Geospatial Analyses of Accessibility to Down Syndrome Specialty Care

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Objective To assess whether the location of 71 Down syndrome specialty care clinics in the US make them inaccessible to a considerable portion of the American population.

Study design Using a population-based representative sample of 64 761 individuals with Down syndrome and a Google Maps Application Programming Interface Python program, we calculated the distance each patient with Down syndrome would need to travel to reach the nearest clinic. Two conceptualizations were used—the state fluidity method, which allowed an individual to cross state lines for care and the state boundary method, which required individuals receive care in their state of residence.

Results Almost 1 in 5 US individuals face significant geographic obstacles to receiving specialty care. This finding is especially prominent in the South, where >33% of patients with Down syndrome must travel >2 hours to reach their nearest clinic.

Conclusions Down syndrome specialty care clinics are inaccessible to a considerable portion of American society. Innovative usage of technology might be useful to minimize these disparities in healthcare accessibility. *(J Pediatr 2019; ■:1-5)*.

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Down syndrome is the most common chromosomal disorder with approximately 5000 babies born annually with the condition,[1] and an estimated 210 000 individuals with Down syndrome living in the US in 2010.[2,3]

The American Academy of Pediatrics provides comprehensive guidelines regarding the prevention and treatment of medical conditions co-occurring with Down syndrome.[4] However, Eaves et al found that only 50% of parents are aware of Down syndrome-specific guidelines and, among this subset, 55% believed the primary care physician was responsible to ensure compliance.[5] This is often not the case.[6] Before attending the Down syndrome specialty care clinic at Boston Children's Hospital, only 9.8% of patients were completely up to date on screenings recommended to be conducted by their primary care physicians.[7] A Down syndrome specialty clinic can address many healthcare needs beyond those that are provided in primary care settings.

The need for multidisciplinary teams to improve outcomes in chronic conditions is well-documented.[8] In Down syndrome specialty care clinics, multidisciplinary care teams collaborate to work with individual patients on a comprehensive care plan. Economies of scale increase efficacy of care: although primary care physicians might only see 1 child with Down syndrome in a 37-year period, these multidisciplinary care teams specializing in Down syndrome may see several hundred patients in a single year.[5,9] The team of specialists seeing a patient with Down syndrome might include a physician, dietitian, speech therapist, and a social worker.[10] Referrals to other specialties are frequently arranged.[11]

Currently, there are 71 Down syndrome clinics in 34 states within the continental US listed on the web sites of 2 national Down syndrome nonprofit organizations (**Figure**; available at www.jpeds.com).[9,12] The locations of Down syndrome specialty care clinics are concentrated in metropolitan areas, which might significantly increase travel time for some patients with Down syndrome to receive specialized care.[13] An increase in distance between patients and medical providers has been shown to be an obstacle in the use of healthcare services.[9] Most specialty physician visits are made to the facilities nearest to a patient's residence, and the frequency of visits tend to decrease when facilities are farther away.[13] The objective of this research was to quantify the distance individuals must travel to attend their nearest Down syndrome specialty care clinic. We created a model to answer this central

API Application Programming Interface

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question: What percentage of individuals with Down syndrome has access to attend a Down syndrome specialty clinic in the US?

Methods

Population data were obtained from the 2015 US Census Bureau estimates.[14] To reflect accurately the distribution of people throughout the US, a sample population of 500 cities was selected from the census data. The sample consisted of the 5 largest cities from every continental state as well as the next most populous 260 cities, thereby incorporating both national- and state-level population dynamics. This approach primarily represents individuals in urban areas and, thus, may overestimate access given the number of rural communities omitted. To convert this raw population sample into a sample of individuals with Down syndrome, a population proportionality factor dependent on geographic location was used. The prevalence of individuals with Down syndrome has been estimated by De Graaf et al for states with available data.[2,3] These prevalence rates were averaged regionally (regional divisions given in Table I) to produce a population proportionality factor for each of the 4 geographic census regions in the US. The raw population of each of the 500 cities was multiplied by the population proportionality factor corresponding to its respective geographical region, resulting in the sample of individuals with Down syndrome used herein. Finally, each city was precisely geolocated at the latitude and longitude provided by Google Maps (Google LLC, Mountain View, California).[15]

There is no centralized database of Down syndrome specialty care clinics in the US, but current locations were extracted from the Global Down Syndrome Foundation and the National Down Syndrome Society web sites.[9,12] In total, these sites list 71 Down syndrome specialty care clinics in the US, spanning 34 states. Each clinic was precisely geolocated at the latitude and longitude provided by Google Maps.[15]

Google Maps Interface

To quantify accessibility using location analyses, we assumed that each Down syndrome specialty clinic has unlimited capacity and that each individual with Down syndrome would attend the nearest Down syndrome specialty clinic that is within a 2-hour drive of his or her home.

Google Maps Application Programming Interfaces (APIs) allow for batch requests to Google Maps' data. We used Google Maps distance matrix API to determine the distances between an individual and a set of Down syndrome specialty care clinics. The Google Maps distance matrix API returns 2 possible indicators: distance (meters) and time (seconds). We used the driving time between an individual and their nearest clinic for the primary analyses.

Using Python (Python Software Foundation, Wilmington, Delaware) to script the Google Maps API, we calculated the distances each individual must travel to reach his or her nearest Down syndrome specialty care clinic. Under this formulation, several population centers can be assigned to a single clinic, potentially exceeding that clinic's capacity. Investigating clinic capacities, however, was outside the scope of our research.

State Fluidity and State Boundary

Although nearly impossible to account for willingness to attend clinics, we approximated the ambiguity by assuming standardized metrics. The first metric assumed that individuals attend their nearest clinic, regardless of location. As such, individuals may travel across state lines to reach their nearest clinic. We refer to this as "state fluidity."

Similarly, we used a "state boundary" metric. This formulation states that an individual will attend the nearest clinic within their state. If there is not a clinic in a state, then the individual was assumed not to receive specialty care. Such a metric is useful in addressing health insurance concerns, whereby an individual may not be able to receive treatment outside his or her state of residence.

Levels of Analysis

Our data consist of 71 clinics and 500 cities in the contiguous US. This unique dataset allowed us to identify national inadequacies in Down syndrome care. The US is a large, diverse country with varying health insurances and geospatial considerations. To account for this diversity, we supplemented our country-wide analysis with regional examination.

According to the US Census, there are 4 regions in the US: Northeast, Midwest, South, and West.[16] The states comprising

Table I. Regional divisions by the US Census*

Region	States	Percentage of Down syndrome population	No. of clinics	Percentage of 71 clinics
Northeast	Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, New Jersey, New York, Pennsylvania	14.3	13	18.3
Midwest	Illinois, Indiana, Michigan, Ohio, Wisconsin, Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, South Dakota	15.1	26	36.6
South	Delaware, District of Columbia, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, West Virginia, Alabama, Kentucky, Mississippi, Tennessee, Arkansas, Louisiana, Oklahoma, Texas	33.0	20	28.2
West	Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Utah, Wyoming, California, Oregon, Washington	33.7	12	16.9

*The percentage of our sample Down syndrome population contained in the corresponding region is represented (column 3). Number of clinics per region are included (column 4) along with percentages of the clinics available nationally (column 5).

these regions are indicated in Table I. The South and West regions are large geographically, spanning from Delaware to Texas and New Mexico to Washington, respectively. The Midwest and Northeast regions are smaller, spanning from North Dakota to Ohio and Pennsylvania to Maine, respectively. Perhaps more important, the size of the region can be determined by the relative Down syndrome population. From our representative sample, the individuals were partitioned by region.

Results

A total of 64 761 individuals with Down syndrome, spanning the contiguous 48 states, constituted our sample. This total is approximately 30% of the entire Down syndrome population of 210 000.[2,3]

The city latitude and longitude coordinates were processed through the Google Maps API program. The distances returned corresponded to both the intended metric and level of analysis. The distances were aggregated into categories for quick identification and examination of accessibility. The categories, in hours (t), were: $0 \le t \le 0.5$, $0.5 \le t \le 1.0$, $1.0 < t \le 1.5$, $1.5 < t \le 2.0$, >2.0, and isolated (for state boundary metric only).

National

National access to Down syndrome specialty care clinics is varied. The results using both the state fluidity and state boundary metrics are presented in Table II. Of special interest are the first and last categories. Regardless of metric, almost 50% of individuals across the US are within 30 minutes of their nearest clinic. However, according to the state fluidity metric, exactly 25% of individuals are >90 minutes away from their nearest clinic. According to the state boundary metric, just >28% of individuals are >90 minutes away or do not have a clinic available in their state of residence.

Regional

Table I indicates the disparity between number of clinics and percent of population in a given region of the US. The resulting percentage of patients by region is shown. Notably, the West is the most populous with 33.7% of the Down syndrome population. The Northeast is the least populous, with only 14.3% of the Down syndrome population. Furthermore, Table I shows the distribution of clinics by region. The Midwest has the largest proportion of clinics, accounting for almost 37%, whereas the West has only 17%. This observation contrast with the percentages of individuals, where the West had the highest proportion and the Midwest had the second least proportion.

Table II. Travel times for our sample population to a Down syndrome specialty clinic are given*

Hours	People (fluidity, %)	People (boundary, %)
$0 \le t \le 0.5$	48.2	47.8
$0.5 < t \le 1.0$	21.6	19.4
$1.0 < t \le 1.5$	5.1	4.5
$1.5 < t \le 2.0$	6.2	4.1
$t > 2.0$	18.8	14.7
Isolated	N/A	9.5

*The fluidity metric assumes individuals can cross state lines to receive care (column 2); the boundary metric assumes this is not possible (column 3). Individuals who live in a state without a Down syndrome specialty clinic are isolated.

Table III. Percentages of Down syndrome sample who must travel the incremental times to attend a Down syndrome specialty clinic, by each Census Regional Division, based on state fluidity metric

Hours (t)	Northeast (%)	Midwest (%)	South (%)	West (%)
$0 \le t \le 0.5$	80.0	58.0	36.8	35.9
$0.5 < t \le 1.0$	14.2	16.4	16.1	33.9
$1.0 < t \le 1.5$	2.1	6.7	4.5	6.5
$1.5 < t \le 2.0$	1.8	4.6	9.2	6.8
$t > 2.0$	2.0	14.3	33.4	16.9

Table IV. Percentages of Down syndrome sample who must travel the incremental times to attend a Down syndrome specialty clinic, by each Census Regional Division, based on state boundary metric*

Hours (t)	Northeast (%)	Midwest (%)	South (%)	West (%)
$0 \le t \le 0.5$	79.4	57.5	36.7	35.5
$0.5 < t \le 1.0$	6.7	16.0	13.4	33.9
$1.0 < t \le 1.5$	2.3	4.5	3.6	6.5
$1.5 < t \le 2.0$	0.0	2.8	4.8	6.6
$t > 2.0$	2.1	14.4	28.0	9.4
Isolated	9.5	5.2	13.6	8.1

*Individuals living in a state without a Down syndrome specialty clinic are classified as isolated.

Table III indicates the regional accessibility classifications for the Northeast, Midwest, South, and West regions using the state fluidity metric, and Table IV details the regional accessibility classifications using the state boundary metric. Based on either metric, the Northeast provides the most comprehensive accessibility for those with Down syndrome. In the Northeast, according to the state fluidity metric, 80% of individuals have access to care within a 30-minute drive. In contrast, the South provides the least accessible care for those with Down syndrome. Only 36.8% of individuals are within 30 minutes of care, and 33.4% of individuals must travel >2 hours to receive care.

The use of the state boundary metric does not change accessibility concerns. The Northeast remains the most accessible region, with almost 80% within 30 minutes. However, almost 10% of individuals in the Northeast are without a clinic in their state of residence. The South remains the least accessible region. Approximately 37% of individuals are within 30 minutes. However, 28% of individuals have to travel >2 hours for care, and an additional 14% do not have a clinic in their state of residence.

Discussion

Many individuals with Down syndrome and their caregivers must travel great lengths to reach their nearest clinic. Almost

1 in 5 individuals must travel >2 hours to reach their nearest clinic, and 1 in 4 individuals either do not have a clinic in their state or are >2 hours away from their nearest clinic. Overall, ≥20% of individuals face significant geographic obstacles to receive Down syndrome specialty care.

There are considerable numbers of individuals very near or very far from Down syndrome specialty care clinics. This dichotomy in travel distance highlights the disparity in accessibility to comprehensive specialized care for individuals with Down syndrome across the US. To identify these differences, we increased the granularity of our analysis, taking into account whether or not families could travel out of state for medical care. Almost 1 in 10 individuals do not have a clinic in their state of residence. Beyond this finding, both the state fluidity and state boundary analyses provided very similar findings. Access to specialty clinics did not differ notably when assuming whether or not individuals with Down syndrome could cross state lines or not owing to insurance constraints. Therefore, we believe that the state fluidity measure, which assumes that individuals can cross state lines, is sufficient in considering access, unless specifically health insurance concerns are under investigation.

Our regional analyses revealed discrepancies in accessibility across the US. The Northeast was the most accessible region for Down syndrome specialty care clinics, and the South was the least accessible. Physician or hospital density in those regions or population size could contribute to this disparity. Further research is warranted to identify the causes of these disparities.

Our accessibility analysis is not without limitations. Individuals in our sample were clustered at city hubs. For example, all individuals with Down syndrome in New York City are entered into the Google Maps API program with the same address. Our findings do not take into account address variation within a city. This factor could impose a bias, depending on actual clinic locations. In large cities, it may take >2 hours to arrive at a Down syndrome specialty clinic after factoring in commute time across the city. However, with 500 cities, we expect these biases to be minimal. Our model considers only the 71 Down syndrome specialty clinics listed on Global Down Syndrome Foundation and the National Down Syndrome Society web sites.[9,12] In so doing, we omit clinics housed in developmental pediatrics or genetics departments that serve individuals with Down syndrome, but are not listed on these web sites. Thus, we may underestimate the network of Down syndrome specialty clinics. Our analyses also do not take into account the capacity of each individual clinic, because these data were not available. Some Down syndrome specialty clinics see only the pediatric population, whereas others provide care restricted to adults. Most of the clinics likely have limits to their capacity. Thus, our model may overestimate the number of individuals with Down syndrome able to be seen in a clinical setting. Future research should analyze the services of a Down syndrome specialty clinic and whether these clinics have sufficient capacity to fulfill the medical needs for all of the patients living within geographic proximity.

Our methodology for acquiring a representative population-based sample of Down syndrome individuals is based on prevalence rates found by De Graaf et al.[2,3] However, such advanced statistics are available only for 9 states because of the limited reporting in public databases. If such data were more widely available, our representative sample would have much greater precision. Regardless, it is evident both nationally and regionally that Down syndrome specialty care clinics are inaccessible to a considerable portion of society.

We believe that our investigation offers a unique approach to studying the healthcare of individuals with Down syndrome. This approach builds a case to leverage innovative technology to extend specialty care for this population and more generally to meet the needs of children and adults with multisystem conditions, involving neurodevelopmental, behavioral, and physical health. Other studies have found similar barriers when considering people who have had strokes[17] or veterans,[18] or when encouraging compliance with referral to specialty care.[19] Telehealth, telemedicine, and online, automated medical information portals might provide creative solutions if the establishment of additional in-person specialty clinics is challenging. ■

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Data Statement

Data sharing statement available at www.jpeds.com.

References

1. Parker SE, Mai CT, Canfield MA, Rickard R, Wang Y, Meyer RE, et al. Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. Birth Defects Res A Clin Mol Teratol 2010;88:1008-16.
2. De Graaf G, Buckley F, Skotko BG. Estimation of the number of people with Down syndrome in the United States. Genet Med 2017;19:439.
3. de Graaf G, Buckley F, Dever J, Skotko BG. Estimation of live birth and population prevalence of Down syndrome in nine US states. Am J Med Genet A 2017;173:2710-9.
4. Bull MJ. Clinical report—health supervision for children with Down syndrome. Pediatrics 2011;128:393-406.
5. Eaves L, Ho H, Laird B, Dickson S. Raising a child with Down syndrome: parents' evaluations of health information and support. Downs Syndr Res Pract 1996;4:65-9.
6. Jensen KM, Taylor LC, Davis MM. Primary care for adults with Down syndrome: adherence to preventive healthcare recommendations. J Intellect Disabil Res 2013;57:409-21.
7. Skotko BG, Davidson EJ, Weintraub GS. Contributions of a specialty clinic for children and adolescents with Down syndrome. Am J Med Genet A 2013;161:430-7.

8. Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. Health Aff 2001;20:64-78.
9. Global Down Syndrome Foundation. Down syndrome medical care centers. www.globaldownsyndrome.org/research-medical-care/medical-care-providers/. Accessed January 9, 2019.
10. Riley Hospital for Children at Indiana University Health. Down syndrome program. https://www.rileychildrens.org/departments/down-syndrome-program. Accessed January 9, 2019.
11. Children's Hospital of Wisconsin. Down syndrome: family-centered care. www.chw.org/medical-care/down-syndrome-clinic. Accessed January 9, 2019.
12. National Down Syndrome Society. Healthcare providers. www.ndss.org/resources/healthcare-providers/. Accessed January 9, 2019.
13. Weiss JE, Greenlick MR, Jones JF. Determinants of medical care utilization: the impact of spatial factors. Inquiry 1971;8:50-7.
14. US Census Bureau. Annual estimates of the resident population for incorporated places of 50,000 or more, ranked by July 1, 2015 population: April 1, 2010 to July 1; 2015. https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=PEP_2015_PEPANNRSIP.US12A&prodType=table. Accessed January 9, 2019.
15. Google. www.google.com/maps/@41.3563235,-93.5708994,15z. Accessed January 9, 2019.
16. US Census Bureau. Geographic terms and concepts–Census Divisions and Census Regions. www.census.gov/geo/reference/gtc/gtc_census_divreg.html. Accessed January 9, 2019.
17. Jewett L, Harroud A, Hill MD, Côté R, Wein T, Smith EE, et al. Secondary stroke prevention services in Canada: a cross-sectional survey and geospatial analysis of resources, capacity and geographic access. CMAJ Open 2018;6:E95.
18. Brown RA, Marshall GN, Breslau J, Farris C, Osilla KC, Pincus HA, et al. Access to behavioral health care for geographically remote service members and dependents in the US. Rand Health Q 2015;5(1):21.
19. Patel MP, Schettini P, O'Leary CP, Bosworth HB, Anderson JB, Shah KP. Closing the referral loop: an analysis of primary care referrals to specialists in a large health system. J Gen Intern Med 2018;33:715-21.

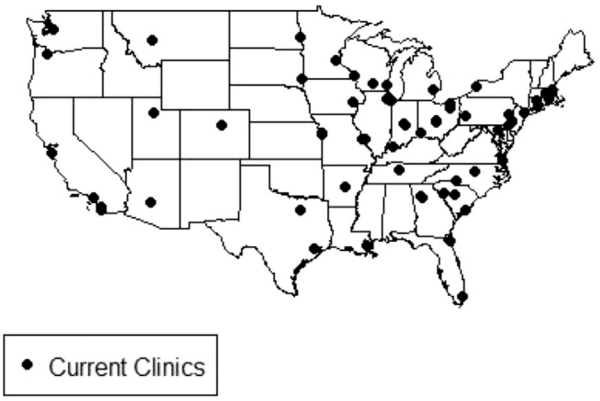

Figure. Current placement of the 71 existing Down syndrome specialty care clinics in the continental US. Clinics are located in 34 states.