

FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Summary of Medical Home Assessment
Survey for Physicians

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The Los Angeles Medical Home Project for Children with Special Health Care Needs, "Summary of Medical Home Assessment Survey for Physicians," November 2001

The American Academy of Pediatrics, "Periodic Survey #44: Health Services for Children with and Without Special Health Care Needs: The Medical Home Concept," 2000.

High Risk Infant Interagency Council of San Francisco, "Young Children with Special Health Care Needs in San Francisco: Assessing our Reach," June 2003

The Medical Home

A medical home is not a building, house or hospital, but rather an approach to providing health care services in a high quality and cost effective manner. Children who have a medical home receive care that they need from a pediatric health care professional whom they trust. The pediatric health care professionals and parents act as partners in a medical home to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential. The American Academy of Pediatrics (AAP) believes that all children should have a medical home where care is:

- accessible,
 - family-centered,
 - continuous,
 - comprehensive,
 - coordinated,
 - compassionate and
 - culturally competent
- (AAP, 2000)

Purpose

The goal of this survey was to document the resource capacity of local pediatricians (primary care and subspecialty) to 1) serve as medical home physicians for children with special health care needs in San Francisco and 2) to accommodate new patient referrals.

Background

In order to gather information about key components of care in a medical home for children with special health care needs and barriers to this care, Support for Families of Children with Disabilities and the University of California San Francisco (UCSF) Pediatric Disabilities Clinic conducted a survey of pediatricians (primary care and subspecialists) in San Francisco. Names were drawn from lists of members of the American Academy of Pediatrics (AAP) Chapter 1 and the San Francisco Medical Society, and from the San Francisco telephone directory. (*Please Note: None of these lists guarantee accuracy, completeness or reliability.*)

In November 2002, this survey, modified from a national and Los Angeles AAP survey, was sent to a random sample of 476 physicians. A total of 54 completed surveys were received, for a response rate of 11%.

This report will focus on the number of respondents who answered "most of the time" from among the choices "most of the time", "sometimes", "occasionally", "never", and "not applicable".

Definition of Children with Special Health Care Needs

The definition of Children with Special Health Care Needs (CSHCN) used in this survey is the one used by the federal Maternal and Child Health Bureau (MCHB).

Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and also require health and related services of a type or amount beyond that required by children generally. (McPherson, et. A., 1998)

Demographics of the Respondents:

Age:

- 30-39 17%
- 40-49 13%
- 50-59 26%
- 60-69 2%
- 70+ 4%
- No response 39%

Gender:

- Male 52%
- Female 41%
- No response 7%

Type:

- Pediatrician 57%
- Specialist 39%
- Family Practice 2%
- Nurse Practitioner 2%

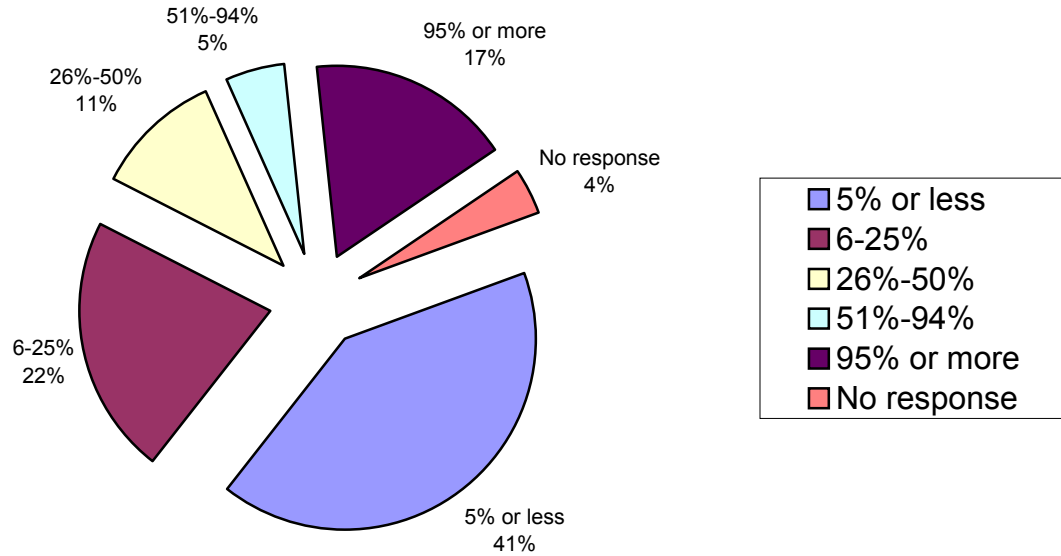
Ethnicity:

- African American 2%
- Asian 28%
- Caucasian 57%
- Latino/Hispanic 6%
- No response 7%

Percentage of practice of children with special health care needs

5% or less	41%
6%-25%	22%
26%-50%	11%
51%-94%	5%
95% or more	17%
No response	4%

Percentage of Children with Special Health Care Needs in Practice



Survey Results

The survey questions were divided into seven separate categories to mirror the components of care in the American Academy of Pediatrics (AAP) definition of a Medical Home:

- accessible,
- family-centered,
- comprehensive,
- continuous,
- coordinated,
- compassionate and
- culturally competent.

The survey contained 49 statements. The respondents were asked to answer, for each statement, if the statement was true:

- Most of the time
- Sometimes
- Occasionally
- Never
- Not applicable

For each statement, the respondent was asked to identify (where applicable) the following barriers that may prevent them from successfully providing any of the components of a Medical Home:

- Reimbursement
- Time
- Lack of office staff
- Restricted by MCO
- Lack of knowledge
- Other

The survey results are reported by the seven Medical Home components. This report discusses the respondent's answers to forty-nine (49) questions and describes identified barriers where applicable.

Accessible:

This set of questions examined such variables as hours of telephone availability, emergency contacts, evening and weekend appointments, accessibility by public transportation, acceptance of Medi-Cal, Healthy Families and California Children Services (CCS), availability of fax, voice mail or email for parent use, ability of parents to speak directly to the provider, and the availability of payment options.

- Ninety-three percent (93%) of respondents indicated that patients have **telephone access** to someone in their offices 24 hours a day, 7 days a week.
- Fifty-seven percent (57%) reported that in **an emergency**, someone from the practice who knows how to care for CSHCN is available on evenings and weekends.
- Few (28%) reported offering **weekday evening appointments**. Lack of office staff (22%), time (28%), reimbursement (11%), and other (4%) were the most frequently reported barriers.
- **Weekend appointments** were reported to be available by 30% of respondents with the following barriers reported: lack of office staff (20%), time (26%), reimbursement (13%), and other (4%).
- Ninety-one percent (91%) reported that their practice is accessible by **public transportation**.
- Seventy-six percent (76%) responded that they accept patients with **Medi-Cal, Healthy Families or CCS**.
- Only 20% reported that their practice offers a **range of payment options** for families, citing reimbursement, time, lack of office staff, lack of knowledge, restrictions by MCO and other reasons as barriers.
- Sixty-seven percent (67%) of respondents indicated that parents may use **fax, voice mail or email to contact** them, and 67% indicated that families are able to speak directly to them when needed, instead of speaking to someone from their staff.

Family-centered:

The questions were intended to gather information about the provider's relationship with families and incorporation of family-centered care principles into their practice. Family-centered care principles recognize that families are members of the health care team and bring with them important information regarding their children. Family-centered care encompasses: collaboration with families, understanding that families play a central role in coordinating care for their children, developing plans of care that consider the needs and values of the family, sensitivity to the emotional needs of the family, encouraging parent-to-parent support, and flexible office practices that can accommodate the needs of families of children with special health care needs.

- Eighty-nine percent (89%) of respondents indicated that they develop a

collaborative relationship with families, while 69% explore all health care options with the family.

- Fifty-seven percent (57%) reported creating an **office environment** that is comfortable for families.
- In 87% of practices, providers reported that **families play a central role** in coordinating care for their children by participating in decision making, 74% reported that they **collaborate with families** to develop an appropriate plan of care, and 76% **encourage parents** to take notes, ask questions, and keep records of their child's care.
- Seventy-eight percent (78%) of respondents indicated that they acknowledge the **families' expertise** and ask questions of them regarding their child's condition.
- Sixty-one (61%) encourage parents to meet **other families** who have children with special needs, and 43% report helping families to identify **coping strategies**.
- Only thirty-five percent (35%) **schedule extra time** for an office visit when seeing a child with special health care needs (or if parents request extra time).
- **Lack of time** creates the greatest barriers to the delivery of family-centered care. Twenty percent (20%) of respondents indicated that time was a barrier to helping families identify coping strategies and twenty-six percent (26%) felt that time was a barrier to their ability to schedule extra time for an office visit. Additional barriers to scheduling extra time for office visits included reimbursement (6%), lack of office staff (6%), restrictions by MCO (4%), lack of knowledge (2%) and other (2%).

Comprehensive:

In the comprehensive care section, questions were asked regarding contacts with community-based programs and services, the provision of preventive and primary care, and the assessment of social, emotional and health status.

- Fifty-nine (59%) percent of respondents reported that they provide **preventive and primary care** to children with special health care needs, with 59% reporting that they **assess the current social, emotional, educational and health status** of the child at each visit.
- Thirty-seven percent (37%) of respondents reported that they or someone in their office **contacts the school** about the child's health and educational needs, as part of coordinating the child's care, and 46% **discuss potential needs** for respite care, equipment or transportation.
- Forty-four percent (44%) give families **information about services and resources** such as Medi-Cal, Healthy Families, California Children Services (CCS), Regional Centers, Head Start or the Special Supplemental Nutrition Program for Women, Infants and Children (WIC).
- Families are referred to **non-medical services** in the community by 54% of

respondents and to **family support** programs or individuals by 43%.

- Finally, 50% reported **providing written information** on a variety of issues affecting children; 35% **reviewed** the written information with families.
- A number of **barriers** to providing comprehensive care were identified by respondents.
 - Barriers to contacting the school about the child's health and educational needs include time (17%), lack of office staff (13%), reimbursement (9%), lack of knowledge (4%), and other (2%).
 - Barriers to discussing potential needs families might have include lack of office staff (11%), time (9%), lack of knowledge (6%) and reimbursement (4%).
 - Barriers to linking families with support services include time (11%), lack of office staff (11%), lack of knowledge (7%), and reimbursement (4%).
 - Respondents identified time (17%), lack of office staff (7%), reimbursement (7%), lack of knowledge (6%) and restrictions by MCO (2%) as barriers to providing written information to families and reviewing it with them.
 - Barriers to providing information about other services and resources (such as Medi-Cal, CCS, Regional Centers, Health Families, Head Start or WIC) include lack of office staff (17%), time (11%), lack of knowledge (9%), and reimbursement (6%).

Continuous:

This section asked questions about assistance with transitions, hospitalizations and the ages of children seen in each practice.

- Thirty-three percent (33%) of respondents reported that they, or someone in their office, assists families at various **transition points** such as between providers, between payers, and between child and adult health services. Barriers include lack of office staff (17%), time (13%), reimbursement (13%), lack of knowledge (7%) and other (2%).
- Fifty-two percent (52%) of respondents meet with **hospital discharge planning teams** to assist with the child's transition back to the community. Barriers to providing this service include time (6%), lack of office staff (6%), lack of knowledge (6%), reimbursement (4%), and other (4%).
- Eight-nine percent (89%) of respondents indicate that their practice consists of **both children and adolescents**.

Coordinated:

This section addresses care coordination activities such as making referrals, assisting

families in scheduling appointments, participating in patient and family conferences, and designating a care coordinator in the practice. This section also asked questions about discussing specialist information with families, maintaining a central record, and providing copies for families.

- When a child is referred to a **specialist**, 61% of respondents indicated that they or their staff assists families in setting up appointments and communicating clinical issues to the specialist, and 65% **communicate the clinical issues** of the visit to the specialist.
- Ninety-one percent (91%) refer to **pediatric sub-specialists**, while 80% refer to **mental health specialists** when needed.
- Fifty-six percent (56%) of respondents consider themselves to be the **primary care coordinator for the child**, 43% **coordinate care** among multiple providers, but only 13% participate in Individual Family Service Plan (**IFSP**) development (for Early Start early intervention services), or Individual Education Plan (**IEP**) development (for special education services).
- Fifty percent (50%) discuss the **results of specialist visits** with the family and answer any questions.
- Fifty-four percent (54%) maintain a **central record/database**, 35% share the **care plan** with others (with parent consent), 65% **provide copies** of letters and 59% provide copies of records free to families.
- **Barriers** to participating in the IFSP or IEP process include time (30%), lack of office staff (13%), reimbursement (11%), lack of knowledge (6%), restricted by the MCO (2%) and other (2%). Identified barriers to discussing the results of specialist visits with families include time (9%), lack of knowledge (4%) and reimbursement (2%). Barriers to coordinating care among multiple providers include time (11%), lack of office staff (7%), reimbursement (6%), lack of knowledge (2%) and other (2%).

Compassionate:

This section on compassionate care includes questions on providers' relationships with families, understanding the needs of children and families, and knowing and respecting various values and beliefs.

- Eighty-one percent (81%) of respondents indicated that they **know the families** in their practice and have a good relationship with each of them, while 87% reported making an **effort to understand** the needs of the family as well as the child.
- Eighty-nine percent (89%) of respondents report **respect** for the families' socio-cultural beliefs, and do not let those values and beliefs affect their interaction with the child and his/her family,
- **No significant barriers** to providing compassionate care were identified. Nine percent (9%) of the respondents cited time as a barrier to getting to know the

families in their practice and 7% identified time as a barrier to understanding the needs of the family.

Culturally competent:

This section addresses the availability of translation and interpreter services, and understanding of the families' beliefs, rituals and customs.

- Forty-three percent (43%) of respondents indicated that a **translator or interpreter** is provided for families for which English is a second language and identified barriers as lack of office staff (15%), reimbursement (2%), time (2%) and other (2%).
- Twenty-two percent (22%) of respondents **distribute written materials** to families in their **primary language**. Barriers include lack of office staff (7%), lack of knowledge (6%), other (6%), time (4%) and reimbursement (4%).
- Forty-six percent (46%) ask about a **family's beliefs, rituals and customs** and incorporate that information into the treatment plan in a nonjudgmental way. Barriers include time (6%), lack of knowledge (2%) and reimbursement (2%).

Comparison with National AAP Periodic Survey of Fellows:

In May 2000, the national American Academy of Pediatrics conducted a similar survey of fellows on the provision of various health care services (elements of the medical home) to children in pediatric practices, both those with special health care needs and those without (Periodic Survey #44: Health Services for Children with and without Special Health Care Needs: The Medical Home Concept, 2000. [Available at <http://www.aap.org/research/periodicsurvey/ps44aexs.htm>]. After six mailings, a total of 925 completed questionnaires were received for a response rate of 56.7. Currently, only partial results of the national survey are available. Appendix A compares the results of the national survey with those of the local survey where that data is available.

In many cases, the local results are higher than those of the national sample. Some of the areas in which local results were lower than national responses concerned

- 1) access to care during weekday evening and weekend appointments,
- 2) scheduling extra time for office appointments, and
- 3) whether or not the respondents considered themselves to be the primary coordinator of care for children with special needs in their practices.

Areas in which the local results were significantly higher than the national results included

- 1) meeting with the hospital team when a child is hospitalized and
- 2) discussing the results of visits to specialists.

Comparison with Los Angeles Medical Home Assessment Survey for Physicians

In February 2001, the Los Angeles Medical Home Project conducted a survey of 500 members of Chapter 2 of the American Academy of Pediatrics. The Los Angeles Medical Home Project has been operative for over five years. The charts in Appendix B reflect a comparison among the three surveys (national, Los Angeles, San Francisco) for selected survey questions.

Limitations

PLEASE NOTE:

This survey is not a scientific study, nor was it designed to be one.

- An initial limitation was in the formulation of the survey addressee list. Because there was no central directory of physicians to draw on, the survey list was compiled from more than one source, and accuracy and completeness were not guaranteed.
- Another limitation to this survey analysis is its small sample size. Of 476 surveys mailed, we received 54 – a response rate of 11%. Given the low response rate, these results may not accurately reflect the practice of the physicians selected for the survey.
- Self-selection among the respondents may bias the results.
- San Francisco is the home to UCSF, a teaching hospital with many pediatric sub-specialists who serve children statewide and nationally, not just in San Francisco. These sub-specialists may naturally serve more children with special health care needs than usual, and thus may be more attracted to this survey. The results may therefore reflect their interest.

Demographics Summary

The survey responses revealed that:

- ❖ The largest percentage of respondents (other than those who did not answer the question) fell in the age group of **50-59 (26%)**, indicating an aging population of physicians. Seventeen percent (17%) were 30-39 years old and 13% were 40-49 years old (half of those in the 50-59 age group).
- ❖ Respondents were 52% male and 41% female.
- ❖ A significant number of respondents were **pediatric sub-specialists (39%)**.
- ❖ Fifty-seven (57%) of respondents were Caucasian, twenty-eight (28%) were Asian, six percent (6%) were Latino and 2% were African-American. The ethnicity of the physicians **does not reflect the demographics of the population** of San Francisco. (A recent HRIIC (High Risk Infant Interagency Council) study – *Young Children with Special Health Care Needs in San Francisco: Assessing our Reach* – found that for children with special health care needs 0-5 in San Francisco, 25% were Hispanic/Latino; 24% were Asian-Pacific Islander; 20% were African-American; 18% were White; 2% were multicultural; and 11% were unknown.)
- ❖ The majority of the respondent practices (63%) were comprised of 25% or less of children with special health care needs, **with 41% serving 5% or less**. On the other hand, 17% of the physicians indicated that the percentage of their practice of children with special health care needs was 95% or more.
- ❖ Respondents predominately practiced in the **94143 area code** – UCSF Medical Center -- with 11% from Pacific Heights/Western Addition (zip code 94115), where CPMC and Kaiser are located. Many neighborhoods were not represented at all – including some with large estimated percentages of CSHCN.

Survey Results Summary

What is the resource capacity of local pediatricians (primary care and subspecialists) to serve as medical home physicians for children with special health care needs in San Francisco?

Accessibility:

Survey results indicate that respondents are generally successful in providing accessible care, with some significant drawbacks. Over 90% of respondents answered that their patients have 24/7 access and that their offices were accessible by public transportation. Most answered that families could reach them in a number of ways and through multiple means of communication, and that they could speak directly to the physician when needed. Although 76% accepted patients with Medi-Cal, CCS and Healthy Families, only 20% offered a range of payment plans. Weekend and weekday evening appointments were largely unavailable.

Family-Centered

For the most part, respondents were able to provide family-centered care, developing collaborative relationships and recognizing the families' central role. Some weaknesses in delivered family-centered care included scheduling extra time for an office visit (35%) and helping families identify coping strategies (43%).

Comprehensive:

Providing comprehensive care produced challenges for many respondents, with less than 50% answering "most of the time" to most of the "comprehensive" statements. Only 59% answered that they provided preventative and primary care to children with special health care needs.

Continuous

Although over 90% of the respondents have practices that include both children and adolescents, responses indicate that only 33% assist families in transition points most of the time. Fifty-two percent (52%), however, do assist with transitions to the community from the hospital.

Coordinated

There were varying degrees of success in providing coordinated care. 91% and 80% of the respondents referred patients to pediatric subspecialists and mental health specialists. Survey answers indicated strength in coordinating care with specialists and discussing the results of specialists' visits. Respondents provided other components of coordinated care less often, and only 13% participated in the IFSP or IEP process. Fifty-six percent (56%) considered themselves the primary coordinator of care for children with special health care needs in their practice.

Compassionate

In an area of strength, over 80% of respondents felt they successfully provided

compassionate care most of the time.

Culturally Competent

Cultural competent care was provided by less than 50% of the respondents most of the time, with only 22% providing translated materials, and 43% providing translators or interpreters.

Strengths and Challenges

Strengths (Over 85% response “most of the time”)

- Telephone access
- Accessibility via public transportation
- Collaborative relationship with family
- Families play central role in care coordination
- Referrals to pediatric subspecialists
- Attempt to understand family needs (not just needs of child)
- Respect of differing socio-cultural values and beliefs

Challenges (Less than 37% response “most of the time”)

- Participation in IFSP and IEP process
- Translation of written materials
- Evening and weekend appointments
- Assisting with transition points
- Scheduling extra time for office visits
- Reviewing information with families
- Making medical care plan available to others
- Coordinating care with school

Discussion

San Francisco is a unique environment to survey. It is a diverse community, representing a multitude of ethnic and language groups, with a concentrated urban population. It is the home of UCSF, a highly respected center of specialty care which serves patients from outside of the local community and well as those living in San Francisco.

Who serves CSHCN?

Demographics of the respondents do not reflect the demographics of the population of San Francisco or its CSHCN in many respects. A large concentration of respondents in older age groups creates concern about future continuity of care for CSHCN. In a city with a large Spanish-speaking majority, it is notable that only 6% of respondents identified themselves as Latino/Hispanic. Since most respondents' offices are presumably located in the hospital-based clinics in central SF, families must travel to obtain care. Responses seem to indicate that CSHCN are not served at all or are served exclusively -- respondents answered that either a small percentage or a vast majority of their practice (up to 100%) is comprised of CSHCN.

What is the resource capacity to serve as medical home?

Responses indicated that physicians endeavor to provide components of a medical home, with varying success. Accessibility, family-centered and compassionate care proved to be areas of strength for most respondents. Comprehensive, continuous and coordinated care presented challenges, although there were areas of great strength within those categories. Culturally competent care also provided surprising challenges, particularly important in a culturally diverse community such as San Francisco. Despite providing culturally competent care less than 50% of the time, this was an area of strength when compared to national results.

Respondents identified various barriers to delivery of medical home components. The special makeup of respondents also may have an impact on respondents' abilities to provide medical homes.

Barriers

Repeatedly, respondents cited time as a chief barrier to effectively providing components of a medical home. Lack of office staff support and inadequate reimbursement were frequent obstacles to successful medical home care. Clearly, respondents felt that they needed more time, support and compensation in order to provide quality medical homes for children with special health care needs.

Sub-specialists:

Because San Francisco is home to UCSF, and because such a large percentage of respondents indicated that they were sub-specialists (39%), some of the survey results could reflect the nature of the respondent's practice (i.e., pediatrician vs. specialist).

Only 56% of the respondents considered themselves the primary coordinator of care and only 59% provided preventative and primary care to children with special health care needs. Fifty-two percent (52%) of respondents indicated that they meet with the discharge planner to discuss transition of a hospitalized child back to the home and community (as opposed to 23% in the national survey results), and 50% discuss the results of specialist visits with the family (far more than the 19% reported nationally). Differences in responses here from the national survey could reflect the large percentage of respondents (39%) who are pediatric specialists.

Specialists are involved in tertiary care, not primary or preventative care. That might account for low response rates in some areas, particularly in areas such as comprehensive and coordinated care. Only thirty-three percent (33%) of respondents assists families in transition points in the child's care (between providers, payers, child and adult health services), 38% report making contact with the child's school about health and educational needs and 13% participate in a child's IFSP or IEP process. The high percentage of respondent sub-specialists in the survey results may have an impact on these responses, as coordination of these activities may normally fall to a primary care pediatrician.

As an illustration, Appendix C breaks down responses (answered "most of the time") to selected survey questions by specialist and non-specialist in San Francisco, provides the combined percentage, and compares it to responses in the Los Angeles survey.

Conclusions:

Consistent with findings of the Los Angeles Medical Home Physician Survey in 2001, our sample of San Francisco pediatricians also reported time, lack of office staff, and reimbursement as barriers to compliance with many of the medical home components. The barriers are logically interrelated, and compounded by productivity demands and time limitations imposed by local managed care and IPA (independent practice association) practice management guidelines.

Our interim project summary of December 2002 listed the following findings:

- There is NO accurate list of currently practicing pediatricians and family physicians in San Francisco.
- Local health insurance and IPA (Independent Practice Association) health insurance entities contribute to restricting access to consistent and continuous medical homes for children and youth with special needs.
- Enormous need exists for undergraduate and CME (continuing medical education) among health professionals regarding children and adults with special needs, as well as medical home tenets and quality assurance.
- California's poor reimbursement rates (Children's health care reimbursement, based on Medi-Cal "plus what the market will bear," is soon to become worse, with the State's economic woes leading to further MediCal cuts in the new budget.)
- No risk adjustment exists to provide enhanced reimbursement or equivalent supports for caring for CSHCN.
- A number of local health insurance plans (commercial and public plans) equate assignment of a primary care provider with "medical home".
- Differences between agency eligibility criteria result in confusion and service denials due to diverse definitions of children with special needs.
- Major needs exist for information and data access and tracking, as well as inter-agency and inter-provider communication and coordination on all levels.
- There is currently increased community interest and commitment in better identifying and serving children with special needs and their families, and various community stakeholders are assuming unprecedented collaborative activities toward this goal.

Our final report reiterates the above findings, as well as the following observations. It is crucial to note that the primary reason for attempting a Medical Home resource capacity survey in San Francisco is the general impression, from a broad constituency (parents as well as pediatricians), that locating and sustaining a Medical Home for children and adults with special health care needs is unnecessarily challenging in this community. This report identifies some of those specific areas of concern.

Differences and similarities with the May 2000 national AAP fellows medical home survey are of interest. (Appendix A). Although time limitations were frequently cited as a barrier to achieving medical home compliance, only 35% of responding San Francisco

pediatricians reported scheduling additional appointment time to accommodate children's special needs.

The participation of families in decision making and playing a significant role in their child's care coordination was remarkably similar (86.2-87.0%) in the San Francisco, Los Angeles, and national surveys (Appendix B). However, surprisingly few (22%) San Francisco respondents provide translations in the family's primary language of informational materials given to the families. Nonetheless, this is a higher percentage than that of the national AAP respondent fellows (16.80%), and undoubtedly reflects the abundance of diverse cultures and languages in both California cities. Both San Francisco and Los Angeles respondents exceeded the national percentage providing a translator for families for whom English is a second language and also in discussing related services, such as respite care, equipment, and transportation.

Percentages of San Francisco respondents exceeded both Los Angeles and national fellows previously surveyed in interaction with subspecialists and hospital discharge planning teams regarding transitioning their patients back into the community. Undoubtedly, this reflects the high percentage of pediatric subspecialists in this community and in our respondent pool (39% compared with 57% primary care). In contrast, 18% of respondents in the Los Angeles survey were subspecialists and 82% primary care pediatricians).

While we were concerned about the relative paucity of available weekend and evening appointments, as well as informed emergency service providers, these differences became even more impressive when subspecialist and primary care responses were sorted and compared (Appendix C). Although hospital based subspecialists and their colleagues understandably can provide informed emergency room care for these children, only 35% of responding primary care pediatricians replied affirmatively.

A remarkably low 21% of primary care pediatricians (and 51% of subspecialists) provide assistance at transition points in the child's life. In contrast, 68% of the primary care pediatricians consider themselves primary care coordinator for their patients with special needs. Increased availability of translator services, written reports, and medical plans are all more evident in subspecialist practices, where enhanced reimbursement supports more staff. Pediatric primary care services in San Francisco are not generally risk adjusted for severity or complexity of needs.

Of our sample of 54 completed responses, 41% reported seeing 5% or fewer children with special health care needs in their practices, 22% reported seeing 25% of their practice panel with CSHCN, and our impressively large sample of subspecialists (39%) accounts for the 17% who report practices comprised of 95% or more CSHCN. Geographic maldistribution of medical home resources is evident in our survey, as well as in the findings of the recent (June 2003) High Risk Infant Interagency Survey of CSHCN. (Appendix D)

A combined focus group and community advisory committee was held to validate information gathered from the survey. Participants readily stated that most pediatricians did not understand the concept of medical home. Pediatric residents felt that the topic was not consistently or adequately addressed in their training and was absent from their medical school curricula. Feedback from community pediatricians at one of several pediatric grand rounds presentations on The Medical Home indicated marked frustration with inadequate reimbursement and lack of informational resources to comfortably deal with challenging complex chronic illnesses and/or disabilities.

Our initial intent of establishing a resource directory cannot be accomplished at this time, as too few (4%) respondents indicated that they would like to be included in such a directory. (Our initial focus group and planning committee strongly advised that such information must be given voluntarily, lest responses be further decreased in numbers.)

Next Steps:

- Alternative means of developing a medical home resource directory continue to be explored by our survey team and community advisory committee members.
- Clearly, enhanced reimbursement for pediatricians providing medical homes for children with special health care needs would support additional staffing, extended appointment times, and augmented services, consistent with quality practice guidelines.
- Detailed education on utilization of reimbursement codes for complex health care services should be immediately addressed.
- Concerted efforts to educate pediatricians and other child health care providers about medical home components and standards of care should be established in this area and statewide. (The Los Angeles Medical Home Project first embarked on a similar effort in 1998, with the support of a four-year MCHB grant, and an additional grant from CA Health Care Foundation, via the CA Medical Home Project. The latter endeavor continues to demonstrate dramatic inadequacies in pediatric understanding of the medical home concept.)
- Education of families and other caregivers of CSHCN must be part of the educational process to improve access to medical homes.
- Supportive information for practicing pediatricians and other health care providers includes information on community referral resources. As a product of our CATCH project, we will distribute a referral “prescription pad” resource to pediatricians surveyed, along with materials regarding resources for children with special health care needs in San Francisco.
- Additional pediatric grand rounds and a final pediatrician focus group by our survey team at participating community hospitals and physician groups are planned to discuss the survey findings and further discuss realization of medical home components in practice.
- With concurrence of our community advisory committee and other stakeholders, we anticipate exploration of funding sources for the development of an ongoing medical home training institute for pediatricians and other health care providers,

relevant agency and school personnel, pediatric office, clinic, and hospital staff, as well as families and other care givers for children with special health care needs.

- A post project stakeholders/community advisory committee meeting will be scheduled in early September to address these next steps, working toward increasing resource capacity and improving access to medical homes for San Francisco children with special needs.
- Copies of this report will be distributed widely to interested parties.

Appendices

FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Appendix A

Survey Questions	National Results (conducted in 2000)	Local Results (Answered “most of the time” (conducted in 2002)
Patients in my practice have telephone access to someone 24 hours a day, 7 days a week	94.5%	93%
In an emergency, someone from my practice who knows how to care for children with special needs is available to see a child in the middle of the night or on weekends	69%	57%
Weekday evening appointments are available in my practice	42.6%	28%
Weekend appointments are available in my practice	59.2%	30%
In my practice, families play a central role in care coordination for their child by participating in decisions about the nature of their child’s care and treatment.	86.2%	87%
I schedule extra time for an office visit when seeing a child with special needs. (Or, if the parents request extra time.)	44.8%	35%
As part of coordinating the child’s care, someone in my office, or myself, contacts the school about the child’s health and educational needs if the family desires.	23.3%	37%
If not myself, someone in my office discusses potential needs families might have for services such as respite care, equipment, or transportation.	40.5%	46%
In my practice, written information on a variety of issues affecting children and families is provided to and reviewed with families.	43.8%	Provided to: 50% Reviewed with: 35%
When a child is hospitalized, I meet with the discharge planning team to assist with the child’s transition back to the community.	23.2%	52%
When a child is referred to a specialist, someone in my office, or myself, assists the family in setting up an appointment and communicating the clinical issues to that specialist.	61.2%	Setting up appointment: 61% Communicating issues: 65%

FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS

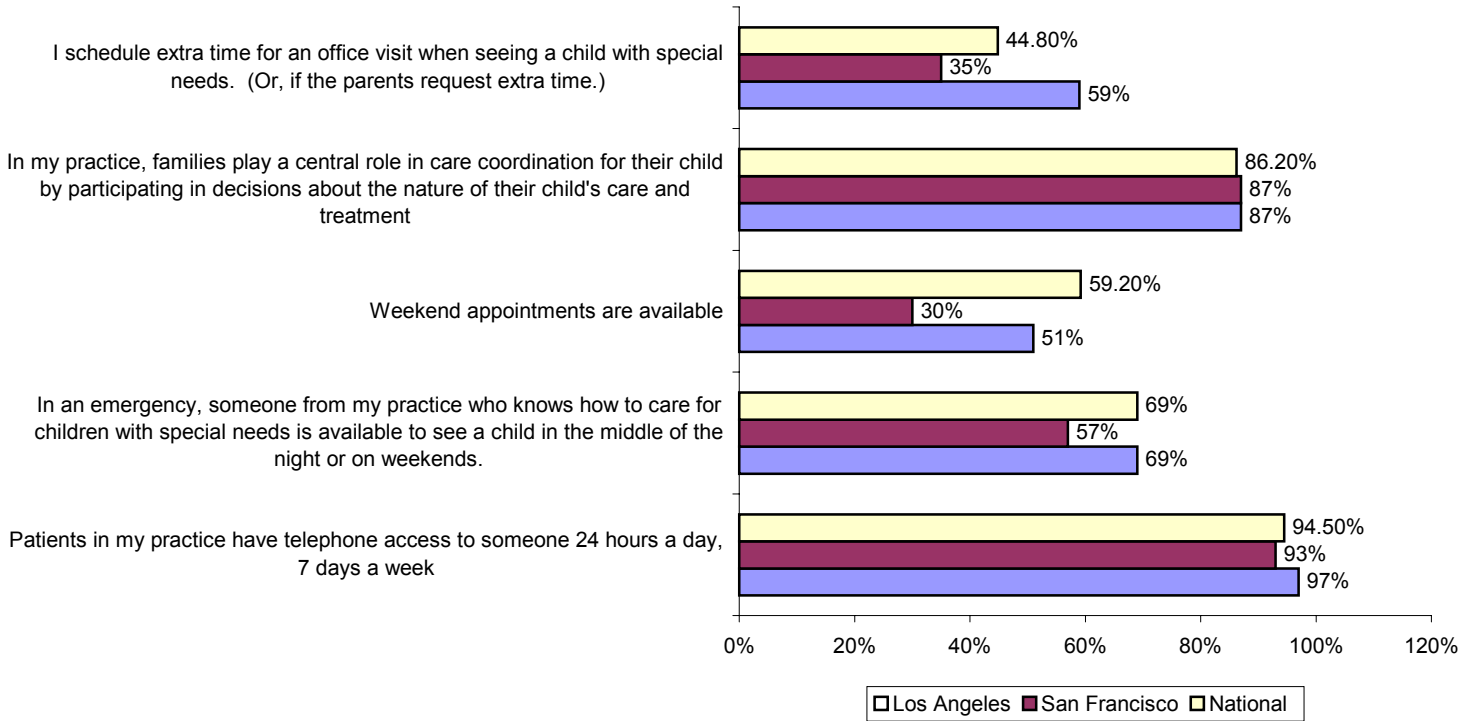
Appendix A

Survey Questions	National Results (conducted in 2000)	Local Results (Answered “most of the time” (conducted in 2002)
I consider myself the primary coordinator of care for children with special needs in my practice.	71.2%	56%
After a visit to the specialist, I discuss with the family the results of the visit to the specialist and answer any questions they may have.	18.7%	50%
I feel like I know the families in my practice and have a good relationship with each of them.	87%	81%
In my practice, an effort is made to understand the needs of the family as well as the child.	82.6%	87%
A translator or interpreter is provided for the families in my practice for whom English is a second language.	34.9%	43%
The materials I distribute to the families in my practice have been translated into the primary language the family uses.	16.8%	22%

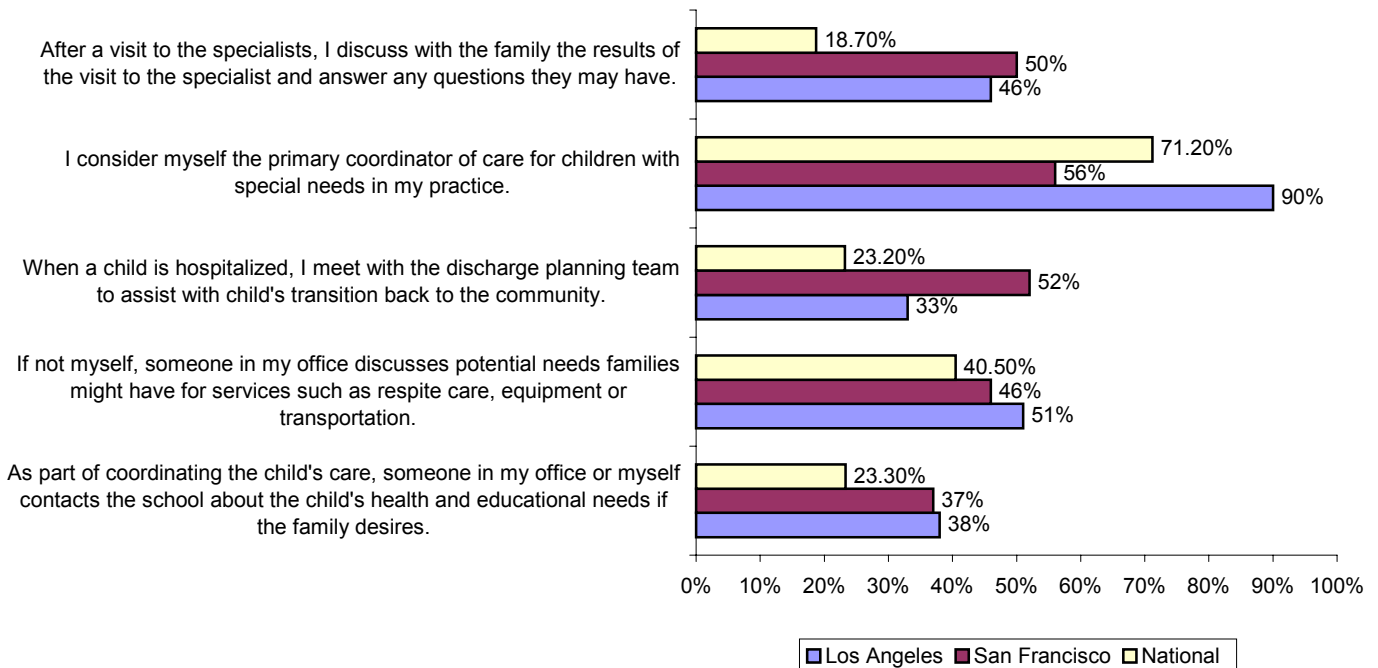
FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Appendix B

Comparison: Los Angeles, San Francisco, National -- Accessible and Family-Centered Care



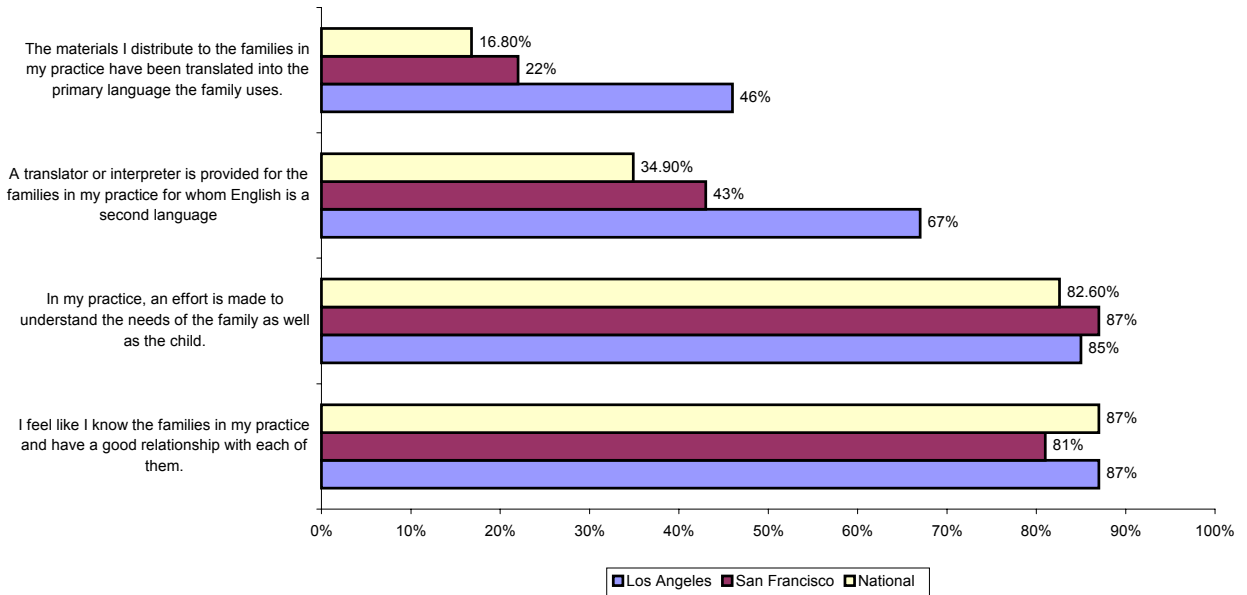
Comparison: Los Angeles, San Francisco, National -- Comprehensive, Continuous and Coordinated Care



FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Appendix B

**Comparison: Los Angeles, San Francisco, National:
Compassionate and Culturally-Competent Care**



FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Appendix C

Question	Specialist %	Non-specialists %	Combined %	Los Angeles
1B. In an emergency, someone from my practice who knows how to care for children with special needs is available to see a child in the middle of the night or on weekends	90%	35%	57%	69%
2H. I collaborate with families to develop an appropriate care plan for their child	90%	62%	74%	77%
3D. In my practice, we provided preventative and primary care to CSHCN including immunizations, screening, growth monitoring and developmental monitoring.	14%	85%	59%	92%
4A. If not myself, someone in my office assists the family at various transition points in their child's care, for instance, transitions between providers, transitions between payors, and transitions between child and adult health services.	52%	21%	33%	44%
5D. I consider myself the primary coordinator of care for the CSHCN in my practice.	33%	68%	56%	90%
5G. The medical plan I develop for the child is made available, with parent permission, for use by others	48%	26%	35%	49%
5J. I provide copies of a) letters b) records free of charge to families	86% 76%	50% 41%	65% 59%	62%
7A. A translator or interpreter is provided for the families in my practice for whom English is a second language	57%	32%	43%	67%

FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Appendix D

COMPARISON BETWEEN HRIIC SURVEY OF CSHCN AND THIS SURVEY BY ZIP CODE

Zip Code*	Neighborhood	% Children 0-5 Total, 2000***	% of CSHCN 0-5	Zip Codes of Respondents to Survey (Physicians)
94110, 94125	Inner Mission/Bernal Heights	12%	16%	2%
94112	Outer Mission Ingleside-Excelsior	13%	13%	0
94124	Bayview/Hunter's Point	8%	10%	0
94134	Visitacion Valley	8%	8%	0
94132	Stonestown/ Lake Merced	3%	6%	4%
94122	Sunset	7%	4%	4%
94109	Russian/Nob Hill	4%	4%	0
94102	Hayes Valley/Tenderloin	3%	4%	2%
94115	Pacific Heights/Western Addition	3%	4%	11%
94116	Parkside/Forest Hill	6%	4%	2%
94121	Outer Richmond/Sea Cliff	5%	4%	0
94103	South of Market	2%	3%	0
94118	Inner Richmond/Presidio/Laurel	5%	3%	4%
94131	Twin Peaks/Glen Park/Diamond Heights	3%	2%	2%
94133	North Beach/Telegraph Hill	3%	2%	0
94127	West Portal/St. Francis Wood	3%	2%	0
94107	Potrero Hill	2%	2%	0
94117	Haight/Western Addition/Fillmore	3%	2%	2%
94114	Castro/Noe Valley	2%	2%	4%
94108	Chinatown	1%	1%	2%
94123	Marina/Cow Hollow	2%	1%	0
Outside SF***	-	-	1%	6%*
94129	Presidio	<1%	1%	0
94130	Treasure Island	<1%	<1%	0
94120	Pacific Heights/Western Addition	-	<1%	0
94111	Embarcadero/Gateway	<1%	<1%	0
94104, 94105, 94119	Financial District, Downtown	<1%	<1%	0
Blank/ Data Entry Error	-	-	3%	
94143	UCSF			33%
94080	South San Francisco*			2%*
94925	Corte Madera*			2%*
94941	Mill Valley*			2%*

PLEASE NOTE: This comparison between population of children and zip codes of respondents is a comparison of children **birth to five ONLY**.

**FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS
APPENDIX E**

Accessible:

Question	<i>Most of the time</i>	<i>Sometimes</i>	<i>Occasionally</i>	<i>Never</i>	<i>Not applicable</i>	<i>No answer</i>
1A. Patients in my practice have telephone access to someone 24 hours a day, 7 days a week.	93%	6%	2%			
1B. In an emergency, someone from my practice who knows how to care for children with special needs is available to see a child in the middle of the night or on weekends.	57%	11%	15%	13%	2%	2%
1C. Weekday evening appointments are available in my practice.	28%	2%	9%	56%	6%	
1D Weekend appointments are available in my practice.	30%	11%	9%	44%	4%	2%
1E My practice is accessible by public transportation.	91%	7%	2%			
1F My office accepts patients with Medi-Cal, California Children Services (CCS), and Healthy Families.	76%	7%	7%	7%	2%	
1G Parents may use fax, voice mail or email to contact me.	67%	19%	6%	4%	4%	2%
1H My patients and their families are able to speak directly to me when needed instead of talking with someone from my staff.	67%	24%	7%		2%	
1I My practice offers a range of payment options for families, including sliding scales or payment plans for families who request this.	20%	17%	19%	19%	13%	13%

Note: Because of rounding, percentages do not always total 100%.

**FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS
APPENDIX E**

Family-Centered:

Question	<i>Most of the time</i>	<i>Sometimes</i>	<i>Occasionally</i>	<i>Never</i>	<i>Not applicable</i>	<i>No answer</i>
2A I develop a collaborative relationship with the child’s family to ensure good health care.	89%	7%	2%		2%	
2B I have created an office environment that is comfortable for all the families who are in my practice.	57%	17%	17%		7%	2%
2C I attempt to explore all health care options with the family.	69%	22%	6%		2%	2%
2D In my practice, families play a central role in care coordination for their child by participating in decisions about the nature of their child’s care and treatment.	87%	9%	4%			
2E I acknowledge the expertise families have in caring for their child and it is not unusual for a parent to teach me about new aspects of their child’s condition.	78%	13%	9%		2%	
2F I encourage parents to take notes, ask questions and keep records of their child’s care.	76%	19%	2%	2%		2%
2G I encourage parents to meet other families who have children with special needs.	61%	22%	15%			2%
2H I collaborate with families to develop an appropriate care plan for their child.	74%	20%	4%			2%

Note: Because of rounding, percentages do not always total 100%.

**FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS
APPENDIX E**

Question	Most of the time	Sometimes	Occasionally	Never	Not applicable	No answer
2I I help families identify coping strategies that they have used in the past, additional coping strategies they might use, and help them build on their strengths.	43%	41%	17%			
2J I schedule extra time for an office visit when seeing a child with special needs. (Or, if the parents request extra time.)	35%	31%	15%	7%	9%	2%

Comprehensive:

Question	Most of the time	Sometimes	Occasionally	Never	Not applicable	No answer
3A As part of coordinating the child's care, someone in my office, or myself, contacts the school about the child's health and educational needs if the family desires.	37%	26%	26%	9%	2%	
3B If not myself, someone in my office discusses potential needs families might have for services such as respite care, equipment, or transportation.	46%	33%	11%	7%	2%	
3C In my practice, information about other services and resources, such as Medi-Cal, CCS, Regional Centers, Healthy Families, Head Start or WIC is provided.	44%	28%	17%	6%	2%	4%

Note: Because of rounding, percentages do not always total 100%.

**FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS
APPENDIX E**

Question	Most of the time	Sometimes	Occasionally	Never	Not applicable	No answer
3D In my practice, we provide preventative and primary care to children with special health care needs including immunizations, screening, growth monitoring, and developmental monitoring.	59%	11%	7%	6%	17%	
3E In my practice, families are referred to non-medical services in the community that meet their specific needs.	54%	31%	13%			2%
3F In my practice, written information on a variety of issues affecting children and families is						
a) provided to families.	50%	33%	17%		2%	
b) And reviewed with families.	35%	37%	19%	6%		4%
3G At each visit, I assess the current social, emotional, educational, and health status of the child.	59%	24%	11%	2%	2%	2%
3H If not by myself, someone in my office links families who are interested with family supports, including support groups, parent-to-parent support groups, and other resources.	43%	26%	28%	4%		

Note: Because of rounding, percentages do not always total 100%.

**FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS
APPENDIX E**

Continuous:

Question	<i>Most of the time</i>	<i>Sometimes</i>	<i>Occasionally</i>	<i>Never</i>	<i>Not applicable</i>	<i>No answer</i>
4A If not myself, someone in my office assists the family at various transition points in their child’s care, for instance, transitions between providers, transitions between payors, and transitions between child and adult health services.	33%	22%	30%	9%	2%	4%
4B When a child is hospitalized, I meet with the discharge planning team to assist with the child’s transition back to the community.	52%	30%	17%			2%
4C My practice includes both children and adolescents.	91%	2%	2%	2%	2%	2%

Coordinated:

Question	<i>Most of the time</i>	<i>Sometimes</i>	<i>Occasionally</i>	<i>Never</i>	<i>Not applicable</i>	<i>No answer</i>
5A When a child is referred to a specialist, someone in my office, or myself, assists the family in						
a) setting up the appointment and/or	61%	26%	4%	2%	4%	4%
b) communicating the clinical issues to that specialist.	65%	24%	4%		4%	4%
5B I refer a child to a pediatric sub-specialist when needed.	91%	6%			4%	

Note: Because of rounding, percentages do not always total 100%.

**FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS
APPENDIX E**

Question	Most of the time	Sometimes	Occasionally	Never	Not applicable	No answer
5C I refer a child to a mental health specialist when needed.	80%	17%		2%		2%
5D I consider myself the primary coordinator of care for the children with special needs in my practice.	56%	13%	6%	7%	17%	2%
5E If not myself, someone in my office participates in the child’s Individual Family Service Plan (IFSP) or Individual Education Plan (IEP) process either by phone, letter or the actual conference.	13%	22%	33%	22%	7%	2%
5F If not myself, someone in my office coordinates the child’s care among multiple providers seen by the child.	43%	30%	19%		7%	2%
5G The medical care plan I develop for the child is made available, with parent permission, for use by others.	35%	31%	17%	2%	7%	7%
5H After a visit to the specialist, I discuss with the family the results of the visit to the specialist and answer any questions they may have.	50%	26%	11%		11%	2%
5I My practice maintains a central record/database containing all pertinent medical information, including hospitalizations.	54%	22%	13%	6%	4%	2%

Note: Because of rounding, percentages do not always total 100%.

**FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS
APPENDIX E**

Question	Most of the time	Sometimes	Occasionally	Never	Not applicable	No answer
5J I provide copies of						
a) letters	65%	15%	11%		6%	4%
b) records	59%	15%	11%	2%	7%	6%
free of charge to families.						

Compassionate:

Question	Most of the time	Sometimes	Occasionally	Never	Not applicable	No answer
6A I feel like I know the families in my practice and have a good relationship with each of them.	81%	11%	4%		2%	2%
6B In my practice, an effort is made to understand the needs of the family as well as the child.	87%	7%	4%			2%
6C I respect the varying socio-cultural values and beliefs of the families and do not let those values and beliefs affect my interaction with the child and his/her family.	89%	9%				2%

Note: Because of rounding, percentages do not always total 100%.

**FINDING MEDICAL HOMES FOR SAN FRANCISCO CHILDREN WITH SPECIAL HEALTH CARE NEEDS
APPENDIX E**

Culturally Competent:

Question	<i>Most of the time</i>	<i>Sometimes</i>	<i>Occasionally</i>	<i>Never</i>	<i>Not applicable</i>	<i>No answer</i>
7A A translator or interpreter is provided for the families in my practice for whom English is a second language.	43%	15%	22%	11%	6%	4%
7B The materials I distribute to the families in my practice have been translated into the primary language the family uses.	22%	41%	15%	13%	6%	4%
7C I ask about a family's beliefs, rituals, and customs, and attempt to understand and incorporate them into the treatment plan in a nonjudgmental way.	46%	35%	17%			2%

Note: Because of rounding, percentages do not always total 100%.

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