

Report

In Their Own Words:

Improving the Care Experience of Families with Children with Special Health Care Needs



Prepared By

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Introduction

The number of reports and published articles detailing the challenges facing children with special health care needs (CSHCN) and their families is incalculable. There is little question, however, that a very large number of talented, committed and caring professionals have worked for many years to document problems families face obtaining needed care and to craft program and policy approaches to address them. While the field and this work are dominated by individuals and groups who consider these questions principally through the lenses of their professional perspectives, importantly, families themselves are also involved.

Inclusion of families in defining the issues and identifying solutions is critical for a number of reasons. Bias is inevitable in research, policy and program development, evaluation and direct services. Families, of course, often bring biases based on their own life experiences, culture and even professional training. However, in general, parents represent only one interest—the health and well-being of their child and family.

With the early implementation of the Affordable Care Act and mounting energy in California and other states to address systemic issues facing CSHCN, opportunities to develop and test new models

Parents placed very strong emphasis on achieving real and effective consumer engagement

have emerged.¹ As a means to inform these new efforts, 10 focus groups of parents of children with special needs were conducted. During the spring and early summer of 2013 in the San Francisco Bay Area, 52 parent participants talked about their lives with children with special needs and their experiences obtaining needed services. Participants offered their recommendations for improving the current system of care.

These focus groups were diverse in language, race and ethnicity, children's age and children's conditions. Participants were recruited with assistance from Family Resource Centers in San Francisco and Oakland and through sample snowballing.

Each group was asked the following three questions:

- What are your children's special needs and how do these affect their health, well-being, functioning and development? How do they affect the rest of the family?
- How well are your children's needs being met? What about the system of care is working well for children and families? What is not working well?
- What specific recommendations do you have about how the system of care can better meet your children's needs?

With the assistance of quantitative data software, common themes were identified from the transcript, and additional manual analyses further refined the themes. The resulting pictures are not intended to represent the full scope of issues that families with CSHCN face, but they do describe the most common issues parents raised.

¹ David C and Rosenstein S. Transitioning the California Children's Services Program to a New System of Care: Stakeholders Issues and Considerations. *Health Management Associates*. Lucile Packard Foundation for Children's Health, Palo Alto, May 2014.

Parents placed very strong emphasis on achieving real and effective consumer engagement, by which they meant meaningful, continual family engagement in decision-making around policy, system design and service delivery quality improvement.

This report provides a summary of findings synthesized into four core themes. This is preceded by a brief description of the “foundational circumstances” of the families in the study.

Part 1: Summary Findings

The Starting Place: All families shared certain “truths” about their circumstances. These common characteristics are foundational to the families’ lives and are the context for the comments and observations:

- All children in this study face medical and/or developmental challenges; many children require *significant* medical, developmental, ancillary and other supportive services.
- All children face both educational and social struggles as a result of their special health care needs.
- Parents report grief, fear, uncertainty and even trauma associated with their children’s condition(s).
- Many also report frustrations with the limitations of medicine to diagnose and treat their children, particularly parents in families with children with more complex and rare conditions.

Four Core Themes

In telling about their experiences, families identified some differences based on linguistic and cultural variations, insurance coverage and, especially, children’s acuity. Despite these variations, four closely related themes emerged. These are described below, including associated subthemes, as well as in Figure 1.

Theme 1: System Complexity and Fragmentation

All of the parents’ children require a wide range of medical and non-medical services to diagnose, treat and, ideally, maintain their health and well-being, care that typically involves multiple providers and multiple systems.

- Many parents report that the system of care is fragmented and disorganized.
- Families report multiple barriers to services associated with: fragmentation within the medical system and between medical care and other services; strict eligibility criteria; and enrollment hurdles, among other factors.
- Families rarely know the full the range of services available to them—or how to gain that knowledge—and struggle to obtain the services that they know about.
- All families need assistance coordinating care, navigating the system and advocating for services; the job is too large for most families to manage.
- Care coordinators are vital links to needed care, but rarely have the full picture of available resources.
- Other families (and organizations of families) are viewed as the most consistent, reliable and experienced sources of guidance and support.

Theme 2: System Not Designed for Families

The current system of medical care and ancillary services is not designed for children and families but for other “players.”

- Many parents share a belief that the service system is designed to accommodate providers, staff and others, rather than families.
- Many also have feelings of not being heard by professionals (though partnerships and support sometimes are found with individual health professionals).

Theme 3: Family Burden Unrecognized

The burdens placed on the families are enormous: parents serve as advocates and case managers for their special needs child while supporting affected siblings and coping with their own fear and grief. Many parents also face extra financial burdens while trying to hold on to jobs and keep marriages intact. These burdens are largely unrecognized, underappreciated and rarely alleviated, even temporarily.

- All families struggle to construct for their child a system of care, including all medical and support services, financial aid, education and social support.
- Some families are in constant crisis mode, even during relative “lulls,” in anticipation of the next crises to occur and/or new issues to emerge.
- Parents describe how the families’ grief and sorrow is compounded by major daily challenges obtaining needed care.
- Children’s conditions and the concentrated attention required to meet multiple needs deeply affect the family as a whole, especially “typical” siblings.
- Most parents report feeling vulnerable, frightened and ill-equipped at least some of the time.
- Many families feel isolated and all families desperately want and need additional supports for individual family members and the family as a whole.

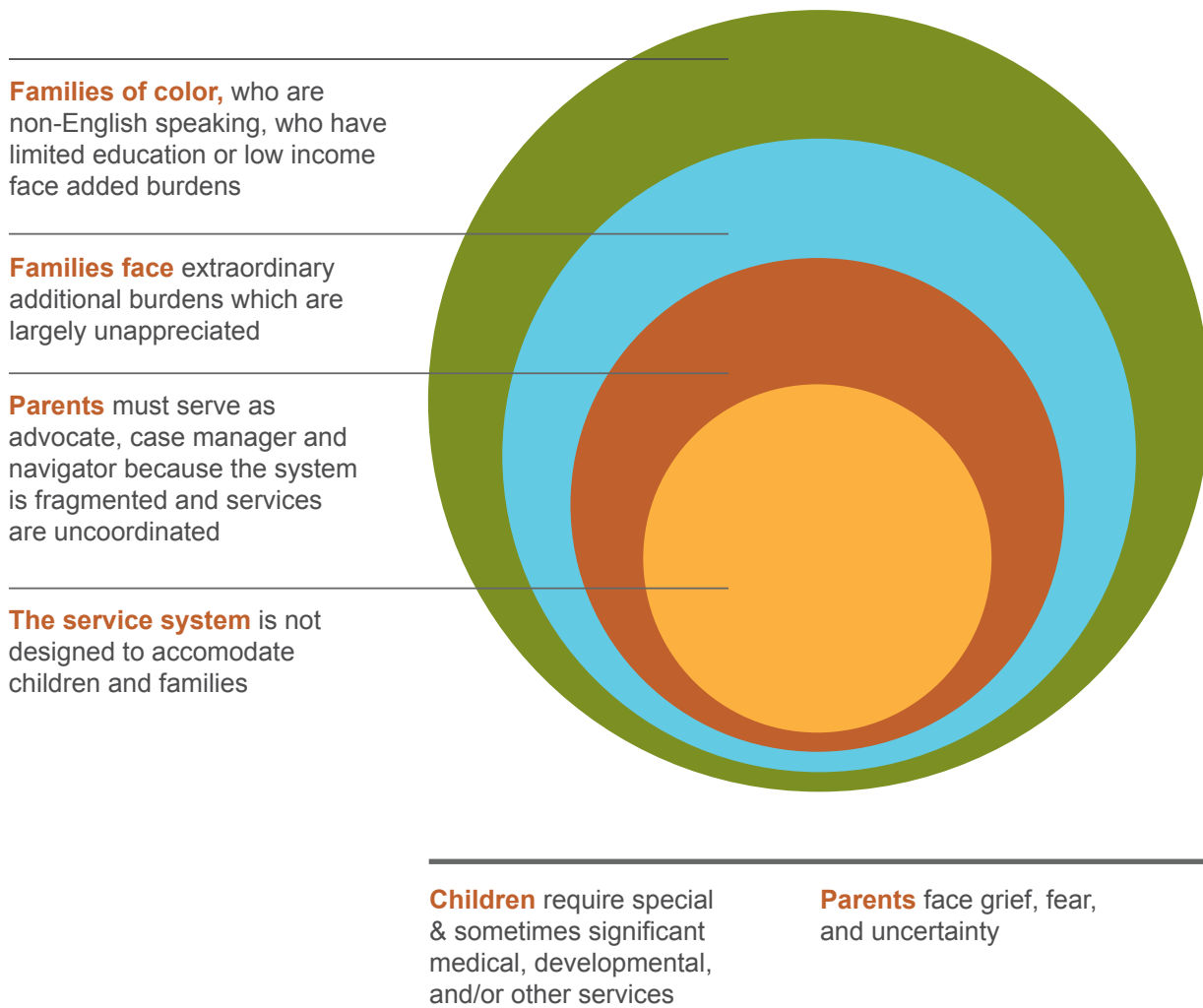
Theme 4: Race, Language and Income Barriers

These issues are compounded by additional challenges for families of color, those who do not speak English, have limited education, or are low income.

- Language can pose barriers to understanding the diagnosis and treatment options, communicating with providers, applying for services and reaching out for support.
- One of the most powerful ways that parents with lower education levels are challenged is the lack of access to information that is understandable and usable.
- Income affects families’ experiences in many ways, including the types of health insurance families have, which can, in turn, influence access.
- Race and racism are powerful forces in all realms of society, including medicine and service delivery. Some parents experience provider bias and erroneous assumptions, which influences their trust in many health care providers.

Fundamentally, parents feel that they don’t have a voice.

Figure 1: Family Experiences: Core Themes



Summary and Recommendations

Most parents experience some dissatisfaction with the health and social service system and many face barriers to needed care due to financial and non-financial barriers. Among families with children with special health care needs, virtually *all* face challenges to gathering trusted information about their children's health, obtaining access to their children's needed services, and obtaining support for themselves and their families. These support services are essential to mitigate the enormous emotional, financial and time burdens associated with the children's conditions, and the demands that the service system places on families to largely fend for themselves.

In addition to telling their stories, families offered recommendations for improving the system. Most of these recommendations from these parents validate findings from previous research:

- Reform programs to simplify eligibility and enrollment and broaden benefits.
- Improve linkages between medical, developmental, school-based, in-home, ancillary and other support services.
- Increase availability of respite care for all family members and improve access to counseling services and other mental health supports for siblings and parents.
- Assure family-centered care, including information- and record-sharing and culturally and linguistically competent care.
- Improve the availability and quality of care coordination, navigation and advocacy.
- Reorganize service delivery to improve convenience for families and efficiency for providers.
- Better educate health care providers to promote empathy, cultural sensitivity, communication skills and knowledge of how to identify and use community-based resources.

Part 2: In Their Own Words: Parents' Observations About the Care Experience of Families with CSHCN

Fifty-two parents in 10 focus groups offered their testimony—their stories—about their experiences as families with children with special health care needs (CSHCN). What follows is a sampling of these stories that collectively gave rise to the four core themes. These quotations and small stories were selected from among the 900-plus minutes of transcripts as illustrative of what was heard from the focus groups.

Theme 1 System Complexity and Fragmentation

All children require a wide range of medical and non-medical services to diagnose, treat and, ideally, maintain their health and well-being—care that typically involves multiple providers and multiple systems.

Many parents report that the system of care is fragmented and disorganized.

“The [Regional Center] helped me in various ways: they were teaching me how to interact with [my son] to decrease the amount of stimulation.... They taught us how to communicate through sign language and various games and things that we did at home which were very useful. I wanted my son to keep doing that, but that was funded by the GGRC—the Regional Center. After that, I found out that because of the insurance or something along those lines, I no longer qualified for that therapy. Some said one thing, and others said it was because my son is 5 and no longer qualifies. It doesn't seem very logical to me that because my son is 5 or has Medi-Cal, because he needs it.”

Families report multiple barriers to services associated with fragmentation within the medical system and between medical care and other services, strict eligibility criteria and enrollment hurdles among other factors.

“Charity was giving me a therapist one-on-one. Of course I wanted that. It was reinforcing what she was getting at school. I'm asking the doctor, ‘Please, help me fill out the application so that Medi-Cal continues paying that extra hour for therapy because when the number of visits is up, it's over.’... So I make a formal request. They made me talk to tons of people—secretaries, the manager, operations, computer staff—a bunch of people that had nothing to do with her therapy, that had nothing to do with her physician. Like administrators. On top of all of that, even a judge because we got a hearing. First of all, they wrote me off: ‘Medi-Cal doesn't pay because she's already getting therapy at school.’ I say, ‘It's three hours a month. On top of that, it's a group session.’”

“They made me talk to tons of people... a bunch of people that had nothing to do with her therapy, that had nothing to do with her physician.”

“I always insisted to the doctor to check him more thoroughly because I thought it was asthma. So they never paid attention to me.... He’s 4 years old, now. Finally, about a year ago they sent him to a specialist. So if you were to ask me what my complaint about this is, it’s that it’s really hard for them to send the children to a specialist. I don’t know if it’s because it’s more expensive, or because they have to do it that way, but—a lot of mothers I’ve listened to say that it’s really difficult for the primary physician to send their child to a specialist to be checked out. That’s very bad.”

“We’re behind because of how long Medi-Cal takes to process an appointment with a specialist. In my case they sent us to a neurologist, but it took nearly six months to approve that appointment. On top of that, it took us nearly three months to make an appointment because of how busy the doctors were. We saw him. He wrote his report. He requested an MRI, which took another couple of months. In other words, a year later, ‘We still don’t know what’s going on with your son....’”

“She needed physical therapy. [The plan] said—we were referred to physical therapy because she was not walking by 13 months, and it just seemed kind of weak. We go in there. The PT (Physical Therapist/Therapy) says, ‘I’m sorry. It appears as though your child qualifies for Golden Gate Regional Center services.’ And I said, ‘Well, who are they? We pay for [the plan]. We’ve always had [the plan]. Why can’t you provide this service to my daughter? She needs it now!’ ‘We don’t provide the kind of intensive services that your daughter needs.’ And I said, ‘Why not? It’s nothing in my plan that says that you won’t.’ She said, “‘Because, you qualify for it over here.’ ... And then the PT encouraged me to place a complaint on the side that said, ‘This is what my daughter needs,’ and I did, and we ended up getting it every other week for a little while, but it was spotty and it wasn’t—she really needed intensive PT, and all kids with Rett Syndrome, which she has, need intensive PT from early, early on. So luckily, I was really on that and I did it, but someone else would have been discouraged.”

“A lot of mothers... say that it’s really difficult for the primary physician to send their child to a specialist to be checked out. That’s very bad.”

“At least CCS (California Children’s Services) is supporting me right now only with her injections and her pills. But CCS doesn’t—it’s an obstacle that it doesn’t help me with, for instance, a neurologist. It doesn’t cover me—or a dentist, because she has a lot of mouth problems. She has infections for the same reason... and they won’t approve me. They won’t approve me. They say, ‘We can only help you with this part of her, but not the other.’ But then, I don’t have insurance. I don’t have money to pay for a dentist because the dentist is a specialist, or a neurologist, because she also tends to use a neurologist as a doctor.... She didn’t see a neurologist after my husband lost his insurance.... CCS doesn’t cover the neurologist and we are not eligible for Medi-Cal either because the thing is that they review the unemployment my husband gets. So they say, ‘Since he has unemployment, we can’t give you coverage.’”

Families rarely know the full the range of services available to them—or how to gain that knowledge—and struggle to obtain the services that they know about.

“We are working with my son’s school; right now, his school district is providing therapy: OT (Occupational Therapist), PT, and speech. He used to have therapy at home, but that ended. They said it was because my son had Medi-Cal.... I think it was last year when Support for Families did their workshops. I was very worried because I heard that people who had Medi-Cal or Healthy San Francisco or Healthy Kids—their services were going to be replaced. That’s what happened. I saw other parents.... Those mothers were happy because they were going to be able

“You have to go knock on another door, another door, another door, until it’s the right one and it opens.”

to get ABA (Applied Behavior Analysis) service at a more reasonable price. They had Kaiser and Blue Cross, so they were going to benefit from the change, but those of us who had Medi-Cal, Healthy San Francisco, etc., were going to lose out. My son right now does not have extra therapy—just the district’s. Sometimes dealing with the district is pretty difficult because often they don’t do their job properly.”

“Yes. They are obstacles that are there, and you have to go knock on another door, another door, another door, until it’s the right one and it opens.... Because right now we’re dealing with that, where I’m going to start checking into who is going to help. I’m going to ask CCS or her doctor, or the social worker. People who have the knowledge. Because I haven’t been able to really find—for her to have a—because I need a neurologist to examine her. And a dentist [for children with special needs].”

“There should be a generic—all of the services that we get are generic services that are available to all—if they’re a member of the severely impaired population, there is a generic pool of resources for all of us, especially with kids who need nursing and things like that. So there should be no variation in the services that [another parent] gets as opposed to what I get—there is huge variation.”

All families need assistance coordinating care, navigating the system and advocating for services—the job is too large for most families to manage.

“I wake up every morning terrified [about] what the day will bring and I’m mad that I have to do it all [for my child].”

“I noticed that it’s getting—things are really getting a lot harder. [My daughter] constantly needs equipment, so that’s also been another thing—letter-writing to justify why it’s medically necessary and doing the legal research and all of that.”

“A lot of people just give up.”

“So now I just kind of gear up. It's like, ‘Okay, here we go.’ Pick up the phone and I don't get worked up about it anymore because it's so typical.... The amount of time that I've spent advocating and case managing has just been enormous. It's hard enough dealing with it on a daily basis. It's almost like, well, what do I really have to look forward to? Do I have more of this until she's 30 or whatever, 40, however long [my daughter's] gonna live, if I'm still here? Is it always going to be like this? And it's like, wow, I really need a break from this. And I don't think it's gonna happen.”

“Sometimes I've got to coordinate the care coordinators.”

“We were terrified in the hospital, you know? And everyone helped us through that. But... when it was time to go, we had a discharge social worker make some arrangements. But, you know, it felt like we were kicked to the curb. OK. We weren't their job anymore. But we didn't know what to do next.”

Care coordinators are vital links to needed care, but rarely have the full picture of resources.

“So we did have a social worker, and they got me hooked into the Golden Gate Regional Center over here. But still, it was very, I guess, almost too specific because that's—that was all that the person did was hook me up with them. They didn't take me through any of the medical process that might have to happen. [I thought having a social worker] that, like you said, can walk you through the process, someone that is going to help you navigate the systems, and that follows up. Follows up on a regular basis. ‘Did this happen? Did that happen? You're eligible for this, this and this.’ But that's not what we got.”

“I get tired because I have to fend for myself.”

“So it's a navigator-social worker-liaison-advocate.”

“Yeah, and then just have someone kind of be there that's kind of a liaison, I guess, that kind of knows what benefits are out there. They don't have to know about it in detail, but just to make the phone call that helps get the paperwork started to get us into the front door. And then you start the process.”

“And they’ll say that Regional Center has them and that In-Home Supportive Services (IHSS) has them, and that Medi-Cal has them. Those people are behind desks. They don’t answer the phone calls... and they don’t know much about their own programs, I have to say.”

“Sometimes I’ve got to coordinate the care coordinators.”

[From a parent who learned about IHSS through word of mouth]: “It’s a state benefit and our social worker had never told me about it. Not because he didn’t mean to. He’s a really sweet man. He just didn’t know much about it.”

“My heart goes out to parents who don’t have the time to advocate... I just can’t even imagine. Oh, my goodness.”

Other families—and organizations of families—are viewed as the most consistent, reliable and experienced sources of guidance and support.

“I have to keep struggling to find therapy.... Support for Families has helped me see the types of therapy that exist, so I write them down and research them and then go to... the only resource that can pay for the services so that my son can get them.”

“Also in Contra Costa—I’ve also had some problems because I learned a lot here [at Support for Families] about how to help my son... advocate, more than anything for his rights and what he needs and has a right to by federal law. I don’t have to fight as much because they know I go to [Support for Families]—I’ve gotten assistance from that place to help advocate and see that I’m not alone. It’s not so bad, but for many years—I didn’t know. I wasn’t an expert and neither was his mom. We’re not experts in asking for help, in advocating for our child. They didn’t offer us anything. Simply,

“They never call us and say, ‘Hey, we have this here for your son.’”

“Swipe in. You need this and this.” Sometimes the therapist didn’t show up. There was a lot of irresponsibility. That was unfair.”

“I didn’t know about the nursing respite until a year and a half ago, and that was through another family, two other families. And that was something that our caseworker... should have told us about, and didn’t. My daughter’s friends are getting it. There’s a communication breakdown there somewhere.”

Theme 2 System Not Designed for Families

The current system of medical care and ancillary services is not designed for children and families but for other “players.”

Many parents share a belief that the service system is designed to accommodate providers, staff and others, rather than families.

“Well I think that for all of us who have children with special needs, it’s difficult. Because we always have to be looking. I mean, they never call us and say, ‘Hey, we have this here for your son.’ We always have to be looking and looking and looking and looking.”

“I carry notes and records whenever we see the specialists because they—I don’t believe—they don’t talk to one another. One is only interested in [my son’s] brain injury. The other only cares about orthopedic issues. They never come together [to share information]. That’s my job.”

“I didn’t have child care. I had a 2-year-old that I was bringing with me. Well, the PT was scolding our 2-year-old while we were trying to do [the exercises]—there just needs to be a family approach.”

Many also have feelings of not being heard by professionals.

“In the end, I left [the hospital]. I said, ‘This isn’t worth it.’ They didn’t listen. They’d say, ‘Why are you worried? She’s reaching her milestones completely perfectly. She’s a beautiful and healthy girl, can’t you see?’ ‘Doctor, it isn’t a physical issue.’ I didn’t know what else to say to make myself clear, ‘It’s not a physical issue.’ Finally, her general physician said, ‘Well, I’m going to refer you to a specialist.’ She scheduled an appointment with the specialist at the General Hospital. At that point my daughter was already 7. I’d begged, and begged, and begged, but they didn’t gauge her mental abilities, just her weight, height, whether she had all her teeth, healthy eyes, and five fingers on her hands. ‘It’s not physical.’ The doctor scheduled an appointment with a neurologist and same thing. We went to the neurologist at [the hospital], and he said, ‘Run from this wall to that one.’ Of course she could run, ‘Hop, hop, hop, on your right foot.’ Of course she could do that.... I’d say, ‘It’s not physical.’ To this day, I can’t believe it. I’m lost here. If these are the professionals Medi-Cal is offering me, no. I won’t accept it.” (Her daughter was later diagnosed with autism.)

“If we weren’t by her bedside the entire time [in the hospital] she could very well have died because... no one’s familiar with her case.”

“I remember... in terms of micromanage, just monitoring her in the hospital. If we weren't by her bedside the entire time, she could very well have died because there's so many different nurses coming in, so many different doctors. No one's familiar with her case. And it's like, 'No, she already had that. Please don't give her more of that.'”

“I remember I took him to the ER and they told me, 'He's fine. Just a stomach bug. Just follow the directions and he'll be fine.' But as a parent, as a mother, you know something is not right, so I ended up taking him like at 1 a.m., and I told them, 'You know what?' I put my foot down, and I said, 'Something's wrong with my son, and it's not a stomach bug, or anything. It's something worse. I don't know what it is. Do whatever tests.' And about 4 a.m. they come back and they give me this Type I diabetes diagnosis.”

“And I was the one who told the doctor I wanted them to check my son, to send him somewhere they said, to see if he had autism. Because I was noticing that he did a lot of things that children with autism do, like he moved his hands, he didn't play with other kids, with my family members. So he told me that he didn't think my son had autism. But that he was going to send him. But they say it to you as though, 'There, so you can stop pestering, ma'am.' And it was positive—they diagnosed him with autism.”

“I think it would be good for them to have someone to listen to us if they don't have time to listen to us.... So in my case, the times I've complained because my son is sick, it came to light. Like his autism and like his asthma. I said that before something worried me and it turned out true. So if my son had been diagnosed before, he would be better, I think, because he would have had more services since a long time ago. So for me, that's really important, that there be more communication with the parents.”

Theme 3 Family Burden Unrecognized

The burdens placed on families with special needs children are enormous; parents serve as advocates and case managers for their special needs child while supporting affected siblings and coping with their fear and grief. Many parents also face extra financial burdens while trying to hold onto jobs and keep marriages intact. These burdens are largely unrecognized, underappreciated and rarely alleviated, even temporarily.

All families struggle to construct for their children a system of care, including all medical and support services, financial aid, education and social support.

“In elementary school, they never gave her anything—not even half an hour of therapy. She gets to middle school and her grades were all Fs and Ds... I had to practically plead with the speech therapist because the school district pays for it. ‘If I have to scream, I will. If I have to stomp, I will, but you make an appointment for an evaluation because this girl needs therapy. No one has ever given her therapy, which is why she can’t write an essay or answer questions, nothing.’ At that point, that was sixth grade, and I had to be forceful. I was threatening him with scandal. The man said, ‘Okay, ma’am, calm down. I’m going to make the appointment.’ And that’s how it happened, by force. He made the appointment, and the results were that she genuinely needed speech therapy. I had to go to extremes.”

“If I have to scream, I will. If I have to stomp, I will, but you make an appointment for an evaluation because this girl needs therapy.”

Most—if not all—parents feel vulnerable, frightened and ill-equipped some of the time.

“[My son is] autistic.... He has not spoken to this day. He communicates through sign language, but even so, our sign language vocabulary isn’t very thorough; that’s currently one of our greatest challenges at home. He’s very clever and is able to communicate his needs, but sometimes it does get difficult because, again, he can’t express what he wants or feels and gets frustrated. Consequently, we also get frustrated.”

“And then [after a trauma], you kinda emotionally deal with it and, ‘Why me? Why is this happening to my child?’ And then it takes its toll on the whole family, especially when you’re not familiar with the disease or type of disability of health condition. You have to be trained and you pray to God that they train you correctly.”

Parents describe how the families' grief and sorrow are compounded by major daily challenges to obtaining needed care.

“There has been a lot of trauma around getting her the right kind of health care—getting her social services hooked into that—and feeling like I was having to do other people’s jobs, that I’ve just let a lot of it go ’cause I just don’t have room for it in my head. I’m just trying to get through day by day. But, oh, there’s just been so much.”

“And our children, like she says, face more problems in their life, they face more—they already changed my apartment because the neighbor bothered me a lot because my son yells. So there are so many problems we go through, that to be fighting for them to also have good health care is really frustrating. So I would like for there to be a change in that. That they take special needs children more into consideration.”

“And I mean, we’re dealing with enough already, and then to have to battle and deal with the bureaucracy and deal with incompetence and people just being overloaded, and not having the time or the patience to really research.... I’d say overall, it’s been a really emotionally traumatic and stressful 13 years, and I just really feel, again, for families that just don’t have the support or resources or whatever it takes to advocate for your child.”

“My son said to me, ‘Call me when my sister is dead.’”

Children’s conditions and the concentrated attention required to meet multiple needs deeply affect the family as a whole, especially “typical” siblings.

“I do have him in counseling because I know that he—the potential for him having more issues is probably increased a little bit more than kids that don’t grow up with a sibling that has so many needs.”

“People forget the impact on siblings so that’s why I allowed my son to go away [to boarding school].”

“My son goes to a teen sibling support group, but it’s not necessarily helpful because of the variety of special needs [represented by the siblings]. They don’t get what he goes through because their siblings have autism or CP. They don’t get it.”

“My son said to me, ‘Call me when my sister is dead.’”

Many families feel isolated and all families desperately want and need additional support for individual family members and the family as a whole.

[In reference to friends] “People don’t really understand what you’re going through and they don’t wanna listen to it.”

“I think that people—even educated ones—don’t know. They might know how to interact with others but don’t know how families feel when there’s a child with special needs. It doesn’t just change the child’s life; the mother and the father need to learn how to fight.”

“I haven’t dared to go to a library for the same reason. When he was little, we’d go, but when he got older and the tantrums started, I don’t dare go to a library, and it was a place where my daughter and I enjoyed going. In fact, we had a special day of the week reserved for the library, but since my son is like this, we don’t dare go to a library because we know that something’s going to happen.”

Theme 4 Race, Language and Income Barriers

All of these issues are compounded by additional challenges for families of color and those who do not speak English, have limited education, or are low income.

Language can pose barriers to understanding the diagnosis and treatment options, communicating with providers, applying for services and reaching out for support.

“For me, there was a woman translating for me... and the rest she gave to me written, explaining... because they’re going to examine his head. So there it explains to me everything they’re going to do to him, in more detail, but in English. And I didn’t understand anything. And it seems very professional to me that they do that, and they explain each thing, but I’m left in the same spot, because if I don’t look for someone to translate it for me, I’ll continue not knowing what they’re going to do to him. And that’s a big obstacle that also—that everyone, I think all of us are trying to learn English, but it is difficult to understand English in conversation, and now a written English with so many doctor things.”

“All of us are trying to learn English, but it is difficult to understand English in conversation, and now a written English with so many doctor things.”

“I’ve encountered times where I go and they don’t give me a translator. And I get nervous.”

“It has to do a lot with when the person knows English. Because I would get very frustrated.... I do understand English, but when it comes to having a conversation, I get stuck.... When he was little, my son would get sick a lot, so I would go to school and I had to leave because... I had to take care of my son.”

One of the most powerful ways in which education levels can contribute to parents’ challenges is by limiting access to information that is understandable and usable.

“There are a lot of doctors who do take [CSHCN patients] because they’re adults, but they’re actually not doctors who have worked with special needs.”

“Upon thinking about it and comparing, I notice that the people who have more education also achieve more things for their children. Aside from the fact they have better insurance. For example, our teacher, Joanna... her daughter is doing very well. I saw her at school; she’s advanced a lot. But she’s a well-prepared person who has really gone in depth with the topic and has found a lot of therapies; she’s found surgeries and everything because she’s always there, [advocating]. And a person who has the same problem, who has a son or daughter with the same problem as her, but didn’t know how to ask, and didn’t know how to be there looking for things is

going to be much lower.”

Income affects families’ experiences in many ways, including the types of health insurance families have, which can, in turn, influence access.

“I’m dealing with insurance, too, because there are a lot of places that don’t accept—that’s what I’ve been noticing, that when they’re 18 years and older, you struggle a lot because there are a lot of doctors who do take them because they’re adults, but they’re actually not doctors who have worked with special needs.”

Race and racism are powerful forces in all realms of society, including medicine and service delivery. Some parents experience provider bias and erroneous assumptions, which influences their trust in many health care providers.

“I didn’t know I was having a Down syndrome baby. Nine months pregnant.... When I was getting ready to have her, they said she wasn’t coming out.... So, they did the C-section, and the doctor was like ‘She’s T-21.’ I’m like, ‘What’s T-21?’ He looks over at me, and he says ‘She’s Down syndrome, so do you want to have your tubes tied?’”

“So the doctor calls me from [a hospital] and he says, ‘We’re going to have to put in a stent.... He may die, but we have to do this stent, and we have to do all this stuff. Do you want—I think you should just let him go...’ You have not even seen me and you’re automatically assuming that—you know. I said, ‘I have insurance.’ I said, ‘I’m a teacher.’ At the time, I was a principal. I said, ‘I’m a principal at Oakland Unified. My husband works for the stock exchange. He had double

coverage. What is the problem? Are you worried about getting paid?' That was the conversation I was having after having emergency C-section, and I felt like I wouldn't have been having that conversation if there weren't certain assumptions."

"One thing I will add to that is they categorize our children and say 'these' children."

Appendix

Table 1: Focus Group Composition

# of Groups	Role	Language	Race/Ethnicity	# in Group
2	Parents of children with chronic disabilities	English	All races/ethnicities	8
1	Parents of children with chronic disabilities	Spanish	Latino	4
2	Parents of children with multiple/on-going crises	English	All races/ethnicities	13
1	Parents of children with multiple/on-going crises	Spanish	Latino	3
1	Parents of children with chronic disabilities	English	African American	5
1	Parents of children with multiple/on-going crises	English	African American	6
1	Parents of young adults with special needs	Spanish	Latino	8
1	Parents of young adults with special needs	English	All races/ethnicities	5

General Methods

The focus groups lasted about 90 minutes each, with some lasting somewhat longer when parents had the time and interest in talking more. All participants were offered a \$25 gift certificate to a local major retail store for their time. Child care was provided when needed and food was available for participants during each focus group.

Protocols

The protocols for both the focus group and interview were grounded in the findings from a previous ethnographic study of eight families of children with serious chronic illness as well as a review of the literature on families' experiences with the health care system. The specific questions asked in

the focus groups reflected a core set of topics that were of interest across all groups. In addition to this core set of questions, additional questions were developed, tailored to the specific demographic characteristics of the parents and the acuity of the children's health. A core protocol was also developed for the semi-structured interviews of providers and policymakers. The questions, as well as the composition of the focus groups, were informed by suggestions received by the study's Advisory Committee.

Analysis

All focus groups and interviews were recorded according to protocols approved by the UCSF Committee on Human Research. Transcripts of these recordings² were analyzed utilizing a modified thematic network approach.³ After initial theme selection and coding through Atlas.ti software,⁴ additional manual content coding was performed to refine the automated coding. This was necessary primarily because of challenges with pattern matching between English and translated Spanish focus group findings. A "quote" is considered to be the unit of analysis in Atlas, and is similar to highlighting lines in a textbook. A "code" is a label or category assigned to quotes that allows researchers to retrieve certain passages or topics and manipulate and analyze the data. Focus group analyses were conducted cross-sectionally for each of the groupings and for the entire sample.

Additional details on sample selection and analysis are available from the author.

2 Six models for understanding how families experience the system of care for children with special health care needs: an ethnographic approach. Lucile Packard Foundation for Children's Health, Palo Alto, December 2012.

3 Attrid-Stirling Jennifer. Thematic networks: an analytic tool for qualitative research. *Qualitative Research* 1(3):385-405

4 Atlas.ti. Thomas Muhr Scientific Software Development, Berlin. 1997.

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2. Six models for understanding how families experience the system of care for children with special health care needs: an ethnographic approach. Lucile Packard Foundation for Children's Health, Palo Alto, December 2012.
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