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

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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

How can the MCHB Core Outcomes for CSHCN provide a framework that is best positioned to promote optimal health development over the life course?

How can we leverage current Life Course knowledge to best improve this framework?
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
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

Community-based services are organized for ease of use.

- CSHCN receive coordinated, ongoing and comprehensive care within a medical home.
- Children are screened early and continuously for special health care needs.
- Youth with special health care needs receive services necessary for a successful transition to adult life.

Families of CSHCN are partners in decision making at all levels.

Families of CSHCN have adequate insurance to pay for the services they need.

Families of CSHCN are influenced by the need to pay for services.

Children are screened early and continuously for special health care needs.

Youth with special health care needs receive services necessary for a successful transition to adult life.

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Families of CSHCN have adequate insurance to pay for the services they need.
Persistent gaps in health care quality and system capacity for CSHCN

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

8 out of 10 CSHCN ages 0-11 experience one or more gaps across five system of care performance criteria

CSHCN 0-11 Years Old

- 0-2 Achieved: 31.4%
- 3-4 Achieved: 48.5%
- All 5 Achieved: 20.1%

CSHCN 12-17 Years Old

- 0-2 Achieved: 26.5%
- 3-4 Achieved: 38.4%
- 5 Achieved: 21.4%
- All 6 Achieved: 13.6%

Fewer than 1 in 5 CYSHCN ages 12-17 meet all six system of care performance criteria
• **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**

- Non-CSHCN: $856
- CSHCN: $3,392
- More Complex CSHCN: $4,831
- CSHCN w/EBD: $4,003
Core Competency: Family and Community Partnerships  
(MCHB Core Outcome #1: Family Partnerships)

**Families**
- Identification of positive and negative inputs
- Discuss family history
- Identify greatest needs
- Positive, optimally timed interventions
- Support during critical periods
- Individualized health care
- Improved self-care and self-awareness
- Informed decisions
- Reduction of familial stress
- Improved daily routines
- Increased use of community resources
- Teach family how to best support child’s development

**Health Care Providers**
- Respect family’s treatment choices
- Discuss range of treatment options
- Encourage and make it easy for family to raise concerns
- Make families feel like a partner in child’s care

*actively engage*

*shared ownership and collaboration yielding the best possible outcomes*
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
Early and Continuous Screening -- Its Potential

1. Children screened prenatally and through transition to adulthood, especially during critical periods and transitions.
2. Screening performed by health care providers, families, teachers and any other adults in working with child.

- Identification of diverse kinds of emerging needs as early as possible.
- Identification of family’s strengths.
- Identification of family or environmental stressors (poverty, mental health issues, difficult family dynamics, etc).
- Identification of family linked to resources in the community that can help relieve stressor(s).

Identification is the first and necessary step to action and improvement of outcomes.

- Minimized short and long-term consequences.
- Improved child well-being and resilience.
- Improved daily inputs and routine for child.
National data findings for CSHCN across key life course concepts: timeline, timing, environment, equity
Methods

- 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
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.
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

Children with emotional, behavioral or developmental problems are over twice as likely to not be engaged in school
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.

Depending on the state a child lives in, rates of developmental screening range from 11% to 47%.
Timing: health trajectories are particularly affected during critical or sensitive periods of development (3)

**Transition to Adulthood Services**

One-quarter of all CSHCN have families who cut back or stopped working due to their child’s health needs.

Youth with a medical home are almost 2 times more likely to receive services to support their transition to adulthood.
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

<table>
<thead>
<tr>
<th>Age in Years</th>
<th>No. of Protective Home Environment Factors</th>
<th>CSHCN who Exhibit Problematic Social Behaviors</th>
<th>Age Group</th>
<th>AOR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>6-7</td>
<td>0-3</td>
<td>28.1%</td>
<td>69.0%</td>
<td>2.12 (1.25-3.58)</td>
</tr>
<tr>
<td>8-9</td>
<td>0-3</td>
<td>32.1%</td>
<td>64.3%</td>
<td>2.07 (1.18-3.63)</td>
</tr>
<tr>
<td>10-11</td>
<td>0-3</td>
<td>29.5%</td>
<td>64.2%</td>
<td>2.55 (1.43-4.54)</td>
</tr>
<tr>
<td>12-13</td>
<td>0-3</td>
<td>24.5%</td>
<td>56.0%</td>
<td>1.47 (0.83-2.58)</td>
</tr>
<tr>
<td>14-15</td>
<td>0-3</td>
<td>29.3%</td>
<td>48.2%</td>
<td>3.10 (1.72-5.59)</td>
</tr>
<tr>
<td>16-17</td>
<td>0-3</td>
<td>20.6%</td>
<td>45.9%</td>
<td>3.60 (2.15-6.04)</td>
</tr>
<tr>
<td>6-7</td>
<td>4-5</td>
<td>5.8%</td>
<td>69.0%</td>
<td>5.07 (2.60-9.90)</td>
</tr>
<tr>
<td>8-9</td>
<td>4-5</td>
<td>14.3%</td>
<td>64.3%</td>
<td>2.21 (1.29-3.73)</td>
</tr>
<tr>
<td>10-11</td>
<td>4-5</td>
<td>12.5%</td>
<td>64.2%</td>
<td>1.85 (1.07-3.21)</td>
</tr>
<tr>
<td>12-13</td>
<td>4-5</td>
<td>13.2%</td>
<td>56.0%</td>
<td>1.62 (0.92-2.86)</td>
</tr>
<tr>
<td>14-15</td>
<td>4-5</td>
<td>5.8%</td>
<td>48.2%</td>
<td>3.50 (1.89-6.44)</td>
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Over 75% of children have families who eat meals together at least 4 nights a week
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.

### CSHCN Exhibiting Problematic Social Behaviors by Age and Meeting Medical Home Criteria, among those with 4-5 Protective Home Environment Factors (2007 NSCH)

- **More protective Home Environment**
  - Age 6-9: 9.4% (AOR=1.22, 0.70-2.13)
  - Age 10-11: 15.3% (AOR=1.07, 1.13-3.78)
  - Age 12-13: 22.8% (AOR=1.57, 0.96-2.58)
  - Age 14-15: 19.6% (AOR=1.57, 0.96-2.58)
  - Age 16-17: 17.8% (AOR=1.57, 0.96-2.58)

- **Less protective Home Environment**
  - Age 6-9: 6.7% (AOR=1.28, 1.13-3.78)
  - Age 10-11: 7.0% (AOR=1.57, 0.96-2.58)
  - Age 12-13: 8.1% (AOR=1.57, 0.96-2.58)
  - Age 14-15: 10.3% (AOR=1.57, 0.96-2.58)
  - Age 16-17: 7.6% (AOR=1.57, 0.96-2.58)

### CSHCN Exhibiting Problematic Social Behaviors by Age and Presence of a Medical Home, among those with 0-3 Protective Home Environment Factors (2007 NSCH)

- **Meet medical home criteria**
  - Age 6-7: 16.7% (AOR=1.64, 0.50-5.54)
  - Age 8-9: 33.4% (AOR=2.98, 1.65-5.39)
  - Age 10-11: 43.1% (AOR=2.98, 1.65-5.39)
  - Age 12-13: 34.3% (AOR=1.54, 0.87-2.71)
  - Age 14-15: 30.5% (AOR=1.54, 0.87-2.71)
  - Age 16-17: 24.3% (AOR=1.54, 0.87-2.71)

- **Do not meet medical home criteria**
  - Age 6-7: 39.9% (AOR=2.98, 1.65-5.39)
  - Age 8-9: 14.7% (AOR=1.54, 0.87-2.71)
  - Age 10-11: 23.1% (AOR=1.54, 0.87-2.71)
  - Age 12-13: 16.1% (AOR=1.54, 0.87-2.71)
  - Age 14-15: 23.0% (AOR=1.54, 0.87-2.71)
  - Age 16-17: 17.1% (AOR=1.54, 0.87-2.71)
Promoting and Monitoring the Life Course Perspective in Systems Serving CSHCN
Where there is to go

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
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)