

## Mental Health Among Children With Special Health Care Needs In Rhode Island

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**Children with special health care needs (CSHCN)** are defined as "...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."<sup>1</sup> In Rhode Island, 17.2% of children younger than 18 years, or 41,783 children, were estimated to have a special health care need in 2005-2006.<sup>2</sup> The prevalence of CSHCN in Rhode Island was higher than the nation as a whole (13.9%).<sup>2</sup>

CSHCN, in general, have higher levels of unmet needs for routine and specialty care and are less likely to have a comprehensive medical home, compared with the general pediatric population.<sup>3</sup> Moreover, CSHCN with mental health problems are even more likely than CSHCN without mental health problems to experience diminished health and quality of life and to have problems accessing and receiving needed care.<sup>4</sup>

The objectives of this study are to 1) estimate the prevalence of mental health problems among CSHCN in Rhode Island and 2) assess disparities in the Federal Maternal and Child Health Bureau's core outcomes between CSHCN with mental health problems and CSHCN without mental health problems.

### METHODS

Data from the 2005/06 National Survey of Children with Special Health Care Needs (NS-CSHCN) were analyzed to examine mental health problems among CSHCN in Rhode Island. The NS-CSHCN is a random digit dial telephone survey administered in all 50 states and the District of Columbia to assess the prevalence and impact of special health care needs. Parents or guardians of CSHCN aged 0-17 years responded to the survey. In Rhode Island, the interviews were completed for 850 CSHCN with an overall response rate of 54.4%. The detailed information on the survey is presented elsewhere.<sup>2</sup>

CSHCN are defined as having a mental health problem if their parents reported that their

child has at least one of the following: 1) any difficulty with behavior problems such as acting-out, fighting, bullying, or arguing; 2) mental retardation or developmental delay; or 3) depression, anxiety, an eating disorder, or other emotional problems. The mental health problems in this study are therefore defined as having **emotional, behavioral, or developmental (EBD)** problems. Since some of the screeners for EBD problems were not asked for children <2 years of age in the survey, this study analyzed the data only for children ≥ 2 years.

Six core outcomes, developed by the **Maternal and Child Health Bureau (MCHB)** to measure progress toward implementing community-based systems of services for CSHCN, were used to assess disparities between CSHCN with EBD problems and CSHCN without EBD problems. These six core outcomes are used as National Performance Measures for all state Title V programs, and Rhode Island must monitor its progress in achieving them. Each core outcome was disaggregated into its essential elements and these elements were then translated into measurable criteria using items contained in the survey.<sup>4</sup> Each of these outcomes and their elements were assessed by mental health status using the chi-square test. Unless noted, all estimates were weighted to reflect the noninstitutionalized population of children 2-17 years of age in Rhode Island.

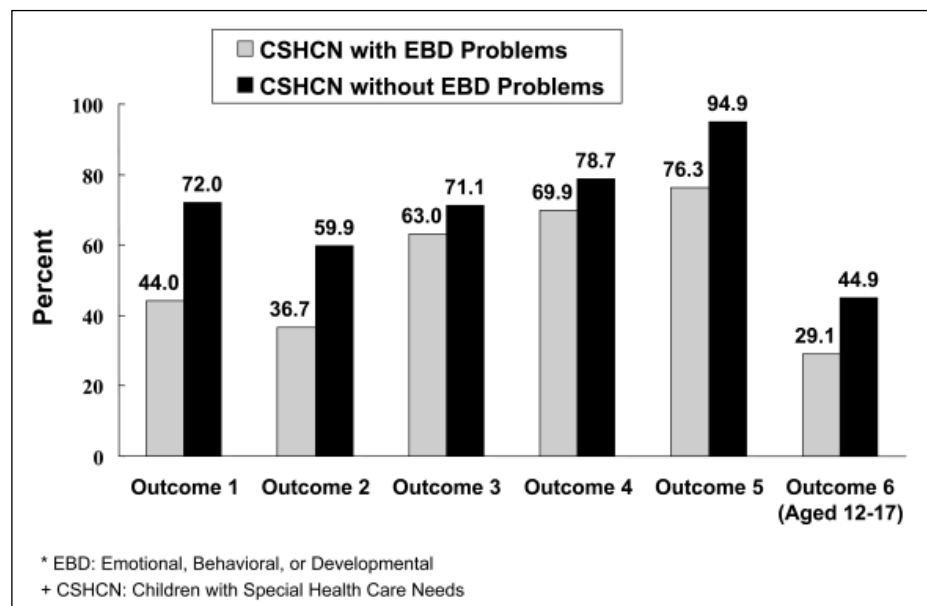


Figure 1. Disparities in Core Outcome Measures by Emotional, Behavioral, or Developmental (EBD) Status among Children with Special Health Care Needs (CSHCN) aged 2-17 years, Rhode Island, 2005/06.

Table 1. Proportion of CSHCN (Aged 2-17) with Emotional, Behavioral, or Developmental (EBD) Problems by Selected Characteristics, Rhode Island, 2005/06

	n*	%	P-Value
<b>Overall</b>	<b>828</b>	<b>40.9</b>	
<b>Age (in year)</b>			
2-5	118	24.4	.0010
6-11	317	41.6	
12-17	393	45.9	
<b>Sex</b>			
Male	529	45.7	.0030
Female	298	33.2	
<b>Ethnicity</b>			
Non-Hispanic	718	39.2	.0307
Hispanic	105	53.4	
<b>Race</b>			
White only	687	38.6	.0795
Black only+	38	45.9	
Other++	92	54.0	
<b>Mother's Education</b>			
< High School	45	59.7	.0114
High School	129	46.5	
> High School	653	36.2	
<b>Poverty Status</b>			
< 200% FPL	245	53.0	.0000
200% - <400% FPL	259	36.0	
At or above 400% FPL	242	28.2	
<b>Insurance Type</b>			
Private	516	28.9	.0000
Public	184	57.5	
Both Private & Public	93	50.7	

I Sample size is too small to produce reliable estimate.

II Other category includes Asian, American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, and multiple races.

\* n is unweighted sample size with non-missing data.

## RESULTS

Overall, 40.9% of CSHCN aged 2-17 years in Rhode Island have EBD problems. (Table 1) The proportions of EBD problems were higher among teens (45.9%), male children (45.7%), Hispanic children (53.4%), children whose mothers have < high school education (59.7%), children living in households with incomes < 200% federal poverty levels (53.0%), and children who have public insurance (57.5%) compared to their counterparts.

Compared with CSHCN without EBD problems, CSHCN with EBD problems had significantly lower rates of meeting all of the six core outcomes. (Table 2) Less than half of families of CSHCN with EBD problems (44.0%) reported that they were partners in decision-making at all levels and were satisfied with the services they received, compared with 72.0% of families of CSHCN without EBD problems (Core Outcome 1). Only 36.7% of CSHCN with EBD problems reported they received coordinated, ongoing, comprehensive care within a medical home, compared with 59.9% of CSHCN without EBD problems (Core Outcome 2). Less than two-thirds (63.0%) of CSHCN with EBD problems reported that they had adequate private and/or public insurance to pay for the services they needed, compared with

71.1% of CSHCN without EBD problems (Core Outcome 3). Fewer CSHCN with EBD problems (69.9%) than CSHCN without EBD problems (78.7%) were screened early and continuously for special health care needs (Core Outcome 4). Significantly fewer families of CSHCN with EBD problems (76.3%) than families of CSHCN without EBD problems (94.9%) reported that community-based services were organized so families could use them easily (Core Outcome 5). Lastly, only 29.1% of youth (aged 12-17 years) with special health care needs who have EBD problems and 44.9% of youth with special health care needs who do not have EBD problems reported they received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence (Core Outcome 6). (Figure 1)

## DISCUSSION

The results indicate that a substantial proportion of CSHCN in Rhode Island has EBD problems and the EBD problems are disproportionately high among certain groups of CSHCN (such as teens, males, Hispanics, children whose mothers have low education, children living in low income families and children who have public insurance). Our results also demon-

strate that these children are at increased risk for not meeting all of the MCHB core outcome measures, which means EBD problems appear to be barriers to obtaining family-centered, coordinated, and community-based care. To improve emotional, behavioral, and cognitive development of children, early diagnosis and effective interventions are necessary, especially for children living in socio-economically disadvantaged families. The Office of Special Healthcare Needs at the Rhode Island Department of Health has initiated such programs to strengthen the coordination between pediatric primary and specialty care while developing a common language among parents and professionals and schools concerning emotional behavioral health. In early 2008, the Department of Health partnered with Bradley Hospital and Hasbro, Inc. to develop and disseminate the Rhode Island Parents' Guide to Children's Mental Health that assists children and their families find answers about mental healthcare and enable them to better access and use the children's mental healthcare system in Rhode Island. Based on the disparities highlighted in this analysis, the Office of Special Healthcare Needs plans to collaborate with Rhode Island Parent Information Network and Parent Support Network to address the coordination between medical and behavioral health.

Table 2. Proportion of CSHCN (Aged 2-17) Who Met the Core Outcomes by Emotional, Behavioral, or Developmental (EBD) Status, Rhode Island, 2005/06

Core Outcome and Element	CSHCN with EBD Problems	CSHCN without EBD Problems	P-Value
	%	%	
<b>Core Outcome 1: Families of CSHCN are partners in decision-making at all levels and are satisfied with the services they receive</b>			
1.1 Doctors usually or always make the family feel like a partner	85.9	92.6	.0129
1.2 Family is very satisfied with services received	46.2	74.5	.0000
<b>Proportion meeting Core Outcome 1</b>	<b>44.0</b>	<b>72.0</b>	<b>.0000</b>
<b>Core Outcome 2: CSHCN receive coordinated, ongoing, comprehensive care within a medical home</b>			
2.1 The child has a usual source of care	93.5	95.0	.4308
2.1a The child has a usual source for sick care	94.6	95.5	.6129
2.1b The child has a usual source of preventive care	98.1	99.2	.1820
2.2 The child has a personal doctor or nurse	96.0	98.7	.0363
2.3 The child has no problems obtaining referrals when needed	86.5	92.5	.1525
2.4 The child receives effective care coordination	49.2	73.3	.0000
2.4a Family usually or always gets sufficient help coordinating care, if needed	62.0	84.3	.0000
2.4b Family is very satisfied with doctors' communication with each other	58.4	76.6	.0001
2.4c Family is very satisfied with doctors' communication with other programs	55.3	69.2	.0408
2.5 The child receives family-centered care	63.1	73.7	.0096
2.5a Doctors usually or always spend enough time	81.1	84.8	.2662
2.5b Doctors usually or always listen carefully	88.8	93.1	.1302
2.5c Doctors are usually or always sensitive to values and customs	87.8	93.0	.0412
2.5d Doctors usually or always provide needed information	75.3	90.0	.0000
2.5e Doctors usually or always make the family feel like a partner	85.9	92.6	.0129
2.5f An interpreter is usually or always available when needed <sup>†</sup>	79.7	77.8	.9255
<b>Proportion meeting Core Outcome 2</b>	<b>36.7</b>	<b>59.9</b>	<b>.0000</b>
<b>Core Outcome 3: Families of CSHCN have adequate private and/or public insurance to pay for the services they need</b>			
3.1 The child has public or private insurance at time of interview	98.6	98.6	.9822
3.2 The child has no gaps in coverage during the year before the interview	91.0	95.4	.0584
3.3 Insurance usually or always meets the child's needs	90.5	94.5	.0727
3.4 Costs not covered by insurance are usually or always reasonable	74.1	78.5	.2068
3.5 Insurance usually or always permits child to see needed providers	91.8	97.1	.0080
<b>Proportion meeting Core Outcome 3</b>	<b>63.0</b>	<b>71.1</b>	<b>.0432</b>
<b>Core Outcome 4: Children are screened early and continuously for special health care needs</b>			
4.1 Child has received routine preventive medical care in past year	80.0	86.6	.0645
4.2 Child has received routine preventive dental care in past year	80.2	86.1	.0971
<b>Proportion meeting Core Outcome 4</b>	<b>69.9</b>	<b>78.7</b>	<b>.0318</b>
<b>Core Outcome 5: Community-based services are organized so families can use them easily</b>			
5.1 Child's family has experienced no difficulties using services	76.3	94.9	.0000
<b>Proportion meeting Core Outcome 5</b>	<b>76.3</b>	<b>94.9</b>	<b>.0000</b>
<b>Core Outcome 6: Youth with SHCN receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence (Youth aged 12-17)</b>			
6.1 The child receives anticipatory guidance in the transition to adulthood	29.6	41.5	.0759
6.1a Doctors have discussed shift to adult provider, if necessary	30.3	51.1	.0513
6.1b Doctors have discussed future health care needs, if necessary	57.8	69.8	.0829
6.1c Doctors have discussed future insurance needs, if necessary	21.5	28.0	.3235
6.2 The child has usually or always been encouraged to take responsibility for his or her health care needs	72.2	86.4	.0038
<b>Proportion meeting Core Outcome 6</b>	<b>29.1</b>	<b>44.9</b>	<b>.0107</b>

<sup>†</sup> Sample size is too small to produce reliable estimate

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## Disclosure of Financial Interests

The authors have no financial interests to disclose.