



# Pediatric Subspecialist Referrals to Peer Support for Families

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## Abstract

**Background and Objectives** Families of children with special health care needs (CSHCN) have reported to benefit from social, emotional, and informational support from other families (peer support) with similarly affected children. Pediatric subspecialists often serve as the primary medical providers for CSHCN, as well as educators for these children's families. The extent to which subspecialists refer families to sources of peer support is unknown.

**Methods** A statewide online survey of California pediatric subspecialists investigated opinions about the potential value and challenges of peer support. Data was obtained on the frequency with which families in their practices were referred to peer support, practice characteristics, and personal demographics. Weighted data, descriptive statistics, and regression models were used to characterize and predict factors affecting referral services.

**Results** There were 388 respondents, a response rate of 14.5%. Subspecialists were generally unfamiliar with peer support resources in their communities, but many more knew of peer support programs in their institutions. Most (> 85%) held positive views about peer support, though only 40% of practices often referred families for such support. Individual opinions did not predict practice referral processes for peer support which were more influenced by knowledge of resources, and availability of time, staffing, and institutional peer support resources.

**Conclusion** Offering referral to peer support services is compatible with pediatric subspecialty care. Educating physicians about available resources, assigning responsibility, providing staff time for referring families, and incorporating parent mentors into subspecialty practices can increase access. Future studies of families' referral experiences are needed.

## Significance

**What's Known on this Subject** Parent-to-parent peer support resources for families with children with special health care needs are highly valued and available in every state. Pediatric subspecialists who care for these children and families are uniquely positioned to facilitate referrals to these support services.

**What this Study Adds** Pediatric subspecialists in California hold nearly universally positive attitudes about peer support, but their practices refer only about 40% of families often or very often for this service. Educating practice staff, assigning responsibility, and engaging family mentors could increase referrals.

**Keywords** Peer support · Children with special health care needs · Pediatric subspecialty care · Care coordination

## Introduction

Nearly one in five families have a child with special health care needs (CSHCN) (Data Resource Center for Children's Health). Families typically are not prepared and need support for the unanticipated and stressful situation of having such a CSHCN are a diverse group, ranging from those with common single-system disorders to those with complex life-limiting conditions (Davis & Broscio, 2007). Parents of CSHCN, especially when the child is newly diagnosed with a serious medical condition, report feeling lost, isolated,

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and concerned about the future. Their perception of social support diminishes according to the complexity of their children's needs and their own mental health and socioeconomic status (Geweniger et al., 2024). These parents need to acquire new knowledge and skills to manage their child's medical condition and navigate the health care system (Mirza et al., 2018). States' Title V CSHCN programs can be a resource helping families meet these needs (Brown et al., 2022). While primary care-based medical homes are often central to the care of CSHCN and family support, most families rely on pediatric subspecialists for early medical information, treatment, and advice (Hartzler & Pratt, 2011). Families also turn to social media for information and social support (Baum, 2004; Niela-Vilen et al., 2014; Bray et al., 2017; Kelly et al., 2021). An important additional support for parents is contact with other parents of CSHCN who have similar experiences and challenges. They tend to find great value in their connections to these other parents, though the availability of and access to such parents varies (Tully et al., 2017; Singer et al., 1999).

Parent-to-parent support, often referred to as peer support (PS), is a non-clinical set of peer-based activities offering personal, ongoing guidance and assistance that health care professionals may not provide (Hughes, 2015; Ireys et al., 1996). Families may require assistance accessing the information, resources, and assistance they need to obtain services and insured benefits, understand and manage their children's health problems, and cope with the emotional and day-to-day challenges they may face. PS services may include providing information along with emotional, social and instrumental support, and advocacy (Hartzler & Pratt, 2011; Hoagwood et al., 2010; Kerr & McIntosh, 2000; Pelentsov et al., 2015); Oakley et al., 2022). PS is often available through community organizations, such as federally funded family-to-family health information centers, local Parent-to-Parent USA operations, or institution-based programs that connect parents, train peer supporters, and offer information and system navigation support. By being empathetic, accepting, and family-centered, peers can help prioritize sources of information, encourage appropriate use of professional services, navigate financial barriers, anticipate and guide responses to home- and family-related issues, and offer suggestions on implementing care plans (Sullivan-Bolyai & Lee, 2011; Klee et al., 2019).

Although research on the effect of PS on parents does not consistently document positive outcomes (Sartore et al., 2021), based on parents' report PS can reduce feelings of isolation, increase confidence and general well-being, and help parents adjust to the new normal created by their child's condition (Hall et al., 2015). Additionally, peers can serve as confidants, reducing anxiety and depression and improving problem-solving skills, thereby allowing

parents to provide more responsive, effective care to their children (Konrad, 2007). Some studies have found that PS can be clinically impactful and cost effective, especially for those with few financial resources, low health literacy, or poor clinical status (Fisher et al., 2015; Ireys et al., 2001). PS can also bring cultural sensitivity to care, which also can improve effectiveness (Ho et al., 2022).

Provider-level barriers to PS include concern that parents will receive unreliable medical information, demand inappropriate therapies, request unnecessary referrals, lose privacy/confidentiality, or negatively impact parent-provider partnerships (Davies & Hall, 2005). Although some research has identified the provision of inappropriate PS advice (Knoepke et al., 2018), there is little evidence that it harms the clinical status of patients or interferes with the clinical management process (Shilling et al., 2013). The American Academy of Pediatrics has encouraged pediatricians to facilitate access to PS (American Academy of Pediatrics, 2012), but the frequency of this assistance remains understudied. Family Voices, a national parent organization ([www.familyvoices.org](http://www.familyvoices.org)), conducted a national survey of family-to-family health information centers, which offer PS, and found that only about 20% of their referrals were from health care providers (personal communication).

CSHCN see pediatric medical specialists (Specialists) for care more than four times as often as other children (Data Resource Center for Children's Health), and those physicians, including neonatologists and a variety of other specialists, play key roles in the diagnosis and early and continuing medical care of this population's chronic conditions. Because most Specialists practice in or are affiliated with medical centers with greater resources than community practices, they are uniquely positioned to initiate referrals of families for PS (Schor & Fine, 2022) yet little is known about their referral practices. This study was designed to learn about the opinions of those physicians regarding PS, to document current referral processes, and to understand what steps might be taken to enhance families' access to PS.

## Methods

### Survey Development

Physicians, families, and experts on content and research developed a survey instrument to elicit Specialists' perspectives about PS for families with CSHCN. Demographic and practice description items were derived from surveys by the American Academy of Pediatrics of its members. The survey was pilot tested by several experienced family representatives and subspecialist pediatricians, and its content was reviewed by the Board of the Children's Specialty Care

Coalition ([www.https://childrens-coalition.org/](https://childrens-coalition.org/)). The survey (Appendix A) was programmed on the Conformat platform for online administration and took, on average, 7 min to complete (mean = 7.33).

## Participants

The sample frame was identified in February 2022 using the publicly available database of the Centers for Medicaid and Medicare Services' National Plan and Provider Enumeration System (NPPES). Physicians (MD, DO) were included if they specialized in one of fourteen fields that most commonly treat children with chronic medical conditions (Table 1) based on their NPPES taxonomy codes and practiced in California according to their practice address. The resulting sample frame was 2668 physicians. Screener items in the survey further confirmed that respondents were in active clinical practice, not trainees, and, for specialists other than neonatologists, spent time in outpatient settings.

**Table 1** Respondent characteristics

Characteristics	Sample Frame	Unweighted Sample (N=388)	Weighted to Sample Frame
<b>Pediatric subspecialty<sup>^</sup></b>			
Neonatal-perinatal medicine	28%	33%	28%
Hematology-Oncology	14%	13%	15%
Cardiology	13%	10%	12%
Endocrinology	7%	8%	9%
Gastroenterology	8%	7%	7%
Neurology	9%	6%	7%
<b>Practice setting: Neonatologists only</b>			
Children's/maternity hospital	Not Available	55%	53%
All other settings		45%	47%
<b>Practice setting: Other subspecialists</b>			
Hospital/Medical school	Not Available	76%	75%
All other settings		24%	25%
<b>Age in years</b>			
Less than 40	10%	14%	13%
40–54	35%	46%	35%
55–64	28%	21%	28%
65 or more	26%	19%	24%
Gender: Female	52%	59%	51%

Total percent may not equal 100% due to rounding

<sup>^</sup>The following specialties had 5% or fewer respondents in the sample: Developmental-Behavioral Pediatrics, Neurodevelopmental Disabilities, Allergy/Immunology, Nephrology, Physical and Rehabilitative Medicine, Pulmonology, Rheumatology, Transplant Hepatology

## Survey Administration

The survey was fielded between April-May 2022 by Mathematica, Inc. All physicians in the sample frame received a push-to-web participation invitation in the mail. Updated email addresses were purchased from IQVIA (IQVIA Onekey Reference Dataset) for 81% of the same frame to improve recruitment. In anticipation of a low response rate, five reminder emails with a unique survey link were sent to physicians who had not completed the survey. In addition, senior administrators at most large pediatric hospitals in California sent 2–3 emails to their organizations' Specialists to promote participation in the survey. Moreover, pediatric professional organizations, including chapters of the American Academy of Pediatrics California, California Children's Hospital Association, California Association of Neonatologists, and Children's Specialty Care Coalition, contacted their members via newsletters and email to encourage them to participate in the study by providing a generic survey link. A donation of \$25 was made to chapters of the Ronald McDonald House Charities in California on behalf of each physician who completed the survey.

Review by an institutional review board was not sought because this study fell under exemptions in the US Code of Federal Regulations 45CFR46.104(d), including interactions involving survey procedures that do not include sensitive topics or contact with vulnerable populations.

## Sample Weights

After determining eligibility for participation, removing records with a large number of missing items ( $n=41$ ) and deduplicating records ( $n=11$ ), a weighting procedure was applied to all eligible cases ( $n=388$ ) to counter potential nonresponse bias that may have skewed the results. Because the sample frame is the best proxy identified by the researchers for this respondent population, weights were applied to all eligible cases, including those who accessed the survey via a generic link, to approximate frame characteristics. Raking, a weighting adjustment method, adjusted the weights one at a time to match the marginal distributions of the control variables in the frame. The weighting control variables used were age, specialty, gender, and practice location by region.

## Survey Measures

### Respondent characteristics

Respondents identified their pediatric subspecialty (e.g., neonatology, cardiology) as well as the practice setting in which they spent most of their clinical time, and the county

in which their practice was located (recoded to reflect larger regions of California). They self-reported gender. Age was determined primarily through IQVIA's OneKey Select database of physicians (IQVIA Onekey Reference Dataset) and was imputed for 27% of the sample based on their self-reported years in practice.

### Resources in the practice

Respondents rated their familiarity with PS resources in their local community using a 4-point familiarity scale (Not at all – Extremely). This variable was dichotomized for the regression model into 'not at all familiar' and 'any degree of familiarity.' Reported availability of PS programs in the specialist's institution or practice was coded as available vs. unavailable or unsure. Whether practice settings had sufficient time to connect families to PS resources was rated on a 4-point agreement scale (Strongly Disagree – Strongly Agree). Responses were dichotomized by agreement vs. disagreement for analyses. Finally, respondents reported on different staff positions present at their practice setting, including family liaison or parent mentor combined into one variable to reflect either position (FamRep), social worker (SW), and care coordinator/case manager (CC).

### Opinions about PS

A definition of PS was provided in the survey: "Parent-to-parent support offers personal, ongoing assistance to families of children with chronic conditions by other families with similar experiences." It was followed by eleven statements about its value to families of CSHCN and the practice. Respondents indicated their agreement with the statements on a 4-point scale (Strongly Disagree – Strongly Agree). Two of the items presented potentially negative outcomes of PS, i.e., provides inaccurate medical information to families, and increases families' questioning of medical recommendations. Because the negative items were not highly and, in some cases, not at all correlated with the positive items, they were excluded from a composite variable, Average Positive Opinion, which was the mean of the 9 positive items; these included such outcomes as providing useful information and emotional support and increasing satisfaction with care (Cronbach alpha = 0.87).

### PS referral processes

Using a 5-point Likert scale (Never – Very Often), respondents reported on the frequency with which five referral processes occurred in their primary practice settings: (1) Referral to PS in the community, (2) Referral to PS in the practice or institution, (3) Information offers about sources

of PS, (4) Encouragement to use virtual support groups (i.e., social media), and (5) Follow-up of PS referrals. A composite variable, Active Referral, was created to reflect the frequency of referral for PS (as opposed to providing information or encouragement) using the higher rating of either (1) Referral to PS in the community or (2) Referral within the institution. The frequency rating was dichotomized to reflect rarely (Never – Sometimes) vs. often (Often – Very Often) referring families to some form of PS.

### Data Analysis

Descriptive statistics were performed on all variables, and unless otherwise specified, are reported based on individually weighted cases that approximate the total sample frame (minus missing data).

A binary logistic regression model predicted the likelihood of Active Referrals from (1) physician opinions about PS, and (2) a set of practice resource variables (time to refer, availability of institutional PS program, presence of FamRep, presence of a CC, and familiarity with community resources), controlling for respondent characteristics. The odds ratios of predictors reflect the likelihood of 'often' referring relative to 'rarely' referring families to PS supports. Each predictor was entered individually into the model with the dependent variable being Active Referral. The dependent variable was not normally distributed, with few respondents reported "rarely" or "never" referring for PS; thus, the variable was dichotomized. Table 2 displays these odds ratios (and corresponding confidence intervals) as the Unadjusted Odds Ratios. All predictors and control variables were then entered simultaneously into the regression model; these results are shown in the third column of Table 2 as the Adjusted Odds Ratios (and confidence intervals).

## Results

### Response Rate

429 eligible physicians responded to the survey. After removing incomplete surveys, the final sample contained 388 physicians (14.5% of sample frame). This sample closely resembled the distribution of respondent characteristics in the original sample frame on measurable variables, e.g., physician gender, age, and subspecialty, such that the weighting procedures did not lead to substantive changes in the sample makeup (see Table 1 for unweighted and weighted sample characteristics).

**Table 2** Frequencies of peer support resources

Resource (weighted <i>n</i> )	Per-cent in weighted sample
<b>Peer support program available in institution or practice (2613)</b>	
Not available	19%
Available in practice	9%
Available in institution	23%
Available in both	24%
Unsure	24%
<b>Familiarity with peer support resources in community (2609)</b>	
Not at all	28%
Somewhat	53%
Very or Extremely	19%
<b>Staff available in practice (2475)</b>	
Social worker (SW)	89%
Care coordinator/case manager (CC)	70%
Both SW and CC	69%
Family liaison or parent mentor (FamRep)	29%
<b>Staff who make peer support referrals (1457)*</b>	
Social worker	68%
Physician	14%
Care coordinator	7%
Nurse	6%
Family liaison or parent mentor	1%
<b>Sufficient staff time for peer support referrals (2463)</b>	
Agree/strongly agree	41%
Disagree/strongly disagree	59%

\*Total N for this variable is smaller because only respondents who reported that their practice refers to P2P resources were presented with this follow-up item. Other response choices were endorsed by fewer than 5% of respondents

## Respondent Characteristics

The 388 specialists who responded to the survey included 33% neonatologists and thirteen other types of subspecialties (67%; see Table 1). 41% of respondents were male, and most (67%) were 40–64 years old. Among neonatologists, about one-third practiced in free-standing children’s hospitals, 20% in children’s hospitals within general hospitals, and 38% in general community hospitals (Table 1). Among other specialists, the majority practiced at medical schools (31%) and in hospital-affiliated settings (45%); less than 10% were in one or, two-person practices or pediatric group practices. 56% of neonatal respondents’ patients and about two-thirds of other patients were estimated to be publicly insured. 17% of respondents reported that they had a child with special health care needs in their family.

## Resources in Practices

Only 19% of respondents were very or extremely familiar with organizations or agencies in their community that provided PS to families of CSHCN and 28% were not at all familiar (Table 3), although family resource centers are widely available across California. 56% of respondents reported that PS services were available in their practices or institutions; 19% reported they were not available, and the remainder were unsure of their availability. Either a SW (89%) or CC (70%) was available at respondents’ practices, and 69% of practices had both. A FamRep, either a family liaison or parent mentor, was less often present (29%); they were more available in neonatology (40%) and hematology-oncology (42%) practices than in other specialties (< 25%).

**Table 3** Physician opinions of peer support and referrals to peer support resources

Opinions about Peer Support	Weighted <i>N</i>	Mean(SD)*	Percent endorsing Agree/Strongly Agree
<b>Positive opinions</b>			
Provides useful medical information	2616	3.00 (0.58)	85%
Provides emotional support	2597	3.63 (0.55)	99%
Encourages following medical advice	2624	3.07 (0.56)	89%
Helps connect with services and resources	2620	3.42 (0.57)	97%
Increases caregiving skills	2635	3.29 (0.57)	96%
Increases caregiving confidence	2544	3.34 (0.52)	98%
Increases satisfaction with care	2523	3.07 (0.57)	88%
Promotes better relationships with practice	2502	3.06 (0.56)	88%
Improves patient outcomes	2522	3.06 (0.56)	88%
<b>Negative opinions</b>			
Provides inaccurate medical information	2624	2.24 (0.64)	29%
Increases questioning of medical advice	2548	2.61 (0.64)	55%
<b>Referrals for Peer Support by Practice</b>			
	<b>Weighted N</b>	<b>Mean (SD)<sup>+</sup></b>	<b>Percent endorsing Often/Very Often</b>
Active referrals to community or institution resources	2509	2.29 (1.07)	42%
Provide information on peer support resources	2432	2.02 (1.15)	38%
Encourage use of virtual support groups on social media	2437	1.36 (1.00)	12%
Follow-up on peer support referrals	2412	1.38 (1.08)	16%

\*Scale ranges 1–4<sup>+</sup>Scale ranges 0–4

Only 41% of respondents agreed that there is sufficient time to make PS referrals in their practice.

### Opinions About PS & Referral Processes

Across the nine positive measures of PS, 85–99% of respondents agreed/strongly agreed with the positive value of PS (Mean of Average Positive Opinion=3.22, Standard Deviation=0.39). For the other two negative items, 29% of respondents thought that PS might give inaccurate information, and 55% thought that PS might cause patients to question medical recommendations (Table 4); 40% agreed with both statements.

About 40% of respondents said their practice often/very often actively referred families to community or institutional PS sources, as well as provided information about PS resources. However, whereas about one-fifth of respondents rarely/never actively referred, one-third rarely/never provided resource information. When PS referrals were made, the SW was responsible 68% of the time and the physician 14% (Table 3). Only 16% of respondents often or very often followed-up on PS referrals to see if they had been completed. Encouraging families to access information and support via social media was infrequent: 58% of respondents rarely/never encouraged accessing virtual support, and only 12.5% did so often/very often (Table 4). Physicians whose own child had a special health care need did not differ from other respondents in their opinions about PS support ( $t[2248]=1.29, p=.198$ ) or their referral processes ( $X^2[1, 2266]=0.288, p=.591$ ).

### Predictors of PS Referral Processes

When positive opinions about PS were entered into a regression alone, they were significant predictors of active referrals (see unadjusted odds ratio, Table 2). However, when control variables (physician demographics, practice characteristics) and other independent variables were included in the regression model, positive opinions were no longer predictive of PS referral processes. Rather, referral processes were positively associated with certain aspects of practices' infrastructure, referred to collectively as "PS resources." In

a logistic regression model, practices that had PS programs in their practice setting (as opposed to externally) were four times more likely to "often" refer patients to PS supports than to "rarely" refer them. Practices with FamRep were almost three times more likely, and practices with a CC and which were familiar with community PS resources were about 2.5 times more likely to refer 'often' than 'rarely.' Those who reported sufficient time for staff referrals were twice as likely to refer 'often' than 'rarely.'

### Discussion

Parents of CSHCN value and benefit from their interactions with experienced parents (Tully et al., 2017). The Council on Children with Disabilities of the American Academy of Pediatrics has encouraged pediatricians to recognize the unique needs of parents and refer them to support groups to promote their and their children's physical and emotional health and well-being (Murphy & Carbone, 2011).

Pediatric specialists strive to provide high-quality, family-centered medical care throughout the entire course of a child's illness to ensure improved child and family outcomes. Families likely differ as to when they would want and benefit from services such as PS, though most parents prefer to have that service at or shortly after the time of diagnosis (Baron et al., 2018). Therefore, pediatric specialists are well positioned to ensure that families receive the appropriate family supports at the appropriate time, (e.g., time of diagnosis; during chronic care). Given the known benefits of PS to families, referrals for PS should be a standard part of practice and routinely offered by pediatric specialists as part of ongoing chronic illness care. Where pediatric specialists and primary care pediatricians operate as team members within a comprehensive medical home, responsibility for facilitating families' access to PS can be a shared responsibility.

This survey revealed largely positive opinions about the potential value of PS among specialists and modest concern that having contact with experienced parents might encourage families to question medical recommendations or receive inaccurate medical information. Holding positive

**Table 4** Logistic Regression Predicting Likelihood of referring to peer support. Resources in the community or practice setting

Independent variable	Unadjusted OR	Adjusted OR (CI)
Availability of program in practice setting	6.43 (6.23,6.63) ***	4.05 (3.82, 4.28) ***
Family liaison/parent mentor in practice	3.71 (3.53,3.89) ***	2.90 (2.66, 3.14) ***
Care coordinator in practice	2.85 (2.66, 3.04)***	2.52 (2.26, 2.78)
Familiarity with community resources	4.64 (4.42,4.86) ***	2.42 (2.15, 2.69) ***
Sufficient time for peer support referrals	2.35 (2.17,2.53) ***	1.94 (1.72, 2.16) ***
Opinions about peer support	1.76 (1.54,1.98) ***	1.14 (0.84, 1.44)

\* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$

Analysis includes the following variables as controls: physician age, physician gender, practice size, specialty, Californian region of practice

opinions about PS did not predict referral practices. Positive opinions may be prerequisite for action, but systemic issues appear to be determinate. Neonatologists comprised a substantial portion of the physician sample, but they did not differ from other subspecialists in the important predictors of referral to PS.

Team-based care, at least the presence of non-physicians in the practice, seemed to increase referral processes. Additional research on the specific roles and processes of health care teams related to PS referrals as well as identification of best practices is needed.

The presence of a FamRep may signal an existing commitment to family-centered care or may function as a reminder of the needs of families; both could explain their effect on PS referrals. Similarly, care coordinators' presence suggests that comprehensive care, in collaboration with social workers and other staff, increased the likelihood of PS referrals. However, the presence of a social worker who may have multiple, competing responsibilities did not predict PS referrals. To systematize PS referrals, assigning social workers or care coordinators specific responsibilities to offer peer referrals and providing the time to do so might be needed.

Specialists' familiarity with community PS resources more than doubled the rate of "often referring families" compared to "rarely referring them" to PS. Family-to-family health information centers supported by the MCHB exist in all states. Their staff assist families with CSHCN by connecting families to community resources and PS (Evidence Tools, 2024). These agencies also welcome referrals from health providers and public agencies Family-to-Family Health Information Centers, 2018). Additionally, condition-specific organizations serve as an important PS resource. State Title V CYSHCN programs are well-positioned to educate health care providers and families about the value of PS resources. They can work to increase the availability and quality by assessing community needs, engaging with and convening community partners and families, and developing policies and programs MCH Evidence). Organizations could increase referrals by educating specialists and their staff about the support services they offer.

Integrating PS into specialty practices and their institutions may require overcoming systemic structural and administrative barriers (Iscoe & Bordelon, 1985; Forman et al., 2005; Moran et al., 2007; Cottrill, 2011) especially since there is little evidence of financial savings for health care systems and no obvious source of payment for widespread availability of PS (Pennington et al., 2013; Manalo, 2008). Some approaches include integrating prompts for PS referral into electronic medical record and hospital discharge templates, hiring FamReps as members of care teams, and allowing sufficient time for care coordination and referrals.

The growing interest in adopting social and educational interventions to enhance the quality of life of families with CSHCN (McLellan et al., 2022; Van Cleave et al., 2022) and in the role of community health workers (Costich et al., 2019; Kåks, 2020) offer opportunities for these changes.

Nationally, several hospitals and organizations have developed guidance for quality PS training and evaluation (Mirza et al., 2018; Ho et al., 2022; Hartman et al., 1992; Olin et al., 2014; Donegan et al., 2016), and concerns have been raised about parents who are not ready to serve as peer mentors (Dodds & Singer, 2018). Although not focused on CSHCN, peer support has long been seen as a part of mental health care. California and more than 35 other states have legislated requirements for the development of PS certification programs for mental health and substance abuse and authorized a funding mechanism (Peer Support Specialist Certification Program Act of 2020; Person- and Family-centered Care and Peer Support). Less progress has been made to ensure the quality of the extensive PS resources available through social media (Bullock et al., 2002; Law et al., 2002; Smith et al., 1994; Mustafa et al., 2015., Seid et al., 2014; DeHoff et al., 2016). Despite parents' almost universal use of social media this study found that specialists rarely encouraged families to use these resources. This may reflect a fear of misinformation and/or lack of familiarity with available resources and indicates a need for vetting of social media sites and guidance so physicians can comfortably direct families to reliable sites.

Limitations: Despite considerable efforts by the research team and pediatric professional organizations in California to encourage participation in this survey, the response rate was low, as is typical of recent surveys of physicians that do not use pre-selected response panels (Golnik et al., 2009; Weaver et al., 2019; Cunninham et al., 2015; Barnhart et al., 2021). This study was conducted during the COVID-19 pandemic during which physicians were especially challenged, fatigued, and unavailable to respond to surveys. Because of this response rate, we cannot rule out a biased sample of physicians who generally favor PS and may have overreported referrals. Such bias could have impacted the results in ways that could not be corrected statistically. For instance, although in this sample, opinions did not impact referrals, it is possible that among physicians with more negative PS opinions, a fundamental objection to the use of PS supports in care may prevent referrals. This study only examined subspecialists and their practices. In general, families with CSHCN also rely on primary care and complex care practices which may also refer to PS, thus decreasing the need for specialists to refer. There is no data on the extent to which these practices make referrals for PS, so additional research is needed. Nevertheless, this study

provides important insights to potential barriers and facilitators to PS for families of CSHCN.

## Conclusion

Ensuring that families caring for CSHCN are well supported decreases caregiver stress, improves wellbeing of family members, and improves the care and health outcomes of children. Offering referrals to peer support services is a valuable adjunct to chronic care and has been recommended as a routine part of a comprehensive medical home for CSHCN. Pediatric subspecialists' positive opinions about peer support align with those of families with CSHCN, yet referrals are far from universal. Families' access to peer support can be improved by increasing pediatricians' familiarity with the availability and benefits of PS, augmenting practice staffing with parent mentors and liaisons to enhance family-centered care and integrating peer support into the practice or institution. Additional research on the actual referral processes used by subspecialty practices and families' experiences accessing and using PS could increase the number of families that benefit from these services.

**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s10995-024-04033-y>.

**Author Contributions** Dr Edward Schor, Holly Henry, and Allison Gray conceptualized the study and drafted the survey instrument. Dr Edward Schor, Tali Klima, Holly Henry, Allison Gray and Megumi Okumura revised the survey instrument and oversaw data collection. Tali Klima conducted the analysis with advice from Megumi Okumura. Dr Edward Schor drafted the initial manuscript and Tali Klima drafted the initial methods section. Dr Edward Schor, Tali Klima, Holly Henry, Allison Gray, and Megumi Okumura critically reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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**Data Availability** Original data is available from the funder, Lucile Packard Foundation for Children's Health. <http://www.lpfch.org>.

## Declarations

**Ethics Approval** Review by an institutional review board was not sought because this study fell under exemptions in the US Code of Federal Regulations 45CFR46.104(d), including interactions involving survey procedures that do not include sensitive topics or vulnerable populations.

**Conflict of Interest** The authors have no conflicts of interest relevant to this article to disclose.

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