

# OHIO MEDICAID ASSESSMENT SURVEY

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*Taking the pulse of health in Ohio*

## AN OVERVIEW OF CHILDREN WITH DEVELOPMENTAL DISABILITIES IN OHIO

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## INTRODUCTION

State level health information for children with developmentally disabilities is scarce. Previous research has demonstrated that most individuals with developmental disabilities do not receive the health care their condition(s) require (Havercamp, Scandlin, & Roth, 2004; Newacheck, McManus, Fox, Hung, & Halfon, 2000). Using the 2012 Ohio Medicaid Assessment Survey (OMAS) as the primary data source, this brief describes the characteristics of Ohio's children with developmental disabilities (DD), including their health behaviors, health status, health care needs, and health care utilization, and addresses the extent to which Ohio's children with DD differ relative to other children in Ohio. Special attention is given to the impact of Ohio Medicaid enrollment for children with DD.

In 2012, 4.3% (125,500) of children 18 years of age and younger in Ohio were reported to have a developmental disability. Two-thirds of these children were covered by Medicaid.

### Definition of children with developmental disabilities

A developmental disability is commonly defined as a lifelong cognitive or physical impairment, usually identified in childhood. Impairment is defined as a mental, behavioral, or physical condition that reduces cognitive or physical functioning (Schalock, et al., 2010). In the 2012 OMAS, data related to developmental disabilities for children was collected by adult proxy method, interviewing the adult most knowledgeable of the selected child's health. In other words, the adult answers the questions from a child interview on behalf of the child. In the OMAS, a child was identified as having a developmental disability if the adult answered all the following questions affirmatively:

- 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?
- Does the child have any limitation in abilities because of **any** medical, behavioral, or other health condition?
- Is this a condition that has lasted or is expected to last 12 months or longer?
- Is the condition related to a developmental disability?

This brief compares children with DD to children who have special health care needs (CSHCN) other than a developmental disability. This is done to examine degrees of need. The CSHCN population is defined as those who have a behavioral, medical or health condition(s) lasting longer than 12 months and who may also require prescriptions special therapy or counseling (McPherson, et al., 1998). In this brief, comparisons are also made to all non-DD children, regardless of the presence or absence of other special health care needs. For the purposes of the report a child is defined as being below 19 years of age.

## RESULTS

### Demographic and household characteristics of children with developmental disabilities

Compared to children without DD, more children with DD are male (63%) and relatively older, with 42% of children with DD being 13-18 years of age, versus 33% of non-DD children. Table 1 illustrates that the DD and Non-DD populations are very similar in terms of racial and ethnic identification. Children with DD are also much more likely to be covered by Medicaid compared to non-DD children (68% vs. 40%). The percentage without insurance is low in both groups (3% vs. 5%).

**Table 1: Demographic characteristics of children with DD, CSHCN, and Non-DD children in Ohio**

		DD		CSHCN		Non-DD	
		# of Children	%	# of Children	%	# of Children	%
<b>Gender</b>	Male	79,251	63%	307,082	56%	1,402,591	51%
	Female	46,251	37%	238,778	44%	1,370,891	49%
<b>Age</b>	0-2	6,964	6%	32,709	6%	412,186	15%
	3-5	15,305	12%	71,604	13%	432,542	16%
	6-12	51,125	41%	224,721	41%	1,015,201	37%
	13-18	52,109	42%	216,827	40%	913,553	33%
<b>Race/ethnicity</b>	White	94,647	75%	410,615	75%	2,062,403	74%
	African-American	19,503	16%	95,417	17%	429,334	15%
	Hispanic	7,198	6%	21,699	4%	135,290	5%
	Other	4,153	3%	18,129	3%	146,456	5%
<b>Insurance</b>	Uninsured	4,167	3%	12,312	2%	135,717	5%
	Medicaid	85,739	68%	302,492	55%	1,109,966	40%
	Employer-Sponsored Insurance (ESI)	25,322	20%	200,508	37%	1,318,733	48%
	Other (Medicare, private, unknown, other)	10,274	8%	30,548	6%	209,067	8%

Household demographics and socioeconomic status influence the healthcare decisions made on behalf of children – this is especially true of families with children with DD (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, & Maisels, 2006; Longmore, 1995). For instance, household composition (single vs. non-single parent), insurance coverage, and annual family income are all important factors that impact child healthcare choices. These demographic and socioeconomic factors are analyzed from the 2012 OMAS data.

Household composition influences the economic and human resources available to children with DD (Emerson, Hatton, Blacher, Llewellyn, & Graham, 2006; Grant & Whittel, 2000). Figures 1 and 2 indicate that children with DD are more likely to live in a single-adult household and live below 100% of the Federal Poverty Level (\$18,530 for a family of three in calendar year 2011). Specifically, 28% of all children with DD live in single-adult households compared to 22% for CSHCN and 17% of non-DD children. Across the DD, CSHCN, and non-DD categories, children enrolled in Medicaid had a higher prevalence of living in a single-adult household, 32%, 32%, and 28%, respectively.

**Figure 1. Percentage of Single-Adult Households by Disability Category**

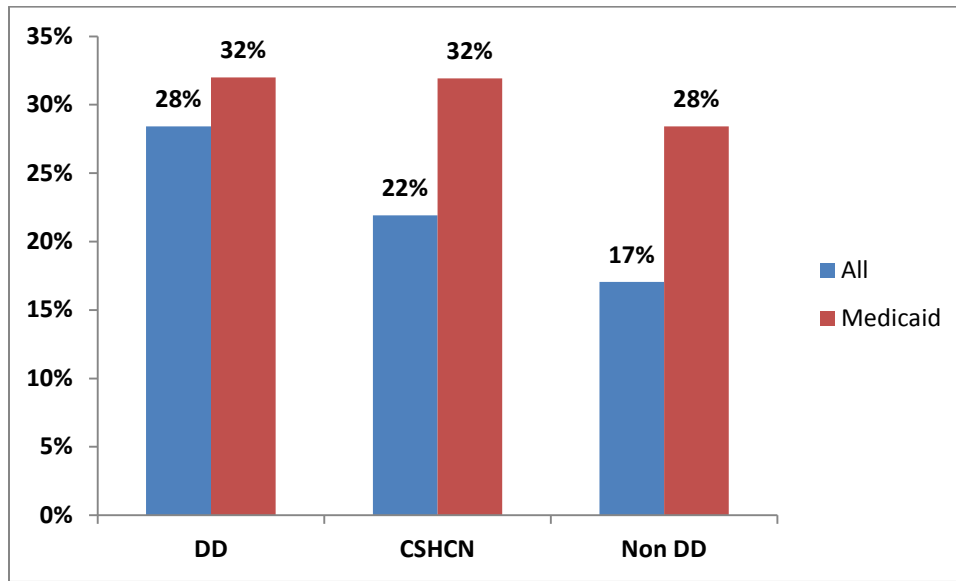
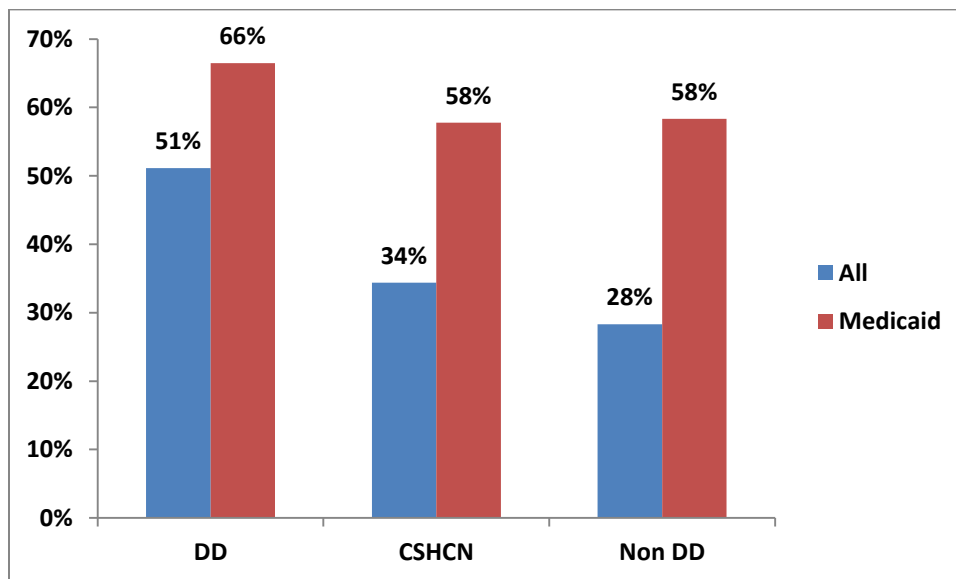


Figure 2 demonstrates that 51% of all children with DD live in households below 100% FPL, compared to 34% of CSHCN children and 28% of non-DD children. For children in the Medicaid program, the percentages are even higher, with 66% of children with DD living in households with income below 100% FPL, compared to 58% for CSHCN and non-DD children. This finding is expected because Medicaid enrollment is largely determined by income limitations (e.g., uninsured children at or below 200% FPL). DD households tend to have less wage earners, and lower overall household income than non-DD households. These statistics are consistent with other studies of the DD population. For instance, Goudie, Havercamp, Ranbom, & Jamieson (2010) found that due to parental/guardian time and work limitations, DD households face more resource restraints and challenges than non-DD households.

**Figure 2. Percentage of Children Below 100% FPL (Ages Less than 19 years in 2012)**

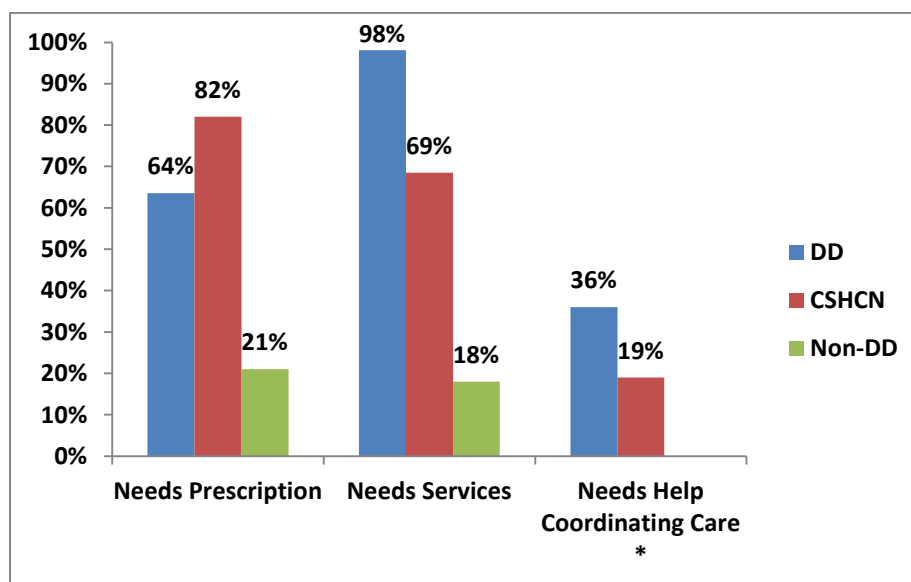


## Health Care Needs of Children with Developmental Disabilities

Children with DD or SHCN tend to have health needs that require more services than non-DD children. Figure 3 illustrates that 64% of all children with DD have a need for prescription drugs compared to 82% for CSHCN children and 21% for non-DD children.

Nearly all (98%) of children with DD indicated a need for services, compared to 69% of CSHCN and 18% of non-DD children. The high rate of reported service needs among the DD population is not surprising given the frequent physical and behavioral demands these children place on families. Finally, 36% of children with DD were reported as needing help coordinating health care for their DD child compared to 19% of CSHCN. Consistent with this finding, Goudie, Fairbrother, Read, & Simpson (2010) found that 28% of parents spent 11 hours or more a week coordinating care for their child with a disability.

**Figure 3: Health Care Needs of Ohio Children with DD (Ages Less than 19 years in 2012)**

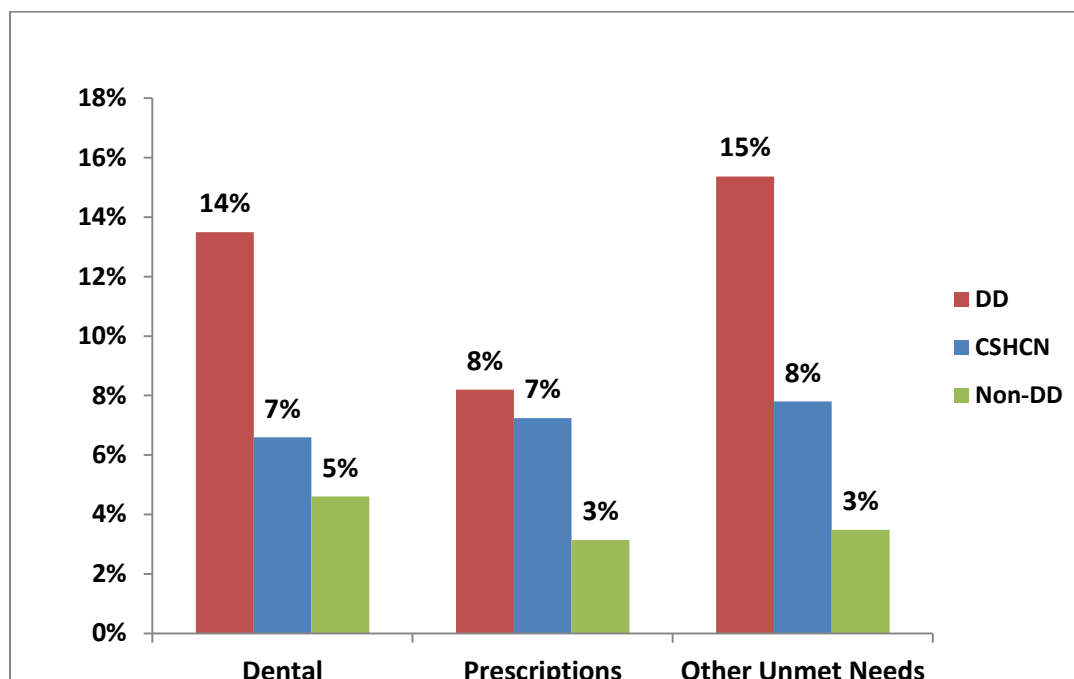


*\*Note: The coordinating care question was only asked of CSHCN.*

## Unmet Needs

A lack of resources, such as income, transportation, and time, as well as inadequate access to health care services are two primary reasons that children with DD have unmet health care needs. Time constraints and transportation limitations may prevent timely visits to the doctor. A lack of access to health care such as specialty and dental care is a challenge to the DD community (Reichard, Marie, & Rutherford, 2004). In Ohio, children with DD have more unmet needs compared to children without DD or to children with CSHCN (Figure 4). Fourteen percent of children with DD did not have their dental needs met in the past 12 months; this is about three times greater than the non-DD population. There were similar disparities in unmet prescription needs and other unmet health needs. Other Ohio-specific studies have shown that children with disabilities have access issues, particularly in finding mental health professionals and dentists (Hayes, Jamieson, Sahr, , Yao, Goudie, & Havercamp, 2011.)

**Figure 4. Unmet Health Care Needs of Ohio Children with DD (Ages Less than 19 years in 2012)**



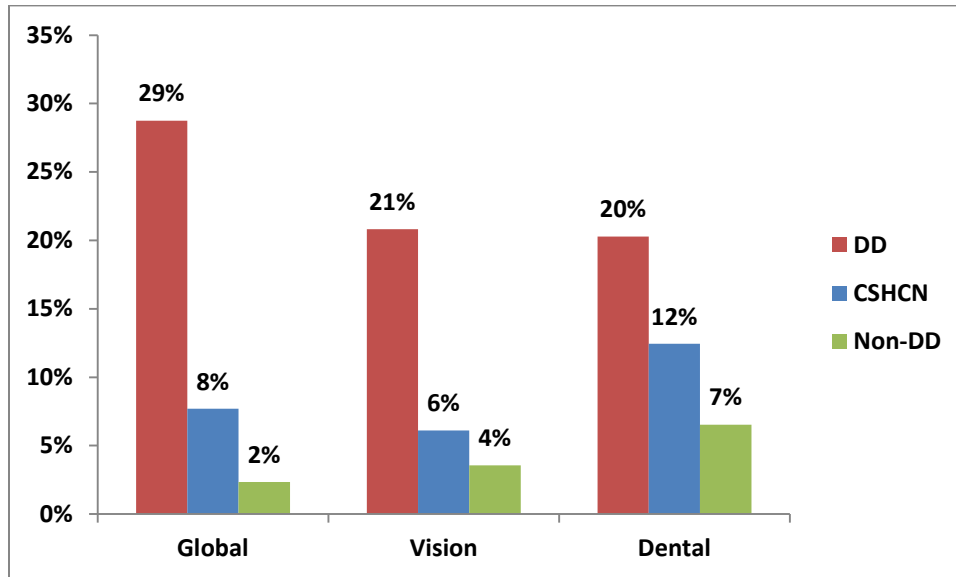
### **Reported Health Status of Children with Developmental Disabilities**

Greater unmet health care needs can lead to relatively poor health outcomes. Figure 5 shows that children with DD are reported as having a significantly higher proportion of fair or poor health status in the categories of vision, dental and overall health when compared to other groups.<sup>1</sup> Consistent with a relatively higher unmet dental need (Figure 4), the percent of children with DD who have fair or poor dental health is nearly three times higher than that of non-DD children (20% vs. 7%). The percent of children with DD who are reported to have fair or poor general health is 14 times that of Non-DD children (29% vs. 2%) and is 3.5 times that reported for CSHCN.

In addition, 26% of children with DD currently have asthma as compared to 9% of non-DD children and 30% of CSHCN children. Although the higher prevalence of asthma among the DD population does not necessarily lead to higher morbidity or unnecessary health care utilization, it is nonetheless important that this population have regular access to primary care in order to prevent poor health outcomes.

<sup>1</sup> Vision status is only asked for children greater than 4 years of age. Dental status is asked for children greater than age 2.

**Figure 5. Health Status of Ohio Children: Percentage Reporting Poor or Fair Health (Ages Less than 19 years in 2012)**

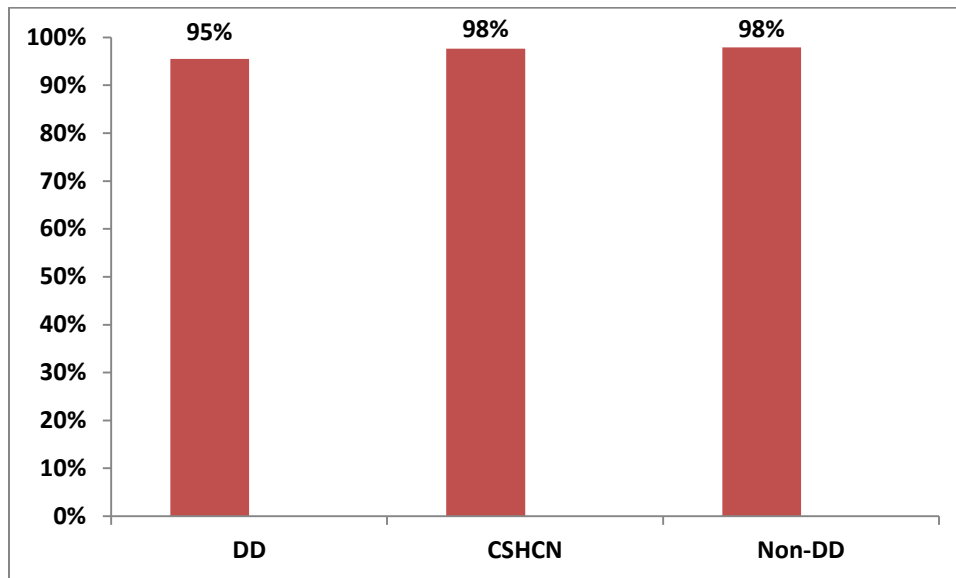


### Usual Source of Care

The vast majority of children in Ohio have a usual source of care (96% for DD, 97% for CSHCN, and 92% for non-DD). A usual source of care is defined as “a particular doctor’s office, clinic, health center, or other place one goes to if one is sick or needs advice about health” (Viera, Pathman, & Garrett, 2006). One benefit of having a usual source of care is having access to proper preventative care.

Where a person receives their usual source of care may indicate access barriers. For children who have a usual source of care, Figure 6 shows the proportion with a usual source of care other than a hospital emergency room, such as a doctor’s office, clinic or hospital outpatient department. Relatively high use of the emergency room as one’s usual source of care could indicate problems in accessing appropriate primary care. However, although children with DD have a slightly lower proportion of non-ER usual source of care compared to CSHCN and non-DD children (95% vs., 98%), the proportion is still quite high. Even though most children with DD have a usual source of care other than the ER, there is widespread evidence indicating that some children in this population have issues accessing basic primary care. For example, there is evidence showing that families of children with DD lack access to wheelchair accessible practices (Lagu, 2013). In addition, some DD children may have appropriate access to primary care but still receive less than optimal health care. For example, many families of children with DD lack access to medical specialists (Hayes et al., 2012)

**Figure 6. Percentage of Children with Usual Source of Care Other than the Emergency Room (Ages Less than 19 years in 2012)\***

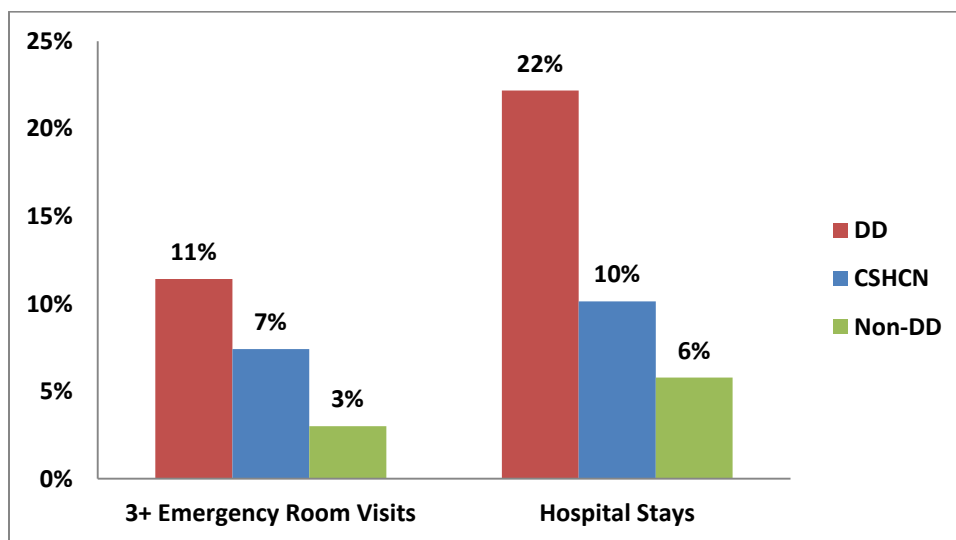


*\*Figure 6 reflects only those children with a usual source of care*

### **Hospital Utilization of Children with Developmental Disabilities**

Children with DD utilize a larger amount and more intensive health care services compared to non-DD children (Boulet, Boyle, & L, 2009; Newacheck, S, Blumberg, & J, 2008). Figure 7 shows that children with DD are more than three-times as likely (11% vs. 3%) to have gone to the emergency room three or more times in the past year compared to a non-DD child. Children with DD are also much more likely to have a hospital stay compared to non-DD children (22% v. 6%) (Figure 7).

**Figure 7. Healthcare Utilization of Ohio Children (Ages Less than 19 years in 2012)**



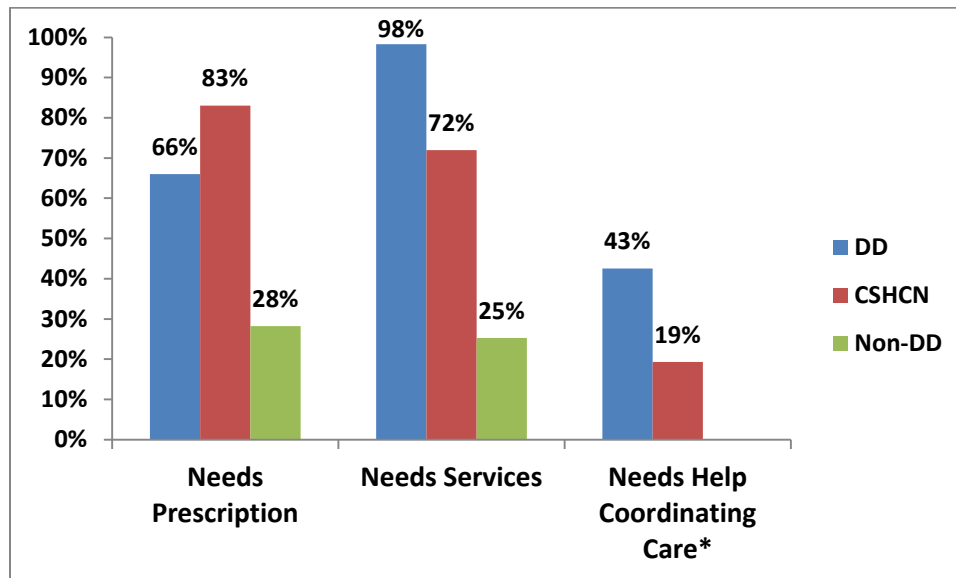


## Children with Developmental Disabilities and Medicaid

As noted, two-thirds of children with DD are covered by Medicaid. In general, children with DD covered by Medicaid share similar health status and health care utilization patterns as the entire population of children with DD.

Figure 8 shows that nearly all children with DD who are Medicaid enrolled have health care needs (98%), compared to 72% of CSHCN and 25% of non-DD Medicaid enrolled children. Most children with DD and SHCN also have prescription drug needs (66% and 84%, respectively) (Figure 8). Finally, 43% of children with DD were reported as needing help coordinating health care compared to 19% of CSHCN.

**Figure 8: Health Care Needs of Ohio Medicaid Children<sup>2</sup>  
(Ages Less than 19 years in 2012)**



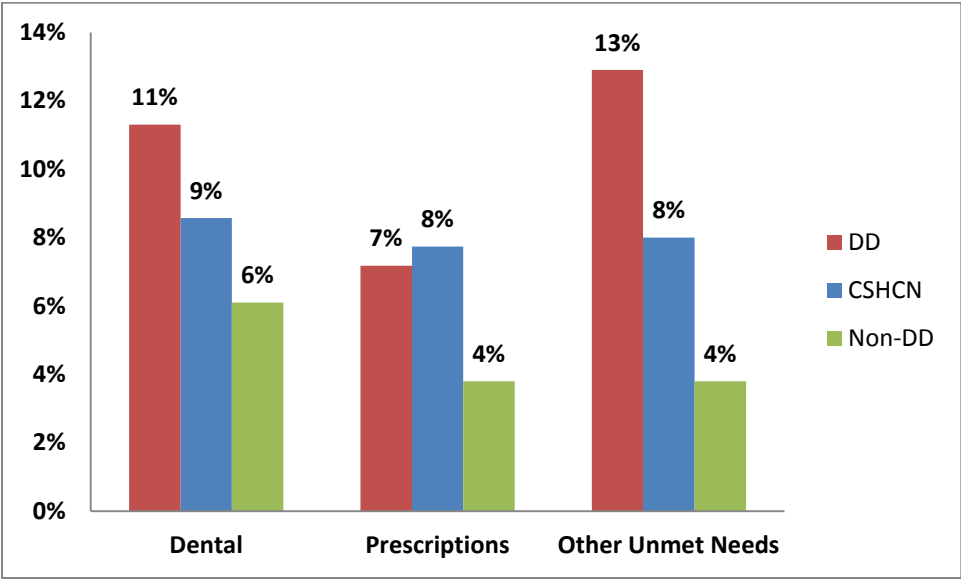
*\*Note: The coordinating care question was only asked of CSHCN.*

Figure 9 illustrates that unmet dental health needs are moderately higher among Medicaid enrolled children with DD (11%) than either Medicaid enrolled CSHCN (9%) or non-DD children (6%). As mentioned earlier, families who have a child with DD often cite troubles finding dentists able to care for DD children (Fenton et al., 2003).

The level of unmet prescription need is roughly comparable for Medicaid enrolled CSHCN and children with DD (7% DD vs. 8% CSHCN). Other unmet needs diverge; with Medicaid enrolled children with DD showing a 5 percentage point difference to Medicaid enrolled CSHCN and a 9 percentage point difference with non-DD Medicaid enrolled children (Other unmet needs may include such areas as medical exam, medical supplies, and mental health care).

<sup>2</sup> “Medicaid children” includes only those children reported to have Medicaid insurance. It does not include children who are insured by both Medicare and Medicaid.

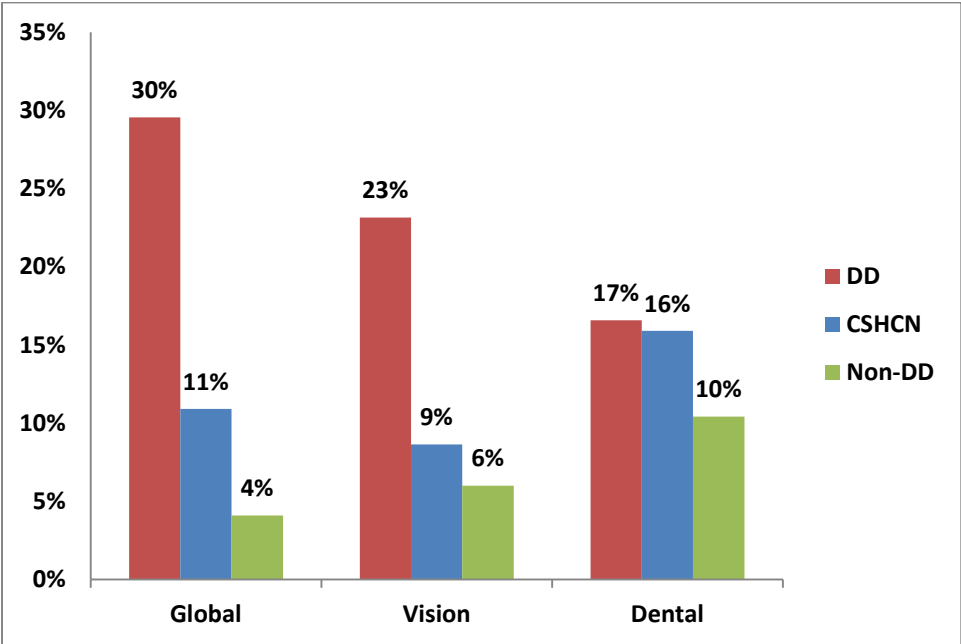
**Figure 9. Unmet Health Care Needs of Ohio Medicaid Children (Ages Less than 19 years in 2012)**



Similar to the patterns observed among the full population of children with DD, the Medicaid enrolled children with DD have consistently higher levels of poor or fair general, vision, and dental health, relative to non-DD children with Medicaid coverage (Figure 10).

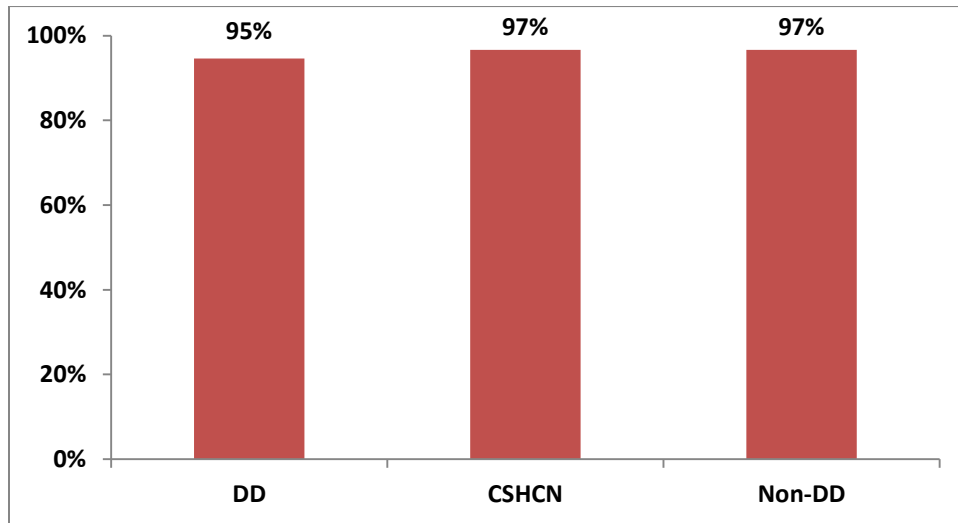
In addition, 31% of DD children and 33% of SCHN children are reported to have asthma compared to 14% for the non-DD Medicaid enrolled children.

**Figure 10. Health Status of Ohio Medicaid Children: Percentage Reporting Poor or Fair Health (Ages Less than 19 years in 2012)**



Among Medicaid enrolled children with a usual source of care, Figure 11 illustrates the percentages reported as having a non-hospital ER usual source of care across the DD, CSHNC, and non-DD categories. For all groupings, most Medicaid enrolled children have a non-hospital ER usual source of care. Medicaid enrolled children with DD rank lowest at 95%.

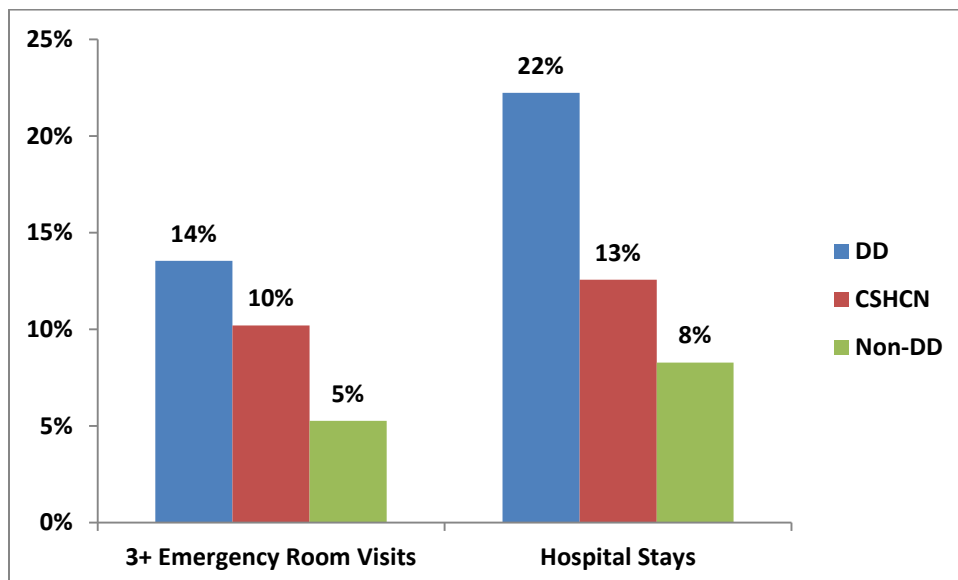
**Figure 11. Percentage of Medicaid Children with Usual Source of Care Other than Hospital Emergency Room (Ages Less than 19 years in 2012)\***



*\*Figure 11 reflects only those children with a usual source of care*

Figure 12 shows that Medicaid enrolled children with DD, compared to Medicaid enrolled non-DD children, are nearly three-times as likely to have gone to the emergency room over three times in the past year (14% vs. 5%). Medicaid enrolled children with DD are nearly three times as likely to have a hospital stay compared to non-DD children (22% v. 8%).

**Figure 12. Healthcare Utilization of Ohio Medicaid Children (Ages Less than 19 years in 2012)**



## **KEY CONSIDERATIONS**

### **Coordination of Care**

Although regular access to either a physician, clinic, or hospital outpatient department is high at 95%, the relatively high use of hospital emergency room services suggests that this population could benefit from more coordinated or more accessible care. Families who spend a significant amount of time arranging for health care for their child would benefit from increased care coordination. Moreover, the literature suggests that individuals with disabilities of all ages lack access to basic health care. As more families who have children with DD are enrolled in managed care plans, there exists greater potential to coordinate services between physicians and medical specialists. Beyond the efforts of the managed care plans, it is recommended that a pilot DD health home be established that would focus on improving care coordination between the various healthcare practitioners of the DD child consumer.

### **DD Training for Health Care Practitioners**

Provider access issues are not just limited to lack of coordination between specialists, but to primary care doctors as well. Primary care doctors are often at a loss as to how to treat or deal a patient with DD. Parents in turn experience medical providers who are either insensitive or unknowledgeable as to how to treat their child. An inexpensive way to increase capacity in providing health care to individuals with DD would be to make available training videos to the medical field. In addition, medical schools could incorporate working with individuals with DD as a part of their curriculum.

### **DD Patient Navigators**

Not only do providers need training, but parents need training in how to find the best health care for their child. A new parent with a child with a disability is often unsure about where and how to get help. This is particularly true given the array of choices consumers will face with the health insurance options provided in the Affordable Care Act. Veteran parents who have dealt with the vagaries of the health care delivery system have considerable expertise in not only finding the right practitioner, but how to best communicate care issues to their medical providers. It is recommended that established parents be employed to act as patient navigators to assist younger parents in finding appropriate health care options for their child.

## **CONCLUSION**

The 2012 OMAS survey data demonstrates that Ohio's children with DD have greater health care needs, greater unmet needs, poorer health status and utilize more health care compared to CSHCN and non-DD children. Although lower than the needs compared to DD children, CSHCN children in most instances have greater health care needs than non-DD children. Similar patterns of health care need and status exists for all DD children and those who have health insurance coverage through Medicaid

The literature suggests that individuals with disabilities of all ages lack access to basic healthcare that the non-DD population enjoys (e.g. preventative care, access to specialists). More research specific to Ohio is needed to determine the extent children with DD lack access to health care and why perceptions about lack of access among this population persist.

As more families who have children with DD are enrolled in managed care plans, there exists greater potential to coordinate services between physicians and medical specialists and hopefully improve outcomes for DD children in Ohio.

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