

# OHIO MEDICAID ASSESSMENT SURVEY

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*Taking the pulse of health in Ohio*



## EMERGING CHALLENGES OF SERVING OHIO'S CHILDREN WITH SPECIAL HEALTH CARE NEEDS FINAL REPORT

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## **ABSTRACT**

Children with special health care needs (CSHCN) are defined as “those who have or are at 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.” Using data from the 2012 Ohio Medicaid Assessment Survey (OMAS) and other sources, we examined how Ohio’s CSHCN population is changing and considered its relevance to health policy.

### **Results**

Overall, 23.1% of children in Ohio have special health care needs, representing nearly 670,000 individuals 0-18 years old. Since 2008, Ohio’s CSHCN population has become larger and poorer. Currently 58.0% of CSHCN have Medicaid and 48.0% live in families with incomes less than or equal to 138% of the federal poverty level. Compared to children without special health care needs, CSHCN report worse health status, greater utilization of acute health care services, and have more unmet health needs. The magnitude of these differences has not changed since 2008.

Among CSHCN, those with Medicaid tend to report greater needs and worse health status compared to CSHCN without Medicaid. For example, 32.4% of CSHCN with Medicaid have functional limitations, versus 23.6% of other CSHCN. Despite this, we found few differences in unmet health needs between these groups.

CSHCN are no less likely than other children to have care consistent with a medical home, (36.2% vs. 36.9%), and lacking such care was not associated with significant barriers.

CSHCN with more complex health needs have greater unmet health needs than CSHCN with less complex needs. For example, CSHCN with functional limitations have more than twice the odds of having unmet dental needs compared to CSHCN who only need prescriptions.

### **Considerations for policy and future research**

These findings demonstrate the important role that Medicaid plays in this population. Medicaid insures more than half of CSHCN and CSHCN covered by Medicaid have disproportionately high levels of complexity and health care need. Notably, across multiple measures of unmet needs, outcomes in Medicaid-covered CSHCN did not differ significantly from those covered by employer-sponsored insurance.

CSHCN are worthy of study, yet we still know little about how such children transition into young adulthood. Future iterations of the OMAS should consider aligning child and adult measures of special health care needs to help study this transition.

Policymakers should also recognize the meaningful differences that exist within the CSHCN population. The OMAS should consider more targeted efforts to study children with complex needs, such as those with disabilities and functional limitations.

## INTRODUCTION

Children with special health care needs (CSHCN) are defined as “those who have or are at 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> Operationally, CSHCN status is given to those with a condition that has lasted or is expected to last at least one year and have the presence of at least one of the following additional criteria: (1) use of or need for prescription medications; (2) use of or need for more medical care, mental health services, or education services than children of the same age; (3) an emotional, developmental, or behavioral problem that requires ongoing treatment or counseling; (4) a limitation in the child’s ability to do the things most children of the same age do; or (5) use of or need for special therapy, such as physical, occupational, or speech therapy.<sup>2</sup> Common conditions among CSHCN include allergies, asthma, ADD/ADHD, developmental delay, and anxiety, with 29% having three or more chronic conditions.<sup>3</sup> These children also face physical, emotional, and social limitations while their families often experience greater medical and out-of-pocket health care costs.

One particular concern facing CSHCN is the increased need for interaction with the health care system. According to the 2000 Medical Expenditure Panel Survey, CSHCN accounted for over 40% of health care expenditures in youths under age 18.<sup>4</sup> This is not surprising, because beyond standard preventive health care, CSHCN often need other health-related services including prescription medications, counseling, physical therapy, and specialist care. However, even with higher overall health care costs, CSHCN often face unmet health care needs, resulting in poor health outcomes and avoidable health care expenditures.

Efforts to develop patient-centered medical homes (PCMH) represent one promising approach to meeting these complex needs. A medical home is a health care delivery model that emphasizes ongoing, comprehensive, and coordinated care.<sup>5</sup> CSHCN may benefit most from such care given their complex needs, yet national studies suggest only 43% of CSHCN receive care that meets this standard.<sup>5</sup> Understanding the impact of having care consistent with a medical home could help determine how best to invest in these efforts.

While all CSHCN experience increased health care needs, teens and young adults face particular challenges. As they enter adolescence, youths need substantial support in transitioning from parental health management to self-management as well as transitioning from pediatric to adult health care providers.<sup>6</sup> Without such support, health status and disease management behaviors often deteriorate significantly.<sup>7</sup> Although provision of necessary transition services to support the health care, work, and independent living for all CSHCN is outlined as a goal in *Healthy People 2020*, nationally only 41% of teens meet the quality indicator standard for appropriate transition care.<sup>8</sup> As such, adolescents and young adults with special health care needs (YASHCN) are an important area of interest for policymakers.

Understanding the characteristics and concerns of Ohio’s CSHCN and YASHCN populations is vital for improving the population’s overall health status, enhancing health equity, and reducing unnecessary health care costs. Analyses of the Ohio Family Health Survey (OFHS) conducted in 2008 and 2010 described Ohio’s CSHCN population in detail and identified specific areas of concern for health care quality, health equity, and health policy.<sup>9,10</sup> Policy considerations identified included the need for culturally appropriate care options for the growing population of Hispanic CSHCN, the need to strengthen transition services for adolescents, and the importance of aligning and coordinating services across providers and systems. That analysis also recommended future research on the role of medical homes.

### What are the aims of this study?

In this report, we build upon past analyses by using the 2012 Ohio Medicaid Assessment Survey (OMAS) – a statewide, dual-frame telephone survey designed to assess health, health care, and insurance coverage for Ohio adults and children. This study aims to:

- estimate the prevalence of CSHCN and YASHCN in the state of Ohio and within demographic sub-populations;
- describe the demographic characteristics, as well as health needs, care utilization, and overall health status of CSHCN and YASHCN in Ohio;
- describe how CSHCN with Medicaid differ from CSHCN with other or no health insurance;
- describe changes in Ohio’s CSHCN population since 2008;
- identify the characteristics of CSHCN who experience barriers to care; and

- describe whether CSHCN who lack care consistent with a medical home may have greater unmet health needs and barriers to care.

A descriptive analysis of CSHCN who met Medicaid's Aged, Blind Disabled (ABD) classification was also planned. However, limited sample size and the uncertain ability of the OMAS to distinguish this group led us to drop this aim.

## **Conceptual model for studying CSHCN**

The discussion and analysis of data for this study are grounded in the Behavioral Model developed by Andersen.<sup>11,12</sup> This model categorizes predictors of health behavior into three constructs: predisposing factors, enabling factors, and needs factors. Predisposing factors are demographic and cultural characteristics that influence the likelihood of a health behavior, independent of need or enabling factors. Such factors considered in this analysis include: age, gender, race/ethnicity, parent/legal guardian's marital status, and parent/legal guardian's education. Predisposing factors are not easily modified but are important from a descriptive perspective because they allow us to identify potential areas of health inequity that could be addressed through delivery improvements and policy responses. (Because many readers may be unfamiliar with the term "predisposing," we instead will refer to these characteristics as "demographic.")

Enabling factors are those characteristics that enhance or reduce access to desired health care utilization and health behaviors. Factors analyzed here include residence (Ohio Medicaid Managed Care Region), residence county type (metropolitan/suburban/rural non-Appalachian/Appalachian), family income, health insurance, usual source of care, and having care consistent with a medical home. These factors are potentially modifiable through policy solutions, such as locations of new health care facilities, health insurance eligibility and coverage, and health services delivery structures.

Finally, need factors are the most proximal predictors of health behaviors. Examples of such factors in our analysis include general health status, a diagnosis of asthma, and level of complexity of need.

## **METHODS**

The 2012 Ohio Medicaid Assessment Survey (OMAS) is a population-based survey that measures the health insurance coverage, health status, and health care experiences of Ohio's Medicaid, Medicaid eligible, and non-Medicaid child and adult populations. A random stratified dual-frame telephone survey design was used to collect data from samples representative of all non-institutionalized Ohio households and residents. This survey included both landline and cell phone frames. The landline sampling was based upon a list-assisted stratified random digit dial (RDD) procedure. African-Americans and households with children were oversampled and Asians and Hispanics were surname list-assisted sampled in the landline sampling. The cell phone sampling was a statewide simple random sample.

From May to October 2012, trained telephone interviewers administered the OMAS to 22,929 Ohio residents. For the landline telephone frame, households were randomly selected through a list assisted 1+block RDD method. Upon reaching the household, the interviewer selected an eligible adult age 19 years and older who had the most recent birthday to complete the adult version of the survey. For the cell phone frame, the adult who answered the phone was interviewed. When a respondent indicated that there were any children age 0-18 years in the household, the interviewer selected the child who had the most recent birthday. In the landline sample, the adult who was most knowledgeable about the selected child's health insurance coverage and health status completed the child version of OMAS on behalf of the child. For the cell phone sample, the adult respondent completed the child version. There were 5,515 respondents to the child portion of the survey. The overall response rate for the survey was 29.4%, including a 30.2% response rate for the landline sample and 24.4% for cell phone sample. A detailed description of the survey methodology can be found at [www.grc.osu.edu/omas](http://www.grc.osu.edu/omas).<sup>13</sup>

We used data from 1,122 respondents age 19 through 25 years to study YASHCN. In 11 of these cases, the index respondent was incapable of completing the survey, so another adult in the household completed the interview on behalf of the index individual.

Most adults (85.6%) responding on behalf of an index child were a parent or legal guardian of the index child. We refer to them as “proxy respondents,” and they include all respondents regardless of their relationship to the child (unless specified otherwise).

To assess recent changes in the CSHCN population, we also analyzed data from the 2008 OFHS. Similar to the OMAS, the 2008 OFHS was a statewide dual-frame telephone survey. Because many survey items from the OFHS are identical to the OMAS and the two surveys used similar sampling designs, it is possible to compare previous findings to assess for changes between 2008 and 2012. One noteworthy difference, however, is that the OFHS defined children as being 0-17 years old. Although our primary descriptive analysis included CSHCN 0-18 years old, in order to make the most appropriate comparisons we limited all 2008/2012 comparative analyses to the subsample of 0-17 year olds in the 2012 OMAS.

We also analyzed data from the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN). The NS-CSHCN is a dual-frame survey of CSHCN that provides state-specific as well as national estimates of the CSHCN population.<sup>14</sup> The data include 812 interviews from Ohio and 40,242 nationally. Analyzing these data enabled us to compare selected findings from the OMAS to findings from the NS-CSHCN in Ohio and the United States. In doing so, it is important to emphasize that the NS-CSHCN only studied children 0-17 years old. Thus, to make the most appropriate comparisons, we limited comparative analyses to the subsample of 0-17 year olds in the OMAS.

## Survey measures

Analyses presented here include single item variables taken directly from the survey instrument (e.g., number of emergency room visits during the past 12 months) as well as constructed variables combining information from multiple items (e.g., health insurance). All of the variables used and their corresponding labels in the public use data set appear in the Appendix. Construction of selected key variables is discussed below.

### CSHCN status

CSHCN status was constructed around five anchor items:

- (1) Does [the child] currently need or use medicine prescribed by a doctor, other than vitamins? {L126a}
- (2) Does [the child] need or use more medical care, mental health, or educational services than is usual for most children of the same age? {L126d}
- (3) Is [the child] limited or prevented in any way in [his/her] ability to do the things most children of the same age can do? {L126g}
- (4) Does [the child] need or get special therapy, such as physical, occupational, or speech therapy? {L126j}
- (5) Does [the child] have any kind of emotional, developmental, or behavioral problem for which he/she needs treatment or counseling? {L126m}

For each question (except for question 5) where a respondent answered “yes”, he or she was then asked “Is [this] because of any medical, behavioral, or other health condition?” When a respondent answered “yes” to this question, he or she was asked “Is this a condition that has lasted or is expected to last 12 months or longer?” (The last anchor item [question 5] only asked if the condition was expected to last 12 months or longer.) Affirmative answers to any one of the anchor questions and its corresponding follow-up questions classified a child as having special health care needs. Overall, we classified 1,302 cases as CSHCN and 3,926 cases as children who did not have special health care needs. An additional 287 cases (5.2% of the sample) could not be classified because of incomplete or missing data.

### YASHCN status

For YASHCN status, we employed two variables from the adult version of the OMAS:

- (1) Do you need or get special therapy? {D31i}
- (2) Do you have difficulty doing or need assistance to do day-to-day activities? {D31f}

For each question where a respondent answered “yes”, he or she was then asked “Is this because of any medical, mental health, or other health condition?” Similar to CSHCN, if a respondent answered “yes” to this question, then he or she was asked “Is this a condition that has lasted or is expected to last for at least 12 months?” Affirmative answers to any one of the two anchor questions and the corresponding follow-up questions classified a young adult



as having special health care needs. Overall, we classified 143 respondents as YASHCN and 941 as without having special health care needs. Among young adult respondents, 38 cases (3.4% of the sample) could not be classified because of incomplete or missing data about their special health care needs.

### Complexity of need

A complexity of need variable was created as a means to stratify analyses by condition severity. Consistent with an approach used in 2008, we grouped CSHCN hierarchically into four mutually exclusive groups in the following order:

1. *Having any functional limitations* is considered to be the most complex level of need. Therefore, CSHCN who identified any functional limitation {L126g} were categorized as “Having a functional limitation.”
2. For CSHCN who do *not* have functional limitations, those who identified the need for both prescriptions {L126a} and services {L126d, L126j, or L126m} were placed in the *Needs prescriptions and services* group.
3. Then, those who identified needing only health services {L126d, L126j, or L126m} were categorized as *Needs services only*.
4. Finally, those who only identified a need for prescriptions {L126a} were placed in the *Needs prescriptions only* group.

### Care consistent with a medical home

PCMH is both a health care concept and a recognition or accreditation which health care providers can obtain. Whereas some people receive health care that is consistent with the concepts underlying the definition of a PCMH, they do not necessarily receive health care from a location that is recognized or accredited as a PCMH. Because the OMAS was designed to measure variables from an individual user care perspective (rather than from a health system perspective), it could not determine whether an individual received health care from a recognized or accredited PCMH, but it was possible to characterize the care that each individual received and compare it to care that should have been observed in a recognized or accredited PCMH. Thus, this document uses the phrase “care consistent with a medical home” to describe the population that we are estimating. Care consistent with a medical home does not indicate whether the respondent received care from a recognized or accredited PCMH.

To measure care consistent with a medical home, the OMAS assessed seven components based on the collective principles of a PCMH outlined by the American Academy of Pediatrics, the joint principles of a PCMH, and the Agency for Healthcare Research and Quality. These components included: (1) usual source of care; (2) usual care from a clinic, health center, doctor’s office, or hospital outpatient department (i.e., non-E.R. usual source of care); (3) personal doctor or nurse; (4) health care visit in the past year; (5) enhanced access; (6) specialist care and coordination; and (7) provider engagement (for adults) or provider appointment reminders (for children). Each component consisted of one or more questions from the survey instrument. Additional details regarding the 2012 OMAS measure of care consistent with a PCMH appear elsewhere.<sup>15</sup>

## **Analytic strategy**

We analyzed all data taking into account the complex survey design (i.e., stratification and weighted sample) of the OMAS. Built into the survey design are weights associated with each survey respondent; therefore, one individual respondent represents a certain number of people within the state of Ohio based on various characteristics. These weights allowed us to generate weighted estimates, or population estimates, and generalize our findings to the entire state of Ohio. Along with each estimate, a standard error was calculated. A standard error is a measure of the extent to which a survey estimate is likely to deviate from the true population; it is a way to assess the accuracy or precision of an estimate in the sample. Large standard errors indicate greater imprecision in our estimate of the population parameter. For all factors of interest, we provided the unweighted counts, statewide population estimated counts (i.e., weighted counts), distributions and prevalence, and each parameter’s standard error.

For many analyses we calculated a 90% confidence interval (CI) – a measure that uses the standard error to calculate a range of values between which the parameter estimate is likely to fall. A 90% CI indicates that we are 90% confident that the constructed interval will cover the true population parameter. For example, we estimated that there are 669,777 CSHCN in Ohio and are 90% confident that the interval of 637,018 to 702,535 will cover the



true population parameter. (For estimated population counts, we report 90% CI's, rather than the more common 95% CI's in order to give a narrower interval for policy considerations.)

It is important to note that missing data are common in surveys. Missing data can occur, for example, because a respondent refuses to answer a question or a respondent does not know the answer to a question. Because of this, not all calculated percentages of survey items will sum to 100% due to missing data. Descriptions of these items appear on the OMAS website.<sup>16</sup> In an attempt to replace some of the missing data, imputation was performed by the OMAS staff using statistical methods described elsewhere.<sup>13</sup> Whenever possible we used the imputed versions of the variables provided by the OMAS.

Because of their inherent design, survey data sometimes produce unreliable estimates. In this report, an estimate was considered unreliable if: (1) the individual unweighted count was less than five, (2) the total unweighted count for that factor was less than 30, or (3) the relative standard error was larger than 50%. The relative standard error is calculated by dividing the standard error by the weighted population estimate. In the few instances when we found an estimate was unreliable, we did not report it in order to avoid misleading readers.


In many sections of the survey, the computer-assisted interview skipped questions that were not relevant to the respondent. These skip patterns created subpopulations, or a smaller subset of respondents than the overall sample population. Only those who had the opportunity to answer the question were included in the denominator. Accurately accounting for these subpopulations is essential when calculating percentages and standard errors from a complex survey like the OMAS.

Unless otherwise noted, we performed unadjusted analyses, which only assess the relationship between two factors without considering the impact of other factors on that relationship. These analyses compared CSHCN to children without special health care needs, and YASHCN to other young adults without special health care needs. Also, among CSHCN, we compared those with Medicaid to those who do not have Medicaid. Statistical significance among these groups was assessed using the Rao-Scott chi-square test, which is a design-adjusted version of the Pearson chi-square test specifically used with complex survey data.

We used multivariable logistic regression to examine various associations of interest while simultaneously adjusting for multiple potential confounders (i.e., factors that may distort the relationship between the variables of interest). In these models, we adjusted for the child's age, sex, race/ethnicity, health insurance, income as a percent of the federal poverty level (FPL), and county type (urban/suburban/rural/Appalachian). We ran three series of models: (1) in the full sample, (2) among CSHCN, and (3) among CSHCN who lack care consistent with a medical home. Table 1 summarizes these models.

**Table 1. Summary of multivariable models**

Research Question	Sample	Categories of dependent variables	Main independent variable(s)
How do CSHCN differ from other children?	all children: 2008, 2012	unmet needs; care utilization; health status	CSHCN status
How is not having a medical home associated with unmet needs, care utilization, and health status?	CSHCN: 2012	unmet needs; care utilization; health status	Lack of care consistent with a medical home
What are the characteristics of CSHCN who experience barriers to care?	CSHCN: 2008, 2012	unmet needs	age, gender, % of FPL, race/ethnicity, health insurance, complexity of need



The multivariable models produced estimates called odds ratios (OR). ORs are a measure of the strength of the association between two factors and assess differences between two groups in the odds of an event occurring. For example, when assessing the relationship between CSHCN status and general health status, the odds of having a fair/poor general health status among CSHCN are 11.9 times the odds of having fair/poor general health status among other children. This indicates that CSHCN have increased odds of having fair/poor general health status compared to children without special health care needs. We calculated 95% CI for all multivariable models.

Due to the differences in survey design, we were unable to pool the 2008 and 2012 data together in order to analyze differences over time. However, we were able to use two-sample z-tests to compare the 2008 and 2012 multivariable model estimates in order to identify statistically significant differences between the 2008 and 2012 surveys. Because we conducted multiple analyses at the same time, we used a p-value < 0.01 to indicate a statistically significant difference. All analyses were performed using SAS 9.3.

## **RESULTS**

We organized this section around six questions that parallel the project's specific aims (see p. 5). For more detailed results please refer to the Appendix.

### **What is the prevalence of CSHCN in Ohio?**

Overall, we estimate that 23.1% of children in Ohio have special health care needs, representing 669,777 individuals 0-18 years old (Table 2). Only 9.4% of 0-2 year olds have special health care needs, compared to 27.8% of 13-18 year olds. Also, about one third (32.5%) of children with Medicaid are CSHCN, compared to 16.7% of children with employer-sponsored insurance (ESI). Overall, Ohio's CSHCN population includes an estimated 388,232 CSHCN with Medicaid and 396,122 CSHCN who lack care consistent with a medical home.

**Table 2. Prevalence and population estimates of Ohio children with special health care needs (CSHCN)**

		<i>CSHCN prevalence (%)</i>	<i>Population Estimate</i>	<i>90% Confidence Interval</i>
<b>TOTAL</b>		23.1	669,777	(637,018 - 702,535)
<b>Gender</b>				
	Male	26.0	385,095	(366,379 - 403,811)
	Female	20.1	284,682	(265,966 - 303,398)
<b>Race/Ethnicity</b>				
	White	23.4	503,678	(487,942 - 519,415)
	African-American	25.6	114,919	(101,211 - 128,627)
	Hispanic	20.3	28,897	(22,505 - 35,289)
	Asian	13.1	17,800	(10,672 - 24,928)
	Other	31.0	4,483	(3,029 - 5,937)
<b>Age (in years)</b>				
	0-2	9.4	39,326	(29,552 - 49,099)
	3-5	19.4	86,908	(73,275 - 100,542)
	6-12	25.8	274,607	(255,900 - 293,314)
	13-18	27.8	268,936	(250,756 - 287,115)
<b>Family income (% of the federal poverty level)</b>				
	≤ 100%	29.6	251,939	(233,080 - 270,799)
	101-138%	24.6	69,560	(58,216 - 80,904)
	139-200%	25.0	83,565	(71,371 - 95,758)
	201-300%	20.5	86,825	(74,491 - 99,160)
	> 300%	17.7	177,888	(162,094 - 193,681)
<b>Health insurance</b>				
	Employer-sponsored	16.7	224,245	(207,319 - 241,171)
	Medicaid	32.5	388,232	(370,120 - 406,343)
	Other	18.6	40,823	(32,593 - 49,052)
	Uninsured	11.8	16,478	(11,219 - 21,738)
<b>Has care consistent with a medical home</b>				
	Yes	23.9	242,670	(224,544 - 260,796)
	No	24.1	396,122	(377,479 - 414,765)

*Note: Prevalence estimates include missing and incomplete data in the denominator. Prevalence and population estimates are weighted to be representative of all CSHCN 0-18 years old in Ohio. For detailed results, refer to Table A1.1 in the Appendix.*

*Source: 2012 Ohio Medicaid Assessment Survey*

## What are the characteristics of CSHCN in Ohio?

### Demographic characteristics of CSHCN

Compared to children without special health care needs, CSHCN are more likely to be male (57.5% vs. 49.4%) and to be older (Table 3). We found relatively small differences between CSHCN and other children in terms of race/ethnicity or parent/legal guardian education. African-Americans were somewhat over-represented and Asians somewhat under-represented in the CSHCN population.

**Table 3. Demographic and enabling characteristics of children with special health care needs (CSHCN) versus children without special health care needs (SHCN): Weighted distributions**

	CSHCN (%)	Children without SHCN (%)	P-Value
Gender			
Male	57.5	49.4	<0.01*
Female	42.5	50.6	
Race/Ethnicity			
White	75.2	74.7	<0.01*
African-American	17.2	14.4	
Hispanic	4.3	5.1	
Asian	2.7	5.3	
Other	0.7	0.4	
Age (in years)			
0-2	5.9	17.3	<0.01*
3-5	13.0	16.3	
6-12	41.0	35.4	
13-18	40.2	31.0	
Parent/Legal guardian's education			
< High school	9.5	7.2	<0.01*
High school graduate or GED	27.6	26.5	
Some college	18.9	15.1	
Associates degree	13.9	11.5	
≥ Four-year college degree	30.1	39.7	
Parent/Legal guardian's marital status			
Married	58.0	70.7	<0.01*
Divorced/Separated	20.9	11.4	
Widowed	1.0	1.1	
Single	20.0	16.8	
Family income (% of the federal poverty level)			
≤ 100%	37.6	25.8	<0.01*
101-138%	10.4	9.6	
139-200%	12.5	11.3	
201-300%	13.0	15.4	
> 300%	26.6	38.0	
Health insurance			
Employer-sponsored	33.5	52.1	<0.01*
Medicaid	58.0	35.7	
Other	6.1	7.0	
Uninsured	2.5	5.2	
Has care consistent with a medical home	36.2	36.9	0.71

*Note: Proportions are unadjusted for other factors and are weighted to be representative of all CSHCN and children without special health care needs (age 0-18 years) in Ohio. Totals may not sum to 100% because of missing or incomplete data. For detailed results, refer to Appendix Table A1.1.*

<sup>①</sup>Among children ages 3 years or older

<sup>②</sup>Among children ages 5 years or older

\* Indicates a significant result ( $p < 0.01$ )

Source: 2012 Ohio Medicaid Assessment Survey

### Enabling characteristics of CSHCN

These characteristics enable an individual to access health care. Compared to children without special health care needs, CSHCN are more likely to live in families with incomes less than or equal to 100% of the FPL (37.6% vs. 25.8%; Table 3). Health insurance varies markedly between the two groups. For example, 58.0% of CSHCN have Medicaid, whereas only 35.7% of other children have Medicaid. Correspondingly fewer CSHCN have ESI (33.5% vs. 52.1%) or are uninsured (2.5% vs. 5.2%). In spite of these differences, CSHCN are no less likely than children without special health care needs to have care consistent with a medical home. Across most of the state's Medicaid Managed Care Regions, the distribution of CSHCN was similar to the distribution of children without special health care needs (see Table A1.1 in the Appendix).

### Needs, health care utilization, and health status of CSHCN

Not surprisingly, CSHCN have worse health status than other children. For example, 29.1% of CSHCN have asthma, compared to 4.3% of children without special health care needs (Table 4). It is important to note that many proxy respondents (n=149) who reported that the index child had asthma nonetheless gave responses that did not meet the CSHCN definition. It is likely that these children have mild asthma that does not require daily medication maintenance or extensive use of health care services.

Another way to understand CSHCN needs is to consider how they meet the definitional criteria for CSHCN status (see METHODS). We estimate that 28.3% of CSHCN have functional limitations, 29.6% need both services and prescriptions, 12.4% need only services, and 27.5% need only prescriptions. In other words, roughly one quarter of CSHCN (those with functional limitations) have very complex health needs that may require targeted research and policy solutions.

CSHCN use more acute care than other children – nearly one third (32.6%) visited an emergency room during the past year, compared to 15.9% of children without special health care needs. CSHCN are also more likely to have had a hospital stay in the past year (12.2% vs. 4.5%). We found no significant differences, however, for preventive care. CSHCN were not significantly more likely to have had a well-child visit (80.1% vs. 79.6%) or a dental visit (82.2% vs. 70.8%) during the past year.

CSHCN also tend to have worse health status than other children. About 11.6% of CSHCN proxy respondents report the index child's general health status as only fair/poor. In addition, 8.9% give such fair/poor ratings for vision health status and 13.9% for dental health status. In comparison, figures for proxy respondents of children without special health care needs are 0.9% for fair/poor general health status, 2.9% for fair/poor vision health status, and 4.8% for fair/poor dental health status.

### Unmet needs of CSHCN

CSHCN are more likely than other children to have unmet health care needs. About 8.2% of CSHCN proxy respondents report that the index child has unmet dental needs, 7.2% report unmet prescription needs, and 9.0% report other unmet needs (Table 4). In comparison, the figures for children without special health care needs are 4.0%, 2.1%, and 2.2% respectively.

Proxy respondents for CSHCN are less likely to report that care is currently just as hard to get as it was three years ago (69.7% vs. 77.9%). Oddly, proxy respondents for CSHCN are more likely to indicate that such care either is harder to get (14.7% vs. 9.9%) or is easier to get (11.5% vs. 6.8%). This pattern may simply mean that parents of CSHCN are more sensitive than other parents about changes in their children's access to care.

**Table 4. Needs, health care utilization, health status and unmet needs of children with special health care needs (CSHCN) versus children without special health care needs (SHCN): Weighted distributions**

	CSHCN (%)	Children without SHCN (%)	P-Value
<b>Needs</b>			
Currently has asthma	29.1	4.3	<0.01*
Level of complexity of need			
Has functional limitations	28.4	--	
Needs prescriptions only	27.5	--	--
Needs services only	12.4	--	
Needs prescriptions and services	29.6	--	
<b>Health care utilization</b>			
Any emergency room visit in past year	32.6	15.9	<0.01*
Any hospital stay in past year	12.2	4.5	<0.01*
Any well-child visit in past year	80.1	79.6	0.84
Any dental visit in past year <sup>①</sup>	82.2	70.8	0.32
<b>Health status</b>			
Fair/Poor general health status	11.6	0.9	<0.01*
Fair/Poor vision health status <sup>②</sup>	8.9	2.9	<0.01*
Fair/Poor dental health status <sup>①</sup>	13.9	4.8	<0.01*
<b>Unmet needs</b>			
Has unmet dental needs <sup>①</sup>	8.2	4.0	<0.01*
Has unmet prescription needs	7.2	2.1	<0.01*
Has other unmet needs	9.0	2.2	<0.01*
Is care is harder to get compared to three years ago? <sup>①</sup>			
Yes	14.7	9.9	
No	11.5	6.8	<0.01*
About the same	69.7	77.9	

*Note: Proportions are unadjusted for other factors and are weighted to be representative of all CSHCN and children without special health care needs (age 0-18 years) in Ohio. For detailed results, refer to Appendix Table A1.1.*

<sup>①</sup>Among children ages 3 years or older

<sup>②</sup>Among children ages 5 years or older

\* Indicates a significant result ( $p < 0.01$ )

*Source: 2012 Ohio Medicaid Assessment Survey*

Another common concern for families with CSHCN is having trouble coordinating care across multiple health care providers. Data on access to care coordination were only available for proxy respondents who reported that the index child has a regular doctor or clinic and who reported that they wanted help coordinating care. For this subgroup, most respondents reported that they always (54.7%) or usually (24.7%) got enough help coordinating care. (see Table A1.1 in the Appendix).

#### Comparing CSHCN findings from the OMAS to the NS-CSHCN

As with any survey that aims to infer characteristics of a population from a representative sample, differences in methodology can sometimes result in different conclusions. For this reason, we compared selected findings from the OMAS with findings from the NS-CSHCN (see METHODS).



Findings related to CSHCN in Ohio from the OMAS are very similar to those from the NS-CSHCN (see Table A2 in the Appendix). Overall, the OMAS estimates that 24.6% of all children (0-17 years old) in Ohio are CSHCN, whereas the NS-CSHCN puts the figure at 17.7%. This difference is likely due to small differences in survey methods. Our finding is consistent with national research demonstrating that the NS-CSHCN found lower CSHCN rates than the National Survey of Children's Health and the Medical Expenditure Panel Survey.<sup>17</sup> Also similar to previous research, the distribution of age, gender, race/ethnicity and parent's education are quite alike in both surveys even though the estimated population rate differed. We did, however, find some possible differences. Compared to the NS-CSHCN, the OMAS estimated that a slightly higher proportion of Ohio CSHCN have family incomes less than or equal to 200% of the FPL (61.1% vs. 52.6%) and have public insurance (59.3% vs. 46.1%). We also found possible differences in the level of complexity of need, with the OMAS estimating a somewhat lower proportion of CSHCN who only need prescriptions (27.7% vs. 37.5%).

The differences by income and insurance may reflect the different years in which the surveys were administered. Even comparing the 2012 OMAS to the 2008 OFHS (see p. 22), we found an increase in the proportion of CSHCN who are low income as well as those who have Medicaid coverage. An alternative explanation relates to differences in each survey's sampling methodology. However, the possible difference in level of complexity of need cannot be easily attributable to changes over time or survey methodology.

In summary, the similar demographic estimates from both surveys suggest that our findings are not especially dependent on the particularities of the OMAS methodology. This strengthens our confidence in the validity of our results.

## **What is the prevalence of YASHCN in Ohio?**

Please note that our definition of YASHCN differs notably from the definition used for CSHCN (see METHODS). Overall in Ohio, 11.7% of young adults, ages 19 through 25 years old have special health care needs. This represents an estimated 124,464 individuals, including 41,222 covered by Medicaid and 28,020 who are uninsured. Also, 90,717 YASHCN lack care consistent with a medical home. Please refer to table A1.2 in the Appendix for details on prevalence and population estimates.

## **What are the characteristics of YASHCN in Ohio?**

### Demographic characteristics of YASHCN

Well over half (60.9%) of YASHCN in Ohio are female (Table 5). There are only a few minor differences by race/ethnicity.

### Enabling characteristics of YASHCN

In considering their enabling characteristics, YASHCN tend to be poorer and are more likely to have Medicaid compared to young adults without special health care needs. Half (49.9%) of all YASHCN have family incomes less than or equal to 100% of the FPL, whereas only 31.8% of young adults without special health care needs have such low incomes. Correspondingly fewer YASHCN report an income of greater than 300% of the FPL (16.1% vs. 31.6%). Similar proportions of YASHCN and young adults without special health care needs report having no health insurance (22.5% vs. 20.9%). Yet compared to other young adults, YASHCN are more likely to have Medicaid (33.1% vs. 16.4%), and are less likely to have ESI (24.1% vs. 41.1%).

The overwhelming majority of young adults, both with and without special health care needs, lack care consistent with a medical home. Whereas YASHCN are more likely to have care consistent with a medical home, the magnitude of this difference was small (15.6% vs. 13.1%).

Figures for other YASHCN enabling characteristics appear in Table A1.2 of the Appendix. For example, similar proportions of YASHCN and young adults without special health care needs report having a usual source of care (85.8% vs. 82.3%). Also, the population distribution is comparable across Medicaid Managed Care Region.

### Needs, health care utilization and health status of YASHCN

We estimate that 32.7% of YASHCN have functional limitations, whereas 66.1% represent YASHCN who need services or therapies (see Table A1.2 in the Appendix). (The OMAS measures available to classify YASHCN status

could only determine whether a respondent had functional limitations or needed to use special services/therapies. No items were available to classify other components used to define CSHCN.)

Overall, YASHCN have high levels of health care utilization. Half (49.7%) of all YASHCN visited an emergency room during the past year, compared to 27.7% of young adults without special health care needs. YASHCN are also more likely to have had a hospital stay in the past year (27.7% vs. 12.9%) but were somewhat less likely to have had a dental visit in the past year (61.9% vs. 69.5%). Similar proportions of YASHCN and other young adults had seen a doctor or other health care provider during the past year (for any reason; 59.1% vs. 58.4%).

**Table 5. Characteristics of young adults with special health care needs (YASHCN) versus young adults without special health care needs (SHCN): Weighted distributions**

	YASHCN (%)	Young adults without SHCN (%)	P-Value
Gender			
Male	39.1	54.6	<0.01*
Female	60.9	45.4	
Race/Ethnicity			
White	80.2	76.7	--
African-American	14.8	14.2	
Hispanic	4.6	4.5	
Asian	--	4.3	
Other	0.4	0.3	
Family income (% of the federal poverty level)			
≤ 100%	49.9	31.8	<0.01*
101-138%	14.4	11.3	
139-200%	8.1	10.1	
201-300%	11.5	15.2	
> 300%	16.1	31.6	
Health insurance			
Employer-sponsored	24.1	41.1	<0.01*
Medicaid	33.1	16.4	
Other	20.2	21.7	
Uninsured	22.5	20.9	
Has care consistent with a medical home			
Yes	15.6	13.1	<0.01*
No	72.9	81.9	

*Note:* Proportions are unadjusted for other factors and are weighted to be representative of all YASHCN and young adults without special health care needs (age 19-25 years) in Ohio. Totals may not sum to 100% because of missing or incomplete data. For detailed results, refer to Table A1.2 in the Appendix. ➤ Because the sample included no Asian young adults with special health care needs, these results were suppressed.

\* Indicates a significant result ( $p < 0.01$ )

*Source:* 2012 Ohio Medicaid Assessment Survey

YASHCN report much worse health status than young adults without special health care needs. About 31.9% of YASHCN report fair/poor general health status, compared to only 7.8% of other young adults. We found similar differences for fair/poor vision health status (27.2% vs. 9.8%) and fair/poor dental health status (37.3% vs. 13.1%).

#### Unmet needs of YASHCN

Overall, YASHCN are more likely than other young adults to have unmet needs. About 32.0% of YASHCN report unmet dental needs and 37.7% report unmet prescription needs (see Table A1.2 in the Appendix). In comparison, corresponding figures for young adults without special health care needs are 14.7% and 13.7% respectively.

YASHCN are less likely to report that care is currently just as hard to get as it was three years ago (51.2% vs. 64.9%). Oddly, YASHCN are more likely to indicate that such care is either harder to get (31.3% vs. 19.7%) or is easier to get (17.3% vs. 12.2%). As with CSHCN (see above), this pattern may simply mean that YASHCN are more sensitive than young adults without special health care needs about changes in their access to care.

### **How do CSHCN with Medicaid differ from other CSHCN?**

Across Ohio, 58.0% of CSHCN have health insurance coverage through Medicaid. To understand the particular characteristics and needs of this important subpopulation, we compared CSHCN with Medicaid to CSHCN who do not have Medicaid. This comparison group consists overwhelmingly of CSHCN with ESI (79.6%), but also includes some uninsured (5.9%) and those with other insurance types such as Medicare, privately-purchased, and unknown (14.5%). Because of this mixed grouping, we advise readers to focus only on the findings from CSHCN with Medicaid. The “other CSHCN” group may be useful for comparison, but does not warrant interpretation on its own. (Ideally we would have compared Medicaid with other discrete insurance types. However, the limited sample size of some groups, the complex survey design and the construction of the health insurance variable made doing so inadvisable.)

#### Demographic and enabling characteristics of CSHCN with Medicaid

Not surprisingly, many CSHCN with Medicaid are from lower socioeconomic status families. Among CSHCN with Medicaid, about half (51.2%) of parents/legal guardians have a high school education or less and 59.7% have family incomes less than or equal to 100% of the FPL (Table 6). This compares to 20.9% and 7.2% respectively for CSHCN not covered by Medicaid. In addition, compared to other CSHCN, those with Medicaid are less likely to be white (69.2% vs. 83.4%) and are more likely to be very young. The proportion of CSHCN with Medicaid who are 0-2 years old is 7.4%, compared to 3.7% for CSHCN with no/other insurance.

Across Ohio, the proportion of CSHCN with Medicaid varies by region. CSHCN in the Northeast (52.6%) and Southwest (52.8%) Medicaid Managed Care Regions are less likely to have Medicaid compared to CSHCN in the Northeast Central (70.1%) and Southeast (75.9%) regions (see Table A1.3 in the Appendix).

**Table 6. Demographic and enabling characteristics of children with special health care needs (CSHCN) with Medicaid versus CSHCN with no/other health insurance: Weighted distributions**

	<i>CSHCN with Medicaid</i>		<i>CSHCN with no/other insurance</i>		<i>P-Value</i>	
	<i>Population Estimate</i>	<i>%</i>	<i>Population Estimate</i>	<i>%</i>		
Gender						
	Male	218,195	56.2	166,900	59.3	0.35
	Female	170,036	43.8	114,646	40.7	
Race/Ethnicity						
	White	268,743	69.2	234,935	83.4	--
	African-American	90,757	23.4	24,162	8.6	
	Hispanic	21,775	5.6	7,122	2.5	
	Asian	--	--	14,095	5.0	
	Other	3,251	0.8	1,231	0.4	
Age (in years)						
	0-2	28,897	7.4	10,429	3.7	<0.01*
	3-5	55,410	14.3	31,498	11.2	
	6-12	167,326	43.1	107,282	38.1	
	13-18	136,599	35.2	132,337	47.0	
Parent/Legal guardian's education						
	< High school	46,801	15.9	5,761	2.2	<0.01*
	High school graduate or GED	104,139	35.4	47,844	18.6	
	Some college	68,509	23.3	35,741	13.9	
	Associates degree	46,613	15.8	30,138	11.7	
	≥ Four-year College degree	28,499	9.7	137,490	53.5	
Parent/Legal guardian's marital status						
	Married	112,415	38.2	207,529	80.8	<0.01*
	Divorced/Separated	85,508	29.0	29,753	11.6	
	Widowed	2,370	0.8	3,380	1.3	
	Single	94,269	32.0	16,196	6.3	
Family income (% of the federal poverty level)						
	≤ 100%	231,738	59.7	20,201	7.2	<0.01*
	101-138%	52,366	13.5	17,194	6.1	
	139-200%	47,097	12.1	36,468	13.0	
	201-300%	32,403	8.3	54,422	19.3	
	> 300%	24,628	6.3	153,260	54.4	

*Note: Proportions are unadjusted for other factors and are weighted to be representative of all CSHCN in Ohio. Totals may not sum to 100% because of missing or incomplete data. For detailed results, refer to Table A1.3 in the Appendix.*

*\* Indicates a significant result (p<0.01)*

*➤ The population estimate and chi-square test results were suppressed because the Asian category violated the relative standard error rules (i.e. the unweighted frequency was too small).*

*Source: 2012 Ohio Medicaid Assessment Survey*

Needs, health care utilization, and health status of CSHCN with Medicaid

CSHCN with Medicaid are more likely to have greater health needs, higher levels of health care utilization, and worse health status (Table 7). Compared to those with no insurance or other insurance, CSHCN with Medicaid are more likely to have functional limitations (32.1% vs. 23.6%) and asthma (32.5% vs. 24.4%). They are also more likely to have had an emergency room visit (39.7% vs. 22.9%) or hospital stay (14.4% vs. 9.1%) in the past year, but there were no significant differences in terms of well-child visits or dental visits. Proxy respondents for CSHCN with Medicaid were more likely than proxy respondents for other CSHCN to report the index child's general health status as fair/poor (15.0% vs. 6.9%) or their vision health status as fair/poor (12.0% vs. 5.0%).

**Table 7. Needs, health care utilization, health status and unmet needs of children with special health care needs (CSHCN) with Medicaid vs. CSHCN with no/other health insurance: Weighted distributions**

	<i>CSHCN with Medicaid</i>		<i>CSHCN with no/other insurance</i>		<i>P-Value</i>
	<i>Population Estimate</i>	<i>%</i>	<i>Population Estimate</i>	<i>%</i>	
<b>Needs</b>					
Currently has asthma	126,248	32.5	68,718	24.4	<0.01*
Level of complexity of need					
Has functional limitations	124,586	32.1	65,283	23.6	
Needs prescriptions only	93,503	24.1	90,950	32.3	<0.01*
Needs services only	45,912	11.8	37,105	13.2	
Needs prescriptions and services	113,072	29.1	85,326	30.3	
<b>Health care utilization</b>					
Any emergency room visit in past year	154,011	39.7	64,502	22.9	<0.01*
Any hospital stay in past year	56,069	14.4	25,496	9.1	0.01*
Any well-child visit in past year	312,498	80.5	224,126	79.6	0.45
Any dental visit in past year <sup>①</sup>	305,141	78.6	245,689	87.3	0.09
<b>Health status</b>					
Fair/Poor general health status	58,312	15.0	19,404	6.9	<0.01*
Fair/Poor vision health status <sup>②</sup>	38,214	12.0	12,414	5.0	<0.01*
Fair/Poor dental health status <sup>①</sup>	57,696	16.1	30,168	11.1	0.04
<b>Unmet needs</b>					
Has unmet dental needs <sup>①</sup>	33,057	9.2	18,949	7.0	0.19
Has unmet prescription needs	28,351	7.3	20,181	7.2	0.84
Has other unmet needs	34,490	8.9	25,832	9.2	0.99
Is care is harder to get compared to three years ago <sup>①</sup>					
Yes	39,667	11.0	53,180	19.6	
No	50,573	14.1	22,000	8.1	<0.01*
About the same	248,230	69.1	191,498	70.6	

*Note: Proportions are unadjusted for other factors and are weighted to be representative of all CSHCN in Ohio. Totals may not sum to 100% because of missing or incomplete data. For detailed results, refer to Table A1.3 in the Appendix.*

<sup>①</sup>Among children ages 3 years or older

<sup>②</sup>Among children ages 5 years or older

\* Indicates a significant result ( $p < 0.01$ )

### Unmet needs of CSHCN with Medicaid

Despite being poorer and sicker than other CSHCN, those with Medicaid are not more likely to have unmet needs (Table 7). Even in models adjusting for demographic and enabling characteristics and other factors, we found that CSHCN with Medicaid and those with ESI have similar odds of having unmet prescription needs, unmet dental needs, and other unmet needs (see Table A4.4 in the Appendix). In fact, compared to CSHCN with Medicaid, those with ESI had twice the odds of having a proxy respondent report that care was harder to get compared to three years ago (OR=2.20, 95%CI=1.25-3.89, p<0.01). These findings may suggest that Medicaid addresses the needs of CSHCN at least as well as ESI.

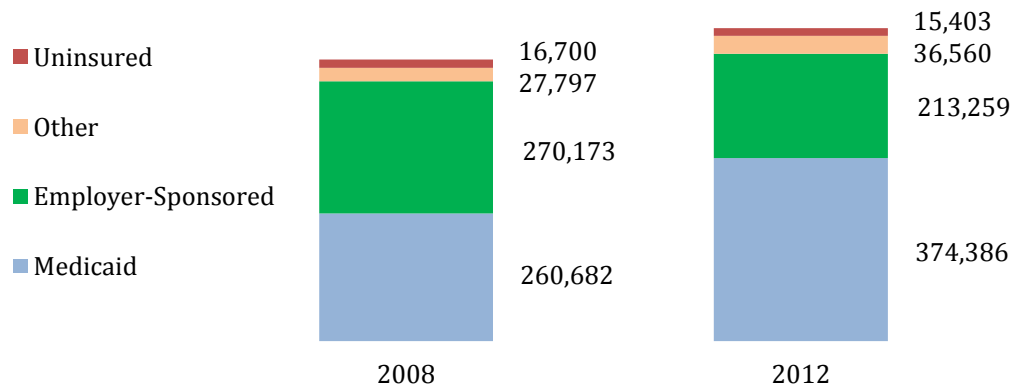
### **How has Ohio's CSHCN population changed since 2008?**

Ohio's CSHCN population is growing – from 575,353 (22.6% of all 0-17 year-olds) in 2008 to 639,609 (24.6%) in 2012. (Please note that the figures for 2012 reported in this section differ slightly from those reported elsewhere in this report because they were limited to children 0-17 years old.)

#### Changes in demographic and enabling characteristics

Overall we found only a few, minor differences in the demographic characteristics of Ohio's CSHCN in 2008 versus 2012 (see Table A3.1 of the Appendix). However, health insurance for CSHCN has changed markedly over the past four years. The proportion of CSHCN with ESI declined from nearly half (47.0%) in 2008 to only one third (33.3%) in 2012 (see Figure 1). Correspondingly, Medicaid coverage of CSHCN jumped from 45.3% (of 0-17 year-old CSHCN) in 2008 to 58.5% in 2012. The percentages of CSHCN with other insurance types remained largely unchanged (4.8% vs. 5.7%), as did the uninsured (2.9% vs. 2.4%).

**Figure 1. Number of Ohio children 0-17 years old with special health care needs, by insurance type/status, 2008 & 2012**



*Note.* Figures are point estimates and do not account for imprecision. See Table A3.1 in the Appendix for details.

*Sources:* 2012 Ohio Medicaid Assessment Survey; 2008 Ohio Family Health Survey

Growth in the CSHCN population was concentrated among families in poverty. Among families with incomes less than or equal to 100% of the FPL, the CSHCN population jumped from 169,133 to 245,132 – an increase of 75,999 individuals. In contrast, the number of CSHCN in families with incomes above the FPL did not change significantly. By 2012, children with family incomes less than or equal to 100% of the FPL comprised 38.3% of the CSHCN population.

Much of the increase in the CSHCN population was concentrated in certain Medicaid Managed Care Regions, specifically Central, Northeast Central, Southeast and West Central. In the Northeast Central region, for example, population estimates for the CSHCN population jumped from 23,165 to 35,122 – a 51.6% increase. By comparison, the number of children in that region without special health care needs remained stable (data not shown).



### Changes in needs, health care utilization, health status, and unmet needs

From 2008 to 2012, we found little change in needs, unmet needs, health care utilization, or general health status among CSHCN (see Table A3.1 of the Appendix). Moreover, adjusted models found that the association of CSHCN status with these outcomes did not change significantly between 2008 and 2012 (see Table A4.1 of the Appendix). Thus, despite the disproportionately large increase in low income CSHCN, the overall level of needs, health care utilization, health status, and unmet needs was similar.

### Changes among CSHCN with Medicaid

Because the population of CSHCN with Medicaid grew markedly, we compared changes in this subpopulation of CSHCN between 2008 and 2012. We found few demographic differences over time. One exception involved 3-5 year-old CSHCN with Medicaid, the population of which doubled between 2008 and 2012 from 27,780 to 55,410 (see Table A3.2 of the Appendix). In comparison, we found no change among other subpopulations of 3-5 year-olds – neither among CSHCN who did not have Medicaid, nor among 3-5 year-olds without special health care needs (data not shown).

Among CSHCN with Medicaid, needs, health care utilization, health status, and unmet needs were largely unchanged between 2008 and 2012 (see Table A3.2 in the Appendix). These contrasts should be interpreted with caution, however, since the response options for this survey question changed slightly from 2008 to 2012.

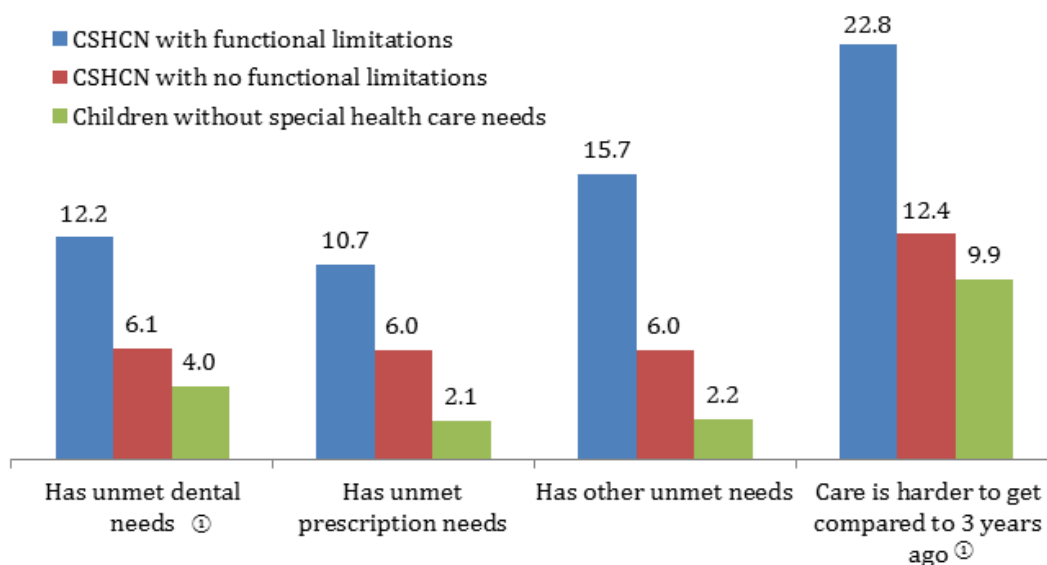
### **Do CSHCN who lack care consistent with a medical home have more health care utilization, worse health status, and more unmet needs?**

Because CSHCN experience many barriers to care, it is worthwhile to consider the importance of medical home to this special population. After controlling for demographic variables, health insurance, general health status, and complexity of need, we found no association between lacking care consistent with a medical home and health status, health care utilization, or unmet health needs (see Table A4.2 in the Appendix). However, proxy respondents for such CSHCN have twice the odds of reporting that care is harder to get compared to three years ago (OR=2.06, 95%CI=1.27-3.34,  $p<0.01$ ).

### **What are the characteristics of CSHCN who have unmet needs?**

CSHCN with functional limitations have greater unmet needs than CSHCN with less complex needs. For example, 12.2% of CSHCN with functional limitations have unmet dental needs, compared to only 6.1% of CSHCN who do not have functional limitations (and 4.0% of children without special health care needs; Figure 2). Among the subset of proxy respondents for CSHCN who need care coordination, 70.9% of those who have CSHCN with functional limitations report that they always/usually get adequate help. In comparison, 85.1% of proxy respondents for CSHCN without functional limitations report this same level of help (data not shown; only select adults were asked about receiving enough help coordinating care for their child: those who reported that the index child has a regular doctor or clinic and who reported that they wanted help coordinating care.).

**Figure 2. The percentage of children with unmet needs and barriers to care: Differences among children with special health care needs (CSHCN) with functional limitations, CSHCN without functional limitations, and children without any special health care needs**



*Note. Figures are point estimates and do not account for imprecision.*

*① Among children ages 3 years or older*

*Source: 2012 Ohio Medicaid Assessment Survey*

These differences persisted, even in multivariable models that controlled for demographics and general health status: compared to CSHCN who only need prescriptions, those with functional limitations have twice the odds of having unmet dental needs and nearly five times the odds of having other medical needs (see Table A4.3 in the Appendix). The strength of these associations did not significantly differ between 2008 and 2012.

In the multivariable models, neither age, gender, nor income was associated with CSHCN having unmet needs. Similarly, we found no differences by race/ethnicity (see Table A4.4 in the Appendix). In contrast, health insurance was consistently associated with CSHCN's barriers to care. Compared to CSHCN with Medicaid, uninsured CSHCN experience much higher levels of unmet prescription, dental, and other medical needs. (Because of the small number of uninsured CSHCN, however, these results should be interpreted with caution.) Interestingly, CSHCN with ESI had similar levels of unmet needs compared to CSHCN with Medicaid.

In summary, these findings suggest that children with functional limitations differ from other CSHCN in their experience unmet needs. In this sense, they may merit targeted research and policy solutions.

## DISCUSSION

Ohio's CSHCN population is growing larger and poorer. The OMAS estimates that there are now nearly 670,000 CSHCN in Ohio – an increase of over 64,000 children since 2008. Growth has been greatest in the Northeast Central (+52%), Southeast (+38%), and West Central (+34%) regions of the state. In each of these regions (as well as elsewhere), Medicaid covered a growing proportion of the CSHCN population.

Our findings demonstrate the important and growing role that access to Medicaid plays in the CSHCN population. Currently, over half of all CSHCN (58%) have Medicaid. Yet even though they tend to report greater needs and worse health status, CSHCN with Medicaid do not fare worse than CSHCN with ESI on measures of unmet health

care needs. In other words, Medicaid may be no less effective than ESI in addressing the needs of CSHCN, despite serving a poorer, needier population.

This study also helped identify what types of CSHCN are most likely to experience unmet health care needs. Even after accounting for differences in demographics and health status, CSHCN with functional limitations were much more likely to experience unmet needs compared to those who only need prescriptions.

## **Key considerations**

The period between the 2008 OFHS and the 2012 OMAS was marked by significant changes in the economic and health care landscape. Economically, unemployment rates reached levels not seen in decades. These job losses were associated with decreased access to ESI and subsequent growth in the uninsured and publically insured populations.<sup>18,19</sup> These economic challenges are reflected in changes in Ohio's CSHCN population. Between 2008 and 2012, the proportion of CSHCN living in families at or below 100% of the FPL increased by 30% (29.4% to 38.3%) and the proportions of CSHCN covered by Medicaid grew from 45.3% to 58.5%.

Although there are recent signs of stabilization in the economy and the job market, changes in the nature of employment (e.g. increased role of part-time and temporary work without health benefits) will likely lead to continued high rates of reliance on public or publically-subsidized health insurance coverage. The good news is that children covered by Medicaid fare no worse on measures of unmet health care needs than those covered by ESI, even given that CSHCN covered by Medicaid are more medically complex. Two important policy questions, however, require further consideration. First, what policies are needed to ensure access to primary care and specialty providers for this relatively low-reimbursement population (especially if Medicaid enrollment continues to grow due to policy or economic changes)? Second, will publically-subsidized health insurance exchanges be truly affordable for the working-class families not covered by ESI? Future targeted research on these questions can help guide policy decisions.

### Children with functional limitations

CSHCN are a diverse population. They can have health challenges ranging from mild asthma and seasonal allergies to severely disabling cerebral palsy and muscular dystrophy. Nationally, 3.2% of CSHCN are classified as "children with medical complexity" (CMC).<sup>20</sup> These children not only need more services than the average child, they also have complex chronic conditions involving more than one organ system and/or require ongoing technical assistance (e.g., feeding tube, ventilator).<sup>20,21</sup> Despite their small numbers, these children are a particular concern for multiple reasons: they are significantly more likely to have more than \$1,000 in annual out-of-pocket medical expenses, are more likely to have a family member stop working to provide care, and often have five or more unmet health care needs.<sup>20,22</sup> Although, the detailed clinical data required to classify youths as CMC are not available in the OMAS, a drill-down analysis of the CSHCN reported to have functional limitations offers some insight into the challenges faced by our sickest CSHCN.

In Ohio, while the number of CSHCN increased between 2008 and 2012, the proportion of CSHCN with functional limitations remained fairly stable. In each year, just over one in four respondents reported that their child with special health care needs was "limited in doing the things most children of the same age can do" (26.5% in 2008 and 28.1% in 2012). Ohio CSHCN who have functional limitations are significantly more likely than other Ohio CSHCN to have unmet prescription, dental, and other needs. These findings suggest that children with functional limitations (including youth who meet the definition of "disabled") could benefit greatly from Ohio's current policy initiative to move most youths covered by the Aged, Blind, and Disabled (ABD) program from fee-for-service coverage to managed care plans. Managed care and accountable care organizations have the potential to operationalize the "medical neighborhood" model which facilitates the linkages between the PCMH and multiple sub-specialists and social service providers.<sup>23</sup> Many of these managed care organizations will, however, need targeted education on childhood disability issues to address a lack of familiarity with this challenged population. Close monitoring of health care utilization and child health outcomes will also be important. Therefore, Ohio should also encourage the use of disability population-specific measures of health care quality to identify successes and opportunities for improvement.

### Patient-centered medical homes

The PCMH is a model of primary care that is patient-centered, comprehensive, coordinated, accessible, and focused on quality and safety. Our analyses found that only 36.2% of Ohio CSHCN met criteria of having care consistent with a medical home: having a usual source of care, having a personal doctor or nurse, having seen a physician in the past 12 months, and having access to specialist care and medical reminders as needed.<sup>5</sup> We found that lack of care consistent with a medical home was significantly associated with reporting that care was harder to get than three years ago. Notably, however, we found no significant association between medical home status and unmet prescription medication, dental care, or other medical needs. Having care consistent with a PCMH was also not associated with differential use of well-child or emergency room visits. These results were surprisingly divergent from other studies that have examined the influence of PCMH on care of CSHCN.<sup>5, 24, 25</sup> One potential explanation is the fact that our definition of PCMH did not include measures of family-centeredness or cultural effectiveness that are often included in other studies.<sup>26</sup> Although our analyses did not find any association between having care consistent with a medical home and various key outcomes, recent research supports that continued focus in this area has the potential to impact primary care utilization,<sup>24</sup> racial health disparities,<sup>27</sup> and transition planning.<sup>28</sup> Therefore we recommend continued investment in efforts to expand the number of recognized or accredited PCMH's in the state. In addition, future administrations of the OMAS should consider employing more complete measures of PCMH.

### Young adults

YASHCN face particular challenges transitioning from parental health management to self-management and from pediatric to adult health care providers.<sup>6</sup> Without such support, health status and disease management behaviors often deteriorate significantly in adolescence.<sup>7</sup> *Healthy People 2020* has outlined provision of transition services for CSHCN to support their health care, work, and independent living. Yet nationally only 41% of teens meet the quality indicator standard for appropriate transition care.<sup>8, 28</sup> As such, young adults with special health care needs are still an important area of interest for policy makers.

Differences between the adult and child OMAS questionnaires precluded any direct comparison between CSHCN and YASHCN findings. To be classified as a YASHCN, respondents, ages 19-25, needed to have functional limitations or need health care services greater than the average person their age. Unlike in children, need for chronic prescription medication did not qualify young adults for SHCN status. This definition identified 11.7% of respondents, ages 19-25 as YASHCN, a rate much lower than the 23.1% found in children using the more complete definition.

Notably, 22.5% of YASHCN are uninsured, even after implementation of expanded dependent eligibility requirements for ESI through the Affordable Care Act. An *ad hoc* drill-down analysis in this population showed that over 87% of the uninsured YASHCN had family incomes at or below 138% of the FPL (this finding is tentative, however, since the sample only included 27 uninsured YASHCN). This fact is particularly relevant to ongoing policy considerations regarding extending Medicaid eligibility to most adults at or below this family income level. Policy discussion should consider the fact that low-income young adults who do not have access to ESI (through their own employment or through their parents) are effectively limited in their insurance coverage. Expansion of government subsidized insurance, Medicaid or an equivalent, is needed to maximize health and minimize long-term costs in this population.

## **Recommendations for future research**

This analysis provides in-depth information on CSHCN, a vulnerable population meriting focused attention from the health care system and policymakers. As always, the findings generated a number of new questions that could enhance our understanding of the population and provide additional support to the policy making process. Recommendations for future research are listed below.

### Alignment across children and young adults

Our original analysis plan included comparing children and young adults with special health care needs. These comparisons were not possible because the health care needs on the adult questionnaire, completed by young adults, varied notably from those on the child questionnaire. Future versions of the OMAS should consider aligning these items to facilitate comparisons. Survey designers should also consider adding a limited number of items measuring transition planning for adolescents who will be entering the adult health care system.

### Clinical descriptions of CSHCN

Consistent with previous research, our definition of special health care needs was constructed based on needs for health and health related services. A more complete profile would have also included information on the population's clinical characteristics. Adding a list of common diagnoses to the OMAS questionnaire would allow grouped analysis by medical and behavioral diagnosis groups and would allow us to understand the underlying population health changes that are driving changes in the CSHCN rate.

### Focused research on people with disabilities

As noted above, we were unable to do a detailed analysis of CSHCN with disabilities or children with medical complexity. Monitoring this population is imperative, especially as their payor type changes from fee-for-service to managed care. Due to the small size of the population, the OMAS may not be the best vehicle for such research. Instead, a longitudinal cohort study of children with disabilities could provide significant new knowledge regarding the relationship between changes in coverage models and health outcomes.

## **LIST OF ABBREVIATIONS**

ABD = Aged, Blind, and Disabled

CI = confidence interval

CMC = children with medical complexity

CSHCN = children with special health care needs

ESI = employer-sponsored insurance

FPL = federal poverty level

NS-CSHCN = National Survey of Children with Special Health Care Needs

OFHS = Ohio Family Health Survey

OMAS = Ohio Medicaid Assessment Survey

OR = odds ratio

PCMH = patient-centered medical home

SHCN = special health care needs

YASHCN = young adults (19-25 years old) with special health care needs

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**More information about OMAS, including the data and electronic versions of reports and research briefs, is available online at:**

<http://grc.osu.edu/omas/>



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