Access to Developmental Pediatrics Evaluations for At-Risk Children

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ABSTRACT: Objective: To determine a national average wait time for developmental pediatric evaluations and to understand differences in access based on whether an appointment is requested by an English or Spanish-speaking caller. Methods: We conducted a mystery shopper study in which a bilingual research assistant called developmental pediatrics programs affiliated with US children’s hospitals listed on a public directory requesting an appointment for his simulated child experiencing a developmental problem. If an appointment was not provided, a wait time estimate was requested. Programs that provided an estimate in English were called within 24 hours using a translated script. We excluded programs that did not include a developmental pediatrician, only accepted referrals from within their health system or plan, focused on specific disorders, or did not conduct initial evaluations. Results: Of 244 hospitals listed, 140 unique programs were identified and called in English. One hundred four programs were reached. Ninety programs met inclusion criteria, 75 provided an estimated wait time. The mean estimate was 5.4 months (standard deviation: 4.5). Among these 75 programs, 62 were reached in Spanish but only 55% provided a wait time estimate; 31% did not provide language accommodations. The difference between average estimates obtained in English and Spanish was not statistically significant. Conclusion: Among a national sample of US children’s hospitals, we identified barriers to evaluations conducted by developmental pediatricians including long wait times and inadequate Spanish language accommodations at some programs. More work is needed to identify optimal strategies to connect children with developmental concerns to evaluations when necessary.


One in 7 children under age 9 has a mental, behavioral, or developmental disorder (e.g., speech disorders, attention deficit hyperactivity disorder, autism spectrum disorder).1 Developmental pediatricians receive fellowship training in the diagnosis and medical management of these conditions. Despite the large number of children who may benefit from these services, there are less than 1000 active, board-certified developmental pediatricians in the United States,2 limiting access to rigorous diagnostic evaluations and early interventions that could improve long-term outcomes at critical developmental periods.3–6

To our knowledge, only one peer-reviewed study has explored wait times for developmental pediatric evaluations.7 This study found a 3-month average wait time for children at risk for autism spectrum disorder but was limited to one metropolitan area. Thus, the findings may not generalize to other areas, especially given anecdotal reports of wait times exceeding 1 year. Given disparities in health care access for children whose parents have limited English proficiency (LEP),8–12 it is also unclear whether this subgroup encounters additional barriers and even longer wait times. Policymakers and administrators can use this information to develop and tailor interventions that better support vulnerable children. Used to assess consumer experiences in other fields, mystery shopper studies can replicate patient encounters with health systems.13,14 This approach minimizes risk to potential subjects and enhances scientific validity by avoiding recall bias and the Hawthorne effect, in which individuals alter their behavior when observed.15–17 In this study, a bilingual study team member attempted to schedule an appointment by phone on behalf of his simulated child in English and Spanish to: (1) determine the average wait time nationally for a developmental pediatrics evaluation, and (2) understand the experience of English and Spanish-speaking caregivers attempting to make the same appointment and compare wait times.
We hypothesized that we would find longer wait times during Spanish-speaking calls.

METHODS
Study Design and Data
We conducted a mystery shopper study in which a trained bilingual research assistant (RA) called developmental pediatric programs affiliated with US children’s hospitals. Children’s hospitals were included if they had a physician listed as a developmental pediatrician, developmental-behavioral pediatrician, neurodevelopmental pediatrician, or developmental disabilities pediatrician. A publicly available list of hospitals belonging to the Children’s Hospital Association, an organization that represents over 200 children’s hospitals nationally, was obtained on the internet. One study team member (MEJ) went through the list and browsed their websites including services and physician directories to identify a developmental pediatrics program at the site or an affiliated center. When a program was not identified by browsing the website, a Google search was conducted pairing 5 terms (developmental pediatrics, developmental-behavioral pediatrics, neurodevelopmental pediatrics, neurodevelopmental disabilities and/or developmental disabilities) with the children’s hospital names until a program was identified. If one was not identified, the hospital was treated as not having one. We excluded programs that only accepted referrals from within their health system or plan, focused on specific disorders, did not conduct initial evaluations, and those staffed by nondevelopmental pediatrics. The RA used a standardized script and requested a developmental pediatrics appointment for his simulated 5-year-old son who was experiencing school difficulty and was referred by his pediatrician (Supplemental Digital Content 1, http://links.lww.com/JDBP/A125). The script was reviewed by developmental pediatricians, schedulers, and parents. Up to 3 attempts were made to contact each program at different times. We did not leave messages since given the national scope of the project we could not leave a local call back phone number and we also wanted to recreate the experience of a busy parent who might have a narrow time window to make an appointment without the flexibility of taking a call back. Calls occurred between December 17, 2015 and January 14, 2016.

Programs were first called in English. To compare wait times, programs that provided an estimate in English were called in Spanish within 24 hours. The bilingual RA translated the script and a second team member (MEJ) reviewed the translation. The child’s name and birth date were changed.

Outcomes
The primary outcome was time to first available initial appointment measured in months. The midpoint was used if a range was provided. Secondary outcomes included whether the program provided a wait time estimate and presence of Spanish language accommodation.

Analysis
Data were summarized using descriptive statistics. We tested our hypothesis that reported wait times obtained in Spanish would be longer than those obtained in English using Wilcoxon signed-rank test since wait times were not normally distributed with \( p < .05 \) defined as statistically significant.

The Institutional Review Board determined that this study was nonhuman subject research.

RESULTS
Of the 244 children’s hospitals listed, 140 unique developmental pediatrics programs were identified and called in English. We could not reach 36 programs (e.g., voicemail). Fourteen were excluded based on the established criteria. Among the 90 included programs, 75 (83%) provided a wait time estimate (Fig. 1).

We were unable to schedule an appointment with any programs. The most common reasons were that programs required a referral from a primary care professional, completion of an intake form or parent interview, or detailed insurance information prior to scheduling an appointment. Many programs required more than one of these.

Among the 75 programs that provided an estimate in English, only 62 were reached in Spanish. Only 34 of these programs (55%) provided an estimate when called in Spanish (Fig. 2). Among the 62 programs that provided an estimate in English and were subsequently reached in Spanish, 31% did not provide language accommodations.

The mean wait time for programs providing an estimate in English was 5.4 months (standard deviation [SD]: 4.5). The mean wait time for programs providing an estimate in Spanish was 4.6 months (SD: 4.2). The difference between wait times was not statistically significant (Table 1).

DISCUSSION
Among US children’s hospitals with developmental pediatric programs, we found a national wait time average of nearly half a year. Despite providing basic information including a child’s name and birth date, we were unable to obtain an appointment during these calls. A substantial number of the programs reached did not have readily available language accommodations for Spanish-speaking callers, suggesting additional access problems for this subgroup.

Developmental and behavioral problems are among the most prevalent health concerns faced by children, yet our findings illustrate that children throughout the US experience lengthy delays in accessing pediatric professionals who specialize in the diagnosis and medical management of these conditions. The growing prevalence of developmental and behavioral concerns and the ongoing shortages of developmental pediatricians highlight the need for policies that promote cross-sector partnerships.
between health care, education, and social services professionals, so that children’s needs can be addressed at the point of care and to ensure that the right children are matched to the right provider for their individual needs. Programs like Help Me Grow that promote early detection of children with developmental and behavioral concerns and provide centralized access to community resources that support healthy development may serve as a model for connecting children to appropriate help.21

Despite regulations and guidelines, we found that nearly one-third of programs reached in Spanish did not have language accommodations readily available. Under Title VI of the Civil Rights Act that prohibits discrimination based on national origin, entities receiving federal funds including Medicare and Medicaid are required to take reasonable steps to accommodate individuals with LEP.22 The Office of Minority Health National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (National CLAS standards) provides guidance on how health systems can provide equal access for individuals with LEP.23 Our findings are consistent with past work demonstrating access barriers

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Figure 1. English phone calls.

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Figure 2. Spanish phone calls among programs that provided an appointment estimate in English.
faced by Latino parents with LEP in trying to make health care appointments and reveal that much work in implementing guidelines is still needed. While we did not find longer average wait times in Spanish versus English, nearly half of the programs we called in Spanish did not provide an estimate which could suggest bias. All of these programs provided an estimate when called in English less than 24 hours before. While it is unclear whether the average wait times would have been longer if more programs had provided an estimate when called in Spanish, at a minimum this finding suggests that access to interpreter services does not fully address barriers faced by individuals with LEP.

Our study is subject to limitations. First, our study sample was limited to developmental pediatric programs affiliated with children’s hospitals, so our findings may not generalize to all practice types. Similarly, we focused on developmental pediatricians defined in this study as developmental behavioral pediatricians or neurodevelopmental disabilities physicians to explore an emerging workforce issue. Other professionals such as psychologists are also trained to conduct evaluations for developmental and behavioral concerns and this study does not provide estimates of wait times for evaluations by these professionals. Second, we only made phone calls in English and Spanish. Therefore, accommodations may have been present for other languages. Third, despite our attempts, we were unable to secure appointments at any of the programs so the actual wait time may vary. However, the fact that we were unable to secure an appointment with basic information including the child’s name, birth date, and chief concern reflects in and of itself, a multistep process parents must navigate. While requiring insurance information at the time of the call may protect families from unexpected charges after the visit, additional studies are needed to understand whether detailed intake information and referrals improve the efficiency of developmental pediatricians and thus facilitate access or whether this only represents an additional step for families to navigate.

### CONCLUSION

Our study reveals that on average, children wait nearly half a year to be seen by developmental pediatricians at US children’s hospitals with such programs. Additionally, we found a large number of programs that did not have language accommodations in place for a Spanish-speaking caller at the time of our call. These findings highlight opportunities to improve access for children with developmental concerns.

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### REFERENCES