

Life Course Indicator: Data capacity to support integrated childhood research

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: Data capacity to support integrated childhood research (LC-47)

Brief description: Ability of state maternal and child health (MCH) programs to support integrated, population-based childhood research (i.e., research using linked program data). For the state level, proportion of priority datasets to which the MCH program always has timely access for program or policy planning purposes. For the national level, proportion of states that always has timely access to at least five priority datasets.

Indicator category: Organizational Measurement Capacity

Indicator domain: Service/Capacity

Numerator: State level: Number of priority datasets (e.g. programs) the Title V agency always has timely access to for policy and program planning purposes (including for linkage). (score of three= Yes, the MCH agency always has this ability). Priority programs are death certificates, Medicaid, WIC, newborn screening, hospital discharge, birth defects surveillance, Pregnancy Risk Assessment Monitoring System (PRAMS) and Youth Risk Behavior Surveillance System (YRBSS). National level: Number of states that always have timely access (score of three) to at least five priority datasets.

Denominator: State level: total number of priority datasets (N=eight). National level: The number of states and the District of Columbia (jurisdictions)

Potential modifiers: None

Data source: Title V Information System (TVIS) - Health Systems Capacity Indicator #9A and #9B

Notes on calculation: At the state level, this indicator will be a percent of priority datasets, where 100 percent indicates that the MCH agency always has timely access to all priority datasets. At the national level, this indicator will be a percent of states that always have timely access to at least five priority datasets.

Life Course Criteria

Introduction

The Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA) adopted life course theory as the conceptual framework for its strategic planning efforts in 2010 (17) and today, encourages state Title V agencies to adopt and integrate the approach into MCH programs and policies (18). As Title V agencies develop and refine programming guided by a life course framework, a fundamental challenge arises in measuring the success of these efforts: states vary in their capacity and methods for collecting, managing, and analyzing the breadth of data on population risk exposure and service utilization relevant to life course health. This indicator of organizational measurement capacity measures access of the MCH program to priority datasets for program planning and policy purposes. It focuses on linkage between a state's birth certificates and priority datasets as well as a number of surveillance and survey activities; these efforts support hypothesis generation and new investigations into the relationships between risks and protective factors and emotional, social, and health outcomes across the life span for MCH populations. Linkage and data sharing are processes that create partnerships and collaboration across programs. Rosenberg et al. found that, "A more permissive data sharing environment can increase a state's ability to accurately assess and forecast problems, determine the best interventions to address these problems, and appropriately evaluate whether interventions are making a difference" (15). Further, increasing the MCH data capacity of a state can support program and policy changes that improve output and outcome performance for public health impact (6, 7). Despite some limitations in HSCI09 as an indicator for the ability of state MCH programs to support integrated, population-based childhood research, it is the only mandatory and quantitative method for systematically assessing MCH data capacity at the state and national level.

Implications for equity

One of the earlier articles applying the life course approach to MCH is the 2003 article by Michael Lu and Neal Halfon published in the *Maternal and Child Health Journal*. In this article, the authors describe life course theory as a mechanism for contextually integrating longitudinal models to describe racial disparities in birth outcomes (8). Since the publication of this article and numerous others, life course theory has served as a conceptual framework for reducing inequalities in health outcomes across the field of MCH. The individual linkage projects and the survey and surveillance activities measured by HSCI09 have been used in a number of states to generate and test hypotheses about disparities with regard to care utilization and behaviors, health care costs, and health outcomes for the MCH population, among others. Examples of research studies within the scope of HSCI09 that generated such knowledge include the following:

- Missouri linked Medicaid data, birth certificates, WIC records, and NICU admissions to examine WIC prenatal participation and its relationship to newborn medical costs (9)
- North Carolina and Kentucky examined low birth weight births among Medicaid patients who obtained care in different settings (10)
- Washington state and Ohio identified differences in the use of and outcomes among fee-for-service and managed care Medicaid enrollees (11, 12)
- Florida investigated race and ethnicity as risk factors for breech presentation, utilizing Medicaid/WIC eligibility data linkage to access a socioeconomic proxy variable (13)

The focus of HSCI09 on linkage with vital statistics allows states to capitalize on the breadth of data items included in the birth certificate, which encompasses a number of social measures such as parental education and socioeconomic status in addition to specific aspects of pregnancy, labor and delivery, infant health, and maternal health factors. Further, data activities that monitor characteristics of care received, the prevalence of birth defects, and health-risk behaviors among vulnerable populations (e.g. women, adolescents, infants) allow states to identify groups at high risk for poor outcomes, to monitor changes in health status, and to measure progress towards goals in improving health. Such analyses inform program planning and policy development to make strides toward reducing disparities in health outcomes across MCH populations.

Public health impact

A question fundamental to MCH data capacity to support integrated childhood research is whether an increase in data capacity will be associated with improved public health outcomes: essentially, does data capacity matter? The question is unique to capacity indicator development, and answering it requires considering how and why capacity is assessed in public health. In their evaluation of various tools for Title V agencies to use in capacity assessment and performance measurement, Handler et al. describe capacity as, “the resources and relationships necessary to carry out the important processes of public health. These resources include the basic infrastructure of the system as well as specific program resources” (14). In their description of the Capacity Assessment for State Title V instrument (CAST-5), the authors state the following:

...In a sense, CAST-5 acts as a *conceptual bridge* [emphasis added] between the EPHS [Essential Public Health Services] framework and measures of program implementation and effects. As such, state MCH programs should be able to strategically link their capacity and process assessment (CAST-5) to their output and outcome performance (Title V “24”) (121).

Applying the model of the ‘conceptual bridge’ to HSCI09, the phrasing of HSCI09 is specific to whether the data are used for MCH program planning or policy purposes – essentially undergirding the performance and enhancing the impact of these initiatives. An additional example may be useful. States that participate in the Centers for Disease Control and Prevention (CDC)-HRSA MCH Epidemiology Program (MCHEP) complete the MCH Epi and Data Capacity Tool as a part of their annual self-review (16). This tool assesses state efforts in a number of linkage, survey, and surveillance activities across the strata of access, analysis, dissemination, and program/policy use (15). The uses detailed in the tool include modifying an existing program/policy, developing a new program/policy, developing a new grant for the agency, and grant reporting. Inherent in this assessment tool is that the data activities support the performance of each of these tasks. In total, a change in the indicator (the number of priority datasets the Title V agency always has timely access to for policy and program planning purposes) can support program and policy changes that improve output and outcome performance for public health impact. Further, the individual activities can have a public health impact through performance management and quality improvement when integrated as a part of a feedback mechanism for program planning.

Leverage or realign resources

Linkage and data sharing are processes that create partnerships and collaboration across programs. Rosenberg et al. found that enhanced MCH epidemiology functioning on an organizational level is associated with ready access to data by the MCH program and external users, as well as increasingly regular data integration (15). The authors conclude, “A more permissive data sharing environment can increase a state’s ability to accurately assess and forecast problems, determine the best interventions to address these problems, and appropriately evaluate whether interventions are making a difference.” These findings uncover an opportunity to not only improve data capacity but also MCH epidemiology functioning through explicitly encouraging cross-program collaboration and systems integration through linkage and data sharing agreements.

HSCI09 currently includes mostly ‘traditional’ MCH data sets, namely vital records, WIC eligibility, and newborn screening, as well as registries and surveys such as birth defects surveillance, PRAMS, and YRBSS. As such, it is not entirely reflective of programs, services, and policies that expand beyond the MCH focus. However, future discussions pertaining to adding or expanding linkage activities included in HSCI09 may allow for seamless inclusion of education, housing, environmental and other programs.

A number of opportunities exist to leverage and realign resources and maximize collective impact in building MCH data capacity. For example, the Health Resources and Services Administration, the Centers for Disease Control and Prevention, and the Council of State and Territorial Epidemiologists could expand upon their unique, long-term collaboration building MCH epidemiology capacity to identify additional synergies in methods by which MCH data capacity is measured at the state agency level. The data collected through the MCHEP tool is detailed and valuable, but limited to those states that participate in the program and receive a CDC assignee. While all efforts should be taken to reduce Title V agency reporting burden, it is worthwhile to consider the value of the breadth of data collected through various federal funding sources.

Further, little incentive exists for data linkages and collaboration between Title V agencies and agencies outside of MCH that collect data of value to measuring life course trajectories, including housing, environmental, and education agencies.

Given that national, state, and local MCH programs informed by the life course approach are launching with increasing urgency, MCH epidemiology stakeholders including federal leadership, learning collaboratives formed of state agencies, and others could identify a consensus list of priority linkages both inside and outside Title V agencies that demonstrate new partnerships through data access. Additionally, both public and private funders could invest in building capacity for data sharing through grants that capitalize on novel partnerships to build life course data capacity. The fundamental focus of the grants would be incentivizing collaboration through data. Federal leadership could encourage cross-program collaboration and systems integration by developing guidance for Title V agencies in executing data sharing agreements and creating permissive data sharing environments.

Finally, information systems integration remains an exciting frontier in real-time data aggregation for long-term and intergenerational health. Data and messaging standards are not uniformly adopted across states and programs, and are a major barrier to the wide scale implementation of systems integration. The MCH community is not well represented in federal advisory committees, standards developing organizations, and others leading the charge for standard setting and adoption in the application of health information technology to the field of public health. MCH representatives from CDC, HRSA, national MCH partners, and state agencies may wish to collaborate with standard-setting entities as they work to identify new methods for improving the health of MCH populations.

Predict an individual's health and wellness and/or that of their offspring

The datasets included in HSCI09 pertain primarily to exposure to risks and access to services and supports during pregnancy, infancy, early childhood, and adolescence; as such, HSCI09 is consistent with MCH program access to data pertaining to critical and sensitive periods in health and development. HSCI09 measures linkage between a state's birth certificates and priority datasets as well as a number of survey and surveillance activities; these efforts support hypothesis generation and new investigations into the relationships between risks and protective factors and emotional, social, and health outcomes across the life span for MCH populations. These activities can support integrated childhood research and alleviate challenges with research-focused primary data collection efforts, which may include a) limitation to a study sample and not the total state MCH population, b) inflexibility to add new variables based upon evolving life course science, and c) defined time horizon as determined by study funding and hypothesis generation at study outset (19). Despite some limitations in HSCI09, including its narrow scope, it is the only mandatory and quantitative method for systematically assessing MCH data capacity, and therefore remains a valuable resource.

Data Criteria

Data availability

During the Title V MCH Block Grant application and annual reporting process, agencies respond to nine Health Systems Capacity Indicators (HSCI) that are considered key indicators of the health systems and program capacity supporting MCH in a state. One of these indicators is HSCI09. Reporting on the indicators is made publicly available through TVIS. States assess their MCH data capacity by completing Form 19 for HSCI09, the purpose of which is for states "to show the State MCH data capacity and whether the MCH program has the ability to obtain timely analyses of certain data for programmatic and policy issues." HSCI09 focuses on eight data activities:

1. Annual linkage of infant birth and infant death certificates
2. Annual linkage of birth certificates and Medicaid eligibility or paid claims files
3. Annual linkage of birth records and WIC eligibility files
4. Annual linkage of birth records and newborn screening files
5. Hospital discharge survey for at least 90 percent of in-State discharges
6. Annual birth defects surveillance system
7. Survey of recent mothers at least every two years (like PRAMS)
8. Youth Risk Behavior Surveillance System (YRBSS)

States score themselves on two criteria for each activity:

1. Does your MCH program have the ability to obtain data for program planning or policy purposes in a timely manner?
Response is a score of one to three indicating no, sometimes, or yes.
2. Does your MCH program have direct access to the electronic database for analysis?
Response is yes or no.

For the eighth data activity (YRBSS), states respond to whether their state participates and if the MCH program has direct access to the State YRBS database for analysis (responses are as above).

There are two distinct strengths of the HSCI09/TVIS data source with regard to data availability (1). First, HSCI09 is the only national indicator measuring administrative linkage and access to databases and surveys among MCH programs in all 50 states and the District of Columbia. Like other block grant measures, reporting on the indicator is consistent, mandatory, and completed on at least an annual basis. In fact, states report on (and update) this indicator twice per year, once for their Block Grant reporting and again for reporting for the State System Development Initiative program. Secondly, TVIS contains the reports on data capacity of the states for the last five years, allowing the TVIS user to observe changes in infrastructure and trends in data capacity over time. Data in TVIS are updated annually following the Title V Block Grant reviews. As of October 2013, TVIS users could access FY2013 data.

The indicator as described measures the capacity of an MCH program to conduct integrated, childhood research. Of note, HSCI09 is limited to a set of four individual linkage projects and four survey and surveillance activities - it is not a measure of longitudinal administrative linkage. Form 19, which includes guidance to states for reporting upon the indicator, also does not give space for states to expand upon the sophistication of a linkage project; for example, if the linkage occurs more often than annually or as the result of integrated information systems, which would further enable integrated childhood research (2).

Data quality

Reporting on HSCI09 is consistent and mandatory, and in general considered of a high quality, especially with regard to the use of categorical and dichotomous variables to assess capacity.

Reporting on the indicator includes the states scoring themselves on two criteria for each linkage or survey activity (1):

1. Does your MCH program have the ability to obtain data for program planning or policy purpose in a timely manner?
2. Does your MCH program have direct access to the electronic database for analysis?

With regard to the first scoring activity, the terms 'ability' and 'timely' are subjective and open to interpretation by the respondent. For example, in response to the third linkage activity (annual linkage of birth certificates and WIC eligibility files), 21 states scored themselves at a level of two ("Yes, the MCH agency sometimes has this ability, but not on a consistent basis") (3).¹ One could interpret this finding to mean that 21 states are able to conduct the linkage between these datasets, however not on a consistent, annual basis (meaning that the responding state does not *gain access* to birth certificates and WIC eligibility data on an annual basis, but could). However, this question could also be interpreted that the state has conducted linkages between these programs, but not on an annual basis (despite always being able to gain access): of significance is that neither the first nor second of the two self-scoring questions inquire as to whether linkage for the first four activities is actually performed, but rather that the ability is present. Stated another way, it is difficult to assess how many states performed linkage between the two data files in the most recent reporting year.

Data users should take care inferring about changing data capacity over the five years available in TVIS: some states indicate an increase in the ability to 'obtain data in a timely manner' (moving from one to two or two to three over reporting years) whereas others indicate a decrease. Additionally direct access to data changes over the years as well, with states losing and gaining access over the five-year period (4). These changes reflect the complexity of measuring data capacity within MCH programs, which is influenced by staff turnover, funding, identified program needs, or other external factors. In summary, while there is consistency in the frequency of reporting and block grant measures are considered of high quality, the subjective nature of both the terminology used to assess the indicator and the self-ranking process, and the measurement of ability to obtain data and access it electronically as opposed to directly measuring whether linkage occurred (and therefore a linked administrative database exists as a capacity to conduct integrated childhood research) are important quality considerations.

A final note with respect to the comparison of capacity across states: 12 states still use the 1989 revision of the standard birth certificate and have yet to implement the 2003 revision, which expanded the contents of the birth certificate to 60 data items (5). While the linkage procedure itself is unaffected, the utility of the linked data was greatly improved by the new sociodemographic items (for example, race categories in the 2003 revision align with those in the U.S. Census).

Therefore the motivation to link and the outcomes of linkage projects, including the knowledge gained from the endeavor, may vary across programs.

¹ As reported by states in their Title V MCH Services Block Grant FY 2011 Annual Report and FY 2013 Application; Form 19

Simplicity of indicator

This indicator is simple to calculate, as it is a component of the annual Title V MCH Services Block Grant reporting process, and the scores on the items are made publicly available through TVIS via a query system. The indicator does not require linkage for calculation. The indicator is less simple to explain with regard to why MCH data capacity is critical for a life course approach in MCH.

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