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Author manuscript

*Cleft Palate Craniofac J.* Author manuscript; available in PMC 2024 December 01.

Published in final edited form as:

*Cleft Palate Craniofac J.* 2024 December ; 61(12): 1969–1980. doi:10.1177/10556656231189940.

## Where is the Care? Identifying the impact of rurality on SLP caseloads and treatment decisions for children with cleft palate

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### Abstract

**Objective:** Challenges providing cleft/craniofacial care in rural communities are often reported, leading to disparities in resources available to clinicians. The purpose of this study was to identify the impact of rurality on caseloads and practice patterns of speech-language pathologists (SLPs) regarding speech and velopharyngeal function for children with cleft lip and/or palate (CL/P).

**Design:** A national, survey of US-based SLPs (N=359 respondents) investigated resources, comfort level, caseloads, and practice patterns for children with CL/P. Sub-county classifications that delineated levels of rurality were utilized. Descriptive statistics and chi-square analyses were conducted to determine the impact of population density on assessment and referral decisions.

**Results:** Nearly 83% of SLPs reported providing care for a child with CL/P and 41.4% of these SLPs reported five or more children with CL/P on caseload throughout their career. There were no significant differences in rurality of practice setting and the likelihood of treating a child with CL/P. Significant differences were present between rural, town, suburban, and metropolitan-based SLPs regarding available resources ( $p=0.035$ ). SLPs in rural settings reported feeling uncomfortable treating children with CL/P compared to those in metropolitan settings ( $p=0.02$ ). Distance to the cleft/craniofacial team and comfort levels impacted referral decisions.

**Conclusions:** Most SLPs report having children with CL/P on caseload regardless of practice location. Rurality impacted assessment and referral decisions, especially surrounding access to resources and comfort levels engaging in team care. Findings have implications for developing support systems and reducing barriers for rural SLPs working with children born with CL/P.

### INTRODUCTION

Globally, health care provision for individuals living in rural areas has been limited when compared with services available for those living in urban areas.<sup>1</sup> Within the United States (US), nearly 21% of the population lives in rural areas.<sup>2</sup> Challenges in providing care in

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Conflict of Interest Declaration:

The work contained in this manuscript was presented at the American Cleft Palate/Craniofacial Association Annual Meeting in March 2022, Fort Worth, TX.

The authors of this manuscript have no conflicts of interest to disclose with respect to the research, authorship, and/or publication of this article.

rural communities are often reported, which can lead to disparities in resources available to clinicians, patients, and families.<sup>3</sup> Thus, rurality has the potential to directly impact healthcare access and provision of services.<sup>4</sup> Further, disparities related to rural healthcare and available resources have the potential to be exacerbated in rehabilitation settings when complex and/or low incidence diagnoses are encountered by providers.

Children with cleft lip and/or palate (CL/P) often present as complex clinical cases, given the heterogeneity associated with the condition. Care provision, beginning at birth and extending through early adulthood, is required for a variety of medical needs within this population. Although CL/P is a relatively low incidence condition compared to other populations seen by speech-language pathologists (SLPs), the impact of appropriate assessment and treatment recommendations is immense for these children.<sup>5,6</sup> Speech errors related to CL/P are related to a variety of anatomical and learned factors. It has been reported that 66–84% of individuals with CL/P receive speech therapy at some point in their lives for speech errors related to the cleft diagnosis.<sup>7–9</sup> Appropriate assessment and referrals are critical to identifying *why* speech errors are occurring and *how* to treat them within this population. Without the use of appropriate treatment strategies by SLPs, these individuals may be subjected to ineffective speech therapy throughout childhood, ultimately leading to decreased quality of life and a negative psychosocial impact.<sup>10</sup>

Treatment of children with cleft and craniofacial conditions relies upon cleft/craniofacial teams to initiate coordinated, interdisciplinary approaches to team care. These multi- and interdisciplinary teams and centers are the standard for ongoing assessment and treatment of children with craniofacial conditions<sup>11,12</sup> Within these teams, SLPs play an important role in the care of children with CL/P, providing expertise in conducting comprehensive assessments of speech and velopharyngeal function and facilitating development of management plans Outside of centralized team care, community-based SLPs play an equally important role in the care team for each individual and are often the primary providers engaged in ongoing intervention for speech disorders associated with cleft palate. These providers help to facilitate communication between the patient, the family, and the cleft/craniofacial team, conduct ongoing screening/assessment, and make referrals, often to the cleft/craniofacial team, if there are concerns which cannot be addressed locally.

However, outside of craniofacial centers, healthcare professionals may be unfamiliar with appropriate assessment and intervention techniques for children with CL/P and may lack resources, including instrumentation or imaging such as nasometry and nasendoscopy or multiview videofluoroscopy, to support reliable and regular assessments.<sup>13–15</sup> This problem has the potential to worsen in rural areas where healthcare resources are more likely to be limited or deficient. Many rural communities lack access to speech-language pathology services, despite the growing need.<sup>16</sup> Rural hospital systems, in general, also frequently report insufficient resources<sup>17</sup>, which may extend to available resources on rural cleft/craniofacial teams. Further, differences in academic training, clinical training, and practice patterns of SLPs for children with CL/P have also been reported,<sup>14,15,18</sup> which has the potential to negatively impact resource utilization and referral decisions for SLPs in general. These differences, however, have not been assessed relative to population density and practice location within the realm of craniofacial care, specifically related to SLP caseloads,

resources, referrals, and decisions related to assessment and intervention for speech and velopharyngeal function in children with cleft conditions.

The purpose of this study was to examine the practice patterns (assessment resources, evaluation, and referral decisions) and caseloads of SLPs serving individuals with CL/P across areas of differing rurality (population density and geographic isolation). Based on the literature, it was hypothesized that practice patterns and the available resources for SLPs practicing in rural settings would differ from those of SLPs practicing in areas of greater population density. It was also hypothesized that differences in available resources would impact clinical decision making for children with CL/P.

## METHODS

A national survey of the United States (US) was conducted to identify the impact of rurality on caseloads and practice patterns of SLPs regarding children with CL/P. All study procedures were approved by the Institutional Review Board (IRB) at the University of Virginia (IRB-SBS #3738), and an institutional affiliation agreement was obtained with the University of Wyoming. Informed consent was obtained prior to survey data collection.

### Participants

Survey participants were licensed speech-language pathologists who hold the American Speech-Language Hearing Association certification/credentials of CCC-SLP (Certificate of Clinical Competence in Speech-Language Pathology) or CF-SLP (Clinical Fellow of Speech-Language Pathology). This indicated that the participants have completed at least a graduate-level education in the survey area of interest. Students, speech-language pathology assistants (SLP-As), and any practitioners that were not licensed or certified SLPs were excluded from the study. The electronic survey was disseminated online to SLPs. Electronic survey announcements were advertised and posted across multiple dissemination outlets, including social media (Instagram, Twitter, Facebook), on state association websites for speech-language pathology, and statewide early intervention groups.

### Survey Development

Areas of interest were identified by the researchers based on related publications<sup>14,16,19</sup> and content areas were assessed by experts in the field to ensure that questions captured the areas of interest. The survey questions were also reviewed by the university statistics and consulting group to ensure formatting of survey questions and response options matched the areas of inquiry. Demographic questions were additionally modeled from a previously conducted survey to allow for comparison to past results.<sup>14</sup> The current survey was constructed and distributed using the Qualtrics XM software (Qualtrics XM, 2021, Provo, UT). The Qualtrics platform was also used to collect data for the anonymous survey. The survey consisted of three parts: 1) provider demographics and care provision, 2) resource availability, and 3) practice patterns. Survey questions can be located in Appendix 1.

## Statistical Analyses

Data was analyzed using SPSS Statistics, v26. Descriptive statistics were used to identify differences in resources, comfort level, and current caseloads for SLPs treating children with CL/P across areas of varying rurality. Sub-county classifications that delineated different levels of rurality, including rural-urban commuting areas and frontier/remote area codes, were utilized. These classifications were based on the Institute of Education Sciences (IES) National Center for Education Statistics (NCES) Locale and Classification Criteria.<sup>20</sup> The NCES framework utilizes four classification types (city, suburban, town, and rural). These classifications rely on the standard urban and rural definitions developed by the US Census Bureau.<sup>21</sup> Using these data, respondents were classified as rural, town, suburb, or city/metropolitan. Chi-square analyses were conducted to examine the relationship between rurality, assessment decisions, and practice patterns.

## RESULTS

### Respondent Demographics & Care Provision for Children with Cleft Lip and/or Palate

The survey received 359 responses from SLPs over a three-month period. Given the electronic dissemination methods across social media platforms, state associations for speech-language pathology, and statewide early intervention groups, the overall response rate cannot be calculated. Responses were received from SLPs residing in 45 states and the District of Columbia. This demonstrated a broad distribution of respondents, covering approximately 90% of the United States (Figure 1).

Respondents included SLPs with a range of experience spanning from approximately one year to 30+ years. The distribution of respondents related to years of experience was broad with approximately 37% of the sample (N=115) reporting between 6–20 years of experience and 35% (N= 110) reporting 5 years or less experience. Approximately 28% of respondents (N=88) reported over 20 years of experience in the field. Of that group, 41 individuals reported having over 30 years of experience. Given this distribution, results likely reflect a balanced perspective from clinicians with a wide range of experience in the field. Primary practice settings of respondents included early intervention, school-based, private practice/outpatient clinic, inpatient hospital-based, outpatient hospital-based, long-term acute care, home health, skilled nursing facility, college/university, and corporate speech-language pathology (Table 1).

### Likelihood for Treating Individuals with Cleft Lip and/or Palate

Nearly 83% of respondents (N= 253) have provided care for an individual with CL/P. Approximately half of these respondents reported having had five or more individuals with CL/P on their caseload throughout their career (41.4%, N= 105). There were no significant differences in rurality of practice setting and the likelihood of treating an individual with CL/P,  $\chi^2(3)= 3.275$ ,  $p= 0.351$  (Figure 2).

### Impact of Rurality on Clinical Resource Availability and Resource Utilization

When asked what resources were available to conduct resonance evaluations for children with CL/P, significant differences were present between rural, town, suburban, and

metropolitan based SLPs,  $\chi^2(9) = 17.97, p = 0.035$ . SLPs, as a whole, relied more heavily on perceptual assessments than other assessment tools (61.9%,  $N = 172$  out of 278 responses). Metropolitan SLPs were more likely to identify that all clinical resources such as perceptual assessments, instrumentation, and imaging, were available at their place of employment (25.2%). In contrast, very few rural (0%), town (1.6%), and suburban (6.3%) SLPs reported having *all* available resources for assessment. Imaging was more likely to be an available resource in metropolitan settings, while instrumentation, such as nasometry, was more likely to be reported in town and suburban settings. Rural SLPs were more likely to indicate “no resources” (24.2%) compared to town (8.1%), suburb (7.9%), and metropolitan SLPs (1.4%) (Figure 3).

When asked which single resource SLPs were most likely to rely on to facilitate assessment decisions, such as the need for referral, need for surgery, or need for speech therapy, the majority of SLPs indicated that they utilized perceptual assessment (63.9%;  $N = 131$  out of 205 responses), while 17.1% ( $N = 35$ ) indicated that instrumental assessment was most likely to be used, and 9.3% ( $N = 19$ ) indicated that imaging was most likely to be used. Approximately 10% of respondents (9.8%,  $N = 20$ ) indicated “none and would not assess”. Of this group, 40% were rural SLPs ( $N = 8$ ), 12.5% were town SLPs ( $N = 5$ ), 9.8% were suburb SLPs ( $N = 6$ ), and 1.2% were city SLPs ( $N = 1$ ).

### Impact of Rurality on Referral Decisions

As a whole, 32.9% ( $N = 80$ ) of respondents indicated that they were not comfortable knowing when to refer to the cleft/craniofacial team. Significant differences were present between rural and city/metropolitan SLPs related to comfort level for referral decisions,  $\chi^2(1) = 5.43, p = 0.020$ . A greater percentage of SLPs in rural settings (46.2%) reported feeling uncomfortable knowing when to refer children to a cleft/craniofacial team for assessment compared to those in town (30.2%), suburb (34.8%), and city/metropolitan settings (29.6%) (Figure 4). However, most SLPs indicated they would refer a child to the cleft/craniofacial team if they had questions related to resonance (57%) and/or if the child had not seen the team in over a year (45%). Figure 5 summarizes reasons for referral to the cleft/craniofacial team. When asked to rank general comfort level on a five-point scale regarding contacting the local cleft/craniofacial team, rural SLPs were more likely to rank their comfort levels lower (mean rank 2.88; between uncomfortable and slightly uncomfortable) than city/metropolitan SLPs (mean rank 4.60; between comfortable and very comfortable). These findings were independent of years of clinical experience,  $\chi^2(7) = 7.27, p = 0.401$ .

No significant differences were present across practice locations related to knowledge of where the nearest cleft/craniofacial team was located,  $\chi^2(3) = 0.639, p = 0.887$ . However, 23.3% ( $N = 68$ ) of survey respondents reported that they did *not* know where the nearest cleft/craniofacial team was located, while 76.7% ( $N = 224$ ) indicated that they had this information. The percentage of SLPs that did *not* know where the nearest cleft/craniofacial team was located was higher in rural practice locations (30.6%) than that of town (20.3%), suburb (21.5%), and city/metropolitan based settings (23.9%). For those that did know where the nearest cleft/craniofacial team was located, the majority reported that the nearest cleft/craniofacial team was less than to approximately one hour away (70.1%).

Approximately one third of respondents indicated that the nearest cleft/craniofacial team was more than one hour away (29.9%). Of those reporting distances over one hour, 11.2% reported that the nearest team was between 2–4 hours away and 1.8% reported distances greater than four hours. SLPs in rural settings most often reported that the nearest cleft/craniofacial team was two or more hours away (40%), with 10% of rural SLPs reporting distances of more than four hours.

## DISCUSSION

The available clinical resources and practice patterns of SLPs differed based on primary practice location, particularly related to rurality. Those practicing in more populated areas reported having more resources for velopharyngeal assessment, as well as feeling more comfortable engaging in team care and making referrals to cleft/craniofacial teams. In contrast, rurality appeared to impact available resources. This, in turn, impacted the decisions that SLPs made regarding how they would assess a child with CL/P and/or refer to the nearest cleft/craniofacial team.

Studies have identified disparities in access to care for children with complex healthcare needs based on geographic location.<sup>22</sup> Access to care has also been reported to differ significantly by state.<sup>22</sup> However, limited research has been conducted on SLPs' experience and comfort level engaging in cleft-related care, particularly as care relates to areas of differing population density and rurality. The current study begins to fill this gap in the literature by reporting the experience, resources, and comfort levels of SLPs concerning care for children with CL/P.

### Children with Cleft Lip and/or Palate on SLP Caseloads

An increase in the number of SLPs that reported having children with CL/P on their caseloads was observed. Compared to a prior report by Bedwinek and colleagues<sup>14</sup>, this number has increased by approximately 10%. SLPs across the United States were similarly likely to have a child with CL/P on their caseload at some point in their careers, regardless of rurality of practice setting. Numerous factors may be at play resulting in a greater likelihood for this population of patients to be on caseload, such as more awareness of speech/language needs for these children, longer lengths of time children with cleft may remain on SLP caseloads, and/or use of less effective treatment techniques due to decreases in graduate level training in cleft-related articulation disorders.<sup>14,15,18,23–25</sup> This highlights a need to provide adequate resources for assessment and intervention for this population of patients.

### Impact of Rurality on Clinical Resource Availability and Resource Utilization

Availability of clinical resources resulted in significant differences in assessment decisions by SLPs based on the rurality of their practice settings. Specifically, metropolitan SLPs demonstrated greater access to resources, including instrumentation and imaging resources, for assessing speech and velopharyngeal function in children with CL/P. Many of these assessment resources were more likely to be available in metropolitan areas and, consistent with Grames<sup>26</sup>, cleft/craniofacial teams as a resource are often affiliated with medical

centers based in metropolitan areas. However, while not especially common, it is not unheard of for outpatient, university, and private practice clinics, as well as rural hospital systems in the United States, to have access to some instrumentation, such as nasometry, at their practice locations. These locations, at times, may not be affiliated with a cleft team. This is seen in our results on resources available to practitioners and highlights the variability of rurality on resource availability. Additionally, cleft teams can also be located in areas in the US that are considered to be rural (and potentially under-resourced in comparison to metropolitan areas), which may influence resources/practice patterns of those clinicians, despite being on a cleft team.

Rural SLPs consistently reported fewer resources to adequately assess children with CL/P. Responses indicated that the lack of resources for these rural-based SLPs resulted in reduced likelihood for assessment in this population of patients. A proportion of SLPs, approximately 10%, indicated they did not have resources and therefore would not assess children with CL/P at all; this included not conducting perceptual assessments of speech and resonance. The percentage of SLPs reporting that they would not assess was higher in rural areas than more populated areas.

Interestingly, minimal resources are necessary to conduct perceptual assessments of speech/resonance, and thus, would not be expected to be influenced by practice location. Perceptual assessment requires no tools other than the clinician's trained ear and SLPs are likely to have access to the resources necessary to conduct perceptual analyses of speech and resonance, provided they have the educational foundation needed to assess and interpret data from perceptual assessment. Therefore, this difference in use of perceptual assessments across rurality may be related to access to training and continuing education for this area of clinical practice. Additional research is needed to determine how SLPs are obtaining their knowledge of assessment and treatment for individuals with CL/P and which continuing education resources would be most useful for the present day.

These findings underscore the need for organizations, such as ASHA and graduate training programs, to facilitate acquisition of knowledge and skills related to cleft/craniofacial care. Perceptual assessment should precede any instrumental assessment and assist the SLP in determining the need for additional diagnostics. These assessments for children with CL/P typically include classification of speech sound errors, assessment of resonance and nasal airflow, and correlating perceptual speech/resonance findings with orofacial exam findings.<sup>27</sup> A free guide for speech sampling to facilitate perceptual assessment has been developed and is available through the American Speech-Language Hearing Association (ASHA) Practice Portal.<sup>28</sup> Additional resources have been described by Mason et al.<sup>18</sup>, Grames and Stahl<sup>29</sup>, and Crowley et al.<sup>30</sup> A variety of mechanisms are also regularly available through ASHA Special Interest Groups, the International Association of Communication Sciences and Disorders, and the American Cleft Palate/Craniofacial Association (ACPA).

### **Impact of Rurality on Referral Decisions**

The majority of SLPs indicated that they were aware of where the nearest cleft/craniofacial team was located, but differences in comfort level making referrals to the team were

seen across areas of differing rurality. Rural SLPs expressed greater levels of discomfort related to making referrals to the cleft/craniofacial team. This may be due to the greater distances reported between practice settings and cleft/craniofacial team locations. Peck et al.<sup>19</sup> identified that travel distances of more than 1 hour may affect more than 25,000 (1 of 4) children with CL/P in the US. Within this geospatial survey, there was noted variation across geographic regions.<sup>19</sup> These data, in combination with the current study, may help to better understand the impact of rurality on access to care and practitioner referral decisions. Survey findings also indicated that SLPs may choose to refer a child with a CL/P to a cleft/craniofacial team for assessment unrelated to velopharyngeal function (such as for audiological, voice, or language assessment). This may be due to cleft/craniofacial teams typically having more resources than community-based practice locations. It is unknown, however, what additional factors may play a role in referrals and comfort levels making these referrals. Additionally, while the study was framed in the context of patients with CL/P, survey questions also related broadly to velopharyngeal dysfunction and resonance assessment as well. While the survey didn't specifically ask about children with submucous cleft or non-cleft VPD and comfort levels referring these specific patients, it is likely that referrals for these patients, who may not be known to the cleft/craniofacial team at birth, are lower and potentially delayed in the event referral occurs.<sup>31,32</sup> SLP knowledge, experience, and/or comfort level in *treating* this population of patients may also play a role when choosing whether or not to make a referral for team care. However, treatment experience and treatment methodologies were not assessed in the current survey.

Grames and Stahl<sup>29</sup> reported initial outcomes for a novel collaborative care program that engaged community-based SLPs with cleft/craniofacial team SLPs. Through this model, local SLPs can earn continuing education credits while gaining hands-on experience in cleft-related speech treatment. Results of this collaborative model provide SLPs with patient-specific knowledge and foster ongoing partnerships between the cleft/craniofacial team and treating clinicians within the community.<sup>29</sup> While this is an ideal approach, it may not be accessible to those SLPs in rural areas where the nearest cleft/craniofacial team is several hours away. There may be additional opportunities to increase access for referring SLPs through telehealth collaboration, particularly for those in rural settings.<sup>33–35</sup> Within the global context, telehealth has been reported to provide beneficial methods to improve access to care, particularly for evaluations in developing countries.<sup>36–38</sup> Additionally, initiatives have been developed to provide advice and intervention to health care professionals for delivery of speech and language services for children with CL/P.<sup>39–41</sup> Areas for collaborations between cleft/craniofacial teams and community SLPs, including relationships via telehealth, should continue be explored.

### Clinical Implications

Continued knowledge of assessment processes and confidence referring to the cleft/craniofacial team is imperative to facilitate coordinated care and improve outcomes for children with CL/P. The impact of rurality for SLPs poses potential barriers to providing care for children with CL/P, particularly related to reduced comfort levels and reduced screenings/assessments to identify clinical needs for children with CL/P. Based on the findings of the present study, this may result in a reduction of necessary referrals for



comprehensive team care at specialized cleft/craniofacial centers. Implications center on educational opportunities for SLPs and increased coordination with cleft/craniofacial teams. Increased experience during graduate training and accessible continuing education opportunities may further help to improve knowledge and increase comfort for providing care for children with CL/P.<sup>14,15,18</sup> Future studies should assess available resources for continuing education for SLPs related to this population relative to rurality. Additional insights may be derived with a detailed understanding of preferred methods for receiving continuing education for SLPs practicing in differing areas of rurality. Continuing education models that facilitate increased comfort in both assessing and treating patients with CL/P and collaborating with cleft/craniofacial teams continue to be necessary.

There is also substantial evidence to support centralization of cleft care in large volume centers, specifically related to facilitating improved patient outcomes and resource utilization.<sup>42-44</sup> Work assessing outcomes related to the centralization of cleft care supports high volume centers where specialist assessments take place.<sup>8,43,45-47</sup> However, differences exist in the execution of centralized care among countries. Within the United Kingdom, a well-known network of National Health Service (NHS) cleft teams exist, which include local SLP practitioners.<sup>43,45,46</sup> In contrast, cleft/craniofacial care in the United States is often positioned in well-organized, high-volume centers situated in individual hospital-based clinics in each state.<sup>44</sup> This is often noted to help facilitate geographical access to care.<sup>44</sup> These high-volume centers are essential in facilitating care in the United States, but efficacy is reduced if community-based SLPs are not consistently referring patients to the centers or actively engaging in coordinated team care. Additional opportunities for collaborations between the cleft centers and community-based SLPs may be beneficial in reducing barriers for coordinated care. The trends suggested by this study point to the need for cleft/craniofacial teams to facilitate better outreach in their states and/or regions and additional study is warranted. Communication and outreach from cleft centers about the services available from cleft centers, when to refer to these centers, and the process for referrals may better facilitate community-based SLPs in accessing team care for their patients. Increasing SLP knowledge of referral options for team care and other cleft-related services may additionally reduce feelings of isolation and increase comfort levels for making referrals when caring for children with CL/P. It remains unknown if increased comfort level and/or knowledge would result in increased referrals or engagement in team care.

### Limitations and Future Directions

The design of the current study is subject to limitations consistent with survey studies. Therefore, caution should be exercised when generalizing the findings of this study. The impact of blank responses by participants is unknown. Respondents may have skipped questions because they lacked definitive views about the topic or were uncertain about the wording of a question.

Results demonstrated that more SLP respondents had caseloads with children with CL/P than prior studies. This may be due to sampling bias, specifically non-response bias, where SLPs that had encountered this population and/or had an interest in this population may have been more likely to respond to the survey than those who did not. Additionally, SLPs who

have strong opinions or substantial knowledge may have been more willing to respond to the survey than those who did not. This may alternatively be due to an actual increase in this population on SLP caseloads compared to prior reports given that the distribution of survey respondents in regards to age, experience, clinical setting, and location/rurality was fairly balanced. Additional research is needed to determine whether the findings observed in this study are representative of the larger population of SLPs in the US.

Participant comfort level was not associated with years of clinical experience, but appeared to be influenced by rurality of practice location. However, it is worth noting that in addition to rurality, comfort could also be influenced by a number of external factors such as clinician knowledge, frequency of interactions with cleft/craniofacial teams (or lack thereof), quality of prior interactions with cleft/craniofacial teams, or individual practitioner characteristics. The survey did not explicitly ask respondents what made them more or less comfortable and additional studies are needed to determine if other factors, in addition to rurality, may influence comfort levels related to cleft/craniofacial team referrals.

Another limitation was that this survey did not ask about the modes of transportation when asking respondents about distance to the nearest cleft/craniofacial team. Therefore, we cannot rule out the possibility that respondents may have under- or over-estimated one-way travel distance and time. Further, it is unknown if results may be influenced by the number of cleft/craniofacial centers in each state. States with fewer cleft/craniofacial teams may result in fewer community-based providers being aware of their role, location, and availability. However, in rural states, these care centers are often located at larger, well-known metropolitan health care systems, which could result in more awareness of the cleft/craniofacial team as a resource. Additionally, distance to cleft/craniofacial team and rurality appeared to be associated with greater levels of discomfort related to cleft/craniofacial team referrals, regardless of years in clinical practice. It is unknown if other factors, such as socioeconomic status of the region(s) or access to transportation, may have influenced this association and additional study is warranted.

## CONCLUSION

SLPs across the United States are very likely to have a child with CL/P on their caseload, regardless of rurality of practice setting. However, many SLPs in rural settings expressed greater levels of discomfort referring children to cleft/craniofacial teams. Reduced resources for assessment were additionally reported by rural SLPs across all practice settings compared to those in areas with a larger population. Rurality of practice location may impact treatment decisions related to the care of children with CL/P, especially surrounding access to instrumentation, imaging, and referrals for comprehensive team care. Furthermore, highly resourced cleft/craniofacial teams should consider the training and continuing professional development needs of rural SLPs to reduce barriers for collaboration and better support rural SLPs working with children born with CL/P.

## ACKNOWLEDGEMENTS

This work was supported in part by the National Center for Advancing Translational Sciences of the National Institutes of Health under Award Numbers KL2TR003016/UL1TR003015. The content is solely the responsibility

of the authors and does not necessarily represent the official views of the National Institutes of Health. The authors would like to additionally acknowledge the contributions of Makaela Purcell, University of Virginia graduate student, and Katelan Rogers, University of Wyoming undergraduate student, for their assistance in survey dissemination and survey data pre-processing.

## APPENDIX 1: SURVEY QUESTIONS

### Provider Demographics

**Are you a licensed and/or ASHA Certified Speech-Language Pathologist or Clinical Fellow?**

Yes, ASHA Certified CCC-SLP

Yes, Licensed SLP

Yes, Clinical Fellow CF-SLP

No

Skip logic: If no is selected, skip to end of survey.

**How many years have you been a practicing SLP?**

< 1 year

1 – 5 years

6 – 10 years

11 – 15 years

16 – 20 years

21 – 25 years

26 – 30 years

30+ years

**In what setting(s) do you currently practice (select all that apply)?**

Early Intervention

School-based

Private Practice/Outpatient Clinic

Inpatient Hospital-based

Outpatient Hospital-based

Long-term acute care hospital

Home health

Skilled Nursing Facility

College/University

Corporate Speech-Language Pathology

Retired

Other: \_\_\_\_\_

**In what zip code is your primary practice location located?**

Select or type zip code

**Is your primary practice location considered: Rural, Town, Suburb or City/Metropolitan?** Please reference this website for more information about these classifications or to identify your classification based on zip code: <https://nces.ed.gov/programs/maped/LocaleLookup/>. This will be cross-referenced with your provided zip code.

Rural

Town

Suburb

City/Metropolitan

**Have you provided care for a child with repaired cleft lip/palate?**

Yes

No

**If yes, approximately how many children with repaired cleft lip/palate have you seen in your caseload over the course of your entire career?**

1

2 – 4

5 – 9

10 – 14

15 – 19

20 – 49

50 – 99

100 – 499

500+

**Do you know where your nearest cleft/craniofacial team is located?**

Yes

No

**If yes, how far away is the nearest craniofacial team from where you practice?**

Less than 1 hour away

Approximately 1 hour away

- Between 1–2 hours away
- Between 2–4 hours away
- Greater than 4 hours away

## Resource Availability

**What resources are available at your place of employment to conduct resonance evaluations for children with repaired cleft lip/palate? (Select all that apply)**

- Perceptual evaluations of speech and resonance
- Instrumentation (e.g.: nasometry)
- Imaging (e.g.: nasendoscopy or videofluoroscopy or MRI)
- None

## Practice Patterns

**Do you conduct resonance (velopharyngeal function) assessments for children with cleft lip/palate at your place of employment?**

- Yes
- No

**Which resource are you most likely to rely on for assessment decisions (i.e.: which resource *most* helps to inform a decision on the need for surgery, referral to cleft team, or need for speech therapy, etc.)?**

- Perceptual evaluations of speech and resonance
- Instrumentation (e.g.: nasometry)
- Imaging (e.g.: nasendoscopy or videofluoroscopy)
- None and would not assess

**When would you refer a child with cleft lip and/or palate to a cleft/craniofacial team? (Select all that apply)**

- When they fail a hearing screening
- If I have questions related to resonance
- If I am unsure of their articulation errors
- If they haven't seen a team in over a year
- Only when imaging is needed
- For comprehensive language assessment
- For instrumental voice assessment
- Never

Other: \_\_\_\_\_

**Do you feel comfortable knowing when to refer to a cleft/craniofacial team for additional assessment?**

Yes

No

**Please rate your overall comfort level contacting your local cleft or craniofacial team from least comfortable (1) to most comfortable (5).**

Equal appearing interval scale

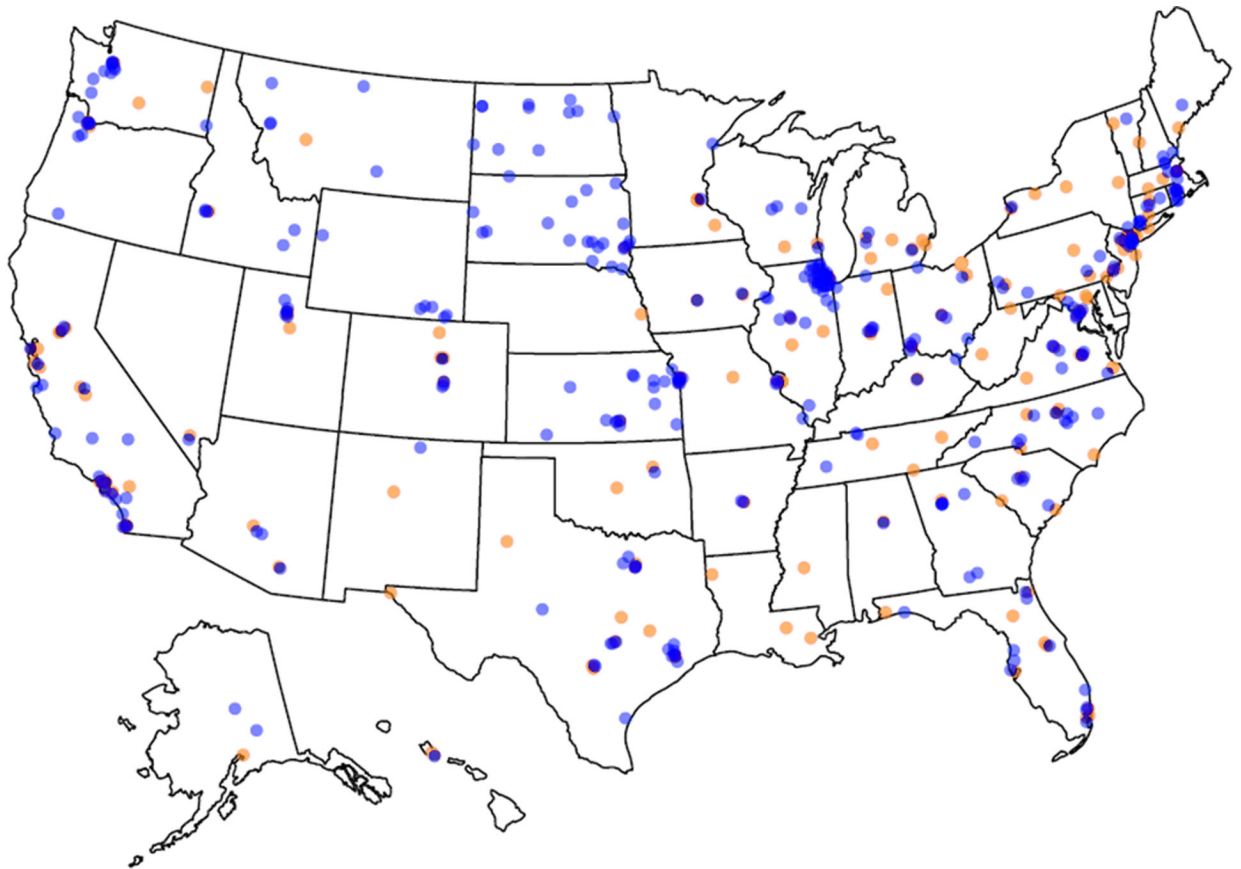
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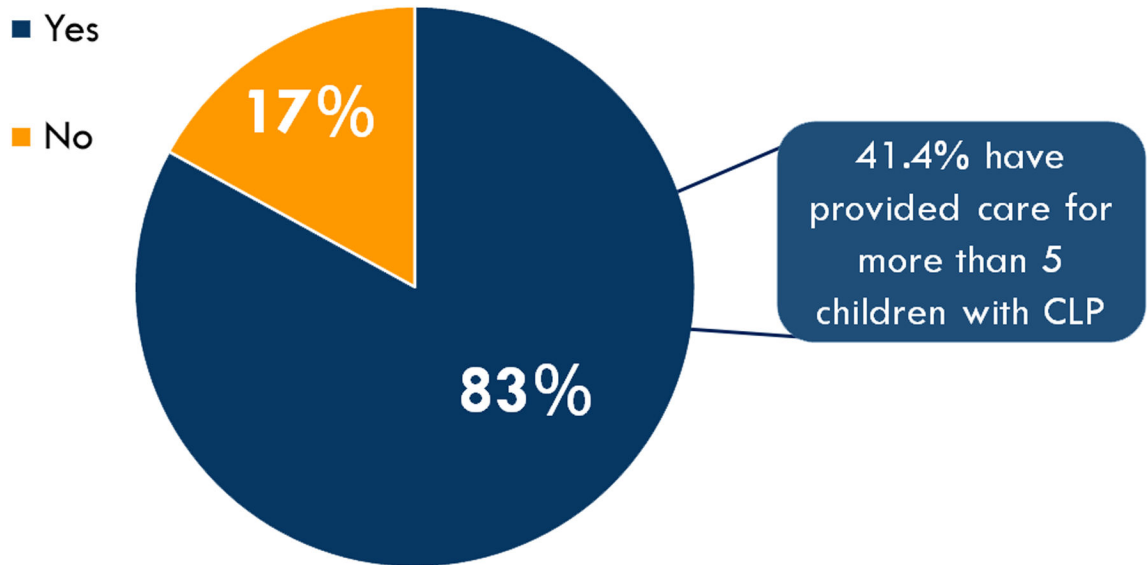
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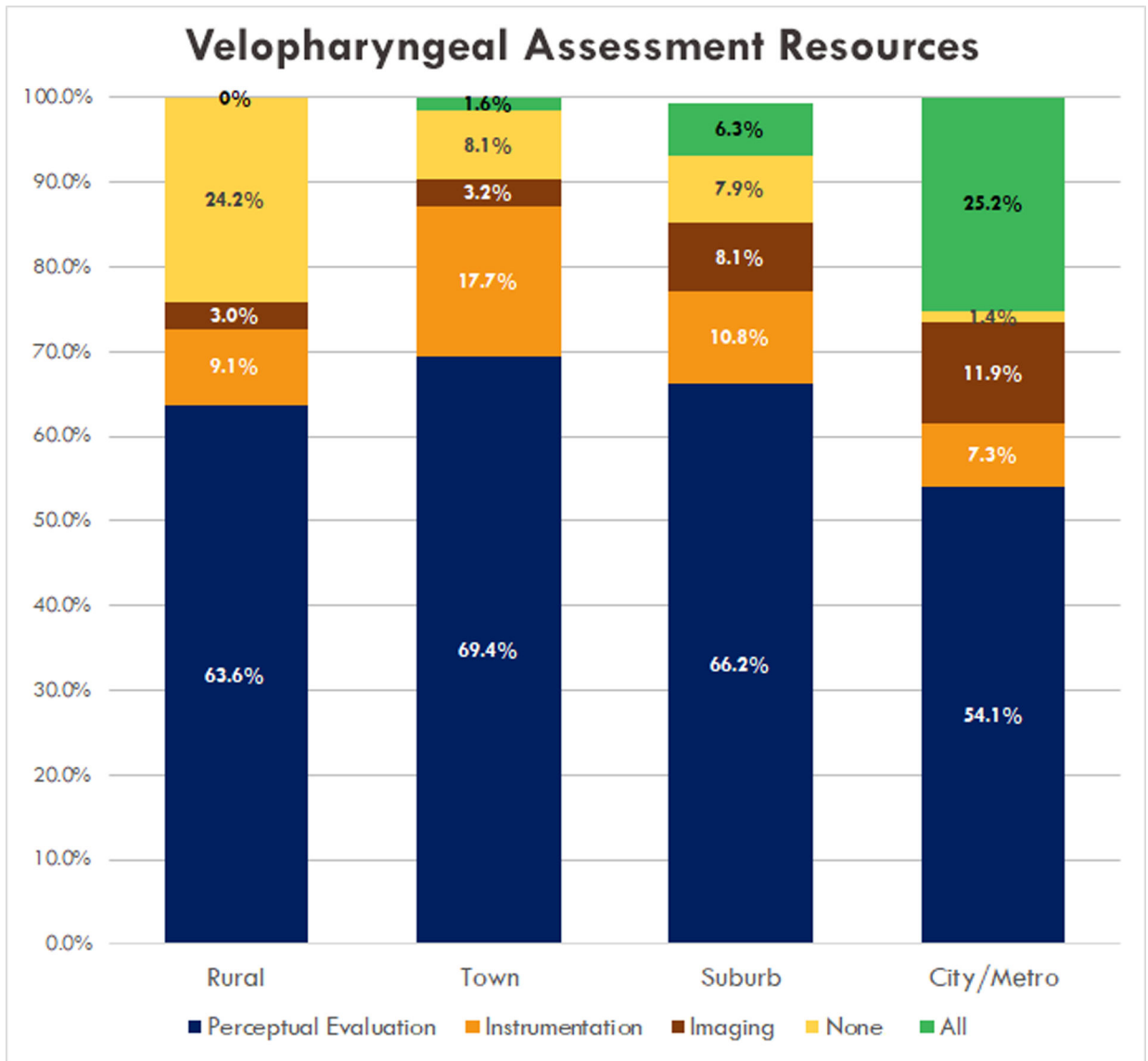


**Figure 1.**  
Density map of respondent locations (blue) and location of ACPA approved cleft/  
craniofacial teams (orange).

## Have you provided care for a child with Cleft Lip/Palate?



**Figure 2.**  
Percentage of SLPs that have had a child with CL/P on their caseload.



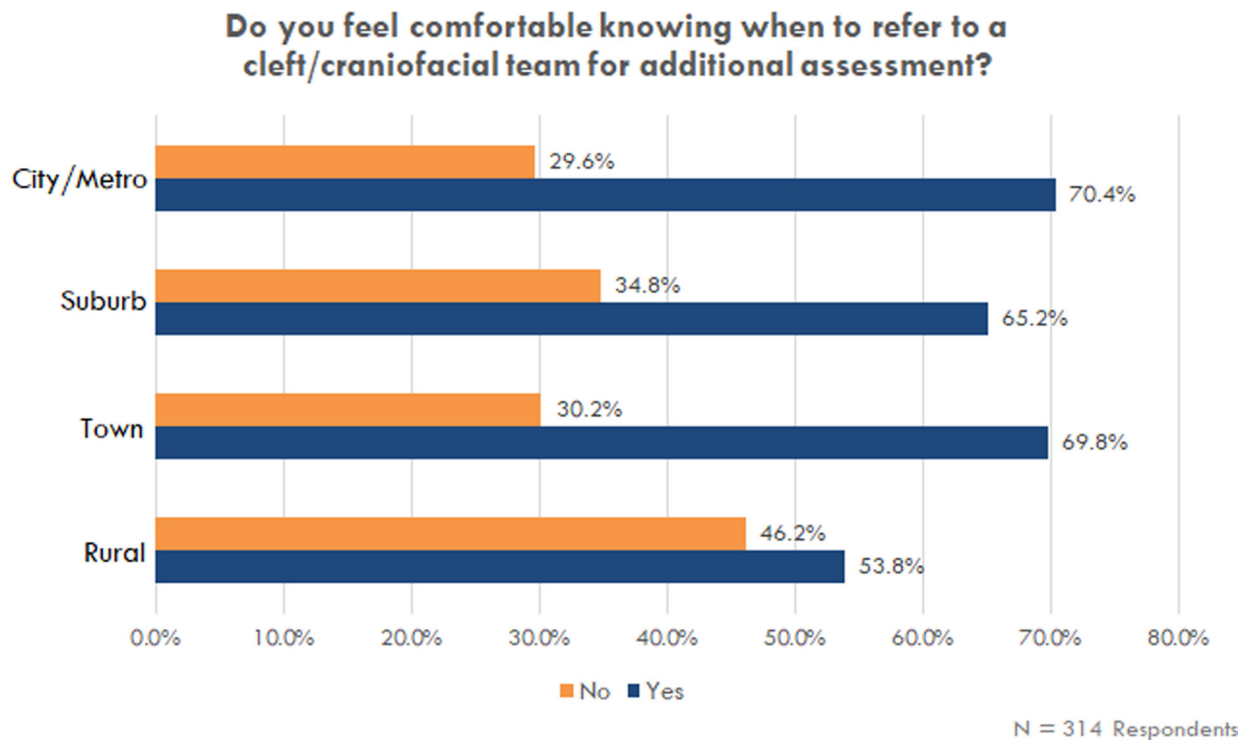
**Figure 3.** Clinical resource utilization across differing levels of rurality.

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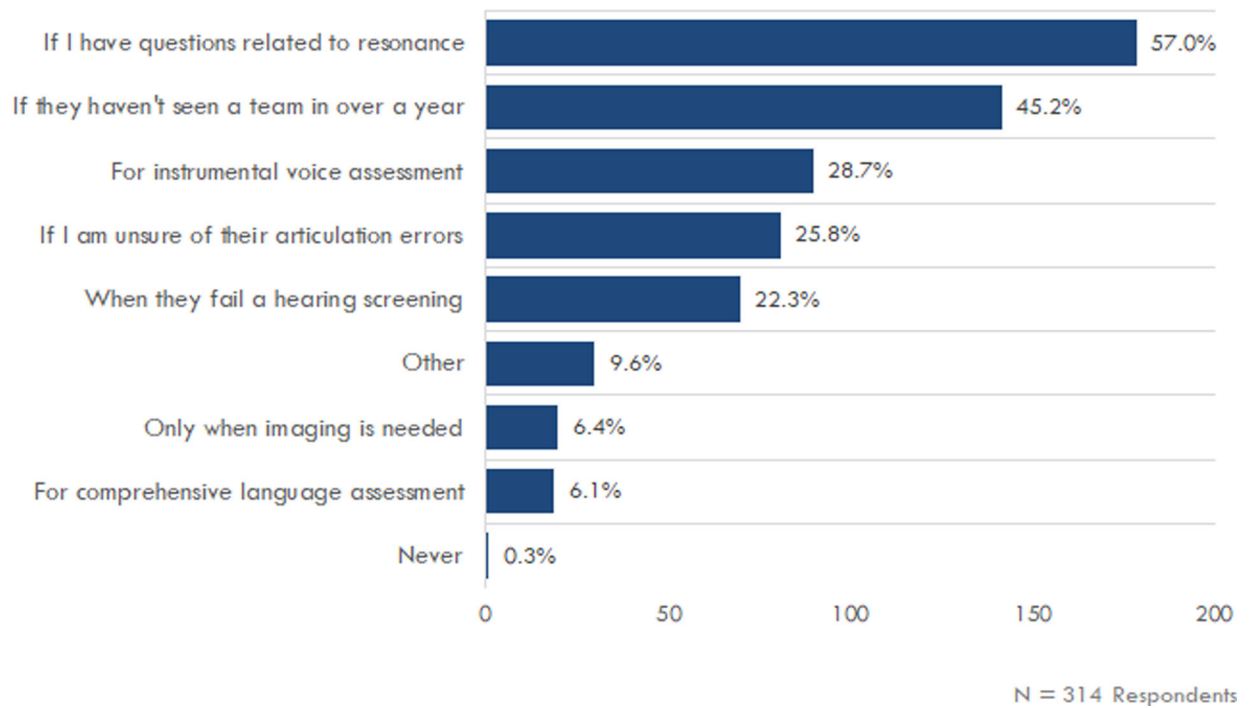
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**Figure 4.** Respondent comfort level related to making referrals to cleft/craniofacial teams.

### When Would You Refer a Child with CLP to a Cleft/Craniofacial Team



**Figure 5.**  
Respondent justification for when referrals would be made.

**Table 1.**

## Respondent Characteristics

	N	%
<b><i>Clinical Practice Setting(s)</i></b>	<b>315</b>	<b>87.74</b>
Early Intervention	73	20.3
School-based	147	40.9
Private Practice/Outpatient Clinic	67	18.7
Inpatient Hospital-based	43	12.0
Outpatient Hospital-based	64	17.8
Long-term Acute Care	6	1.7
Home Health	18	5.0
Skilled Nursing Facility	13	3.6
College/University	27	7.5
Corporate Speech-Language Pathology	7	1.9
Retired	9	2.5
Other	8	2.2
<b><i>Years in Clinical Practice</i></b>	<b>313</b>	<b>87.18</b>
< 1 year	25	8.0
1 – 5 years	85	27.2
6 – 10 years	67	21.4
11 – 15 years	31	9.9
16 – 20 years	17	5.4
21 – 25 years	22	7.0
26 – 30 years	25	8.0
30+ years	41	13.1
<b><i>Have you ever provided care for a child with CLP?</i></b>	<b>306</b>	<b>85.23</b>
Yes	253	82.7
No	53	17.3
<b><i>Number of children with CLP seen over the course of your career</i></b>	<b>243</b>	<b>67.68</b>
At least 1	26	10.7
2 – 4	87	35.8
5 – 9	45	18.5
10 – 14	17	7.0
15 – 19	9	3.7
20 – 49	17	7.0
50 – 99	9	3.7
100 – 499	15	6.2
500+	18	7.4
<b><i>Primary Practice Location</i></b>	<b>315</b>	<b>87.74</b>
Rural (including Frontier & Remote)	39	12.4
Town	70	22.2
Suburb	82	26.0

	N	%
City/Metropolitan	124	39.4
<b><i>Knowledge of where nearest cleft team is located</i></b>	<b>292</b>	<b>81.33</b>
Yes	224	76.7
No	68	23.3
<b><i>Distance of Practice Location to Nearest Cleft/Craniofacial Team *</i></b>	<b>224</b>	<b>100</b>
Less than 1 hour away	113	50.5
Approximately 1 hour away	44	19.6
Between 1–2 hours away	38	16.9
Between 2–4 hours away	25	11.2
Greater than 4 hours away	4	1.8

Total Number of Survey Respondents = 359

\* Note: This question was only provided to respondents that indicated “yes” for the question related to knowledge of where the nearest cleft team is located (N=224)