

Closing the Gap for the Nation's Most Vulnerable Population

Guest Editorial by Thomas W. Chapman, MPH, FACHE
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Over the last few years, the health care system and the Federal government have increased attention to socio-cultural barriers to health care access and how they affect the lives of minority and low-income Americans. Now more than ever, the government and the health care industry are taking a hard look at ending the disparities in access, health status, and quality of care. However, as our awareness of these issues increases, so does the recognition of an emerging subgroup: the 12.6 million children under age 18—prevalently male, African American, from low-income and single parent households—who suffer from chronic physical, developmental, behavioral, or emotional conditions.

A 1998 study published in *Pediatrics* (vol. 102, no. 1) revealed that these children with special health care needs represent 18 percent of the nation's population, yet present its most needy and vulnerable citizens, with complex medical, social, and educational needs that are pressing and difficult to coordinate.

For low-income and minority families, navigating the rapidly evolving health care system has always been a challenge. When these families include children with special health care needs, the task is magnified. These families face substantial obstacles to health care access such as lack of transportation and language barriers. For children with special needs, this often translates into missed appointments, poor patient compliance, and reliance on episodic health care—often in emergency rooms.

These barriers impact other aspects of these children's lives, carrying over from the sickroom to the classroom. Children with special health care needs experienced three times as many sick days in bed and school absences annually as those without special needs. According to the 1994 National Health Survey on Disability, an estimated 11 percent of these children were uninsured, and 6 percent were without a usual source of health care. Eighteen percent reported being dissatisfied with one or more aspects of care received at their usual source of care, and 13 percent had one or more unmet health needs in the past year.

There are at least 930,000 children receiving Supplemental Security Income (SSI), according to the Social Security Administration. There may be many more children who qualify for these benefits but for a number of reasons, do not receive them. In addition, new eligibility rules for SSI required by welfare reform legislation resulted in about 143,000 children losing their SSI eligibility by the end of 1997. Due to gaps in transitioning to the new system, many of these children may have lost their Medicaid benefits as well. According to Family Voices, a national advocacy group for parents of children with special needs, although the

Social Security Administration invited families to appeal, many were discouraged and confused by a review process that is complicated, lengthy, and requires expert legal assistance.

The Federal government is also encouraging states to enroll children with special needs who are SSI/Medicaid beneficiaries into managed care programs. But this policy comes with limited guidance and liberal guidelines on how best to serve this population in a competitive model. There does not appear to be a well-defined strategy focused on addressing the issues of transitioning families with special needs into the managed care system, nor a strategy focused on addressing the social needs which often undermine access to care.

What can be done?

- The Federal government and states should support programs that involve children with special needs and their families in the planning and design of health care and outreach programs, particularly under the Title V Maternal and Child Health block grant and CHIP block grant programs.
- Managed care organizations and Medicaid agencies should be required to focus on well-organized coordination systems, customized provider networks with a focused number of experienced and capable organizations, and the development of primary care management programs, versus capitated arrangements.
- Regulation and implementation of the SSI program should be improved through development of enhanced outreach and education activities to insure that all children who need benefits will receive them, and that children who have been denied SSI will be tracked, and their situations resolved.
- We should fund and support efforts to develop comprehensive programs and wrap-around services that enable families of children with special needs to maximize access and efficiently utilize their time in managing their family's health needs.

Mr. Chapman is director of the "Opening Doors: Reducing Socio-cultural Barriers to Health Care" program, sponsored by the Robert Wood Johnson Foundation and the Henry J. Kaiser Family Foundation. Opening Doors funds and supports service and research projects to identify and break down non-financial, culturally-based barriers to health care. For more information, call (202) 974-4690. ❖

