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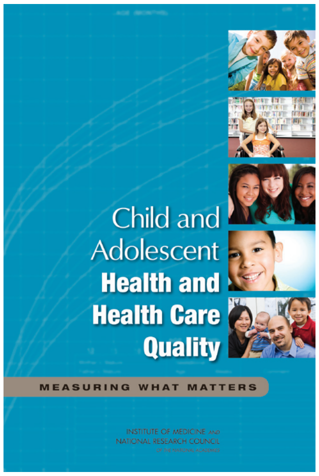
Child and Adolescent Health and Health Care Quality

Measuring What Matters



Health and health care quality measures can provide valuable information about the health status of children and adolescents, as well as the outcomes associated with medical care, policy, and social programs. These measures are especially useful in monitoring general health and health care trends as well as identifying disparities among disadvantaged populations. Despite the fact that the U.S. government currently supports hundreds of data sets and measures through federal surveys and administrative data systems, the United States lacks robust national- and state-level information about the health status or health care quality of children and adolescents, particularly in areas that could provide guidance to policy makers and health care providers.

Currently, there is no single data source that can provide valid and reliable indicators about the health and health care quality of children and adolescents.

In the *Children's Health Insurance Program Reauthorization Act of 2009*, Congress directed the Institute of Medicine (IOM) and the National Research Council (NRC) to evaluate the state of efforts to measure child and adolescent health and the quality of their health care services. The IOM and the NRC formed the Committee on Pediatric Health and Health Care Quality Measures, which reviewed hundreds of population surveys, such as census records and health surveys, and administrative data sets, such as those based on payment and health records.

The Nature, Scope, and Quality of Existing Data Sources

Currently, there is no single data source that can provide valid and reliable indicators about the health and health care quality of children and adolescents. Policy makers and researchers therefore must examine data from a variety of federal and state data sources to get a clear picture of child and adolescent health and the quality of health care they receive. The committee concludes that a lack of standardization in key areas—such as race and ethnicity, socioeconomic status, primary language spoken at home, and parental English proficiency—limits the ability of those who use data to identify, monitor, and address persistent health and health care quality disparities among children and adolescents. Measurement in these areas is especially important given the growing ethnic and racial diversity of children and adolescents and the increasing number of children who live in poverty. The U.S. Department of Health and Human Services (HHS) should provide leadership to standardize data in key areas, including developing precise definitions and utilizing consistent data collection methods.

Gaps in Measurement Areas

Research shows that physical and social environments (for example, safe neighborhoods or crowded housing), personal health behaviors, and social relationships (for example, parent-child attachment) influence the health status of children and adolescents and their use of health care services. These contextual factors have significant effects on the short- and long-term health outcomes of children and adolescents, yet information about them often is lacking in existing data sets.

Another significant gap is the general absence of information about the content and quality of preventive services that are used by children and adolescents. This information is especially relevant because screening and early interventions may mitigate serious health disorders later in life.

A life-course approach to measurement is one new strategy to closing the gaps in measuring child and adolescent health and health care quality. This approach, which considers how events at each stage of life influence subsequent health and health care quality, is particularly important in developing measures for children and adolescents. This approach to measurement will focus on the needs of the "whole child" as opposed to individual clinical concerns and will better address the distinct needs of younger populations, including their unique patterns of morbidity and mortality, their dependent status, and their developmental stages. Measuring transitions of care between primary care and specialty care also is important, especially for children with special health care needs.

Methodological Areas that Deserve Attention

The committee endorses the use of innovative measurement practices that can adapt to changing conditions, changing populations, and opportunities for health improvement. This will require efforts that track key child and adolescent populations over time to ensure that groups with the greatest risk for poor outcomes are included in the relevant data sources. To facilitate innovation in measurement, the strengths and limitations of different surveys need to become more transparent.

In some cases, HHS can link or aggregate multiple data sources—connecting one database to another, for example—and therefore reduce the burden of data collection on individual states, providers, health plans, and households. Longitudinal studies, which include multiple observations for the same children/families over time, also would enrich the quality of indicators. And the capture of electronic data offers opportunities to enhance future measurement activity. Such efforts need to offer protections for privacy and confidentiality. They also have the potential to capture important state-level policy and community-level characteristics and enable analysis of the variability and impact of coverage, eligibility, and payment policies.

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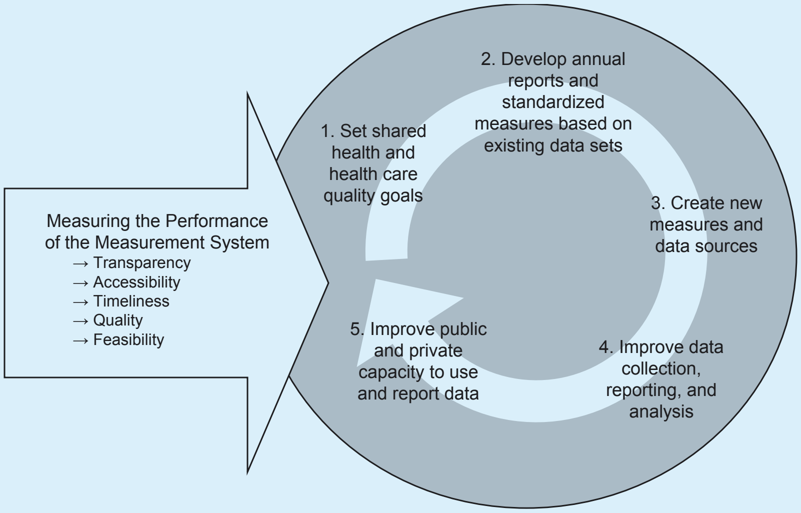
A Stepwise Approach

The committee recommends a stepwise approach (see Figure 1) for improving data sources and measures of health and health care quality for children and adolescents. This approach is designed to stimulate and support collaborative efforts among federal and state agencies and key stakeholder groups through the following five steps:

1. Set shared health and health care quality goals for children and adolescents in the United States
2. Develop annual reports and standardized measures for existing data sets of health and health care quality that can be collected and used to assess progress toward those goals
3. Create new measures and data sources in priority areas
4. Improve methods for data collection, reporting, and analysis
5. Improve public and private capacities to use and report data

This stepwise approach is necessarily continuous and calls for the evaluation of the measurement system itself for transparency, accessibility, timeliness, quality, and feasibility. The entire approach will be informed by private initiatives as well as government–sponsored efforts. This approach is meant to align existing and future efforts to measure health and health care qual-

Figure 1: A Stepwise Approach to Measuring Health and Health Care Quality for Children and Adolescents



SOURCE: Committee on Pediatric Health and Health Care Quality Measures, 2011 ity for children and adolescents. Some improvements to measurement can be made immediately under the leadership of the Secretary of HHS; others require longer-term consensus-building efforts among multiple federal agencies.

Conclusion

Improving health outcomes for children and adolescents is essential to achieving a healthy future for the nation. A life-course approach to the measurement of health and health care quality, with new emphasis on the social and behavioral determinants of health and monitoring disparities in health and health care quality, will deepen understanding of key opportunities to achieve these outcomes.

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