

# Prevalence of Children with Special Health Care Needs in Milwaukee, Wisconsin: Data from the Milwaukee Metropolitan Statistical Area

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## ABSTRACT

*Background:* The Milwaukee Health Department and the Wisconsin Southeast Regional Center for Children with Special Health Care Needs (CSHCN) were interested in understanding the level of need and prevalence of CSHCN in the city of Milwaukee. It was determined that a survey of the Milwaukee area was needed to obtain a prevalence estimate.

*Methods:* A survey to identify children with special health care needs in the Milwaukee metropolitan statistical area (MSA) was conducted using the CSHCN Screener®. The survey was administered as part of the Greater Milwaukee Survey in October and November of 2004. Results from this survey were compared to state and national data from the National Survey of Children with Special Health Care Needs, 2001.

*Results:* The prevalence of CSHCN in Milwaukee (23.5%) was found to be almost double that of the surrounding Milwaukee MSA counties (12.1%), the state (13.4%), and the nation (12.8%). The number and type of positive screener questions were not significantly different among the geographic areas.

*Conclusions:* The prevalence of CSHCN has been consistently associated with poverty in numerous other

studies. The survey conducted in Milwaukee MSA indicated increased prevalence in Milwaukee among poor and African American children. Improvement and augmentation of services available to urban poor is necessary to alleviate this excessive burden.

## INTRODUCTION

The National Survey of Children with Special Health Care Needs (CSHCN) was conducted in 2000-2002 by the National Center for Health Statistics. The survey was administered as part of the State and Local Area Integrated Telephone Survey (SLAITS) and used the CSHCN Screener® developed by the National Foundation for Accountability.<sup>1,2</sup> Nationally, there were 373,005 children in 196,888 households screened. The national prevalence estimate of CSHCN was 12.8%. In Wisconsin, 3642 households and 6948 children were screened. The Wisconsin statewide prevalence estimate of CSHCN was 13.4%. However, the survey methodology was not designed to provide prevalence data at the county or municipal level but to estimate prevalence on a state and national level. The City of Milwaukee Health Department and the Wisconsin Southeast Regional Center for CSHCN were interested in understanding the level of need and prevalence of CSHCN in the city of Milwaukee. It was determined that, although much data existed related to the health of children in Milwaukee from a wide variety of sources, most of it was inaccessible or unusable to make a CSHCN prevalence estimate. Therefore, it was necessary to conduct a survey of CSHCN in the Milwaukee metropolitan area, using the CSHCN Screener® as a way to get an unbiased estimate of the prevalence of children with special health care needs in Milwaukee. This paper describes the methods used and examines the need for enhanced resources for assisting children with special health care needs in the Milwaukee urban community.

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**METHODS***Participants and Setting*

A total of 857 households in the Milwaukee Metropolitan Statistical Area (MSA) were interviewed from October 2, 2004 to November 9, 2004. The 291 households had a total of 664 children <18 years of age. Of the 664 children screened, 121 were identified as CSHCN. The Greater Milwaukee Survey (GMS), described in more detail below, is a semi-annual telephone survey of residents ( $\geq 18$  years) in the Milwaukee MSA and includes 4 counties: Milwaukee, Ozaukee, Washington, and Waukesha.

*Survey Instrument*

The CSHCN Screener<sup>®</sup> was developed by the Child and Adolescent Health Measurement Initiative, a group coordinated by the Foundation for Accountability.<sup>2</sup> This tool was developed as a standardized method of identifying children with special health care needs based on the presence of functional limitations and service use needs that result from a physical, emotional, behavioral, developmental, or other health condition. The screener can be used as a mail or telephone survey and consists of 5 main questions:

1. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?
2. Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age?
3. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?
4. Does your child need or get special therapy, such as physical, occupational, or speech therapy?
5. Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets treatment or counseling?

Questions 1 through 4 have 2 sub-questions (a and b):

- a. Is this because of ANY medical, behavioral, or other health condition?
- b. Is this a condition that has lasted or is expected to last for at least 12 months?

Question 5 follows with sub-question b only. To be scored as a positive screen, all parts of any of the 5 questions must be answered yes. Additionally, the screener can identify 3 definitional domains: dependency on prescription medications, service use above that considered routine, and functional limitations.

*Survey Methodology and Procedures*

The Institute for Survey and Policy Research at the

University of Wisconsin-Milwaukee was contracted to include the CSHCN Screener<sup>®</sup> on the fall 2004 round of the Greater Milwaukee Survey. The GMS is a semi-annual telephone survey of the residents ( $\geq 18$  years) in the Milwaukee metropolitan statistical area. The GMS is an omnibus survey; that is, it includes questions purchased by a number of separate clients in addition to questions related to demographics and socioeconomic status. Interviews were conducted from the Survey Research Laboratory using a computer-assisted telephone interviewing system. The sample of households in the survey was selected using a computer-assisted random digit dialing procedure. The interviewer randomly selected the respondent within the household by asking to speak to the person  $\geq 18$  years who had had the most recent birthday. If this person was not available, the interviewer called the selected respondent back at another time. Any generated phone number was called 8 times before it was discarded. In addition, any number determined to be unassigned, disconnected, or assigned to a business, government office, or other non-residence was discarded. Callbacks were made to convert initial refusals into completed interviews. A Spanish-speaking interviewer was available when needed.

*Data Analyses*

Child level data from the GMS were weighted to reflect the mean number of children per household in each geographic area and to account for increased selection probability based on number of phone lines. All weights were calculated based on Census 2000 data.<sup>3</sup> Data from the 2001 administration of the SLAITS was used to compare the GMS CSHCN Screener<sup>®</sup> results to national and state results.<sup>4</sup> Demographic characteristics of children who screened positive were compared by geographic area using chi-square and Fisher's exact tests. CSHCN Screener<sup>®</sup> results from the 2001 SLAITS were computed for Wisconsin and the United States using Software for the Statistical Analysis of Correlated Data (SUDAAN).<sup>5</sup> SUDAAN is a statistical package for analysis of data from complex sampling designs such as SLAITS. It takes into account weights and correlations to produce accurate variance estimates not possible with statistical software that assumes a simple random sample.<sup>6</sup> Percents and 95% confidence intervals were computed for children with positive screens, positive individual screener questions, and domain areas for both the GMS and SLAITS. The results from the 2004 GMS administration were compared to the 2001 SLAITS. Analysis of GMS survey data was completed using SPSS Version 11.5.2.1 (SPSS, Inc. Chicago, IL).

**Table 1.** Demographic Characteristics, Children with Positive Screens\*

Characteristic	Place			B. vs. C. Comparison†
	A. Milwaukee MSA (All Children) n=121	B. City of Milwaukee n=84	C. Counties Outside City of Milwaukee n=37	
	Number (%)‡			P
<b>Gender</b>				
Male	73 (60.9)	48 (57.1)	25 (69.4)	.21
Female	47 (39.1)	36 (42.9)	11 (30.6)	
<b>Age Groups</b>				
0–4 years	18 (15.0)	15 (17.9)	3 (8.3)	.33
5–11 years	48 (40.0)	31 (36.9)	17 (47.2)	
12–17 years	54 (45.0)	38 (45.2)	16 (44.4)	
<b>Race/Ethnicity (Primary Response)</b>				
African American	60 (51.3)	58 (71.6)	2 (5.7)	<.001
White	40 (34.6)	13 (16.0)	27 (77.1)	
All other race/ethnicities	16 (14.1)	10 (12.3)	6 (17.1)	
<b>Number of Children in Household</b>				
One	24 (20.0)	17 (20.2)	8 (21.6)	.86
More than 1	96 (80.0)	67 (79.8)	29 (78.4)	
<b>Household Income</b>				
Less than \$30,000 per year	50 (41.4)	48 (57.1)	2 (5.4)	<.001
\$30,000 or more per year	51 (42.2)	22 (26.2)	29 (78.4)	
Don't know/refused	20 (16.3)	14 (16.7)	6 (16.2)	

MSA=Milwaukee metropolitan statistical area

\*Weighted analysis.

†Chi-square, Fisher's Exact test used for comparisons containing cells with expected counts <5.

‡Number does not always equal N due to refusals, don't know responses, and rounding that occurred in the weighting procedure.

## RESULTS

### *Children with Positive Screens: Comparison of Demographics by Geographic Area*

Table 1 displays demographic characteristics of children with positive screens by geographic area. On the CSHCN Screener,<sup>®</sup> 121 children scored positively. Of these, 61% were male. When race was identified 51% were African American, 35% were white, 14% were Asian or Pacific Islander, American Indian or Alaska Native, or Hispanic, and 3% refused to answer. These categories were combined into 1 grouping (all other races/ethnicities) for analysis. Age breakdowns were: 15% were ≤4 years old, 40% were 5-11 years old, and 45% were 12-17 years old. Twenty percent were the only children in their household, 41% came from households with <\$30,000 per year income in 2003, and 42% lived in households with income of ≥\$30,000. When the city of Milwaukee and Milwaukee MSA counties were compared, there were statistically significant differences in race/ethnicity and income. Compared to the Milwaukee MSA counties, the city of Milwaukee had a greater proportion of children with positive screens who were African American (71.6%) and had household incomes in 2003 of <\$30,000 per year (57.1%).

### *CSHCN Screener<sup>®</sup> Results: Comparison of GMS and SLAITS*

The percent (95% confidence interval) of children with positive screens and positive screening questions among the geographic areas of the GMS and the national and Wisconsin SLAITS data are displayed in Table 2. Using the confidence intervals to compare the percentages (non-overlapping confidence intervals indicate proportions that are significantly different), there were significant differences among the city of Milwaukee, Milwaukee MSA counties, SLAITS National, and SLAITS Wisconsin in the percentage of children surveyed who screened positive. Milwaukee had a significantly greater proportion of children who screened positive (23.5%) when compared to the Milwaukee MSA counties outside the city (12.1%) and SLAITS National (12.8%) and Wisconsin (13.4%). When the responses to individual questions were examined, there were no significant differences in the percentages of positive scores among the surveys and geographic areas. The percentages of CHSCN identified as positive on the 3 differential domains and the total number of screening questions scored positive was also similar among the surveys and geographic areas. The GMS had

**Table 2.** CSHCN Screener © Results: Comparison of GMS 2004 to SLAITS 2002, Percent and 95% Confidence Intervals\*

Screening Results by Child CSHCN Screener©	Milwaukee MSA (All Children)	City of Milwaukee	Counties Outside City of Milwaukee	SLAITS† National (73,166,625)‡	SLAITS† Wisconsin (1,373,917)‡
<b>All Children</b>	<b>n=664</b>	<b>n=357</b>	<b>n=307</b>	<b>n=372,174</b>	<b>n=6948</b>
<b>Percent and (95% Confidence Interval)</b>					
Positive Screen	18.2 (15.5 – 21.3)	23.5 (19.4 - 28.2)	12.1 (8.8 – 16.2)	12.79 (12.6 – 13.0)	13.42 (12.6 – 14.3)
<b>Children with Positive Screens</b>	<b>n=121</b>	<b>n=84</b>	<b>n=37</b>	<b>n=48,690</b>	<b>n=955</b>
Positive Screen Question 1 (Dependency Domain)	80.2 (72.3 – 86.3)	83.3 (74.0 – 89.8)	73.0 (57.0 – 84.6)	74.3 (73.6 – 74.9)	78.2 (75.1 – 81.1)
Positive Screen Question 2	38.0 (30.0 – 46.9)	36.9 (27.4 – 47.6)	40.5 (26.3 – 56.5)	45.6 (44.9 – 46.4)	47.0 (43.5 – 50.6)
Positive Screen Question 3	21.7 (15.8 – 30.6)	26.5 (18.0 – 36.5)	10.8 (4.3 – 24.7)	21.3 (20.7 – 22.0)	20.7 (17.9 – 23.7)
Positive Screen Question 4	22.3 (15.8 – 30.5)	22.6 (15.0 – 32.6)	21.6 (11.4 – 37.2)	17.4 (16.9 – 18.0)	18.1 (15.5 – 21.0)
Positive Screen Question 5	30.0 (22.3 – 38.4)	23.5 (17.8 – 36.6)	37.8 (24.1 – 54.0)	28.7 (28.0 – 29.4)	30.7 (27.5 – 34.1)
Functional Limitations Domain Positive	10.0 (5.8 – 16.5)	10.7 (5.7 – 19.1)	8.3 (2.8 – 21.3)	10.0 (9.5 – 10.4)	10.1 (8.2 – 12.4)
Service Use Domain Positive	55.0 (45.7 – 63.1)	51.2 (40.7 – 61.6)	63.9 (46.4 – 75.6)	59.5 (58.8 – 60.2)	59.9 (56.4 – 63.3)
Positive Questions 1 or 2 or both	89.3 (82.5 – 93.6)	89.3 (80.9 – 94.3)	89.2 (75.3 – 95.7)	88.7 (88.2 – 89.2)	92.8 (90.7 – 94.4)
Positive on a single screening question	49.2 (40.1 – 57.5)	48.2 (37.3 – 58.1)	51.4 (35.9 – 66.5)	52.1 (51.3 – 52.8)	47.9 (44.4 – 51.4)
Positive on 2 screening questions	25.8 (18.7 – 34.1)	26.5 (18.0 – 36.5)	24.3 (13.3 – 40.1)	22.4 (21.8 – 23.0)	24.5 (21.5 – 27.6)
Positive on 3 or more screening questions	25.0 (18.0 – 33.2)	25.3 (17.0 – 35.1)	24.3 (13.3 – 40.1)	25.5 (24.9 – 26.2)	27.7 (24.6 – 31.0)

CSHCN=National Survey of Children with Special Health Care Needs; SLAITS=State and Local Area Integrated Telephone Survey; GMS=Greater Milwaukee Survey; MSA=Milwaukee metropolitan statistical area.

\* Weighted analysis.

† Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001.

‡ Weighted n, estimated from complex sample design.

a similar survey response rate (60%) to that reported by Bethell and colleagues.<sup>7</sup>

## DISCUSSION

The results of the GMS administration of the CSHCN Screener© demonstrated a significantly larger burden of children with special health care needs in the city of Milwaukee compared to the surrounding Milwaukee MSA, the nation and the state. The prevalence of CSHCN in Milwaukee (23.5%) was almost double that of the nation (12.8%), Wisconsin (13.4%), and the Milwaukee MSA counties (12.1%). In addition, when compared to neighboring counties, the children in the city of Milwaukee who screened positive were more often poor and African American. This is likely due to the race and income distribution among the counties of the Milwaukee MSA. In the 2000 Census, the proportion of children <18 years old in the city of Milwaukee who were African American was 51.5%; in other geographic areas of the Milwaukee MSA the proportions ranged from 0.55% to 2.75%.<sup>3</sup> Similarly, median household income in the city of Milwaukee in 1999

was much lower than the surrounding counties (\$38,100 versus \$57,033-\$62,839).<sup>3</sup>

Most of the children who screened positive (in all surveys and geographic areas) screened positive on questions 1, 2, or both. Question 1 queried the use or need for prescription medication and question 2 identified above average use or need of medical, mental health, or educational services. In children who screened positive, there were no statistically significant differences among the surveys or geographic areas in the percentages of individual questions screened that were positive or in the definitional domains. Based on these data, it appears that there were not significant differences in type of need and level of need, simply a greater proportion of children affected.

It is important to note some study limitations that may have resulted in a lack of comparability between the 2 datasets. Differences existed in the type of survey respondent and time of administration between the 2 surveys. The GMS respondent was the adult in the household ≥18 years with the most recent birthday; in SLAITS the re-

spondent was the parent or guardian. It is possible that, if the respondent was not the parent or guardian, he or she may not have been familiar with the special needs of the children in the household and could not answer the screener questions. If this was the case, the actual prevalence of positive screens would most likely be higher than reported here. Since the percentages of individual questions scored positive and positive domain scores were the same between the surveys, it is unlikely that a significant amount of uninformed respondents were contacted. The SLAITS survey was administered between October 2000 and April 2002, and the GMS survey in October and November of 2004. This temporal difference may have affected responses as well. However, it is unlikely that a systematic difference between groups occurred due to a 2-4 year difference in administration time. There has been only 1 administration of this survey at the national level and no available data to indicate that the prevalence of CSHCN as measured by the CSHCN Screener® has changed over time.

Despite these study limitations, the results reported herein have policy implications for future administration of the CSHCN program in Wisconsin. In fiscal year 2003 the Wisconsin Department of Health and Family Services (DHFS) allocated more than \$7 million to CSHCN programs. This represented 31% of the total budget for Maternal and Child Health programs funded by the Maternal and Child Block Grant Program (Title V).<sup>8</sup> Services provided by the Wisconsin CSHCN program include Regional Children with Special Health Care Needs Centers, Wisconsin Sound Beginnings—A Universal Newborn Hearing Screening Program, Medical Home for Children with Special Health Care Needs, Nutrition Services for Children with Special Health Care Needs, and The Wisconsin Birth Defects Prevention and Surveillance System.<sup>9</sup> The Regional CSHCN Centers provide information, referrals, and service coordination to CSHCN families. Funding to the 5 Regional Centers in 2000 was \$1,370,000, and was reduced to \$1,301,500 in 2005.<sup>10,11</sup>

According to Census 2000 data, there were 170,984 children under the age of 18 living in the city of Milwaukee.<sup>3</sup> Assuming the GMS sample was representative, as many as 40,181 children in Milwaukee could be expected to have a special health care need. In 2003, DHFS reported that 4161 CSHCN were served statewide under Title V.<sup>12</sup> The Southeast Regional CSHCN Center serves 8 counties: Ozaukee, Washington, Jefferson, Waukesha, Racine, Kenosha, Walworth, and Milwaukee and provided services to approximately 1856 children in 2003.<sup>13</sup> Even if most of the 1856 chil-

dren served were from the city of Milwaukee, this figure indicates a significant service gap with only a small percentage of CSHCN in Milwaukee having received any service in 2003.

In a study using 2000 Medical Expenditure Panel Survey data, Newacheck and Kim found that CSHCN's health care expenditures were 3 times higher compared to other children (\$2099 versus \$628).<sup>14</sup> Using these figures, the potential annual health care expenditures for this group in the city of Milwaukee could be as high as \$84,339,919 annually and is likely higher due to increases in the cost of services in the past 5 years. Newacheck and Kim also found out-of-pocket expenditures paid by families of these children were twice those of children without a special health care need and that poorer families spent a larger percent of their income on these expenditures.<sup>14</sup> In a report on family cost-sharing in employer-based managed care plans, Nyman and colleagues found that, in 2001, families paid 10.8% of health care costs for CSHCN, a 20% increase from 1999.<sup>15</sup> In an analysis of CSHCN using SLAITS data, van Dyke and colleagues found that families living in poverty were more likely to report financial problems than those families living above the poverty level.<sup>16</sup> Caring for CSHCN represents a large and increasing financial burden on the community as well as individual families. Programs that promote coordination of care and case management for CSHCN may help to control health care expenditures and increase quality of and access to care. Many of these services are offered through the CSHCN Regional Centers; however, funding for the Centers is limited and decreasing.

It is likely that Milwaukee is not alone among large urban areas in its higher prevalence of CSHCN. Milwaukee, like other urban areas, has a very large proportion of children living at or below the federal poverty line. In fact, 35% of all Wisconsin children living in poverty live in the city of Milwaukee (Census 2000).<sup>3</sup> Poverty has been consistently associated with increased prevalence of children with disabilities and special health care needs.<sup>13,16-19</sup> It appears that the families most likely to be affected are those who can least afford the increased cost associated with caring for a child with special health care needs. Increased funding to the Regional Centers, particularly those that serve urban areas, for care coordination and family support would help to alleviate the excess burden experienced in urban areas. The small percentage of potentially eligible children in the city of Milwaukee who are being served highlights the need for outreach programs that target families and service providers who may be working with these chil-

dren. At a policy level, there is a need for the development of programs that offer financial support to address the excessive financial burden and out-of-pocket expenses incurred by low income CSHCN families.

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