

New Estimates of Children with Special Health Care Needs and Implications for the State Children's Health Insurance Program

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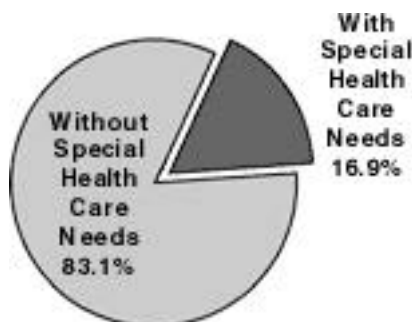
This fact sheet on children with special health care needs is intended to provide background material for states to better understand Title XXI coverage issues for these children. A previous fact sheet in this series (No. 1) provided background information on children with disabilities. Children with disabilities are a subset of the population of children with special health care needs. Comparison of this fact sheet with the previous one will provide readers with an understanding of how the populations differ in their health insurance status and health needs.

We defined children with special health care needs using the service-based definition developed in 1995 by the federal Maternal and Child Health Bureau: *Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*

In developing estimates for this population, we used this definition but had to exclude children "at increased risk," as there is no accepted method of defining the "at risk" population. Hence, estimates presented here refer to children with *existing* special health care needs.

Data are drawn from the 1994 National Health Interview Survey on Disability and are specific to the target population for Title XXI—uninsured children living in low income families (with incomes below 200 percent of the federal poverty level).

Special Health Care Needs among Uninsured Children in Low Income Families



Source: 1994 National Health Interview Survey

National Population Estimates

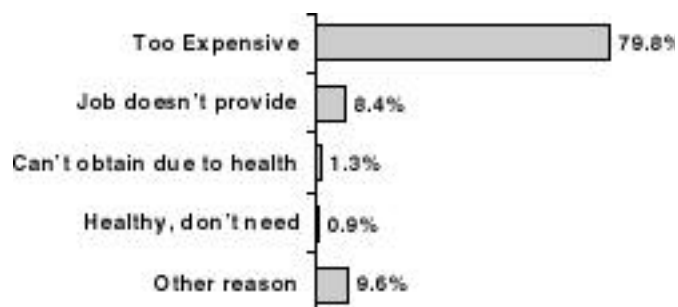
An estimated 16.9 percent of low income uninsured children had a special health care need in 1994. This translates to approximately 1,210,000 children nationwide. By comparison, an estimated 6.3 percent of low income uninsured children, or 460,000, experienced a disability in 1994, as defined by a limitation in

school or play activities due to a chronic condition (see *Fact Sheet No. 1*).

Reasons for Lack of Coverage

Not surprisingly, most low income families who have a child with a special health care need cited the high cost of health insurance as the primary reason for lack of coverage for their child. The high cost of coverage was cited by 80 percent of these families. The next most common reason for lack of health insurance coverage—cited by 8 percent of families—was the absence of

Reasons for Absence of Insurance



Source: 1994 National Health Interview Survey

employer-based coverage. Much smaller proportions of low income families with a child who had a special health care need reported that they attempted to purchase health insurance for their child but were denied it. Presumably, individually purchased coverage is available for children with special health care needs, but it either is priced too high or exclude coverage for services related to the child's condition.

These survey results suggest that many low income families with a child who has a special health care need would be interested in purchasing health insurance if the cost of that coverage were lowered. Since Title XXI permits only nominal premium and other cost-sharing charges for those at or below 150 percent of poverty and limits the amount of out-of-pocket premium and other cost-sharing expenses for covered services to no more than five percent of family income, it is likely that large numbers of uninsured children with special health care needs would take advantage of CHIP coverage.

Access Barriers

Low income, uninsured children with special health care needs now eligible under CHIP have faced significant obstacles in accessing health care. Upon enrollment into CHIP, therefore, they are likely to need more services than other children and require care coordination. More than one out of five uninsured children with a special need was without a usual source of care compared to one out of 20 insured children with a special need. This four-fold difference (22 percent versus 5 percent) is particularly problematic given the adverse health status of this child population. These children also averaged about half as many physician contacts as their insured peers (five contacts versus 11 contacts) and were almost three times more likely to have unmet

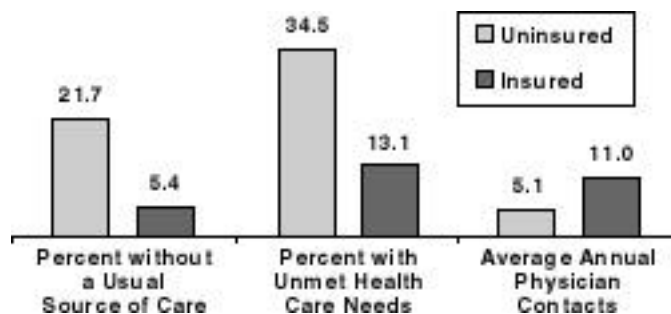
health needs. As many as 35 percent needed medical services, dental care, prescription medications, or eye-glasses but were unable to obtain them.

These results indicate that absence of insurance coverage puts low income children with special health care needs at significant disadvantage compared to their insured counterparts. However, it is important to note that among low income children with special health care needs many of those with insurance also experienced unmet health care needs.

Conclusion

These new data from the National Health Interview Survey indicate that an estimate one in six children in the CHIP-eligible population has an existing special health care need. Moreover, the number of children with special health care needs is almost three times that of disabled children. It is also clear that low income children with special health care needs, even when insured, have substantial unmet health needs.

Access to Care for Low Income Children with Special Health Care Needs



Source: 1994 National Health Interview Survey

Thus, states must carefully consider the scope of the benefits covered and the cost-sharing required in the new CHIP plans. They will also have to consider the important role that public programs serving children, namely the Title V Maternal and Child Health Program, the Early Intervention Program, the Special Education Program, and the Children's Mental Health Program need to play in providing direct and enabling wraparound services to this vulnerable population.

For more information on issues related to eligibility, benefits and cost-sharing under Title XXI, please refer to *additional Issue Briefs and Fact Sheets* from the Maternal and Child Health Policy Research Center or our website: www.mchpolicy.org

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