Translation of the Life Course Approach from Theory to Public Health Practice

Andria Cornell, *Senior Program Manager, Women's Health*
AMCHP

Presentation Goals

- **Share** an overview of the life course approach and the growing momentum for measurement
- **Share** the process for the Life Course Metrics Project
- **Consider** challenges and opportunities in measurement
- **Share** project resources

Who is AMCHP?

AMCHP is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

AMCHP Mission and Vision

Mission: AMCHP supports state maternal and child health programs and provides national leadership on issues affecting women and children

Vision: AMCHP envisions a society where healthy children and healthy families live in healthy communities

Who are our Members?

- State public health leaders
- High-level state government officials
- Directors of MCH programs (Title V directors)
- Directors of CSHCN programs
- Adolescent health coordinators
- Families
- Academic, advocacy and community-based family health professionals

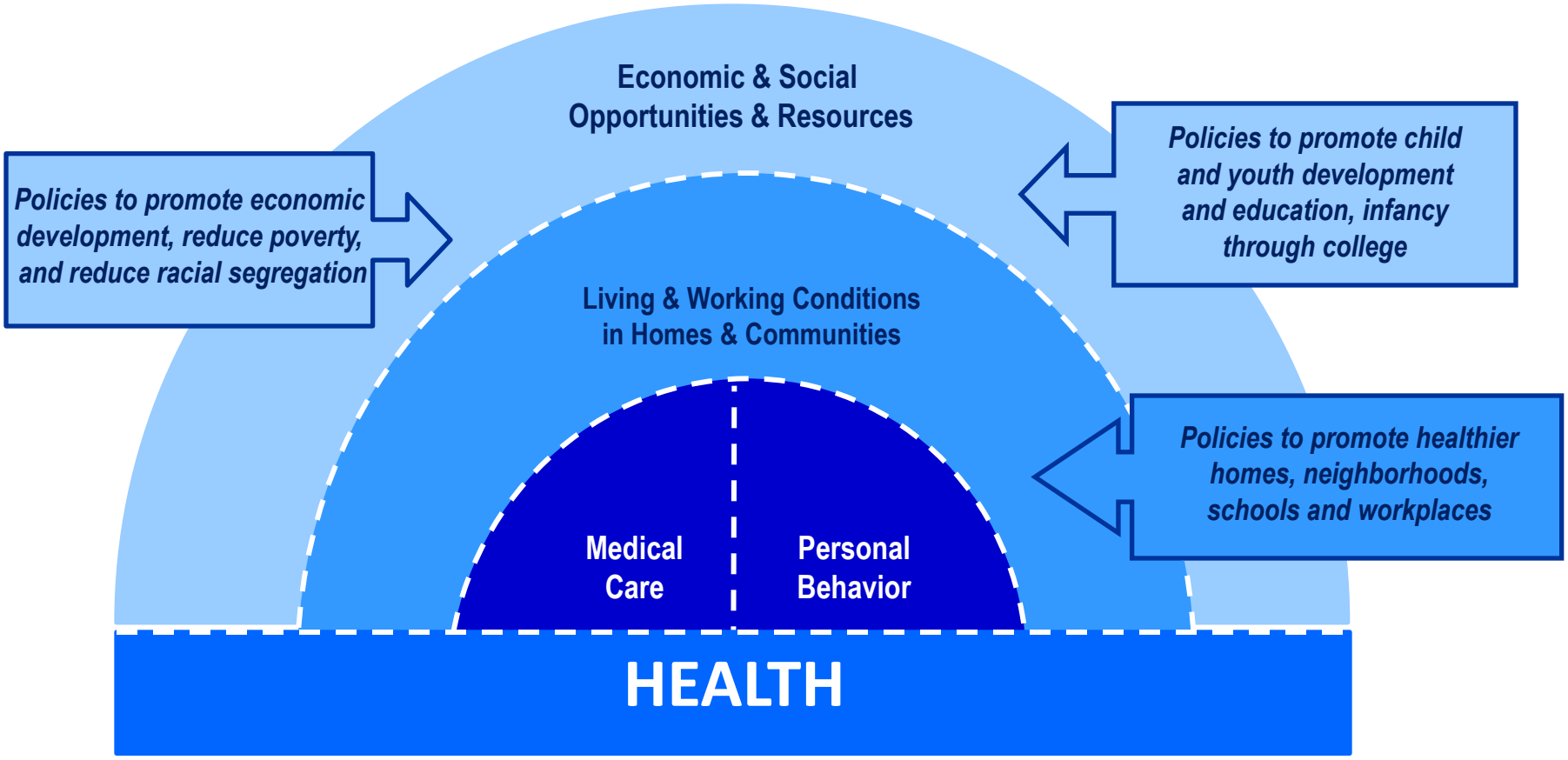
Growing Focus on Life Course

2010	•Concept Paper
2011	•SSDI guidance
2012	•Kellogg funding

The Life Course Approach

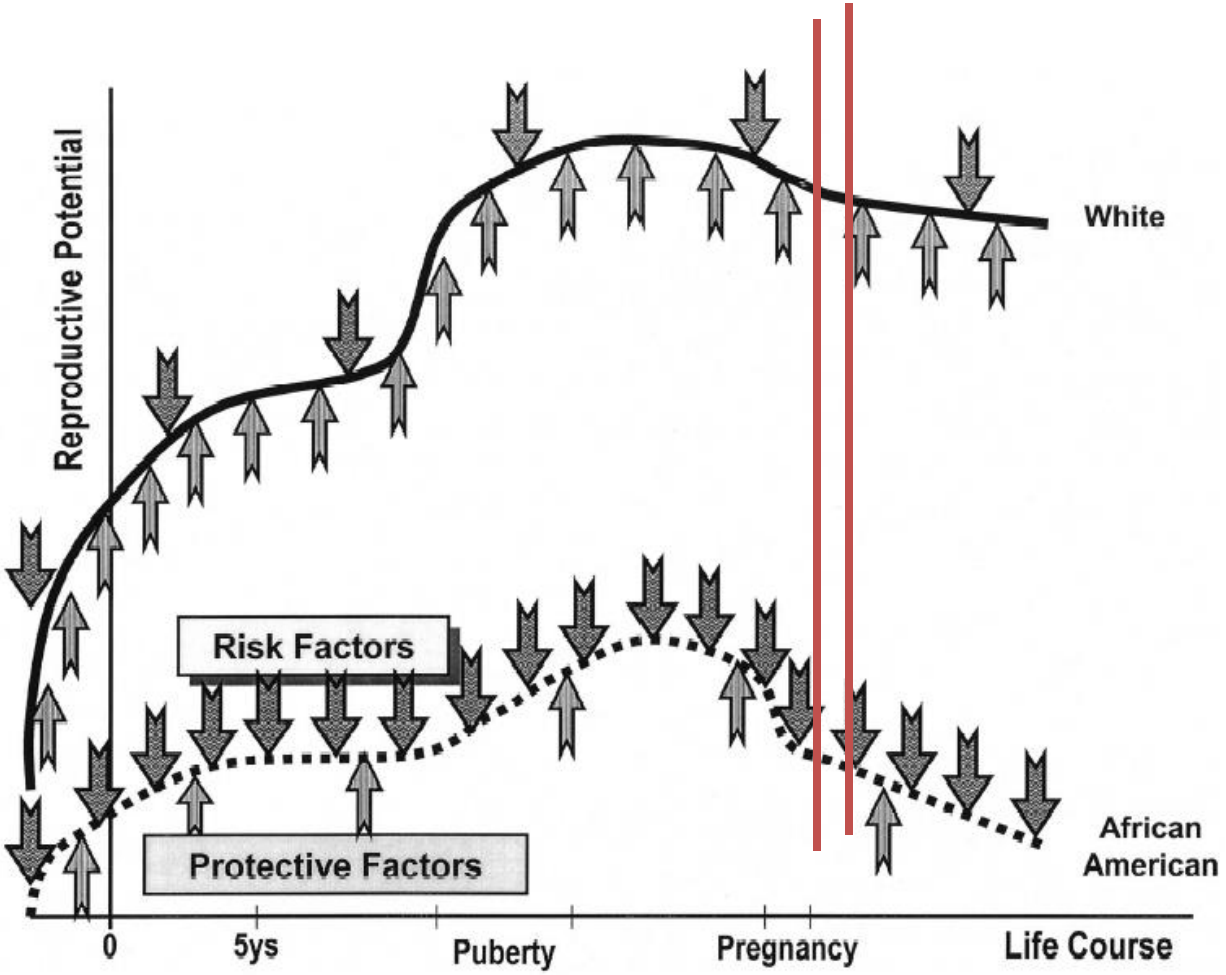
- **Our health today reflects our exposures** to diverse, complex, and interacting risk and protective factors during our lifetime and our parent's lifetime;
- The impact of these factors can **accumulate** over time;
- The **timing** of exposure to these factors matters;
- The **environment and community** in which we live, learn, and grow impacts our exposure to these factors;
- The **differential exposure** to risk and protective factors across population groups leads to **health disparities**

Many Models…



Source: P Braveman, *Pediatrics*, 2009

Many Models…



Lu MC, Halfon N. Racial and ethnic disparities in birth outcomes: a life-course perspective. Maternal Child Health J. 2003;7:13-30.

Purpose of Metrics Project

Develop tools to help state MCH programs and their partners emphasize a life course health perspective throughout:

- **Assessment** of risks, capacity, & services
- **Planning** programs
- **Monitoring** and **evaluation** of outcomes
- **Engaging** and **educating** partners

Domain	Perinatal/ Infancy	Early Childhood	Childhood/ School age	Adolescent	Young adult	Adult
Risk						
Services						
Outcomes						
Capacity						

State Teams

Florida

North Carolina

Nebraska

Iowa

Michigan

Louisiana

Massachusetts

Evaluation Criteria

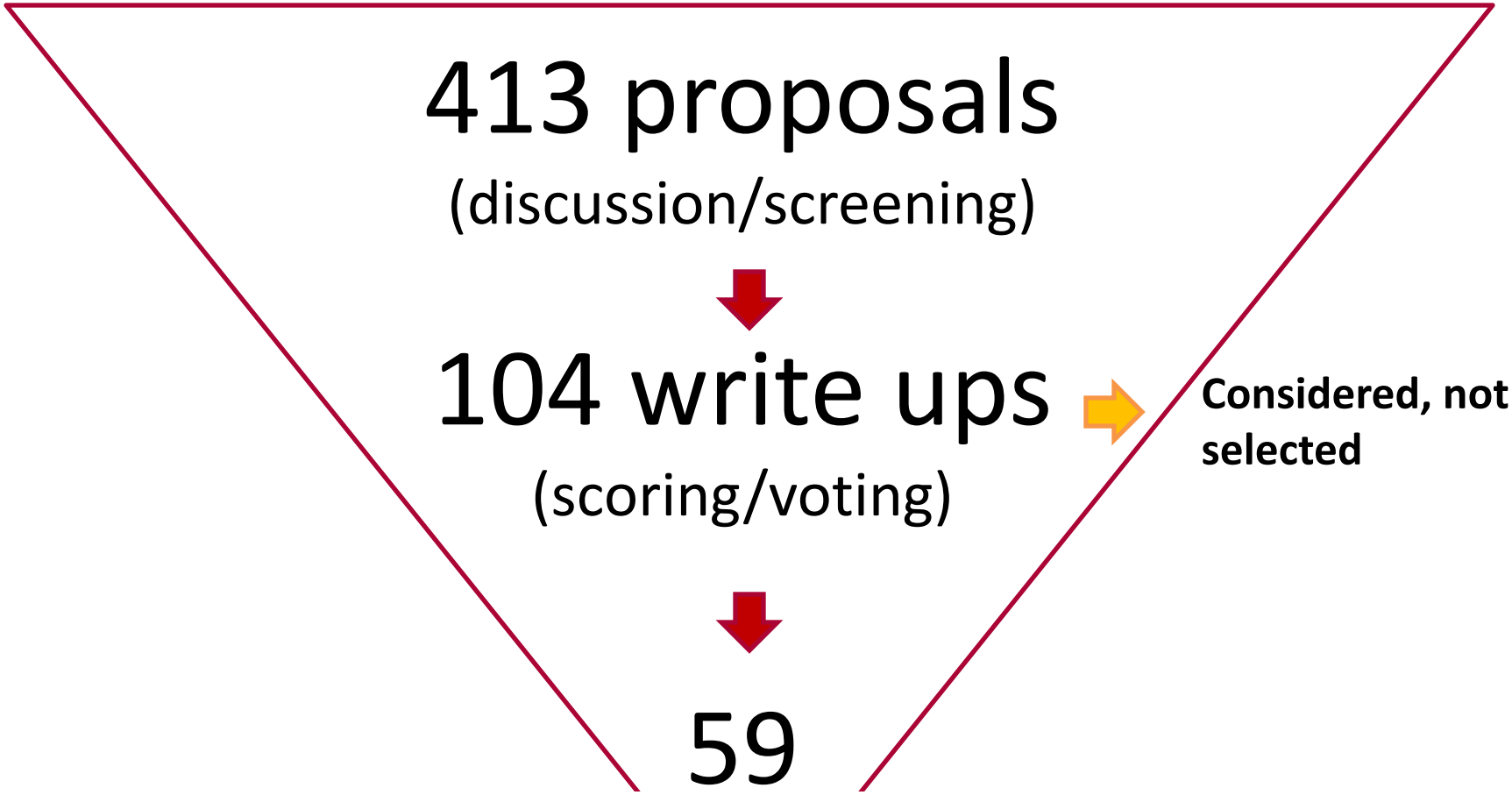
Data criteria

1. Data availability
2. Data quality
3. Simplicity

Life course criteria

1. Implications for equity
2. Public health impact
3. Ability to leverage or realign resources
4. Improve the health and wellness of an individual and/or their children
5. Consistent with evidence base

Selection Process



The Final Set

59 indicators across 12 categories

1. Childhood experiences
2. Community health policy
3. Community wellbeing
4. Discrimination and segregation
5. Early life services
6. Economic experiences
7. Family wellbeing
8. Health care access and quality
9. Mental health
10. Organizational measurement capacity
11. Reproductive life experiences
12. Social capital

AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Sign In

GO

About AMCHP | About Title V | Calendar | Policy & Advocacy | Programs & Topics

- Data & Assessment Home
- The Life Course Metrics Project
- Life Course Indicators Online Tool
- Resources

AMCHP > Programs & Topics > Data & Assessment > Life Course Indicators Online Tool

Life Course Indicators Online Tool

Explore the set of 59 life course indicators by Category, Data Source, or Domain (tabs) and click on the names to expand the section. Individual indicators are denoted by an ID number (e.g. LC-47) and include numerous details, such as a brief description, numerator, denominator, data source, similar measures in other indicator sets, and national comparison data, where appropriate. Throughout Fall 2013, AMCHP will continue to add PDF narratives for each indicator, which will include important notes on calculating the indicator as well as information on how the indicator aligns with the data and life course screening criteria.

Download a printer-friendly version of the list of indicators
Download an excel spreadsheet to sort and explore the indicators on your own

Category | Data Source | Domain

- **Childhood Experiences**
- **Community Health Policy**
- **Community Wellbeing**
- **Discrimination and Segregation**
  - **LC-12: Bullying**

Brief Description: Percent of 9-12th graders who reported being bullied on school property or electronically bullied

Narrative: PDF

Numerator: Number of 9th through 12th grade students (12-17 years) who reported having been bullied on school property or electronically during the past 12 months.

Denominator: 9th through 12th grade student population (12-17 years)

Data Source: Youth Risk Behavior Surveillance System (YRBSS)

Similar Measures in Other Indicator Sets: Healthy People 2020 focus area IVP-35.

National Comparison: 25.50% (for notes on calculation, please view the narrative)

www.amchp.org/lifecourseindicators

Fall 2013

Life Course Indicator:
Children and Youth with Special Health Care Needs

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Children & Youth with Special Health Care Needs (CYSHCN) (LC-25)

Brief description: Percent of children (0-17 years) with a special health care need

Indicator category: Family Wellbeing

Indicator domain: Risk/Outcome

Numerator: Children, ages 0-17 years with a special health care need

Denominator: Children, ages 0-17 years

Potential modifiers: Race, ethnicity, sex, age, SES/poverty, geographic location, access, language, medical home status, insurance status

Data source: National Survey of Children's Health (NSCH)

Notes on calculation: Children with special health care needs (CSHCN) are defined in the National Survey of Children's Health (NSCH) as those who have one or more chronic physical, developmental, behavioral or emotional conditions for which they require an above routine type or amount of health and related services, based on the definition set forth by the Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB). On the NSCH, to be counted as a child with special health care needs, a respondent must have qualifying responses on one or more of the five CSHCN Screener criteria (K2Q12; K2Q15; K2Q18; K2Q21; K2Q23). Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: HP 2020 Focus areas MICH-30 and MICH-31 are specific to CSHCN; Title V Programs report the number of CSHCN served but not prevalence

Life Course Criteria

Introduction

Children and youth with special health care needs (CYSHCN) is an indicator consistent with current life course science. When compared to non-CYSHCN, CYSHCN and families with CYSHCN experience lifetime societal barriers and face significant disparities, particularly in health care access and health equity. Additionally, the complex relationships between socioeconomic status, race/ethnicity, and access to programs, services, and supports for families points to significant implications of the indicator for the components of life course theory specific to the socio-ecological model.

Implications for equity

CYSHCN and families with CYSHCN face a myriad of barriers which contribute to health disparities and health inequity. Disparities found within the general child population are mirrored, and sometimes exacerbated, within the CYSHCN population. Factors contributing to equity issues for minority CYSHCN include: poverty, insurance and underinsurance, partnership in decision making, access to care, cultural competency, and communication and language barriers. [5]

Research suggests the following observations provide evidence to support implications for inequity among children and youth with special health care needs:

- Low income, minority children are more likely to report childhood disability. [6]
- Children with special health care needs are more likely to suffer from depression and other mental health problems. CYSHCN also are more likely to experience negative psychological and social impacts throughout the life course. [7]
- When compared to white families with CYSHCN, Hispanic and non-white families with CYSHCN report having a more difficult time accessing and utilizing community-based services due to a lack of available services, long wait times, and the absence of linguistic services. [8]
- Children with special health care needs are at risk for diminished health-related quality of life. Families of CYSHCN devote considerable time and effort to providing health-related care, and often experience financial burden, work loss, poor mental and physical health, and negative social consequences. [6]
- Communities and health systems are frequently unable to provide adequate resources necessary to achieve optimal health and social outcomes for children with special health care needs and their families. [6]

In summary, a large body of research suggests that the indicator measuring CYSHCN inherently reflects equity-related measures. These inequity measures include, but are not limited to: racial and ethnic minority disparities, cultural competency issues, socioeconomic status disparities, insurance status issues, language barriers, access to care and ease of use, strained relationships with health care professionals, and limited physical environments. [5] Public health systems must prioritize the elimination of health inequities in order to ensure all CYSHCN face positive trajectories throughout the life course.

Public health impact

Data from the 2011-2012 NSCH indicates 19.8 percent of children residing in the United States have a special health care need. [9] This translates to nearly 1 in 5 children, indicating a significant portion of the U.S. child population. As mentioned previously, CYSHCN and families with CYSHCN face lifelong barriers, ongoing care and access issues, and complicated health trajectories. Many CYSHCN require highly specialized or ongoing care, placing a burden on care providers and families. The current changing health care environment provides opportunities for health care systems to address managed care for CYSHCN and enhance systems of care serving CYSHCN.

Families with CYSHCN face significant financial burdens throughout the life course. When compared to families with typical children, families with CYSHCN are more likely to have public insurance, less likely to live in higher income families, and more likely to face financial problems. [10]

Financial burdens for the overall public health system also are vast. Economists predict that CYSHCN are a very high cost population for public and private insurers. For example, in 2004, the per-member, per-month (PMPM) cost for CYSHCN averaged $328 compared with a PMPM of $84 for non-CYSHCN. Additionally, children with catastrophic conditions had an average PMPM cost of $2,867. [11] Given the high cost of this population, there is a vested economic and public health interest in controlling costs for this population while also continuing to provide quality care.

AMCHP

Indicator Resources:

www.amchp.org/lifecourseindicators

National Comparisons

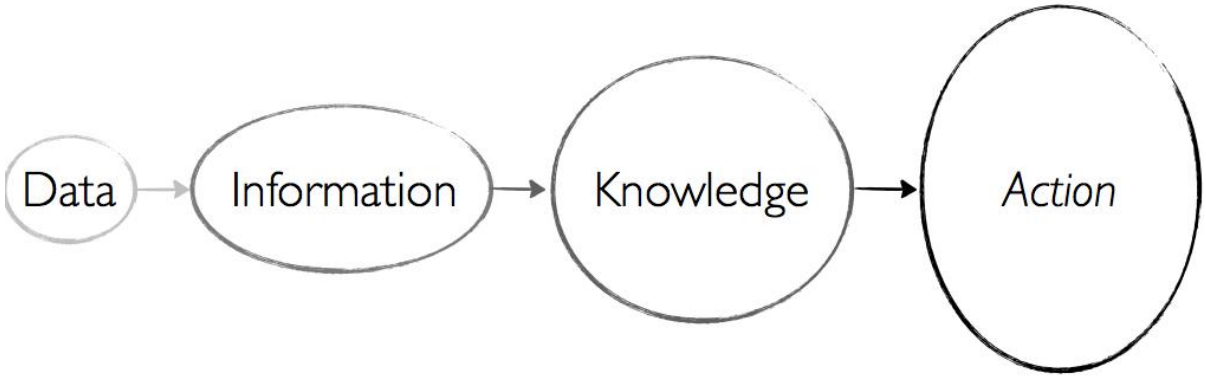
‘Short List’ Indicators

AMCHP

Domain	Indicator
Risk/Outcome	Adverse childhood experiences among children (NSCH)
	Experiences of race-based discrimination among pregnant women (PRAMS)
	Experiences of discrimination among children (NSCH)
	Households with a high level of concentrated disadvantage (ACS)
	Children living in households where smoking occurs inside the home (NSCH)
	Children or adults who are currently overweight or obese (NSCH, YRBSS, BRFSS, PRAMS)
	Depression among youth (YRBSS)
	Household food insecurity (USDA ERS)
	Preterm births (NVSS)
	Stressors during pregnancy (PRAMS)
	Incarceration Rate (BOJ, NPSP)
Capacity/Services	Children who receive services in a medical home (NSCH)
	4^{th} graders scoring proficient or above on math and reading (NAEP)

Challenges

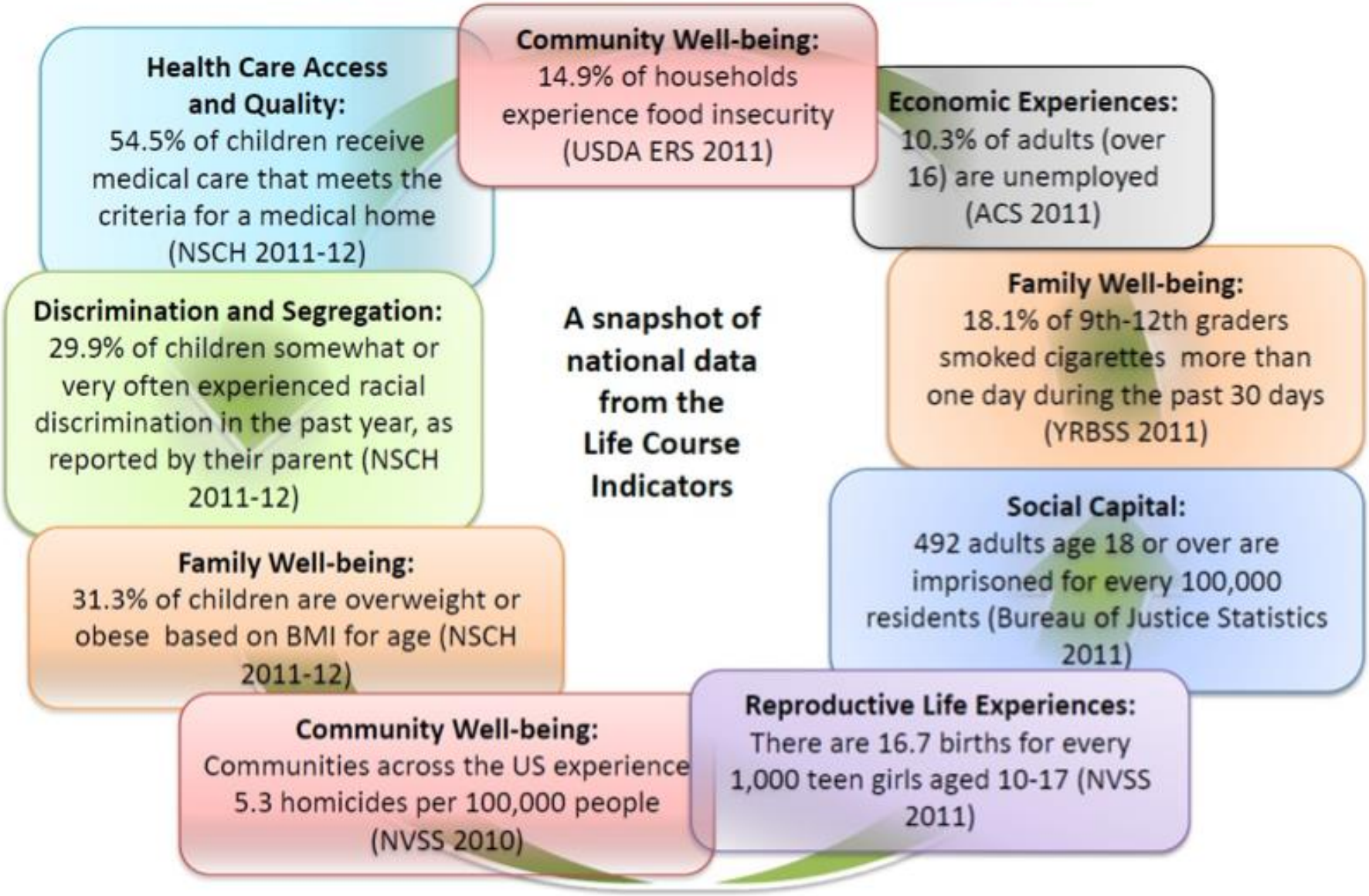
- Compromise with availability of data, and interested in translation of indicators at the local level
- Availability of/familiarity with non-traditional data sources
- Balance root causes with sentinel indicators
- Risk versus resilience focus in public health
- **Limited in our ability to capture the life course – event-centered and not person-centered data**



Opportunities

- **Leverage or realign resources** – each narrative includes a section on how novel partnerships and coordination of investments can impact the indicator
- **Expanding partnerships** – taking a "whole person approach" brings new opportunities under the MCH umbrella (economic experiences, mental health, education, etc.)
- **State pilot projects** – adding questions to BRFSS, Title V needs assessment, aligning with the Health Impact Pyramid

How Do You Measure Key Factors Of A Life Course Approach To Maternal And Child Health?



When a final set of life course indicators exists, what will the impact be for the health of moms, kids, and families throughout your communities?

"Help state health departments…come out of their silos and think outside the box to better design programs and interventions that impact the life course trajectory for mothers, children, and families."

Andria Cornell – acornell@amchp.org

www.amchp.org/lifecourseindicators