



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

PARENT PERSPECTIVES ON CARE RECEIVED AT PATIENT- CENTERED MEDICAL HOMES FOR THEIR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

January 2014

Office of the Assistant Secretary for Planning and Evaluation

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the Department of Health and Human Services (HHS) on policy development issues, and is responsible for major activities in the areas of legislative and budget development, strategic planning, policy research and evaluation, and economic analysis.

ASPE develops or reviews issues from the viewpoint of the Secretary, providing a perspective that is broader in scope than the specific focus of the various operating agencies. ASPE also works closely with the HHS operating agencies. It assists these agencies in developing policies, and planning policy research, evaluation and data collection within broad HHS and administration initiatives. ASPE often serves a coordinating role for crosscutting policy and administrative activities.

ASPE plans and conducts evaluations and research--both in-house and through support of projects by external researchers--of current and proposed programs and topics of particular interest to the Secretary, the Administration and the Congress.

Office of Disability, Aging and Long-Term Care Policy

The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This report was prepared under contract #HHSP23320095642WC between HHS's ASPE/DALTCP and Mathematica Policy Research. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/office_specific/daltcp.cfm or contact the ASPE Project Officers, Hakan Aykan and David de Voursney, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Their e-mail addresses are: Hakan.Aykan@hhs.gov and David.DeVoursney@hhs.gov.

PARENT PERSPECTIVES ON CARE RECEIVED AT PATIENT-CENTERED MEDICAL HOMES FOR THEIR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Dana Petersen
Lisa Schottenfeld
Caroline Massad Francis
Henry Ireys
Joseph Zickafoose

Mathematica Policy Research

January 2014

Prepared for
Office of Disability, Aging and Long-Term Care Policy
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
Contract #HHSP23320095642WC

The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

TABLE OF CONTENTS

ACRONYMS	ii
EXECUTIVE SUMMARY	iii
I. INTRODUCTION	1
II. METHODS	3
A. Recruitment.....	3
B. Data Collection	4
C. Data Coding and Analysis	5
III. FINDINGS: PERSPECTIVES OF CONSUMER PARENTS	6
A. Provider Characteristics that Matter to Parents.....	6
B. Practice Characteristics that Matter to Parents	10
IV. FINDINGS: PERSPECTIVES OF PARENT LEADERS	18
A. Features of Patient-Centered Medical Home Models That Matter to Parent-Leaders.....	18
B. Potential Expansions of Patient-Centered Medical Home Models Noted by Parent-Leaders	20
V. SUMMARY	23
VI. DISCUSSION	25
REFERENCES	28
APPENDIX A. 2008 NCQA STANDARDS AND ELEMENTS	30

ACRONYMS

The following acronyms are mentioned in this report and/or appendix.

ASPE	Office of the Assistant Secretary for Planning and Evaluation
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CNA	Certified Nurse Assistant
CSHCN	Children with Special Health Care Needs
ER	Emergency Room
GI	Gastrointestinal
HIT	Health Information Technology
ICU	Intensive Care Unit
NCQA	National Committee for Quality Assurance
PCMH	Patient-Centered Medical Home
PPC	Physician Practice Connections
RN	Registered Nurse

EXECUTIVE SUMMARY

Parents are important stakeholders in the process of implementing medical homes for children, especially for children with special health care needs (CSHCN). Some medical home initiatives, however, may not adequately take parent and family perspectives into account (Zickafoose et al., 2013; Bechtel & Ness, 2010; Berenson et al., 2008). As patient-centered medical homes (PCMHs) become a more prevalent pathway for health care delivery system reform, information about parents' experiences with and expectations for their children's care in these settings can help ensure that PCMH initiatives are designed and implemented to meet consumers' needs (Detsky, 2011; Bechtel & Ness, 2010).

The purpose of this study, sponsored by the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services as part of the Center on Excellence in Disabilities Research, is to describe parents' perspectives on the care received at medical homes and offer suggestions for ensuring that PCMH models benefit CSHCN and their families. The study is based on key informant discussions with a convenience sample of nine parents of CSHCN receiving primary care at practices recognized as medical homes and six parents who have become leaders in consumer organizations. The findings include the following:

- Parents were generally unfamiliar with the concept of medical homes and were not aware that the practices were so designated.
- Parents cited having a primary care provider who knew and cared about their family, had both expertise in and a willingness to learn more about their child's special needs, respected their own knowledge and opinions, and engaged them in shared decision-making as characteristics that mattered to them.
- Parents, when discussing practices as a whole, stressed the importance of continuity in care, welcoming and well-informed care teams, care coordination support, easy access, and linkages between the practice and other community supports.
- Parent-leaders emphasized the value of PCMH models because they place children and their families at the center of care and highlighted care coordination as a key feature.
- Parent-leaders suggested expanding the reach of PCMH models into behavioral and mental health, social services, and education and expanding the roles for specialists.

- Parent-leaders recommended building parents' awareness of the PCMH concept, engaging parents in the PCMH-recognition process, and using parent input to guide quality improvement.

These findings must be interpreted in the context of our methods. We interviewed a very small sample of parents whose children were receiving care from an even smaller number of practices formally recognized as a PCMH for at least two years. As a result, our findings highlight key consumer perspectives but they cannot be viewed as generally representative of parents of CSHCN.

Our findings suggest that policymakers and program administrators who lead transformation efforts may consider three areas of action: (1) educating parents about the features of medical homes to help them make informed health care choices; (2) providing practices with information about the value of including parents as partners both in the care their children receive and as contributors to quality improvement activities; and (3) developing strategies to incentivize practices to include parent feedback as an integral part of continuous quality improvement.

I. INTRODUCTION

The medical home concept emerged in the 1960s as a means for improving care for children with special health care needs (CSHCN) (Sia et al., 2004). Since then, policymakers across the health care spectrum have grown increasingly interested in the medical home as a potential model for transforming the health care system (Peikes et al., 2012; Kilo & Wasson, 2010). Patient-centered medical home (PCMH) models typically emphasize care that is personalized, coordinated, and comprehensive and is managed by a health care professional from an accessible location. Some evidence suggests that practices that adopt procedures consistent with a medical home show both improvements in quality of services and cost savings (Peikes et al., 2012; Solberg et al., 2011; Reid et al., 2010; Reid et al., 2009). Studies also suggest that pediatric practices that have implemented components of medical home models provide better care to their patients than those without such components (Cooley et al., 2009; Homer et al., 2008). Overall, many primary care medical societies, payers, providers, and consumer groups endorse the PCMH model (Rittenhouse et al., 2012).

Parents are important stakeholders in the process of implementing medical homes for children, especially CSHCN. Some medical home initiatives, however, may not adequately take parent and family perspectives into account (Zickafoose et al., 2013; Bechtel & Ness, 2010; Berenson et al., 2008). Moreover, a preponderance of existing research emphasizes issues related to correcting financial and systematic inefficiencies, using evidence-based care, and obtaining positive clinical outcomes (Detsky, 2011). Few studies have focused specifically on either strategies for incorporating consumer perspectives into practice transformation or the outcomes resulting from doing so. Given the frequently complex, costly, and long-term health care needs faced by CSHCN, researchers have suggested that particular attention should be paid to these children and their families as the process of transforming practices to medical homes proceeds (for example, Iezzoni, 2013). As PCMHs become a more prevalent pathway for health care delivery system reform, information on parents' perspectives on their expectations for care received at medical homes and their experiences with such care becomes increasingly important. Such information can help ensure that PCMH initiatives are designed and implemented to meet consumers' needs (Detsky, 2011; Bechtel & Ness, 2010).

This report, a study conducted through the Center on Excellence in Disabilities Research and funded by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) at the U.S. Department of Health and Human Services, helps to close this information gap. The study focused on what parents like and want from primary care for children with special needs and how medical home models can meet those wishes. Answers to our study questions help balance a conversation that sometimes overlooks the very individuals who use health care services. We provide information relevant for policymakers and organizations leading PCMH transformation

efforts, as well as for practices implementing PCMH models or otherwise seeking to increase patient and family satisfaction with the care they provide.

Specifically, the study addressed the following questions:

- How do parents experience and describe the health care they receive from recognized PCMHs?
- What do parents value and expect in the primary care they receive for their CSHCN?
- How might current conceptualizations of PCMH models be expanded to further benefit CSHCN and their families?

The rest of this report is divided into five sections. In Section II, we briefly describe our research methodology. In Section III, we present findings from discussions with parents of CSHCN receiving primary care at PCMHs. In Section IV, we present the findings from discussions with parents who are leaders at advocacy or governmental organizations. In Section III and Section IV, we identify each finding and discuss the data supporting it, including illustrative quotations. The number of findings and the amount of supporting discussion varies by finding, and reflects the depth and detail of responses provided by participants. Section V summarizes key study findings, and Section VI discusses program and policy implications.

II. METHODS

This study is based on a key informant data collection design with a convenience sample of parents identified by practices recognized as PCMHs by the National Committee for Quality Assurance (NCQA) before 2010 and an additional sample of parent-leaders identified by directors at consumer organizations. Data were collected between November 2012 and January 2013, with the goal of capturing information about parents' expectations of medical home models and experiences with medical homes (Appendix A includes a summary of the 2008 NCQA medical home standards and elements). The research team conducted a total of 15 individual discussions with parents of CSHCN from two groups.

The first group included nine parents of CSHCN. Each of these parents had at least one child with a special health care need who currently received primary care at a practice recognized as an NCQA Level 3 PCMH. We refer to these individuals as "parents" or as "consumer parents." The children of these nine parents received care from six different physicians at four PCMHs. Three practices were in Colorado and served five of the children in this study. One practice was in Texas and served four of the children in this study. We spoke to parents in this group primarily because we wanted to learn about parents' preferences and values related to their children's primary care.

The second group included six parents of matured CSHCN. Each parent in this group had become a leader in an advocacy or governmental organization related to CSHCN. We refer to these individuals as "parent-leaders." This group included three parents in Colorado and three in Texas. In addition to raising children with special needs, five of the parents held leadership positions in advocacy organizations, and one worked for a state governmental agency. We spoke to these parents to learn about their perspectives on programmatic and policy issues related to medical homes.

A. Recruitment

We recruited parents by asking 20 pediatricians and family physicians at primary care practices in Colorado and Texas to distribute research fliers. These physicians were identified from a list of practices recognized as Level 3 NCQA medical homes¹ and had participated in a companion study exploring the changes practices did or did not undergo in seeking PCMH-recognition. To be recognized by NCQA as a PCMH, practices must verify that they have care processes in place that meet standards related to access and communication, patient tracking and registries, care management, patient

¹ See NCQA Recognition Directory, available at <http://recognition.ncqa.org/>.

self-management support, electronic prescribing, referral tracking, performance reporting and improvement, and advanced electronic communications.

We asked providers at these recognized practices to nominate up to five parents of CSHCN for participation in our study and distributing research fliers to them. The research flier described the study, offered a \$100 stipend, and provided a toll-free phone number for parents to call if interested. In total, 15 of the 20 providers agreed to nominate parents and distribute fliers. We asked providers to nominate parents of patients with a variety of special needs, including single chronic conditions that require a moderate amount of care, such as attention deficit hyperactivity disorder or asthma, as well as children with multiple complex comorbidities. We asked physicians to consider parents who are struggling and are difficult to engage in addition to those who are managing their child's needs effectively. Twelve parents volunteered to participate in the study, nine of whom met our screening criteria. Parents were eligible for participation if they had a CSHCN, considered the provider that gave them the flier their child's primary care provider, and spoke English.

We recruited parent-leaders purposively, using a list of individuals provided by staff at the Catalyst Center, a nationally recognized center dedicated to improving care for CSHCN. These parents were nominated as experts in the area of CSHCN and as being knowledgeable and involved in medical home initiatives in Colorado and Texas. Using this list, we held discussions with four parent-leaders. At the end of each discussion, we solicited names of additional advocacy or policy contacts from their states with whom they thought it would be useful for us to speak. In this way, we obtained participation from two additional parent-leaders. Mathematica offered a \$100 stipend to parent-leaders' home organizations, or their designees, to compensate them for their time.

B. Data Collection

Mathematica research team members conducted parent discussions via telephone. For both samples, the telephone call included an overview of the study, a description of the specific purpose of the call, the informed consent process, the discussion itself, and an explanation of the distribution of stipends. We used semi-structured discussion guides that included open-ended questions to direct the conversations. Discussion protocols for both groups of parents were reviewed and approved by project officers at ASPE. During the conversations, the research team took detailed notes on all responses and used probes to capture and clarify views and perspectives as needed. Conversations were also recorded so that notes could be refined and quotes verified. These recordings were subsequently erased. Discussions lasted 20-40 minutes.

C. Data Coding and Analysis

Typed notes were entered into a database using NVivo 9 software, which supports qualitative data management and analysis. A code book was developed based on the discussion protocol and was refined throughout the coding process. We used the software to apply codes to the transcripts. At least two transcripts in each sample were coded independently by three members of the research team. Team members then met to reconcile differences in coding through discussion and consensus. After achieving a shared understanding of the coding scheme, research analysts coded the remaining discussion notes with review and approval by a second coder.

Analysis included the following six steps: (1) review of all data extracted by code; (2) estimation of relative frequency of topics mentioned within thematic codes; (3) assessment of primary patterns and trends within the themes; (4) identification of illustrative quotations; (5) summation of primary themes; and (6) discussion of similarities and differences in themes between parent groups. One team member summarized data for each code and generated themes. The research team discussed themes to clarify, confirm, refine, or elaborate them and consider implications. The resulting themes were used as the basis for this report. Although strict frequencies are not possible in qualitative data collection when discussions are semi-structured and not all respondents are asked the same questions, we apply the following general scheme when defining the relative rate of mention of topics: For the group of nine parents, “few” refers to mentions by at least three parents; “several” refers to mentions by at least 4-6 parents; “almost all” refers to mentions by at least 7-8 parents. For the group of six parent-leaders, “several” refers to mentions by at least 3-4 parents, whereas “almost all” refers to mentions by at least five leaders.

III. FINDINGS: PERSPECTIVES OF CONSUMER PARENTS

Parents of CSHCN, like most parents, worry about the health services that their children receive and often have strong beliefs about the quality of the care that doctors, nurses, and other health professionals provide to their families. This section describes beliefs and attitudes of parents of CSHCN who receive primary health care at NCQA Level 3 recognized medical homes. All parents we spoke to described and valued elements of care that are common to conceptualizations of PCMH models, though eight of the nine parents were unfamiliar with the term “patient-centered medical home.” When asked to describe their experiences with their child’s primary care provider and that provider’s office and what they valued most in the health care that they received for their children, respondents most frequently raised issues related to: (1) their provider’s personal characteristics; and (2) the overall functioning of the primary care office.

A. Provider Characteristics that Matter to Parents

When asked to describe the health care they received from their child's primary care provider and what they liked and valued most about that care, parents often described personal qualities of the provider. Responses related to provider characteristics generally fell into three categories: (1) dedication to knowing and caring for the child and family; (2) expertise related to the child’s special need; and (3) respect for parent knowledge and participation in shared decision-making.

Parents receiving care at PCMHs valued that their primary care provider knew and cared about their child and family.

Several respondents placed a high priority on the feeling of being known and cared for by the provider and by the office as a whole (see more detail on this below). One parent stated, “I just really get the feeling that [the physician] cares about [my child].” Another felt that her daughter’s physician “makes you feel like you’re her only patient. I think that’s what I like about it ... she doesn’t just treat you as a number.” One respondent liked that her child’s physician seemed to “know” her family, and felt that this was an important part of care: “I feel like [the physician] knows us. It’s not like I have to walk in and reintroduce myself every time I’m there ... it really has a lot to do with just feeling known. I never feel like a stranger in there. I really feel like my children matter and that they’re important to the doctor.”

“I feel like [the physician] knows us. It’s not like I have to walk in and reintroduce myself every time I’m there ... it really has a lot to do with just feeling known. I never feel like a stranger in there. I really feel like my children matter and that they’re important to the doctor.”

Notably, a few parents felt that this was not an easy characteristic to find in a physician. One reported that “We’ve been to doctors who don’t seem to even enjoy children, [but our current primary care provider] enjoys children and he relates to them very well.” One parent said that she had seen nine “horrific” pediatricians before finding her child’s current provider, and each of them had made her feel that “we were just a number to them just to get their checks.”

Several respondents felt it was critical for a primary care provider to take her time during office visits to avoid making them feel rushed. This helped the parent feel that the physician cared about them and their needs. One parent reported that “[being rushed] makes me feel very unimportant, or like it doesn’t matter, or like it’s just another ... visit to them.” Not being rushed also gave parents the opportunity to talk at length about the child’s health care needs and to ask any appropriate questions: “They need to make you comfortable and make you feel wanted and not rushed in like cattle through a stockyard ... [like] ‘we’re here to see you, ok, done.’ They need to talk to you.” One respondent talked specifically about how her child didn’t react well to providers who tried to rush through appointments. Of her current physician, she said, “He just takes his time with [my child], and I love that.”

“Basically it is just ... not looking at her as her syndrome They see her as an individual who will achieve whatever she will achieve. She’s not labeled by her syndrome. That’s important to me, and they do a very good job with that.”

Several parents felt that it was important for their child’s physician to be “good with kids,” and to view and treat their children as valued individuals. One parent said she wanted her child’s physician to speak directly to her child rather than only to her and appreciated his good “bedside manner with kids.” Two parents of children with more severe disabilities and developmental delays felt that the physician’s ability to connect with their children was a particularly critical aspect of their children’s care because it demonstrated the physician’s ability to see that the child was a whole person rather than a set of complex issues. For example, one parent felt that it was very important for primary care providers to “take a personal” view of her child, “not looking at her as her syndrome.” She appreciated the way that her child’s physician saw her daughter “as an individual who will achieve whatever she will achieve. She’s not labeled by her syndrome. That’s important to me and they do a very good job with that.” Another parent talked about her struggle to find doctors who had this trait: “Yes, [my daughter is] non-verbal, but she still understands what people are saying to her ... Sometimes doctors ... kind of act like she’s not there.” She felt that her current physician was able to relate to her daughter well, and “treats her as an individual.”

“I got that he was going to do whatever it took to help us figure out [the child’s diagnosis] ... I felt he was really dedicated I really feel like he went above and beyond.”

A few respondents also emphasized that they wanted a doctor who was dedicated to their child's care. These parents discussed the difficulty of having a child with special needs and felt that they needed a provider who could serve as an ally in the difficult process of securing appropriate care and resources for their children. One noted, "Having a handicapped child, you have to fight for everything. And it just makes it hard, especially when you don't have that rapport with a doctor that is willing to listen to you and willing to help you in a situation when you need that help. You don't need to be fighting with the provider that's supposed to be there to help you. You need that support from them ... you need someone on your side." Another parent, while reflecting on why she chose her provider, said that "I got that he was going to do whatever it took to help us figure out [the child's diagnosis] ... I felt he was really dedicated I really feel like he went above and beyond."

Parents saw provider expertise and a willingness to learn about children's special needs as an important element of care at PCMHs.

Several parents felt that provider expertise on their child's specific health care needs was a crucial element of care. This expertise had two components: medical knowledge about the child's specific condition and an understanding of the "level of response [that] needs to happen" when the child becomes acutely ill. Despite the importance they placed on this factor, several parents reported difficulties in locating physicians with the necessary expertise. "We run into the fact that not a lot of physicians, even in our specialty group, have knowledge of [my daughter's condition]," noted one parent. Another said, "The key with special needs is that the doctors need to have a very good understanding of that. I believe that most doctors do not have an understanding [of the needs of CSHCN] ... [Before we found our current physician], we saw so many different doctors who knew nothing about special needs, so they were of absolutely no value to us because they couldn't point us in the right direction." For these parents, this type of expertise was one of the most important physician traits: "That's the biggest key, finding someone who knows about your child."

Although parents understood that primary care providers may not have learned about their child's specific condition as part of their medical school education, several shared a belief that "if you're going to take on patients who have rare concerns, ... you probably should educate yourself in some more detail" about the child's special need. These parents highly valued their physician's willingness to put in extra effort to gain expertise about a specific condition and felt that it was a cornerstone of the physician's ability to provide high-quality care. One parent noted that her child's primary care provider "admitted he'd never heard of [the child's special need], but I could tell with each visit he had read more on it; ... he gave excellent care since the very early days because of his willingness to research what is available." Another stated that "It's extremely important for us for the primary care physician to be abreast of things even if not at a granular specialty level, but at a general level, and he has taken the time on his own to become familiar with [our daughter's] condition."

Knowledge of the medical condition was important, but the provider's ability to leverage this knowledge to respond appropriately to potential medical emergencies was crucial. A few parents reported that their children sometimes grew very ill very quickly, noting that the child "has a tendency to go from zero to ICU in a matter of hours" or that when the child became sick, "it's more of a life-threatening [situation]." Given this tendency, these parents felt that it was crucial for physicians to understand the urgency and intensity of their child's health care needs and to be able to quickly distinguish between situations when a child could be cared for by the primary care provider and when he or she needed to be sent for emergency specialty care.

Parents appreciated that providers respected their knowledge and opinions and engaged them in shared decision-making.

Several parents valued having a provider who respected the knowledge and insight they themselves brought to the table. This knowledge can be divided into two categories: parental knowledge of the child's special health care need gained through independent research and insight gained by caring for the child around the clock. Further, several parents appreciated provider efforts to fully involve them in decisions about their child's health care.

"It's really important how well [the primary care provider] listens to what we're bringing to her."

Respondents who had acquired substantial knowledge about their child's condition placed great value on their primary care provider's willingness to take their knowledge seriously and incorporate it into decision-making. A few parents had devoted a significant amount of time to learning more about their child's special need through independent reading or research or by consulting other parents of children with the same medical condition. One parent of a child with a very rare disease noted that "I'm not going to say [my wife and I] are more expert [on our child's special need] than doctors. But we've educated ourselves in ways beyond what the typical pediatrician would know. We are privy to details, and we've seen his history and all those things. I don't think we know more about the medical side ... but it's really important how well [the primary care provider] listens to what we're bringing to her." Three parents emphasized that they wanted their provider to listen to their observations about their child's behavior and current health and incorporate their insights into the plan of care. One respondent highly valued the primary care provider's "willingness to listen to us [when we say], 'Here's what we're seeing, here's what we're observing [with our child].'"

Although all nine parents confirmed that their provider found ways to involve them in decisions about their child's care, several valued this characteristic particularly highly. These parents discussed specific ways in which their child's physician involved them in decisions by presenting them with multiple options and asking questions about their treatment preferences. When one parent had to make a decision about whether to admit her child to the hospital for care, she appreciated that her physician gave her detailed information about her options and fully involved her in the conversation about the best course of action for her child. She noted that the doctor "presented it as,

'Here's what my recommendation would be. I know someone at Children's Hospital. I can contact them and get some information from them about what they might do. If you're uncomfortable about it, then we can talk about it some more, and make a decision.' And that's exactly what he did; ... he emailed [his contact and] in a few days I was back in the office and we were talking about it again with more information." Another parent liked that his child's primary care provider always gave them a range of options: "[It's important] to work with us to adapt the appropriate plan of care for her ... [The physician] and his nurses have been great about saying, 'Here are your three options, ... here's what I would do, I think you should do X, but you could Y and Z, it's your call.' ... They're just very good at letting us be a part of the decision-making process, which is very important to us There's a high level of involvement and we're very satisfied with it." These parents felt that they were consulted by their child's physician and made to feel as if they were part of their child's care team.

"They're just very good at letting us be a part of the decision-making process, which is very important to us."

Though most respondents indicated that they felt involved in a team decision-making process, they had differing feelings about whether parents or doctors should behave as team leaders. One parent felt that "we know our children better than any doctor ever will" and liked that her physician trusted her to make decisions about her child's health care. Another liked it when a provider was "willing to do what I wanted with no questions asked." However, two other parents wanted more of an equal decision-making partnership. One liked that her child's primary care provider will "address my concerns but he puts his wisdom into it. That's what I really like. I don't want to tell him what to do because I don't have that experience, I don't have that background or that training, but I don't want him to ignore [my input]. I feel like he does a very good job balancing that."

B. Practice Characteristics that Matter to Parents

Respondents also emphasized the value of certain characteristics of the medical practice itself. Many of these characteristics align with NCQA standards for PCMH-recognition. Descriptions of valued practice characteristics generally related to one of six categories: (1) continuity of care; (2) care teams; (3) care coordination and management; (4) dedicated care coordination staff; (5) access and communication; and (6) community supports.

Parents described and attached importance to having continuity in the care they received at PCMHs.

Almost all parents discussed continuity as an aspect of care that was important to them. Although some felt it was important to see the same primary care provider each time, others discussed continuity on the care team level. Several parents felt they received higher quality care when they were able to see the same physicians or care team members each time and build relationships with them. One noted, "I really

appreciate it when primary care providers for my kids, as much as possible, have the same assistants or CNAs every time. They get to know my kids too, and they get to know me, and I think it just provides overall better care.” Another parent felt that seeing the same care team allowed her providers to get to know her son’s baseline and thus be able to understand when he could be treated in the primary care office and when he needed to be transferred to a higher level of care. She noted that, “A month ago ... we had to transport him from the doctor’s office to the hospital in an ambulance, and the reason they did that was because [the physician] looked at him and said ... he was really sick, and this does not look like normal [for him]. And so, for me, it’s ... not someone different always seeing him. The people who see him really know who he is. And so when they look at him and say he’s very lethargic, because he has a lot of energy normally, they know that about him. And that to me is very important.” Another respondent discussed the stress she experienced when her daughter aged out of pediatric care and had to be referred to another provider, as this meant she had to build a relationship with a new physician.

Two parents discussed their willingness to sacrifice convenience or immediate access for continuity. One respondent whose physician saw patients only one day each week preferred to rearrange her own schedule to have her child see him rather than bring the child in to an unfamiliar physician in the practice at a more convenient time. Another said that although her provider’s office could usually get her an appointment soon after she called, “Most of the time, I usually try and wait until his [primary care provider] is available.”

Two respondents brought up the challenges they faced when circumstances forced them to sacrifice continuity of care for immediate access. One, whose son often had to be rushed to the hospital, said that “because of his history, as soon as he sees that blood pressure cuff coming or a needle, he has reactions that are pretty rough. And so if you get somebody who’s experienced with him, you know, someone who’s seen him for three or four visits in a row, that’s ok. But that’s not always possible; That’s a big challenge.”

Parents valued receiving care from welcoming and well-informed teams of providers and staff at PCMHs.

“You walk in and they know exactly who you are. They always acknowledge [my child and ask him how he’s doing] ... and it’s ... the secretaries, it’s the nurses, everyone is like that with him.”

Although many parents liked feeling known and cared for by their providers, almost all parents appreciated being made to feel this way by the entire office staff, including front desk staff and nurses. These parents appreciated it when staff were warm, friendly, and took the time to build relationships with parents and their children. One parent noted, “[The office] is friendly ... My kids feel welcome there. [The staff] are very warm. They smile; they use my child’s first name ... and they look at my child instead of just at me when they’re [doing] the initial check-in, you know, stand here to get weighed, let me measure you and see your blood pressure. I feel like they’re engaged with my

child and not just with me.” Others noted that they appreciated it when everyone in the office knew them and welcomed them during visits: “You walk in and they know exactly who you are. They always acknowledge [my child and ask him how he’s doing] ... and it’s ... the secretaries, it’s the nurses, everyone is like that with him.” One parent appreciated it when the office staff recognized her when she called, saying that it made her feel that the office cared about her and her child: “When I call, [the RNs] know who I am by name That is very helpful, because my child is not just a number to them. They know and care about her.”

“When I call, [the RNs] know who I am by name That is very helpful, because my child is not just a number to them. They know and care about her.”

Several parents discussed the importance of communication within a provider’s office as a factor in high-quality care as it ensured that all staff who care for their child would be well-informed about the child’s situation. Two parents felt that their care team had excellent internal communication, and regarded this as a crucial element of their care. One parent who saw both a physician assistant and a physician in the same office liked that her care team “had good communication [and] good teamwork.” Another noted that “If I call one nurse and leave a message or speak with them and get a response [later] from another nurse, there’s never been a time that I can remember [when the second nurse] didn’t have the full story That is an invaluable tool to us -- the dissemination of information.”

One parent discussed the problems she experienced when providers in her office failed to communicate effectively about her child’s needs. This resulted in the provision of suboptimal care by team members who were not well-informed of the details of her child’s special health care need. She said, “When we go in for visits and well checks, my one biggest complaint ... is just that the nurses would ask questions that were very not pertinent to [my child] at all At one year [my child] was [developmentally] a four-month old baby. They were asking me questions that run along the lines of a typical one-year-old: is she doing this, is she doing that? No, no, she’s not. And I could see how that would bother some parents who have a harder time accepting who their child is and then having those questions of all those things your kid is not doing. Your kid is *not* doing this, you know, all those typical milestones. I think it would be appropriate to evaluate that before you go in, see what questions really need to be asked, and go from there [We need a] nurse who just knows ... where [my child] is or just [has] a reference to look at [to see] this is what she was doing last time, ok, is she doing the appropriate milestone beyond that, not just the appropriate one for her age.”

Parents regarded the care coordination support provided at PCMHs very highly, especially coordination with specialists.

All nine parents valued their provider’s willingness to help to coordinate and manage their child’s care. Some parents liked that their primary care provider took a broad view of their child’s entire plan of care and helped them to manage all aspects of their child’s health. This was particularly critical for parents whose children had extremely complex health care needs and needed help coordinating specialist care,

nursing care, feeding and medical supplies, and at-home care. One parent described his child's primary care provider as "the quarterback" on her care team, saying that the physician "is looking out for things not only in the specific sense, [like] the routine 'do you have your shots and records done, how's her feeding going,' those kinds of things. He also steps back a distance from the plan of care to look at all of the disciplines, and weighs this decision from this doctor and this decision from that doctor against the whole picture of her care ... he very much helps to coordinate."

"[They] are extremely proactive on our behalf in contacting other physicians that we're in contact with [and] getting information from [specialists] We have much less enigmatic information and a lot more clarity because of the proactive nature of [our physician] and his office."

Several parents greatly appreciated their physician's efforts help them navigate through an often complex set of health care services from multiple providers, and emphasized the value of physicians' efforts to communicate with specialists, acquire information from them, and thus better coordinate their child's care. Parents noted that they sometimes struggled to navigate complicated health care systems, particularly when multiple hospital departments and specialists were involved in their child's care. For some parents, being responsible for transferring information related to their child's care among multiple providers could be overwhelming. One parent noted, "I really like how ... [my child] has three different doctors that he sees ... and all of them communicate. [The primary care provider] is always adamant about [that. She'll say], 'Please have the [specialist] ... email his notes.' It's just helpful for her because she constantly knows the history about him, ... [and] she always follows up to make sure that all of his notes are in there. And if I drop the ball, ... she will have me sign a [release, so she can get the notes]. She says, 'We need this, so that we know how to better treat him in the long run. So that, I really enjoy.'" Another said, "What we have found with is that they are extremely proactive on our behalf in contacting other physicians that we're in contact with [and] getting information from [specialists] We have much less enigmatic information and a lot more clarity because of the proactive nature of [our physician] and his office, their willingness to make those calls, to review those chart notes, to go get those lab results, and incorporate it into the plan of care."

Three parents also liked that their primary care provider helped them to manage their child's medications and prescriptions, sometimes by coordinating with specialists or with medical supply companies. When one child's gastrointestinal (GI) specialist died suddenly, leaving the family to wonder how they would navigate Medicaid's complicated rules for prescribing GI medications, the primary care provider "stepped up to the plate, got the records, reviewed them, and helped us get her prescriptions renewed, [and] helped us get plugged in to another GI doctor." A parent of a child who often needed blood work was grateful that her physician coordinated lab work with her specialist, "so that it's all done on one lab, one poke Lab work is very hard for my daughter."

At least two parents praised their practice's efforts to track and be proactive about various aspects of a child's health. One noted that the physician tracked a child's immunizations and coordinated this aspect of care with the child's cardiac team.

Another parent shared her relief that the primary care office called her when her daughter needed to be brought in for a twice-yearly well visit: “The great thing about them is they call me. Because they know that ... my daughter sees so many specialists and I have to keep up with so many appointments, they won’t make me call them.”

Similarly, at least two parents appreciated it when their physician followed up with them to help with care transitions after visits to the emergency room (ER) or hospitalizations. One liked that when her child “gets sent to the hospital or to the emergency room, [the primary care office is] good about following up [the] following day and just checking to see if he’s ok or if I need to bring him back in.” Another noted that when her child was sick for two weeks, she received phone calls from the office three times a week. When the child had to go to the ER on a Friday night, she remembered that the physician “called me the next day to check in on him. For me, that’s the kind of service I need, you know? I’m a single mom ... with a sick child.”

Parents liked that some PCMHs had staff specifically dedicated to coordinating their child’s care.

“Having coordinators in the office that handle just special needs cases [is so important]. Since that’s all they do, they know everything. They can give me a list of a million nursing companies, or product companies, or supplies ... I think it’s so much better than just having doctors that see special needs kids. These people coordinate.”

A few children received care in an office with a “special needs clinic,” which parents valued highly. This clinic was staffed by two nurses who offered care coordination services, along with specialized expertise on CSHCN. These nurses were able to build ongoing relationships with families and provide important information and resources to parents. One parent observed that, “Having coordinators in the office that handle just special needs cases [is so important]. Since that’s all they do, they know everything. They can give me a list of a million nursing companies, or product companies, or supplies I think it’s so much better than just having doctors that see special needs kids. These people coordinate.” Another parent discussed the way in which the nurses served as care coordinators who could, for example, take care of sending prescription requests from supply companies to the physician. This parent found the nurses to be an invaluable resource and source of support when dealing with her child’s complex health care needs, noting, “In the past, medical supply [companies were] one of my big frustrations They just didn’t seem to get it right So I could call that special needs clinic, and say, am I expecting too much? What is normal? Are my expectations too high? So she would assure me ... ‘no, you need to be getting the supplies you’re supposed to be getting.’ So she would just assure me. Because in the beginning, I [didn’t] know what normal [was]. So to run that by the special needs nurse was good.” Another parent appreciated the care that these nurses gave his child, saying that they “bring to the table great experience, knowledge, compassion. They just have this great compassion and sympathy, and caring for the kids. It’s not just another appointment to check off to them.”

PCMHs offered superb access to providers and other care team members.

All nine parents felt that their provider was easily accessible and placed a high value on this practice characteristic. Three important aspects of access for parents included: (1) having direct access to advice and support; (2) getting a quick response; and (3) having a way to get medical advice after normal business hours.

Several parents valued having direct access to a medical provider who knew them and could provide medical advice, rather than being forced to go through the front desk or a complex phone system. One parent said, “What I love about it is when I call in, I have the extensions of the special needs coordinators, and so when I call I can go straight to them and I don’t have to go through a [main] line.” Another parent liked that his primary care office was “very easy to get a hold of; ... there’s always someone on the [other] end of the phone.” Parents also valued e-communication as a direct connection to their provider. As one parent described, “with email I know it’s going right to her. I don’t have to sit on hold or spend a lot of time waiting to figure out which button I should push to talk to who I’m trying to talk to.”

“After-hours they have what’s called telecare.”

Due to the complex, urgent, and frequently changing nature of their child’s special health care needs, parents greatly appreciated receiving timely responses. “As a parent of a sick child, if I need [the doctor], I really need [her] right now,” said one parent. One parent noted, “When I need someone right now for [my child], if I have a question right now, I can call. [The nurse] is able to email [the physician] right away if I need a quick response. She can even go find him and ask him. So I have a quick way to get what I need if needed That’s very important to me.” Another parent liked that her provider was “very accessible. She returns calls very quickly and I don’t feel like there’s a point that I couldn’t get a hold of her if I needed to.”

“One thing that I’m really pleased about is whenever [my son] does get sick ... I can call them and they have [an] available answering service. Even if it’s at two or three o’clock in the morning, they’re always there for me.”

Several parents valued that their provider was available for advice and support outside of normal business hours. These parents liked having access to physicians or nurses through an answering service, or having the ability to call and make a next-day appointment if the child became sick in the middle of the night. One parent noted that, “After-hours they have what’s called telecare. With that, you initially contact ... more of a secretarial [person] ... and then they’ll give the message to a nurse and the nurse will call you back ... [but] that initial person, though, is able to schedule appointments ... I can call at four o’clock in the morning and make an appointment for the next morning.” Another parent said that, “One thing that I’m really pleased about is whenever [my son] does get sick ... I can call them and they have [an] available answering service. Even if it’s at two or three o’clock in the morning, they’re always there for me, and [tell me] about what I need to do to take care of [him],” noted one parent. Another noted that, “They do have a nurse line which I think is really important so that parents can reach a

nurse day or night, any day of the week. I've used that several times. I really like having access to a nurse, even if it's just over the phone." Two parents wished that their providers could offer in-person care on an expanded basis. One thought it would be helpful if her child's physician saw patients on the weekends, whereas another wished that the office was open on weekdays outside of normal business hours: "I'd like to see hours a little bit earlier than eight o'clock Like, even at 7:30. And I'm not saying every day, but a couple times. You know, eight o'clock is a typical time for people to go to work. And as a teacher ... it would be nice to have ... one or two days where [the office is] open a little later or open an hour early, just to accommodate those working people."

A few parents observed that being able to easily access advice and support for their child helped them avoid unnecessary office visits and trips to the ER. Being able to talk to their physician when a medical need arose helped parents to think carefully about the best course of action and to determine whether home care was appropriate or whether the child needed immediate medical attention in the primary care office or ER. One parent said, "If I have a concern about [my child's] health, I know I can pick up that phone and I can call them and I can easily leave a message for their assistant, and they'll call me back, and they try to talk about [my] concerns and ... what I can do to get [my son] to feel better, or they suggest ... you need to bring him in, or you need to take him to the emergency room." Another parent liked that her entire provider's office is "always willing to have me call, ... and they'll either say, let's try and treat it this way [at home] or, yeah, he definitely needs to come in." Still another parent valued his provider's willingness to respond to his calls after normal office hours rather than simply sending him to the ER: "[Our physician] doesn't have office hours 24 hours a day; ... sometimes if we need to contact her, you know, sometimes she's just not there. But, ... she's been really good about being available even when she was not necessarily on service."

Parents appreciated their PCMH connecting them to community supports and other outside resources.

Several parents discussed ways in which their provider had facilitated a connection to important resources outside the office or sponsored various types of community supports to bring parents of CSHCN together.

One parent remembered that her primary care provider had told her about the Women, Infants, and Children program, which was able to provide the family with the expensive special formula that her child needed. Another mentioned that her provider had referred her son to Child Find: "She was a really big help on that, because they wouldn't call back, I was really struggling, and ... I felt bad because it wasn't really [the provider's area], ... and she took it all [over] and she called them and we had an appointment within a week, and I had been dealing with it for over a month at that time. She was very helpful on that."

One provider's office offered a variety of support groups and other events for parents of CSHCN, which the parents valued highly. One talked about an event that had been organized by the office's special needs clinic that she found helpful, particularly for her other children: "Once a year [the special needs nurses] organize a party of sorts where a lot of different businesses that [serve] the special needs community will come and have a booth. But it's a very informal event where ... the business will have a game for the kids to play And then you just go through, enjoy all the different stations and games, and there's also a meal that's provided for families. It's supposed to be a lot of fun for the kids ... it was really neat for my [older] kids to get a positive [experience, like]; you've got a sister with special needs so you get this special thing ... It's not a bad thing to have a sister with special needs." Others talked about support groups provided for mothers and fathers of special needs children that "help to navigate not just problems of the child but of the family unit."

IV. FINDINGS: PERSPECTIVES OF PARENT LEADERS

In addition to being able to comment on the aspects of care provided by PCMHs that would be most valuable to CSHCN and their families, parents who are leaders at advocacy and governmental organizations supporting CSHCN were also able to talk more generally about programmatic and policy issues related to medical home initiatives and models. The parent-leaders in our study spoke both on the basis of their first-hand experiences (because all were also parents of children with disabilities or special needs) and on behalf of other parents of CSHCN they routinely interact with.

All the parent-leaders we interviewed said the PCMH concept was valuable to CSHCN and their families. Some expressed the view that CSHCN, their families, and advocates have been the driving force behind the development of the PCMH models, because as one parent-leader said, “Children with special health care needs, by default, require all the things that define the medical home approach.” In this section we describe parent-leaders’ responses regarding important features of PCMH models for CSHCN, and ways that PCMH models and initiatives could be expanded to further benefit parents.

A. Features of Patient-Centered Medical Home Models That Matter to Parent-Leader

When asked to identify those features of PCMHs they thought were particularly valuable for CSHCN and their families, parent-leaders often identified characteristics that corresponded closely with the provider and practice characteristics that the consumer parents identified as important (see Section III).

Parent-leaders emphasized the value of PCMH models putting patients and their families at the center of care and involving them in shared decision-making.

Within the category of provider characteristics, parent-leaders concur with consumer parents that it is highly valuable to have a primary care provider who makes parents feel known and cared for, listens to them, does not rush, is sensitive to the patient experience, and engages in shared decision-making. Most leaders described providers that acted in these ways as being “patient-centered” and said that these types of behaviors were important components of the medical home concept. One leader said, “Until we understand what’s important to the individual family, we may not be providing the optimal [or] most efficient care for them.” Parent-leaders emphasized that gaining an understanding of what is important for each child and family requires that providers spend adequate time listening and answering questions during appointments.

It also requires that providers reach out to families who do not readily express their opinions.

“Until we understand what’s important to the individual family, we may not be providing the optimal [or] most efficient care for them.”

More than half of the parent-leaders we talked with discussed the importance of shared decision-making in PCMH models, and one leader said that medical homes were distinguished by the fact that parents know they will “have a voice for [their] child” and be a part of health services planning for them. Parent-leaders described this aspect of PCMHs as parents being “empowered” or being “partners” in determining their children’s health care. For parent-leaders, this was a byproduct of putting patients at the center of care. Putting patients at the center required that providers take parents’ preferences and opinions into account and that they work collaboratively with parents when deciding on the best course of action for their children.

Parent-leaders highlighted care coordination as a key feature of PCMH models.

All six parent-leaders described care management and coordination as a vital component of medical homes for parents of CSHCN. These leaders valued efforts by provider to share information among each other among and to link families to supportive services. Similar to preferences expressed by consumer parents, some leaders said that because many CSHCN see multiple specialists, having a physician that communicates with specialists and ensures the sharing of information is a critical support. One leader described this quality of PCMHs by saying, “I think [a PCMH] pulls together all the care into one place.” Another leader said, “[The] medical home really is the teamwork. It’s not a place. When we talk about medical home, we talk about the verb, the action part of what is being done, ... the integration piece.”

“Care coordination ... doesn’t rely on parents or family members to be the carrier of information between specialists and [primary care] providers.”

More than half of the parent-leaders mentioned that the care management and coordination services provided in a PCMH lessens the burden on parents, who otherwise must convey information between providers. One parent-leader also noted that parents lack medical expertise needed to determine which pieces of information are important to convey. He said, “Care coordination ... does a couple of things for [families of CSHCN]. Probably the biggest one for me, and, I think, for the improvement of the quality of care, is that it doesn’t rely on parents or family members to be the carrier of information between specialists and [primary care] providers In our own case as parents, there’ve been times where we’ve heard news from a provider that we thought sounded really important and really big, and that wasn’t important to the other provider, just because we don’t know as much about neuroscience and those kinds of things. We don’t know what we’re looking for. So that’s huge. And the other thing that makes the coordinating piece so big for us is that it cuts down on the number of people or number of phone calls that we have to make at any given time The to-do list for most of our families is already longer than we can complete.” Another leader commented that she

thinks collaboration and coordination between providers is important because “a lot of concepts or knowledge [get] lost in translation” when parents serve as the go-between.

B. Potential Expansions of Patient-Centered Medical Home Models Noted by Parent-Leaders

Because of their familiarity with the medical home concept both from first-hand experience as the parents of CSHCN and also as involved leaders at advocacy and governmental organizations supporting this population, the parent-leaders were able to offer a variety of suggestions for expanding PCMH initiatives and models so that they further benefit CSHCN and their families. Suggested expansions related to four areas: (1) extending the reach of PCMH models beyond medical care; (2) considering a role for specialists; (3) increasing parent awareness of PCMHs; and (4) increasing parent involvement.

Parent-leaders suggest expanding the reach of PCMHs into mental and behavioral health, social services, and education.

Parent-leaders want medical homes to offer support in a broader range of arenas than traditional physical medical care, including mental and behavioral health services and other social services. At least two leaders discussed the ongoing challenge of what they described as an inadequate integration of behavioral and mental health services in primary health care. This is of particular concern for CSHCN, as many in this population have both physical and behavioral health needs. As one leader said, “Mental health and physical health are going to have to collaborate We don’t separate our kids’ heads from their bodies.”

Several parent-leaders also discussed a desire to expand the PCMH model to include coordination and linkages with additional systems outside of health care, including education, social services, and vocational supports for older CSHCN. One leader said, “I think the medical home allows for an environment that is truly comprehensive. My concern is that in many practices ... that comprehensive nature can tend to be limited to the medical world. When you have kids like ours, the social arena and the educational arena can be equally as big and convoluted as the medical arena.”

Parent-leaders recommend a larger role for specialists in PCMH models.

A few parent-leaders pointed out that for many CSHCN, visits to a specialist provider may be more frequent than those to the primary care provider, and questioned whether specialists would be better suited to leading care teams than primary care providers as a result. “[For] a lot of the families I know, their primary care provider is not their consistent source of care -- it’s the specialist that’s most closely related to the child’s biggest need [and who is seen most frequently].” The primary care provider is “part of the team, but is not the critical player,” she explained. One parent-leader wondered if the PCMH model, which is currently positioned as a primary care model

with a primary care provider as the lead, could be transferred and implemented in specialty settings.

Parent-leaders believe it is important to increase parents' awareness of the PCMH concept.

All but one parent-leader we talked with thought that awareness of the PCMH concept was unacceptably low among parents of CSHCN. Parent-leaders cited a few possible reasons for this low level of awareness, including parents often being overwhelmed by the day-to-day activities of managing their children's health and therefore not having time to read information that comes their way and ineffective messaging from medical homes and organizations promoting the concept.

Nearly all of the parent-leaders stressed the importance of raising parental awareness of the PCMH concept so that parents can make educated choices when selecting a primary care provider and feel comfortable when asserting their preferences to providers. One leader said, "If anything, that's the part that I would want to have developed more [in the medical home concept] ... for families to know what [a medical home] is, and that they can have one, and that they should be at the center [of their child's health care.]" Nearly all of the leaders provided suggestions for strategies to increase parental awareness of the PCMH concept. Suggestions included enhancing pediatricians' ability to explain the concept to their patients' families; working with other providers such as social workers, nurses, school districts, and day care providers to encourage them to either disseminate written materials or explain the concept verbally to parents; and encouraging collaboration with parent advocacy groups. One parent-leader suggested working with hospitals to educate parents about medical home models "when their children are born."

Parent-leaders strongly recommend including parents in the PCMH-recognition process and using their input to guide quality improvement.

All but one of the parent-leaders explicitly called for an increased emphasis on parent involvement and input as part of the routine functioning of medical homes. Leaders agreed that patient experience should be included in the recognition process and that parents, based on their personal experiences of receiving care, could offer unique insights of which providers and practice management might not otherwise be aware. One parent-leader said "[Practices] should definitely ask the parents what's working and what's not to see what changes need to be made or [what] improvements [they could make], or if everything is just fine." As an example, one parent-leader discussed working with a practice that implemented a feedback mechanism. Through this feedback, the practice learned that its "phone call answering wasn't up to par and the waiting time was too long." Parent-leaders also suggested several methods of incorporating parent input into the processes of recognizing and transforming practices into PCMHs. The most frequently mentioned methods included explicitly asking for feedback from parents while they sit in the waiting room, doing questionnaires or surveys, running focus groups, or informally asking parents about the services they

received at the end of office each visit. Other ideas included developing standing parent advisory panels or holding parent forums. One parent-leader said, “It’s absolutely key for parents to be able to be on a panel or have a forum where they can provide feedback,” so that practices can hear parents’ perspectives on the care they provide. Parent-leaders also suggested that organizations recognizing practices as PCMHs include comparative survey tools like the Medical Home Index in their processes. This index can be used to gather and compare provider and parent perspectives on the care experience.

“[Practices] should definitely ask the parents what’s working and what’s not working to see what changes need to be made or [what] improvements [they could make], or if everything is just fine.”

Two parent-leaders suggested that practices use parents as peer resources for other parents. These parent liaisons could share information based on their knowledge and experiences with other families and could aid other families in addressing issues with insurance companies, school districts, and other systems. As one leader said, “[Parents are] an incredibly valuable resource that I believe every practice in the country has available to them, but because they haven’t seen that being modeled ... they don’t know how to access it so all of their families get the benefit of it [Peer parent resources] can fill the non-medical pieces of the medical home.”

V. SUMMARY

Findings from this study are consistent with previous studies documenting the primary care provider and practice characteristics that families of CSHCN value most (DeCamp et al., 2013; Han et al., 2013; Zickafoose et al., 2013; Bechtel & Ness, 2010; Nelson et al., 2005; Sia et al., 2004). With regard to providers, these characteristics included having confidence that the physician knew and cared about their child and family; had expertise or sought out information related to their child's special needs; listened to them; respected their knowledge, opinions, and values; and involved them in decision-making. Valued characteristics related to the practice as a whole included having continuity in the care they received, feeling welcomed by well-informed staff, receiving care management support (including information sharing with specialists and other providers), having superb access to the care team and dedicated care coordination staff, and being linked to community supports. Parent-leaders in our sample discussed the ways in which a number of these characteristics worked together to create a culture of patient-centeredness in PCMHs. Parent-leaders also emphasized that provision of care management and coordination services was an important and valued feature of PCMH models. Comments offered by parent-leaders showed that they are strong supporters of PCMH initiatives, especially for CSHCN and their families due to the multiple providers and complex coordination required to meet these children's needs. Nonetheless, they offered a variety of suggestions for enhancing PCMH initiatives and models so that they further benefit CSHCN and their families. Suggestions included expanding the reach of PCMHs into additional arenas important to CSHCN, devising a larger role for specialists, increasing parents' awareness of the PCMH concept, and including parents' input during recognition processes and ongoing quality improvement activities.

This study was designed to be exploratory. The design and methods have three primary limitations. First, study participants represent small convenience samples of parents in two states and an even smaller number of PCMHs. This limitation precludes generalization of findings to parents of CSHCNs generally. Second, all respondents participated voluntarily in the study rather than being randomly drawn from a full population. Voluntary participation creates self-selection bias. Parents of children who receive primary care at PCMHs were recruited based on their response to a flier given to them by their physician. This could bias the data in two ways. For one, providers could have distributed fliers only to those parents with whom they knew to have a favorable view of his or her practice, thus overstating the quality and characteristics of care at PCMHs generally. Also, parents who responded to the flier may be significantly different (potentially higher functioning and generally more positive) than parents who did not respond to the flier. Parent-leaders at advocacy or policy organizations also volunteered to participate in the study and were identified based on the recommendations of experts in the area of CSHCN. It is possible that those who were recommended and chose to participate in the study were different in important ways

from those leaders who were not recommended and did not participate. For example, those who agreed to participate may have had stronger positive or negative feelings about medical home initiatives and activities. Third, the study lacks a counterfactual against which to compare preferences of parents of CSHCN who receive services from pediatric practices not recognized as medical homes. In spite of these limitations, the study yielded compelling information which can be used to draw findings about parents' experiences with and perspectives on medical home models.

VI. DISCUSSION

Many of the characteristics of care parents described as receiving and valuing at medical homes correspond with core components of PCMH models. The parents included in this study received care at practices recognized as PCMHs through the 2008 NCQA Standards and Guidelines for Physician Practice Connections-Patient-Centered Medical Home (PPC-PCMH). This recognition process included standards related to access and communication, care management, patient self-management support, referral tracking, and advance electronic communications -- all of which were described by parents as valued elements of the primary care their children received. Given that parents can only realistically comment on those aspects of PCMHs that they directly encounter and interact with, they may be unaware of processes related to additional PPC-PCMH standards operating in the background, such as patient registries and test tracking, even though these functions might indirectly improve their experience of the quality of their child's care. For example, parents attached great value to care coordination, many aspects of which are facilitated by the presence of health information technology (HIT) and patient registries. Although many parents of CSHCN reported challenges in getting needed care coordination in the National Survey of Children with Special Health Care Needs (Strickland et al., 2004), the parents in this study described positive experiences with care coordination in their children's primary care practices, all of which were recognized as NCQA Level 3 PPC-PCMH practices. This suggests that the NCQA medical home recognition program, as implemented in practices in our study, is satisfying the preferences of parents of CSHCN and that recognition processes may identify practices that are more able to support families in taking care of their children.

Some researchers and policymakers have concerns, however, that recognition processes currently focus too heavily on practice infrastructure and too lightly on patient experience (Bechtel & Ness, 2010; Berenson et al., 2008). The concern is that underemphasis of patient-centered qualities downplays what some perceive as most important in the PCMH movement (Rogers, 2008) and to parents like those in our study. As one parent-leader said, "I am sad that the medical home model has moved down a direction of certifying places instead of really, really drilling down on the patient experience. That's where I think we lost the fidelity to the intent." That is, some recognition programs may "emphasize infrastructure and forget that relationship-centered care is the core of the PCMH and that the purpose of infrastructure is to support patient-centered care, not divert from it" (Roger, 2008). For example, NCQA's 2008 PPC-PCMH tool has nine standards, which some feel overemphasize infrastructure over patient-centered features, such as assigning more weight to HIT-related components than patient-centered components like care continuity and a focus on knowing your patients (Landon et al., 2010). The underemphasis on recognizing many of the characteristics parents value is likely because these characteristics are more difficult to measure. Finding a balance between infrastructure and patient-related

characteristics and incorporating feasible measurements of both seem to be worthwhile procedures to address this concern.

To measure and implement the features of care that are most important to parents of CSHCN, practices will need to engage parents in decision-making related to their children's care, as well as in practice-level quality improvement efforts (Han et al., 2013). The call of parent-leaders in this study to incorporate parents in PCMH-recognition processes and use their input to guide quality improvement is aligned with the growing research base on including parents and families in setting priorities for medical home implementation (Han et al., 2013; Zickafoose et al., 2013; Bechtel & Ness, 2010; Berenson et al., 2008). Assessments of patient satisfaction and experiences (in this case, the views of parents of CSHCN) would likely uncover issues for practices to consider when engaging in the PCMH transformation process. Although patient-centeredness is not yet an explicitly scored standard by NCQA, that body's updated PCMH 2011 recognition guidelines include requirements for increasing patient and family engagement in health care and give credit for collecting information on patient experiences using the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey for primary care. Under the 2011 standards, practices also can apply for an optional and additional distinction for reporting patient experiences collected using the CAHPS survey (NCQA, 2011; Han et al., 2013).

Because implementing surveys such as the CAHPS requires time, money, and expertise, it may not be feasible for many practices interested in becoming a PCMH to do so. Thus, to further the opportunity to include parents in quality improvement activities, policymakers and organizations leading PCMH transformation efforts can consider alternative ways to support practices -- especially small ones -- in doing so. At the systems level, developing approaches to involve parents, gather information on the patient experience, and use that information to guide practice transformation will be challenging. It will also likely require changing the culture of primary care service delivery and financing such that the provision of high-quality patient-centered care becomes an integral aspect of health care. Possible ways of supporting these cultural changes include providing additional financial incentives (e.g., higher capitation and fee-for-service rates for patients served through PCMHs) and incorporating expectations for collecting and reporting patient experiences in health care delivery systems (Han et al., 2013; Landon et al., 2010). Some states, including Colorado, Minnesota, and Massachusetts, are currently experimenting with ways of doing this. For example, Colorado certifies and provides enhanced Medicaid and Children's Health Insurance Program reimbursement to pediatric medical homes that meet standards the state established. As part of the PCMH certification process, the Colorado Department of Health Care Policy and Financing contracted with organizations to send facilitators to visit practices and conduct interviews with parents to get a sense of practices' "medical home-ness" including family centeredness, cultural competency, and care continuity. Parent feedback is used to guide quality improvements (see Colorado Children's Healthcare Access Program at <http://www.cchap.org/support-services/>). Additionally, managed care organizations contracting with state and local governments are often required to administer patient experience surveys with beneficiaries, and several states

(for example, Massachusetts and Minnesota) have public and private sector efforts to field patient experience surveys across broad populations, offering potential models for collecting patient feedback on a wide scale.

Results from our study also highlight a significant misalignment between the PCMH movement in the policy and program arenas and in the knowledge base of parents. Although all consumer parents in this study received services at recognized PCMHs, eight of the nine were unfamiliar with the term and concept of medical home. If this unfamiliarity also exists in the larger population of parents, then parents are unlikely to use recognized PCMH status when making health care choices for their families. If PCMH-recognition indeed signifies high-quality care that embodies many of the characteristics that parents value, it will be important to identify effective programmatic and policy strategies for increasing parents' knowledge and awareness of the concept, as well as their access to listings of recognized PCMHs in local communities. Parent-leaders in this study identified potential strategies for increasing parents' knowledge and awareness, including enhancing pediatric providers' ability to explain the concept; working with other providers such as social service workers, nurses, school districts, and day cares to disseminate information; and encouraging provider collaboration with consumer organizations. Additionally, several states and some regional partnerships have begun to implement efforts to make information on PCMH-recognition easily accessible and publicly available (for example, Massachusetts and Minnesota), and the NCQA makes its list of recognized practices available on its website. Primary care practices could also make this information available to potential patient families. State Medicaid and Title V programs for CSHCN could also play a role in closing this knowledge gap by providing parents with listings of PCMHs in their area during enrollment or re-enrollment.

In conclusion, parents in this study articulated that they valued a variety of characteristics in the primary care they received at PCMHs for their children with special needs. The features of care that mattered most to parents most often related to patient-centered qualities of the care. Although parents were able to describe these characteristics, they were unfamiliar with the medical home concept. Parent-leaders discussed this lack of awareness as a target for future efforts to improve the reach and impact of medical home initiatives meant to improve the care of CSHCN. Leaders also emphasized the importance and potential value of including parent feedback and input during and after the recognition process as a key driver of quality improvement efforts. Organizations involved in recognizing practices as medical homes and policymakers interested in PCMH initiatives may consider investing in educating parents about the features of medical homes, educating practices about the value of including parents as partners, and developing strategies to incentivize practices to gather and use parent feedback as an integral part of continuous quality improvement.

REFERENCES

- Bechtel, C., and D.L. Ness. "If You Build It, Will They Come? Designing Truly Patient-Centered Health Care." *Health Affairs*, vol. 29, no. 5, 2010, pp. 914-920.
- Berenson, R.A., T. Hammons, D.N. Gans, S. Zuckerman, K. Merrell, W.S. Underwood, and A.F. Williams. "A House Is Not a Home: Keeping Patients at the Center of Practice Redesign." *Health Affairs*, vol. 27, no. 5, 2008, pp. 1219-1230.
- Colorado Children's Healthcare Access Program. Available at <http://www.cchap.org/support-services/>. Accessed April 30, 2013.
- Cooley, W.C., J.W. McAllister, K. Sherrieb, and K. Kuhlthau. "Improved Outcomes Associated with Medical Home Implementation in Pediatric Primary Care." *Pediatrics*, vol. 124, no. 1, 2009, pp. 358-364.
- DeCamp, L.R., E. Kieffer, J.S. Zickafoose, S. DeMonner, F. Valbuena, M.M. Davis, and M. Heisler. "The Voices of Limited English Proficiency Latina Mothers on Pediatric Primary Care: Lessons for the Medical Home." *Maternal and Child Health Journal*, vol. 17, no. 1, 2013, pp. 95-109.
- Detsky, A.S. "What Patients Really Want from Health Care." *Journal of the American Medical Association*, vol. 306, no. 22, 2011, pp. 2500-2501.
- Han, E., S.H. Scholl, S. Morton, C. Bechtel, and R. Kessler. "Survey Shows That Fewer Than a Third of Patient-Centered Medical Home Practices Engage Parents in Quality Improvement." *Health Affairs*, vol. 32, no. 2, 2013, pp. 368-375.
- Homer, C.J., K. Klatka, D. Romm, K. Kuhlthau, S. Bloom, P. Newacheck, J. Van Cleave, and J. M. Perrin. "A Review of the Evidence for the Medical Home for Children with Special Health Care Needs." *Pediatrics*, vol. 122, 2008, pp. e922-e937.
- Iezzoni, L.I. "Imperatives for HSR Addressing Individuals with Disabilities -- The Canaries in Health Care's Coal Mine." *Medical Care*, vol. 51, no. 2, 2013, pp. 133-136.
- Kilo, C.M., and J.H. Wasson. "Practice Redesign and the Patient-Centered Medical Home: History, Promise, and Challenges." *Health Affairs*, vol. 29, no. 5, 2010, pp. 773-778.
- Landon, B.E., J.M. Gill, R.C. Antonelli, and E.C. Rich. "Prospects for Rebuilding Primary Care Using the Patient-Centered Medical Home." *Health Affairs*, vol. 29, no. 5, 2010, pp. 827-834.
- National Committee on Quality Assurance. "Standards and Guidelines for the Patient-Centered Medical Home, 2011." Washington, DC: NCQA, 2011.
- Nelson, C.S., S. Higma, C. Sia, E. McFarlane, L. Fuddy, and A. Duggan. "Medical Homes for At-Risk Children: Parental Reports of Clinician-Parent Relationships, Anticipatory Guidance, and Behavior Changes." *Pediatrics*, vol. 115, no. 1, 2005, pp. 48-56.

- Peikes, D., A. Zutshi, J.L. Genevro, M.L. Parchman, and D.S. Meyers. "Early Evaluations of the Medical Home: Building on a Promising Start." *American Journal of Managed Care*, vol. 18, no. 2, 2012, pp. 105-116.
- Reid, R.J., K. Coleman, E.A. Johnson, P.A. Fishman, C. Hsu, M.P. Soman, C.E. Trescott, M. Erikson, and E.B. Larson. "The Group Health Medical Home at Year Two: Cost Savings, Higher Patient Satisfaction, and Less Burnout for Providers." *Health Affairs*, vol. 29, no. 5, 2010, pp. 835-843.
- Reid R.J., P.A. Fishman, O. Yu, T.R. Ross, J.T. Tufano, M.P. Soman, and E.B. Larson. "Patient-Centered Medical Home Demonstration: A Prospective, Quasi-Experimental, Before and After Evaluation." *American Journal of Managed Care*, vol. 15, no. 9, 2009, pp. e71-e87.
- Rittenhouse, D.R., L.A. Schmidt, K.J. Wu, and J. Wiley. "The Post-Katrina Conversion of Clinics in New Orleans to Medical Homes Shows Change Is Possible, but Hard to Sustain." *Health Affairs*, vol. 31, no. 8, 2012, pp. 1729-1738.
- Rogers, C. "The Patient-Centered Medical Home Movement -- Promise and Peril for Family Medicine." *Journal of the American Board of Family Medicine*, vol. 21, no. 5, 2008, pp. 370-374.
- Sia, C., T.F. Tonniges, E. Osterhus, and S. Taba. "History of the Medical Home Concept." *Pediatrics*, vol. 113, no. 5, 2004, pp. 1473-1478.
- Solberg L.I., S.E. Asche, P. Fontaine, T.J. Flottemesch, L.G. Pawlson, and S.H. Scholle. "Relationship of Clinical Medical Home Scores to Quality and Patient Experience." *Journal of Ambulatory Care Management*, vol. 34, no.1, 2011, pp. 57-66.
- Zickafoose, J.S., L.R. DeCamp, D.J. Sambuca, and L.A. Prosser. "Parents' Preferences for Enhanced Access to the Medical Home." *Journal of Ambulatory Care Management*, vol. 36, no. 1, 2013, pp. 2-12.

APPENDIX A. 2008 NCQA STANDARDS AND ELEMENTS

Standard		Definition and Selected Examples
1	Access and Communication	The practice provides patient access during and after regular business hours, and communicates with patients effectively. <ul style="list-style-type: none"> • Patients have personal clinicians. • Same day appointments, based on triage, are available. • Telephone advice lines are available with timely response.
2	Patient Tracking and Registry Functions	The practice has readily available, clinically useful information on patients that enables it to treat patients comprehensively and systematically. <ul style="list-style-type: none"> • The practice can generate lists of patients and take action to remind patients or clinicians proactively of services needed.
3	Care Management	The practice maintains continuous relationships with patients by implementing evidence-based guidelines and applying them to the identified needs of individual patients over time and with the intensity needed by patients. <ul style="list-style-type: none"> • The practice follows guidelines for screenings, immunizations, risk assessments, and counseling and uses patient reminders for appointments, medication refills, and tests.
4	Patient Self-Management Support	The practice works to improve patients' ability to self-manage health by providing educational resources and ongoing assistance and encouragement.
5	Electronic Prescribing	The practice seeks to reduce medical errors and improve efficiency by eliminating handwritten prescriptions and by using drug safety checks and cost information when prescribing.
6	Test Tracking	The practice works to improve effectiveness of care by using timely information on all tests and results. <ul style="list-style-type: none"> • The practice tracks test orders to ensure results are received, flags abnormal tests, and follows-up.
7	Referral Tracking	The practice seeks to improve effectiveness, timeliness and coordination by following through on consultations and referrals.
8	Performance Reporting and Improvement	The practice seeks to improve effectiveness, timeliness and other aspects of quality by measuring and reporting performance, comparing itself to national benchmarks, giving physicians regular feedback and taking actions to improve.
9	Advanced Electronic Communication	The practice maximizes use of electronic communication to improve timeliness, effectiveness, efficiency and coordination of care. The practice offers patients the use of an interactive website.

CENTER OF EXCELLENCE IN RESEARCH ON DISABILITY SERVICES AND CARE COORDINATION AND INTEGRATION (CERDS)

REPORTS AVAILABLE

Abstracted List of Tasks and Reports

HTML <http://aspe.hhs.gov/daltcp/reports/2014/CERDS.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/CERDS.pdf>

Association between NCQA Patient-Centered Medical Home Recognition for Primary Care Practices and Quality of Care for Children with Disabilities and Special Health Care Needs

HTML <http://aspe.hhs.gov/daltcp/reports/2014/ChildDisV3.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/ChildDisV3.pdf>

Children with Disabilities and Special Health Care Needs in NCQA-Recognized Patient-Centered Medical Homes: Health Care Utilization, Provider Perspectives and Parental Expectations Executive Summary

HTML <http://aspe.hhs.gov/daltcp/reports/2014/ChildDisES.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/ChildDisES.pdf>

Descriptive Study of Three Disability Competent Managed Care Plans for Medicaid Enrollees

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2014/3MCPlanses.shtml>
HTML <http://aspe.hhs.gov/daltcp/reports/2014/3MCPlans.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/3MCPlans.pdf>

Effect of PACE on Costs, Nursing Home Admissions, and Mortality: 2006-2011

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2014/PACEeffectes.shtml>
HTML <http://aspe.hhs.gov/daltcp/reports/2014/PACEeffect.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/PACEeffect.pdf>

Effectiveness of Alternative Ways of Implementing Care Management Components in Medicare D-SNPs: The Brand New Day Study

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2014/OrthoV2s.shtml>
HTML <http://aspe.hhs.gov/daltcp/reports/2014/OrthoV2.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/OrthoV2.pdf>

Effectiveness of Alternative Ways of Implementing Care Management Components in Medicare D-SNPs: The Care Wisconsin and Gateway Study

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2014/OrthoV1es.shtml>
HTML <http://aspe.hhs.gov/daltcp/reports/2014/OrthoV1.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/OrthoV1.pdf>

Evaluating PACE: A Review of the Literature

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2014/PACELitReves.shtml>
HTML <http://aspe.hhs.gov/daltcp/reports/2014/PACELitRev.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/PACELitRev.pdf>

Factors Predicting Transitions from Medicare-Only to Medicare-Medicaid Enrollee Status

HTML <http://aspe.hhs.gov/daltcp/reports/2014/MMTransV2.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/MMTransV2.shtml>

Identifying Medicare Beneficiaries with Disabilities: Improving on Claims-Based Algorithms

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2014/algorithmes.shtml>
HTML <http://aspe.hhs.gov/daltcp/reports/2014/algorithm.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/algorithm.pdf>

Impacts of Waiting Periods for Home and Community-Based Services on Consumers and Medicaid Long-Term Care Costs in Iowa

HTML <http://aspe.hhs.gov/daltcp/reports/2014/IAWaitPd.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/IAWaitPd.pdf>

Integrating Physical Health Care in Behavioral Health Agencies in Rural Pennsylvania

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2014/ruralPAes.shtml>
HTML <http://aspe.hhs.gov/daltcp/reports/2014/ruralPA.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/ruralPA.pdf>

Non-Elderly Disabled Category 2 Housing Choice Voucher Program: An Implementation and Impact Analysis

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2014/Cat2Housinges.shtml>
HTML <http://aspe.hhs.gov/daltcp/reports/2014/Cat2Housing.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/Cat2Housing.pdf>

Parent Perspectives on Care Received at Patient-Centered Medical Homes for Their Children with Special Health Care Needs

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2014/ChildDisV2es.shtml>
HTML <http://aspe.hhs.gov/daltcp/reports/2014/ChildDisV2.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/ChildDisV2.pdf>

Physician Perspectives on the Influence of Medical Home Recognition on Practice Transformation and Care Quality for Children with Special Health Care Needs

HTML <http://aspe.hhs.gov/daltcp/reports/2014/ChildDisV1.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/ChildDisV1.pdf>

Strategies for Integrating and Coordinating Care for Behavioral Health Populations: Case Studies of Four States

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2014/4CaseStudes.shtml>
HTML <http://aspe.hhs.gov/daltcp/reports/2014/4CaseStud.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/4CaseStud.pdf>

Transitions from Medicare-Only to Medicare-Medicaid Enrollment

HTML <http://aspe.hhs.gov/daltcp/reports/2014/MMTransV1.shtml>
PDF <http://aspe.hhs.gov/daltcp/reports/2014/MMTransV1.pdf>

To obtain a printed copy of this report, send the full report title and your mailing information to:

U.S. Department of Health and Human Services
Office of Disability, Aging and Long-Term Care Policy
Room 424E, H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201
FAX: 202-401-7733
Email: webmaster.DALTCP@hhs.gov

NOTE: All requests must be in writing.

RETURN TO:

Office of Disability, Aging and Long-Term Care Policy (DALTCP) Home
http://aspe.hhs.gov/office_specific/daltcp.cfm

Assistant Secretary for Planning and Evaluation (ASPE) Home
<http://aspe.hhs.gov>

U.S. Department of Health and Human Services (HHS) Home
<http://www.hhs.gov>