

Delays in Access to Pediatric Subspecialty Care in California

Methods

Purpose

Comprehensive and coordinated care in primary care settings relies on having timely access to subspecialty care and services as needed. However, that access is becoming more difficult to attain for many pediatric subspecialties.¹ For families of children with chronic health conditions, also known as children and youth with special health care needs (CYSHCN), delays in access to pediatric subspecialty care can impact development, diagnosis, and prognosis. The research team sought to understand delays in access to pediatric subspecialty care as well as Applied Behavioral Analysis therapy, and the impacts of these delays on CYSHCN and their families. Delays in access to Applied Behavioral Analysis (ABA) therapy, a common treatment for autism and similar conditions, was also assessed. In addition, this survey explored experiences with peer-to-peer support, also known as family-to-family support, in which families of CYSHCN provide help to other families of children with similar conditions.

Instrument

The survey instrument included questions about new pediatric subspecialist visits within the last year. Respondents were asked to estimate the time they waited between referral to the visit and attending the visit, and about impacts of the wait times to see a subspecialist. Other features of the visit were assessed, such as the modality (in person, virtual), travel time, obstacles to travel, etc. Caregivers of children who had started Applied Behavioral Analysis therapy, a common treatment for autism and related conditions, were asked about the time between referral and the start of ABA therapy.

The survey also assessed the receipt of peer-to-peer support, formal or informal assistance provided by caregivers of other children with similar conditions, and impacts of that support. Finally, respondents were asked a series of demographic questions.

The survey was programmed as a web-based survey available in English and Spanish, with audio options in which respondents could press a button to hear question and response choices read aloud to them.

Sample

The protocol for the study was approved by the UCSF Institutional Review Board (23-39316).

The study team recruited a convenience sample of caregivers of CYSHCN who were clients of 17 Family Resource Centers (FRCs) across California. FRCs are not-for-profit community agencies serving families of children with developmental delays and chronic medical conditions.

Eligible participants were English- or Spanish-speaking adult caregivers residing in California whose child had a visit with a new pediatric subspecialist within the previous 12 months. Because low-income families may face particular challenges accessing care for their children, the study team sought to collaborate with FRC's that serve large numbers of low-income families. The final sample reflects this effort, with 78% of children classified as low-income based on Medi-Cal enrollment or uninsured status. Half of the children (49%) were ages 0-5 years old, and about a quarter each were ages 6-11 years (23%) and ages 12-18 (25%). Just over half (56%) of respondents identified as Hispanic or Latino/a/x and 41% identified as White. Smaller numbers identified as Southeast Asian (6%), Black or African American (6%), Asian (5%), or Chinese (4%). Participants were from Southern California (28%), the Central Valley (12%), the Central Coast (23%), and Northern California (37%). More than half (57%) live in a small city or suburb, while 34% live in a large city and 9% in a rural area.

¹ Klima, T. (2023). Access to Pediatric Specialty Care in California: Results of The Children's Specialty Care Coalition 2022 Member Survey (pp. 1–11). California: Practical Research Solutions.

Distribution of the survey

A survey link was generated for each site. FRCs distributed the link through their email listservs and printed flyers with a QR code link to the survey. Because of limited ability of FRC partners to provide custom links through their listservs, the survey was distributed through an anonymous link. Data was collected in August – October 2023. Respondents received a \$30 electronic gift card in recognition of their time.

Fraud detection protocol

The research team anticipated the distribution of the survey through an anonymous link to large groups of people would make the survey vulnerable to fraudulent responses. In particular, the team had concerns about bot attacks in which an individual writes code to submit multiple survey responses that appear to be submitted by eligible respondents. Based on the sparse literature and consultation with colleagues, the team utilized fraud detection tools in Qualtrics survey platform, such as invisible ReCaptcha technology, as well as embedded questions that required internally consistent logic (e.g., birth year and age), monitored open-ended questions for nonsensical responses, and verified Internet Protocol (IP) addresses through an external server of suspicious addresses.

The number of responses was monitored multiple times each day, and spikes in responses were immediately investigated. Research associates completed a logbook entry for responses that triggered any concern. A decision tree was developed to determine whether records were valid or fraudulent. In some cases, additional follow-up was necessary with the respondent.

Data Analysis

Datasets from each FRC were cleaned and cases were reviewed for final disposition (e.g., valid, ineligible based on various criteria, fraudulent). The English and Spanish versions of the survey were collapsed. Incomplete responses were removed if the respondent did not complete key survey items. Datasets were combined into one primary dataset. Open ended responses to “other” categories were reviewed and recoded as appropriate into existing or new categories.

Appointment wait times.

The investigator leading data analysis ran descriptive statistics for key variables of interest. She also examined the difference in wait times by subspecialties with at least 40 responses. Demographic variables, such as region, were examined to determine if some groups (in this case, geographic areas) experienced longer wait times than others.

Peer support.

The analyst examined descriptive data about receipt of peer support and differences in receipt of support by subgroups, e.g., region, urbanicity, gender, race/ethnicity, survey language, child age, and insurance, as well as developmental disability status and medical complexity. Additionally, she analyzed various aspects of peer support, such as the referral process and positive and negative effects of peer support.