CHIRI
The Child Health Insurance Research Initiative

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Mental Health Needs of Low-Income Children With Special Health Care Needs

Children with special health care needs (CSHCN) comprise 13.9 percent of all children in the United States. Nearly 22 percent of households with children include at least one child with a special health care need. Low-income and minority CSHCN have higher rates of mental health problems yet are less likely than their counterparts to receive mental health services.

Early intervention has been shown to minimize the impact of mental health problems in children and significantly reduce the need for more costly interventions. Early identification of mental health needs in children, particularly CSHCN, is critical to obtaining mental health services. Families play a crucial role in obtaining and coordinating care for CSHCN, including mental health screening, diagnosis, and treatment.

This Issue Brief summarizes a Child Health Insurance Research Initiative (CHIRI™) study that compared the prevalence of mental health problems among CSHCN to family perceptions of mental health needs. Researchers found:

- Mental health issues (e.g., attention and behavior disorders) were second only to asthma as the top health problems in CSHCN, as reported by their families.
- More than one-third of CSHCN had a mental health problem, but only one-quarter of caregivers recognized the need for mental health services.
- Families underestimated the need for mental health services in young children with special health care needs but slightly overestimated this need in adolescents with special health care needs.
- White families of CSHCN were more than twice as likely as their black counterparts to perceive a need for mental health services, although there was no difference in the prevalence of mental health problems.

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Mental health problems were one of the most common health care problems reported by families of CSHCN.

WHAT WAS LEARNED

Researchers surveyed families of CSHCN enrolled in Medicaid who were receiving services in six primary health care clinics in an urban midwestern city. Children were identified as having a special health care need using the CSHCN Screener, a nationally recognized and validated screening instrument. Researchers then compared family perceptions of their child's mental health needs with the results of the Child Behavior Checklist (CBCL), a standardized tool that uses parent report to assess emotional, behavioral, and social problems in children.

Definition of CSHCN

CSHCN are defined by the Federal Maternal and Child Health Bureau as those children 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.

More Than One-Third of CSHCN Experienced a Mental Health Problem

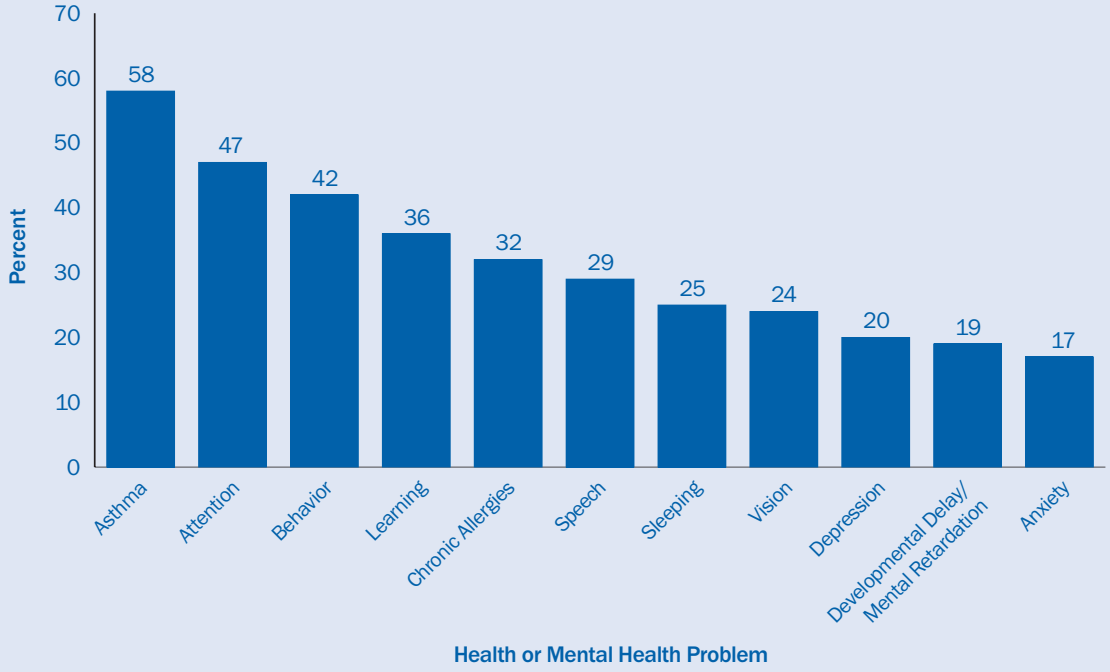
Approximately 30 percent of children surveyed were identified as having a special health care need by the CSHCN Screener. Of CSHCN, more than one-third (38 percent) had a mental health problem in need of treatment based on the results of the CBCL.

There were no significant differences in the overall prevalence of mental health problems in CSHCN by race, gender, age, or other demographic characteristic (e.g., parental marital, educational, and employment status). When asked about their child's top health problems, parents of CSHCN rated attention and behavioral health problems second only to asthma (47 percent and 42 percent versus 58 percent, respectively) (see Figure 1).

Families Were Less Likely To Recognize a Need for Mental Health Services in Young Children Than in Adolescents

Even though more than one-third of CSHCN had a mental health need, only one-quarter of families perceived a need for mental health services in their

Figure 1. Percentage of Health and Mental Health Problems in Medicaid CSHCN



child. The disparity between actual versus perceived mental health needs was greatest for 2- to 5-year-old children. For children in this age range, 11 percent of families recognized a mental health need even though 31 percent of these young children had a mental health problem. In contrast, families slightly overestimated the mental health needs of adolescents (ages 13 to 17 years) (see Figure 2).

Of children whose families thought their child needed mental health services, nearly all (98 percent) had received some type of mental health service (e.g., counseling, treatment) in the past. Mental health treatment was received primarily from mental health providers (e.g., psychologists, psychiatrists, social workers) and primary care providers (e.g., nurses, pediatricians, other primary care doctors).

Black Families Were Less Likely To Recognize a Mental Health Need Than Their White Counterparts

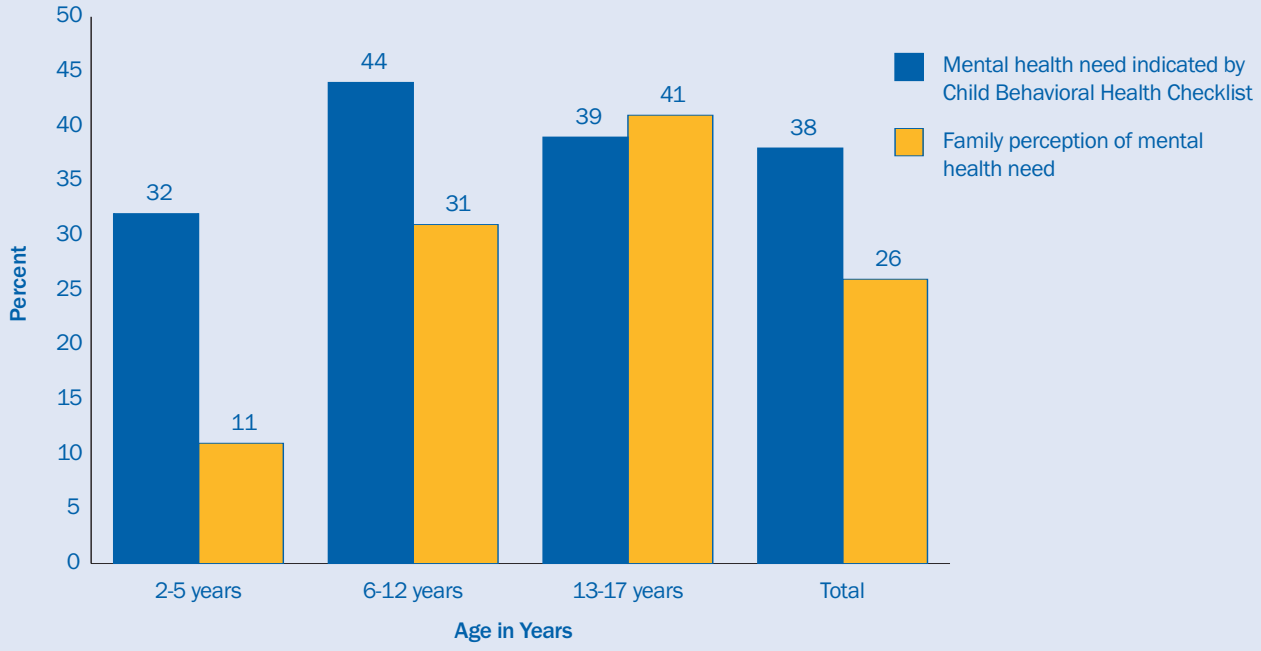
The prevalence of mental health needs in CSHCN was similar for white and black families in the study group. However, black families of CSHCN were less than half as likely as their white counterparts to recognize a need for mental health services (18 percent versus 38 percent, respectively). Urban community stressors (e.g., poverty, crime, substance abuse), race, and the child's health status were significantly associated with behavioral and emotional problems among CSHCN.

CONCLUSION

A significant proportion of children with special health care needs in this study had a mental health problem. However, it is not clear from this study whether the mental health need was a primary or secondary diagnosis, a factor that might affect how families perceive mental health needs in their child. A family struggling with a child with physical special needs might be less likely to also identify a mental health need in that child.

Many families did not perceive that their child needed mental health services. Many child-serving systems (e.g., child care, schools, primary care) are implementing efforts to identify children who may be at risk for or experiencing mental health problems. This study suggests that routine mental health screening in settings that serve CSHCN (e.g., primary

Figure 2. Comparison of Family Perception and Need for Mental Health Treatment, by Age



Families of young children with special health care needs underestimated their child's need for mental health services.

and specialty care) would identify children previously unrecognized as needing mental health services.

Families underestimated the need for mental health treatment in young children with special health care needs and slightly overestimated the need in adolescents with special health care needs. Mental health needs in young children may be more likely attributed to developmental issues (e.g., behavioral issues) than mental health problems and may be less likely to be diagnosed early. Conversely, research indicates that families may be more likely to perceive typical adolescent behavior as a mental health problem. These differences underscore the need to screen for mental health issues in both children and adolescents, because parental assessments of a child's mental health needs may not be fully reliable. In addition, these findings highlight the need to educate parents about the range of normal development in children and adolescents, particularly in CSHCN.

Educating parents and increasing identification of mental health problems has implications for the pediatric primary care and mental health workforce. There is a nationwide shortage of well-trained providers available to serve children and adolescents, particularly in rural and low-income areas. Furthermore, pediatric mental disorders are routinely being seen in primary care. Therefore, many States and communities are advancing programs to integrate mental health services into primary care settings.

Differences in black and white families' perceptions of the need for mental health services may contribute to or be caused by health care disparities. Other studies indicate that minorities are less likely to look for and obtain mental health services due to cultural differences in seeking help for mental health needs. These differences may also reflect unequal access to care, particularly in low-income communities. Black children are less likely than white children to have a doctor's visit. White families therefore have more opportunity to be alerted to their child's mental health problems by health and mental health professionals.

In contrast to other studies, nearly all CSHCN whose families perceived their child as needing mental health treatment had previously received some sort of mental health treatment or counseling. It may be that referral to mental health services by child care, education, or health professionals was the mechanism by which these families became aware of their child's mental health condition. Nonetheless, caregiver perceptions of treatment needs are associated with receipt of services.

POLICY IMPLICATIONS

This CHIRI™ study suggests strategies for policymakers to consider in strengthening health and mental health care for CSHCN. These strategies include the following:

- Educate families about typical child development and the possible signs of mental health problems in children, including CSHCN, particularly for families with young children and adolescents.
- Develop culturally appropriate education programs to educate, raise awareness, and reduce the stigma regarding mental health problems in children, including CSHCN.
- Implement early intervention programs and related referrals in a range of child-serving settings (e.g., schools, preschools and child care centers, recreation programs) to identify mental health needs in children, including CSHCN.
- Strengthen routine and periodic mental health screening, assessment, and referral for children, including CSHCN, as part of routine care within a primary care setting.
- Strengthen reimbursement for mental health screening and assessment in States as part of Medicaid's Early Periodic Screening, Diagnosis, and Treatment standard.
- Increase access to mental health services for children, including CSHCN, particularly in underserved areas. Possible strategies include expanding the number of pediatric mental health providers and integrating mental health services into pediatric primary care settings (e.g., training pediatric providers on mental health issues, colocating mental health providers in pediatric practices).

STUDY METHODOLOGY

Randomly selected primary caregivers (N=1,220) were asked to complete a CSHCN Screener and a demographic questionnaire when they brought their children for primary care visits at one of six urban midwestern community health centers between September 2001 and May 2002. The CSHCN Screener is a nationally recognized and validated screening instrument that identifies CSHCN. It consists of five questions related to the child's functioning, need for health care, service use, and use of prescriptions. To determine whether a child had a behavioral or mental health problem, researchers used the Child Behavior Checklist (CBCL), a validated and widely used measure that uses parent report to detect children's emotional, behavioral, and social problems.

Caregivers who were asked to participate in the study had black or white children between the ages of 2 and 18 years enrolled in Medicaid and positive responses to one or more questions on the CSHCN Screener (N=368). Of the eligible caregivers, 340 (92.4 percent) agreed to participate in the study, with a final sample size of 257 (79 percent of those asked to participate). Caregivers were called within one week of the child's clinic visit to schedule a computer-assisted phone interview and were paid $10 to participate in the study.

Descriptive statistics were used to assess the prevalence of mental health problems and caregiver perceptions of the need for mental health counseling or treatment. T-tests were used to detect differences between mental health problems in CSHCN and CBCL scores. A logistic regression model was used to determine whether caregivers' perceptions of mental health care and counseling needs differed by race, after controlling for demographic variables and CBCL scores.

SOURCES AND RELATED STUDIES OF INTEREST

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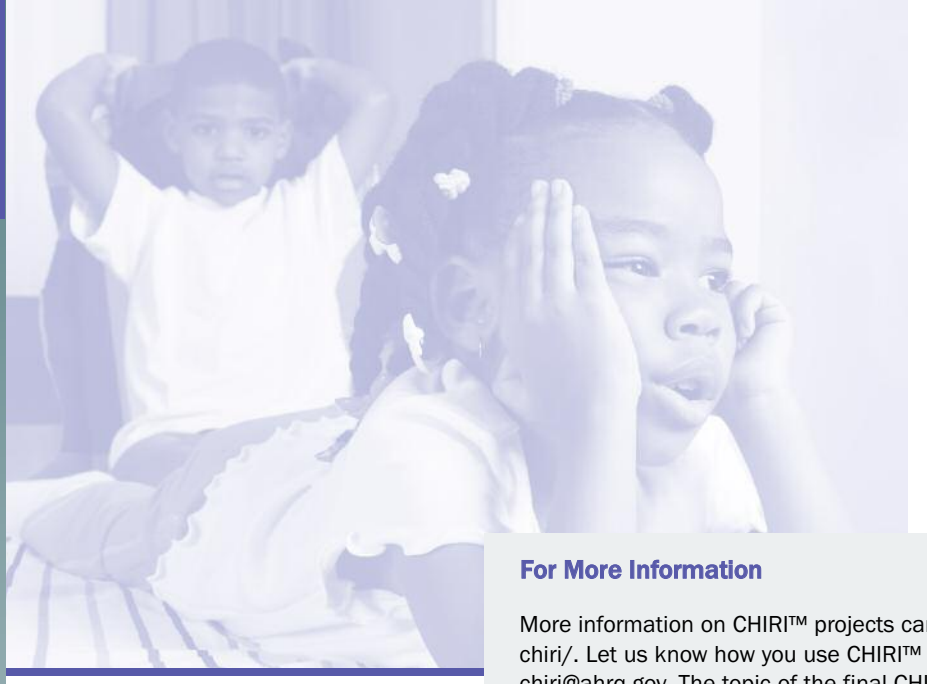

For More Information

More information on CHIRI™ projects can be found at www.ahrq.gov/chiri/. Let us know how you use CHIRI™ research findings by contacting chiri@ahrq.gov. The topic of the final CHIRI™ Issue Brief is: What Has Been Learned from CHIRI™?

ABOUT CHIRI™

The Child Health Insurance Research Initiative (CHIRI™) is an effort to supply policymakers with information to help them improve access to, and the quality of, health care for low-income children. Nine studies of public child health insurance programs and health care delivery systems were funded in the fall of 1999 by the Agency for Healthcare Research and Quality (AHRQ), The David and Lucile Packard Foundation, and the Health Resources and Services Administration (HRSA). These studies seek to uncover which health insurance and delivery features work best for low-income children, particularly minority children and those with special health care needs. This Issue Brief is based on research conducted by the CHIRI™ project "Health Care Access, Quality and Insurance for Children With Special Health Care Needs" (Principal Investigator: Nancy Swigonski, Indiana University School of Medicine).

CHIRI™ FUNDERS

The Agency for Healthcare Research and Quality, part of the U.S. Department of Health and Human Services, is the lead agency charged with supporting research designed to improve the quality of health care, reduce its costs, address patient safety and medical errors, and broaden access to essential services. AHRQ sponsors and conducts research that provides evidence-based information on health care outcomes; quality; and cost, use, and access.

The David and Lucile Packard Foundation is a private family foundation that provides grants in a number of program areas, including children, families and communities, population, and conservation and science.

The Health Resources and Services Administration, also part of the U.S. Department of Health and Human Services, directs national health programs that provide access to quality health care to underserved and vulnerable populations. HRSA also promotes appropriate health professions workforce supply, training, and education.

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