Development of a Survey Instrument for Caregivers of Children and Youth with Special Health Care Needs to Assess Self-Management Support

The AFFIRM Pilot Study

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Practical Research Solutions

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Executive Summary

Children and youth with special health care needs (CYSHCN) have chronic conditions that require extensive health care and supportive services. Self-Management Support (SMS) for caregivers of CYSHCN refers to assistance to increase families' skills and confidence in managing their children's health. Little is known of the extent to which SMS is provided in pediatric care for CYSHCN, and there are no measures tailored to this population. The study team sought to develop an instrument through which families of diverse backgrounds and abilities could report on SMS offered by their child's provider.

A 28-item instrument assessing SMS across six domains was designed and extensively tested by the research team in close collaboration with caregivers of CYSHCN, pediatric health care providers, and other experts in the field. A pilot study testing the instrument's feasibility and acceptability, as well as recruitment methods for this population, was conducted with 52 caregivers in two urban, academic primary care pediatric practices. The sample consisted of low-income families with children of different ages whose child had varying conditions, including 87% with a physical or developmental disability, 56% with a chronic condition, and 48% with a behavioral health diagnosis. Overall, respondents endorsed many SMS items in the survey, indicating that they are receiving support from their child's usual source of health care. There were no significant differences in the level of SMS reported by language preference of the caregiver, diagnosis category, level of impairment, or number of years since diagnosis. Higher SMS scores were associated with greater reported self-efficacy, greater trust in the provider, and having more hospital admissions and ED visits. Associations between SMS and these external variables provides support for validity of the new instrument, but more data from a larger sample must be collected in order to further test the psychometric properties of the instrument.

The AFFIRM Pilot Study also offered important insights into clinic-based recruitment with this population. On the whole, caregivers of CYSHCN were willing and able to participate in this short survey during or after their appointment, as well as at home when contacted by the study team. Perhaps due to the survey length and accessibility, completion rates were high. However, certain biases in sampling and participant responses were raised by involvement of the clinic staff during recruitment, which suggests that during a broader administration of the survey, to the extent that clinics allow it, in-person recruitment by study personnel would be preferable to the direct involvement of clinic staff.

Assessment of SMS is a vital step to improve care delivery for CYSHCN. The SMS instrument developed in this study appeared to be accessible to caregivers across health literacy levels and across both English-and Spanish-speaking participants. A survey with more participants across California in 2024-25 will provide greater understanding of the degree to which families are receiving support and help identify subgroups or SMS domains in need of more support. Results from this statewide survey will help clinical leaders, policymakers, and funders focus on development of resources and processes in clinic that are the most valuable to families of CYSHCN.

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Background

Children and youth with special health care needs (CYSHCN) have chronic conditions that require health care and supportive services beyond those usually delivered to children. Finding and coordinating those services often falls to caregivers, who may include parents, foster parents, and extended family members providing support. Self-Management Support (SMS) delivered by pediatric health care providers helps caregivers by working with them to set realistic goals and action plans, and by providing informational, social, emotional, and technological tools. A 2011 synthesis of 24 studies of CYSCHN found that collaborative SMS was associated with children's improved health status, access to care, family functioning, and efficient use of services (Kuhlthau et al., 2011). Despite evidence of its effectiveness, SMS is underutilized in pediatric care. There is limited training in evidence-based practices for health care personnel on SMS, and it is often not recognized as a reimbursable service. Moreover, disparities exist in access and quality of care for families with CYSHCN from historically marginalized populations, such as families from racial or ethnic minorities, and families who speak a language other than English, who are of low socioeconomic status, or living in rural areas.

Greater understanding of the experience of families of CYSHCN and their needs for SMS is a vital first step to inform improvements to policies and systematic practices for this population, particularly at a time of rapid change in provision of services (e.g., telehealth), accelerated by the COVID-19 pandemic. There are no instruments that measure non-disease-specific self-management support from the perspective of caregivers of CYSHCN. Instruments measuring SMS in adult populations fail to capture the remarkable efforts required of CYSHCN caregivers in the contemporary health care system in the United States to secure access to needed care and supports; to coordinate care across multiple health care providers and settings; to set and work toward goals in collaboration with providers; to organize multiple treatments, appointments, medications, and activities; to maintain relationships with various providers and agency representatives; to engage in problem solving when faced with barriers; and to navigate complex ecosystems of agencies that have variable degrees of capacity for serving CYSHCN. This is especially true of families with limited resources or whose primary language is not English, who may require additional assistance and encouragement to navigate a complex health care system. New methods of assessment are needed that (1) capture the unique needs and perspectives of caregivers, and (2) are accessible to all sociodemographic groups, overcoming barriers of language and health literacy.

In 2021-22, the Assessing Family Friendly Care in Realizing Self-Management (AFFIRM) pilot study team partnered with caregivers of CYSHCN, advocates, and health care professionals to develop a novel survey instrument to measure delivery of SMS by health care providers, as reported by caregivers. The instrument underwent multiple rounds of cognitive and user testing followed by a pilot administration that included more than 50 low-income, racially and ethnically diverse, English- and Spanish-speaking caregivers across two primary care pediatric sites in California. Simultaneously, the team tested several methods of recruitment to reach caregivers through health care settings and tested various survey features designed to support caregivers with language access needs.

This report summarizes the findings of the AFFIRM pilot study and includes implications of these findings in a larger statewide administration of the survey. The statewide survey seeks to recruit at least 500 caregivers from pediatric primary and specialty care practices across California in order to better assess the state of self-management support provided to families. However, the instrument developed in this pilot study assesses SMS constructs that are applicable in diverse clinical settings and geographic settings beyond California.

Survey Development

The AFFIRM self-management support (SMS) instrument was co-developed through an iterative, collaborative process with caregivers, pediatric providers, and research experts in the field.

Development of Domains and Constructs

Self-management supports. The study team versed itself in available literature, such as a publication outlining the necessary SMS for families of children with chronic health problems (Henry & Schor, 2015) and various survey instruments. Initial brain-storming meetings were held with caregivers of CYSHCN and the Lucile Packard Foundation for Children's Health (LPFCH) staff, and the advice of pediatric health care providers specializing in CYSHCN was sought.

It was determined that caregivers would report most reliably on SMS by identifying their child's current usual source of care and answering questions about the supports received from that provider's health care team, recognizing that supports are provided not only by the provider identified but often by their staff (e.g., care coordinators, social workers, nurses) as well. "Usual source of care" was defined as the health care provider that the families most often went to with questions and day-to-day care (non-emergencies), which could include primary and specialty care medical providers, as well as therapists or other health care providers central to the child's care. The study team acknowledges a tradeoff in this approach: it does not allow assessment of supports provided to families by other sources (health care or otherwise), but by focusing on one source it increases the reliability of reports.

To ensure that all aspects of SMS were covered (content validity), subject matter experts, including self-advocates with disabilities, caregivers of CYSHCN, and pediatric providers, collaborated with the study team to identify the following six domains of SMS, along with associated constructs for each (see Appendix A for constructs):

1. Being available/accessible to patients and caregivers
2. Providing information on disease management and resources within the health care system
3. Helping access supports outside the health care system
4. Helping organize, prioritize, and plan care
5. Empowering, strengthening, and emotionally supporting caregivers
6. Preparing caregivers/patients for transitions or changes in condition/care

Potential survey items (i.e., questions on the survey) were developed for each construct, which were written at a fifth grade reading level.

The study team developed an advisory board for the study by asking for referrals for caregivers, health care providers, and advocates with disabilities from physicians and staff at the selected pediatric primary care sites and other study advisors. A research associate interviewed each individual, and the study team selected for the final advisory board a group of caregivers for children of diverse ages, conditions, racial/ethnic identities, socioeconomic levels, and languages. Advisors helped to define the key domains, reviewed and provided feedback on survey items, and helped the study team interpret findings from user testing and the pilot study. The advisory board met virtually over videoconference, and members were compensated with a $100 electronic gift card for each meeting attended.

The study team integrated feedback from these groups, as well as LPFCH staff, and revised the prospective survey items. In the interest of producing a short instrument to accommodate caregivers' busy schedules, some items were removed and only the most central aspects of SMS about which caregivers, rather than health care professionals, could report were included. A 4-point agreement scale for response choices (Strongly Disagree to Strongly Agree), streamlined from longer response scales at the advice of advisors, was finalized.

Self-efficacy. Because the purpose of SMS is to increase capacity to manage conditions and secure needed resources, four items (i.e., survey questions) were designed that were related to caregivers' confidence in their ability to manage their child's condition. The study team drew from standard scales of general adult self-efficacy (e.g., Strengths Self-Efficacy Scale, General Self-Efficacy Scale) and scales on self-efficacy to self-manage a child's disease (Foster et al., 2023). Four items were generated to assess confidence in one's ability to:

1. Determine how to access necessary services for the child

2. Find answers to questions about the child's care/condition

3. Care for the child when something unexpected happens with their health

4. Tell the clinician that they disagree with them about their child's care

While the first two items aim to assess self-management tasks more broadly, the third item assesses unpredictable adversity (a common construct in scales of self-efficacy), and the fourth item seeks to set a high bar for self-efficacy by defining a situation with a clear status differential between the caregiver and provider. Response choices were on a Likert-type scale ranging from 1 (not at all confident) to 4 (very confident).

Cognitive and User Testing

The study team conducted two rounds of user testing of the survey instrument in English and two in Spanish. In the first round, "cognitive," or "think aloud," interviewing was completed. Cognitive interviewing is defined as a method to study "the ways in which individuals mentally process and respond to survey questionnaires" (Lavrakas, 2008), and it can help to ensure that survey items measure what they purport to measure. Eleven interviews were conducted with caregivers who completed the survey and explained out loud how they understood and answered each question. Participants in user testing were compensated with a $100 electronic gift card.

Several findings stood out from the cognitive interviews (see Appendix B for detailed summary). Importantly, the need was identified to distinguish supports that were not needed by a particular caregiver from those that were seen by the caregiver as needed but not being provided. Additionally, the language of certain items required simplification.

After the instrument had been revised based on results from the cognitive interviews, an additional round of user testing was conducted to test options addressing key questions that arose during the cognitive interviews, such as the need for SMS screening items, the addition of a response choice indicating lack of need for support, and different response scales. Results of the testing and decisions based on those results are summarized in Appendix B.

Final Survey

The survey was revised based on the user testing and final input from LPFCH staff and clinical experts. Because Spanish is the second most common language spoken in California, the final survey was then professionally translated and checked by multiple native Spanish speakers with dialects from Mexico, Central America, and South America. The final survey instrument was programmed in the Qualtrics survey administration platform and audio recordings of all survey questions were added so that respondents could listen to, rather than read, the questions and response choices. Quality assurance testing was completed by multiple study team members to ensure that the survey functioned correctly, including presentation of all items and complex skip logic programming. Due to complex skip logic, all respondents viewed the items in the same order.

Table 1 provides a brief overview of the topics assessed in the survey. The final survey instrument can be found in Appendix C. Note that the survey in Appendix C represents the version finalized for and used in the pilot study; however, further revisions are anticipated.

Table 1. Overview of Topics Assessed in Survey

Section	# items	Sample constructs
Screening for study eligibility	9	• Child with chronic condition • Standard screener for Special Health Care Needs (4 items adapted from National Survey of Children's Health) • Language of survey (English or Spanish) • Income[1] • Caregiver often joins child for medical visits[2]
Demographics (child & family)	6	• Caregiver: highest education in household, preferred language, health literacy • Child: race/ethnicity, age, health insurance coverage
Child condition	7	Diagnosis (3 items), years since diagnosis, impairment due to condition, emergency department and hospital admissions
Usual source of care	4	Number of regular providers, usual source of care[3], provider trust
Screening for SMS	5	Children who need or have: • Disability related benefits • Accommodations at school due to chronic condition • Durable medical equipment (DME) Patients whose health care providers have: • A patient portal • Video visits
Self-management support	28	• 20 items received by all respondents • 8 received based on specific screening items
Self-efficacy	4	Self-confidence to access necessary services, find answers to questions, care during unexpected circumstances, and disagree with clinician

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[1] This was a screening item for the pilot only to ensure that all respondents meet the low-income eligibility criterion, which was below 400% of the Federal Poverty Level. This is not expected to remain a screener in the statewide study in which other populations will be included.

[2] This screening item ensured that the caregiver responding to the survey has sufficient knowledge of interactions and supports offered at their child's medical appointments to report on them.

[3] If no source of usual care was identified, SMS items were skipped.

Methods

Sites

To field the pilot survey, the study team partnered with two primary care pediatric practices that serve a significant number of medically complex CYSHCN from low-income households: one hospital-based pediatric practice and one community-based practice.

Both sites serve primarily low income, publicly insured populations, and both are training sites for medical residents. Physician site champions were identified at each site who secured the support of their medical directors and served as senior advisors on the project. In this capacity, the champions provided expertise on development of the survey instrument, guided identification of target populations, and supported outreach to families to serve on the community advisory board, take part in cognitive interviews and user testing, and engage in the pilot survey.

The community-based site has more than 11,000 active pediatric patients, of whom 68% (7,520) come from families who are under 200% of the federal poverty level. More than 90% of patients are enrolled in Medi-Cal, California's Medicaid program. Data from the electronic medical record show that 14% of caregivers at the clinic report Spanish as their primary language, 34% identify as Black or African American, and 30% identify as Latinx.

The hospital-based clinic serves around 7,000 active pediatric patients, 100% of whom are publicly insured (including Medi-Cal as well as county-specific health care programs). A large proportion of patients screen positive for social needs, including one in five families at the site that report food insecurity. Half of the patients are from households that are primarily Spanish speaking, 15% identify as Black or African American, and 76% identify as Latinx.

Recruitment Methods

Two different recruitment methods were tested, one at each clinic. The advantages and disadvantages of these methods were assessed in order to understand how best to scale up the survey in a larger statewide administration. Both methods were alternatives to the originally proposed method of recruiting patients in the waiting rooms of practices, a method that was not an option due to COVID-era limitations on placing research personnel in person at clinical sites.

Method 1, conducted at the community-based clinic, relied on recruitment of survey participants by clinic staff, whose time was compensated by the study. In this method, a clinician reviewed the schedule daily and flagged charts of children who might be eligible. A research associate, who was employed by the clinic, approached identified families in the exam room and invited them to take part in the study. They provided participating caregivers with an iPad for survey self-administration and toys to occupy their children.

The clinic-based research associate (RA) did not speak Spanish. Because the study team anticipated that wider administration using Method 1 could entail recruitment by staff not proficient in languages other than English, they took advantage of the opportunity to test methods for recruitment of Spanish-speaking caregivers by non-Spanish-speaking RAs, including use of an introductory video in Spanish and use of the clinic's iPad-based interpreter services.

Method 2, used at the hospital-based clinic, entailed primary care clinicians referring eligible patients to the study team and subsequent outreach by a bilingual member of the team by phone. Telephonic outreach was not timed to coincide with clinic visits. When a potential participant was interested in taking part, they were screened for eligibility and an individualized survey link was shared via text message. In this way, Method 2 relied more heavily on the involvement of research personnel, whereas Method 1 was self-contained in the clinic environment.

Both methods successfully reached caregivers of patients with diverse ages, medical conditions, languages, and races/ethnicities. Advantages and disadvantages of the two methods are summarized in Appendix D. Clinic staff recruitment (Method 1) resulted in a high response rate but required greater time on the part of clinic staff than did outreach by the research team (Method 2), which only required initial identification of patients by clinic staff. Participation rates of Spanish-speaking caregivers at the site using a video introduction and iPad-based interpreter services were high. Participants in the study received a $50 gift card in recognition of their time upon completion of the survey.

Comparing Survey Administration Options for Future Survey Administration

Observations from this pilot suggest that either survey recruitment and administration method would be a viable option for broadscale recruitment to reach caregivers who are often left out of survey research, including those with low socioeconomic status (SES) and individuals whose primary language is not English. Both methods successfully engaged caregivers of children of diverse ages, conditions, and races/ethnicities. Clinic staff recruitment (Method 1) resulted in an ability to reach more prospective participants and less "dormant" time, the periods of time that respondents are not answering questions after beginning the survey due to other non-survey related tasks (median of 9.5 minutes "dormant" time for Method 1 versus 291 minutes for Method 2). A two-sample Wilcoxon rank-sum test confirmed a statistically significant difference between the two methods on dormant time ($z=-4.76$, $p<0.001$). In short, during in-person administration in the clinic, people completed the survey immediately, whereas with remote administration, people were more likely to set aside the survey for hours or days before completing, although–importantly–they still completed it after receiving reminder calls.

Based on past research experience, the original proposed method of recruitment (waiting room recruitment using study staff) is suspected to have certain advantages, including the perceived impartiality of researchers if a respondent wished to report lack of provider support. It does not rely on clinician referrals, reducing bias stemming from a natural tendency to refer individuals with whom clinicians have a good relationship. Moreover, waiting room recruitment by research staff optimizes a higher rate of participation without burdening clinic staff with additional responsibilities. However, it requires protocols to ensure that study personnel do not impose selection bias by approaching caregivers of children who are visibly disabled and missing those with "invisible" disabilities or chronic conditions. At this stage in the pandemic, clinics are open to allowing research teams to conduct studies on site; thus, a broader survey administration could realistically include any of these three methods, in order of preference:

1. Recruitment by research staff in practice waiting rooms

2. Clinic staff recruitment (Method 1)

3. Outreach by research team (Method 2)

Ultimately, selection among these three viable options will likely take into account the advantages and disadvantages outlined in Appendix D, while also depending on factors external to research considerations, such as site resources and policies. For example, clinics that are approached due to key recruitment criteria (e.g., rural location, high proportion of patients who are CYSHCN) may not allow the presence of research staff in their waiting room or may not be able to provide an internal research associate who can recruit patients during their visit. In general, clinics and patients often have limited resources–time and effort–to devote to research endeavors, an overarching consideration that the study team must individually address at every recruitment site. Having multiple viable methods of recruitment can help to ensure that this instrument is feasible across settings with diverse resource levels.

Results

Participation

Among people approached to take the study survey (n=77), only 8 people (10%) declined to participate (Figure 2). Most of the individuals that declined to participate expressed concern that they did not have time to complete the survey, with several offering to come back at another time to complete it. Most of these cases (5 of 6) were from the community-based site, which required immediate survey administration.

Figure 2. Participation Outcomes (n=77)

Refusals, **10%**

Do not identify child as having SHCN*, **7%**

Income, **7%**

No chronic condition, **5%**

Do not attend visits with child, **3%**

Partially completed, **1%**

Completed survey, **68%**
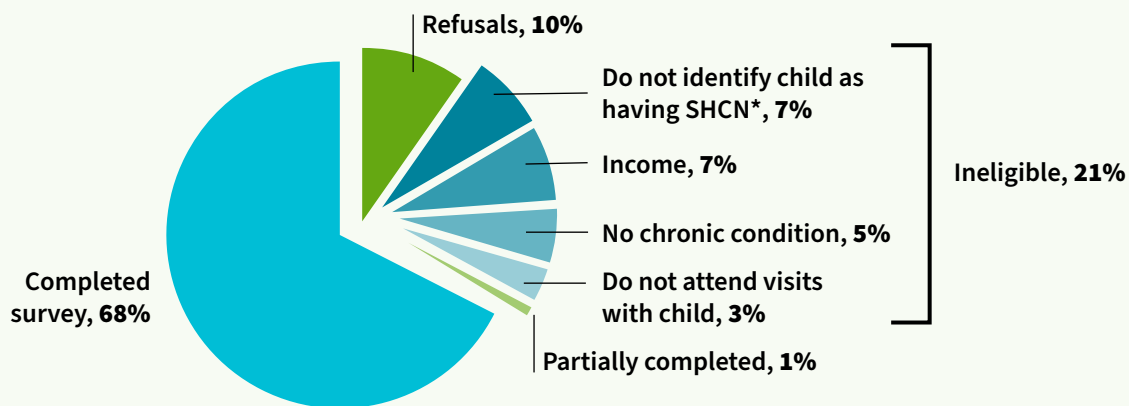
Ineligible, **21%**

Based on four screening questions to identify children with special health care needs. See Appendix for more details.

A larger number (16/77) of people approached (21%) were found to be ineligible upon screening for reasons such as not identifying their child as having a special health care need or a chronic condition, income above 400% federal poverty level, or not attending medical visits with their child. Of interest, all caregivers approached had children whose health care providers believed they met the criteria for CYSHCN, i.e., the provider believed the children had relevant conditions and utilized more health care and other services than their peers. These criteria were explicitly assessed through four standard screening questions, which required at least one positive response to meet eligibility for the study (see Appendix E). It is important to recognize for future survey administrations that caregivers who do not recognize that their child has a chronic condition and that they use more health care, therapy, or behavioral services than other children will self-exclude, even if their health care providers consider them eligible. The needs and experiences of this group of caregivers and their children might be different from those identifying with the study criteria.

> **Implications for statewide administration**
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> - A revised screening question about chronic conditions may be used. For example, the *Delays in Access in Pediatric Subspecialty Care in California* study referred to "long-term health conditions and disabilities" in its screening. This language was more easily understood by participating families both in pre-testing and during data collection. Further consideration of such language would be valuable for a statewide study.
>
> - Addition of follow up questions when a potential participant screens out would be useful to gather information about conditions or other commonalities associated with screening out.

Survey Completion Time

The average active time for completion of each section of the survey was calculated to ensure that the total survey time fell within the targeted time of 20 to 30 minutes. The median time required for completion was 17 minutes, with only 4.3 minutes required to complete the SMS questions. For additional information about time to completion, partial completions, and missing survey data, see Appendix F.

Sample

Caregiver characteristics. Of caregivers who participated, the vast majority (90%) reported income under 200% of Federal Poverty Level (Table 3). Forty-two percent reported sometimes needing help reading health information. Most reported either having no high school diploma (39%) or a high school degree (40%) as the highest level of educational attainment in the household. These data are consistent with the goal to recruit a sample of caregivers with limited educational attainment and low income.

Table 3. Characteristics of Caregiver Respondents (n=51)[5]

Characteristic	Percent (n)
Educational attainment	
No high school diploma	39% (20)
High school degree (may incl. trade program, some college)	40% (21)
Bachelor's degree or more	19% (10)
Limited health literacy	
(needs help reading health information at least sometimes)	42% (22)
Income (<400% FPL)[6]	
<100% FPL	52% (27)
100-200% FPL	38% (20)
200-400% FPL	8% (4)

Child characteristics. Caregivers responded to the survey based on their experiences in the care of one child. In the event that they had more than one child who qualified for the study, they were asked to think about their experiences with the child whom they spend the most time caring for due to the child's condition.

The children described in the survey were evenly spread between young children, school-aged children, and teenagers (Table 4), and roughly half were female. Most caregivers reported their children being Latinx (58%), Black/African American (25%), or Asian/ Pacific Islander (23%). These figures are roughly aligned with the racial/ethnic breakdown of patients at the two recruitment sites. Almost all respondents were covered by Medi-Cal, and 37% received services from California Children's Services.[6]

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[4] One respondent did not provide a response to each of the following questions: educational attainment, health literacy, and income.

[5] This sample was recruited in the San Francisco Bay Area, which has a very high cost of living. As such, an income cutoff of 400% of the Federal Poverty Level was chosen to include not only those families defined as having low incomes based on federal criteria, but also families who likely experience many of the same barriers due to limited financial resources relative to the cost of local services. As an example, 400% FPL for a household of four people was $106,000 in 2021, the year of the survey. Use of 400% FPL as cut off for eligibility is consistent with the income up to which a family is eligible for a federal tax credit on their health insurance premium.

[6] California Children's Services (CCS) is a state program for (mostly) low-income CYSHCN (up to 21 years old) with "certain diseases or health problems" that provides health care and other services for enrollees and their families. According to the CCS website, at this time, approximately 70 percent of CCS-eligible children are also Medi-Cal eligible (https://www.dhcs.ca.gov/services/ccs/Pages/ProgramOverview.aspx).

Table 4. Characteristics of CYSHCN in Sample (n=52)

Characteristic	Percent (n)
Age of child	
0-5 years old	33% (17)
6-10 years old	38% (20)
11-17 years old	29% (15)
Gender of child[7]	
Female	46% (24)
Race/Ethnicity[8]	
Latinx	58% (30)
Black/African American	25% (13)
Asian/Pacific Islander[9]	23% (12)
White	10% (5)
Native American/Alaskan Native	2% (1)
Middle Eastern/North African	2% (1)
Health care coverage[10]	
Medi-Cal	96% (50)
California Children's Services	37% (19)
Private insurance	2% (1)

Special health care needs were assessed using four standard items from the CYSHCN screener (Bethell et al, 2002) used in the National Survey of Children's Health. Although endorsement of only one question was required to screen into this study, the majority of caregivers endorsed multiple questions with more than half of respondents (54%) endorsing all four CYSHCN eligibility screening questions included in this study (for more on responses to the SHCN screener, see Appendix E).

Child condition and impairment. This study sought to include a diverse range of conditions that fall under the definition of special health care needs. Caregivers indicated if their child had been diagnosed with any of five mental health disorders, nine physical or developmental disabilities, and 12 chronic medical conditions, and the survey included fields to write in additional diagnoses (see Appendix C for survey items). The type of condition was assessed because it was hypothesized that severity or complexity of condition would be related to SMS. For instance, it was hypothesized that more SMS would be provided to caregivers if their child had a more complex condition or had more conditions overall, the latter usually signifying greater complexity. Table 5 presents the frequencies of respondents who reported that their child had the three types of conditions. Note that respondents could report multiple conditions in each of the three categories, which is common among CYSHCN.

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[7] Two individuals did not provide child's gender.

[8] Respondents could select more than one category of race/ethnicity.

[9] Primary subgroups in the Asian category (n=12) included 6 individuals who were Southeast Asian and 3 Native Hawaiian or Pacific Islanders.

[10] Respondents could select more than one insurance type.

Table 5: Conditions by Category

Condition type	N	Number reporting any condition
Mental health disorder	52	48% (25)
Physical/developmental disability	52	87% (45)
Chronic medical condition[11]	51	57% (29)

Participants in this pilot had a wide range of conditions. The conditions were predominantly physical or developmental disabilities, which affected 87% of children. While the majority of children with a mental health (68%) or chronic medical condition (62%) had a single diagnosis within that cluster of conditions, children with physical or developmental disabilities were more likely to have multiple disabilities: 69% had at least 2 disabilities and a third had 3 or more disabilities.

Figure 6: Years since Diagnosis (n=50)

< 1 year, **16%**
1-2 years, **12%**
3-5 years, **30%**
6+ years, **42%**
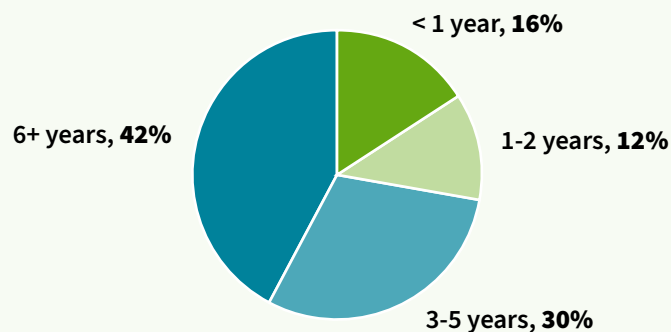
Years since diagnosis. The majority of respondents (72%) in the sample reported that their child had been diagnosed with their primary condition three or more years prior to the study (Figure 6). In other words, most participants in the pilot were "veterans" at caring for their child and likely have different perspectives, needs, and abilities than do caregivers who are just starting out on the "journey" of caring for their chronically ill child.

Implications for statewide administration

- **Greater diversity is needed among respondents on the length of time since families first received their child's diagnosis to capture a wide range of experiences in care and interaction with the health care system.**

Impairment associated with condition. An item inquiring about the ways in which the child's functioning has been affected by their condition was included to assess condition severity or complexity. Adapted from standard impairment scales in the field (Goodman, 2001), multiple areas of impairment were offered, and respondents could mark all that applied. As shown in Figure 7, the most common impairments reported were those affecting communication (74%), learning (68%), and friendship (62%).

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[11] Although, by definition, all of the conditions included in this study were chronic, the conditions under the chronic medical condition category were physical in nature (e.g., cerebral palsy, diabetes, cystic fibrosis, gastrointestinal or pulmonary disease, etc.).

Figure 7: Impairment Associated with Conditions (n=50)

Condition	Percentage
Communication	74%
Learning	68%
Friendships	62%
Play activities	60%
Personal care	58%
Home life	50%
Movement	30%

Because it was hypothesized that greater impairment is a proxy for medical complexity and likely impacts the level of SMS that health care providers may offer, a composite variable counting the total number of impairment areas endorsed was created. The mean number of affected areas was 4.06 (SD=2.06), with a wide range of 1 to 8 areas endorsed by respondents. More than a quarter (28%) of respondents reported 1-2 impairment areas, 30% reported 3-4 areas, 24% reported 5-6 areas, and 18% reported 7 or more areas.

The impairment count was correlated ($r=.47$, $p<.001$) with a variable summing the total number of conditions, including mental health, disability, and chronic medical conditions. Impairment count was correlated with number of disability conditions ($r=.59$, $p<.001$) but not with number of mental health ($r=.02$, $p=.916$) or chronic medical conditions ($r=.20$, $p=.159$). The impairment count was not correlated with emergency department visits ($r=.08$, $p=.585$) or hospital admissions ($r=.04$, $p=.801$) in the last year, which, after quantitative and qualitative analysis, are believed to be key markers of condition severity/complexity (see "Validation of SMS with external criteria" below). Due to these mixed results in which impairment was not associated with several variables in expected ways, it was difficult to interpret this variable as a clear measure of medical complexity.

Implications for statewide administration

- **Alternative measures for medical complexity will be considered, as the study team continues to consider measurement of this variable central to the understanding of individual differences in the provision of SMS.**

Emergency department (ED) & hospital admissions. Consistent with other studies, the distributions of the number of admissions to the hospital and visits to the ED were skewed such that most respondents had no visits or admissions in the past year (Figure 8). A composite variable of ED visits and hospital admissions together (i.e., no admissions or visits, ED visits or admissions to the hospital, or both ED visits and hospital admissions) resulted in a fairly even distribution between the three categories (Figure 8).

Figure 8. ED Visits and Hospital Admissions in the Last Year (n=50)

	None	1	2 or more
ED Visits	48%	28%	24%
Hospital Admissions	64%	22%	14%
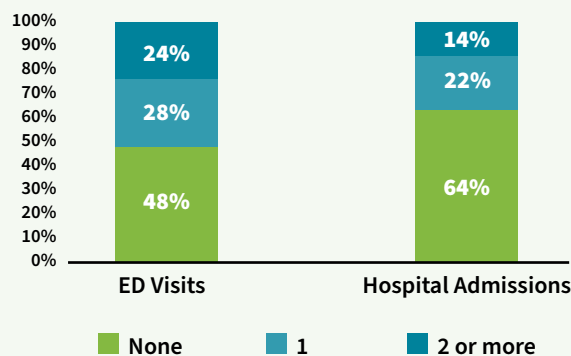
Figure 9. Composite Variable for ED Visits and Hospital Admissions (n=50)
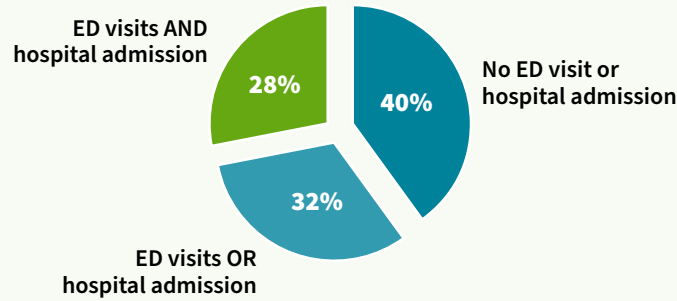
Self-Efficacy

Self-efficacy was rated very highly in this sample. See Table 10 for results of individual items, which were rated on a scale of 1 (not at all) to 4 (very confident).

Table 10: Self-Efficacy Items

Characteristic	N	Mean (SD)	Range
Item: Confidence in ability to…			
Get child needed services	51	3.45 (.76)	1 – 4
Find answers to questions	52	3.40 (.75)	2 – 4
Care in unexpected situation	51	3.67 (.68)	1 – 4
Disagree with provider	51	3.61 (.67)	2 – 4
Mean self-efficacy score		**3.54 (.62)**	

The four items were moderately to strongly correlated with one another (r = .45-.88 for each pairwise comparison). The average self-efficacy score for this sample was 3.54, indicating strong feelings of self-efficacy among participants to manage their child's condition and care. More than half of respondents (54%) had an average self-efficacy score of 4.00, the highest possible score, indicating that they felt "very confident" in doing all four self-management tasks. These results were consistent with high SMS ratings (discussed below) and correlated with greater provider trust (r=.33, p<.05). In addition, high self-efficacy is consistent with the fact that this sample is largely composed of "veteran" caregivers, who received their child's diagnosis at least three years prior to the study and who have likely gained confidence in caring for their child over time.

Health Care Providers

Figure 11: Usual Source Care (n=52)

Specialty care (MD specialists), **4%**

No usual source of care, **4%**

Other (non-MD clinicians, e.g., PT/OT, psychologists), **21%**
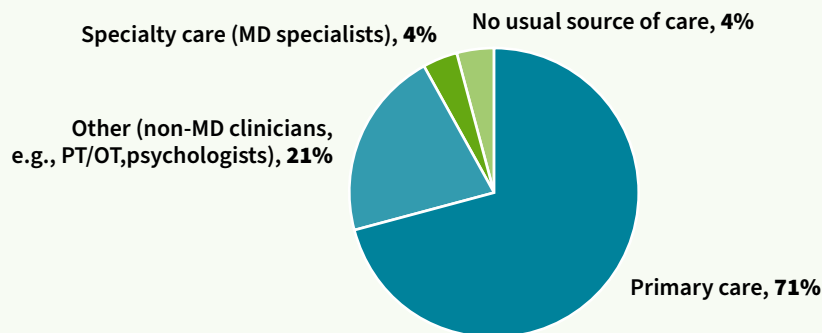
Primary care, **71%**

Usual source of care. For this study, "usual source of care" was defined as the health care provider that the families most often go to with questions and day-to-day care (non-emergencies), which could include primary and specialty care medical providers, as well as therapists or other health care providers central to the child's care.

Over 70% of this sample identified a primary care provider as the main source of non-emergency care and advice for their child (Figure 11). Although respondents could have identified any health care professional, their choice was perhaps not surprising, given that they were recruited at their child's primary care clinic and that clinicians at these recruitment sites take a particular interest in CYSHCN (and likely demonstrate exceptional skills in caring for this population). Although many children had multiple complex conditions, only two respondents identified a specialist as their usual source of care. These figures should not be generalized to the larger population of CYSHCN based on this pilot data. Two out of 52 participants reported that their child had no usual source of care.[13]

Trust in health care provider. One item about provider trust was included in order to obtain a global evaluation of the usual source of care. On a scale of 1 (a little) to 4 (completely), respondents were asked how much they trusted this provider in the care of their child. The mean score of respondents in the pilot sample was 3.71 (SD=.58), indicating a very high degree of trust in their usual source of care.

Figure 12: Number of Health Care Providers (n=52)

Category	Percentage
1	17%
2 to 4	25%
More than 5	27%
No answer	29%

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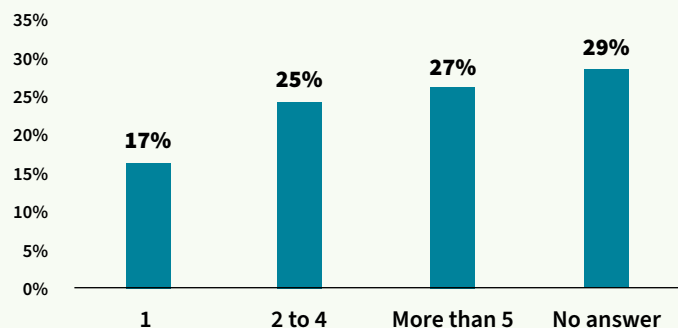
[13] Caregivers who did not identify a usual source of care did not receive the SMS items in the survey, because the stem of the self-management support questions asks about experiences at the usual source of care, but they did receive an open-ended question about why their child did not have a usual source of care, and they continued with the survey after the section of SMS items.

Number of health care providers. Among the 36 respondents who answered this question, three-quarters reported 2 or more providers and 39% reported having more than 5 regular health care providers, indicating that many children in this sample likely have medically complex conditions (Figure 12). Fifteen respondents (29%) did not respond about their child's total number of regular health care providers. In qualitative follow up, respondents explained that it was difficult to determine who to include in their count (e.g., speech therapists with the school district, specialists who created custom orthotics) and what it meant to see them regularly. In addition, they reported that it required significant mental effort to tabulate health care providers, and they felt that use of categories would be helpful in facilitating response.

> *Implications for statewide administration*
>
> - **Since the number of regular health care providers is viewed as an indicator of need for SMS (coordinating among many providers, health care systems, and likely electronic medical records), it will be retained in the next administration of the survey.**
> - **However, the item will be revised as follows: (a) clarification of the term "regular" providers, (b) instruction about the types of providers to include, and (c) categorical response choices with ranges will be offered (e.g., 1-2 providers, 3-5 providers, etc.)**

Self-Management Supports

"Do Not Need" (DNN) response choice. As described above, all SMS items included the response option "I do not need this support from this provider." The two items with the greatest number of DNN responses were: connecting to peer supports (n=12; 24%) and assistance with insurance coverage (n=11; 22%; Table 13), and even in these cases, three-quarters of caregivers reported needing the SMS supports. Other items that had relatively higher numbers of DNN were: offers resources to learn about child's condition (n=7); teaches how to recognize and care for symptoms (n=6); and supports prioritizing care tasks (n=6).

The fact that relatively few respondents indicated that they "do not need" the SMS items in the survey indicates that these supports are relevant to caregivers. Moreover, in a sample in which 70% of respondents had received their child's diagnosis at least 3 years earlier, it makes sense that the supports that caregivers indicated they did not need, such as disease education or peer support, were those that may have been provided at an earlier stage of diagnosis or had already been acquired through another source (e.g., school, Family Resource Center). A wider sample including more caregivers whose children have newer diagnoses in a statewide study may be less likely to indicate that they do not need these supports.

Responses to individual SMS items. Overall, the mean scores for SMS items were high in the pilot sample, indicating that caregivers agree or strongly agree that their child's health care provider had provided them with most of the supports described (Table 13). Because respondents in this sample rated most items so highly, the standard deviations, which indicate variability of each item, were relatively small. Likewise, when the relationships among items within each domain were examined, they were highly correlated with one another. In fact, Cronbach alpha coefficients — which are a statistical measure of consistency, or correlation, among multiple items and can range from 0 to 1.00 — were all above .88 for the six domains (see Table 13).[14]

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[14] High Cronbach alphas and correlations across all SMS items are believed to be the result of exceptional care provided by the two clinics in this pilot study. Qualitative data and stakeholder reports on the ground, however, suggest that this level of care likely does not reflect the diversity of SMS provided by clinics throughout California. It is this diversity, called variability in statistical terms, that is necessary in order to better ascertain relationships among different types of SMS (for instance, if emotional support/empowerment is usually provided together with pragmatic support to organize and plan).

Table 13. SMS Item Summary

Survey item: This health care provider's team…	N of valid reponse	DNN	Mean (SD)	Range	Disagree	Missing responses[15]
Domain 1: Being available/accessible to patients/caregivers *(Cronbach alpha= .883)*						
1a …gets me answers on time when I have questions about this child's care.	49	4% (2)	3.57 (0.58)	2 - 4	4% (2)	6% (3)
1b …has shown me how to use the electronic patient portal.	31	16% (5)	3.31 (0.84)	1 - 4	13% (4)	40% (21)
1c …has shown me how to connect for a video visit.	31	13% (4)	3.52 (0.80)	1 - 4	10% (3)	40% (21)
Domain 2: Providing information on disease management & resources within medical system *(Cronbach alpha= .918)*						
2a … reminds me about the things we need to do to keep this child healthy, like screening, blood tests, and immunizations.	48	2% (1)	3.57 (0.68)	1 - 4	6% (3)	8% (4)
2b … offers me resources to learn more about this child's condition, for example, through classes, websites, or videos.	50	14% (7)	3.49 (0.70)	1 - 4	6% (3)	4% (2)
2c … teaches me how to recognize and take care of this child's symptoms as they come up in day-to-day life.	48	13% (6)	3.50 (0.71)	1 - 4	6% (3)	8% (4)
2d … makes sure that I am clear about new care instructions or decisions that were made during a visit (for example, by asking me to summarize care decisions at the end of the visit).	50	6% (3)	3.55 (0.62)	1 - 4	2% (1)	4% (2)
2e … makes sure that I am comfortable using this child's medical equipment, for example, by asking me how it's working or showing me how to use it.	8	50% (4)	3.75 (0.50)	3 - 4	0% (0)	85% (44)
Domain 3: Helping access supports outside the medical system (i.e., access to the medical neighborhood) *(Cronbach alpha= .947)*						
3a … helps me get insurance coverage for the care this child needs, such as giving me words to use when I talk to the insurance company or helping me if coverage is denied.	50	22% (11)	3.41 (0.82)	1 - 4	8% (4)	4% (2)
3b … has explained how to get programs and benefits that might help me pay for this child's day-to-day care, like Supplemental Security Income (SSI) or In Home Support Services (IHSS).	25	12% (3)	3.45 (0.80)	2 - 4	32% (8)	52% (27)
3c … has connected us to other families with similar experiences, for example, through online support groups or family resource centers.	50	24% (12)	3.26 (0.86)	1 - 4	16% (8)	4% (2)
3d … has helped this child get accommodations at their school through an IEP or informally.	20	10% (2)	3.39 (0.78)	2 - 4	15% (3)	62% (32)
3e … has provided information on how to get the right behavioral or mental health services for this child, e.g., ABA, therapy, or counseling.	39	8% (3)	3.44 (0.74)	1 - 4	8% (3)	25% (13)

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[15] Missing responses may be due to logical skips in survey programming (e.g., respondent screened out of item) or because they chose not to respond to the item.

Survey item: This health care provider's team…	N of valid reponse	DNN	Mean (SD)	Range	Disagree	Missing responses[15]
Domain 4: Helping organize, prioritize, and plan *(Cronbach alpha= .939)*						
4a … helps me solve problems in this child's care based on what works best for our family.	50	10% (5)	3.56 (0.69)	1 - 4	6% (3)	4% (2)
4b … makes sure my voice is heard in this child's treatment goals and decisions.	49	4% (2)	3.55 (0.62)	1 - 4	2% (1)	6% (3)
4c … helps me organize the things I need to keep track of for this child's care, like appointments, medications, and important contacts.	49	10% (5)	3.48 (0.73)	1 - 4	8% (4)	6% (3)
4d When there are a lot of things to do to care for this child, this health care provider's team plans together with me what is most important to do first.	50	12% (6)	3.52 (0.55)	2 - 4	2% (1)	4% (2)
4e … communicates with this child's other health care providers to make sure that everyone who cares for this child is on the same page.	50	0% (0)	3.46 (0.76)	1 - 4	8% (4)	4% (2)
Domain 5: Empowering, strengthening, and emotionally supporting *(Cronbach alpha= .956)*						
5a … respects that I know a lot about this child's needs and condition(s).	48	2% (1)	3.53 (0.65)	1 - 4	4% (2)	8% (4)
5b … asks me about my needs at visits, including my mental health or stress.	50	2% (1)	3.37 (0.78)	1 - 4	14% (7)	4% (2)
5c … encourages me when I advocate for this child to make sure this child gets the care they need.	49	8% (4)	3.51 (0.70)	1 - 4	6% (3)	6% (3)
5d … backs me up if I get stuck with other agencies by contacting them directly or providing resources, such as a letter.	50	8% (4)	3.48 (0.75)	1 - 4	6% (3)	4% (2)
5e … goes above and beyond in helping me take care of this child.	50	2% (1)	3.45 (0.74)	1 - 4	6% (3)	4% (2)
5f … takes a personal interest in this child.	49	4% (2)	3.47 (0.75)	1 - 4	10% (5)	6% (3)
Domain 6: Preparing caregivers/patients for transitions or big changes in condition/care *(Cronbach alpha= .915)*						
6a … helps me plan ahead so that I am always ready to take care of this child, even when this child is very sick.	49	8% (4)	3.53 (0.73)	1 - 4	4% (2)	6% (3)
6b … has helped me find ways to meet this child's changing needs as they have grown, e.g., starting a new school or becoming more independent.	26	4% (1)	3.48 (0.65)	2 – 4	8% (2)	50% (26)
6c … includes this child in conversations so that [child] can participate in more of his/her care as they grow.	33	12% (4)	3.45 (0.57)	2 – 4	3% (1)	37% (19)
6d … has talked with me about my hopes and long-term goals for this child.	50	2% (1)	3.45 (0.84)	1 - 4	10% (5)	4% (2)

Composite SMS score. Because scores on individual SMS items were highly correlated, an average SMS score was created as a rough indicator of each respondent's rating of support provision from their health care provider. For the entire sample, this score was 3.49 (SD=.60). When this score was broken down by recruitment site, there were significant differences (t[46]=3.58, p<.001). Respondents at the community-based clinic reported an average SMS score of 3.71 (SD=.57); whereas those who were recruited from the hospital-based site reported a lower average score of 3.15 (SD=.47). These differences, along with other site differences, are discussed below.

Disagreement with SMS provision. A different way to examine SMS responses is the degree to which respondents disagreed that they had received supports (i.e., Strongly Disagree or Disagree). Disagreement indicates that respondents had not been offered the supports described in the corresponding SMS items. The items with the highest number of respondents who disagreed were: connecting to peer support (n=8), inquiring about caregiver's mental health (n=7), taking a personal interest in the child (n=5), and asking about caregiver's hopes for the future (n=5; Table 13). Although this was a very small sample from which it is not possible to generalize, the results provide an avenue for exploration in a survey with a larger sample size.

An analysis was undertaken to identify whether a specific subgroup of respondents was more likely to report disagreement, i.e., they were less satisfied with the support they were receiving overall. A composite variable was created that counted the total number of items in which respondents reported any disagreement (Table 14).

Table 14: Total Number of SMS Disagree Responses (n=48)

- 10 or more disagree, **8%**
- 3 to 9 disagree, **6%**
- 1 to 2 disagrees, **31%**
- 0 disagree responses, **54%**
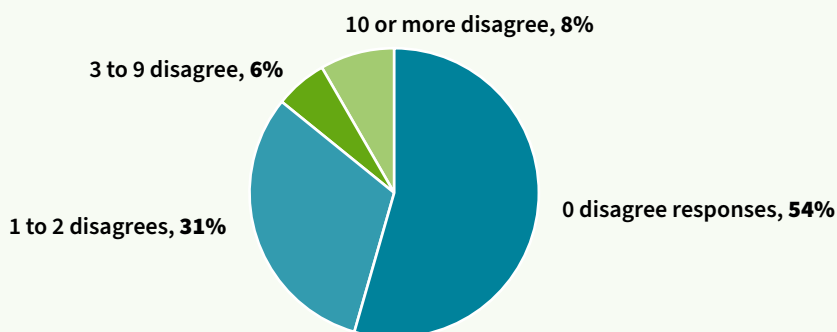
The vast majority of respondents (86%) were satisfied with support from their usual source of care. Only 6 respondents reported a more substantial number of disagreements, which can be interpreted as dissatisfaction with care or need for more support. This group was too small to reliably characterize.
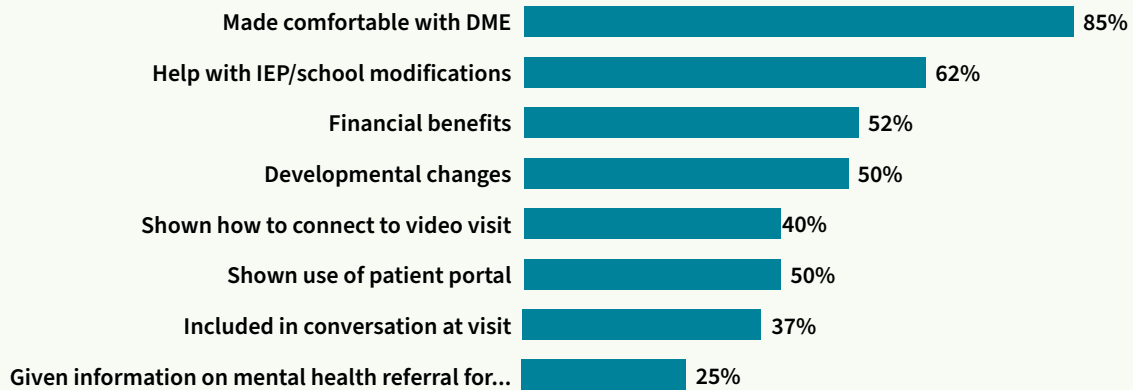
Implications for statewide administration

- **Using a larger, more diverse sample, items with high levels of disagreement will be identified to understand which supports are least provided by patients' usual source of care.**

- **In the pilot study, respondents reported that peer support was the SMS offered least to their family (after excluding those who said they did not need it). LPFCH has established through other research (e.g., a peer support survey of pediatric subspecialists) that despite positive attitudes about peer support, physicians face practice-based resource obstacles to offering peer support referrals. If a statewide administration of this survey is consistent with the results of the pilot, it would suggest that caregivers agree with the data from providers that peer support referral is lacking.**

- **Another interesting avenue to explore in the larger study is whether health care providers tend to provide more logistical supports for self-management (e.g., education about disease management, organizing and prioritizing tasks) as compared to emotional supports, such as assessing caregiver mental health or taking a more personal approach to their child.**

Missing SMS responses. As noted earlier, very few respondents chose to skip items, including SMS questions. This suggests that the SMS questions have face validity, that is, that the items ask about meaningful concepts to respondents, and that respondents in the pilot understood the intent of the questions and could provide a response that was consistent with their perspective or experience.

It is important to note, however, that the SMS screeners for eight items resulted in large amounts of missing data, because those items were not applicable and therefore were not displayed (i.e., respondents screened out of those items). For example, if an individual reported that their child did not have durable medical equipment, they were not shown the item addressing support to use DME ("made comfortable with DME"; Figure 15). In addition, two individuals did not receive any SMS items because they reported that they did not have a usual source of care.

Figure 15: Missing Data for SMS Items (n=52)

Item	Percentage
Made comfortable with DME	85%
Help with IEP/school modifications	62%
Financial benefits	52%
Developmental changes	50%
Shown how to connect to video visit	40%
Shown use of patient portal	50%
Included in conversation at visit	37%
Given information on mental health referral for…	25%

Implications for statewide administration

- **The amount of missing data is important because future efforts to look at the relationships between items (e.g., a factor analysis) will require a large sample size to ensure that there are enough responses for each item that it can be included in the analyses.**

- **A statewide study should include at least several hundred participants who complete the survey, with the aim of collecting at least 50 responses for each of the 8 items above, which will allow for robust data analysis.**

Validation of SMS with external criteria. One of the ways to demonstrate validity of a survey instrument is by examining whether it correlates with other measures in ways that are expected. The pilot data provided an opportunity to explore preliminary relationships between SMS and other measures that would be expected to be associated with SMS. Due to the small sample size, this analysis must be replicated and expanded with a much larger sample, which will be collected in a statewide study.

It was hypothesized that higher SMS score would be associated with greater trust in the health care provider, greater self-efficacy, a greater number of medical conditions, and fewer ED visits and hospitalizations (Table 16). While three hypotheses were supported by the pilot data, one was not. For complete results, see Appendix G.

Table 16. Association of SMS Score and Other Variables

| Measure	Hypothesis *Greater SMS scores associated with…*	Supported by pilot data
Trust in the health care provider	… greater trust	Yes
Self-efficacy	… greater self-efficacy	Yes
ED visits and hospital admissions	… less likelihood of an ED/hospital visit	No
Number of conditions	… more diagnoses	Yes

Trust in health care provider. As predicted, greater SMS support was associated with greater trust in the health care provider (r=.46, p<.001), which is consistent with the expectation that caregivers trust a provider who offers more support (see Appendix G for more on this analysis).

Self-efficacy. Greater SMS support was also associated with greater self-efficacy (r=.32, p<.05), consistent with the expectation that caregivers who receive more support feel more efficacious in caring for their child.

ED visits/hospital admissions. Average SMS score was related to ED visits and hospitalizations (F[2,43]=4.46, p<.05), but in the opposite way than expected: people with both hospital admissions and ED visits had the highest average SMS scores, followed by those with either a hospital admission or ED visit, with lowest SMS scores among those with neither (Figure 17). Lower SMS scores for people with ED visits and hospital admissions were anticipated because ED visits or hospital admissions were conceptualized as evidence of lack of self-management, consistent with work in adult populations seeking to reduce "preventable hospitalizations". Alternatively, health care teams may focus their SMS resources on families that they perceive to be struggling to manage their child's condition and/or those who have greater medical complexity, for whom occasional ED visits and hospitalizations may be inevitable or even planned. In other words, hospitalization or ED visits may serve as an alert to the health care team that a family is in need of additional support. Additional information about the timing of the provision of SMS could elucidate the best explanation for the relationship of SMS and hospitalizations and ED visits.

Figure 17. Mean SMS score by ED Visits and Hospital Admissions (n=46)
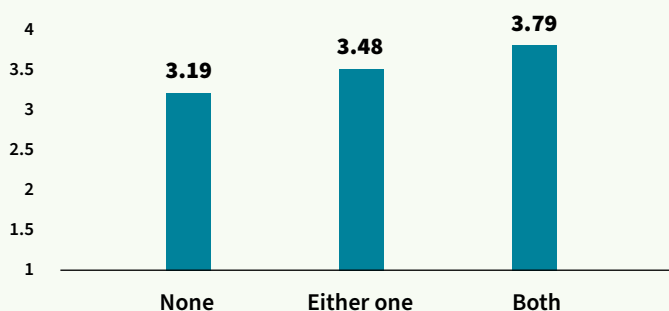

Number of conditions. The total number of medical conditions approached significance, such that a greater number of conditions was associated with greater reported SMS (rTOTAL = .26, p=.08). This is consistent with findings from ED visits and hospitalizations, suggesting that health care providers may focus provision of SMS resources on families of children with greater medical complexity. See Appendix G for additional analyses about categories of conditions.

Years since diagnosis. Although there was not an a priori hypothesis about the relationship between SMS and years since diagnosis, the relationship between these variables was examined. There were no significant differences in SMS scores by years since diagnosis (F[3,42]=1.82, p=.16).

Figure 18 suggests that there may be ebbs and flows in the provision of support during the child's lifespan, as they develop, their diagnoses change, and their condition progresses. During the course of the study, multiple caregivers described a process in which they were unsatisfied with their child's care early in their child's diagnosis; however, with time and experience, they transferred to providers who offered better care. If these anecdotes are representative of this population more generally, one would expect that "veteran" caregivers would report higher SMS than would those with recent diagnoses (see Appendix G for additional details).

Figure 18: Mean SMS Score by Years since Diagnosis (n=46)

	Less than 1 year	1-2 years	3-5 years	6 or more years
	3.44	3.55	3.18	3.68
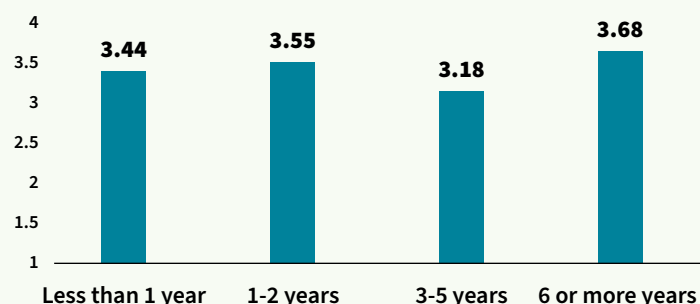
Implications for statewide administration

- To further investigate this relationship, the study team plans to recruit a diverse sample with respect to years since diagnosis, possibly oversampling caregivers of children with newer diagnoses.

Differences by Language and Site

Differences in survey responses by language and site were examined. No significant differences in SMS score or other key variables were found by language of survey participation (English v. Spanish; Appendix H).

However, as noted above, when the SMS score was broken down by recruitment site, there were significant differences (Appendix H). Respondents at the community-based clinic reported a higher average SMS score than those at the hospital-based site (3.71 v. 3.15; p<.001). As previously described, that respondents at the community-based site were recruited by clinic staff and completed their survey at the clinic (Method 1); whereas those from the hospital-based site were referred by clinic staff to the research team, who contacted them and sent them a survey to complete at home (Method 2).

This finding suggests one of several possibilities:

1. the providers at the community-based clinic were better at providing SMS to their patients;

2. the survey administration procedures at each site had a differential impact (i.e., completing the survey in clinic creates greater bias for positive responses than does completing in the home); or

3. the samples differed from each other in other ways that were not measured.

These possibilities were explored in greater detail because of their relevance to a successful statewide administration of the survey (see Appendix H). Briefly, there was evidence from qualitative and quantitative data that both pilot sites were high performing, and that the community-based site was exceptionally so (hypothesis 1). There was more limited evidence that in some specific cases, elements of in-clinic administration, such as using a clinic device to take the survey and handing it back to clinic personnel, caused a few participants to hesitate about sharing their true evaluations (hypothesis 2).

Implications for statewide administration

- The findings indicate that in a larger statewide administration, site selection must include a careful screening process whereby clinics are assessed along various dimensions such that "exceptional" clinics that are deeply invested in the care CYSCHN but are not necessarily reflective of the reality of most Californians are excluded.

- In addition, methods of survey participation that allow participants to answer on the device and in the place that they feel most comfortable will be offered to avoid any potential bias. their survey at the clinic (Method 1); whereas those from the hospital-based site were referred by clinic staff to the research team, who contacted them and sent them a survey to complete at home (Method 2).

Conclusions

The pilot study served to inform the survey content and structure, as well as the research methodology, that will be utilized in a larger study of caregivers of CYSHCN throughout California. Below are the key lessons that will be applied in the statewide study and can be implemented in similar studies throughout the country with pediatric clinics.

Survey Content

The pilot study demonstrated that the content of the AFFIRM survey was relevant to caregivers of CYSHCN and easily understandable to those who responded in English and Spanish. The length of the survey proved feasible for this population, and the online format and structure of the survey were easily navigable. Potentially "sensitive" topics such as income and child's diagnosis, demonstrated high response rates and short response times, suggesting that these items were not a deterrent for caregivers in answering the survey.

Self-Management Support. Early in the process of the survey design, it was decided that SMS would be measured in reference to the child's usual source of care, rather than all providers, in the interest of a short, manageable instrument with less recall burden. Evidence from qualitative follow-up inquiries and the advisory board suggests that reporting about supports provided by the usual source of care is reliable overall. However, during qualitative inquiry, a distinct disadvantage of this approach was brought into focus: it limits assessment of care provision to one (albeit central) provider at a particular point in time. Thus, if other health care professionals currently or in the past have not or do not provide needed SMS, the current instrument cannot identify them. The study team is considering ways to quickly (globally) assess previous or other experiences with health care providers that would complement the snapshot obtained from the usual source of care. Although the validity of the SMS items as a whole was supported, the study team is considering small ways to revise or remove a few SMS items that appeared to be redundant. On the other hand, SMS questions about peer support will be expanded to better assess components of this type of support (e.g., one-on-one vs group support, online vs in-person, etc.).

Additional Revisions. Based on results of the pilot, additional minor revisions to the survey will be made, such as rephrasing the question that asks how many regular providers a child has (Appendix F). In addition, the team will focus on alternate ways to measure medical complexity, likely substituting the current item on impairments with other measures. For example, the advisory board suggested asking about the amount of time spent caring for or spent at appointments for the child in an average week or assessing the number of agencies, including those outside the health care system, that care for the child as a measure of complexity.

Study Methodology

The pilot study clearly demonstrated that recruitment of study participants in health care settings was a viable way to reach diverse and targeted groups of caregivers. Low SES, racially diverse populations that historically have been difficult to recruit for research participation were successfully included. Moreover, non-English speakers were recruited and completed the survey reliably. In California, where a large percent of the population speaks other languages or is not proficient in English, it is especially important to capture the experiences and perspectives of people who may receive differential supports from their health care providers.

Sample. In order to rigorously analyze the SMS data (e.g., factor analysis, subgroup analyses), the California-wide study must include a sufficiently large sample size. Moreover, it should include families with diverse experiences that were not represented in the pilot, such as people from rural regions, middle class backgrounds, and more individuals whose primary language is not English. In addition, variability in time since diagnosis must be ensured to capture "the journey" of becoming confident in caring for the child and other changes that occur over time.

Recruitment. The very high scores on multiple variables in the pilot study highlighted the problem of recruiting patients from clinics that focus on CYSHCN and excel at providing quality care and support. In a statewide study, the team will seek to include clinic sites that are more representative of the quality of care routinely offered to CYSHCN and their caregivers, which anecdotal evidence suggests is not comparable to the care provided by the pilot clinics.

Second, during the pilot, a principle for guiding recruitment methodology emerged: aim for the benefits of in-person recruitment (greater participation rates, shorter completion time) while allowing flexibility in the time and location of survey administration. In the statewide study, this flexibility will allow the study team to accommodate caregivers who are not available immediately after an appointment or who are concerned about the confidentiality of their responses when provided in clinic. Given this principle, a waiting room recruitment managed by a research team (rather than an internal clinic team) is preferred; however, other variations of this recruitment can be accommodated using the guiding principle.

Analysis. The pilot study provided initial evidence of the validity and reliability of the SMS survey as an assessment instrument. The larger statewide study with diverse populations and locations will provide an opportunity to deepen this analysis. For example, a greater number and variance in SMS responses will allow analysis of the relationships among individual SMS constructs and larger domains (e.g., when a caregiver receives a certain type of support, which other supports are they likely to receive from their provider). Moreover, analyses of SMS with external variables can be expanded to both validate the instrument and increase understanding of the effects of SMS. For instance, the study team is interested in the relationship of years since diagnosis to specific domains of SMS, and the direction of this relationship in the larger group of caregivers, as well as in particular subgroups of caregivers in California. In sum, instrument development usually requires assessing different populations to better understand how constructs of interest "behave" in each population; the statewide survey will afford the opportunity to collect data from diverse populations in order to gain a better understanding of SMS and related constructs.

Families of CYSHCN manage care of their child's condition daily. This requires not only treatment of the child's symptoms, use of medical equipment, and recognizing when to escalate care, but also coordination of care across multiple providers and agencies; ensuring insurance coverage for costly appointments, procedures, and equipment; and managing financial, emotional, and logistical challenges associated with the child's condition. Health care providers can help caregivers by offering a wide range of supports for self-management. The AFFIRM self-management support tool, developed in collaboration with families of CYSHCN, pediatric health care providers, and researchers, can provide a critical tool to better understand the degree to which pediatric health care providers are offering these vital supports. In addition, it may help to identify gaps in supports or inequities for groups that are not receiving self-management support. A prospective large, statewide study will serve to address these questions and provide practical information to stakeholders who seek to improve the care of CYSHCN, for example, in clinic-based administration for quality improvement purposes or health care policy on mandated and billable services by health care providers.

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Appendix A. Self-Management Supports Domains and Constructs

Domain 1: Being Available/Accessible to Patients/Caregivers

a) Single, direct point of contact for clinic that has skills to answer questions and resolve problems

b) Access to useful information on the patient portal (EHR)

c) Option to use telehealth and its utility

Domain 2: Providing Information on Disease Management & Resources within Medical System

a) Remind regarding routine preventative care (e.g., screening, bloodwork, immunizations)

b) Ensure understanding of medical condition, including referral to condition-specific classes, refreshers, & materials

c) Teach recognition/management of symptoms

d) Assess caregiver's understanding of and ability to carry out agreed upon next treatment steps

e) Teach use/management of durable medical equipment & assistive devices

Domain 3: Helping Access Supports Outside the Medical System

Coach on how to obtain services/benefits by teaching unique jargon, eligibility criteria, and key personnel in external agencies/systems [Later edited to be insurance specific]

a) Direct to and explain financial supports (public benefits, e.g., SSI, IHSS)

b) Assist in connecting with peer supports

c) Help caregiver with school supports (e.g., IEP)

d) Support caregiver in accessing behavioral or mental health services for patient

Domain 4: Helping Organize, Prioritize, and Plan

a) Help caregivers to problem-solve based on their priorities

b) Share in decision making

c) Train on organizational skills, including tracking administration of medications, making emergency checklists, following treatment plans, and tracking appointments

d) Assess caregiver priorities and manage care based on identified priorities

e) Coordinate care with other healthcare providers

Domain 5: Empowering, Strengthening, and Emotionally Supporting Caregiver

a) Recognize caregiver/patient agency and expertise

b) Teach stress management & refer caregiver to relevant mental health/respite services

c) Instill caregiver self-efficacy/confidence to advocate for themselves in the face of agencies/systems OR Mobilize caregiver/patient to fight for their rights/needs

d) Support caregiver in advocating for child's needs

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[16] Some constructs originally proposed were ultimately removed from the final instrument due to the need for brevity

Domain 6: Preparing Caregivers/Patients for Transitions or Big Changes in Condition/Care

a) Assist in planning for emergencies

b) Support transition to adulthood & other developmental transitions (e.g., childhood to adolescence)

c) Increasingly include child in care in order to transition care from caregiver to patient over time

d) Plan care over time based on caregiver's long-term goals

Appendix B. Issues Identified and Resolved through Testing

Issue identified during cognitive interviewing	Possible solutions explored	Decision based on user testing
Need for a "Do not need" option: Distinguish between SMS that was not needed versus that which was needed but not provided. Use of the "disagree" response when SMS was not needed could imply a service provision gap that does not exist.	Two methods to identify services not needed were compared: a) Asking screening questions to determine the need for support before asking about receipt of supports; and b) Including a "Do not need" response option for all SMS items that was worded and formatted such that it stood out to respondents.	• A "do not need" response that was visually distinct from other response choices was an effective mechanism to distinguish between supports needed but not received and supports not needed • While screening questions that sought to identify the need for domains of support were not easily understood by participants, some specific screening questions appeared effective at distinguishing people for whom support was relevant from those for whom it was not. Eight such screeners were included in the final survey.
Ideal response options: Responses to the cognitive interviewing raised the question of whether a 4-point Likert scale made important distinctions between intensity of agreement or whether a simple yes/no response would adequately capture distinctions made by respondents.	Two sets of response scales were compared: a) Likert scale (strongly disagree — disagree — agree — strongly agree); and b) Binary option (yes/no).	Likert style questions were preferable to yes/no responses because respondents were able to differentiate between intensities in agreement, reflecting more subtle variability in families' experiences.
Need to simplify items: A small number of items were identified that were confusing for caregivers. In addition, there were indicators that reverse coded items may be difficult for respondents to understand, especially in a Spanish language survey.	Original items were directly compared to revised, simplified items. Reverse coded items were directly assessed for comprehension with participants in user testing.	Simplified items successfully captured the core constructs better than the original items. Reverse coded items were removed from the survey in English and Spanish.
Wording and response options for self-efficacy items: Two approaches to assessing self-efficacy and corresponding response choices were explored to evaluate the most reliable method of assessing self-efficacy.	Items with the word "confident" (similar to other standard measures of self-efficacy) were tested in contrast to wording describing abilities (e.g., "I can tell my child's health care team that I disagree with them about my child's care" A 4- versus a 6-point response scale was also tested.	Items using the word "confident" gave caregivers permission to express a lack of self-efficacy which should improve item variability. Caregivers better understood the 4-point scale and had difficulty distinguishing between points on the 6-point scale. Therefore, a 4-point scale was determined to be more appropriate.

Appendix C: Survey Instrument in Pilot Study

This instrument will be further revised based on findings of this pilot study.
Text in *gray italic* denotes survey programming instructions and is not included in on-line version.

Thank you for your interest in this survey for caregivers of children and youth with special healthcare needs!
Gracias por su interés in esta encuesta para cuidadores de niños y jóvenes con necesidades especiales de salud!

This survey may be taken in different languages. What language would you prefer to read and answer survey questions in?
Se puede responder a esta encuesta en otros idiomas. ¿En cuál idioma prefieres leer y contestar a las preguntas?

○ English (Inglés) (1)
○ Spanish (Español) (2)
○ Other: which one? (Otro: ¿en qué idioma?) (99) _____

English language branch: Information page

This survey is for caregivers of children and youth with special health care needs. We want to understand how healthcare providers support you in caring for your child.

> *Children with special health care needs are those who have or are at greater risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services beyond those required by other children.*

If you are not sure if your child has special healthcare needs, please answer the first questions of the survey to find out if you are eligible.

Your responses are confidential. There are no right or wrong answers. We just want to know about your experiences.

Answering these questions will require about 20 minutes of your time. We will send you a $50 gift card at the end to thank you.

You can review an information sheet about the survey by clicking here. For any questions or concerns regarding the survey, please email [name and email of RA].

If you agree to participate in the survey, please click the arrow to begin. Thank you!

Eligibility Screener

Do you have at least one child **(ages 0-17)** in the house with a **chronic condition**? We define chronic condition as a medical, emotional, developmental, behavioral, or other health condition that has lasted or is expected to last **at least 12 months**.

○ Yes (1)
○ No (0) **→ *Not eligible for survey***

Write below the name or initials of the child with a chronic condition(s) to remind you later who you are thinking about. If you care for more than one child with a chronic condition, please choose the child who you spend the most time caring for due to their condition.

_____ *[→ This name/initials piped into subsequent questions in place of "this child"]*

You will answer all of the questions below **only** about this child.

Does [child's name] need or use more medical care, mental health, or educational services than is usual for most children of the same age?

○ Yes (1)
○ No (0)

Does [child's name] have any limitations or problems doing things due to their chronic condition that most children of the same age can do?

○ Yes (1)
○ No (0)

Does [child's name] need or get special therapy, such as physical, occupational, or speech therapy?

○ Yes (1)
○ No (0)

Does [child's name] have any kind of emotional, developmental, or behavioral problem for which they need treatment or counseling?

○ Yes (1)
○ No (0)

[If responds "no" to ALL of previous 4 questions, not eligible for survey]

Do you often join [child's name] for their medical visits?

○ Yes (1)
○ No (0) → *Not eligible for survey if confirms response; elicits email of caregivers who interacts with team*

[If answers "No" to question about joining child for medical visits] This survey is about communication and services from [child's name]'s doctor or healthcare team, so we need the caregiver who talks the most with your child's doctor or healthcare team to answer the survey. If this is NOT you, please **stop the survey** and enter here the email of that person here: _____

Income screener[17]

How many people live in your household? Include yourself and everyone who lives with you and depends on your household income, even if they are not part of your immediate family.

○ 2 (2)
○ 3 (3)
○ 4 (4)
○ 5 (5)
○ 6 (6)
○ 7 (7)
○ 8 or more (8)

To determine if you are eligible for this study, we would like to ask you about your household income. This information will remain completely confidential and will not be shared outside this study.

Income response options change based on response to number of people in household

Thinking about everyone living in your household and the various ways your family supports itself financially, what was your total household income **before taxes** in the last 12 months?[18]

○ Under $17,400 (1)
○ $17,400-$34,700 (2)
○ $34,800-$69,600 (3)
○ $69,700 or more (4)

———

[17] This screener was included in the pilot study to recruit a low-income sample, but will likely be removed as a screener in a statewide administration.

[18] MIncome ranges in the response choices varied based on the number of people in household, reported in the previous question. Response choices corresponded to: <100% Federal Poverty Level (FPL), 100-199% FPL, 200-399% FPL, and 400+% FPL

Demographic information

Your family

How well do you speak English?

○ Not at all (1)
○ Not well (2)
○ Well (3)
○ Very well (4)

Please indicate the highest level of education or degree that **any adult in your household** has completed in any country. When you think about your household, include everyone who lives with you and depends on your household income.

○ 8th grade or less (1)
○ 9th-12th grade, no diploma (2)
○ High school graduate or GED (3)
○ Completed a vocational or trade program (4)
○ Some college credit but no degree (5)
○ Associate degree (AA, AS) (6)
○ Bachelor's (BS, BA) (7)
○ Graduate degree (such as MBA or MD) (8)
○ I don't know (-9)

Your child

Please choose the answer that best describes [child's name]'s age:

○ 0-11 months (1)
○ 1-5 years old (2)
○ 6-10 years old (3)
○ 11-17 years old (4)
○ 18+ years old (5) → *Not eligible for study*

Please indicate [child's name]'s gender

○ Male (1)
○ Female (2)
○ Other (such as gender non-binary) (99)

Please indicate [child's name]'s race and ethnicity. Mark all that apply.

○ African American / Black (1)
○ Native American / Alaskan Native (9)
○ Southeast Asian (e.g., Filipino, Hmong, or Vietnamese) (2)
○ Chinese / Chinese-American (3)
○ South Asian (e.g., Indian) (4)
○ Native Hawaiian / Pacific Islander (5)
○ Other Asian (6)
○ Hispanic / Latinx (7)
○ Middle Eastern/Northern African (8)
○ White (10)
○ Other (99) _____

Medical conditions

The next 3 questions ask about the conditions or diagnoses that [child's name] currently has.

Has a doctor or other healthcare provider told you that [child's name] currently has any of the **Behavioral or Mental Health Conditions** listed below? Mark all that apply.

○ Anxiety disorder (1)
○ Attention deficit disorder (Attention Deficit Disorder or Attention Deficit/Hyperactivity Disorder) (2)
○ Bipolar disorder (3)
○ Behavioral or conduct disorder (Oppositional Defiant Disorder or Conduct Disorder) (4)
○ Depressive disorder (Major Depressive Disorder or dysthymia) (5)
○ Other (99) _____
○ None of the above (0)

Has a doctor or other healthcare provider told you that [child's name] currently has any of the **Physical or Developmental Disabilities** listed below? Mark all that apply.

○ Autism spectrum disorder (including Asperger's disorder, Pervasive Developmental Disorder) (1)
○ Developmental delay (2)
○ Difficulty hearing or hearing loss (3)
○ Down syndrome (4)
○ Intellectual disability for other causes (like Fetal alcohol syndrome, Fragile X syndrome) (5)
○ Learning disability (like dyslexia) (6)
○ Physical disability (7)
○ Speech delay or speech disorder (NOT due to English as a Second Language) (8)
○ Visual impairment or blindness (9)
○ Other (99) _____
○ None of the above (0)

Has a doctor or other healthcare provider told you that [child's name] currently has any of the **Chronic Medical Conditions** listed below? Mark all that apply.

○ Allergies to food (1)
○ Asthma (2)
○ Blood disorders (like Sickle Cell Disease, Thalassemia, or Hemophilia) (3)
○ Cerebral palsy (4)
○ Congenital or chronic heart disease (5)
○ Cystic fibrosis (6)
○ Diabetes (type I or II) (7)
○ Epilepsy or seizure disorder (8)
○ Gastrointestinal disorders (like Gastronomy Tube Dependence, Chronic Abdominal Pain) (9)
○ Kidney disease (10)
○ Pulmonary disorders (like chronic lung conditions, ineffective airway clearance, sleep apnea) (11)
○ Spina bifida (12)
○ Other (99) _____
○ None of the above (0)

In the rest of the survey, wherever we ask about [child's name]'s health condition(s), we mean the conditions that you indicated in the previous 3 questions **and** that have lasted **at least 12 months** (or are expected to last at least 12 months).

Thinking about [child's name]'s main medical condition(s), how long ago were you first told by a doctor or nurse that [child's name] had this condition(s)?

○ Less than a year ago (1)
○ 1-2 years ago (2)
○ 3-5 years ago (3)
○ 6 or more years ago (4)

Some children who have chronic condition(s) are not able or need help to do things that other children can do on their own.

Compared to other children their age, which of the following areas of [child's name]'s everyday life are affected because of their chronic condition(s)? Mark all that apply.

○ Home life (1)
○ Friendships (2)
○ Learning (3)
○ Play activities (such as hobbies, games, sports) (4)
○ Personal care (such as eating, dressing, bathing) (5)
○ Movement (such as moving head, crawling/walking, or playing) (6)
○ Communication (7)
○ Other (99) _____

Does [child's name] need or have any of the following? Mark all that apply.

○ Disability-related benefits, like Supplemental Security Income (SSI) or In Home Support Services (IHSS)
○ *[If child at least 6 years old]* Accommodations at school due to special needs (for example, in an IEP)
○ Special medical equipment, such a wheelchair or walker, ventilator or oxygen, gastronomy tubes, nebulizer, or injections? (This does not include medications which are taken by mouth.)
○ None of these.

How many doctors or healthcare providers does [child's name] **regularly** visit to get care for their chronic condition(s).

_____

Is there one place you **usually** contact when you need advice or help caring for [child's name]'s health condition(s) on a day-to-day basis (for non-emergencies)?

○ Yes, primary care (like general pediatrician, family doctor) (1)
○ Yes, specialty care (like neurologist, immunologist): What is their specialty? (2)
○ Yes, other (like psychologist, physical/speech therapist): What is their expertise? (99) _____
_____

○ No, I don't have a place like this (0) → *If confirms response, skip remainder of this section and all Self-Management Questions and go to Children's Health Insurance Questions*

[If answers No to having primary healthcare provider] Tell us about some of the reasons that you do not have a place that you usually contact about [child's name]'s care?_____

What is the name of this doctor or healthcare provider? (To remind you later about which person you are thinking about)
_____ *[→ This name piped into subsequent questions]*

How much do you trust [provider name] in [child's name]'s care?
○ (1) A little
○ (2) Somewhat
○ (3) Mostly
○ (4) Completely

In many clinics, doctors care for patients in a team with other staff members. In [provider's name]'s clinic, **who is part of the healthcare team** that **often** helps care for [child's name]? Mark all that apply.

○ Doctor or Nurse practitioner (1)
○ Nurse or Medical Assistant (2)
○ Care coordinator or case manager (4)
○ Mental health professional (like social worker or psychologist) (5)
○ Administrative staff (like front office or billing) (6)
○ Other - please describe: (99) _____

Which of these does [provider's name] have? Please select all that apply.

○ A patient portal, which is a secure website that can be used to find information about your child's care and send messages to the healthcare team
○ Video visits, which take place using a device like a smart phone or computer to connect you to the healthcare team
○ None of these

Self-efficacy

Your feelings

Now we want to know how confident you feel about taking care of [this child].

How confident are you in your ability to figure out how to get the services that [this child] needs?

○ (1) Not at all confident
○ (2) Somewhat confident
○ (3) Fairly confident
○ (4) Very confident

How confident are you in your ability to find answers to your questions about [this child]'s condition and care?

○ (1) Not at all confident
○ (2) Somewhat confident
○ (3) Fairly confident
○ (4) Very confident

How confident are you in your ability to care for [this child] when something unexpected happens with their health?

○ (1) Not at all confident
○ (2) Somewhat confident
○ (3) Fairly confident
○ (4) Very confident

How confident are you in your ability to tell [provider's name] that you disagree with them about [child's name]'s care?

○ (1) Not at all confident
○ (2) Somewhat confident
○ (3) Fairly confident
○ (4) Very confident

Self-Management Support items

Support from [provider's name]'s team

The statements below are about your experiences in caring for [child's name] with [provider's name]'s team.

Thinking about the entire team, please mark how much you agree or disagree with each statement. If you do not need help with this part of your child's care, please mark "**I do not need this from [provider's name]'s team.**"

[Provider's name]'s team gets me answers on time when I have questions about [child's name]'s care.

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team reminds me about the things we need to do to keep [child's name] healthy, like screening, blood tests, and immunizations.

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team helps me get insurance coverage for the care [child's name] needs such as giving me words to use when I talk to the insurance company or helping me if coverage is denied.

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team makes sure my voice is heard in [child's name]'s treatment goals and decisions.

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team respects that I know a lot about [child's name]'s needs and conditions.

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team helps me plan ahead so that I am ready to take care of [child's name], even when [child's name] is very sick.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team offers me resources to learn more about [child's name]'s condition, for example, through classes, websites, or videos.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team has connected us to other families with similar experiences, for example, through online support groups or family resource centers.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team helps me solve problems in [child's name]'s care based on what works best for our family.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team takes a personal interest in [child's name].

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team has talked with me about my hopes and long-term goals for [child's name].

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team teaches me how to recognize and take care of [child's name]'s symptoms as they come in day-to-day life.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team helps me organize the things I need to keep track of for [child's name]'s care, like appointments, medications, and important contacts.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team encourages me when I advocate for [child's name] to make sure [child's name] gets the care they need.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team makes sure that I am clear about new care instructions or decisions that were made during a visit, for example, by asking me to summarize decisions at the end of the visit.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

When there are a lot of things to do to care for [child's name], [Provider's name]'s team plans with me what is most important to do first.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team backs me up if I get stuck with other programs by contacting them directly or providing resources, such a letter.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team communicates with [child's name]'s other healthcare providers to make sure that everyone who cares for [child's name] is on the same page.

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team goes above and beyond in helping me take care of [child's name].

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[Provider's name]'s team asks me about **my** needs at visits, including **my** mental health or stress.

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[If Provider has patient portal:] [Provider's name]'s team has shown me how to use the electronic patient portal.

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[If child has medical equipment:] [Provider's name]'s team makes sure that I am comfortable using [child's name]'s medical equipment, for example, by asking me how it's working or showing me how to use it.

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[If child eligible disability-related benefits:] [Provider's name]'s team has explained how to get programs and benefits that might help me pay for [child's name]'s day-to-date care, like Supplemental Security Income (SSI) or In Home Support Services (IHSS).

- ○ (1) Strongly disagree
- ○ (2) Disagree
- ○ (3) Agree
- ○ (4) Strongly agree
- ○ *I do not need this from [provider's name]'s team*

[If child is at least 6 years old and has had primary diagnosis for at least 3 years:] [Provider's name]'s team has helped me find ways to meet [child's name]'s changing needs as they have grown, for example, starting a new school or becoming more independent.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[If provider offers video visits:] [Provider's name]'s team has shown me how to connect for a video visit.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[If child has or needs IEP or other accommodations:] [Provider's name]'s team has helped [child's name]'s get special services or accommodations at their school through an IEP or informally.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[If child is at least 6 years old:] [Provider's name]'s team includes [child's name] in conversations so that [child's name] can participate in more of their care as they grow.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

[If child has emotional, developmental, or behavioral condition:] [Provider's name]'s team has provided information on how to get the right behavioral or mental health services for [child's name], for example, ABA, therapy, counseling, or psychiatric care.

○ (1) Strongly disagree
○ (2) Disagree
○ (3) Agree
○ (4) Strongly agree
○ *I do not need this from [provider's name]'s team*

You are almost done! Just a few final questions!

Insurance and hospital visits

Is this child covered by any of the following types of health insurance or health coverage plans? Mark all that apply:

○ Medi-Cal (1)
○ California Children's Services (CCS) (2)
○ Private insurance (from work, Covered California, or other) (3)
○ TriCare (4)
○ No insurance (0)
○ Other: (99) _____

During the last 12 months, how many times was this child **admitted to the hospital** to stay for at least one night? Please write a number on the line below. _____

During the last 12 months, about how many times has this child **visited a Hospital Emergency Room**? Please write a number on the line below. _____

More about your family

How often do you need to have someone help you when you read written materials in your preferred language from your doctor or pharmacy?

○ Never (5)
○ Rarely (4)
○ Sometimes (3)
○ Often (2)
○ Always (1)

What is the one thing that you **most need** from [child's name]'s healthcare team to help you care for [child's name]?

_____

_____

Is there **anything else** you'd like us to know about the support you receive from [provider's name]'s team to care for [child's name]?

_____

_____

Thank you for taking part in this study! What you shared will help shape policies and programs to support caregivers like yourself. We are trying to learn how to make this survey better for other caregivers. If we have questions about you answered a question, would it be okay to call you? We will provide another gift card as a thank you for your time.

○ Yes (1)
○ No (0)

Would you like to receive a summary of our survey results at the email or mailing address you listed above?

○ Yes (1)
○ No (0)

Appendix D: Advantages and Disadvantages of Recruitment Methods Tested

	Advantages	Disadvantages
Method 1 Clinic staff recruitment	• High response rate • Fast survey completion • Selection of patients based on visit schedule rather than clinician impression/relationship with patient • In person contact facilitates access to patients who may not respond through other means (e.g., phone)	• May miss people who do not attend appointments • Clinician/staff time required • Possible bias in assessing SMS because clinics with resources to recruit this way may be better resourced in general, including for providing support to caregivers of CYSHCN
Method 2 Outreach by study team	• Minimal requirements of clinical site • May be easier to recruit less resourced clinics for participation if offering this method	• Relies on many clinicians taking time to provide lists of prospective participants • Clinicians may refer people with stronger engagement or certain types of diagnoses (e.g., more complex) • Lower response rates among all families referred by clinic (although high response rates among those who answered phone) • Longer survey administration times (i.e., surveys not completed in one sitting) risk greater potential for survey noncompletion (which was not substantiated in this pilot)
Potential future method Waiting room recruitment by study staff	• High response rate • Fast survey completion • Selection of patients based on visit schedule rather than clinician impression/relationship with patient • In person contact facilitates access to patients who may not respond through other means (e.g., phone)	• More resource intensive • Need to clearly distinguish research staff from clinic staff and provide flexibility in how and where to complete survey to avoid potential of bias • Requires protocol to ensure that staff do not selectively approach caregivers of children with visible disability or illness

Appendix E: Special Health Care Needs Screening

Four items from the Special Health Care Needs Screener were used to determine eligibility. All four items were endorsed by most respondents; needing "more medical care, mental health, or educational services than child their age" was the most common criteria for CYSHCN designation (90% of respondents; Figure 19) followed by needing special therapy (83%). Over 80% of respondents endorsed at least 3 screening questions, with half endorsing all four screening questions.

Figure 19: Special Health Care Needs Criteria endorsed by Respondents (n=52)
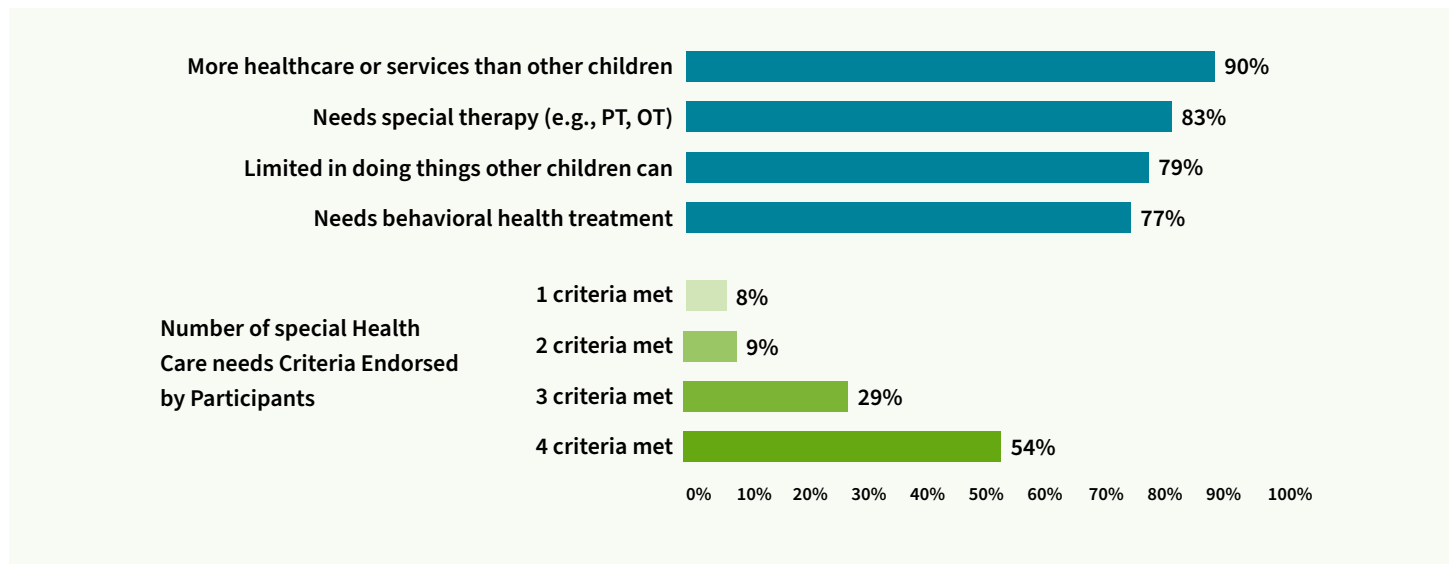
Appendix F: Survey Metadata

Completion time

Because participants sometimes paused participation to take part in medical visits, tend to children, or respond to other tasks, timing functions were embedded on each page so as to be able to account for pauses. Median time for completion for each page was 15-30 seconds. To adjust for survey pauses, timing per page was capped at the higher number of either 60 seconds or when 90% of respondents had completed the page.

Excluding long pauses yielded the median completion times outlined in Table 20 for each survey section, with a total mean time of 18.0 minutes (median time of 17.3 minutes), which was well within the study target. Although factors influencing the length of time for completion are not currently identifiable, research associates reported anecdotally that listening to the survey using the audio option required a longer administration time.

Table 20. Completion Time by Section (n=52)

Section	Median time (minutes)	Range (minutes)
Screening for eligibility	2.0	0.5 – 5.5
Non-SMS questions (demographics, child condition, provider identification, and self-efficacy)	8.6	2-30
SMS questions	4.3	0-13.5
Open ended text	1.0	0-4.5

Partial completions

Early in the process of survey development, there was concern that a population already taxed by other demands would not have the resources (e.g., time) to complete this survey. As such, extensive efforts were made to aggressively cut down on the number and type of items. The final count was 62 items. The pilot revealed that given the current structure and length, partial completion is not a concern. Only 1 participant accessed the survey site but did not complete the survey (in fact, they did not complete any of the items). Thus, even for the home-based completion of Method 2 in which some respondents stopped and resumed the survey over multiple days, every participant who completed the first section ultimately completed the entire survey. Participants received a $50 gift card upon completion of the survey, which may help account for such high completion rates.

Missing data

It is perhaps surprising that missing data was not a problem in a self-report survey such as this one that asks sensitive questions about caregivers and their children. Almost all respondents chose to answer items about demographics, including income, insurance coverage, education, and race/ethnicity. Similarly, respondents chose to answer questions about their child's diagnosis and other descriptors of their child's condition, which is often considered private.

Whereas respondents had no trouble reporting on the child's usual health care provider and the associated care team, an item asking caregivers to report the number of health care providers that their child sees on a regular basis appeared challenging. This issue was explored during the final advisory board meetings and in qualitative inquiries. It appears that several issues were particularly difficult for answering this question:

1. The understanding of "regular" provision of care where no frequency was provided: caregivers were unsure whether to include providers that they see infrequently (e.g., 1-2 times per year) or follow up with only as needed (e.g., a cardiologist for a heart problem that is presumed resolved)

2. Interpretation of the word "provider": caregivers asked if that included dental providers, physical therapists, clinical case managers, people fitting orthotics, audiologists, or ABA providers, for example.

Participants in the post-pilot qualitative inquiry and on the advisory board also commented that it required greater mental energy to calculate a total number of providers. They agreed that providing categories (e.g., 1-2, 3-5, or more than 5), giving examples of people to include, and being more specific about timeframe would help them provide a better estimate.

Appendix G: Validation of SMS with External Criteria

Table 21. Association of SMS Score and Other Variables

Measure	n	Measure of association: *Pearson correlation coefficient or F-statistic*	Significance
Trust in the health care provider	50	r=.46	p<.001
Self-efficacy	50	r=.32	p<.05
ED visits and hospital admissions	48	F[2,43]=4.46	p<.05
Areas of impairment	48	r=-.50	p=.74
Number of conditions	49	r = .26	p=.08
Mental/behavioral health	50	r= .07	p=.62
Disability	50	r = .23	p=.11
Chronic conditions	49	r = .17	p=.26
Years since diagnosis	48	F[3,42]=1.82	p=.16

Provider trust

Trust in the health care provider is positively correlated with average SMS score (see Table 18), which is consistent with the expectation that caregivers trust a provider who offers more support. However, since these constructs are assessed simultaneously in a cross-sectional research design, it is possible that this relationship also reflects a response bias known as the "halo effect" in which, once a caregiver has decided that they trust a provider, they are more likely to report that this provider offers good care and support. The SMS instrument attempts to limit the impact of the halo effect by framing items in a way that focuses on specific, "objective" behaviors by providers rather than subjective evaluations.

Self-efficacy

SMS is positively correlated with mean self-efficacy, which is consistent with the expectation that caregivers who receive more support feel more efficacious in caring for their child.

ED visits/hospital admissions

In an Analysis of Variance (ANOVA), average SMS score was found to vary significantly with more ED visits/hospital admissions (F[2,43]=4.46, p<.05) such that respondents with no visits or admissions had the lowest average SMS score and those with both ED visit(s) and hospital admission(s) had the highest score (see Figure 5). ED visits and hospital admissions may be driven primarily by medical complexity, and health care teams may focus their resources for self-management support on those families that they perceive to have greater medical complexity (and greater need for support). This interpretation is supported by qualitative interviews with caregiver participants and pediatric clinicians in which some described a hospital admission or ED visit serving as a trigger to the health care team for more support.

Impairment

Much like ED visits/hospital admissions, which may be an indicator of condition severity, the number of areas of impairment was tested against average SMS score. This relationship is not significant.

Number of conditions

Likewise, the number of conditions in each category was not significantly related to SMS ratings. However, the total number of medical conditions approached significance, such that a greater number of conditions was associated with greater reported SMS (r_{TOTAL} = .26, p=.08). This is consistent with findings from ED and hospitalizations, suggesting that health care providers may focus provision of SMS resources on families of children with greater medical complexity.

Years since diagnosis

There is no significant difference in SMS scores by years, although there is considerable variance by category of diagnosis years (e.g., at 3-5 years since diagnosis, SMS score was 3.18 and at 6 or more years since diagnosis it was 3.68). Below, several possible explanations are posited for the lack of findings, which will be pursued in a statewide study in which participants may be specifically selected along this dimension (i.e., ensure variability in years since diagnosis).

In conversations with caregivers over the course of the study, the study team developed ideas about receipt of SMS over time. Many caregivers explained that early in the diagnosis of their children, they were not satisfied with the care they received from their child's health care provider. With time, experience, and connections to peers, caregivers often transferred care to providers whom they feel deliver better care. If this is true, then in a large and diverse sample of practices, one would expect that "veteran" caregivers would report higher SMS than would those with recent diagnoses. On the other hand, in geographic areas with more limited access to pediatric providers or for certain specialties, caregivers may have less ability to change providers. In addition, as detailed below, there is evidence that the sites included in the pilot are especially good at supporting CYSHCN; therefore, caregivers recruited at and likely reporting on these clinics, regardless of the duration since diagnosis, should have high SMS scores. In fact, this is what the pilot data show.

Another interpretation of the findings is that the relationship between duration since diagnosis and SMS (and health care supports more broadly) may not be linear. There may be ebbs and flows to the timing of support received over a child's lifespan, as the child develops, conditions change or progress, and diagnoses are added or modified. Finally, during qualitative follow-up discussions, a contradictory hypothesis was raised that may also be true. That is, caregivers who recently received their child's diagnosis may not yet know what they can expect from health care providers. As such, they may rate provider support as higher early on, and less so as their expectations change over time. Although this survey provides specific examples of SMS that could be answered irrespective of expectations for care, such subjective evaluations are inherent in any self-report instrument.

Appendix H: Differences in Results by Recruitment Site & Language

Differences by language

Differences in survey responses were examined by language. No significant difference was found by language of survey participation (English v. Spanish; Table 22).

Table 22. Differences by Language

Measure	n	English Mean(SD) or %(N)	Spanish Mean(SD) or %(N)	Significance
SMS mean score	50	3.48 (.60)	3.45 (.59)	t[46]=-.30, p=.77
3+ years since diagnosis	51	79% (26)	56% (18)	χ2=4.05; p=.13
Trust in provider	49	3.81 (.40)	3.56 (.78)	t[47]=1.48; p=.14
Self-efficacy	52	3.62 (.56)	3.39 (.70)	t[50]=1.28; p=.21
Both Hosp/ED visits within last year	50	24% (8)	35% (6)	χ2=.68; p=.41

Differences by site

Table 23. Differences by Site

Measure	n	Community-based site Mean(SD) or %(N)	Hospital-based site Mean(SD) or %(N)	Significance Test statistic [degrees of freedom], p-value
SMS score	50	3.71 (.57)	3.15 (.47)	t[46]=3.58; p<.001
3+ years since diagnosis	50	76% (16)	69% (20)	χ2=1.66; p=.44
Trust in provider	49	3.86 (.35)	3.50 (.76)	t[25]=1.99; p=.06
Self-efficacy	52	3.71 (.43)	3.31 (.76)	t[31]=2.24; p<.05
Both Hosp/ED visits within last year	50	43% (12)	9% (2)	χ2=7.33; p<.05

Differences in survey responses by site were investigated. When the SMS score is broken down by recruitment site, there are significant differences in SMS scores and other variables (Table 23). Respondents at the community-based clinic reported a higher average SMS score than those at the hospital-based site. This finding suggests one of several possibilities:

Hypothesis 1: Providers at the community-based clinic are better at providing SMS to their patients;

Hypothesis 2: Survey administration procedures at each site had a differential impact; or

Hypothesis 3: The samples differ from each other in other ways that were not measured.

Several of these possibilities were investigated in the qualitative inquiry phase at the end of the study. In support of hypothesis 1, respondents noted that the community-based site was an outlier in terms of the high quality of care provided. Respondents who provided high scores to SMS items at that site provided detailed examples of the kinds of SMS care provided, and they contrasted that care with care they had received in previous settings.

Regarding hypothesis 2, many respondents reported that they would not hesitate to provide a lower rating if they felt it was warranted, because they felt that honest feedback was vital to unearthing problems in care delivery and improving care for others. However, a few voiced concerns about sharing responses critical of health care providers with personnel from their provider's clinic, on devices provided by clinic staff, or simply responding in those sites (all features of Method 1, which took place in the community-based clinic).

In addition to qualitative inquiry, other variables that might provide insight into SMS differences by site were compared. Respondents from the community-based site tended to report greater trust in their health care provider (3.86 v 3.50; p=.06), supporting hypothesis 1. Community-site respondents were also more likely to report having had an ED visit and a hospital admission in the past year compared to those from the hospital-based site (43% v. 9%; p<.05), suggesting that there could be differences between the populations of the sites, which may not have been captured (hypothesis 3).

Respondents from the community-based clinic reported a higher self-efficacy than did those from the hospital-based site (3.71 v. 3.31; p<.05). Because self-efficacy is an evaluation of one's own abilities, it would not be expected to be affected by a bias to report positively about clinicians at the recruitment site (i.e., it does not support hypothesis 2). It could support hypothesis 1 if caregivers felt more confident because of care they received from their health care providers at the community-based site, or it could suggest other differences between the respondents at each site (hypothesis 3).

Higher self-efficacy scores at the community-based site could also reflect differences in recruitment method. For example, Method 1 (in clinic) relies on recruitment during patient visits, which biases against the recruitment of patients who are less engaged in treatment, no-show, or must cancel more often. In a statewide administration, in those clinics in which recruitment will take place in waiting rooms (with a similar potential for bias), specific "quotas" for recruiting patients who have not visited in many months will be set to counter such a bias.