

# Healthcare Disparities between Children with Developmental Disabilities and Typically Developing Children in Ohio

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**Abstract** This article examines the effects of insurance type and Care Consistent with the Patient-Centered Medical Home (CC-PCMH) on health disparities between children with developmental disabilities (DD) and typically developing (TD) children. Data from a stratified random sample of Ohio households were used to compare children with DD ( $n = 419$ ) to TD children ( $n = 7701$ ) on health indicators including health status, utilization, quality, access, and unmet healthcare needs. Children with DD were more likely than TD children to have a fair or poor health status (27.7% vs. 1.1%;  $P < 0.001$ ), have two or more overnight hospitalizations (8.5% vs. 0.7%;  $P < 0.001$ ), experience delayed treatment (10.1% vs. 2.4%;  $P < 0.001$ ), and have one or more unmet healthcare needs (19.6% vs. 5.7%;  $P < 0.001$ ). The impact of insurance type and CC-PCMH on these health disparities was then explored. Although disparities

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remained when data were stratified by insurance type, Medicaid was associated with fewer difficulties accessing healthcare and fewer unmet healthcare needs for both groups of children. Children with DD who received CC-PCMH were less likely to report having a fair or poor health status than children with DD who did not have that model of care (18% vs. 33.1%;  $P = 0.005$ ). Children with DD who had CC-PCMH experienced less delayed treatment (2.0% vs. 14.5%;  $P < 0.001$ ) and fewer unmet healthcare needs compared to children with DD who did not have that model of care. This study suggests that, in Ohio, Medicaid and CC-PCMH may reduce health disparities, providing potential avenues for achieving health equity for children with DD.

**Keywords** Healthcare · Disparities · Developmental disabilities · Children

### Abbreviations:

CC-PCMH	Care Consistent with the Patient-Centered Medical Home
DD	developmental disability
ER	emergency room
OMAS	Ohio Medicaid Assessment Survey
PCMH	Patient-Centered Medical Home
PCP	primary care provider
TD	typically developing

## 1 Background

Children with developmental disabilities (DD) such as cerebral palsy and intellectual disability have significant health care needs that put them at risk for poor health outcomes. Despite having a greater need for health care services, DDs are associated with barriers to accessing quality health care including physical barriers to the health care facility and knowledge and attitudinal barriers on the part of health care providers (Heslop et al. 2014). Health disparities are preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations. Healthcare barriers put children with DD and other special health care needs at risk for poor health outcomes and significant health disparities (Strickland et al. 2015; Boulet et al. 2009).

New models of health care have emerged that promise to improve the access and quality of care for patients, especially patients with special health care needs. Medicaid was designed to cover a broad range of medical and long-term care services for children with DD and other special health care needs. Many individuals with disabilities rely on Medicaid to cover the cost of necessary healthcare services such as health maintenance exams, long-term therapies, and hospitalizations. While eligibility requirements and covered services vary from state-to-state, Medicaid continues to be a vital safety net for the health of children with DD in the U.S. (Parish and Cloud 2006; Shogren et al. 2006). Much of what we know about the healthcare of people with disabilities based on insurance status was conducted prior to significant changes in the American health care system with the implementation of the Affordable Care Act and Medicaid expansion (Agili et al. 2004; Shogren et al. 2006; Drainoni et al. 2006; Newacheck et al. 1998).

Federal policies have recommended that children with DD and other special health care needs receive a Patient-Centered Medical Home (PCMH) model of care (Homer et al. 2008). PCMH is a model of healthcare delivery intended to be patient-centered, improve accessibility to and quality of care, and control healthcare costs. It is unclear how many children with DD are receiving a PCMH model of care, as not all health care providers are accredited as such. In order to assess the effects of PCMH on the health disparities of children with DD, we used specific indicators to identify children receiving care that is consistent with PCMH (CC-PCMH)- that is, care that fulfills the PCMH requirements. Given the significant healthcare disparities experienced by children with DD, it is vital that we understand the impact of insurance and models of care delivery.

While this study focuses on children with DD, the implications extend to other health disparate populations. If Medicaid or PCMH is associated with different health outcomes for children with DD, these findings could inform policy and practices regarding population health, particularly with respect to other vulnerable populations. For example, these findings could inform decisions about expanding Medicaid to cover more children and adults and decisions about continued funding for the Child Health Insurance Program (CHIP), which covers children whose parents earn too much for Medicaid, but not enough to afford other health insurance coverage.

The purpose of this paper is to present data from the Ohio Medicaid Assessment Survey (OMAS) to identify and quantify the healthcare disparities between Ohio children with and without DD with a focus on whether insurance type and a PCMH model of care affect the magnitude of these disparities. The major research questions are a) what significant health disparities exist for children with DD; b) do health disparities differ across health insurance types; and c) is care consistent with patient centered medical home (CC-PCMH) associated with better health indicators for children with DD.

## 2 Review of the Literature

### 2.1 Defining Developmental Disabilities

Children with DD represent a small subset of the broader category of children with special healthcare needs (CSHCN). DDs are defined as severe, chronic conditions that negatively impact cognitive and/or physical functioning, are diagnosed prior to the age of 22, and persist throughout the lifespan (US Department of Health and Human Services Act 2000). DDs result in substantial limitations in at least 3 of the following activities of daily living: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (Developmental Disabilities Assistance and Bill of Rights Act 2000). The term DD encompasses various types of conditions, including intellectual disability, cerebral palsy, autism spectrum disorder, Down syndrome, and fetal alcohol syndrome.

### 2.2 Health Needs of Children with Developmental Disabilities

Children with DD have significant developmental and healthcare needs that put them at risk for poor health outcomes. The limitations associated with DDs necessitate

interdisciplinary services, individualized supports, and other forms of assistance throughout the individual's lifetime (US Department of Health and Human Services Act 2000). Children with DD often require early intervention services, special education, allied health treatment (e.g., speech therapy, physical therapy, occupational therapy), and a high rate of health care utilization (Boyle et al. 1994; Guralnick and Bennett 1987). They often have chronic, complex medical needs that require durable medical equipment, hospitalizations, surgical interventions, and the care of various medical specialists (Russell and Simon 2014).

### 2.3 Health Disparities in Developmental Disabilities

Health disparities are preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations. The evidence for racial, ethnic, and socioeconomic disparities in health and access to healthcare in the United States is unequivocal (Flores and Tomany-Korman 2008; Sorlie et al. 1995). This paper focuses on children with DD as a socially disadvantaged population. Health disparities have been attributed to many factors including income, bias, differential access to and utilization of health care, and health insurance (Adler and Rehkopf 2008; Hatzenbuehler et al. 2013; Williams and Jackson 2005). Children with DDs are differentially impacted by each of these social circumstances in addition to genetic factors that contribute to higher rates of associated health conditions (e.g., thyroid problems associated with Down syndrome) resulting in what has been described as a cascade of disparities (Krahn et al. 2006).

Children with DD tend to have low socioeconomic status (Boulet et al. 2009; Fisher 2004; Krauss et al. 2003), experience social exclusion and bias, and poor health outcomes (Boulet et al. 2009; Krauss et al. 2003; Krahn et al. 2006; Scior 2011; Staniland 2009; Wilson and Scior 2015). Because of their significant health needs, children with DD utilize health services to a greater extent than children without DD (Boulet et al. 2009; Scheive et al. 2012). Nevertheless, children with DD experience significant barriers to accessing this needed healthcare (Krauss et al. 2003; Betz et al. 2004). Research efforts focused on the broader group of CSHCN have documented significant health disparities compared to TD children (Strickland et al. 2015; Boulet et al. 2009).

### 2.4 Access to Healthcare among Children with DD

DD is associated with barriers to accessing quality healthcare. A study of premature death among people with intellectual disability found that poorer health and delayed identification and diagnosis of illnesses resulted in preventable premature deaths in this population. In fact, intellectual disability was associated with a median age of death 16 years earlier than adults without disabilities. The authors identified the following contributing factors: lack of physician knowledge about common health problems for people with disabilities; lack of physician skill in assessing, diagnosing, and treating illnesses in people with intellectual disability; physical inaccessibility of healthcare facilities; and failure of providers to respond to the concerns of caregivers (Heslop et al. 2014). Another study focusing on children with autism and other DDs found families reported significant difficulties using healthcare services, getting referrals, obtaining

adequate insurance coverage, and obtaining quality healthcare, and care coordination (Krauss et al. 2003). Beyond healthcare, having a child with DD significantly impacts the family's finances, employment, and time burden (Vohra et al. 2014). While much of what is known about health disparities of people with DD was learned through studies of morbidity, mortality, and quality of life of small samples of people with DD in countries other than the United States (Beange and Durvasula 2001; Bittles et al. 2002; Emerson 2009), the current study leveraged a state-wide, representative sample of children with DD.

## 2.5 Key Health Indicators for Children with Developmental Disabilities

Health disparities are measured across a number of health indicators. Previous research identified important health indicators for children with DD including health status, difficulties accessing healthcare, unmet healthcare needs, urgent care, and hospitalization. Children with DD are more likely to have a poor or fair health status (Boulet et al. 2009; Krauss et al. 2003; Krahn et al. 2006; Betz et al. 2004), experience difficulties accessing needed healthcare, and report unmet healthcare needs (Fisher 2004; Krauss et al. 2003; Krahn et al. 2006; Betz et al. 2004). Children with DD utilize health care services to a greater extent including more visits to the emergency room and more overnight hospital stays compared to typically developing children (Boulet et al. 2009; Schieve et al. 2012).

## 2.6 The Role of the Patient-Centered Medical Home

PCMH is a care delivery model whereby patient treatment is coordinated through their primary care physician (PCP) to ensure patients receive the necessary care when and where they need it, in a manner they can understand. It is designed to improve accessibility to and quality of care, while controlling healthcare costs. The PCMH model is particularly well-suited for people with disabilities who, as described earlier, report significant difficulties with access and quality. In families of children with autism spectrum disorder, PCMH was associated with improved experience of care. Families were significantly more satisfied with care, reported greater shared decision making, and fewer unmet health care needs compared to families who did not receive PCMH (Golnik et al. 2012). Positive outcomes associated with PCMH in patients with DD include fewer hospitalizations and shorter lengths of stay, greater vaccine rates, and improved diabetes management (Weedon et al. 2012).

## 2.7 The Role of Health Insurance

In United States, families of children with DD and other special health care needs rely on health insurance to offset the cost of necessary therapies and medical equipment (CDC 2004). The estimated costs of these services surpass ordinary costs incurred by unaffected persons in the US population. These costs include direct medical and non-medical costs (healthcare visits, inpatient hospital stays, assistive devices, home and vehicle modifications), special education, and productivity losses resulting from increased morbidity and premature mortality and vary from approximately \$383,000 to

\$1,014,000 per person depending on the nature of the child's developmental disability (e.g., intellectual disability, cerebral palsy, hearing loss).

Medicaid is a Federal and State public assistance program that covers the cost of medical care for certain groups of Americans- including older individuals, people with disabilities, children, and pregnant women- who meet financial eligibility requirements. The financial eligibility requirements vary by group and state. In Ohio, Medicaid for the Aged, Blind, and Disabled (ABD) requires an income that is 133% the federal poverty level. Services covered through the ABD program include prescription medications, doctor visits, home healthcare, x-rays, medical equipment and supplies, vision services, mental health services, dental care, and other health services ([odh.ohio.gov](http://odh.ohio.gov)). When used as a primary form of insurance, Medicaid is designed to provide these health services at an affordable cost. If a child with disabilities is covered by another primary insurance, Medicaid can be used as a secondary payer to fill in coverage gaps and reduce cost sharing.

In a U.S. study encompassing 20 states, CSHCN with Medicaid were significantly less likely to have problems accessing care at the health plan level, provider level, and overall compared to CSHCN with private insurance (Krauss et al. 2003). Another study of children with autism spectrum disorder found that those with Medicaid received significantly more services than those with private insurance (Wang et al. 2013). Wang et al. found that, compared to Medicaid, children with private insurance were less likely to have plans that cover the recommended autism-specific services..

A study of Massachusetts residents, on the other hand, reported a variety of structural insurance barriers related to both Medicaid and private insurance, including health plan and insurance policies and procedures, difficulties related to eligibility and service delivery, poor coordination within providers' offices, as well as a lack of understanding on the part of insurance companies about people with disabilities and the services they need (Drainoni et al. 2006). Another study of Alabama children with disabilities found greater access barriers among those with public insurance compared to private insurance (Agili et al. 2004). Additionally, many healthcare providers report a hesitancy to accept patients with public insurance due to perceived administrative burdens, concerns of reimbursement rates, and restrictive rules regarding eligibility and covered services (Shogren et al. 2006). Inconsistencies in the literature may be due to the evolving nature of healthcare and healthcare policies and differences in Medicaid programs across the states.

### 3 Methods

The 2015 Ohio Medicaid Assessment Survey (OMAS) is a telephone survey that samples both landline and cell phones in Ohio. The survey examines access to the health system, health status, and other characteristics of Ohio's Medicaid, Medicaid-eligible, and non-Medicaid populations. In 2015, researchers completed 42,876 interviews with adults and 10,122 proxy interviews of children. The 2015 OMAS is the sixth iteration of the survey (Ohio Colleges of Medicine Government Resource Center and RTI International 2015a). Data were collected from January 2015 through June 2015. OMAS used single imputation to handle missing data for key items such as insurance status (see

OMAS Methodology Report for more information, Ohio Colleges of Medicine Government Resource Center and RTI International 2015a, b). Each question used in this study had fewer than 10% responses missing.

### 3.1 Statistical Methods

This study used the child-level weights provided within the OMAS public release data, producing population-level estimates. Group differences were analyzed using the Rao-Scott chi-square test, a version of Pearson's chi-square test that adjusts for the complex survey design features. All analyses were conducted in SAS version 9.4. Due to the small size of the DD population, several values presented in this study should be interpreted with caution. For survey questions with a sample size of less than 200 respondents, percentages and confidence intervals were rounded to the nearest whole number.

### 3.2 Study and Comparison Groups

Two mutually exclusive but not exhaustive populations were constructed for comparison: (1) children with DD and (2) typically developing children (TD) without special health care needs. Because we were interested in confining our sample to children who met the federal definition of DD, DD was identified using a series of items that capture each facet of the DD definition. A child was defined as having DD if his or her adult proxy answered "yes" to each of the following questions from the OMAS survey instrument: (1) Does [child] currently have a developmental disability? (2) Is [child] limited or prevented in any way in [his/her] ability to do things most children of the same age can do? (3) Is this because of any medical, behavioral or other health condition? (4) Is this a condition that has lasted or is expected to last for at least 12 months? Children were classified as TD if their adult proxy answered "no" to both of the following: (1) Does [child] currently have a developmental disability? And (2) Is [child] limited or prevented in any way in [his/her] ability to do things most children of the same age can do (Ohio Collects of Medicine Government Resource Center and RTI International 2015a, b)? Children who neither met the DD nor the TD definition were excluded from this study since our interest was in comparing children with DD to typically developing children.

### 3.3 Definition of Insurance Type

This study compared children enrolled in Medicaid to children enrolled in private insurance. Medicaid is a jointly funded, Federal-State health insurance program for low-income and needy Americans. It covers children, the aged, blind, and/or disabled and other people who are eligible to receive federally assisted income maintenance payments. Medicaid was defined as Medicaid alone and dual Medicaid/Medicare coverage. Private insurance was defined as employer-sponsored, other directly purchased, and exchange coverage. The small percentage of children who were uninsured (2%) or had other/unknown insurance (4%) were excluded from analyses by insurance type.

### 3.4 Definition of Care Consistent with the Patient-Centered Medical Home

Patient-centered medical home (PCMH) is a care delivery model whereby treatment is coordinated through a primary care physician (PCP) to ensure patients receive the necessary care when and where they need it, in a manner they can understand. The OMAS survey did not explicitly ask respondents whether their healthcare was delivered through an accredited PCMH model. This study assessed care consistent with patient-centered medical home (CC-PCMH), which was defined as follows: (1) Has an appropriate and usual source of healthcare, such as a physician's office; (2) Has a PCP; (3) Has had a visit with his or her PCP in the past year; (4) PCP communicates effectively with the family; (5) Receives needed urgent care on the same or next day; (6) Receives needed after-hours care without any issues; (7) Receives needed specialty care without problems (Wickizer et al. 2016)).

### 3.5 Child Health Indicators

Health indicators were selected based on previous research on the health of children with DD and CSHCN. An adult proxy answered questions related to the child's health status, healthcare utilization, healthcare quality, and healthcare access. Healthcare utilization was defined as emergency room (ER) use and number of overnight hospitalizations. Quality was assessed by the following two items: how much time their PCPs spend with them and whether their PCPs explain health information well. We assessed healthcare access through questions related to having a regular source of care, delayed treatment, problems obtaining needed care, days waited for urgent care, ability to receive after-hours care, and difficulties seeing a specialist. Questions regarding the child's dental care, vision care, prescription needs, and other medical care were used to determine unmet healthcare needs (Ohio Colleges of Medicine Government Resource Center and RTI International, 2015a, b).

## 4 Results

Overall, 4.6% of children in this sample had DD (419 respondents) and 75.1% were TD (7701 respondents). The remaining 20.3% represents children who did not meet criteria for having DD nor criteria for being typically developing and were excluded from these analyses ( $n=2002$ ). The demographic characteristics of children with DD and TD are presented in Table 1. The ratio of males to females with DD was approximately 1.5. Children with DD were more likely to be older than TD children (81.4% vs. 65.7%;  $P < 0.001$ ). Most children with DD were enrolled in Medicaid (68.5%; CI 63.4–73.5%), while the majority of TD children had private insurance (51.6%; CI 50.3–52.9%). Few children were uninsured, with only 1.1% (CI 0.2–2.0%) of children with DD and 2.5% (CI 2.1–2.9%) of TD children reporting no insurance coverage. Children with DD were more likely to live in households with a family income less than 200% of the federal poverty level (58.3% vs 46.0%;  $P < 0.001$ ). Children with DD had



**Table 1** Demographic characteristics

	Developmental disability ( <i>N</i> = 419, <i>Wt freq</i> = 127,585, 4.6%*)				Typically developing ( <i>N</i> = 7701, <i>Wt freq</i> = 2,093,659, 75.1%*)				P-value
	<i>N</i>	<i>Wt freq</i>	%	95% <i>CI</i>	<i>N</i>	<i>Wt freq</i>	%	95% <i>CI</i>	
Gender									0.002
Male	259	75,471	59.2	53.5–64.8	3852	1,044,724	49.9	48.6–51.2	
Female	160	52,114	40.8	35.2–46.5	3849	1,048,934	50.1	48.8–51.4	
Age (Years)									<0.001
0–5	69	23,679	18.6	14.0–23.1	2496	718,317	34.3	33.0–35.6	
6–18	350	103,906	81.4	76.9–86.0	5205	1,375,342	65.7	64.4–67.0	
Race/Ethnicity									0.51
White	290	91,887	72.0	67.0–77.1	5405	1,543,908	73.7	72.6–74.9	
African American	65	20,332	15.9	11.6–20.2	1114	298,357	14.3	13.4–15.2	
Hispanic	27	5406	4.2	2.4–6.1	548	113,617	5.4	4.8–6.0	
Other	37	9960	7.8	4.9–10.7	634	137,776	6.6	5.9–7.2	
County Type									0.02
Metro	242	77,938	61.1	55.8–66.4	3812	1,108,643	53.0	51.9–54.0	
Rural Appalachian	60	17,966	14.1	10.3–17.9	1314	366,350	17.5	16.8–18.2	
Rural Non-Appalachian	52	13,567	10.6	7.5–13.7	1228	298,214	14.2	13.6–14.9	
Suburban	65	18,115	14.2	10.7–17.7	1347	320,452	15.3	14.6–16.0	
Insurance									<0.001
Medicaid	259	87,333	68.5	63.4–73.5	2751	876,819	41.9	40.5–43.2	
Private	137	35,547	27.9	23.0–32.7	4329	1,080,125	51.6	50.3–52.9	
Other	16	3303	2.6	1.2–4.0	370	84,494	4.0	3.5–4.5	
Uninsured	7	1402	1.1	0.2–2.0	251	52,221	2.5	2.1–2.9	
Family Income $\leq$ 200% FPL	240	74,328	58.3	52.7–63.8	3333	964,105	46.0	44.7–47.4	<0.001
Meets CC-PCMH Criteria	142	45,249	35.5	29.9–41.0	3001	827,752	39.5	38.2–40.8	0.17

*N* unweighted frequency, *Wt freq* weighted frequency, *FPL* federal poverty level, *CI* confidence interval

\*Percent of children with developmental disabilities and typically developing; missing 20.3% are the excluded children with special healthcare needs

similar rates of CC-PCMH, regardless of insurance type (34.0% Medicaid versus 39.0% Private Insurance).

#### 4.1 Health Status

As shown in Table 2, children with DD were more than 25 times more likely to report a fair or poor health status than TD children (27.7% vs. 1.1%;  $P < 0.001$ ). Having private insurance decreased the likelihood of having a reported fair or poor health status in children with DD ( $P = 0.02$ ) and in TD children ( $P = 0.001$ ; Table 3). Further, children with DD who had CC-PCMH were less likely to report having a fair or poor health status than children with DD who did not have CC-PCMH (Table 4; 18% vs. 33.1%;  $P = 0.005$ ).

**Table 2** Health indicators

	Developmental disability				Typically developing				P - value
	N	Wt freq	%	95% CI	N	Wt freq	%	95% CI	
Health status: fair or poor	119	35,303	27.7	22.7–32.6	87	22,895	1.1	0.8–1.4	<0.001
Utilization*									
2 or more overnight hospitalizations	35	10,692	8.5	5.5–11.4	50	14,151	0.7	0.5–0.9	<0.001
2 or more ER visits	101	30,109	23.8	19.1–28.6	470	144,225	7.0	6.3–7.7	<0.001
Quality*									
PCP usually or always spends enough time with child	330	101,028	91.6	88.0–95.1	5155	1,429,618	90.8	89.9–91.8	0.71
PCP usually or always explains things well	343	104,505	94.7	91.4–98.0	5460	1,514,360	96.4	95.8–96.9	0.25
Access*									
Usual source of care	415	126,078	98.8	97.5–100.0	7288	1,996,725	95.5	95.0–96.0	0.01
Delayed treatment	43	12,852	10.1	6.8–13.4	215	50,066	2.4	2.0–2.8	<0.001
Other problems getting needed care	62	17,510	13.7	10.1–17.4	160	44,274	2.1	1.7–2.5	<0.001
Received same-day care for urgent needs	161	50,637	47.5	41.3–53.7	3320	916,131	61.1	59.6–62.7	<0.001
Waited 2 or more days for urgent care needs	102	31,871	29.9	24.3–35.5	870	241,385	16.1	14.9–17.3	<0.001
Usually or always received needed after-hours care from PCP	183	59,455	59.4	53.0–65.7	2990	839,606	61.6	60.0–63.2	0.50
Any problem seeing a specialist †	83	24,901	24.6	19.2–30.0	310	83,695	19.3	17.0–21.6	0.06
Unmet healthcare needs*									
Dental	31	10,173	8.3	5.1–11.4	229	62,638	3.3	2.8–3.8	<0.001
Vision	24	6126	5.0	2.6–7.3	130	34,140	1.8	1.4–2.2	<0.001
Prescription	42	12,140	9.7	6.4–13.0	131	34,512	1.7	1.4–2.0	<0.001
Other (e.g. medical exam, medical supplies)	46	13,243	10.6	7.3–13.9	142	34,342	1.7	1.4–2.0	<0.001
1 or more unmet needs	85	24,516	19.6	15.2–24.0	437	115,577	5.7	5.0–6.3	<0.001

*N* unweighted frequency, *Wt freq* weighted frequency, *CI* confidence interval

\*During the past 12 months

† Among respondents who needed specialist care. 19.3% of respondents with DD and 78.4% of TD respondents did not need specialist care

## 4.2 Utilization

Table 2 demonstrates that children with DD had greater healthcare utilization than TD children. Children with DD were more than 3 times as likely as TD children to have

**Table 3** Health indicators by insurance type

	Developmental disability					Typically developing						
	Insurance	N	Wt freq	%	95% CI	P-value <sup>a</sup>	N	Wt freq	%	95% CI	P-value <sup>b</sup>	P-value <sup>c</sup>
Health status: fair or poor	Medicaid	83	26,963	30.9	24.5–37.3	0.02	47	13,978	1.6	1.1–2.1	0.001	<0.001
	Private	28	6695	19	11–26		23	6009	0.6	0.2–0.9		<0.001
Utilization*	Medicaid	26	8654	10.0	6.1–14.0	0.10	30	9051	1.1	0.6–1.5	0.003	<0.001
	Private	7	1727	5	1–9		15	4115	0.4	0.2–0.6		<0.001
2 or more ER visits	Medicaid	74	23,567	27.3	21.1–33.6	0.006	318	101,646	11.9	10.5–13.3	<0.001	<0.001
	Private	21	5057	14	8–20		125	36,451	3.4	2.7–4.1		<0.001
Quality*	Medicaid	199	67,599	89.4	84.5–94.3	0.06	1630	528,067	87.5	85.6–89.3	<0.001	0.49
PCP usually or always spends enough time with child	Private	114	29,744	96	92–100		3277	842,592	93.9	92.9–94.8		0.37
PCP usually or always explains things well	Medicaid	210	71,512	94.6	90.4–98.7	0.93	1763	571,009	94.8	93.6–95.9	<0.001	0.92
	Private	116	29,342	95	89–100		3419	877,966	97.9	97.4–98.4		0.11
Access*	Medicaid	257	86,221	98.7	96.8–100.0	0.50	2569	828,247	94.8	93.9–95.7	<0.001	0.04
Usual source of care	Private	136	35,348	99	98–10		4199	1,053,209	97.5	97.0–98.0		0.10
Delayed treatment	Medicaid	16	6233	7.1	3.3–10.9	0.02	49	13,259	1.5	1.1–2.0	0.003	<0.001
	Private	23	5782	16	9–23		123	29,115	2.7	2.1–3.3		<0.001
Other problems getting needed	Medicaid	32	8725	10.0	6.1–13.9	0.005	61	19,903	2.3	1.7–2.9	0.04	<0.001
	Private	25	7668	22	13–30		60	15,979	1.5	1.0–2.0		<0.001
Received same-day care for needs	Medicaid	99	32,643	45.1	37.3–52.9	0.23	1006	322,557	55.6	52.9–58.3	<0.001	0.01
	Private	54	16,179	53	43–64		2123	548,727	64.6	62.7–66.5		0.03
Waited 2 or more days for needs	Medicaid	63	22,616	31.2	24.0–38.4	0.35	382	121,201	20.9	18.7–23.0	<0.001	0.003

**Table 3** (continued)

	Developmental disability				Typically developing					
Usually or always received after-hours care from PCP	Private	32	7784	26	17–35	440	109,934	12.9	11.6–14.3	<0.001
	Medicaid	118	41,906	60.9	53.0–68.8	1001	330,395	60.7	58.0–63.5	0.27
	Private	56	15,159	55	43–66	1837	475,216	62.7	60.6–64.7	0.17
Problem seeing a specialist <sup>†</sup>	Medicaid	50	17,164	24.7	17.9–31.5	132	42,722	23.9	19.8–28.0	0.001
	Private	28	6945	24	15–33	150	34,643	14.9	12.2–17.5	0.02
Unmet healthcare needs <sup>*</sup>										
Dental	Medicaid	17	6445	7.7	3.8–11.5	96	30,296	4.0	3.0–4.9	0.002
	Private	9	2920	8	3–14	91	23,112	2.3	1.7–2.8	<0.001
Vision	Medicaid	11	3242	3.9	1.1–6.6	50	14,616	1.9	1.3–2.6	0.11
	Private	8	2096	6	1–11	50	13,267	1.3	0.9–1.7	<0.001
Prescription	Medicaid	18	6705	7.9	3.8–11.9	35	11,351	1.3	0.9–1.8	<0.001
	Private	18	4359	12	6–18	72	18,804	1.8	1.3–2.2	<0.001
Other (e.g. medical exam, supplies)	Medicaid	19	5761	6.7	3.3–10.2	46	12,604	1.5	1.0–2.0	<0.001
	Private	20	6048	17	10–25	64	15,501	1.5	1.0–1.9	<0.001
1 or more unmet needs	Medicaid	43	13,945	16.3	11.0–21.6	162	50,482	6.0	4.9–7.0	<0.001
	Private	33	9023	26	17–34	204	50,992	4.8	4.0–5.6	<0.001

N, unweighted frequency; Wt freq, weighted frequency; CI, confidence interval

<sup>a</sup> comparing Medicaid versus private insurance for children with DD

<sup>b</sup> comparing Medicaid versus private insurance for TD children

<sup>c</sup> comparing children with DD and TD children within each insurance category

<sup>\*</sup>During past 12 months; <sup>†</sup> Among respondents who needed specialist care. 19.3% of respondents with DD and 78.4% of TD respondents did not need specialist care

**Table 4** Health indicators by CC-PCMH versus no CC-PCMH

	Developmental disability					Typically developing						
	CC-PCMH Status	N	Wt freq	%	95% CI	P-value <sup>a</sup>	N	Wt freq	%	95% CI	P-value <sup>b</sup>	P-value <sup>c</sup>
Health status: fair or poor	No CC-PCMH	94	27,229	33.1	26.7–39.5	0.005	69	16,332	1.3	0.9–1.6	0.13	<0.001
	CC-PCMH	25	8073	18	10–25		18	6564	0.8	0.3–1.3		<0.001
Utilization*	No CC-PCMH	28	9043	11.2	7.0–15.4	0.009	31	8355	0.7	0.4–0.9	0.93	<0.001
	CC-PCMH	7	1650	4	0–7		19	5796	0.7	0.4–1.1		<0.001
	No CC-PCMH	72	21,455	26.5	20.4–32.6	0.14	331	101,819	8.3	7.3–9.3	<0.001	<0.001
Access*	CC-PCMH	29	8654	19	12–26		139	42,407	5.1	4.1–6.1		<0.001
	No CC-PCMH	38	11,944	14.5	9.6–19.4	<0.001	175	39,432	3.2	2.6–3.7	<0.001	<0.001
	CC-PCMH	5	908	2	0–4		40	10,634	1.3	0.8–1.7		0.39
Other problems getting needed care	No CC-PCMH	54	14,946	18.2	13.2–23.1	0.005	133	36,560	2.9	2.3–3.5	<0.001	<0.001
	CC-PCMH	8	2564	6	1–11		27	7714	0.9	0.5–1.3		<0.001
	No CC-PCMH	24	8247	10.4	5.9–14.8	0.05	182	49,498	4.3	3.5–5.1	<0.001	<0.001
Unmet healthcare needs*	CC-PCMH	7	1926	4	1–8		47	13,140	1.7	1.1–2.3		0.03
	No CC-PCMH	18	4442	5.6	2.6–8.6	0.51	112	28,331	2.5	1.9–3.0	<0.001	0.005
	CC-PCMH	6	1683	4	0–8		18	5809	0.8	0.4–1.2		0.002
Prescription	No CC-PCMH	35	9893	12.3	7.8–16.7	0.05	101	25,099	2.1	1.6–2.5	0.01	<0.001
	CC-PCMH	7	2247	5	1–9		30	9413	1.1	0.7–1.6		0.001

Table 4 (continued)

	Developmental disability				Typically developing											
	No CC-PCMH	CC-PCMH	No CC-PCMH	CC-PCMH	No CC-PCMH	CC-PCMH	No CC-PCMH	CC-PCMH								
Other (e.g. medical exam, medical supplies)	41	5	12,112	1131	15.0	3	10.2–19.9	28,542	5800	2.4	0.7	1.8–2.9	276,669	276,669	<0.001	0.008
1 or more unmet needs	70	15	19,786	4730	24.5	11	18.6–30.5	87,908	341	7.2	3.3	6.3–8.2	276,669	276,669	<0.001	0.001

*N* unweighted frequency, *Wt* freq weighted frequency *CI* confidence interval

<sup>a</sup> comparing CC-PCMH versus no CC-PCMH for children with DD

<sup>b</sup> comparing CC-PCMH versus no CC-PCMH for TD children

<sup>c</sup> comparing children with DD and TD within each CC-PCMH status

\*During past 12 months

had two or more ER visits in the past year (23.8% vs. 7.0%;  $P < 0.001$ ). Children with DD were also 12 times as likely to have had two or more overnight hospitalizations in the past year (8.5% vs. 0.7%;  $P < 0.001$ ). Children with DD who were enrolled in Medicaid demonstrated greater healthcare utilization compared to children with DD enrolled in private insurance (Table 3). Among children enrolled in Medicaid, children with DD were 9 times as likely to have two or more overnight hospitalizations as TD children (10.0% vs. 1.1%;  $P < 0.001$ ). Children with DD who had private insurance were more than 12 times as likely to have had two or more overnight hospital visits as TD children who had private insurance (5% vs. 0.4%;  $P < 0.001$ ). CC-PCMH was associated with lower healthcare utilization among children with DD (Table 4). In fact, children with DD who had CC-PCMH were 3 times less likely to have two or more hospitalizations than those without CC-PCMH (Table 4; 11.2% vs. 4%;  $P = 0.009$ ).

### 4.3 Quality

The difference between children with DD and TD across our quality indicators was not statistically significant (Table 2). Further, no substantial difference was observed between children with DD who were enrolled in private insurance versus Medicaid (Table 3).

### 4.4 Access

The vast majority of children with DD (98.8%; CI 97.5–100.0%) and TD children (95.5%; CI 95.0–96.0%) had a usual source of care for their healthcare needs; however, children with DD had greater difficulties accessing this care compared to TD children (Table 2). Children with DD experienced delayed treatment at a rate 4 times higher than TD children (10.1% vs. 2.4%;  $P < 0.001$ ) and were over 6 times as likely to have other problems obtaining needed care (13.7% vs. 2.1%;  $P < 0.001$ ). Children with DD were 86% more likely to wait two or more days for urgent care needs (29.9% vs. 16.1%;  $P < 0.001$ ). Children with DD also had higher reported rates of problems seeing a specialist compared to TD children, though this difference was not statistically significant.

Access disparities between children with DD and TD children remained when data were stratified by insurance type (Table 3). The magnitude of this disparity was smaller for children enrolled in Medicaid than for children with private insurance. Among children enrolled in Medicaid, children with DD were over 4 times more likely to have delayed treatment (7.1% vs. 1.5%;  $P < 0.001$ ) and to have problems receiving needed care compared to TD children (10.0% vs. 2.3%;  $P < 0.001$ ). Among children enrolled in private insurance, children with DD were about 6 times more likely to have delayed treatment (16% vs. 2.7%;  $P < 0.001$ ) and almost 15 times more likely to have problems getting care than TD children (22% vs. 1.5%;  $P < 0.001$ ). The likelihood of receiving after-hours care from their PCPs and receiving same-day care for urgent care needs was not significantly different between children with DD enrolled in Medicaid versus private insurance.

CC-PCMH was associated with better access to care for children with DD and TD children (Table 4). Among children without CC-PCMH, children with DD were over 4 times more likely to experience delayed treatment than TD children (14.5% vs. 3.2%;

$P < 0.001$ ). Among children with CC-PCMH, there was no statistically significant difference between children with DD and TD children in regards to having delayed treatment.

## 4.5 Unmet Healthcare Needs

### 4.5.1 Dental

The prevalence of children with DD who had unmet dental needs was more than twice as high as among TD children (Table 2; 8.3% vs. 3.3%;  $P < 0.001$ ). The difference between unmet dental needs in children with DD enrolled in Medicaid compared to private insurance was not statistically significant (Table 3). However, TD children enrolled in Medicaid had higher rates of unmet dental needs than TD children who had private insurance (4.0% vs. 2.3%;  $P < 0.002$ ). Children with DD who had CC-PCMH were 62% less likely to have unmet dental needs than children with DD without CC-PCMH (Table 3; 4% vs. 10.4%;  $P = 0.05$ ).

### 4.5.2 Vision

Children with DD were almost 3 times as likely to have unmet vision needs compared to TD children (Table 2; 5.0% vs. 1.8%;  $P < 0.001$ ). Children with DD who had private insurance were 1.5 times more likely to have unmet vision needs compared to children with DD enrolled in Medicaid, although this difference was not statistically significant (Table 3). Among children with private insurance, children with DD were almost 5 times more likely to have unmet vision needs compared to TD children (6% vs. 1.3%;  $P < 0.001$ ). Although not statistically different, children with DD without CC-PCMH were 40% more likely to have unmet vision needs than children with DD who had CC-PCMH (Table 4).

### 4.5.3 Prescription

Children with DD were almost 6 times more likely to be unable to obtain needed prescriptions due to cost compared to TD children (Table 2; 9.7% vs. 1.7%;  $P < 0.001$ ). The difference between children with DD enrolled in private insurance versus Medicaid was not statistically significant (Table 3). Children with DD who had CC-PCMH were 59% less likely to report unmet prescription needs than children with DD who did not have CC-PCMH (Table 4; 5% vs. 12.3%;  $P = 0.05$ ).

### 4.5.4 Other Needed Healthcare

Other needed healthcare included medical exams, medical supplies, mental health care, and eyeglasses. The prevalence rate of children with DD reporting problems obtaining other needed healthcare was over 6 times greater than TD children (Table 2; 10.6% vs. 1.7%;  $P < 0.001$ ). Children with DD who had private insurance were more than twice as likely to report other unmet needed healthcare as children with DD enrolled in Medicaid (Table 3; 17% vs. 6.7%;  $P = 0.006$ ). Children with DD who had CC-PCMH



were 80% less likely to have other unmet healthcare needs than children with DD without CC-PCMH (Table 4; 3% vs. 15.0%;  $P < 0.001$ ).

## 5 Discussion

Children with DD experience significant healthcare disparities compared to TD children. Consistent with previous studies, we found that children with DD were more likely to have a poor or fair health status (Boulet et al. 2009; Krauss et al. 2003; Krahn et al. 2006; Betz et al. 2004), difficulties accessing needed healthcare, and unmet healthcare needs (Fisher 2004; Krauss et al. 2003; Krahn et al. 2006; Betz et al. 2004). Children with DD also utilized healthcare services to a greater extent (Boulet et al. 2009; Schieve et al. 2012).

We found that disparities remain between children with DD and TD children when comparing within the same insurance type; however, the magnitude of these disparities was smaller for children enrolled in Medicaid than for children enrolled in private insurance. Although not all differences were statistically significant, children with DD who had Medicaid experienced better access to care and reported fewer unmet healthcare needs compared to children with DD who had private insurance. These trends suggest that Medicaid may better meet the healthcare needs of children with DD than private insurance, a finding consistent with previous research (Krauss et al. 2003; Wang et al. 2013).

The finding that Medicaid insurance was associated with better access to care for children with DD has broad implications. It suggests that health inequities may be addressed by policies and programs that provide insurance coverage for health disparate populations. In fact, a recent study found that, among children with disabilities with a family income of less than 400% of the federal poverty level, children enrolled in Medicaid were less likely to report unmet healthcare needs than children with private insurance (Mullin et al. in preparation). These findings suggest that Medicaid expansion up to 400% of the federal poverty level for children with DD may improve health equity in this population. Research is needed to explore the impact of Medicaid insurance in other vulnerable groups such as children and adults disadvantaged by race, ethnicity, or spoken language.

In addition to Medicaid coverage, having parent-reported CC-PCMH resulted in better healthcare outcomes for children with DD. PCMH is a primary care-focused model of care that is patient-centered, coordinated, accessible, and comprehensive. The Affordable Care Act increased the implementation of PCMH models throughout the country (Ashmead et al. 2016). This study found that CC-PCMH mitigated the specific healthcare disparities experienced by children with DD. Among children who had CC-PCMH, disparities for children with DD compared to TD children were still present; however, for children with DD, CC-PCMH was associated with less utilization of the healthcare system, greater access to care, and fewer unmet healthcare needs. No prior studies have reported on the effects of CC-PCMH on health equity for children with DD; however, our results are consistent with studies that found similar improvements among children with special healthcare needs (Raphael et al. 2009; Strickland et al. 2009). PCMH model of care may be especially beneficial to other health disparate populations,

especially to patients with complex health care needs. Research is needed to explore the impact of PCMH on health outcomes in other vulnerable populations.

These findings suggest that health care financing and patient-centered models of care may reduce health disparities in children with DD. Although better access to high quality health care would likely improve health outcomes for children with DD, broader social factors must be addressed in order to significantly reduce health disparities. Risk factors at the child, family, community, and policy level contribute to systematic differences in child health (Gehlert et al. 2008; Larson et al. 2008; Marmot 2005). People with disabilities, like other disadvantaged groups, may be exposed to numerous conditions (e.g., prejudice and discrimination, poor housing conditions, nutrient-poor diets, economic insecurity, exclusion from the labor market) experienced less often by more advantaged groups (Emerson et al. 2011). Each of these social determinants of health must be addressed. Clinicians may improve child health outcomes by routinely assessing social risk factors and arranging comprehensive community-based interventions when needed. In addition to programs, social and economic policies can improve child health outcomes through providing adequate family income, adequate time for parenting and generous supportive services (Larson et al. 2008). Policies that provide children with disabilities access to appropriate levels and combinations of resources are required for them to have an equal chance of enjoying good health (Emerson et al. 2009).

This study has limitations. It excluded children whose parents were not fluent in English or Spanish who did not have an available proxy. Furthermore, the 2015 OMAS had a slightly greater response rate among suburban counties (Ohio Colleges of Medicine Government Resource Center and RTI International 2015a). Although careful weighting was completed, response bias, social desirability bias, and inconsistencies related to self-reported data may have occurred. As a result of these limitations, our DD study group may not be fully representative of the true population of children with DD in Ohio. Additionally, we did not perform regression analyses or further stratify analyses to tease out complex relationships among study variables. We felt that analyses that stratified beyond insurance type or CC-PCMH were not supported by the sample size due to the small size of the DD population.

Despite these limitations, this study contributes quantitative data on health disparities of a large representative sample of children with DD. The existing evidence base is quite limited and largely qualitative in nature. Our results are validated by the strength of the 2015 OMAS, which had a substantial sample size and produces population-level estimates.

## 6 Conclusions

Children with DD are largely underrepresented in healthcare literature and experience statistically significant and meaningful healthcare disparities. Our findings support the promotion of the PCMH model and Medicaid expansion for children with DD in Ohio. Research is needed to evaluate the impact of policies and practices on the health and healthcare of children with disabilities and on other vulnerable groups. These findings

can inform the creation of effective health strategies and policies to promote health equity.

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#### Compliance with Ethical Standards

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