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Geospatial Demand for Approved Cleft Care in the United States

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Background: Geographic information systems are powerful tools for characterizing the geospatial factors influencing access to care. As patients with cleft lip and/or palate (CL/P) require long-term care, with numerous operations and therapies, access to timely, quality care is extremely important. This study uses population level analysis and geographic information systems to identify United States counties with limited access to American Cleft Palate Association–approved cleft teams.
Methods: Natality data were queried from the National Vital Statistics System. Population and geographic data were obtained from the US Census Bureau. The Social Vulnerability Index (SVI) was utilized to account for social inequality. Total births with CL/P, population estimates, SVI, distance to the nearest center, and total centers within 50 km were used to generate the cleft care demand index (CCDI).
Results: Ninety-two counties had CCDIs between 66.7 and 100. The highest scoring county, Hidalgo County, Texas, had 62 births with CL/P, population estimate of 888,367 persons, distance to the nearest cleft center of 368.4 km, and SVI of 0.99.
Conclusions: This study demonstrates the power of geographic information systems for identifying areas with limited access to approved cleft teams. The CCDI measures cleft burden, socioeconomic disadvantage, and geographic barriers to quantify the demand for approved cleft care in each county. Utilizing these scores can help direct future interventions, outreach efforts, and cleft care center planning. *(Plast Reconstr Surg Glob Open 2024; 12:e6090; doi: 10.1097/GOX.0000000000006090; Published online 26 August 2024.)*

INTRODUCTION

Geographic information systems (GIS) are computer-based software tools used to visualize, analyze, and interpret various forms of geographically referenced data.[1,2] These data can be referenced by addresses, coordinates, zip codes, or any location that can be mapped.[3] Frequent applications of GIS include identifying locations for retail marketing, disaster relief planning, and civil engineering projects.[2] In health research, GIS enable users to characterize how the social and physical environment (geographic location) influence a person's or population's health.[4] GIS transform spatial data into useful and actionable information by allowing users to describe national disease trends, patterns of care utilization, and limitations in care access.[5–8] In this study, we demonstrate how GIS can be used to characterize disease burden and access to care for patients born with cleft lip and/or palate (CL/P).

Patients with CL/P require long-term care, often undergoing numerous operations and interventions to treat the aesthetic and functional consequences of their deformity.[9,10] To ensure that requisite care is provided to meet each patient's developmental, medical, and psychological needs, the American Cleft Palate Association (ACPA) publishes Standards for Approval of Cleft Palate and Craniofacial Teams.[11] Teams approved by the ACPA are deemed capable of providing this care after demonstrating compliance in interdisciplinary team composition and management, patient and family/caregiver communication, cultural competence, psychological and social services, and outcomes assessment.[11] Although approved cleft centers are not the only place to receive cleft care, families are urged to consider these institutions first.[11]

Unfortunately, many children born with CL/P cannot access approved teams. Previous geospatial analyses of 1-hour access to ACPA-approved cleft centers estimate that one in four children face geographic barriers to access.[12] However, access to appropriate and timely cleft care depends on a variety of factors extending beyond mere physical distance. Cleft epidemiology, race,

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financial disparities, and social history also negatively affect a patient's ability to receive care.[13–15]

A comprehensive assessment of the geographic heterogeneity of these barriers is required before definitive steps can be taken to improve access. In this study, we use GIS to visualize epidemiologic, socioeconomic, and geographic barriers to approved cleft teams in the United States. We generate a composite index from these barriers to quantify the geospatial demand for approved cleft care in each county, providing targets for future intervention and organization of cleft care.[16]

METHODS

Population and Natality Data

Population estimates and geographic areas for each county were obtained from the US Census Bureau.[17] All births between 2018 and 2022 were queried from the National Vital Statistics System (NVSS) Restricted-Use Vital Statistics Data.[18] For each US county, total births and births with and without a diagnosis of CL/P (cleft palate only or cleft lip with/without cleft palate) were summed and used to calculate cleft birth prevalence (per 10,000 births).

The Social Vulnerability Index (SVI) was used to account for the degree of social inequality in each county.[19] The SVI is a normalized score comprising 16 census variables divided into four main groups (socioeconomic status, household characteristics, racial and ethnic minority status, and housing type and transportation). Scores range from 0 (least vulnerable) to 1 (most vulnerable).[20] SVI estimates are provided for each US county on the Centers for Disease Control and Prevention (CDC)'s Agency for Toxic Substances and Disease Registry website.[21]

Geospatial Data

Approved cleft centers from the ACPA website were geocoded with the Google Maps Application Programming Interface.[22,23] Driving distances between county centroids and the nearest cleft center were calculated using the Openrouteservice Application Programming Interface.[24] Euclidean distances were used where driving distance could not be calculated. Buffer zones were generated for each county to calculate the number of approved cleft centers within a 50-km radius. An adapted shapefile from the US Census Bureau was used for all distance calculations and geographic visualizations.[25,26] All distance measurements were converted to kilometers, using American National Standards Institute conversion metrics.[27]

Cleft Care Demand Index

Total births with CL/P, population estimates, SVIs, distances to the nearest approved cleft center, and cleft centers within a 50-km radius were assigned values between 1 and 10 through quantile binning to provide homogeneity between score components. For each county (c), the values for total births with CL/P, population estimate, SVI, and distance to the nearest approved cleft center were summed to give an overall cleft demand estimate (CDE).

> **Takeaways**
>
> **Question:** How can we identify which areas of the United States have the greatest need for increased access to approved cleft care?
>
> **Findings:** Using GIS and cleft epidemiology, population analysis, and geospatial analysis, we identified 95 counties with high demand for approved cleft care access.
>
> **Meaning:** GIS can be used to identify high-demand counties for further outreach and investigation.

The CDE was then divided by the value for cleft centers within 50 km (W) to filter out counties that already have access to one or more approved care teams regardless of high cleft burden or SVI values. Final cleft care demand index (CCDI) scores were scaled between 0 and 100 to improve visualization.

$$\text{Formula}: CCDI_c = \frac{CDE_c}{W_c}$$

Geospatial Analysis

Descriptive statistics were calculated for each state, county, and the nation. Mean [95% confidence interval (CI)] was used for normally distributed continuous variables, and median [interquartile range (IQR)] was used for variables that violated normality assumptions. Categorical variables were portrayed as frequencies (%). Choropleth maps were used to visualize individual metrics and CCDI in relation to approved cleft care teams. To preserve patient privacy, only counties with 10 or more people born with CL/P were included in the tables and visualizations of county CL/P frequencies (per the NVSS data use agreement). All analyses were conducted with Python (version 3.11).

RESULTS

Between 2018 and 2022, 3139 counties registered natality data, and 1297 counties reported one or more births with CL/P. Of the 18,000,405 births, 12,827 were reported with CL/P. The birth prevalence for any cleft in the United States was 7.13 per 10,000 births. A total of 197 cleft centers were identified on the ACPA website, 185 of which were in the contiguous United States. The median distance from each county centroid to the nearest cleft center was 144.8 km (85.9-222.0).

As most cleft centers are located in highly urbanized areas and major cities, our initial analyses demonstrated a concentration of approved cleft centers near densely populated counties and less densely populated counties in the watershed zones between centers (Fig. 1).[12] The 978 counties with one or more cleft centers within 100 km had a median population of 67,751 persons (IQR 25,523–225,636) and accounted for 8996 (70.1%) births with CL/P. The remaining 2153 counties had a median population of 18,181 (IQR 8011–40,193) and accounted for 3831 (29.9%) births with CL/P.

The CCDI had a median of 23.6 (IQR: 18.0–30.3; Fig. 2). Stratification of counties by CCDI validated

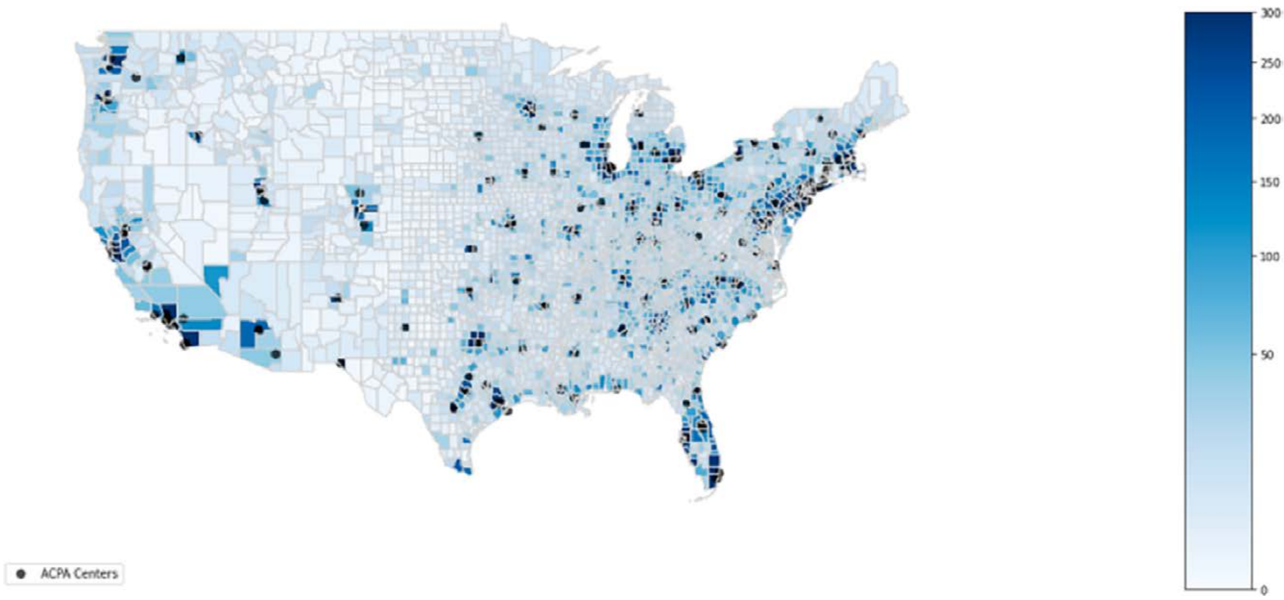

Fig. 1. A choropleth map of the population density (persons per km²) in each US county. To improve visualization, population density was capped 300 at persons per km².

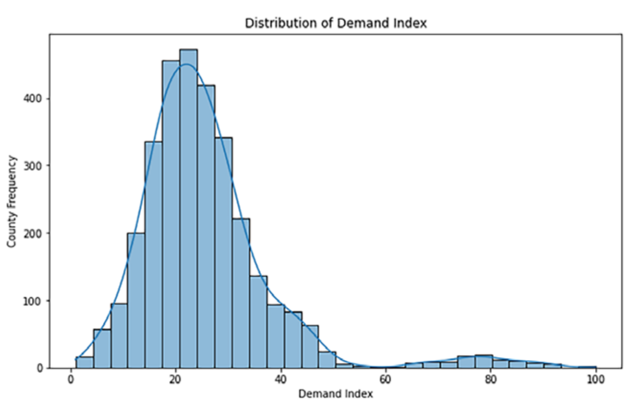

Fig. 2. Graph of the CCDI distribution for all US counties.

the performance of this score, with the highest scoring group consisting of socially disadvantaged counties with high frequencies of births with CL/P, lacking physical access to an approved cleft care team (Table 1). The highest scoring county, Hidalgo County, Texas, had 62 births with CL/P, population estimate of 888,367 persons, distance to the nearest cleft center of 368.4 km, and SVI of 0.99. Table 2 provides measures of individual score components for the 10 highest-scoring counties.

DISCUSSION

Understanding the interplay between the numerous spatial and nonspatial barriers limiting patient access is crucial to optimize care delivery.[28] Peck et al previously outlined the geographic availability of approved cleft care teams in the United States.[12] The investigators mapped a 1-hour travel radius around each of the approved centers and used estimates of CL/P to approximate the number of children without access.[12] Our study expands upon this work by providing county-level analyses of CL/P frequencies, population estimates, and socioeconomic barriers to care.

The NVSS databases are the most complete natality data repositories, collecting demographic, geographic, and medical data for more than 99% of all US births each year. Importantly, these data remain a vital source of comparable health data for small geographic communities such as the Native American and Native Alaskan populations.[29,30] Leveraging this data allowed us to quantify the number of reported cases of CL/P for each US county, identifying counties with substantially higher (or lower)

Table 1. CCDI Groups and Score Components

CCDI	No. Counties	Total Births with C/LP (n Births)	Cleft Birth Prevalence (per 10,000 Births)	Population Estimates	SVI	Distance to Nearest Cleft Center (km)
Score	n	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)
First (0–33.3)	2578	0.0 (0.0–1.0)	0.0 (0.0–4.8)	19,452 (8730–44,130)	0.44 (0.21–0.70)	140.3 (84.1–215.7)
Second (33.3–66.7)	458	5.0 (3.0–9.0)	9.5 (5.8–13.6)	88,199 (43,525–201,974)	0.71 (0.50–0.87)	161.1 (85.2–235.6)
Third (66.7–100)	172	15.0 (12.0–24.0)	10.0 (6.9–13.1)	207,842 (135,591–302,200)	0.73 (0.52–0.86)	171.0 (124.3–235.7)

Table 2. CCDIs and CDE Components for the 10 Highest Scoring Counties

County, State	CCDI	Average No. Births with CL/P Per Year	Cleft Birth Prevalence (per 10,000 Births)	Population (n Persons)	SVI	Distance to Nearest Cleft Center (km)
Hidalgo County, Texas	100.0	12.4	8.1	888,367	0.99	368.4
Clark County, Nevada	97.4	14.2	5.4	2,322,985	0.86	386.9
Bibb County, Georgia	92.9	6.2	16.2	156197	0.96	207.7
Washoe County, Nevada	91.7	6.4	11.1	496,745	0.67	311.6
Yuma County, Arizona	91.5	3.0	9.7	207,842	0.99	231.7
Cameron County, Texas	91.3	2.6	3.9	425,208	0.98	429.9
Webb County, Texas	91.2	3.8	7.8	267,780	0.98	230.9
Chatham County, Georgia	90.5	8.0	13.4	301,107	0.83	180.0
Jackson County, Oregon	90.0	3.4	14.4	221,644	0.70	395.7
Tulsa County, Oklahoma	89.4	13.4	10.5	677,358	0.78	170.7

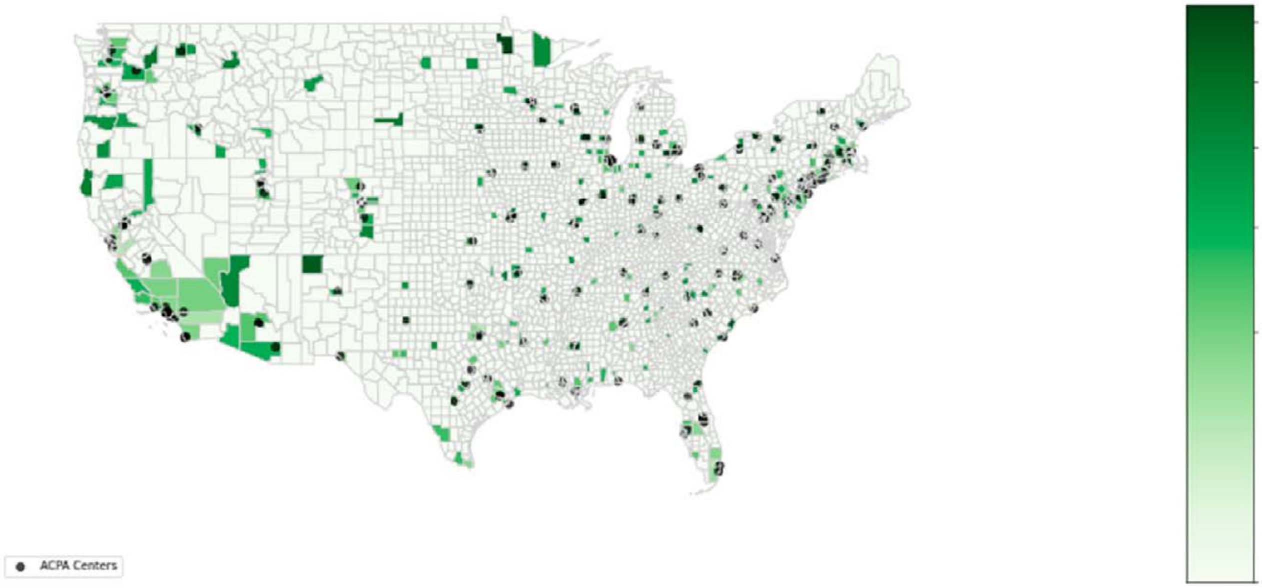

Fig. 3. A choropleth map of the birth prevalence of CL/P (per 10,000 births) in each US county. To ensure patient privacy, totals were not visualized for counties with fewer than 10 cleft births.

disease burden than what is portrayed through general estimates (Fig. 3).[31]

To ensure that the index focused on high-demand counties in the watershed areas between approved centers, we incorporated two separate distance components. Dividing by the binned value of cleft centers within 50 km shifted the focus of this analysis to the heavily burdened areas without reasonable access to one or more centers. However, due to the diversity of US geography and infrastructure, driving 50–100 km for specialty healthcare services can be common, particularly when coordinated-multidisciplinary care is required.[32] Adding driving distance as a score component awarded higher scores to counties where driving is a much less feasible option.

Social inequality also poses a significant barrier to healthcare access and contributes profoundly to discrepancies in health outcomes across the nation.[33] Patients from underserved regions often travel farther to receive cleft care and typically receive treatment at lower-volume hospitals.[13] Thus, we sought to account for the heterogeneity of sociodemographic barriers to care across the United States. Recognizing that much work has already been done to quantify these barriers, we used a previously defined score. The SVI estimates of the degree of social inequality present in each county, and low values are consistently associated with poor health outcomes (Fig. 4).[34–37] Incorporating the SVI into our demand index weighted counties where patients may be disproportionately affected by physical distance and disease burden more heavily.

The composite index, the CCDI, quantifies cleft burden, socioeconomic disadvantage, and geographic barriers to measure the demand for approved cleft care in each US county. This novel score was inspired by previous spatial accessibility models such as the two-step floating catchment area (2SFCA), and its subsequent iterations, and indices such as the Jarman score and Community Need Index.[38–40] These indices have demonstrated various applications in health policy, research, and administration to expand access to patients not covered by local supply. Their uses range from guiding the establishment telehealth satellite campuses to reorganizing the national healthcare infrastructure.[38,41–43]

As the previous indices are typically created for much smaller geographic areas, scaling the CCDI required

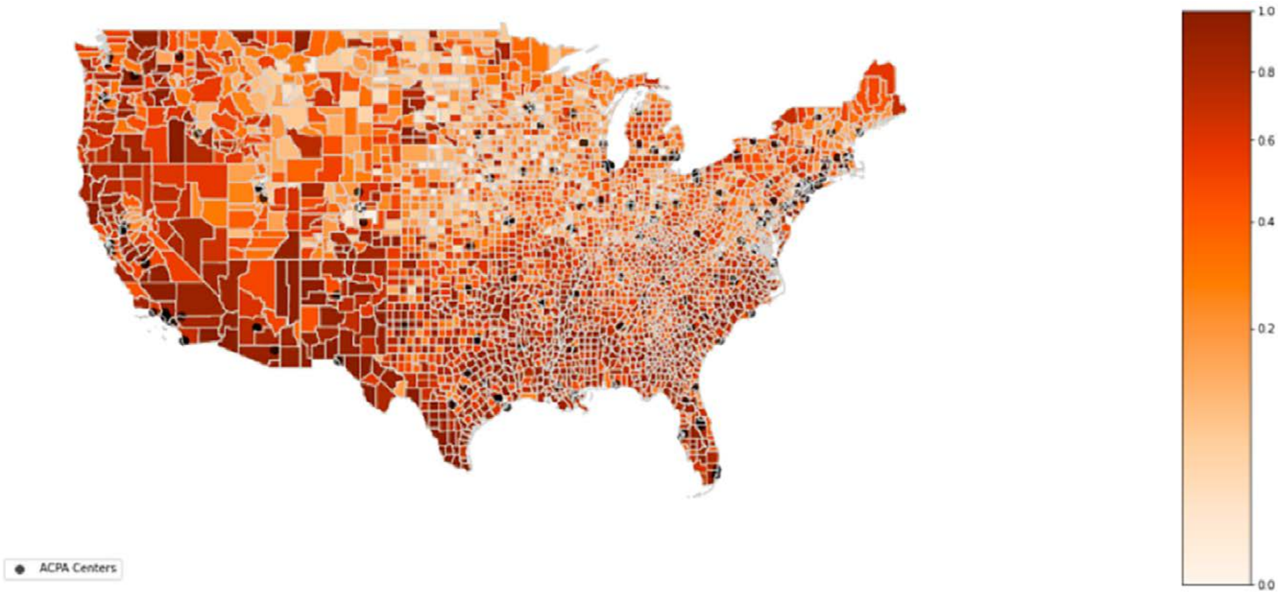

Fig. 4. A choropleth map of the SVI for each US county.

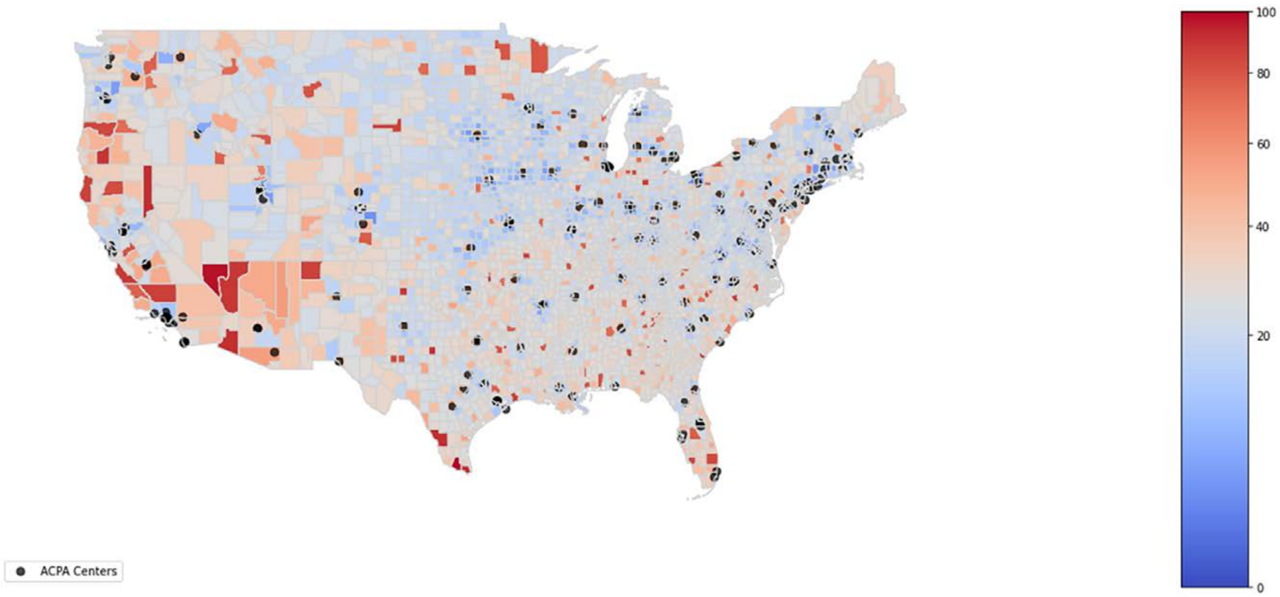

Fig. 5. A choropleth map of the CCDI generated for each US county.

deviation from these traditional models and provides a more general overview of the demand for cleft care. Using equal weights for each CDE component, the CCDI paints with broad strokes to identify targets where coordinated intervention may increase access to care (Fig. 5). It serves to guide outreach efforts from existing cleft care centers (approved and nonapproved) to ensure coverage of these high-demand areas. Given the size, geography, and diversity of populations in the United States, the CCDI alone cannot be used to drive the creation of new cleft centers. Determining which intervention is most appropriate will require analysis of care utilization patterns and patient outcomes within these counties. However, the CCDI gives important insight into the geospatial availability of cleft care and narrows the scope for future analyses to a much more manageable cohort.

Limitations

Geospatial analysis of approved cleft care access at the US county level is not granular enough to suggest which interventions would provide the greatest benefit. Furthermore, it does not analyze or comment on the quality of any existing nonapproved cleft care in these areas. The objective of this study is neither to propose nor identify suitable interventions but rather to offer a more comprehensive outline of each US county's access to approved cleft teams. Our results provide a basis for future research to identify existing cleft infrastructure and possible interventions for these high-demand counties.

Additionally, we recognize that weighing each score component equally in our current index may overlook counties that would not be missed had specific score components been weighted more heavily. This iteration of the CCDI succeeded in identifying many high-demand counties; however, the CCDI is easily modifiable, and future analyses will be calculated with different weights to identify these additional counties.

CONCLUSIONS

By describing barriers separately and as a composite score, our study demonstrates the utility of geospatial analysis with GIS to identify areas with limited access to approved cleft care teams. The CCDI can systematically rank counties with the greatest demand for cleft care according to cleft burden, socioeconomic disadvantages, and limited physical access to provide actionable targets for further investigation and intervention.

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DISCLOSURE

The authors have no financial interest to declare in relation to the content of this article.

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