Are Families of Children with Disabilities Receiving the Support Services They Need?

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Nearly 12 million U.S. children have special health care needs that require medical and other health services above and beyond the care required by their typically developing peers.[1] Most of these children live at home and are cared for by their parents.[2] Raising children at home is not only the wish of the vast majority of parents, but it is also consistent with the goals of *Healthy People 2010,* the comprehensive national public health strategy, which emphasizes reducing the numbers of people with disabilities living in congregate care.[3] If parents are to remain the primary caregivers of their children with special needs, comprehensive and coordinated support services are imperative for the financial and psychological well-being of these families. This policy brief reports analyses of data for nearly 39,000 children from the National Survey of Children with Special Health Care Needs, and focuses on how policies might improve these families' access to support services.

Policy and State Options

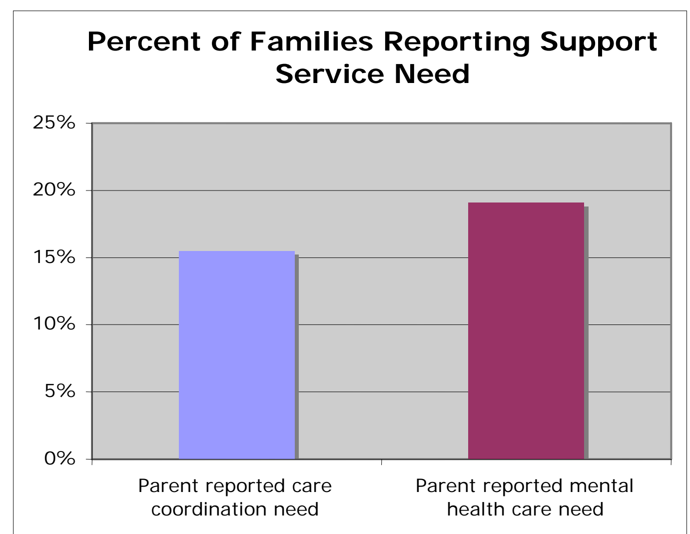
Policies that affect families include those directed at children with disabilities, such as the Individuals with Disabilities Education Act, or those directed to the broad population of poor families, such as Temporary Assistance for Needy Families.[4,5] Although these programs were established by federal mandate, service availability is typically determined by state policies regarding eligibility, services, and funding; there is considerable state variation in these support services.

The Parents' Challenge

Whether the needed service is mental health care, physical therapy, or financial assistance to purchase a wheelchair for a child with disabilities, the job of securing that service most often falls to the child's parents. However, few parents are prepared for their unique role as a caregiver for a child with disabilities, and they face a daunting job in obtaining the appropriate services for their children[4,7] Caregivers frequently report feeling overcome by the difficulty of navigating the support services system, deciphering eligibility criteria, trying to work with inflexible policies, and becoming frustrated by the crisis-driven nature of the service system.[7] Not surprisingly, families often report their care management responsibilities leave them feeling overwhelmed and defeated.[7–9]

Mental Health Care

Caring for children with disabilities affects many aspects of parental health and well-being, including overall mental health. Mothers of children with disabilities often have elevated rates of depression and other mental health problems. In addition, research has shown that both mothers and fathers of children with chronic illnesses are more likely to report receiving inpatient and outpatient mental health treatment compared to parents of nondisabled children. The ongoing pattern of elevated mental health concerns among this population reinforces their pressing need for mental health services.

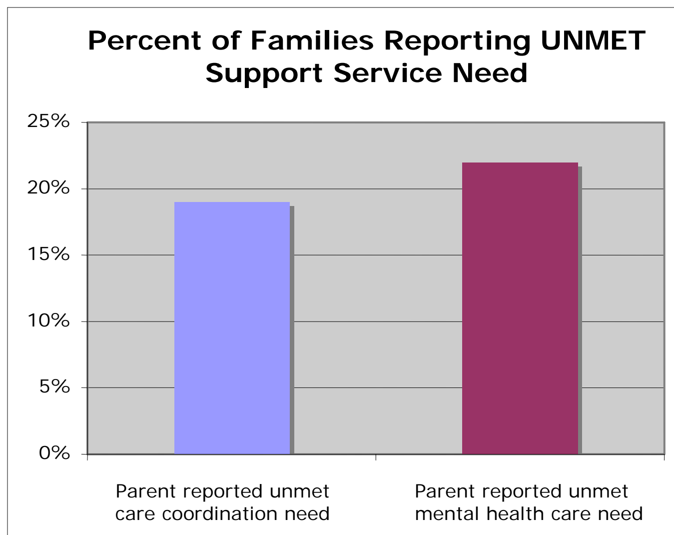


Mental health care services typically include supportive counseling for individuals and families, psychiatric treatment, support group involvement, and other services designed to facilitate coping and promote healthy psychological functioning.

Professional Care Coordination

Professional care coordination is one solution to the numerous hurdles faced by families raising children with special care needs is. It can play a critical role in helping families identify resources and secure the services needed by their child with disabilities. Professional care coordination involves connecting children and families with needed services, facilitating communication among

and between providers and families, ensuring that services are not duplicated, providing resource referrals, and advocating for children and families.



Care coordination improves both the quality of care and the effectiveness of support services for families.[10] However, care coordination is still not used by all families raising children with disabilities because of state variability in the availability of these services.

Investigation Results

This section summarizes the findings of data analyses for nearly 39,000 children from the National Survey of Children with Special Health Care Needs.

Mental Health Care

Parents residing in states with a greater number of children receiving State Children's Health Insurance Program (SCHIP) services are also more likely to receive needed mental health care than those living in states with fewer children enrolled in SCHIP. SCHIP is the public health insurance program for working families who are unable to afford private insurance, but earn too much to qualify for Medicaid. Some family characteristics are related to a *decreased* likelihood of receiving mental health care, including parents who speak limited English, children who are uninsured, families with household income below three times the federal poverty level ($60,000 for a family of four in 2006), and children with more severe impairments. In addition, families of children with a usual source of health care are more likely to receive needed mental health services.

Professional Care Coordination

We found families living in states with more expansive SCHIP eligibility requirements are more likely to receive needed professional care coordination services. In addition, we found certain characteristics are related to a *decreased* likelihood of receiving care coordination, including if the parents speak limited English, if the child is uninsured, if the family has income below three times the federal poverty level, or if the child's impairments are more severe. Families whose children have a usual source of care were almost twice as likely as other children to receive professional care coordination services.

Conclusions

Families that live in states with expansive State Children's Health Insurance Program programs are more likely to receive needed mental health services (when greater numbers of children are served in SCHIP) and are more likely to receive professional care coordination (when states have higher income limits for SCHIP participation).

There is likely a direct relationship between SCHIP generosity and the receipt of needed family support services. Families living in states with more expansive SCHIP programs are likely to have better access to health care, including mental health care and professional care coordination. Increased funding for children's health insurance since SCHIP's inception in 1997 has reduced the number of uninsured children, even while private insurance coverage has declined over the same period. [11]

Troubling among the study findings was the numerous individual characteristics associated with decreased likelihood of receiving needed support services; these characteristics included parents who spoke limited English, children who were uninsured, families with total household income below three times the federal poverty level, and children with severe impairments.

However, these disparities in service provision are likely to be mitigated with appropriate policy intervention. States could likely improve access to support services by specifically targeting intervention measures to the children and their families with these characteristics.

Our finding that health insurance and the generosity of specific health insurance programs are positively associated with better access to health care is hardly surprising—it is consistent with decades of research on the nondisabled population.[12] Therefore, efforts to improve families' receipt of support services should include the expansion of health insurance coverage for children with disabilities and their families. These findings suggest that the SCHIP expansion passed by Congress and which the President vetoed in October 2007 would likely have realized improved receipt of support services for families of children with special health care needs. Expanded funding is warranted to increase access to the program by families who are unaware of the important support SCHIP offers.

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This policy brief reports analyses of data for nearly 39,000 children from the 2002 National Survey of Children with Special Health Care Needs. Hierarchical Generalized Linear Modeling was used to analyze the relationship between individual characteristics, 10 state policy variables and support services. State policies included Supplemental Security Income, the State Children's Health Insurance Program, the Early Periodic Screening, Diagnosis and Treatment, Medicaid and special education services funded through the Individuals with Disabilities Education Act (IDEA).

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