

# A Survey of Caregivers of Children and Youth with Special Health Care Needs

## Family Perspectives on Peer Support

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Children with chronic health conditions, known as Children and Youth with Special Health Care Needs (CYSHCN), often have complex health needs that require more treatment and therapy than other children. Their caregivers must coordinate their care with multiple providers, organize treatments and medications, navigate a complex health care system as well as health care coverage, and access external resources in the community or education system. These caregivers may benefit from informational as well as emotional support in managing their child's care and condition.

The current study was undertaken in California to better understand the perspectives of these caregivers. In collaboration with Family Resource Centers throughout the state (facilitated by the Family Resource Centers Network of California), caregivers of CYSHCN were recruited to participate in a short web-based survey on their experiences accessing specialty care for their child and receiving support from other caregivers. The latter topic, which is known as peer support, is the focus of this report.

### About this study:

During Summer/Fall 2023, caregivers responded to a short web-based survey in English or Spanish. In total, 646 Californian caregivers participated. The families represent diverse geographic areas, including 37% of respondents from Northern California, 28% Southern California, 23% Central Coast, and 12% Central Valley (57% live in a small city or suburb, 34% large city, and 9% rural area).

Most children of respondents in this survey (77%) were covered by Medi-Cal (Medicaid in California), indicating a low-income sample. 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%).<sup>2</sup> About half of the sample (56%) identified their child as Latino in ethnicity. Forty-one percent identified their child's race as White, 6% as Black, 6% as Southeast Asian, and 20% as other races.

For more information about the study, such as the sampling strategy, please visit: <https://cepc.ucsf.edu/delays-access-pediatric-subspecialty-care-california>

### Receipt of peer support:

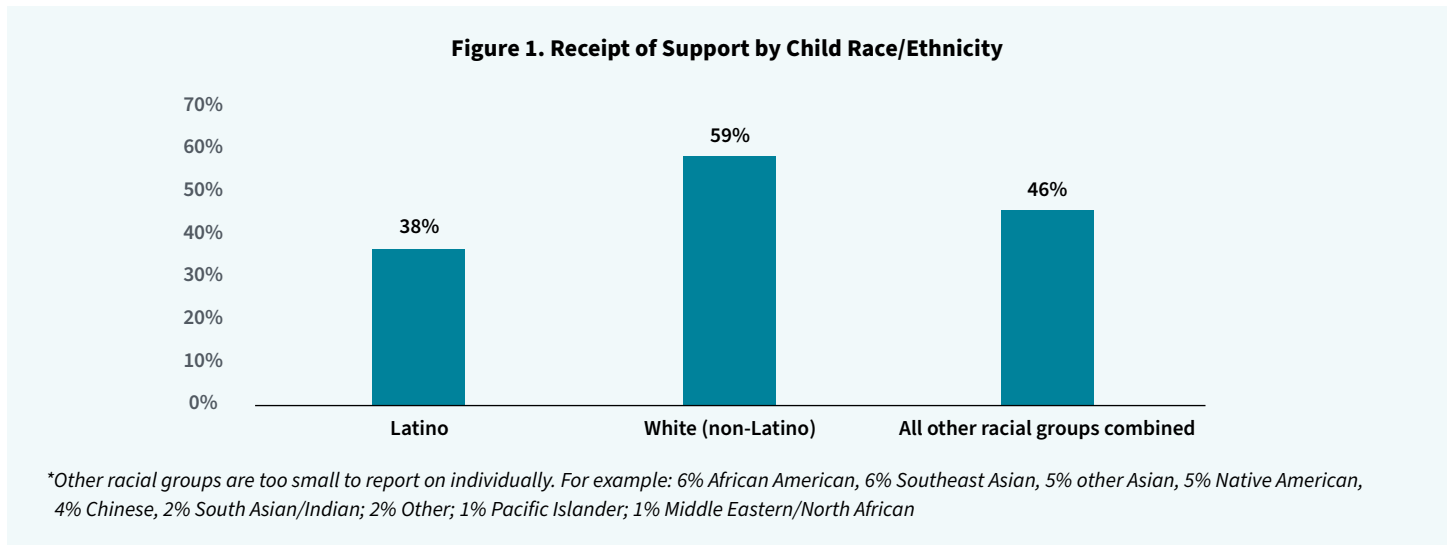
Just under half of caregivers (45%) reported that they had received peer support from other families in the past five years. This estimate is likely higher than what would be reported by families of CYSHCN generally because families that participated in the study were recruited through Family Resource Centers that provide peer support, among other services.

*Peer support, also known as family-to-family support, is when families offer help and information to other families of children with similar health conditions, such as ways to navigate the health care and other relevant systems (like schools). Caregivers may connect with each other one-on-one, in groups, or online through social media. This is different from social support that many caregivers receive from their family and friends in that it is support focused on the child's condition and care provided by caregivers who have condition-specific experience and knowledge.*

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<sup>2</sup>Three percent were ages 19-20. Although no longer minors, the study allowed caregivers to report on their care because California Children's Services (CCS), which serves CYSHCN, covers individuals until they turn 21.

There were no differences in receipt of support by most demographics, like age or gender of child or family income. However, significantly fewer families of Latino children reported receiving peer support (Figure 1).

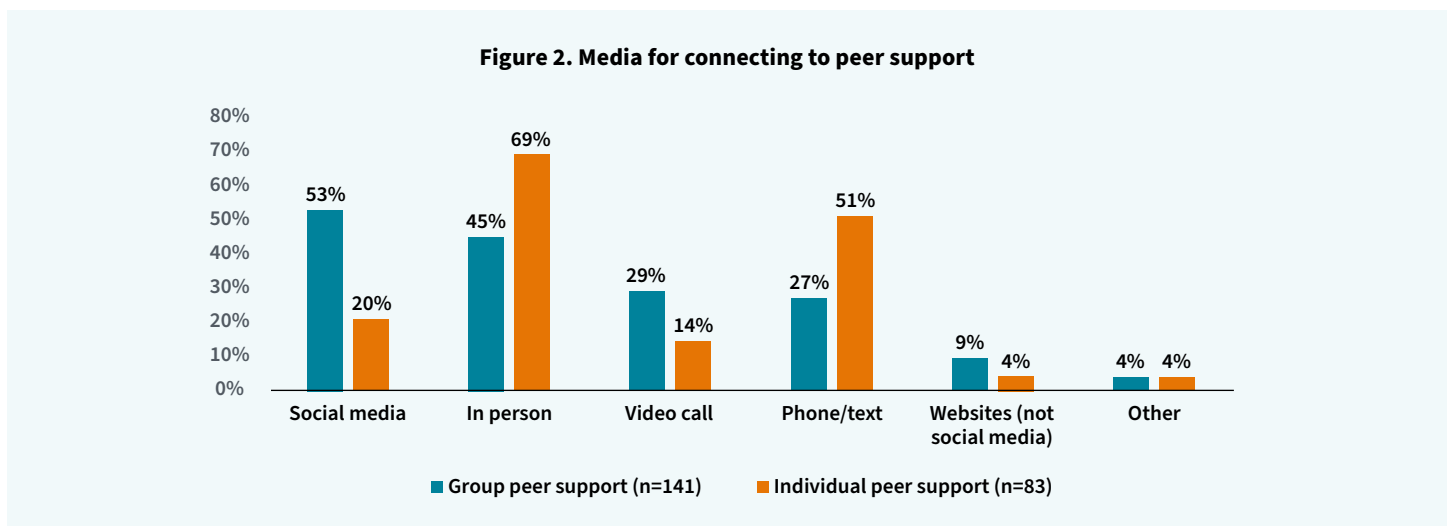


Caregivers who chose to take the survey in Spanish, likely indicating lower English proficiency than their Latino counterparts who completed the survey in English, had the lowest rates of peer support (27% vs 42% for other Latino families). Caregivers of children who require more medical care<sup>3</sup> also were more likely to report receiving peer support (51% vs 42% for families of children with fewer medical needs).

### Format of support:

Fifty percent of caregivers who received support did so in a group setting, while 30% received support from an individual. Twenty percent reported both group and individual peer support.

Many caregivers who received support in both group and individual formats did so through in-person contact (45% and 69%, respectively; Figure 2). However, about half (53%) of those who received group support also relied heavily on social media to connect with other families, whereas those who received individual support relied more on phone and text messages (51%).

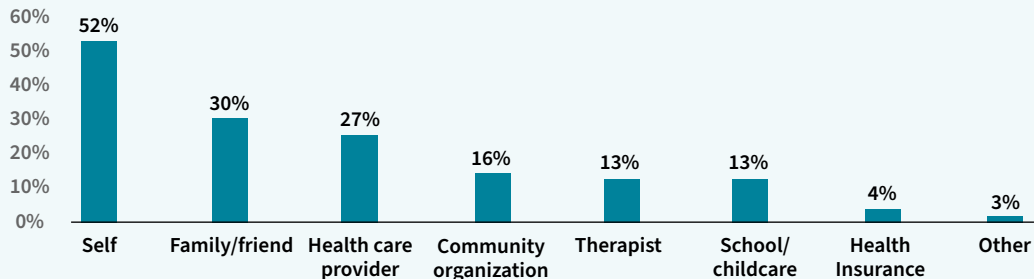


<sup>3</sup> Defined as an average of four or more hours per week of medical and therapeutic appointments.

## Referral to peer support:

By far the most common source of referral to peer support was self-referral (that is, finding the support themselves). Only about a quarter (27%) of caregivers who received peer support were referred to this support by a health care provider.

**Figure 3. Source of referral to peer support**



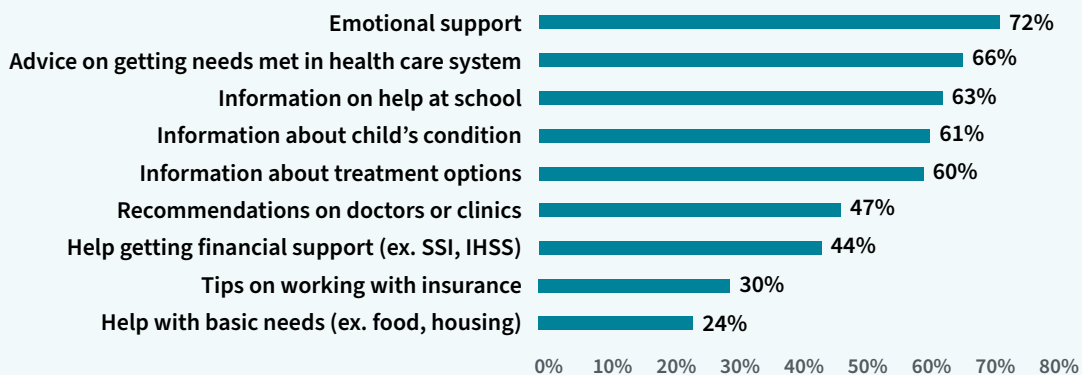
The survey also asked all respondents, even those who did not receive peer support, if they were ever referred to peer support by a health care provider. Only 36% (221) of respondents received a referral from a health care provider to any kind of peer support. Furthermore, among those who received such a referral, only 25% (55) reported that the peer support they ultimately received was a result of the referral from their provider. In other words, the majority of provider referrals do not result in receipt of support. This corroborates findings from a recent survey of pediatric subspecialists in California that showed that although some practices provide referrals (42%), very few follow up on their referrals (16%; Schor et al., 2023).

In the current sample, 75% of caregivers who received a health care provider referral to peer support received this referral within six months of their child's diagnosis. However, this figure should be treated with caution as the sample contains many children with developmental delays (69%), which may not be representative of the referral process for other types of conditions, for example, chronic mental illnesses or complex medical conditions.

## Supports received from other families:

Caregivers were asked which, if any, supports they received in the context of their peer support activities (Figure 4). Most respondents reported receiving emotional support, advice on meeting the child's needs in the health care system, and information related to getting help at school, treatment options, or the child's condition.

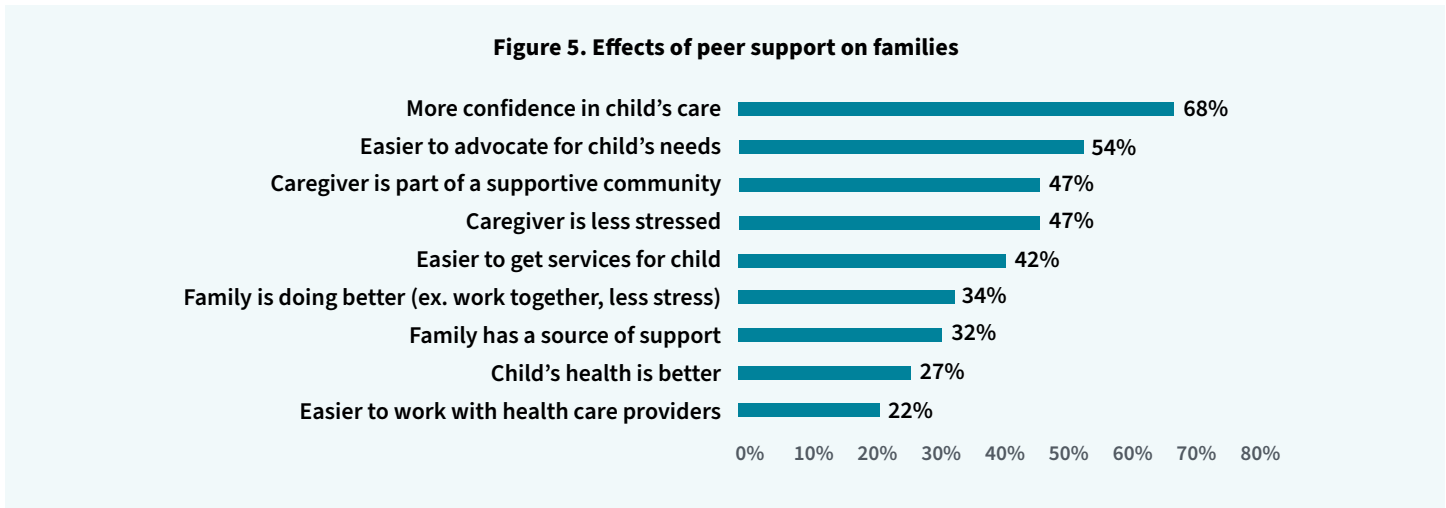
**Figure 4. Types of peer supports received by families**



“ I better understand the process for accessing a resource we’ve wanted for several years, it helped me take the steps to making it happen and helped me feel less guilty that I haven’t figured it out earlier.”

### Positive effects of peer support:

Caregivers were asked about positive effects they experienced from the peer support they received (Figure 5). Many caregivers reported that they felt more confident in caring for their child and that it was easier for them to advocate for their child’s needs. In addition, caregivers reported feeling less stressed about and more supported in the care of their child as a result of peer support.



“ Peer support has been the best resource. I gained most of my knowledge on navigating the health system from parents/caregivers who had lived experience. I felt that though I assumed I would be receiving the resource information I needed from hospital units, doctors’ appointments etc. it was almost as though the resource information was a secret and definitely not transparent.”

### Negative effects of peer support:

In a recent survey of pediatric subspecialists, 29% of respondents worried that peer support could provide inaccurate medical information to patients. In the current survey of families, only 20% of caregivers endorsed that they had received medical information or treatment advice with which a doctor would disagree. Qualitative data suggest that many respondents feel, however, that they can identify that the information is not aligned with medical recommendations and choose to disregard it.

“ I’m in multiple Facebook groups - where the education level varies. I trust science, and ignore other viewpoints on medical treatment for my child.”

## Providing peer support to others:

Forty-five percent of this sample reported providing peer support to others. However, this figure is likely to be higher than what would occur in the general population of caregivers of CYSHCN because respondents were recruited through Family Resource Centers that regularly provide peer support programs and trainings.

When asked whether the support respondents provided was offered through a program or by informally connecting with other caregivers, only 27% endorsed programs, while 87% said it was informal (some endorsed both). Of the 75 respondents who provided support through a program, 9 (12%) were paid for this service and 28 (37%) were trained to provide peer support. Thus, the data suggest that most peer support provided to caregivers takes place informally and that even in formal programs, most peer support providers are untrained and unpaid.

## Conclusions:

Consistent with other studies (e.g., Bray et al., 2017; Kerr & McIntosh, 2000; Singer et al., 1999), parents in this study indicated that they receive varied types of peer support and benefit from it in meaningful ways. Such supports aid them in navigating both the health care and education systems, provide valuable information about their child's condition, inform their decisions about treatment options and providers, and offer critical emotional support in the care of their children. Receipt of these types of support results in greater confidence in care (i.e., self-efficacy), improved emotional well-being for the caregiver and entire family, and expanded support networks for families who often experience challenges and stressors.

“ I firmly believe in peer support as a source of comfort and empathy as well as valuable resources.”

Despite these benefits, this study showed that less than half of caregivers had been connected with peer support in the past five years, and even fewer (36%) were referred to peer support through their health care providers. While past research indicates that some providers worry about misinformation, the current survey of families suggests that only a small number of caregivers believed that they received misinformation through peer support from other families, and that some who did report receiving misinformation also reported being able to filter out non-scientific, unsubstantiated, or irrelevant recommendations. Health care providers could support caregivers of CYSHCN by identifying the best sources of peer support, local and otherwise, and referring their patients to those sources.

This study found a discrepancy in support received by Latinos/as, by far the largest ethnic group in the sample (as well as in California). This could be due to a lack of linguistically, culturally, or logistically accessible services. Cultural differences – such as stigma related to health conditions or disability, discomfort talking to strangers about personal situations, and distrust of the health care system – may also come into play. Other racial and ethnic minorities were not well represented in this sample; therefore, it is unknown if they too receive less peer support than White non-Latino families and the systemic or cultural factors at play for them. However, it is telling that the group that reported the least support were those Latino/a caregivers who were least comfortable in English (as suggested by their choice of language on the survey), indicating that language is a significant barrier to peer support, much as it is for other health care services and supports. Availability of information about peer support in multiple languages or linguistically concordant navigators could help health care providers and educators better connect families with existing resources. Peer support program administrators could help bridge this gap in access by recruiting staff and volunteers who could offer workshops, support groups, and parent mentorship in languages other than English, based on the local need. Many Family Resource Centers, for example, offer peer support services in Spanish. Fewer reported linguistic capabilities exist for other languages such as Vietnamese, Dari and Pashto (languages spoken by recent Afghani immigrants), or Cantonese, for example.

Families of CYSHCN who require more medical care reported receiving more peer support on average. It could be that, due to greater medical complexity, these families have greater need for support or greater likelihood to be referred to support from other families. However, it is also possible that families who receive peer support learn to better navigate the health care system and can access more services for their children, which lead to more overall hours of care than families of children with similar conditions who do not receive this support.

Data on the provision of peer support suggest that the vast majority of contacts between caregivers take place outside the context of formal programs. Furthermore, most respondents who had provided peer support to others reported being largely unpaid and untrained. This suggests that there is little opportunity to ensure that the information and even emotional support provided to families is high quality, evidence-based, and effective. Providing accessible training opportunities and increasing paid peer support, housed within clinic settings or organizations such as Family Resource Centers, could help to better support families of CYSHCN.

## Policy implications:

The perspectives of families of CYSHCN expressed in this study, when integrated with past research and a recent study on the perspectives of pediatric specialists about peer support, indicate that families value peer support and find it helpful. Most pediatric subspecialists similarly believe that peer support is valuable for families, ultimately improving satisfaction with care and patient outcomes (Schor et al., 2023). However, even in this sample, which was recruited from Family Resource Centers, less than half of respondents had received peer support in the last five years, and even fewer are finding their way to peer support through medical providers. This may be due to logistical obstacles – such as the staff needed to make the referral, payment structures supporting referral processes, and availability of internal peer support programs – faced by clinics and represents a missed opportunity to link families who might otherwise not have access to this important source of support.

In addition, this survey highlighted the need to provide training and support to families. Few of the caregivers who reported having provided peer support had received training, even though they were recruited through Family Resource Centers, which offer peer support training and services. Even fewer were able to access resources in languages other than English. State or federal investment in training and mentorship could leverage significant resources and expertise from families with lived experience.

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