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Geographic Disparities in Availability of General and Specialized Pediatricians in the US and Prevalence of Childhood Neurodevelopmental Disorders

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Abstract

General pediatricians and those specialized in developmental-behavioral and neurodevelopmental disabilities support children with neurodevelopmental disorders, such as autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD). We identified substantial geographic disparities in pediatrician availability (eg, urban > rural areas), as well as regions with low pediatrician access but high ASD/ADHD prevalence estimates (eg, the US Southeast).

Keywords

autism spectrum disorder; attention-deficit/hyperactivity disorder; geographic information system; pediatricians; health care disparities

Autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) are both neurodevelopmental disorders (1) with ASD characterized by social communication and interaction challenges, as well as restricted repetitive behaviors, and with ADHD defined by persistent inattention and/or hyperactivity and impulsivity that interferes with

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functioning across several settings (eg, home, school, work). Both ASD and ADHD emerge early in development and thus represent two diagnoses in which health providers (eg, pediatricians) can make a substantial impact on developmental trajectories and outcomes through early identification and access to intervention (2-8). Moreover, both disorders are not uncommon. In the United States (US), nationally, ASD impacts 2.8% of 8-year-olds (9), while ADHD impacts 8.7% of children ages 3-17 (10). However, these rates vary geographically. At a state level, ASD prevalence ranges from 2.3% in Maryland to 4.5% in California (9). At the county level, rates vary even more dramatically, with small-area estimation (SAE) showing counties ranging from <1.0% to 24.3% for ASD (11). For ADHD, at a state level, prevalence estimates range from 5.6% in California to 15.7% in Louisiana (12) but range from <1.0% to 39.7% at the county level when using SAE (13).

Combined, their prevalence estimates and the key roles of identification and intervention mark ADHD and ASD as two disorders for which understanding service availability early in development is critical. Pediatricians are one crucial aspect of the supports available for families. For ASD, general pediatricians (GP)[1] monitor children's development (eg, via developmental screeners (6,14,15)) and refer families to specialized providers if they are concerned, with regular autism screenings recommended at 18 and 24 months (16-18). GPs also monitor parental concerns and consider additional risk factors, such as having an older autistic[2] sibling (18). For ADHD, GPs tend to utilize parent- and teacher-reported behavior rating scales to help determine if a child meets criteria for ADHD, as well as weigh information regarding relevant historical factors, and then support treatment management via prescribed medication and/or recommending behavioral therapies and/or educational interventions (20-23). For both ASD and ADHD, given GPs role in monitoring development, GPs often act as a "frontline" for accessing services and are thus important to consider when understanding patterns in the identification of neurodevelopmental disorders.

Specialized pediatricians with training specific to ASD and ADHD include developmental-behavioral pediatricians (DBPs) and neurodevelopmental disabilities pediatricians (NDDPs). While they may use similar screening tools as GPs, these specialized pediatricians receive targeted training in: 1) developmental processes in infancy through young adulthood; 2) biopsychosocial influences on emotional, social, motor, language, and cognitive development; 3) identification and treatment of behavioral and developmental disorders; and 4) integrated diagnoses of children with neurodevelopmental disabilities (24,25). Thus, DBPs and NDDPs are equipped to identify, diagnose, and treat children with ASD and/or ADHD (25-27).

It is essential to know if the medical specialists who can diagnose and serve children with neurodevelopmental disorders are geographically accessible to those children and their families. Geographic and demographic disparities in the prevalence of ASD and ADHD are clear (eg, 9,11,13,28,29); however, data gaps exist in how prevalence estimates relate to provider access. It is crucial to identify which communities require additional support

[1]Note, the American Board of Pediatrics (ABP) uses the acronym "GP" to refer to general pediatricians and not to general practitioners.

[2]Both identity-first and person-first language will be used to reflect the range of preferences in the ASD community (19).

to minimize disparities in care. Therefore, this brief report aimed to identify pediatrician availability per 100,000 children per county: 1) in totality, by US Census division, and by rurality, as well as 2) by county-level ASD and ADHD prevalence estimates.

Methods

Choropleth univariate (Figure 1A, Supplemental Figure 1) and bivariate maps (Figure 1B, 1C, Supplemental Figures 2 and 3) were made using Esri's ArcGIS Pro 2.9.1 (30) with natural breaks (Jenks) classification. The Jenks optimization approach is a process that creates thresholds which groups more similar counties together and maximizes differences between counties. It is very widely used in choropleth mapping, and it has been used to understand prevalence estimates in ADHD previously (13). Because natural breaks rely on underlying data, thresholds cannot be compared between maps that illustrate different disorders (eg, the ASD versus ADHD maps in this brief report). Rather, comparisons between the ADHD and ASD categories (ie, the same colors on the maps; eg, low provider access versus high disorder prevalence, Box 3) for each county are more informative. Descriptive analyses were performed using R 4.0.5 (31; Table I). We extracted the number of certified GPs, DBPs, and NDDPs from the American Board of Pediatrics (ABP) to determine pediatrician availability. Data sources for the ABP include the ABP Certification Management System (September 2021), the American Community Survey 5-Year Estimates (2019), and the American Board of Medical Specialties (April 2021). ABP reports the number of pediatricians per 100,000 children per county. County rurality status was then determined based on the 2013 Rural-Urban Continuum Codes (RUCC), in which RUCC codes 1-3 were considered urban and RUCC codes 4-9 were considered rural (32). Pediatrician availability was also examined at the US Census division (eg, New England, Pacific).

ASD and ADHD county prevalence estimates (ie, percentages) were obtained using model based small-area estimation (SAE) with poststratification from the 2016-2018 National Survey of Children's Health (33) using child-level and area-level predictors (11,13), including sex, race/ethnicity, highest parental education level, survey year, US Census division, the proportion of school funding provided by local government, and percentage of households speaking limited English. All county-level information was linked via Federal Information Processing Standard (FIPS) codes.

For the choropleth maps and descriptives, per 100,000 children, counties with a specific number of pediatricians (ie, 0, 0.01-1, 1.01-2, 2.01-3, and 3+ specialized pediatricians; 0, 0.01-50, 50.01-100, 100.01-150, and 150+ general pediatricians) were examined in totality, by US Census division, and by rurality. ABP provided pediatrician counts per county for 3,220 counties, from which 78 counties in Puerto Rico were excluded, leaving 3,142 counties to analyze. For rurality and US Census division, 3,140 counties were analyzed, as two counties (Oglala Lakota County, SD; Kusilvak Census Area, AK) were renamed and had their county FIPS codes changed in 2015, which was after the 2013 Rural-Urban Continuum Codes were published (34). In addition to counts of pediatricians, percentages of counties with a given number of pediatricians (eg, 0, 0.01-1, 1.01-2, 2.01-3, and 3+ specialized pediatricians) per 100,000 children were also calculated. For the bivariate

choropleth maps, ASD and ADHD prevalence estimates (ie, percentages) were contrasted against the number of pediatricians per 100,000 children.

Results

Per 100,000 children, the number of specialized and general pediatricians varied considerably across counties (Table I; Figure 1A, Supplemental Figure 1). For simplicity, written results will summarize the availability of combined specialized pediatricians (ie, DBP+NDDPs), but see Table I and Supplemental Figure 1 for results specific to DBPs and NDDPs. Per 100,000 children, across the US, 90.8% of counties had 0 DBP+NDDPs and 44.9% of counties had 0 GPs. In contrast, per 100,000 children, 4.4% of counties had 3+ DBP+NDDPs and 2.5% of counties had 150+ GPs. As expected, urban counties tended to have more pediatricians than rural counties. Per 100,000 children, urban counties had 0-107.0 ($\bar{x}$ = 1.0) DBP+NDDPs and 0-952.4 ($\bar{x}$ = 53.6) GPs, while rural counties had 0-97.3 ($\bar{x}$ = 0.3) DBP+NDDPs and 0-389.9 ($\bar{x}$ = 17.9) GPs.

Similar discrepancies arose when examining pediatrician availability by US Census division. Per 100,000 children, the New England division had the *fewest* counties with 0 DBP+NDDPs (59.7%) and 0 GPs (3.0%); conversely, the West North Central division had the *most* counties with 0 DBP+NDDPs (97.2%) and 0 GPs (69.5%). Per 100,000 children, the New England division also had the *most* counties with 3+ DBP+NDDPs (31.3%) and 150+ GPs (14.9%); the West North Central division then had the *fewest* counties with 3+ DBP+NDDPs (1.6%) and the West South Central division had the *fewest* counties with 150+ GPs (0.4%). Interestingly, per 100,000 children, individual counties in the South Atlantic, not the New England, division had counties with the most DBP+NDDPs: Radford City, VA (107); Kent County, MD (97); and Dickenson County, VA (69). Per 100,000 children, counties with the most GPs were dispersed across the Mountain, Middle Atlantic, and West North Central divisions: Golden Valley County, MT (952); Montour County, PA (595); and Adams County, ND (390).

Regarding ADHD and ASD, there appeared to be pockets of need throughout the US, in which diagnostic prevalence estimates were high and GP availability was low, illustrated in the brightest red in the bivariate maps (ie, a mismatch between need and availability; Figures 1B, 1C; Box 3). For ADHD, there was a particular mismatch between need and availability in the Southeast (eg, Arkansas, Louisiana, Missouri, Texas). For ASD, this mismatch was not as severe in the Southeast; instead, some counties in more Western states (eg, Arizona, Colorado) appeared to have a clear mismatch between need and GP availability. Notably, for both ASD and ADHD, there was not a distinct area in which need and availability were high (ie, a *match* between need and availability; Figures 1B, 1C; Box 9). However, in the New England division, there were more counties where both need and availability were moderate (Figures 1B, 1C; Box 5). For specialized pediatricians, this pattern of a mismatch between need and availability held for both ADHD (in Southeastern states) and ASD (in Western states) as well (Supplemental Figures 2-3; Boxes 3). However, for specialized pediatricians, there were not distinct areas in which need and availability were moderately or highly aligned for ADHD or ASD (Supplemental Figures 2-3; Boxes 5 and 9).

Discussion

This analysis demonstrates the vast geographic disparities in the US regarding general and specialized pediatrician availability in relation to need. There is a stark lack of GPs in the Midwest and Southeast (in particular, the West North Central and West South Central US Census divisions), as well as a much higher concentration of pediatricians on the East and West coasts, particularly in the New England division and in urban counties. These general disparities mirror those of specialized pediatricians, in which higher rates of specialized pediatricians can be found in the New England division and in urban counties. However, throughout the country, extremely sparse pockets of higher specialized pediatrician availability (Supplemental Figure 1) are often surrounded by counties with no specialized pediatrician availability, which indicate that individuals may not even be able to obtain the care they need in bordering counties. Beyond geographic disparities, these findings also highlight a substantial lack of service availability, in which many counties have 0 specialized pediatricians (up to 96.4%) and 0 GPs (44.9%). Moreover, particularly for ADHD but also for ASD, the Southeast is characterized by a mismatch between need (ie, higher prevalence) and access (ie, lower pediatrician availability) for both specialized pediatricians and GPs. Given the frontline role GPs play in monitoring for neurodevelopmental disorders, this mismatch is non-trivial. In contrast, need and availability were better matched in New England for ASD and ADHD for GPs but not for specialized pediatricians. Note that a county may show a high prevalence of ASD/ADHD despite its low number of pediatricians, as pediatricians may collaborate with other clinicians and providers (eg, school psychologists) to establish diagnoses or families may travel outside of their county to receive a diagnosis.

This general trend towards a lack of accessible pediatric care outside of the East and West coasts, particularly in the East South Central and West North Central divisions, suggests that many families and children (not just those with neurodevelopmental disorders) in these areas may not be getting the care they need. Simultaneously, the discrepancy between ASD/ADHD prevalence rates and pediatrician availability signals that providers are not located in areas with high need. For ASD, routine screening by GPs is recommended at 18 and 24 months by the American Academy of Pediatrics (18), and for ADHD, in recent years, the majority of children are diagnosed by a pediatrician (23). Therefore, across these neurodevelopmental disorders, in counties with few pediatricians and with care and access discrepancies, it may be much more difficult to obtain 1) routine screenings and diagnoses from GPs, 2) more comprehensive evaluations and diagnoses from specialized pediatricians, and 3) treatment support. Diagnoses are often a prerequisite for insurance to cover treatment and therapies, so this is not a trivial barrier, potentially compounding pre-existing socioeconomic barriers to care (35-38). Given the critical role of identification and intervention for neurodevelopmental disorders, these geographical disparities may hinder positive developmental outcomes and quality of life and may be contributing to additional familial stressors (39-41).

To direct specialized pediatricians to communities in need of care, it is first important to consider why specialized pediatricians are absent from those communities. The majority of specialized pediatricians work in hospital settings (42,43), which are

generally located in urban communities. Given this, is it possible that urban areas yield more job opportunities, incentivizing specialized pediatricians to remain in urban communities. Programs specifically encouraging specialized pediatricians to work in rural and underserved communities, such as the loan repayment programs typically developed for primary care physicians (44), could shift this incentive to rural communities or those with currently no-to-low specialized pediatricians. Moreover, a recent study highlighted substantial burnout and strain in DBPs, with close to 1/3 of DBPs surveyed reporting plans to retire in the next 3-5 years (45). Coupled with the dearth of specialized pediatricians in many counties generally, as well as the misalignment between high prevalence rates of ASD/ADHD and low specialized pediatrician access in regions like the Southeast, this clearly calls for more specialized pediatricians. However, it is not reasonable to expect all pediatricians to embark on the extensive training required to become a DBP or an NDDP. Roberts and colleagues recently developed a successful “mini” DBP fellowship program (6 hours/week for 1 year) for primary care physicians to expedite and increase access to developmental evaluations (46). A similar model could be enacted to distribute specialized neurodevelopmental knowledge from DBPs and NDDPs to GPs or even family physicians in areas of need, such as in the Southeast or rural communities; to facilitate this, federal or state agencies could even incentivize providers in regions of no-to-low specialized pediatricians to develop these fellowship programs. However, care would need to be taken to not overburden GPs or family physicians. To balance the need to distribute neurodevelopmental knowledge with GP/family physician work capacities, future studies could identify the most critical aspects of such “mini” fellowship programs before implementation. Moreover, family physicians are providers who serve the full lifespan across all health conditions, help patients navigate the health system labyrinth, and provide critical care in rural and underserved communities (47-50), so they may be a helpful service avenue. Enhancing GPs’ and family physicians’ knowledge of neurodevelopmental disorders, or leveraging family physicians more in the developmental screening process (51-53), could help increase access to neurodevelopmental-specific care across the US

Three important limitations of this brief report are worth noting. First, low-child population areas may cause certain counties to appear as though they have more pediatricians than higher-population areas. For instance, Goldman Valley County, MT has the most (952) GPs per 100,000 children; however, that county only has 1 GP for the county’s 105 children. While this limitation exists for all work considering population-level data, it is essential to recall that high rates of pediatricians do not necessarily equate to high counts of pediatricians; nonetheless, high rates still speak to increased access to care, as these pediatricians proportionally have fewer children to care for. Second, these analyses do not consider children with co-occurring disorders (eg, ASD-only vs. ASD+Down syndrome). Third, while these three types of pediatricians (GPs, DBPs, and NDDPs) all support children and families with ASD and ADHD, they are not the only service providers qualified to support these populations. These maps and analyses do not consider family physicians, who often provide critical care to more rural communities, nor do they consider other integral providers, such as child/adolescent psychiatrists, neurologists, clinical/school psychologists, occupational and physical therapists, speech-language pathologists, behavioral therapists, and special education teachers. Likewise, these analyses do not incorporate the growing

neurodevelopmental telehealth solutions that aim to expand access to services to more rural or underserved communities (54-56). While these findings highlight distinct geographical disparities in access to *specific aspects* of pediatric care, they do not necessarily speak to disparities in all types of care. Additional work looking at other critical providers and treatment modalities (eg, telehealth versus in-person) is a crucial next step to a more complete understanding of the care landscape in neurodevelopmental disorders, especially as telehealth practices become more common (57).

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Availability Statement:

Data from this study will be made available upon reasonable request to the corresponding author.

Abbreviations:

ADHD	attention-deficit/hyperactivity disorder
ABP	American Board of Pediatrics
ASD	autism spectrum disorder
DBP	developmental-behavioral pediatrician
FIPS	Federal Information Processing Standard
GP	general pediatrician
NDDP	neurodevelopmental disabilities pediatrician
RUCC	Rural-Urban Continuum Codes
SAE	small-area estimation
US	United States

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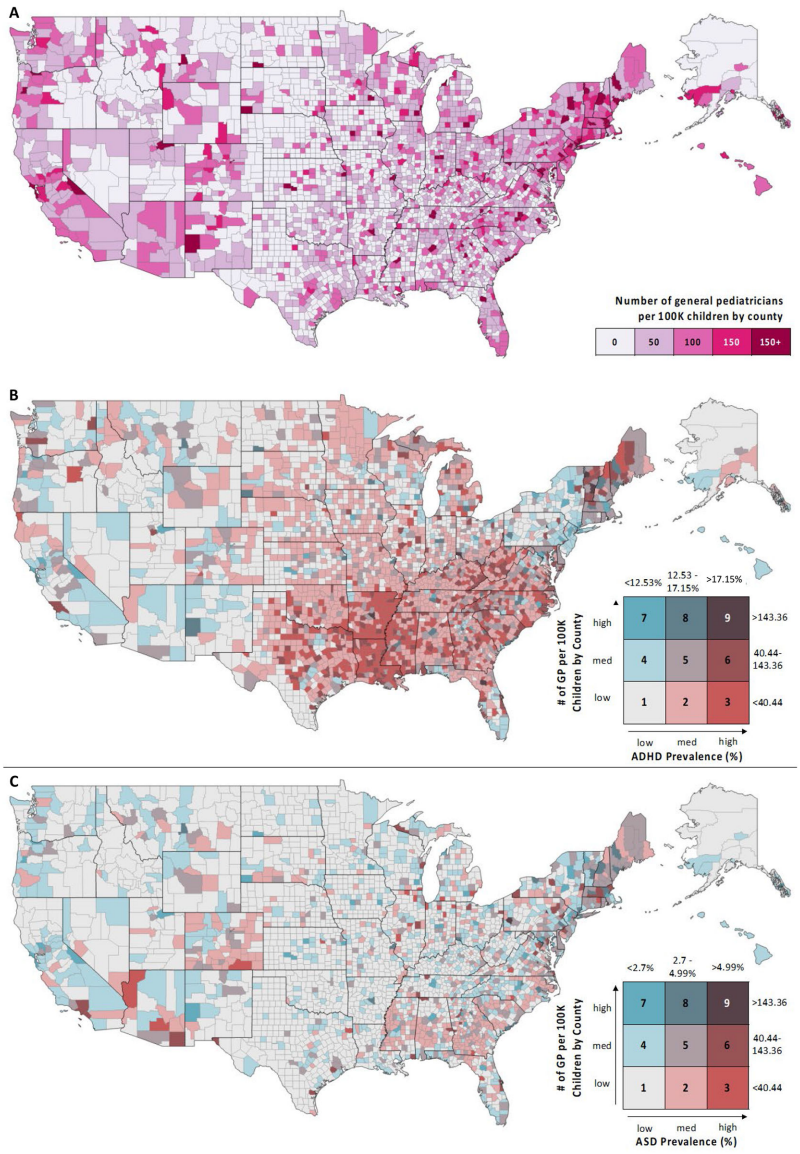

Figure 1: General Pediatrician Availability, ASD prevalence, and ADHD prevalence per 100K Children per County

A. Univariate map showing counties with 0, 50, 100, 150, or 150+ general pediatricians per 100,000 children.

B. Bivariate map of general pediatrician availability and ADHD prevalence per 100K children by county. Pediatrician availability and ADHD prevalence were classified into three groups (low, medium, and high) based on the natural breaks (Jenks) method and then combined to form a bivariate map consisting of nine categories: 1) low prevalence/low availability; 2) medium prevalence/low availability; 3) high prevalence/low availability; 4) low prevalence/medium availability; 5) medium prevalence/medium availability; 6) high prevalence/medium availability; 7) low prevalence/high availability; 8) medium prevalence/ high availability; 9) high prevalence/high availability. Low ADHD prevalence was <12.53%, medium prevalence was 12.53-17.15%, and high prevalence was >17.15%.

C. Bivariate map of general pediatrician availability and ASD prevalence per 100K children by county. Pediatrician availability and ASD prevalence were classified into three groups (low, medium, and high) based on the natural breaks (Jenks) method and then combined to form a bivariate map consisting of nine categories: 1) low prevalence/low availability; 2) medium prevalence/low availability; 3) high prevalence/low availability; 4) low prevalence/ medium availability; 5) medium prevalence/medium availability; 6) high prevalence/medium availability; 7) low prevalence/high availability; 8) medium prevalence/high availability; 9) high prevalence/high availability. Low ASD prevalence was <2.7%, medium prevalence was 2.7-4.99%, and high prevalence was >4.99%.

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Table 1

Counties with Specific Types of Pediatricians per 100,000 Children per County by Rurality and U.S. Census Division

	0 Pediatricians		0.01-1 Pediatricians		1.01-2 Pediatricians		2.01-3 Pediatricians		>3 Pediatricians	
Specialized Pediatricians	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**
DBP										
Total[a]	2883	91.76	41	1.30	72	2.29	45	1.43	101	3.21
Urban[b]	917	78.64	41	3.52	72	6.17	45	3.86	91	7.80
Rural[c]	1964	99.49	0	0.00	0	0.00	0	0.00	10	0.51
New England[d]	40	59.70	1	1.49	3	4.48	2	2.99	21	31.34
Middle Atlantic[e]	113	75.33	6	4.00	9	6.00	6	4.00	16	10.67
East North Central[f]	405	92.68	3	0.69	8	1.83	9	2.06	12	2.75
West North Central[g]	601	97.41	1	0.16	3	0.49	5	0.81	7	1.13
South Atlantic[h]	526	89.46	13	2.21	15	2.55	12	2.04	22	3.74
East South Central[i]	349	95.88	1	0.27	5	1.37	3	0.82	6	1.65
West South Central[j]	443	94.26	7	1.49	12	2.55	2	0.43	6	1.28
Mountain[k]	267	95.02	5	1.78	6	2.14	0	0.00	3	1.07
Pacific[l]	137	82.53	4	2.41	11	6.63	6	3.61	8	4.82
NDDP										
Total[a]	3027	96.34	41	1.30	25	0.80	17	0.54	32	1.02
Urban[b]	1063	91.17	41	3.52	25	2.14	17	1.46	20	1.72
Rural[c]	1962	99.39	0	0.00	0	0.00	0	0.00	12	0.61
New England[d]	56	83.58	4	5.97	3	4.48	0	0.00	4	5.97
Middle Atlantic[e]	123	82.00	5	3.33	9	6.00	7	4.67	6	4.00
East North Central[f]	423	96.80	6	1.37	4	0.92	2	0.46	2	0.46
West North Central[g]	610	98.87	3	0.49	2	0.32	0	0.00	2	0.32
South Atlantic[h]	562	95.58	7	1.19	2	0.34	5	0.85	12	2.04
East South Central[i]	360	98.90	1	0.27	2	0.55	0	0.00	1	0.27

West South Central[j]	462	98.30	6	1.28	2	0.43	0	0.00	0	0.00
Mountain[k]	273	97.15	1	0.36	0	0.00	3	1.07	4	1.42
Pacific[l]	156	93.98	8	4.82	1	0.60	0	0.00	1	0.60
DBP+NDDP										
Total[a]	2854	90.83	40	1.27	64	2.04	47	1.50	137	4.36
Urban[b]	898	77.02	40	3.43	64	5.49	47	4.03	117	10.03
Rural[c]	1954	98.99	0	0.00	0	0.00	0	0.00	20	1.01
New England[d]	40	59.70	1	1.49	3	4.48	2	2.99	21	31.34
Middle Atlantic[e]	110	73.33	5	3.33	4	2.67	5	3.33	26	17.33
East North Central[f]	401	91.76	3	0.69	6	1.37	11	2.52	16	3.66
West North Central[g]	600	97.24	1	0.16	2	0.32	4	0.65	10	1.62
South Atlantic[h]	513	87.24	11	1.87	16	2.72	15	2.55	33	5.61
East South Central[i]	349	95.88	0	0.00	5	1.37	3	0.82	7	1.92
West South Central[j]	441	93.83	9	1.91	11	2.34	1	0.21	8	1.70
Mountain[k]	262	93.24	5	1.78	6	2.14	1	0.36	7	2.49
Pacific[l]	136	81.93	5	3.01	11	6.63	5	3.01	9	5.42

	0 Pediatricians		**0.01-50 Pediatricians**		**50.01-100 Pediatricians**		**100.01-150 Pediatricians**		**>150 Pediatricians**	
General Pediatricians	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Total[a]	1411	44.91	1015	32.30	502	15.98	135	4.30	79	2.51
Urban[b]	247	21.18	431	36.96	323	27.70	102	8.75	63	5.40
Rural[c]	1163	58.92	583	21.83	179	16.36	33	5.17	16	0.81
New England[d]	2	2.99	14	20.90	25	37.31	16	23.88	10	14.93
Middle Atlantic[e]	10	6.67	68	45.33	42	28.00	21	14.00	9	6.00
East North Central[f]	144	32.95	199	45.54	69	15.79	18	4.12	7	1.60
West North Central[g]	429	69.53	110	17.83	59	9.56	9	1.46	10	1.62
South Atlantic[h]	192	32.65	214	36.39	124	21.09	33	5.61	25	4.25
East South Central[i]	176	48.35	122	33.52	52	14.29	9	2.47	5	1.37

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West South Central[j]	261	55.53	153	32.55	48	10.21	6	1.28	2	0.43
Mountain[k]	147	52.31	80	28.47	39	13.88	11	3.91	4	1.42
Pacific[l]	49	29.52	54	32.53	44	26.51	12	7.23	7	4.22

Notes. DBP = Developmental-Behavioral Pediatrician; NDDP = Neurodevelopmental Disabilities Pediatrician

[a] out of 3142 counties

[b] out of 1166 urban counties

[c] out of 1974 rural counties

[d] out of 67 New England counties (CT, ME, MA, NH, RI, VT)

[e] out of 150 Middle Atlantic counties (NJ, NY, PA)

[f] out of 437 East North Central counties (IN, IL, MI, OH, WI)

[g] out of 617 West North Central counties (IA, KS, MN, MO, NE, ND, SD)

[h] out of 588 South Atlantic counties (DE, DC, FL, GA, MD, NC, SC, VA, WV)

[i] out of 364 East South Central counties (AL, KY, MS, TN)

[j] out of 470 West South Central counties (AR, LA, OK, TX)

[k] out of 281 Mountain counties (AZ, CO, ID, NM, MT, UT, NV, WY)

[l] out of 166 Pacific counties (AK, CA, HI, OR, WA)