

Families Are Key in Improving Quality

Nora Wells, MEd; Lee Partridge, BA

From Family Voices, Inc, Lexington, MA (Ms Wells); and National Partnership for Women and Families Washington, DC (Ms Partridge) The opinions expressed herein are those of the authors and do not necessarily represent the views of the US Department of Health and Human Services, the Agency for Healthcare Research and Quality, or the Centers for Medicare & Medicaid Services. The authors have no conflicts of interest to disclose.

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Address correspondence to Nora Wells, MEd, Family Voices, Inc, c/o ERG, 110, Hartwell Avenue, Lexington, Massachusetts 02421 (e-mail: nwells@familyvoices.org).

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WE HAVE A national problem, one that must be addressed if future generations are to grow up as healthy, productive members of society. A 2007 study by Rita Mangione-Smith and her colleagues at RAND involving a national sample of children's outpatient medical records revealed that fewer than half (46.5%) of our children received the indicated care. Sadly, the evidence with regard to the percentage of children getting recommended preventive care was even lower, clocking in at only 40.7%.¹ Moreover, the children and adolescents in the study were predominantly white, living in a metropolitan area, and were privately insured—precisely the group we might expect to be receiving the best care.

Given known access and provider scarcity issues, the quality of care for children who are members of minority populations is even lower. The 2007 National Survey of Children's Health, led by the federal Maternal and Child Health Bureau, found that Hispanic, Asian, and black children are less likely than white children to experience care within a medical home, (including such elements as a personal doctor or nurse who listens carefully, spends enough time, engages families as partners in care, is sensitive to family values, provides referrals, provides information needed, and helps to coordinate care).²

As noted in the Agency for Healthcare Research and Quality's *National Healthcare Disparities Report, 2008*³:

- Black children were less likely than white children to receive all recommended vaccines.
- Asian children and children of multiple race were less likely than white children to have received advice about physical activity.
- Hispanic children were twice as likely as white children to experience poor provider-patient communication.

The US Department of Health and Human Services' adoption of a core set of performance measures recommended for use by Medicaid and the Children's Health Insurance Program (CHIP) marks a major step forward in improving the quality of health care received by the more

than 40% of America's children and teens enrolled in these programs.

Looking ahead, it is clear that measuring performance is an essential first step, but to be effective, the performance information collected must be meaningful both to policy makers and to those on the front lines: health care providers and families. It must allow us to understand how well our insurer, or medical provider, or community is doing when measured over time and against others. It must also allow us to pinpoint inequalities in care. Because what we measure is what we will focus on; we must collect information that addresses priorities and is actionable for improvement.

The core measurement set draws principally on measures that are already standardized and widely used by states and private insurers; if openly and transparently reported in understandable language, this information will allow users to make valid comparisons within a state, among states, and across the nation. Most of the measures can also be used to examine the care given to a particular population subgroup and to identify disparities in access or treatment. Moreover, the recommended set includes the requirement that Medicaid and CHIP administrators get direct feedback from families on their experiences of care, including children both with and without chronic conditions. Questions about having a "personal doctor or nurse who knows your child," "who talks to you about how your child is feeling, growing, or behaving," "who tells you about choices in treatment or care" and "who helps you get answers to your questions" are among the questions in the patient and family experience measure in the recommended set. Getting answers to such questions will provide the building blocks of a family-centered health care system. The inclusion of patient feedback measures in this recommended set is central to moving closer to the family-centered goal.

However, the current measures are just the beginning. For quality measurement to become more meaningful going forward, we need to develop additional measures and effective processes for involving families at all stages

of the development, adoption, and reporting of measures, as families have an essential perspective on what constitutes quality. Other kinds of family-oriented questions might include the following: Were you and your child treated respectfully? Were there language barriers between you and the doctor or the staff that were hard to overcome? Did your doctor help you connect with needed community services? If you disagreed with a recommended treatment for your child, were you able to discuss this with your doctor? Families have important contributions to make in the development of new measures that evaluate the effectiveness of care coordination among providers and the community; that ask about a providers' understanding of how family values may affect treatment options; that acknowledge family roles in providing health care and the impact of these roles on the family; and that measure successful transitions to adult care and effective family participation in electronic health records. Families can help to identify gaps in measurement and better ways to share measurement information with the public.

As principal caregivers for their child, families are responsible for a child's day-to-day health care. Close partnerships between families and providers are essential. Families know critical information about their child; they identify symptoms and problems; they watch for reactions. They are the ones who encourage good health habits; take their child to the doctor, therapist, or hospital; give medications; and for children with complex needs, carry out therapies and treatments; assist with activities of daily living; coordinate care among multiple providers; find community and needed services; and speak up when a recommended protocol isn't working. Families care deeply about ensuring quality health care for their own child and improving the system for all children. They are ready and willing to help in measurement activities that will be relevant to improving care.

Measuring performance in Medicaid and CHIP is an important step forward, but alone, it won't move us much closer to erasing that dismal 46.5% quality-of-care statistic. We have to use the performance data effectively to reward good results and to fix the problems. And the "we" has to include us—the parents and the patients as well as providers, policy makers, and other professionals. In order to improve care, the system must engage families at every level of quality measurement. We must educate ourselves and all families about the importance of responding to those patient surveys. We must report the findings honestly, and the reports must make sense to families. We must engage communities in spreading the word about the quality information that is available to us—about provider performance and about treatment options—and how this information can help guide our decisions. We must engage families and youth in policy discussions about what the quality measurements mean and how improvements can be made. We must speak up if we think our providers, insurers, and public leaders aren't responding to our personal needs or the needs of our communities. Improving the quality of care provided to all our children isn't someone else's job—it's a job for all of us. Together we can do it.

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