the department are grounded in **whole-person health**, driven by **equity**, and responsive to the lessons learned responding to the greatest health crisis in more than a generation.*

Behavioral Health & Resilience

We need to offer services further upstream to build resiliency, invest in coordinated systems of care that **make mental health services easy to access** when and where they are needed and to **reduce the stigma** around accessing these services.

Child & Family Well-Being

We will work to ensure that North Carolina's children grow up safe, healthy and thriving in nurturing and resilient families and communities**. Investing in families and children's healthy development builds more resilient families, better educational outcomes and, in the long term, a stronger society**.

Strong & Inclusive Workforce

We will work to strengthen the **workforce that supports early learning, health and wellness by delivering services to** North Carolina. And we will take action to be an equitable workplace that lives its values and ensure that all people have the opportunity to be fully included members of their communities.

Child & Family Well-Being

NC DEPARTMENT OF HEALTH AND HUMAN SERVICES

All children have the opportunity to develop to their full potential and thrive.

- **Recovering stronger from COVID-19**
- **Focusing on the whole child and the whole family**
- **Encouraging needed and comprehensive investments in children and families**

Child & Family Well-Being

Child behavioral health

Bring together programs and data to support children's behavioral health needs in their communities

Child welfare

Strengthen the services and supports available across NC for our most vulnerable children and families

Nutritional insecurity for children & families

Increase access to heathy, nutritious food through innovative strategies

Maternal & infant health

Equitably improve women's health and birth outcomes

Early care and learning network

Equitably Strengthen high quality early education to allow parents to work and children to get the best start possible

Division of Child & Family Well-Being (DCFW)

- **Integrates behavioral health, physical health, and social programs to support whole child and family health**
- **DCFW Sections**

  - **Whole Child Health:** Child behavioral health & child and youth health programs
  - **Early Intervention**: Infant Toddler Program for young children with developmental delays or conditions
  - **Community Nutrition Services**: WIC & Child and Adult Care Food Programs
  - **Food & Nutrition Services**: FNS/SNAP program

DCFW: Early Wins for Children & Families

- **Infant Formula Shortage: Centering our response on infants and families**
- **Behavioral Health Supports in Schools: Leveraging COVID resource flexibilities**
- **WIC & SNAP Cross-Enrollment: Using data to address child hunger**

Leadership Structure: NC Commission on CSHCN

- **Commission on Children with Special Health Care Needs (CSHCN)**
  - Established by NC General Assembly in 1998
  - Charged with monitoring and evaluating the provision and quality of health services for CSHCN in NC.

- **Current workgroups** partner with Medicaid and stakeholders in four areas to influence policies and processes impacting CYSHCN:
  - Behavioral Health
  - Oral Health
  - CAP/C (Community Alternatives Program for Children)
  - Home Health Nursing Shortage

https://medicaid.ncdhhs.gov/providers/programs-and-services/long-term-care/community-alternatives-program-children-capc

NC Commission on CSHCN: Influence on Policies

- Ushered in the special needs component of SCHIP program in 1998 and most recently supported the merger of the Medicaid and Health Choice (CHIP)
- Provided feedback and recommendations on Medicaid Transformation, including the Standard and Tailored Plans
- Provided ongoing review of Medicaid service definitions impacting CYSHCN

Image: https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn

Discussion Question

- **What are some examples of partners that you already have or could you work with?**
- **What are some ways that you can involve families of CYSHCN and YSHCN in the process?**

Thank You!

Questions?

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