

Optimizing systems of care for children with special health care needs (CSHCN) using a life course perspective

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Christina Bethell has disclosed that she has no financial relationships to disclose and no conflicts of interest to resolve

Background

LCT: Dynamic nature of health and well-being

Across life (timeline)

At key points (timing)

In complex contexts
(environment)

With *continuous learning to reduce disparities* and improve population health
(equity)

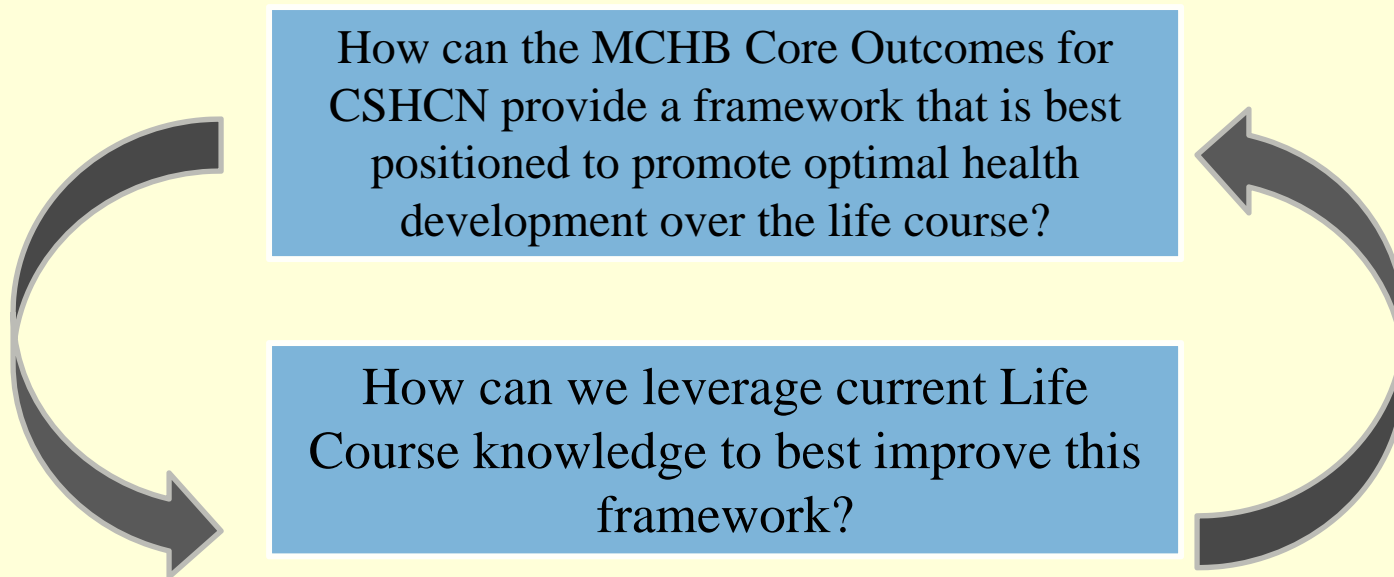
Implications for health care

Explicit focus on promoting and optimizing health
(beyond acute care model)

Enhanced capacity (knowledge, skills resources)
to enable consideration of context, timing and
impacts over time

Starting Point Question

- **Establish a system of services for CSHCN that yields optimal health and wellbeing over the life course**

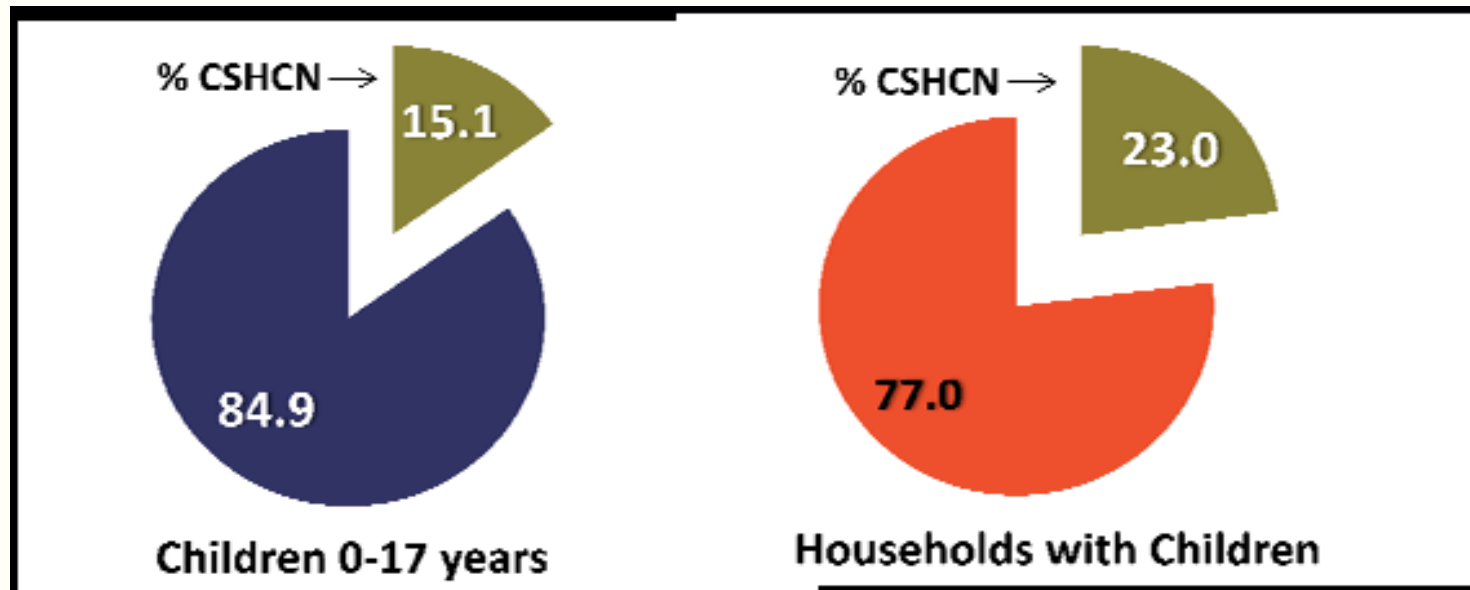


Objectives

- 1) Outline the special importance of a life course approach for CSHCN
- 2) Present illustrative data findings from national surveys that begin to inform a life course focus on CSHCN in research, policies and programs
- 3) Portray key challenges and opportunities for existing and emerging health care system reform efforts to further promote the life course health development of CSHCN

Who are CSHCN

- *Ongoing health condition-physical, mental, behavioral, etc.*
- *Need or use an above routine amount or type of health and related services*
- 15-20% of children age 0-17; Nearly 1 in 4 US households





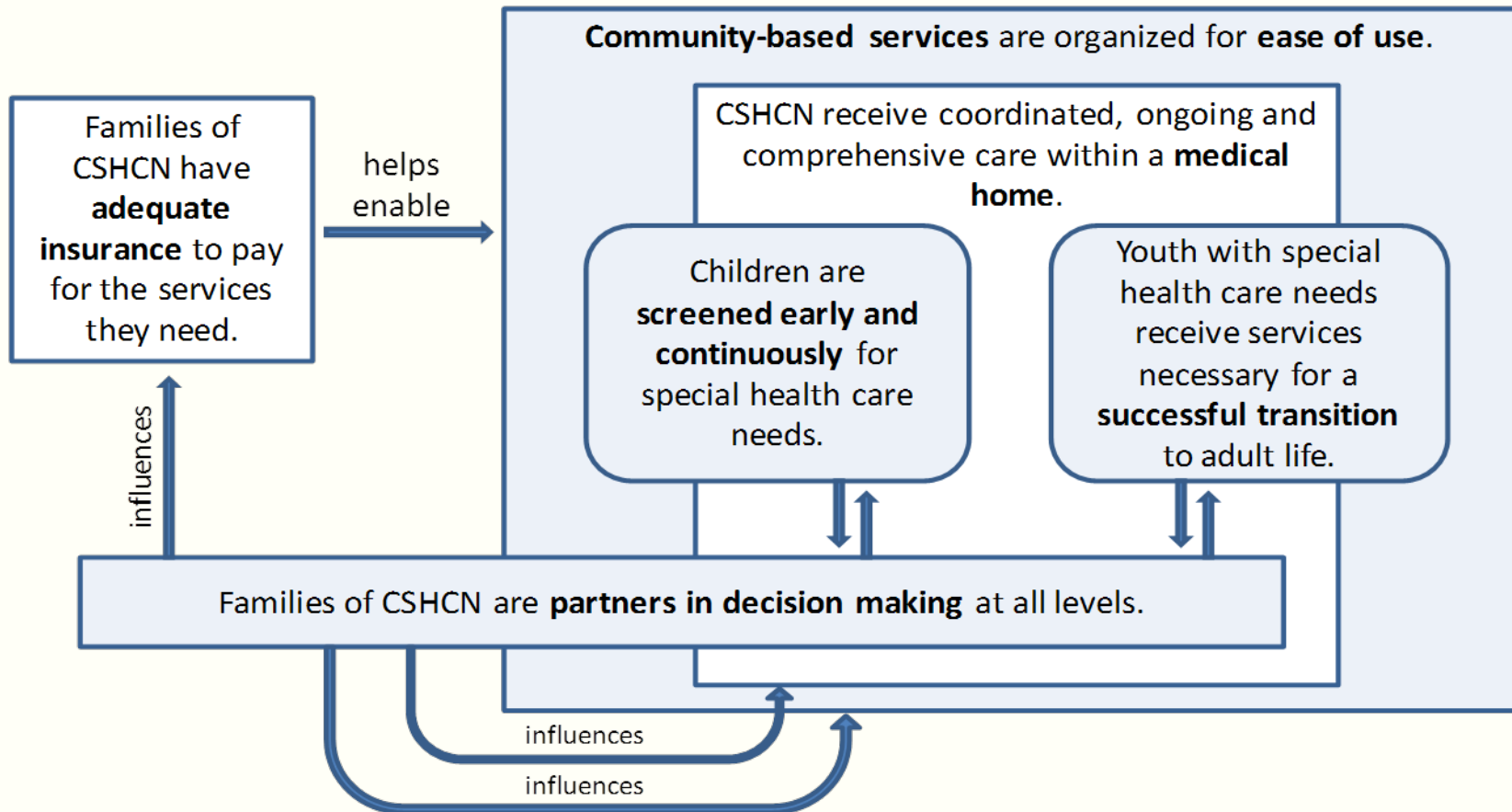
Importance of a LC approach for CSHCN and Alignment of Existing Systems of Services Model

- 1) The above routine and growing complexity of health care needs and functional impacts CSHCN and their families experience
- 2) The enhanced vulnerability of CSHCN to weaknesses in the health care system that a life course approach may address
- 3) The growing strength of the evidence linking child and adult health, health care needs and quality of life

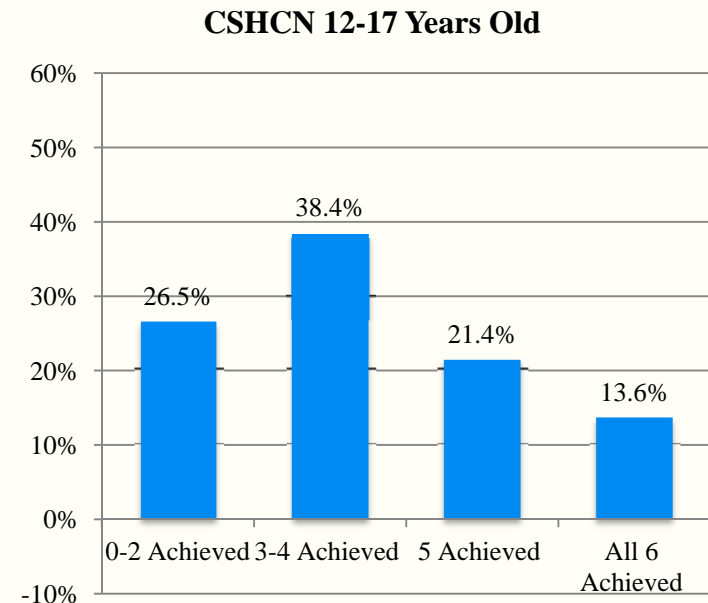
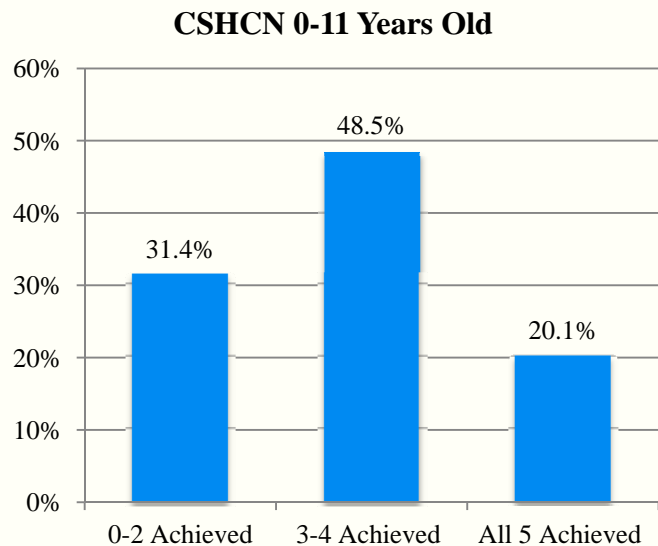
Existing needs and service and system capacity gaps

- Over 90% of CSHCN experience **functional difficulties**
- Majority of CSHCN have **co-occurring** health conditions and require **multiple specialized services**
- Prevalence of **impacting conditions** growing --more than doubled between 1979 and 2009 .
- Emotional, behavioral and developmental (EBD) conditions are currently the leading cause of activity limitations
- The health care system in the US is **ill-equipped** to appropriately care for people with multiple chronic conditions and especially **falls short** in addressing the social, psychosocial and behavioral dimensions of chronic illness

Capacity and Competency Gaps Reflected in Performance in MCHB's System of Service Model for CSHCN



Proportion of CSHCN Meeting MCHB CSHCN Systems of Care Quality Indicators, Nationwide (2009/10 NS-CSHCN)



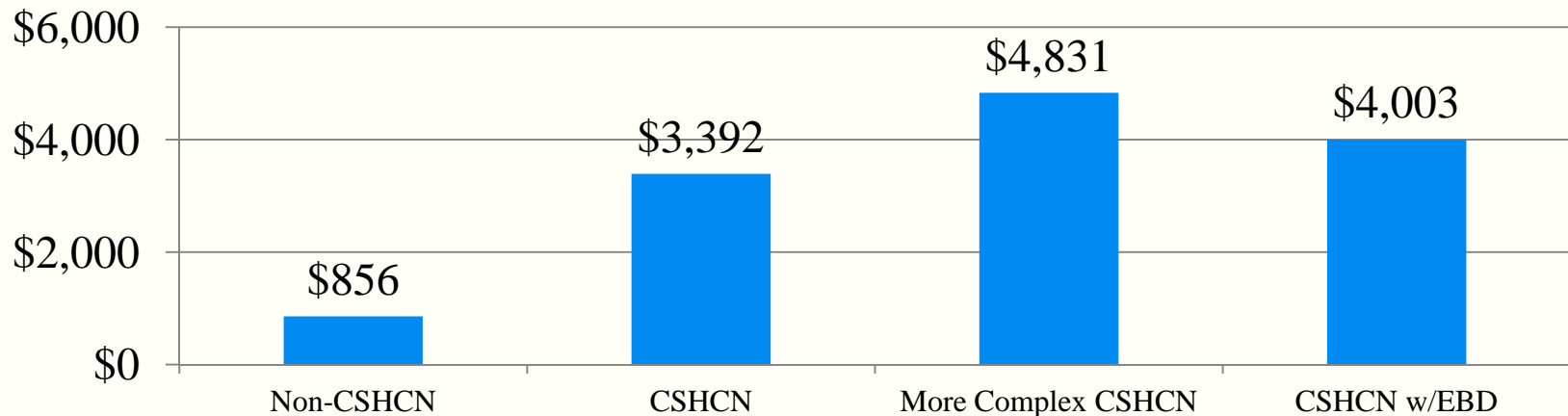
Examples of key gaps

- **Focus on families and community**: vital role that families, communities and the environment have in the support and care of CSHCN
- **Focus on whole child**: Accounting for the potentially long-term impact of challenges experienced by many CSHCN and their families
 - Impact on developing self-image and sense of meaning, school performance, friendships and purpose and opportunities in life
 - Suffering associated with the impact having a child with a special health care need can have on their family
- **Focus on health promotion**: prioritize and proactively address the influence of lifestyle factors in preventing or managing chronic conditions
 - Stress management, physical activity and nutrition

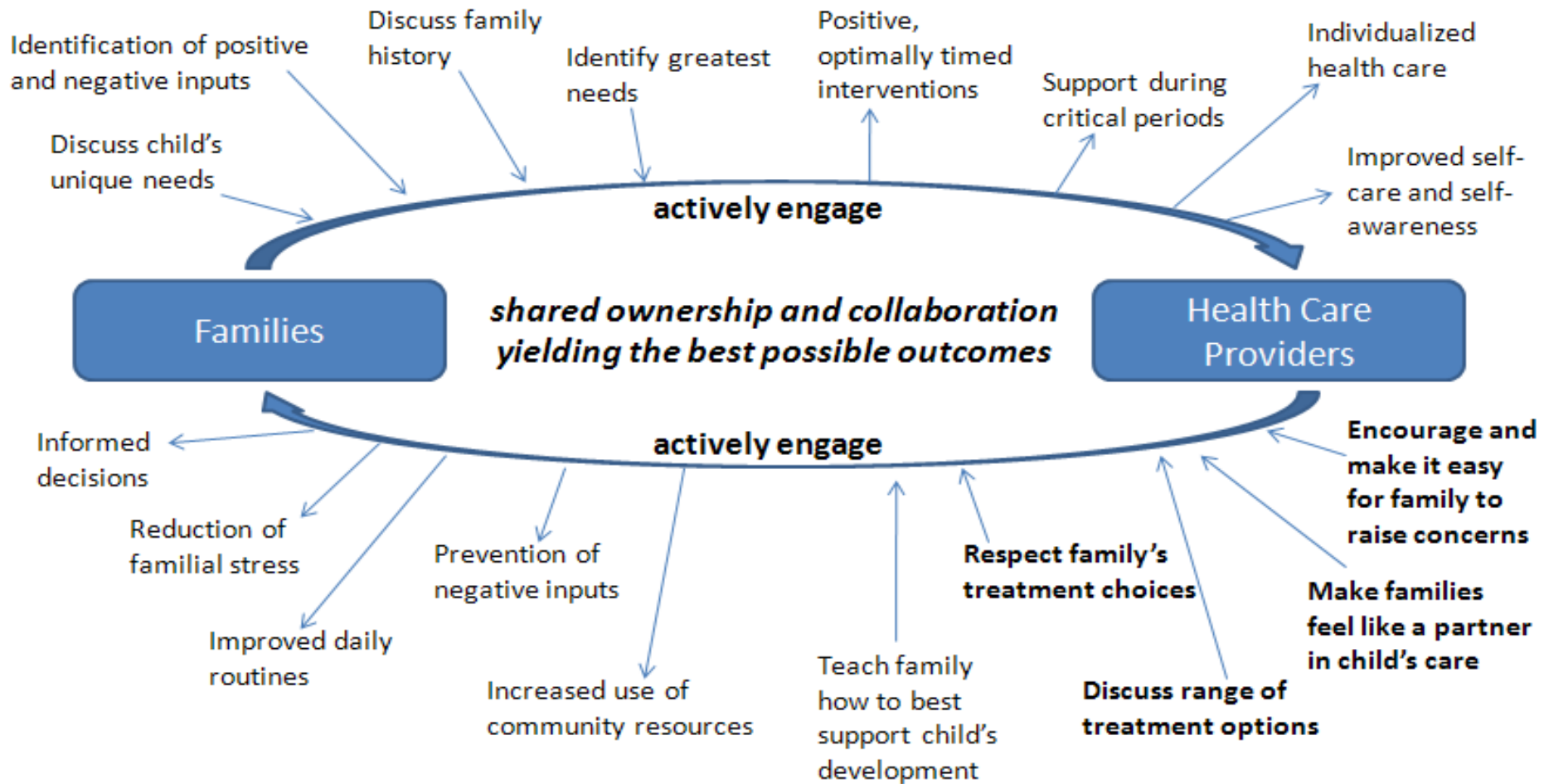
Links between child and adult health

- Adult chronic disease, well-being and functioning are often anchored to childhood well-being and health
 - 1/3rd of adult disability days are attributable to conditions and risks that arose in childhood
- Shorter term health care costs savings-in form of reduced acute events and efficiencies through coordination and partnership are anticipated

Average Adjusted Medical Expenditures



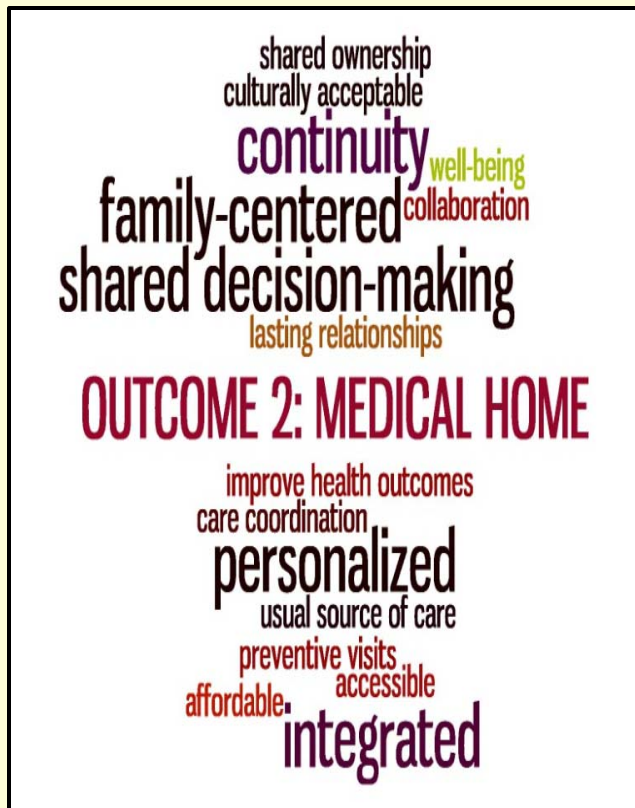
Core Competency: Family and Community Partnerships (MCHB Core Outcome #1: Family Partnerships)



Core Competency: Whole Child and Whole Systems View (MCHB Core Outcome #2: Medical Home)

A Closer Look at The Medical Home -- its Potential

Supports whole-person development through **integration and stability**.

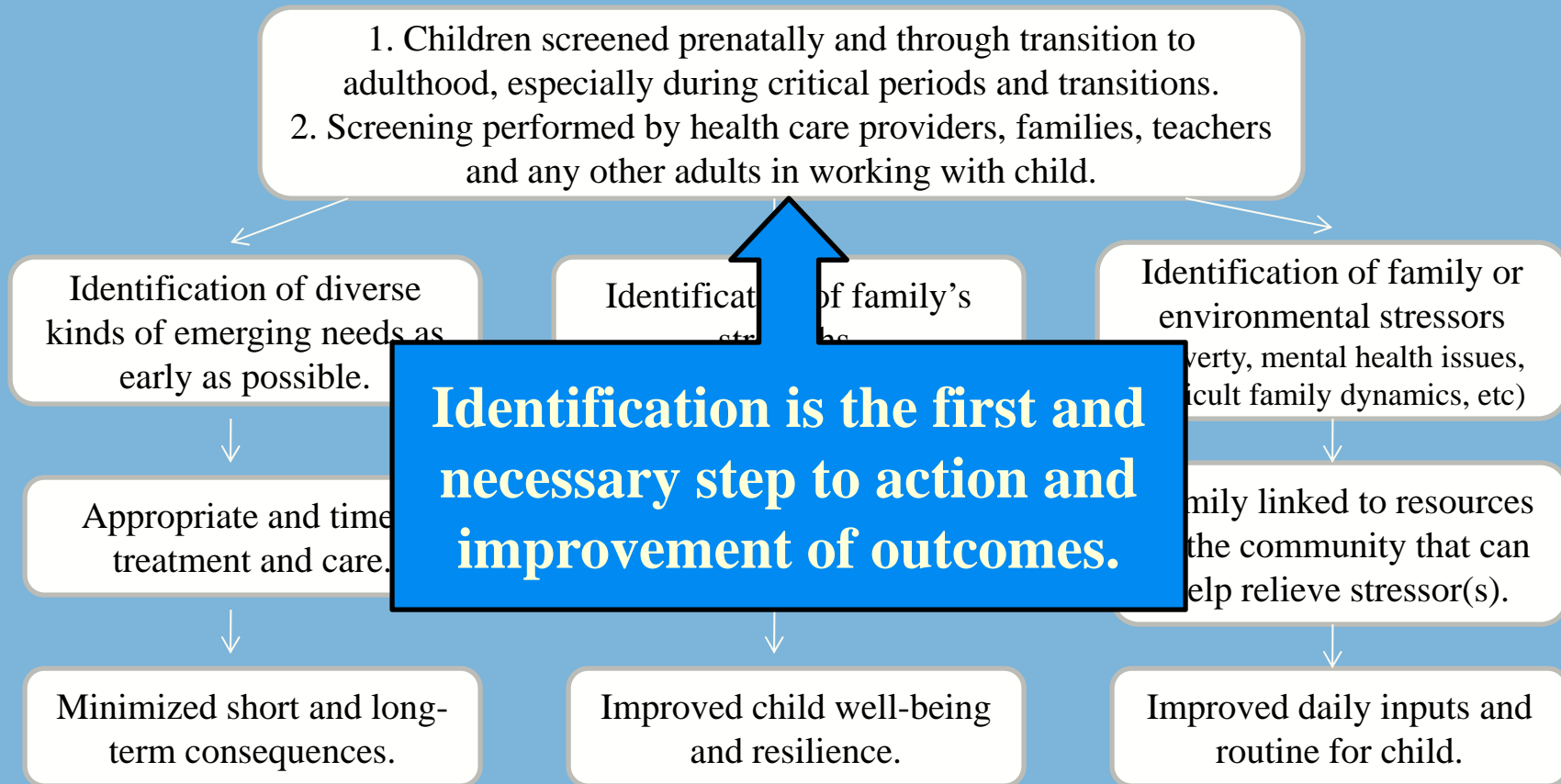


- Easy and timely access to appropriate, individualized and comprehensive health care
- Families given the information and mechanisms to be actively engaged in their child's care
- Provides support and consistency throughout diverse developmental stages
 - Ideally from pre-natal maternal care through transition to adulthood
- Lead to better interventions through a thorough understanding of an individual's risk and protective factors
- Appropriate health promotion and preventive care that's integrated and focused on positive long-term outcomes



Core Competency: Continuous Surveillance and Response (MCHB Core Outcome #4: Early & Continuous Screening)

Early and Continuous Screening -- Its Potential



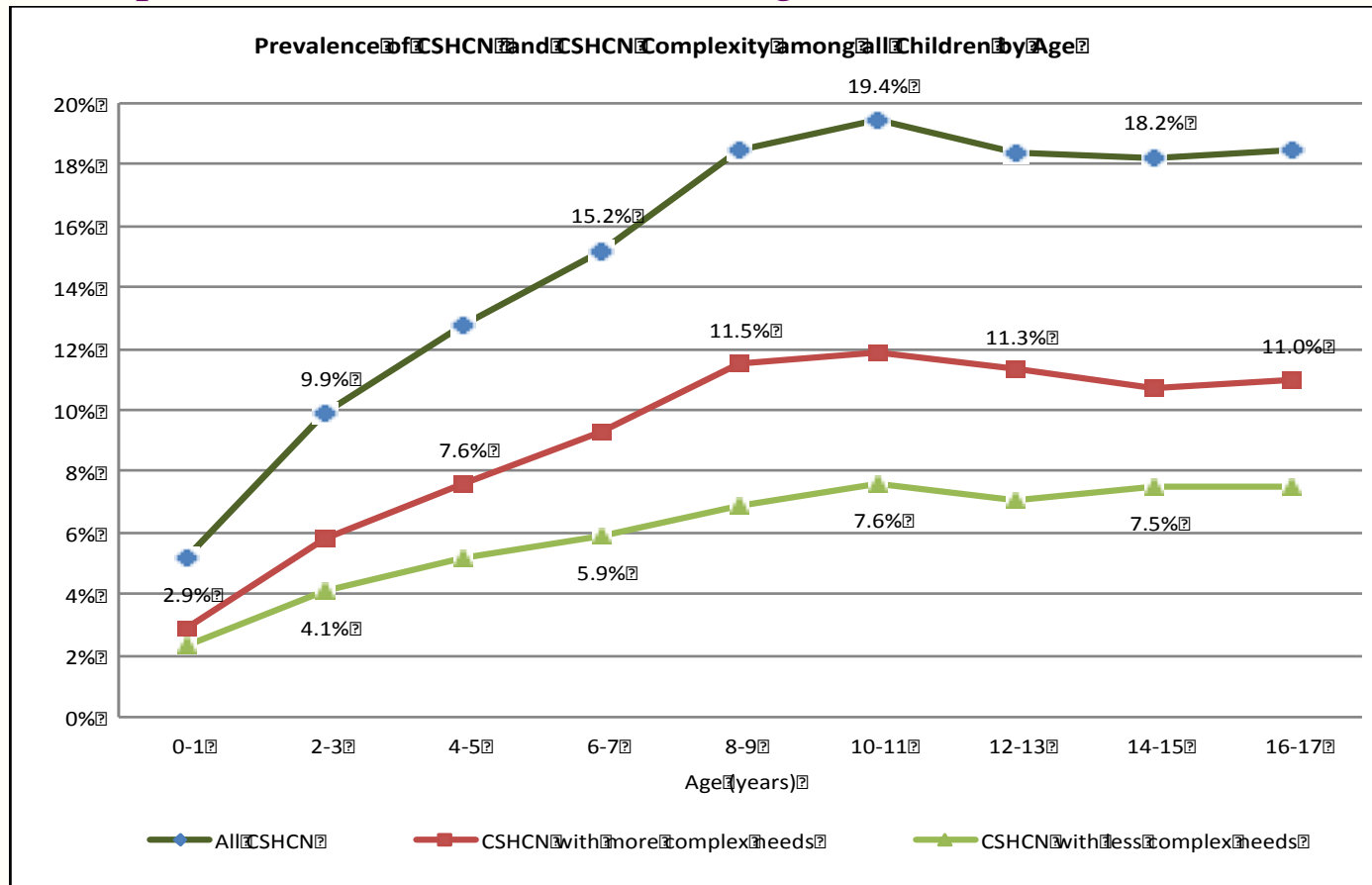


National data findings for CSHCN across key life course concepts: timeline, timing, environment, equity

- **Synthetic timeline** across seven **age groups** of children
- Identification of **hypotheses and questions** related to:
 - Interplay between *biopsychosocial environmental factors and child health and well being* (e.g. home environment; access to medical home; school success; social behaviors; functioning)
- Bivariate analyses and Multivariate logistic regression models were run and **adjusted odds ratios** assessed variations in variations
 - Example: Variations in association between factors across ages by (1) CSHCN Status; (2) Complexity of CSHCN, etc.
 - Adjustment: Household income, insurance type, family structure, race & gender; where appropriate CSHCN “type”

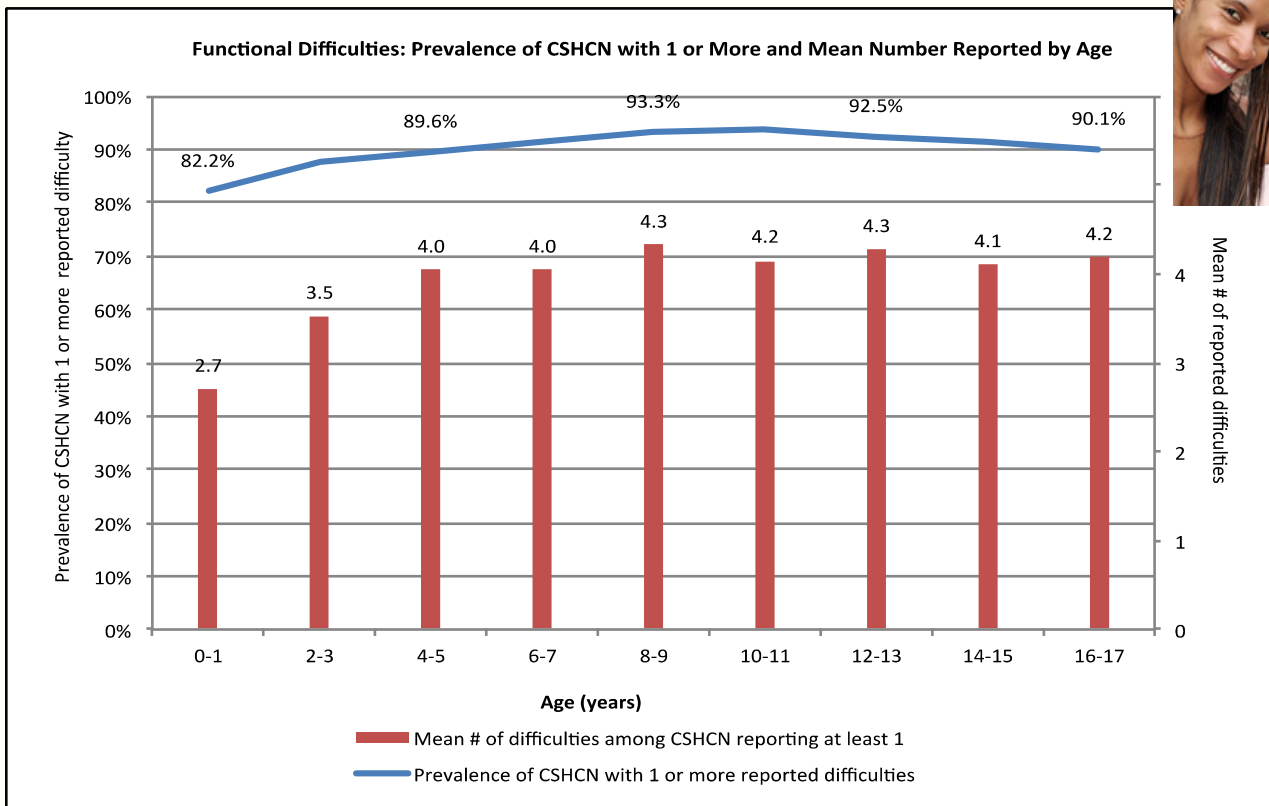
Timeline: Today's experiences and exposures influence tomorrow's health

The health status and needs of CSHCN increase in impact and complexity across life stages – prevalence of CSHCN, both those with more and less complex needs increases with age



Timeline: Today's experiences and exposures influence tomorrow's health

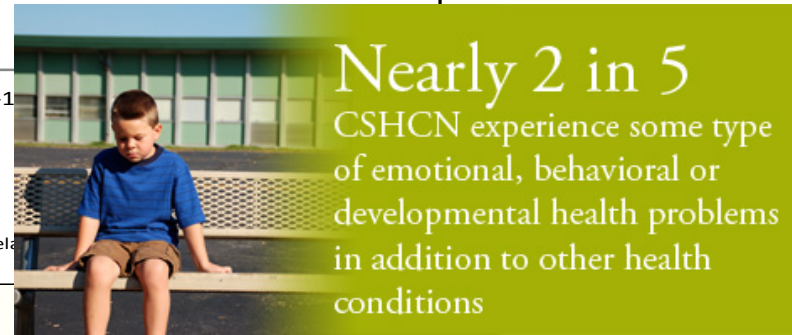
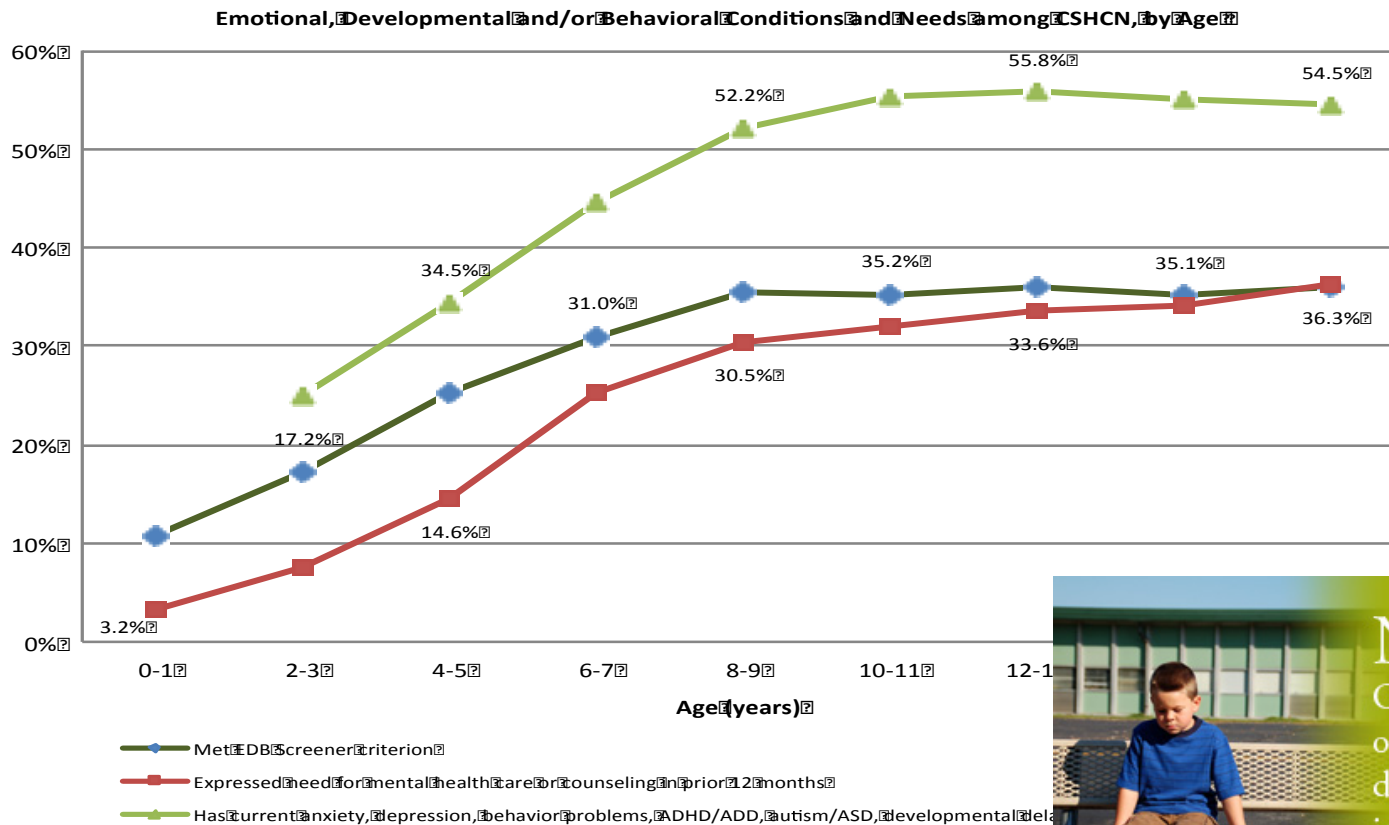
The health status and needs of CSHCN increase in impact and complexity across life stages – as CSHCN get older, not only does the prevalence of any functional difficulties increase, so does the mean number experienced



Co-morbidity of health conditions is common—
One quarter of CSHCN have 3 or more conditions asked about in the survey

Timeline: Today's experiences and exposures influence tomorrow's health

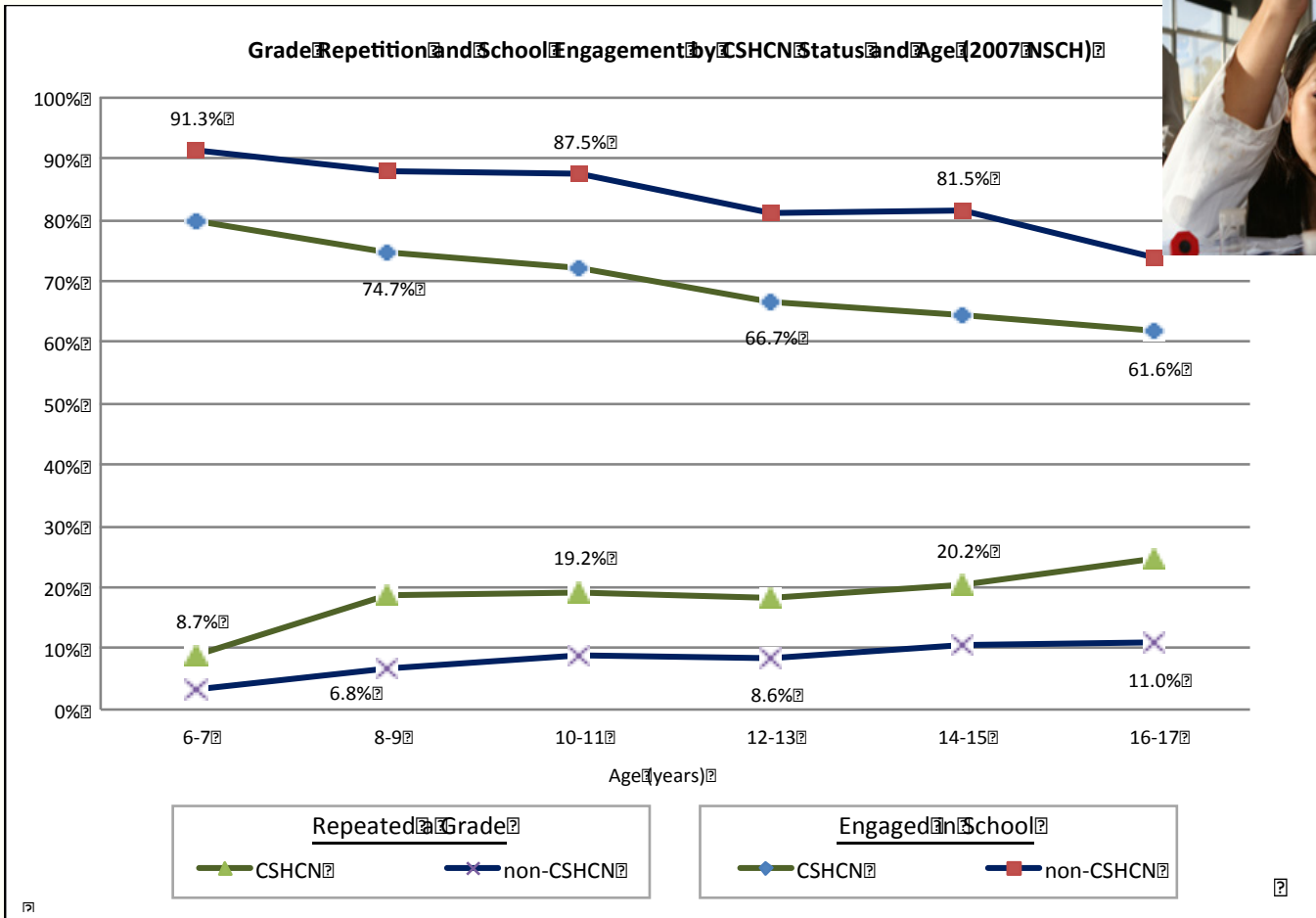
The health status and needs of CSHCN increase in impact and complexity across life stages - emotional, developmental and behavioral problems increase with age



Nearly 2 in 5
CSHCN experience some type of emotional, behavioral or developmental health problems in addition to other health conditions

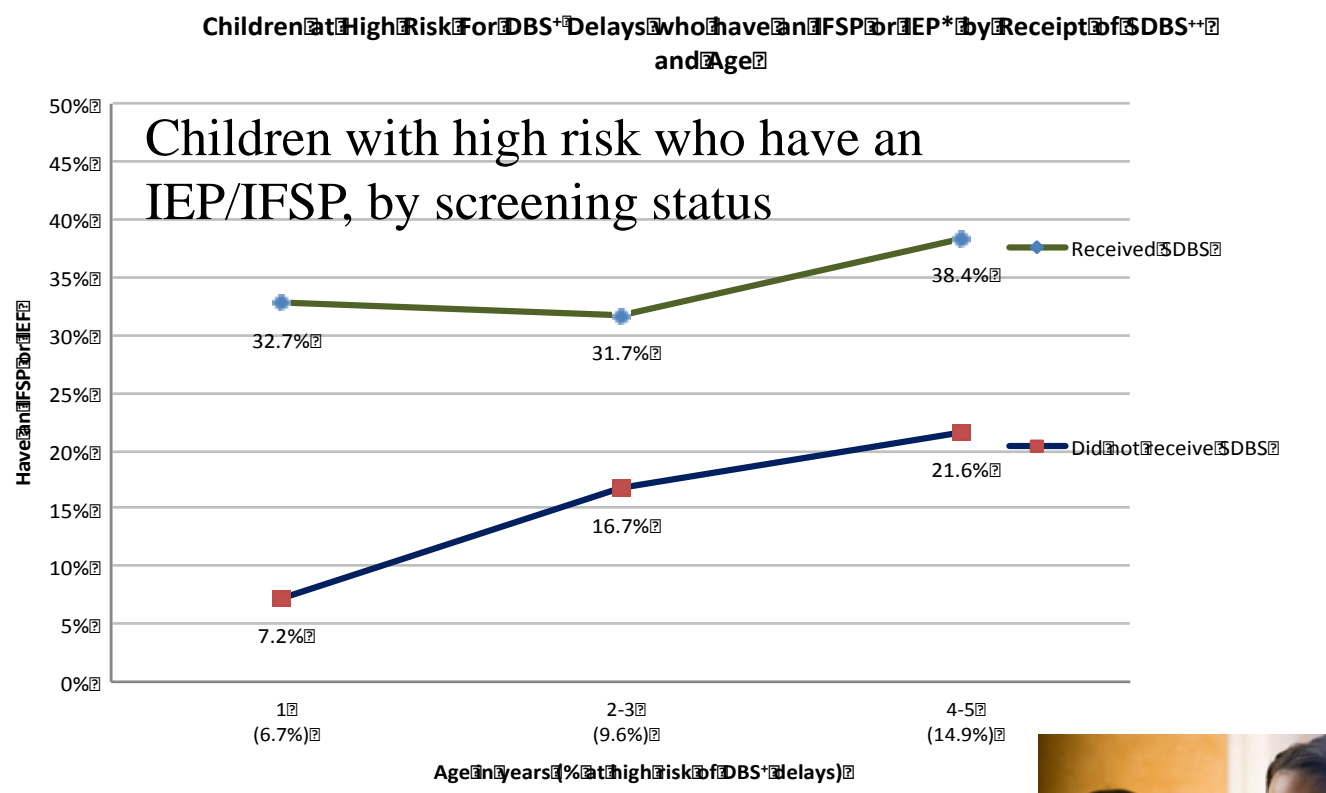
Timeline: Today's experiences and exposures influence tomorrow's health

Life course trajectories of CSHCN differ from those of other children, but there are also parallels



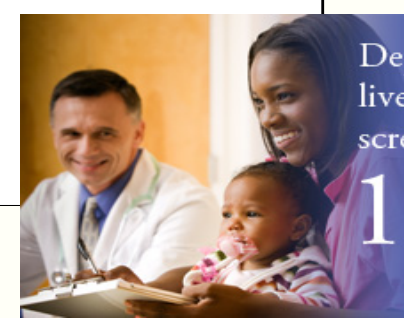
Timing: health trajectories are particularly affected during critical or sensitive periods of development

Opportunities to improve readiness for school are pronounced



Standardized screening associated with receipt of IFSP and IEP among children at high risk of delays and problems.

⁺DBS: Developmental, Behavioral or Social
^{*}IFSP: Individualized Family Services Plan; IEP: Individualized Education Plan
⁺⁺SDBS: Standardized Developmental and Behavioral Screening



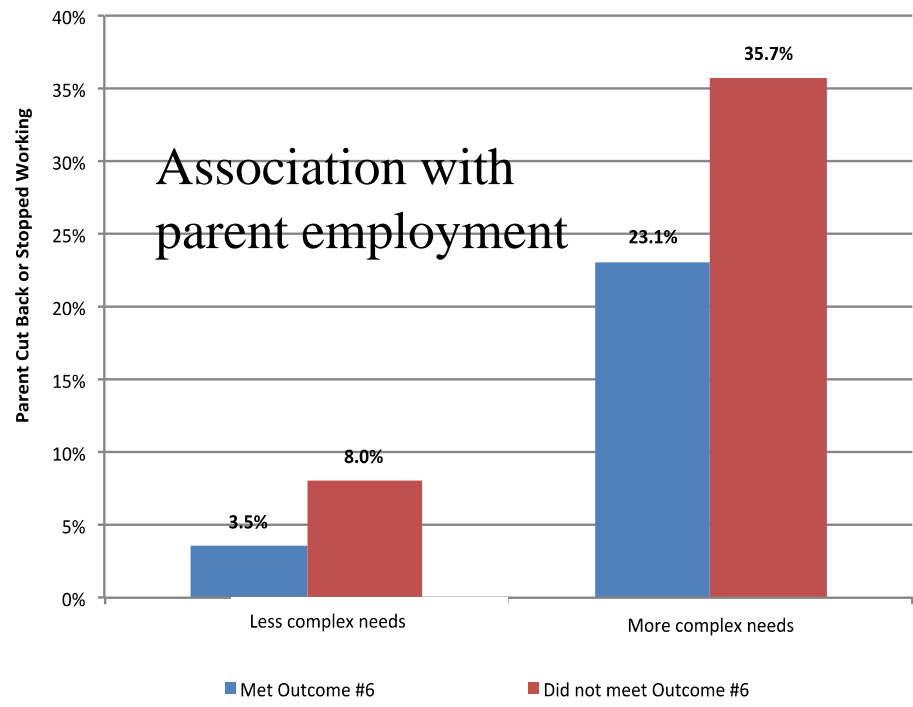
Depending on the state a child lives in, rates of developmental screening range from

11%-47%

Transition to Adulthood Services



CSHCN age 12-17 Whose Parents' Employment was Affected by Their Health Needs by Receipt of Transition Services (Outcome 6) and Complexity of Health Needs

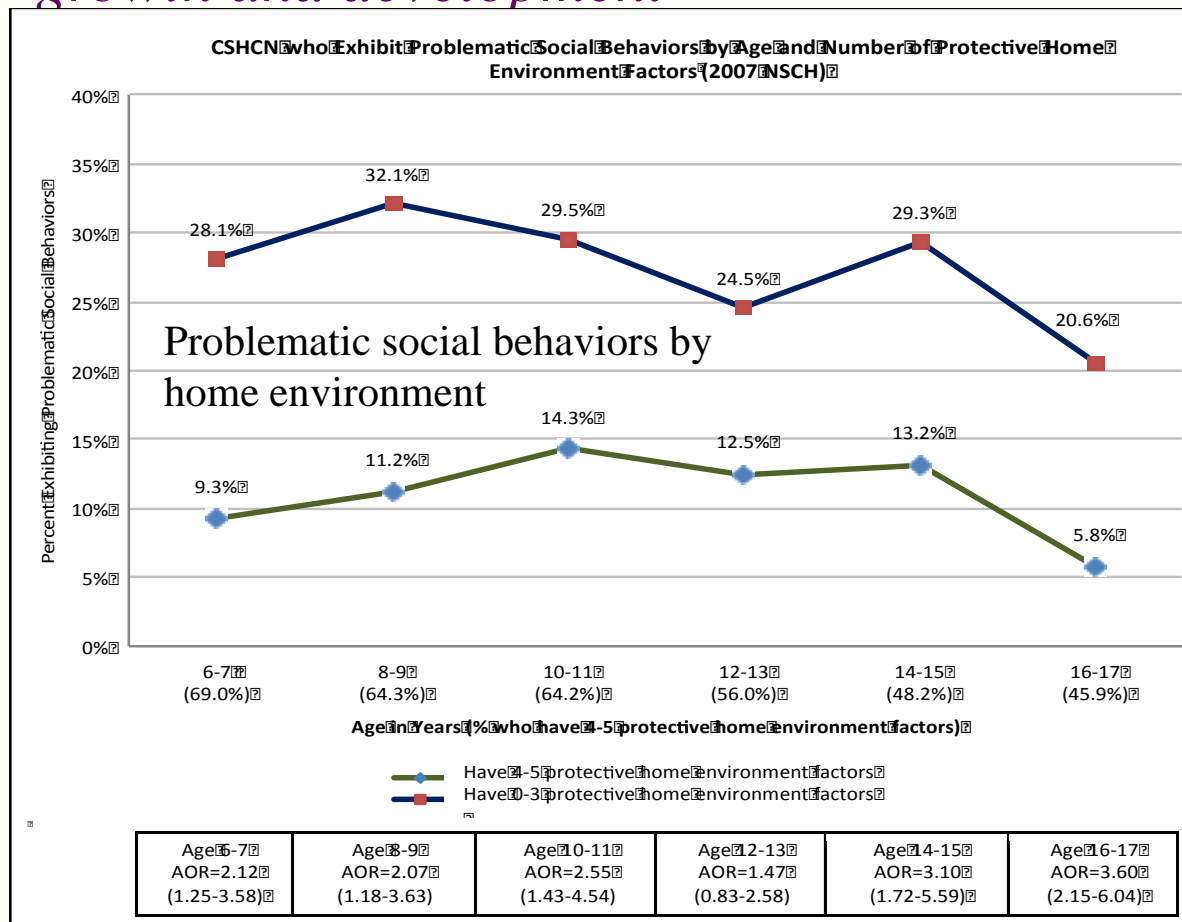


Environment: the broader community environment – biologic, physical, and social – strongly affects the capacity to be healthy (1)

Home environment impacts the well being of CSHCN across all stages of growth and development



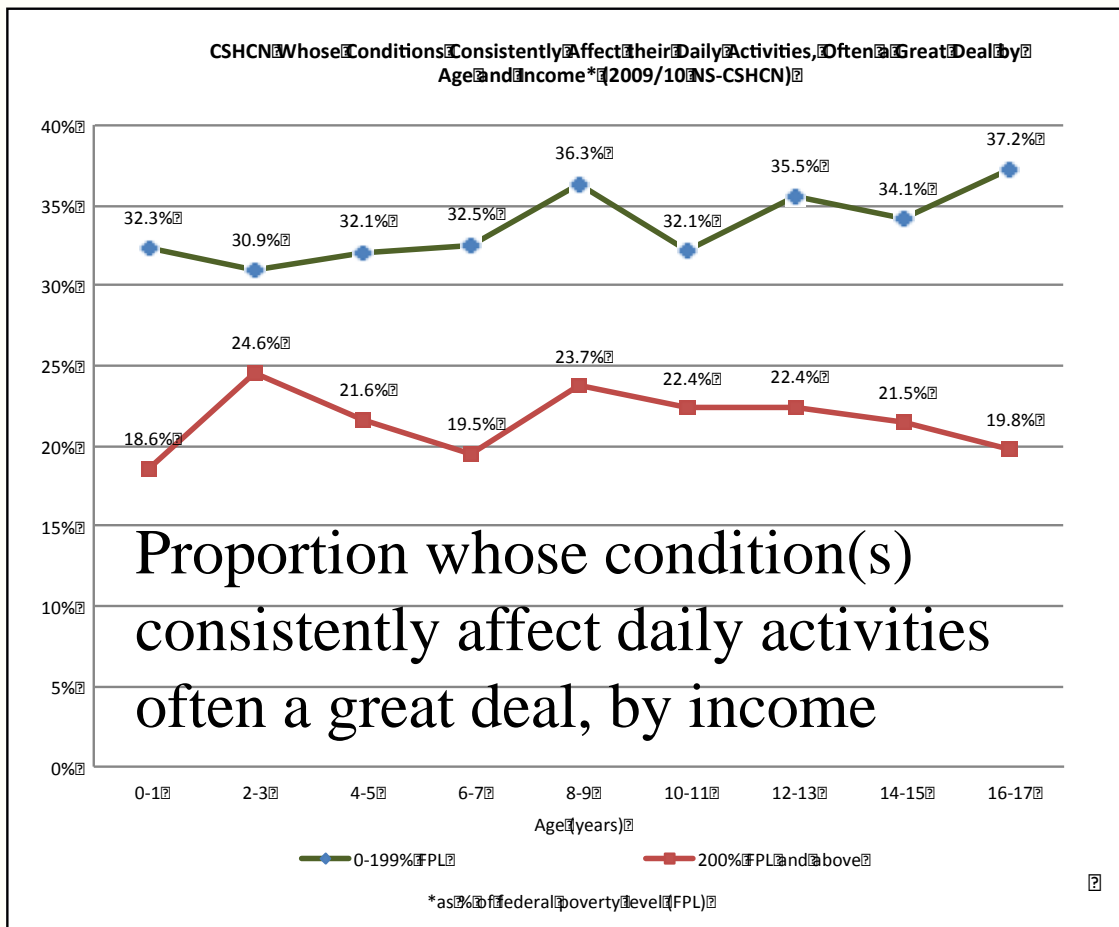
Children living in poverty are over 5 times more likely to be exposed to smoke inside their home



Over 75% of children have families who eat meals together at least 4 nights a week

Environment: the broader community environment – biologic, physical, and social – strongly affects the capacity to be healthy (2)

Home environment impacts the well being of CSHCN across all stages of growth and development, but varies across income groups

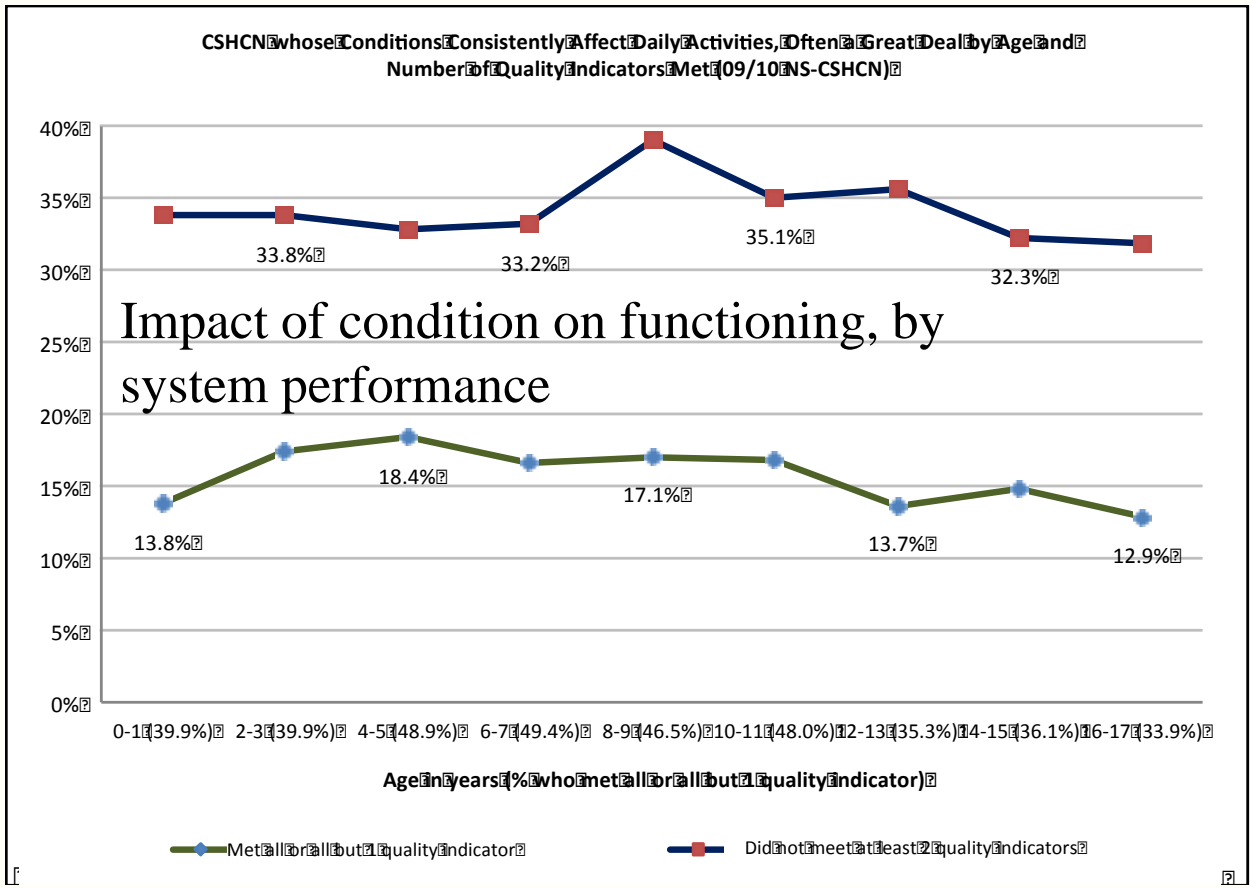


- The observed **increasing trend** for CSHCN in the **lower income group** and a **gradual decrease** for CSHCN in the **higher income group** suggest a possible cumulative impact of lower income for CSHCN in terms of impact on daily life.

Equity: inequality in health is impacted by the services and care children receive and reflects more than genetics and personal choice

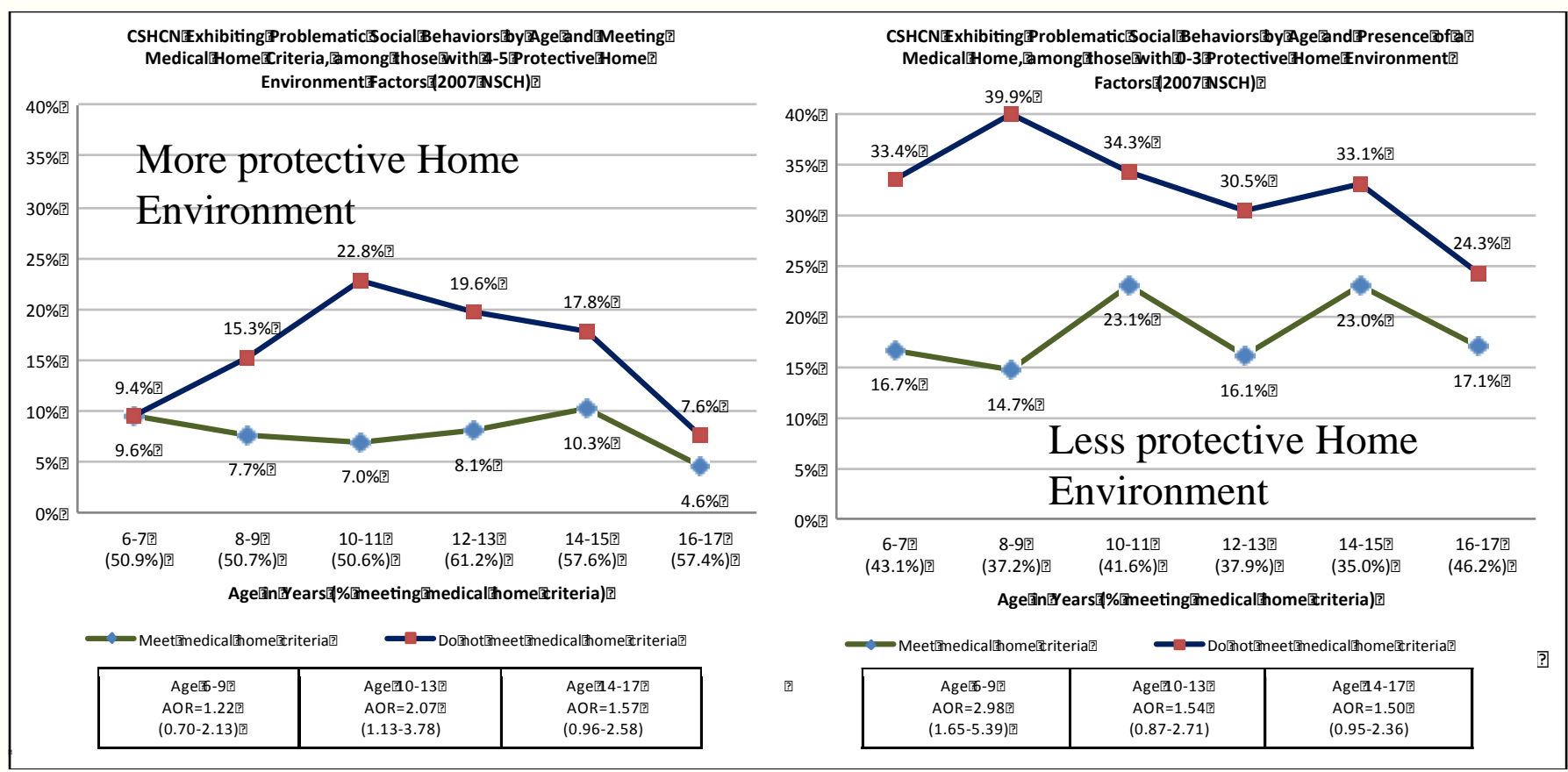
Health care system quality gaps are associated with functional status of CSHCN...

- CSHCN who meet *fewer* of the federal Maternal and Child Health Bureau CSHCN systems of care *quality indicators* are *more likely* to suffer greater *limitations* in their daily activities due to their conditions



Equity: inequality in health is impacted by the services and care children receive and reflects more than genetics and personal choice

Medical homes are associated with a lower prevalence of problematic social behaviors at all ages, irrespective of the home environment factors





Promoting and Monitoring the Life Course Perspective in Systems Serving CSHCN

Accelerate Learning

- Effects of early life experiences
- Role of critical and sensitive periods during the life course
- Impact of positive and negative environmental influences on health and well-being across life
- Cumulative impact of adverse and protective factors
- How the life course of CSHCN is similar and different from other children

Address persistent barriers to establishing comprehensive systems of services:

Financing

- Aligning incentives, including payment and performance measurement
- Cover services essential to promote health, coordinate care and support families

Culture

- Partnership based
- Oriented to promote positive health

Organization and Capacity

Skills and structures to support **relationships and information flow**

Delivering on the potential a life course perspective presents

- A life course perspective in MCH states that “*throughout life and at all stages, even for those whose trajectories seem limited, risk factors can be reduced and protective factors enhanced, to improve current and subsequent health and well-being*” (Fine and Kotelchuck)