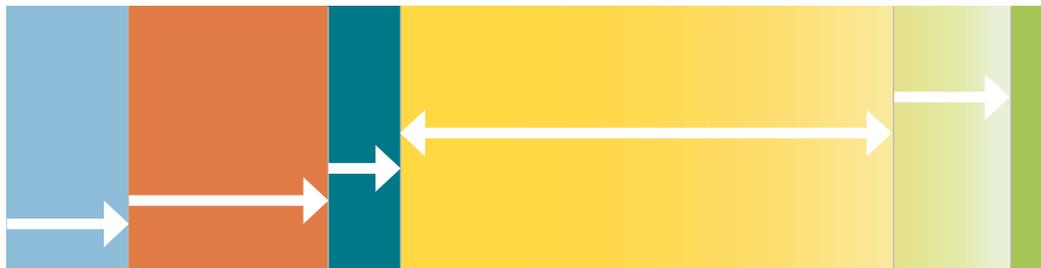


## Report

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# Reflections and Responses:

## Six Models for Understanding How Families Experience the System of Care for Children with Special Health Care Needs



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## Abstract

During the spring and summer of 2013, some 61 stakeholders—including 52 parents of children with special health care needs and nine providers and policymakers—were systematically interviewed for their responses to and reflections on six ethnographic models produced for the Lucile Packard Foundation for Children’s Health in 2009. Another 60 workshop participants at an academic meeting also provided input. The purpose of the models is to illustrate the experiences of patients and families as a means to support efforts to improve the system of care for children with special health care needs. The findings from this study strongly support the notion that the models have the potential to—if they haven’t already—contribute to achieving better understandings of these experiences.

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## Introduction

In 2009, the Lucile Packard Foundation for Children’s Health commissioned an ethnographic study of the experiences of families in obtaining care for their children with special health care needs.<sup>1</sup> While the multitude of challenges facing families of children with special health care needs is well documented,<sup>2</sup> this study is unique in that it sought to identify *patterns of experiences* through intensive observations and interviews of a small subset of families, through which information could be obtained to support the process of creating an enhanced system of care for children with special health care needs.

Among its many findings, the report identified a range of challenges within the context of sequential experiential stages, which the authors defined as:

- Just prior to and shortly after their child’s diagnosis;
- The period of initial intensive focus on treatment and the attention that is directed around identifying the most effective treatment;
- Subsequent transition from hospital-based care to having to piece together needed services in the community;
- Adjusting to a “new normal” in which virtually all aspects of family life, including routines, relationships, finances and priorities are new and different;
- Preparing the child for transition to adulthood; and
- The inevitable shock and devastation that accompanies the recognition of the lack of services available to their children as young adults.

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1 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, CA, December 2012

2 See, for example, The Child and Adolescent Health Measurement Initiative. Children with special health care needs: a profile of key issues in California. Lucile Packard Foundation for Children’s Health, Palo Alto, 2010

The authors found that each of these stages can bring forth labile emotional responses from individuals, parents, affected children and the family as a whole which, in turn, can affect health, well-being and functioning. Until this study, these emotions were often unacknowledged or unrecognized for their significance, and certainly not adequately addressed.

In addition to identifying and acknowledging normal—and predictable—emotional reactions associated with the process of learning about and learning to live with special health care needs, the study identified several major gaps between what families need in terms of medical care, social services and other supports and the resources that are available and accessible.

One example of the misalignment between needs and resources is at crucial transition times, such as from hospital to community and from childhood to adulthood, when services are needed not only to aid in the transition but also to meet ongoing health and social service needs post-transition. However, whereas needed services can be relatively plentiful within the hospital, for example, the availability of services within community settings is far more limited. Moreover, even when services are offered, families may not have access to them either because they are unaware of them or because the coordination required to manage multiple, complicated services and systems is beyond the families' capabilities and means.

The study also found that families cope with the individual and family emotional challenges differently, as they do with resource gaps and difficulties accessing services. According to the authors, family styles, which are characterized as *vulnerable*, *compliant*, *advocate* and *activist*, can influence the extent to which families are accepting—or even fearful—of the health care system, are active participants in decision-making around their child's care, or are advocates not just for their children but for others as well.

**This study is unique in that it sought to identify patterns of experiences through intensive observations and interviews of a small subset of families.**

Understanding the particular style of families can suggest the type and level of support they may require to best address their needs because, the researchers found, more actively engaged families tend to obtain the most resources. Finally, although families in the study described multiple challenges affecting nearly all aspects of their lives and those of their children, another commonality among the families was a sense of hope, not necessarily for a cure for their child, but that their overall situations would improve.

The goal of the ethnographic study was to gain a deeper understanding of the experiences of families of children with special health care needs by identifying commonalities and patterns that would allow the authors to characterize these experiences in the form of models. The models are intended to serve as characterizations of experiences—but not to represent a complete list of all possible experiences—as a vehicle for informing discussions and debates about how to better meet children's and families' needs.

According to the Foundation, early reactions to the models were positive, especially among physicians for whom the models provided new insights into how to better understand and anticipate families' emotional, social service and health care needs, as well as a framework for thinking about program and policy reforms. Inasmuch as the principal aim of this work was to document and understand families' experiences, its primary value lies in capturing, synthesizing and interpreting

these experiences for a range of audiences. As ethnographers, the authors did not systematically seek to identify needed clinical, program or policy responses to the issues they found; while some needed reforms are implied, this report is principally a framework for understanding families' experiences and is not a road map for addressing problems it reveals in the system of care for children with special health care needs.

**Early reactions to the models were positive, especially among physicians for whom the models provided new insights.**

The achievement of lasting improvements in the system of care for children with special health care needs is a major goal of the Lucile Packard Foundation for Children's Health; as such, the Foundation is interested in how the findings from this ethnographic report can inform system reforms. Toward this end, researchers from the Philip R. Lee Institute for Health Policy Studies at the University of California, San Francisco, brought this work to different audiences to seek their responses to these models and to consider how they may be used for addressing the various challenges they reveal. It was of particular interest to the Foundation to know how the models resonated with different audiences, having received comments primarily from physicians.

In order to obtain these different perspectives and suggestions for better addressing children's and families' needs, the authors conducted focus groups with parents of children with special health care needs, and interviews with physicians and policymakers. All study participants were asked to reflect upon their own experiences and observations, comment on the conceptual models developed by the ethnographers and offer their recommendations for addressing families' emotional, social service and medical needs. The purpose of this report is to present findings from these conversations in an effort to draw in additional perspectives and to formulate recommendations.

## Methodology

The purpose of this study was to obtain feedback on the ethnographic models by a range of audiences for whom the study findings could support the formation of recommendations to enhance the system of care for children with special health care needs, and to elicit recommendations based on the ethnographic study. The authors utilized two principal data collection methodologies tailored for different audiences: focus groups of parents of children with special health care needs and semi-structured interviews of providers and policymakers. (The initial study design called for focus groups of providers and policymakers in addition to parents, but significant recruitment challenges for the provider and policymaker focus groups required that we substitute telephone interviews.) In addition, the authors presented the ethnographers' models at a session of the annual meeting of the Pediatric Academic Society (PAS) in May 2013 during which the session participants were invited to provide feedback. The comments and suggestions from this session are incorporated into the findings below.

### Focus Groups

A total of 10 focus groups—including 52 parent participants—were conducted during the spring and early summer of 2013 in the San Francisco Bay Area. The authors sought diversity in language, race and ethnicity, children's age and children's conditions to capture known differences in experiences for each of these groups. Groups were stratified by children's conditions (those with multiple/ongoing conditions and those with chronic disabilities) and age (with two groups comprising parents of children who are older teens or young adults).

Groups were also composed of parents who primarily speak English and Spanish, groups of Latino parents only, African American parents only and all races and ethnicities. (See Table 1 in the Appendix for details on each group.) Participants were recruited with assistance from Family Resource Centers in San Francisco and Oakland, as well as through sample snowballing. 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.

### Interviewees

Nine interviews were conducted with well-known health care providers, researchers and program administrators during the summer of 2013. A list of those interviewed is presented in the Appendix in Table 2. Subjects for the semi-structured interviews were identified to reflect CCS Medical Directors, Regional Center Medical Directors, and physicians—both specialists and primary care doctors—and non-physician providers. The breadth of this sample was designed to tap into a range of professionals who have firsthand knowledge and experience with the process of—and challenges associated with—obtaining comprehensive services. The final sample was selected in conjunction with members of an Advisory Committee (Table 3 in the Appendix) for their knowledge of the issues and experience with children with special health care needs and their families. All interviews were conducted over the phone and each lasted approximately one hour.

## Protocols

The protocols for both the focus group and interview were grounded in the findings from the ethnographic report 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.

## Pediatric Academic Society

The ethnographic models were presented at the annual meeting of the Pediatric Academic Society (PAS) in Washington, DC, in May 2013. Of the approximately 50 participants, the majority were pediatric general and subspecialty physicians but also included were nurses, program managers and care coordinators/case managers. The workshop participants were invited to comment on each of the models from their various perspectives. The session was recorded, transcribed and analyzed. These results are incorporated into the presentation of findings below.

## Analysis

All focus groups and interviews were recorded according to protocols approved by the UCSF Committee on Human Research. Transcripts of these recordings were analyzed utilizing a modified thematic network approach.<sup>3</sup> After initial theme selection and coding through Atlas.ti software,<sup>4</sup> 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. Focus group analyses were conducted cross-sectionally for each of the groupings and for the entire sample. Similarly, analyses of interviews were conducted for each interviewee and for all interviewees collectively.

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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.

## Findings: Reflections and Responses

### General Responses to the Models

Overall, respondents were impressed by the work presented in the ethnographers' report and believe it to be an important contribution to the field. All with whom the authors spoke saw value in documenting, synthesizing and translating families' experiences into a format that can be understood and used by a wide range of audiences. The models acknowledge and point to the need for remedies at all levels of the system of care for children with special health care needs: from the content and delivery of clinical care, to the organization of service delivery and programs, to training and workforce composition to health care financing.

One of the major contributions cited by some was the potential for some of the models to serve as the basis upon which families, providers and policymakers can collectively discuss the challenges faced using similar language and the same points of reference. Some respondents offered that while there is utility in the models for all audiences, they may be of greatest value to policymakers who may not be familiar with the issues that families face; through the visual tools that the models employ and the straightforward messages that many of them deliver, they can provide a mechanism to educate important audiences, which can help facilitate the essential policy reforms that should be part of a comprehensive improvement package. Others were eager to take these to the next step—to quantify the concepts and transform them into models that offer providers practical tools for supporting their patients and families and better meeting their needs.

The models were especially appreciated for the attempt to communicate complex ideas in an uncomplicated fashion. Parents and providers both found portions of each model—if not the full model—to resonate with their experiences, though many could also find ways in which the models did not resonate or otherwise had suggestions about how they felt they could be improved. Reactions to the report also varied some, at least in part, by the perspective of the respondent relative to the families' experiences (e.g., family member vs. provider or policymaker) and training or practice type (primary care vs. specialty medicine). There were some differences among parents in

**The models were especially appreciated for the attempt to communicate complex ideas in an uncomplicated fashion.**

focus groups based on acuity and demographics, but these differences were generally matters of degrees of emphasis. There also was some variation in whether the parents had suggestions for expanding or elaborating upon the models.

One of the more consistent findings, particularly among parents but also among some providers and policymakers, was a difficulty appreciating the utility of using *models* to generalize the families' experiences. For those who objected to the use of models, the reaction generally was that there were simply too many exceptions to the rules. Sometimes the resistance related to a failure to understand why it was of value to try to generalize. While most parents understood conceptually the notion of the study findings as archetypes rather than all-encompassing descriptions of all families' experiences, many still felt that some of the models oversimplified what they undergo and face. "There's a lot a data available to tell you exactly the

horrible time parents like me have getting even basic services for our kids,” a father said. “I don’t get why you want to gloss it over with generalities.”

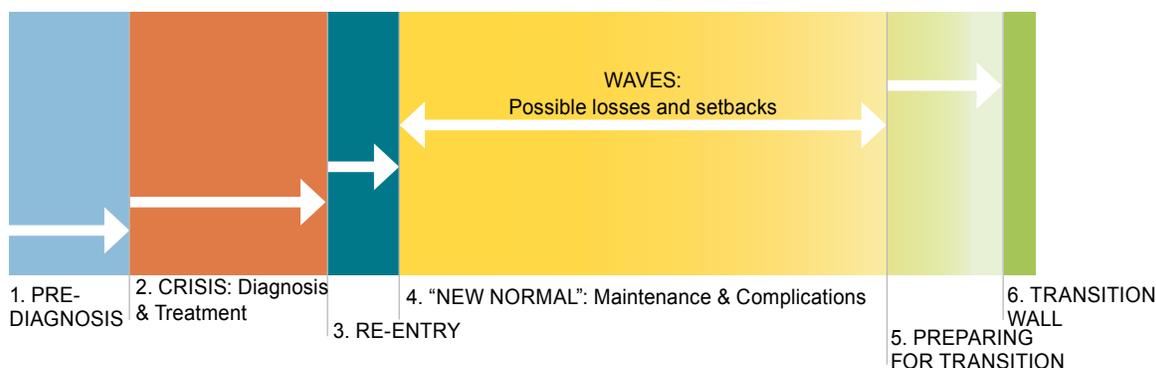
Parents remarked that they perceived several models as not adequately reflecting the complexities of their children’s conditions, the large number of providers and services that their children need, or the fact that their children’s health crises are often recurring and unpredictable. “I don’t really see our family in [the models],” one parent said, “because they don’t show how really difficult, you know, every day is for our whole family.” Another said, “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]. Where is that in the [study findings]?”

**Many parents felt that some of the models oversimplified what families undergo and face.**

Parents and some providers noted that the models imply a sequencing of experiences and relationships which are frequently parallel or circular. For a few providers and policymakers, this limited the applicability of the models because as they considered how to use the information to construct new processes or practices, they found more exceptions to the model than not. This wasn’t universal, however.

One physician interviewed indicated that the models tied together for him concepts and experiences that he has thought about for several years as a clinician and an administrator and they provided him with the tools to communicate his thoughts more effectively to local policymakers. As indicated, most providers (naturally) viewed the findings through the lens of their (professional) experiences and, as such, some found the models wanting. Community practice physicians, for example, found the models overly focused on hospital settings. One physician told us that the models should be more “medicalized” to be meaningful among clinicians.

Despite the many critiques offered by focus group respondents and interviewees, the response, on balance, was positive. With some modifications to the graphics and the narrative descriptions, most regard the models as useful tools. Specific suggested modifications are presented below as they relate to individual models.



## Model 1: The Stages of Patient and Family Experience

The first model, Stages of Patient and Family Experience, describes six stages that a child and family may move through as they live with a complex health condition. These stages include: pre-diagnosis; crisis (diagnosis and treatment); re-entry; “new normal” (maintenance and complications); preparing for transition; and transition wall. According to the ethnographers, these stages were consistently reported by the families in their study.

Among the parents and providers in this study, responses were relatively consistent as well: both groups described having either witnessed or experienced most if not all of these transitions and all found the model easy to understand.

Many physicians saw this model as a framework through which they can learn to better understand their patients, similar to Kubler Ross’s “Five Stages of Grief.” One physician reported that he showed it to a number of patients for their feedback—which was positive—and it served as a platform for discussing where the family saw their progression along the continuum. Some physicians also saw it as a useful tool for creating systems of care through mapping resource use and gaps, such as the general lack of support for families as children transition from inpatient to ambulatory setting—an area in need of additional attention and resources.

One common criticism among respondents was the implied linearity in this model (as well as in Model 2). Parents recognized the stages from their own lives, though for many the duration of specific stages was different than depicted in the graph, and most did not see the progression as linear as suggested, particularly parents of children with multiple conditions. Parents described the pre-diagnosis stage as sometimes lasting for years as their doctors searched to identify the condition. Others talked about stages of “new normal” that were quite bumpy. Unlike the families in the ethnographic study, many of the focus group parents felt that they never emerged from the “constant crisis and treatment mode.”

Several physicians offered that the stages rarely occur in such an orderly fashion as suggested in the graphic, particularly for children who are not chronically ill. Instead, children can experience re-crisis or new crises, which, in turn, can lead a family to re-enter at any stage back to the pre-diagnosis or crisis (diagnosis and treatment) stages—not retain them within the new normal stage as implied here. One physician said, “This is not a uni-directional process for families. Even after pre-

diagnosis, a crisis can happen at any point, leading the family back to the same ‘re-entry’ or ‘new normal’ issues.” Another physician suggested that mistakes in the original diagnosis and ongoing improvements in diagnostic tools also lead families to loop through the stages in multiple directions.

Regarding Model 1, a respondent said,

*“Take a kid with cardiac disease or a transplant, anything with a surgical correction. That surgical period, pre-surgical, post-surgical, and sometimes it’s several procedures or corrective stuff, that whole period is predictable and a crisis. That’s covered in this model.... That’s one thing, but the bigger thing is the unpredictable crises which govern a lot of kids’ lives. While often times, more often than not, many of these kids do not have diagnoses, have unclear diagnoses, and whether or not they do, are living in fear of the next crisis. While they’re in that new normal period, there’s the anticipation of the next crisis, not knowing when it’s going to come, knowing that it’s going to come, and it usually rears its head in terms of a hospitalization or a near-hospitalization.”*

Parents and physicians also questioned the implied assumption that medical and developmental conditions alone drive movement within and between these stages. Instead, movement (or lack thereof) can be related to other factors, such as a child’s age and other temporal changes. It is increasingly well-acknowledged (and reflected briefly in the model) that transitioning into adulthood is a major turning point for children with special needs, in large part because of the dearth of services available for adults, even young adults.

There are other major age-related transitions, such as starting school, moving to middle school and high school and graduation, as well as other temporal transitions such as school vacations at holiday time and in the summer. Each of these transitions involves changes to schedules, routines, providers and caregivers; the logistics of these changes, as well as any needed rescheduling of regular doctor visits, therapy appointments, etc., are just part of the adaptation. Every member of the family must also adjust emotionally as well. Though seemingly minor, all of these, too, can cause major upheaval for families.

Similarly, transitions between systems within childhood also can be traumatic for families. When responsibility for certain therapies shifts from the Regional Center to the school district as a child approaches school age, families often must make major adjustments to understand and adapt to the new system, as well as determine how to bridge new gaps in services that the school system doesn’t provide which the Regional Center did (or which continue to be unmet through either system).

Many parents and providers also noted that the transition to adulthood reflected in stages 5 and 6 involves many changes, including changes in insurance, providers, facilities, and the transfer of responsibility and authority from parent to the child. It was suggested that the study should more pointedly acknowledge the significance of this transition.<sup>5</sup>

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<sup>5</sup> It should be noted that the fact that it is not covered in more depth in the ethnographic study is not a reflection of a lack concern by the Lucile Packard Foundation for Children’s Health but rather a reflection of relatively young ages of the children in the study, which meant that this transition was not yet a pressing issue for these families.

When asked about the best approaches to addressing families' needs throughout the stages as well as during transitions, parents and providers both stressed that supporting families within and between the stages needed to be tailored to individual family needs and circumstances, rather than “cookie cutter” policies or programs designed for a standardized patient or family. Moreover, effective responses must also recognize that needs and circumstances can change rapidly and almost always evolve over time. Parents and providers pointed to the importance of periodic needs assessments as a means to understand point-in-time situations as well as to gather information to project future needs.

There was, however, a lack of consensus, particularly among the providers interviewed, as to with whom responsibility for ongoing needs assessment and subsequent coordination should reside. Most agreed that the ideal is for this responsibility to rest with the primary care physician (PCP). As part of his/her role as the primary care provider, the PCP should be knowledgeable about the child's (and family's) full needs, as well as the range of specialists and other providers from whom the child is receiving care. The PCP also may be paid under some insurance plans to serve as a “gatekeeper,”

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which from a definitional perspective should include the role of care coordinator.<sup>6</sup> However, it was also noted that too many children with special health care needs don't regularly see a PCP both because many PCPs don't feel equipped to address the needs of children with complex medical conditions, even for their primary care, and because such children spend so much time with specialists.

Ensuring sufficient reimbursement to support ongoing needs assessment and care coordination, whoever is responsible, was identified as a necessity if this recommendation is to become a reality. As one doctor pointed out, thorough assessments of children with complex conditions take a lot of time. He finds that he must allocate three

hours per patient per visit, including one hour of preparation, a one-hour appointment and one hour to wrap up, follow up and communicate with other providers. He works in a setting that covers his time for this degree of assessment; most physicians do not and therefore cannot afford such thorough assessments and follow-through.

Assessing families' needs is a crucial component of this process, as is communication. Parents and providers commented on and offered suggestions related to communication between physicians and families. For parents, communication about their child's diagnosis, treatment and prognosis—or lack thereof—is a central concern. None of the parents interviewed through focus groups felt satisfied with the amount of and way in which they received essential information about their child. They felt that they received either too little information, too much, or incomprehensible data that they didn't know how to use.

Parents commented, and some providers independently also offered, that the amount of information and the manner in which it is delivered is family-specific. Some people cope by immersing themselves in details; others are overwhelmed by lots of information provided at the same time. One provider said that his/her approach is to have the team gauge where the family is in terms of

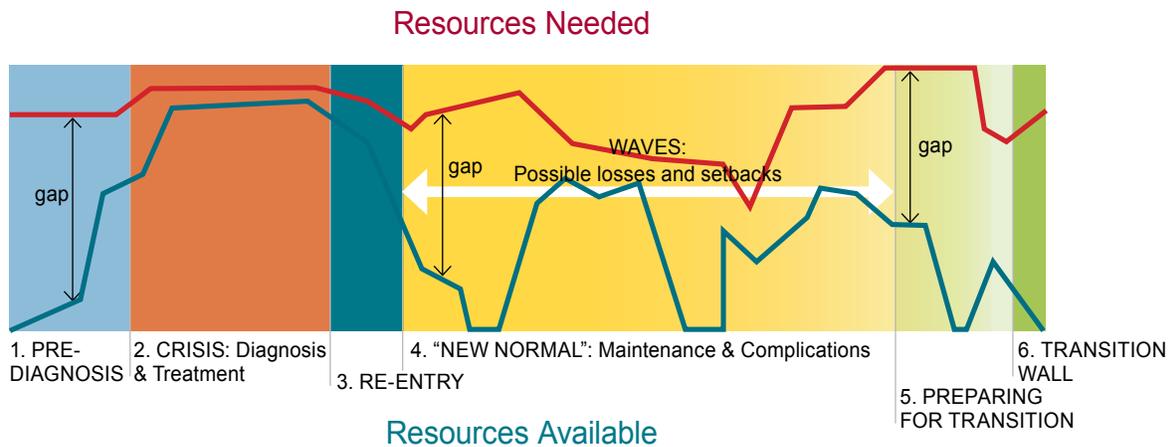
<sup>6</sup> Bodenheimer T, Lo B, Casalino L. Primary care physicians should be coordinators, not gatekeepers. *JAMA*. 1999 Jun 2; 281(21):2045-9

information-sharing. While they would never withhold information from a family, they do respect each family's communication style, checking back periodically as needs and desire for information shift. "The correct amount will depend on the family," another physician said, "and where they are in the stages of their experience with the child's illness."

Communication between providers was also noted as a concern. Several parents commented that they frequently have to piece together information from different specialists and frequently served as the conduit of information between specialists since, according to the parents, most physicians were only familiar with that part of their child's condition that related to each physician's specialty and didn't have a full picture of their child's health. Similarly, parents described having to continually update physicians on the testing and treatment course directed by others physicians. The responsibility they assumed for communicating key medical information to clinicians was described by the parents as an enormous emotional and logistical burden. A parent explained,

*"I carry notes and records whenever we see the specialists... because they, I don't believe they 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."*

Parents and providers also pointed to the importance of non-language communication methods and cues. When a physician is fixed on the computer screen, s/he can't look at the family, which affects the quality of communication as well as trust. This was underscored by a physician who described how the Electronic Medical Record (EMR) can make it easy to organize and print information and keep records, but that its use can remove the physician's attention from the patient to the computer screen at the cost of missing visual cues to the family's state of being. "It's vital for physicians to be cognizant of families' mental states because information that was given in the last appointment may not have been remembered or interpreted as intended," this doctor said.



## Model 2: Resource Needs and Availability

The second model, Resource Needs and Availability, builds on the Stages of Patient and Family Experience model, overlaying on the stages an estimation of when during these stages resources are needed and what is generally available. In this way, the model shows when there may be substantial gaps between resources a child and family need and the resources that are available and provided.

In that Model 2 is built on Model 1, it has the same strengths and potential areas for improvement, according to respondents. Like the first model, it is considered easy to understand and interpret. Like the first, this model conveys a message that parents and providers agreed is correct: families must make significant adjustments throughout the childhood of their special needs child. Model 2 illustrates that there is a serious misalignment between children's and families' needs and available *and* accessible resources, especially at certain stages and especially when children are not hospitalized.

However, similar to a critique of Model 1, some respondents pointed out that Model 2 applies only to patients whose crises are predictable: generally patients with one or two conditions or a chronic condition. From this perspective, the model's references to resources, both needed and available, related only to children with predictable conditions, rather than children with special health care needs more generally. It was suggested that the model should at least acknowledge the added medical and service complexities for many children by categorizing crises:

- Predictable crisis—This category covers children with a condition that requires surgery (one or more) and the aftermath, such as cardiac surgery, liver transplant, leukemia, etc. Models 1 and 2 apply to this group.
- Unpredictable crises—The group of children who do not have a diagnosis or have unclear diagnosis and live in fear of next crisis. For these children and their families, the threat of an impending, unpredictable crisis governs their lives. The “new normal” in these cases is less about “maintenance and complications” than finding ways to adapt to anticipating the next crisis.
- Progressively debilitating illness—This group includes children who need palliative care and for whom each crisis can mean death. (Examples of conditions in this category are Rhett syndrome, cystic fibrosis, Spinal Muscular Atrophy.)

This model does, however, point to variability in resources that is correctable with policy change and system redesign. One provider offered a specific example of how such resource gaps can affect use of needed services. Through a study he is currently conducting on service use variations for the same diagnoses, he found wide variation in hospitalizations for dehydration among children with severe developmental disorders, for whom the standard of care is outpatient treatment. In those communities with high rates of hospitalization, the availability of needed outpatient care is severely restricted. This leads to preventable hospitalizations, increased trauma for families, inappropriate use of limited resources and higher costs. Such resource gaps are implied in this model and with further study can be documented and addressed.

While the gaps represented in this model are real, the inability of parents to obtain needed services for their children is not always related to availability, *per se*. Many respondents remarked that they interpreted the model to suggest that availability or presence of resources was the same as access to them, and that the primary key to reducing the gap was integration of services. Respondents repeatedly stated that the gap between needed resources and use is the result of a host of factors, including, but not limited to, service fragmentation.

Parents discussed at length barriers to care related to fragmentation that left them with the responsibility to research, enroll, organize and coordinate most if not all of the medical, ancillary, social and educational services that their children need. While formidable, these are not the only challenges they face in obtaining needed care for their children. In addition, they face financial and insurance-related barriers, as well as non-financial barriers such as lack of transportation and/or child care, language barriers, inability to take off work, lack of knowledge about services, etc.

**Focus group parents not only were forced to “fend for [themselves]” but also described having to “coordinate the care coordinators.”**

Ensuring the availability of services that are well integrated is seen as key to closing the gap between needed resources and utilization, but it is only part of the remedy. Parents also must be relieved of the burden of serving as the chief advocate, which requires that the full complement of needed services be known and readily available to families, with easy, if not automatic or at least standardized eligibility criteria and enrollment processes.

In the absence of full integration of services, parents and providers identified care coordinators as the critical link to needed resources. In ideal situations, care coordinators support families by identifying services and other resources and supports, assisting families through complex application processes, arranging essential logistical support such as transportation, coordinating the multitude of services that many children need, and even communicating among various providers.

In general, families described how there are far too few care coordinators available and those who are funded tend to be associated with a single program or resource and don't have the knowledge or scope of practice to link families to the full range of needed care. This is borne out consistently in the literature in which the need for universally available, high-quality care coordination that is responsive to parents' needs is identified as a high priority among parents, advocates and providers.<sup>7</sup>

<sup>7</sup> See, for example, California Advocacy Network for Children with Special Health Care Needs survey findings. Lucile Packard Foundation for Children's Health. Palo Alto, CA. August 2012; American Academy of Pediatrics, 2002; Antonelli R. C., Stille C. J., and Freeman L. Enhancing collaboration between primary and subspecialty providers for children and youth with special health

Focus group parents not only were forced to “fend for [themselves]” but also described having to “coordinate the care coordinators.”

Another form of support for families mentioned by respondents is patient navigators. In an elaboration of her/his interview responses, one physician wrote, “The role of the navigation guide or concierge would involve understanding the families and their concerns as well as understanding the system’s capacities. More often than not, small glitches in the system pose major barriers, and it is difficult for families to try to change them. It is also difficult for health care providers. On the other hand, the navigation guide or concierge may be in the best position to use their experiences to help train the families and also to attempt to modify the system.” This respondent also offered the following:

*“I believe it is too challenging for families to try to navigate the system; the onus should not be on the families but really on a navigation guide or concierge, whether this is someone from the insurance organization or the health care organization. Even the most experienced and resourceful families just get exhausted repeating the navigation over and over again, in part because the system is both complex and also ever-changing. At the same time, it is helpful to train families to become less dependent over time, so that there is growth.”*

Barriers to needed care created through rigid program eligibility criteria emerged as another recurring theme among parents and some providers. Eligibility rules governing program participation are necessary, it is acknowledged, particularly in the context of limited resources. However, inasmuch as eligibility criteria are generally designed to exclude participants rather than to be inclusive, both the criteria and the application processes tend to make it more difficult than easy to enroll.

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

Moreover, because programs and services generally result from political processes rather than rational planning and needs assessments, requirements for different programs frequently differ and can even conflict. As perceived needs and priorities shift, so can program content and eligibility criteria. The result is a dizzying array of eligibility rules and requirements that place an enormous burden on families to research and comprehend, as well as a huge challenge to complete the extremely complex enrollment processes. The problem is compounded when official definitions of conditions change, since this can change eligibility rules too.

A recent example cited is the change in the Diagnostic and Statistical Manual of Mental Disorders (DSM) definition of autism spectrum disorder that led to changes in program eligibility and caused confusion for patients and providers alike as to who was eligible for what. (The person making this comment underscored that it was not intended to imply that such changes shouldn’t be made when appropriate but rather that this particular redefinition illustrates the power of program eligibility in

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care needs. *Georgetown University Center for Child and Human Development*, Washington, D.C. 2005; Wise P. H., Huffman L. C., and Brat G. A critical analysis of care coordination strategies for children with special health care needs. *Agency for Healthcare Research and Quality*, Rockville, MD: 2007, No. 07-0054.

affecting access.) The result is restrictive, conflicting and ever-changing eligibility criteria that not only limit participation to (often narrowly) defined groups but that can impede access for those who are eligible because of confusing and complicated enrollment processes.

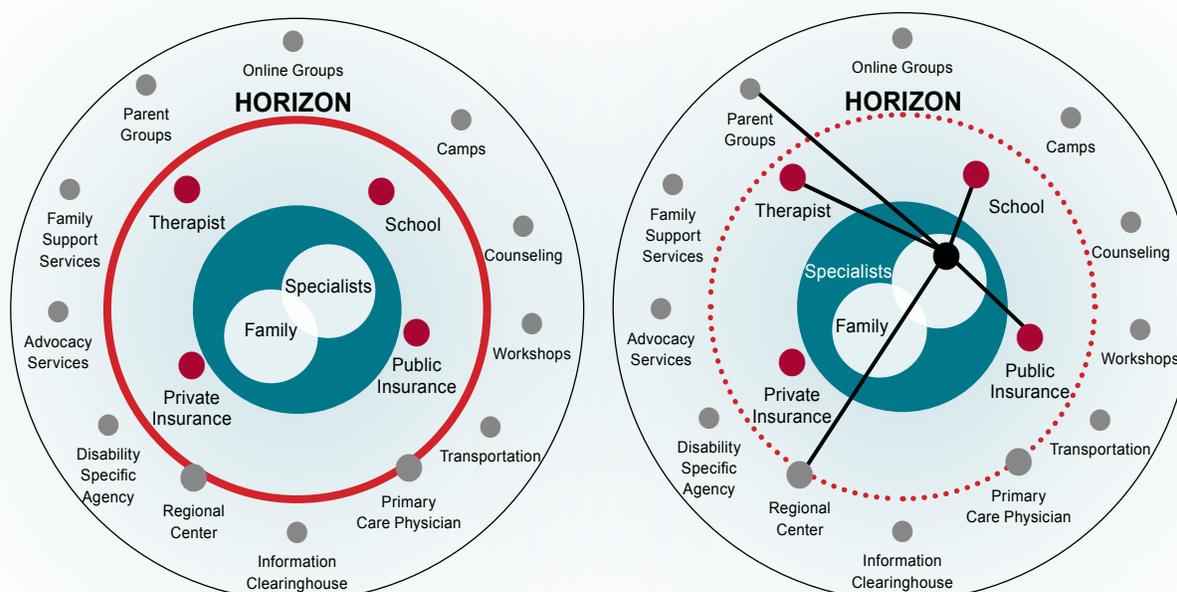
One physician explained:

*“Program funders use eligibility [criteria] as a mechanism to ensure that their resources reach the intended population but we [administrators and providers] are frustrated by checking for and staying within those eligibility lines. More time can be spent checking for eligibility than providing actual services.”*

One dimension of families’ experiences not captured in this model is the effects of race/ethnicity and language on the gap between resource needs and availability. For families of color and non-English-speaking families, the gaps depicted in this model are often even wider, exacerbated by a paucity of providers who speak their language and share their cultural approaches to health.

Parents remarked that they often prefer to utilize providers “who look like [them]” because they are more likely to trust and feel comfortable with providers from their community. However, when providers “who look like [them]” are not available, families must turn to others who may communicate less effectively and do not always gain the trust of the families. The gaps are especially wide when parents are unable to communicate effectively with providers because no one speaks the families’ primary language. Translation services are sometimes available to help, but these too are not widespread and often are inadequately staffed with personnel who can translate medical terminology. A provider elaborated on the gaps and challenges related to language. S/he said:

*“And I’ll throw another thing in which is very important in the demographics of the state of the nation, which is actually limited English proficiency, and in my world, limited health literacy, which are measurable constructs. There are people who just because of their limited language or literacy skills have a much more difficult time navigating the system, so particularly if it’s a single parent who everything depends on them, and they have limited English skills or limited literacy skills. Forget it, you know, asking them to follow up on three appointments and make these calls and dose this medication based on some other variable. That’s a bigger struggle. They’re going to need a lot more home-nursing support.”*



### Model 3: Perspective on Resources

Model 3, Perspective on Resources, illustrates how patients and families view and gain access to the resources that are available to assist their child. It is designed to illustrate the ethnographic study finding that families are aware of only those service providers with whom their child's illness has brought them into direct contact. For example, for families who have a child under the care of specialists, even the child's primary care provider may not be within their "horizon" and may not be considered a core health care provider. Of note, this model is not intended to present the ideal but rather what families in the original study reported to the researchers.

This model resonated with most respondents as a general concept. The notion that parents' view of services and their availability is limited by those with whom they are in direct contact is intuitive. However, many also expressed that the effort to characterize the families' perspectives on resources within a model oversimplified these perceptions. On the one hand, some respondents said that it is of course true that in a fragmented "non-system," in which primary responsibility for identifying and obtaining services is that of families and caregivers, parents are aware of only that of which they are aware.

On the other hand, some argued that there is considerable variability among parents in terms of what they perceive as available. The child's age, the county and community within which they live, the school the child attends and the family's relationship with other families with children with special needs all significantly affect perceptions of resources. How "close" a family is to their primary care provider or specialists varies significantly depending on the child's diagnosis, condition severity, and the family's relationships with their clinicians. Experiences and perceptions can vary widely even within the same diagnosis. As one respondent explained, the same illness can play out differently for different families depending on their economic and social resources. Provider behavior can also influence this process, as the length of time a provider spends with the family can directly affect trust and thus the provider's relative position within the diagram. Since some of these factors can change, a family's access to and perspective on resources is more fluid than the concentric circles imply.

Several respondents raised concerns that the model didn't adequately depict the complexity of the relationships even inside the innermost circle. It was raised, for example, that many specialists don't communicate well with one another or with parents; parents' perceptions of these different players is sometimes altered by which specialist is most dominant or whom the child sees most frequently at any given time. Another respondent spoke to the issue of continuity among specialists beyond communication, which is not reflected here. Most specialty care takes place at academic hospitals where young specialists tend to disappear after a fellowship, for example, making continuity of providers an issue for families who depend on consistency in order to establish trusted relationships with providers.

**What differed, however, were the views expressed as to what care coordination constituted and who was to perform it.**

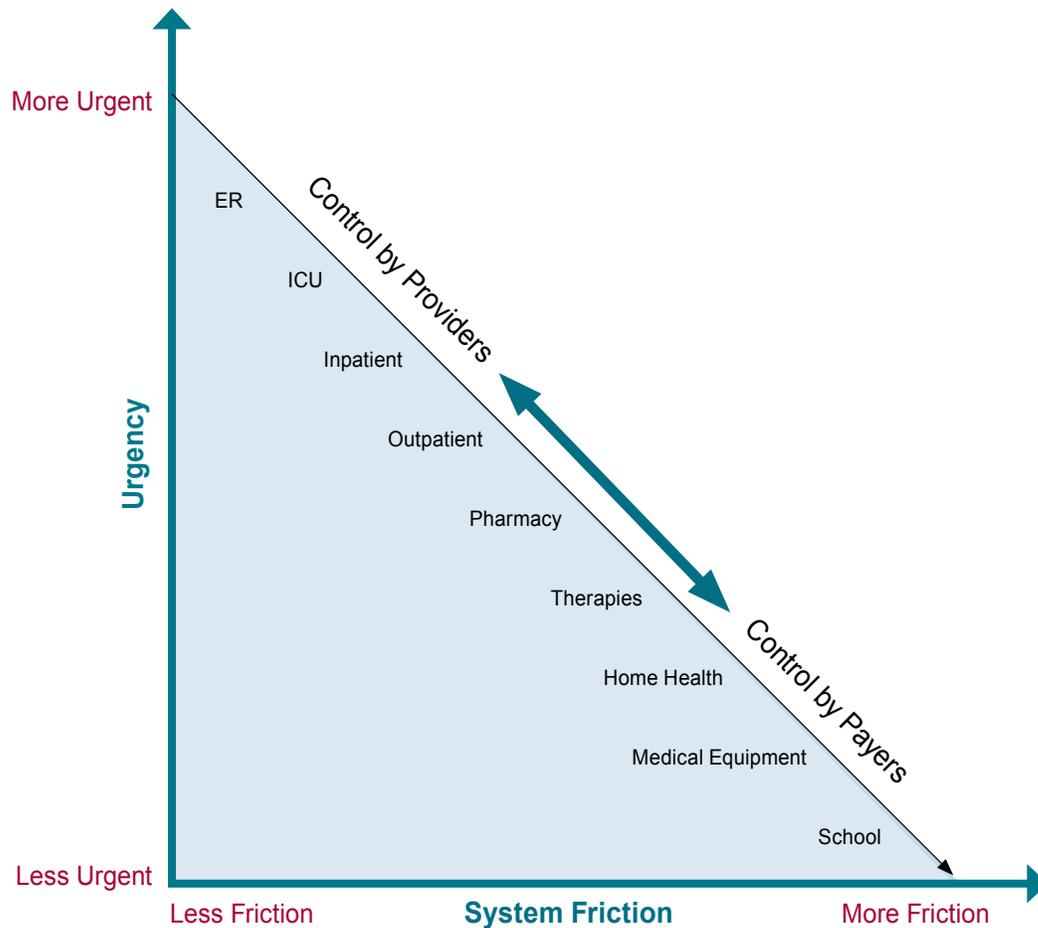
The topic of care coordination as the glue that expands parents' perceptions of what is available, facilitates access to those services, communicates between providers and programs and otherwise creates seamlessness for families was raised by all respondents. What differed, however, were the views expressed as to what care coordination constituted and who was to perform it. Parents described how they sometimes had care coordinators but the scope of their knowledge and practice is often too narrow to meet their needs. One parent said, "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 person did was hook me up with them. They didn't take me through any of the medical processes that might have to happen."

Most physicians saw the primary need for care coordination as between PCPs and specialists, though all recognized that coordination with other providers and services is also essential. The majority of physicians interviewed asserted that care coordination is best performed through teams based with the PCP as a critical component of an advanced medical home. In support of the team approach, one physician offered that in his/her experience, parents feel more comfortable speaking with a social worker or case manager than with a physician. (A few parents concurred, indicating that they prefer to speak with nurse practitioners because they are more available and tend to speak in "a more accessible way.")

**Several parents commented that referrals from other parents is one of the most effective resources they have.** The description of care coordination offered by the physician respondents generally supported the definition of "high performing care coordination for children" offered by Antonelli et al,<sup>8</sup> though it was perhaps less encompassing. These respondents described care coordination as ideally entailing scheduling appointments, collecting and consolidating the perspectives of each specialist as to the child's goals and treatment plans, family education and referrals regarding ancillary services and supports, assistance to families in contacting additional services and providers and applying for same, and communication among all the child's providers on critical clinical issues (e.g., changes in medications). They also said that care coordination should be a reimbursed service.

<sup>8</sup> "Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes." Antonelli R, McAllister JM and Popp J. Making care coordination a critical component of the pediatric health system: a multidisciplinary framework. *Commonwealth Fund*. May 2009.

Several parents commented that the location of parent resources in this graph did not resonate with their experience. Instead, information and referrals from other parents is one of the most effective resources they have. One parent said, “Yeah, I didn’t know about the nursing respite until a year or so ago, and that was through another family. Our caseworker through the Regional Center should have told us about it and didn’t.” Another parent offered, “I have to say the way I find out about benefits and things that would benefit [my daughter], things that she’s eligible for, is through other parents.”



### Model 4: System Friction

The fourth model, System Friction, is intended to illustrate the increasing difficulties that children and families have in obtaining needed services as the urgency of service needs decreases. The notion is that services that address urgent conditions, particularly those that are life threatening, are most readily obtained and present the least amount of friction to the family. Less urgent conditions, such as those that are met in outpatient settings like specialty care and some forms of therapy, are generally more difficult to obtain, reflecting a greater degree of friction.

The concept of system friction, in general, and this depiction of how it operates in the context of children with special health care needs specifically, resonated with most respondents. The dichotomy between the relative ease of acquiring services within the hospital setting compared to the community and outpatient setting rang true for virtually everyone. Parents recounted their numerous experiences feeling relatively well served in the hospital but feeling uninformed, unconnected and isolated once their children were discharged and sole responsibility for care rested with them. “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.”

The physicians agreed, whether they were hospital-based or community-based: that which is in the locus of an individual physician's control is significantly greater for inpatients than outpatients, including access to testing and procedures, treatment, and specialty consultations, as well as social services, physical and speech therapy, and referrals. The model especially resonated with outpatient providers, however. One physician said:

*“And particularly those of us like me who work mainly in the outpatient and community settings really get it and really appreciate it. And we really appreciate this being emphasized when our hospital-based colleagues are in the room. What do I mean by that? There are a lot of people—many people who are responsible for operating the system of care who are hospital-based people... but they're not as acutely aware of this fact of how families really experience their chronic illness. They see these kids in the hospital. They see all the medical complexity. They're really caring people. They understand that there's social complexity, generally, but they don't understand this lower right-hand corner [of the model], and what really happens, which is that when they're in the hospital and they order physical therapy or a teacher to come by or even durable medical equipment, it gets taken care of, and a delay in the hospital for it to be taken care of might be a day or two, and that would be a very frustrating delay for the people who live in the upper left-hand corner.*

*“But for most of us who are outpatient providers and for all the families who are experiencing this, most of the days of their lives are spent in that lower right-hand corner, who are even on the right half of this graph struggling to get this stuff done. And they are rightfully frustrated, not just with the schools and the durable medical equipment people, but with me, the outpatient people who need to fill out the third sheet of paper that needs to be faxed.”*

The gap between “hospital and home” in terms of attention, access and support for families, and authority and control by physicians is fundamentally a system problem, as parents pointed out, because families never really have “control” whether in the hospital or at home. What changes is the perception by the system that “care is done” after the child is discharged, according to parents. Some physicians agreed, particularly in the current context of growing popularity of hospitalists whose role does end at discharge.

As one physician put it: “Everybody knows it's a horrible transition, hospital to home. But it's, again, it's usually spoken out of the mouth of the hospitalist. They get it. They get it's not ideal, but when they think of home, you're right. They don't think of that whole—they don't think of it as a continuum off to the right. They just think of it of this big black box of the outpatient world.”

The principal critique of this model relates to the concept of urgency as the principal driver of the friction. As one mother stated, “Urgency is relative. This is urgent to who? The family? The doctor?” Another said: “Parents can feel just as urgent in outpatient setting when we can't get services for 6 or 9 months.” One physician independently offered a similar perspective, commenting

that from the family’s perspective, items on the “less urgent” portion of the diagram may be very urgent to them. Another remarked, “What about the ‘non-urgent’ patient who uses the emergency room? Where does that fit in this graph?”

For these respondents, “urgency” is just one of many variables that contribute to degrees of “system friction.” The model itself points to one of these variables: payer responsiveness. In fact, one respondent commented how this model shows the “hidden” and “dysfunctional” payer system that rewards acute care but doesn’t pay well for care that supports children’s stabilization and supports the whole child—and produces the conditions that recreate sufficient “urgency” to obtain needed care.

One physician gave the example of a 21-year-old patient who cannot access an adult wheelchair until he has been assigned an adult physical therapist. In the absence of a therapy or equipment, this patient’s condition worsened such that he was forced back into the hospital, causing undue trauma and pain for the patient and his family and unnecessary additional costs.

Families also noticed the role of payment as the driver of this friction. “I know I don’t have to worry about paying for my kid’s care, you know, when she’s in the hospital,” one mother said. “Even before we got Medi-Cal, it was like the [hospital] was okay with us being there ’cause they knew they could get her in the program and they’d be paid. This doesn’t happen outside of the hospital, you know? Well, there the first question is, what insurance do you have?”

Another described how her child was “bounced around” between different community programs after discharge until one would accept her daughter for physical therapy and speech therapy. “No one wanted her, OK, because she needs a lot of therapy. So they would do a lot of assessments and tell us she wasn’t eligible but we could go to [another program.] It took almost a year to find a good program for her that would take her.”

Another variable that was noted as contributing to this friction is communication, particularly overly complicated and poorly coordinated communication in the outpatient setting, in contrast to increasingly digitalized communication in the inpatient setting. The differences in the dominant modes of communication between the right and left portions of diagram are striking: whereas the left side of the graph utilizes more electronic modes of communication based on Electronic Medical Records (EMR), the right side of the graph utilizes older technology such as faxes and phones, in large part because of its dependence on paper records.

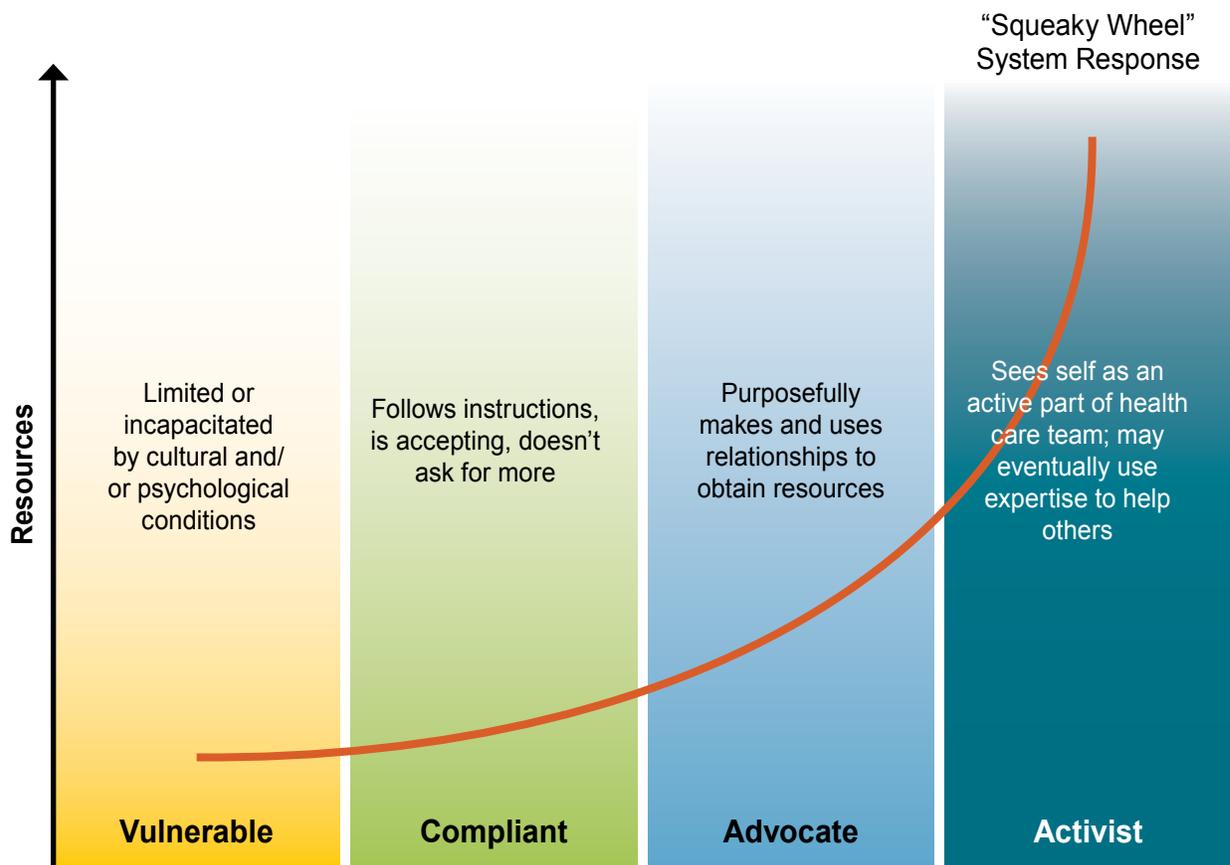
The multilayered maze of communication through faxes, EMR, email, and phone calls make coherent and efficient communication between the PCP and hospitalist difficult, at best. The 20th century technology that dominates outpatient, community-based communication is slow, inefficient and prone to errors—and a very real source of the system friction.

One physician described communication options in the right portion of the model as “agonizing.” Another physician added, “You spend a couple days in any clinic around here, and you’ll be scared

**One physician added, “You spend a couple days in any clinic around here, and you’ll be scared for your family. It’s just ridiculous. Just piles of paper need to be faxed back and forth upon which people are depending for their, you know, home oxygen, getting the kids ready for school. I mean, all the, like, really critical day-to-day stuff.”**

for your family. It's just ridiculous. Just piles of paper need to be faxed back and forth upon which people are depending for their, you know, home oxygen, getting the kids ready for school. I mean, all the, like, really critical day-to-day stuff." These physicians argued strongly that digital vs. facsimile communication be added as another dichotomy to the diagram, parallel to providers vs. payers.

Several physicians offered that the "good news" is that these are systems-related problems that can be addressed through payment reforms. One physician argued for capitation and salaries for physicians to realign financial incentives. Another suggested a "step-down" service for the first month out of discharge during which the hospital remains responsible for the child's care. Still another thought that comprehensive, high-quality, adequately reimbursed care coordination is the answer. While there was no consensus on the remedy, there was agreement that "we have to think of a way to address this gap."



## Model 5: Family-System Interaction

The fifth model, Family-System Interaction, presents the ethnographers' description of families' different "styles" as they interact with the medical and service systems. These styles range from *vulnerable* ("limited or incapacitated by cultural and/or psychological conditions") to *compliant* ("follows instructions, is accepting, doesn't ask for more") to *advocate* ("purposefully makes and uses relationships to obtain resources") to *activist* ("sees self as an active part of the health care team; may eventually use expertise to help others"). The authors note that "many families move back and forth between models, depending on their changing circumstances and the support services they receive."

This model generated some of the strongest reactions among the study participants. It is possibly the most controversial of all models and generated considerable comments and criticism from families, providers and policymakers alike. Virtually all understood conceptually what was trying to be conveyed but respondents' acceptance of the accuracy and value of the message varied.

Generally, the physicians and policymakers interviewed felt that the family-system interaction is far more complex and nuanced than this model communicates. They had a number of comments about the model including one remark that pointed to the fact that unlike many of the other models, which focus on inpatient settings, this one applies primarily outside of the hospital (because, as the previous model illustrates, system friction is relatively low when children are hospitalized). This respondent felt that

**This model generated some of the strongest reactions among the study participants.**

this distinction was important to the interpretation. In more than one way, the model was described as more “subjective” than “analytical.”

For example, a few respondents indicated that they found the model to be overly *provider-centric* and that it fails to include the perspective of families. “This shows the language of the health care system and providers and excludes the family voice,” one physician commented. Physicians felt that families’ “styles” are never stagnant, but move between these categories as their child’s state of health or age changes, and the family’s relationship with their providers and their familiarity with the system shift and grows. Another provider put it this way:

*“For clinicians who live in that world, we kind of forget that because we’re living in it day to day. And then we try to have a care conference or inform the family, or we’re doing what we’re told we’re supposed to be doing in terms of family-centered care, and we meet a family who doesn’t seem to us to be engaged, and we forget that we weren’t there 48 hours ago when this child was being intubated in the emergency room, and these families are still experiencing—or, I don’t know, four weeks ago—and the families are still sort of experiencing some level of PTSD, and that it’s really hard for them to engage.*

*“It doesn’t make them vulnerable. They’re just—maybe a good word might be—I’m just playing around with words—traumatized, you know. And that’s that time-crisis mode to it, and again coming back to that first model, the anticipation and fear of the next crisis that tends to cause us to be a little closed.”*

It was also suggested that the model may altogether have missed the mark. One provider remarked that “there are no quiet parents.” Rather, a family’s behavior, or lack of “squeakiness,” may be explained by a generational norm, education level, or cultural background. For some cultures it is disrespectful to be assertive with a doctor, look them in the eye, or ask questions. One physician stated that in San Francisco, 50% of babies born are of immigrant parents, so he has directly observed parents struggle to “loosen up” to ask him questions. For this reason, community organizations like Support for Families were praised for the empowerment they give to families. Moreover, according to physician interviewees, trust plays a significant role in determining families’ interaction with the system and providers. Some families who may be interpreted as vulnerable, for example, simply just may not trust doctors. One physician commented that trust is “difficult to build but easy to destroy.”

Finally, some providers and policymakers asked about the purpose of the model and whether it contributed constructively to conversations among a range of audiences the way that most of the other models did. Other respondents also raised this question about the value and utility of this model.

Critiques of the model from parents were even more pointed. Many parents also considered some of the characterizations of parents as “condescending,” “judgmental” and “accusatory.” Parents had the most difficulty with the terms “compliant” and “vulnerable” because they felt the words equate to obedient, weak, and childlike. The use of these terms to characterize parents fails to take into

account both cultural norms and lack of trust in the system that many families experience, which the researchers interpreted as compliance and weakness.

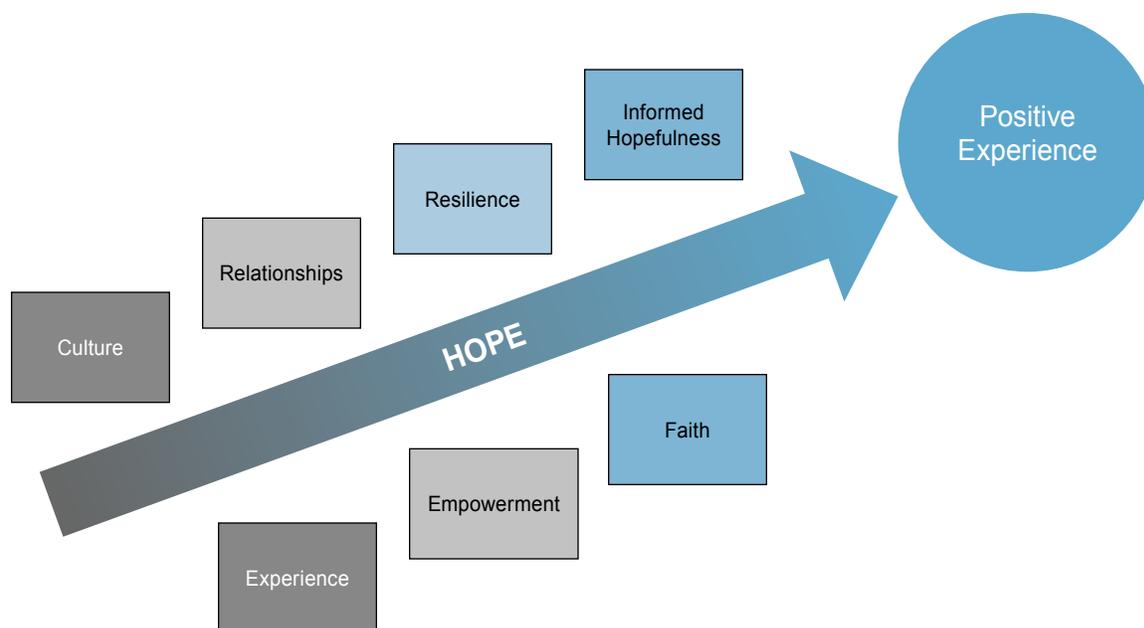
In the view of parents, the terms also apply negative connotations to the legitimate fear and true defenselessness that many parents feel at different times during the stages of patient and family experiences depicted in Model 1. Many parents were also offended by the terms “advocate” and “activist” as these sometimes have negative associations (although the narrative didn’t assign such associations). Assertiveness is seen by some in the health care field as aggressiveness and pushiness, as opposed to appropriate levels of insistence that are required to ensure that one’s child’s needs are met (even though Model 2 demonstrates this). Many parents described not just having to manage their children’s care but having to fight for it. Indeed, it is the parents who are the best if not the only repository of critical information about their children’s health. Parents sleep overnight in the hospital to ensure that shift nurses and others have the latest information about tests and medications. A parent told the focus group:

*“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.’”*

Parents frequently can most accurately interpret what is occurring in the middle of a crisis. One parent reported on such an instance: “For me, just the last emergency room visit we had a couple of months ago, the emergency room doctor, who was in charge of the emergency room, told me that [my daughter] was still seizing...I said, ‘She’s not seizing. Look at her. She’s not seizing any more.’”

Many parents found the graphic devoid of their perspective. Parents described how their approach to the system and to providers varied over time depending on the health status of their children and how well the system and providers met their needs. Virtually all parents said that they could recall feeling vulnerable or acting dependent on the health care system at times when they were overwhelmed with grief or fear or faced with challenges getting their child’s needs met. Many said that at times they have also been more assertive out of necessity, generally when faced with a sick child and an unresponsive system. These same families can also quickly become “vulnerable” with the next crisis or setback. All of these are appropriate and normal behaviors, they said, and should not be stigmatized.

Like some physicians and policymakers, some parents wondered out loud whether this model was a positive addition to the story told through this report. It was viewed as “out of place” by focusing on an aspect of the patient and family experience that did not point to any remedies, unlike the other models. It was also regarded as a distraction, drawing negative attention to one model among others that were generally considered of value.



## Model 6: Hope

The sixth model addresses the “power of hope” in the lives of families with children with complex health conditions as a source of motivation, energy and determination. It specifically depicts families’ various sources of hope. Most study participants generally agreed that hope is a concept that has value and importance in the context of meeting the needs of children with special health care needs and their families. Some parents could relate the model to their own experiences, recounting how drawing on their faith and family helped them endure some of their darkest days.

A physician remarked that the model pushed him/her to look beyond the clinical binary perspective of living and dying, to one in which the child’s life offers additional value. Another physician discussed the role a family’s sense of hope has on treatment decisions, stating that they may hold off on an invasive treatment in the hope that a child will get better.

Some respondents were more puzzled by the model. For example, a number of people raised confusion about the layout: Is there special meaning to the layout of the boxes and the color gradation? Are these sources of hope more of a constellation than a progression? Is this purely conceptual or is it at all analytical? Are there direct applications, such as teaching trainees about the need to be respectful of patients’ different coping mechanisms? In general, respondents found that they could understand this model but wondered out loud whether it belonged among the others.

## Summary and Recommendations

**D**uring the spring and summer of 2013, some 61 stakeholders—including 52 parents of children with special health care needs and nine providers and policymakers—were systematically interviewed for their responses and reflections of the six ethnographic models produced for the Lucile Packard Foundation for Children’s Health. Another 60 workshop participants at an academic meeting also provided input. The purpose of the models is to illustrate the experiences of patients and families as a means to support efforts to improve the system of care for children with special health care needs. The findings from this study strongly support the notion that the models have the potential to—if they haven’t already—contribute to achieving better understandings of these experiences.

In general, study participants reported that the models provide a useful perspective on patterns in families’ experiences that can support providers and others in better understanding and anticipating families’ emotional, social service and health care needs. The models provide a focal point around which families, providers and policymakers can collectively discuss families’ needs, as well as program and policy responses that are required to more effectively address the full complement of services and supports needed by families.

Overall, respondents were impressed by the ethnographers’ work and regard it as an important contribution to the field. The models successfully acknowledge and point to the need for remedies at all levels of the system of care for children with special health care needs: the content and delivery of clinical care; the organization of service delivery and programs; training and workforce composition; and health care financing.

Some respondents see potential for some of the models to serve as the basis upon which families, providers and policymakers might collectively discuss the challenges they face, using similar language and the same points of reference. Some respondents suggested that while there is utility in the models for all audiences, they may be of greatest value to policymakers who may not be familiar with the issues that families face; through the visual tools that the models employ and the straightforward messages that many of them deliver, they can provide a mechanism to educate important audiences, which can help facilitate the essential policy reforms that should be part of a comprehensive improvement package.

A number of constructive critiques of most of the models were also offered, which sometimes entailed slight modifications to the visual presentations. Most of the critiques lent themselves to changes in the narrative descriptions that accompany the models, to provide readers with more information about the application of the models, along with acknowledgements and descriptions about how the models do not reflect all or even a majority of patients’ and families’ experiences. Two models—Models 5 and 6—drew the most criticism, for different reasons. Many respondents recommended that they be taken out of the report because they drew attention away from the other, more useful models.

The critiques of the models yielded suggestions for providers and, in some cases, policy ideas:

### *Model 1: Stages of Family Experience*

#### **Provider must:**

- Address transitions into adult care, age-related transitions (e.g., starting school, moving, vacations), and transitions between systems when responsibilities change
- Do periodic needs assessments
- Assume responsibility for care coordination
- Communicate about diagnosis, treatment and prognosis, providing essential information
- Deliver information in a manner that is family-specific and specific to the stage of their experience with their child's illness
- Communicate guided in part by the family members' mental state

#### **Policy**

- Reimbursement for services related to transition to adult care must be provided
- Ongoing care planning and needs assessment should be supported

### *Model 2: Resource Needs and Availability*

#### **Provider**

- Must advocate for patients in order to improve access to services
- Care coordination should be a service provided by the child's medical home
- Practices should be prepared to provide clinical services in a manner and language appropriate to families' preferences and capacities

#### **Policy**

- Adequate access to ambulatory care services is essential to overcome gaps in service
- System fragmentation should be reduced in order to facilitate access to services
- Care coordination by knowledgeable and effective individuals needs to be a covered service for CSHCN
- Health plans should be responsible for providing navigation services as part of their care coordination obligations
- Eligibility determination should be designed to maximize inclusion rather than exclusion of eligible children
- Eligibility across public programs should be standardized and unified

### *Model 3: Perspective on Resources*

#### **Provider**

- Team-based care is desirable as it facilitates coordination
- Linking parents with other experienced parents is extremely helpful

### *Model 4: System Friction*

#### **Provider**

- Inpatient providers must be better informed about outpatient care and service limitations
- Ambulatory care providers should more rapidly adopt new electronic technology to improve, coordinate and expedite communication with patients and other providers
- Hospitals should be responsible for patients' care for the first month after a child is discharged, and special "step down" services should be developed

#### **Policy**

- More stringent expectations of payers must be enforced so that payment is provided more expeditiously
- Statutory guidance is needed to determine the order of responsibility for payment for services by different agencies and programs; first dollar responsibility should be clear
- Public policies should be enacted to expedite the adoption and use of electronic medical records, email, texting, telephone consultation and telehealth
- Payment reform should be designed to facilitate access to appropriate services and equipment in homes, schools and communities

### *Model 5: Family-System Interaction*

#### **Provider**

- Providers should be aware that families' sense of vulnerability changes with experience and their child's health status

### *Model 6: Hope*

#### **Provider**

- Providers should appreciate the value of hope to families and the different forms it can take as a method to cope with difficult situations

## Appendix

**Table 1: Focus Group Composition**

<b># of Groups</b>	<b>Role</b>	<b>Language</b>	<b>Race/Ethnicity</b>	<b># in Group</b>
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

## Table 2: Provider and Policymaker Interviewees

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