



## Report

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

An Ethnographic Approach



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## Table of Contents

2	Introduction
3	Model 1—The Stages of Patient and Family Experience
6	Model 2—Resource Needs and Availability
7	Model 3—Perspectives on Resources
10	Model 4—System Friction
12	Model 5—Family-System Interaction
15	Model 6—Hope
17	Looking Ahead



## Introduction

In 2009, the Lucile Packard Foundation for Children's Health initiated a program to improve the system of health care for California's children, with a particular emphasis on children with special health care needs. As part of this work, the Foundation sought to understand the experiences and viewpoints of these children and families during their interactions with the health care system as it is currently organized.

Children with special health care needs are those whose medical conditions are likely to require long-term, complex medical treatments. Their families face many challenges in obtaining appropriate medical treatment and in coordinating other necessary services. Chronic conditions also cause many families severe financial difficulties.

The Foundation engaged ethnographers to study families raising a child with special health care needs. Ethnography, a branch of anthropology, seeks to understand human experiences by conducting interviews with individuals and families, and also by participating in their daily lives to observe and document their activities.

The ethnographers conducted in-depth interviews with eight families in Northern California. The goal of these interviews was to understand the entire experience of care, from the onset of symptoms, through the initial diagnosis, treatment, and resulting outcomes. The interviews lasted about three hours each. The ethnographers supplemented the interviews by accompanying families during their interactions with selected care coordinators and care providers who were working with the children and their families.

The research team looked for patterns in the experiences of the eight families, and consolidated their findings into six conceptual models. The models are intended to help deepen our understanding of the families' experiences, and to provide context for the experiences of other families who are dealing with similar issues.

The families who were studied were not chosen at random, and the findings are not intended to be valid from the standpoint of quantitative research methods. However, experts who have reviewed these models have found them both compelling and useful as meaningful descriptions of important aspects of the process of caring for children with complex and chronic conditions.

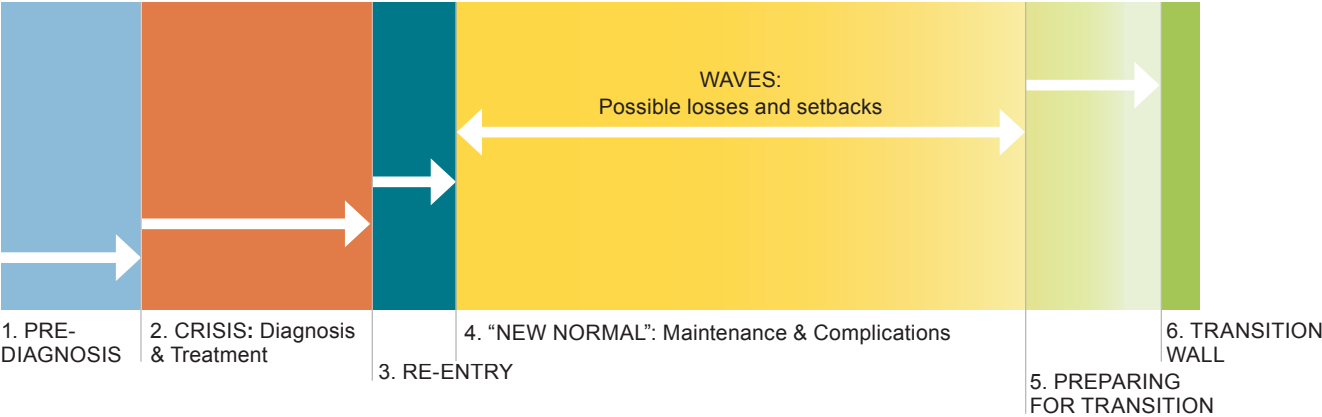
Such understanding can help inform the process of creating an enhanced system of health care for children with special health care needs.



# Model 1

## 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 were consistently reported by the interviewed families, indicating a commonly shared experience.



### Stage 1: Pre-Diagnosis

The first stage, during which the family realizes that the child is ill but no specific diagnosis has been made, can generate much fear and anxiety. Worried about their obviously unwell child, parents often become frustrated with the uncertainties and delays inherent in the normal process of diagnosing many complex pediatric conditions.

### Stage 2: Diagnosis and Beginning Treatment

In the second stage, once the diagnosis has been made and treatment begins—frequently in the hospital setting—many parents develop a form of tunnel vision. They find themselves unable to focus on anything other than their sick child and the ups and downs of their initial treatment. This concentrated attention can be detrimental to other aspects of their lives, including relations between parents, care of their other children, and their employment.

### Stage 3: Transition to the Community (Re-entry)

In the transition stage, the immediate health crisis is over. Suddenly, many of the resources that were available in the hospital, or during the diagnostic stage, disappear. Families often find themselves struggling on their own to construct a system of care for the child as they try to re-establish their former lives.

The context of their lives has changed permanently, as their child most likely will have ongoing medical needs. The challenge now is to get connected to the available resources they and their child will need. The transition stage also requires much cooperation from other family members.

### Stage 4: New Normal

The families who were interviewed explained that once they had completed the transition from the intense phase of medical care and were no longer in constant crisis and treatment mode, they discovered that they had settled into a routine. This was not the life they led when their child was healthy,

**This transition to “new normal” is a time of high stress on relationships with family members and others close to them.**

but a “new normal,” in which their routines were strongly influenced, and sometimes centered around, providing care for the child with special needs. During this period many families also experience a phase of mourning for the loss of their healthy child and for their previous family life.

This transition to “new normal” is a time of high stress on relationships with family members and others close to them. Many children with special health care needs experience recurrences or complications that may require re-hospitalization. The sometimes cyclical model of setbacks and recoveries of the child, especially when unanticipated, places additional stress on an already challenging situation.

### Stage 5: Preparing for the Child's Transition to Adulthood

As children with special health care needs reach their teenage years, families must begin to think about building new support systems. Many of the services they have been relying on may not be available after their child reaches age 18 or, in some cases, 21. Some families are aware or forewarned and make preparations, but many do not.

### Stage 6: Transition Wall

Families that are not prepared for the transition out of the child serving systems often refer to the end of these services as “hitting the wall,” which can be devastating as they are left without services for a young adult who continues to have multiple needs.

## Conclusions

Model 1, the Stages of Patient and Family Experience, seems to describe the experience of a significant percentage of children and families with special health care needs. To help ease the path for families, care providers routinely should make them aware of these common stages and provide counseling and support to anticipate and deal with them.

At the first stage, when a diagnosis has not yet been made, caregivers can assist parents in coping with their stress by providing as much information as is available.

In stage two, when a diagnosis has been made and treatment begun, families are at risk of being overwhelmed by the medical care system they and their child have entered. Care providers can help

**Families report that the key is to establish positive relationships with various caregivers and support persons.** parents by encouraging them to actively participate in the treatment process, discuss options, represent their child's interests, and support their child emotionally. The most successful parents insert themselves into the care processes and make their voices heard. If the child is hospitalized, families find it helpful to be included in rounds, and to participate as part of the health care team.

At stage three, when the child returns to the community, it is important that hospital staff connect families with the breadth of services that will be needed. Families who persistently ask for help are the most successful in creating a viable network of services.

During the inevitable ups and downs of the “new normal” in stage four, families that report the most success explain that the key is to establish positive relationships with various caregivers and support persons. These individuals often control access to additional resources, or have the information a family needs to find services and equipment.

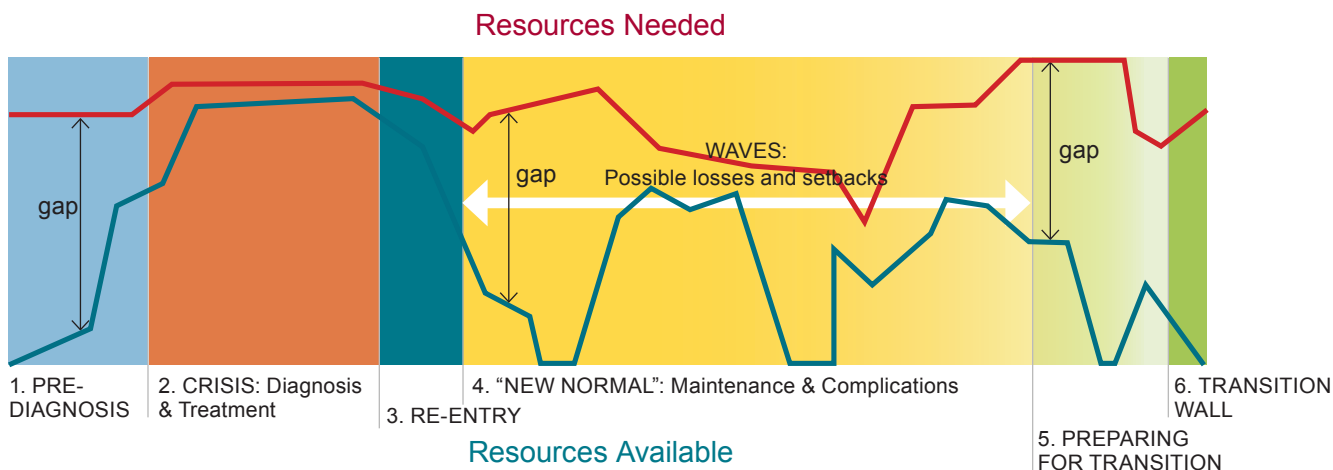
Throughout the course of a child's treatment, care providers can help ease the eventual transition to adulthood by consistently reminding families of the need for long-term planning for chronic conditions. While parents must initiate the planning, it also is important for the child to assume as much responsibility as possible for his or her lifetime condition.



## Model 2

### Resource Needs and Availability

The second model, Resources Needs and Availability, builds on the Stages of Patient and Family Experience model. Model 2 is illustrative of the many occasions when there may be substantial gaps between the resources a child and family need and the resources that are available and provided.



The families who were interviewed noted that needs and resources frequently are not aligned, and that this is especially true at the time of discharge from the hospital and during the transition from pediatric to adult care. Many families recounted the lengths to which they and other families must go, and the strategies they must develop, to fill the many gaps in service.

### Conclusions

The current system of care does not meet the breadth of services required to maintain a child with complex special needs at home. The system is characterized not only by fragmented services but also by an absence of any efforts to integrate them. Some families noted that they rarely are able to get the attention of public officials to address the underlying deficiencies in the care system for special needs children. An enhanced system must address this significant problem.

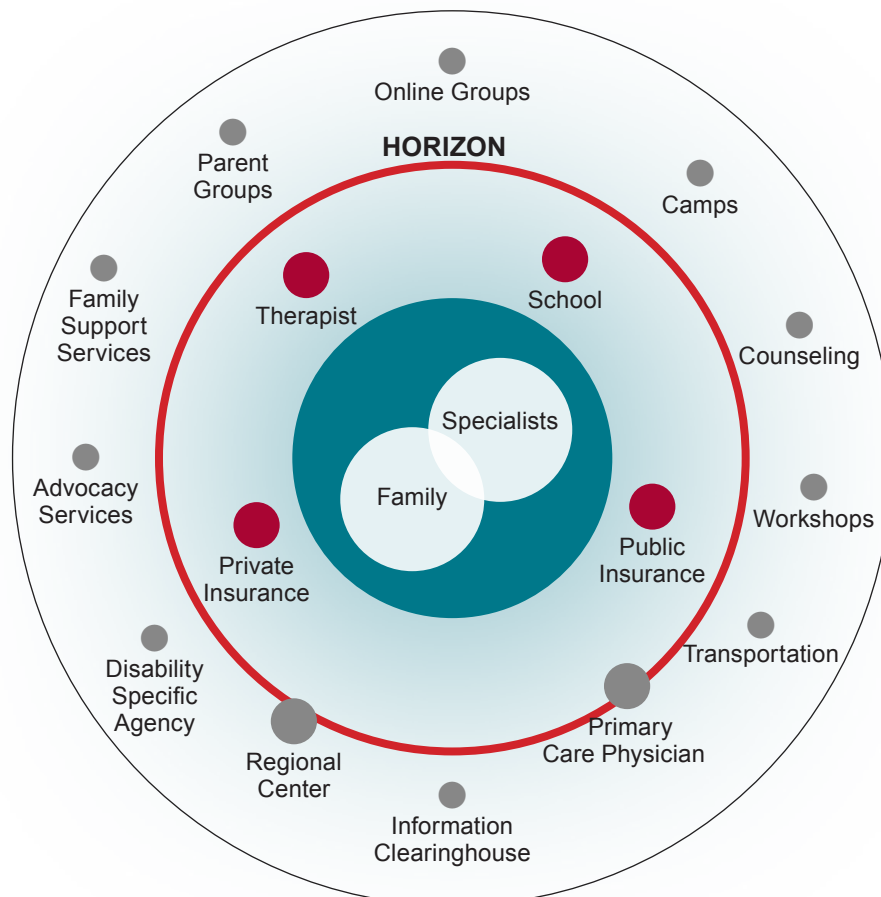


## Model 3

### Perspective on Resources

**M**odel 3, Perspective on Resources, illustrates how patients and families view and gain access to the resources that are available to assist their child. In general, families are aware of only those service providers with whom their child's illness has brought them into direct contact. Initially, this may be limited to the hospital-based specialists and their staff. This narrow view limits a child's options for additional services and supports simply because they are "out of sight."

For many families who have a child under the care of specialists, even the child's Primary Care Physician (PCP) is not within their horizon and is not considered a core health care provider. For example, if the child catches a cold, these families may not think to consult the PCP but rather will go straight to the specialty doctor.

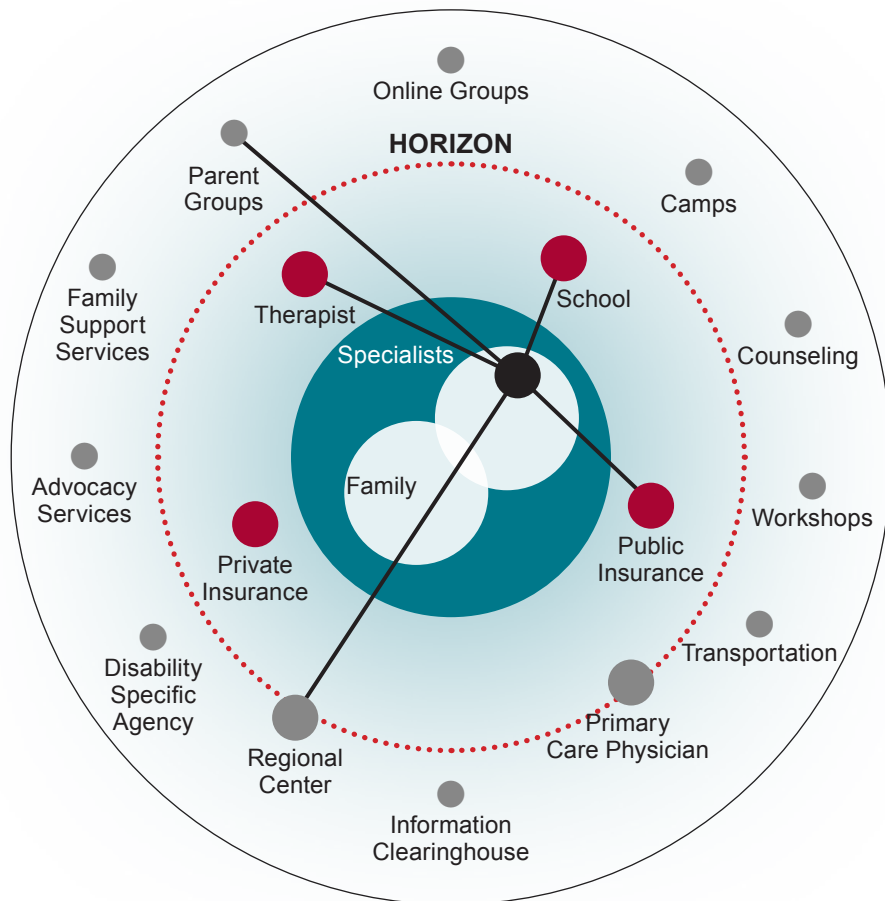




This has major implications for the ability of the family to obtain comprehensive health care. The child's "medical home", which should be an array of integrated medical and related services, becomes limited. Though the PCP is generally considered to be a central figure in the care of healthy children and children with episodic chronic illness, families of children with complex special needs often do not continue to seek the benefits of their relationship with the PCP. They therefore may miss out on a valuable partner in their child's care.

It often is difficult for families to see additional resources that are beyond their horizon and experience; this can limit their ability to coordinate the care their child needs. Parents rarely see outside this horizon unless they have access to care coordination services. Care coordinators provide invaluable services by educating families about other available resources and helping them gain access to these resources.

Care coordinators may be social workers, nurse practitioners, or some other professional in the hospital, the primary care physician's office or in the community. Whatever the title or professional training, care coordinators provide information and linkages that families otherwise might not have available to them.



## Conclusions

The Perspective on Resources model highlights the importance of helping families expand their knowledge of available resources and broadening their horizon to encompass valuable services. Effective care coordination depends on knowing about and having relationships with a wide variety of service providers and understanding the range of services to which the child is entitled. Care coordination is an essential component of a high quality system of care for children with special needs.

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This essential service generally is not reimbursable under most health insurance and health care financing programs. Hospitals, public health agencies and other care providers that do offer care coordination generally do so out of a sense of responsibility and in the interest of their patients. As resources become increasingly scarce, this unreimbursed service may be at risk. Changing the benefits of health care programs for children would clearly improve families' access to the range and quality of services, and would enhance the life experience of children and families.

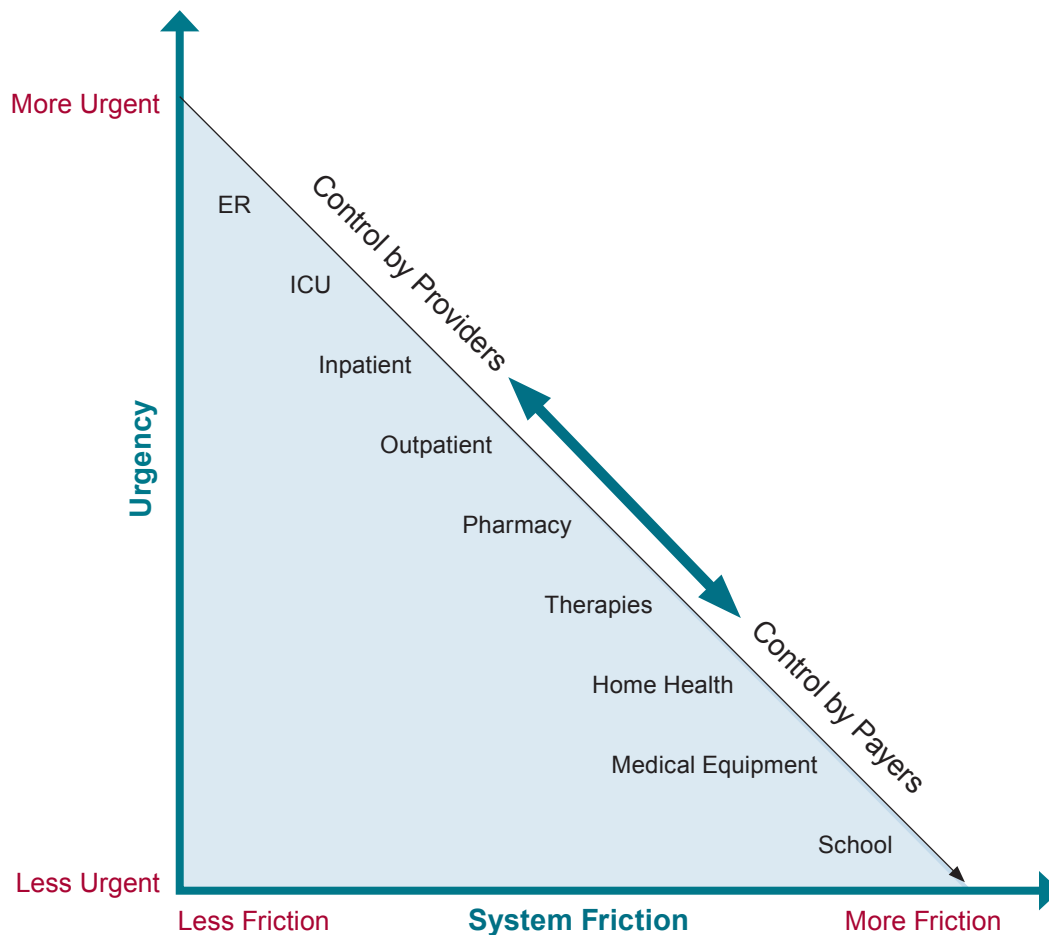


## Model 4

### System Friction

**M**odel 4, the System Friction model, describes the increasing difficulties that children and families have in obtaining services as the urgency of service needs decreases.

Services that address urgent conditions, especially those that are life threatening, are most readily obtained and present the least amount of friction. For example, if a family arrives in the Emergency Room with an acutely ill child, their child is likely to get immediate service, including medical care, laboratory and diagnostic test and procedures, specialty consultation and the initiation of treatment—all in one location. Care sought in other outpatient settings, especially some specialty care and some forms of therapy, are more difficult to obtain, reflecting a greater degree of friction.



Other areas of high friction that families mentioned included obtaining mental health services and durable medical equipment, and working with schools on Individual Education Programs (IEP).

On the horizontal axis of the model illustration, the time of a health crisis begins on the left and progresses to the right. As time passes from the initial crisis and care needs become less acute, the amount of friction that the children and families experience increases. One reason for this model is the concentration of medical care and the control exerted by the medical team on access to services, medication and equipment during the precipitating event.

**Other areas of high friction include obtaining mental health services and durable medical equipment.**

However, as a child moves farther in time from the acute crisis and into a chronic phase, control shifts to the payers. Health insurers have well established, responsive and, generally, predictable coverage policies for hospital care, less so for some outpatient services, and very few for what they consider to be ancillary services like care coordination. Payment for other services, including durable medical equipment, mental health care and educational services are less likely to be covered benefits. Eligibility for many of these services is restricted and the services themselves may be limited. Thus, as time passes, friction increases and families experience more difficulty obtaining services for their child.

## Conclusions

This System Friction model illustrates how the actual or perceived difficulty obtaining resources increases as children progress from acute to chronic care. The health care system needs to be adjusted to provide adequate access to appropriate resources to meet the needs at all levels of acuity.



## Model 5

### Family-System Interaction

The fifth model, Family-System Interaction, describes different styles in which families tend to interact with the medical and service systems. Many families move back and forth between models, depending on their changing circumstances and the support services they receive.

Styles of family interactions range across a spectrum. Some families exhibit a model of behavior that might be called “overwhelmed.” Such families may be fearful of and/or unfamiliar with the health care system and are made more overwhelmed by their anxiety about their child’s condition. Some are so overwhelmed by the diagnosis that they become almost incapacitated.

“Compliant” families exhibit a strong dependence on health care professions. They tend to do what they are told, neither more nor less. They accept instructions and do their best to comply, but they ask few questions and are not assertive in seeking additional help. These are families that behave in

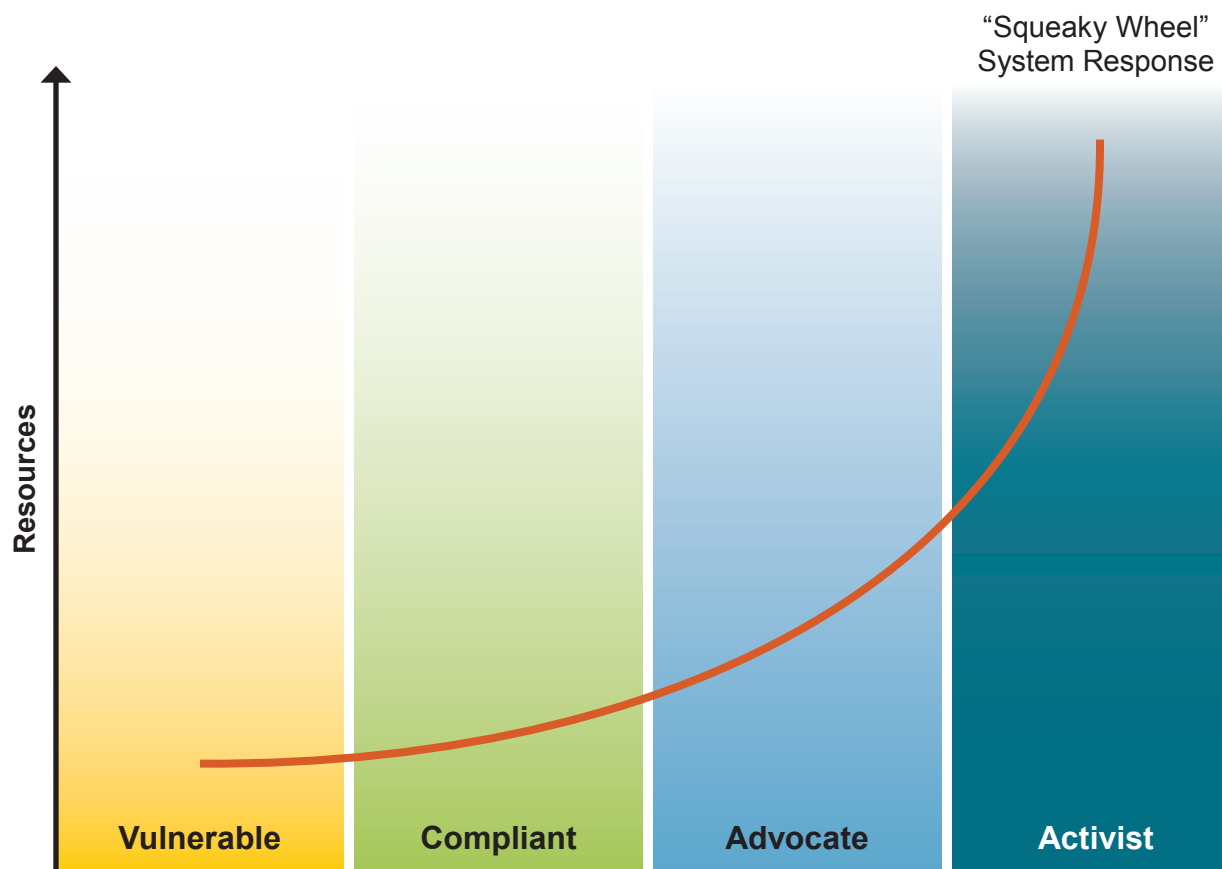


an “old-fashioned” manner, in the sense that they exhibit a model of behavior characteristic of a time when family-centered care was not understood or practiced.

A third style is seen among families who are actively engaged in their child’s care, participate in decision-making, and advocate effectively for their children. Many of these parents understand that developing solid working relationships with service providers is the best way to gain access to the resources and services they feel their children need. These families also tend to seek out other families with similar experiences and needs as a way to increase their own knowledge of their child’s illness, the health care delivery system and available community resources.

A more assertive style is the “activist family,” in which a parent or parents have taken their sense of advocacy to a higher level by becoming part of the health care system. They use their accumulated expertise in dealing with the system to advocate on behalf of others, and teach others how to advocate for themselves. Some of these individuals find opportunities to work professionally within the system as employees of medical practices, hospitals, information and referral agencies or care coordination programs. Activists also often find opportunities to educate local, state and federal policy makers about the needs of the children and ways to improve existing systems of health care financing and service.

This model demonstrates that, to some degree, the families that are the most actively engaged tend to receive access to the most resources. The system seems to be more responsive to these “squeaky wheels.”



## Conclusions

This Family-System Interaction model illustrates different ways in which families interact with the health care system that can affect the services and resources they, as well as other families, need to assure the best care for their children. It is unfortunate that children's access to important services, many of which are mandated by law, should depend on whether their parents are knowledgeable or demanding. Ideally, the systems serving these families and children would be designed to make individual advocacy unnecessary, and that should be a goal for system reform. This model reflects the current situation and the need to educate all families to become more effective advocates for their children.

**Ideally, the system would be designed to make individual advocacy unnecessary.**

One way to advance parents' ability to advocate, at least for themselves, is to introduce them to other parents who have developed effective advocacy skills. Many who might otherwise take a passive approach can be coached on ways to navigate the system effectively. Successful advocacy is based on developing relationships, and using those relationships to ensure the quantity and quality of a child's services.



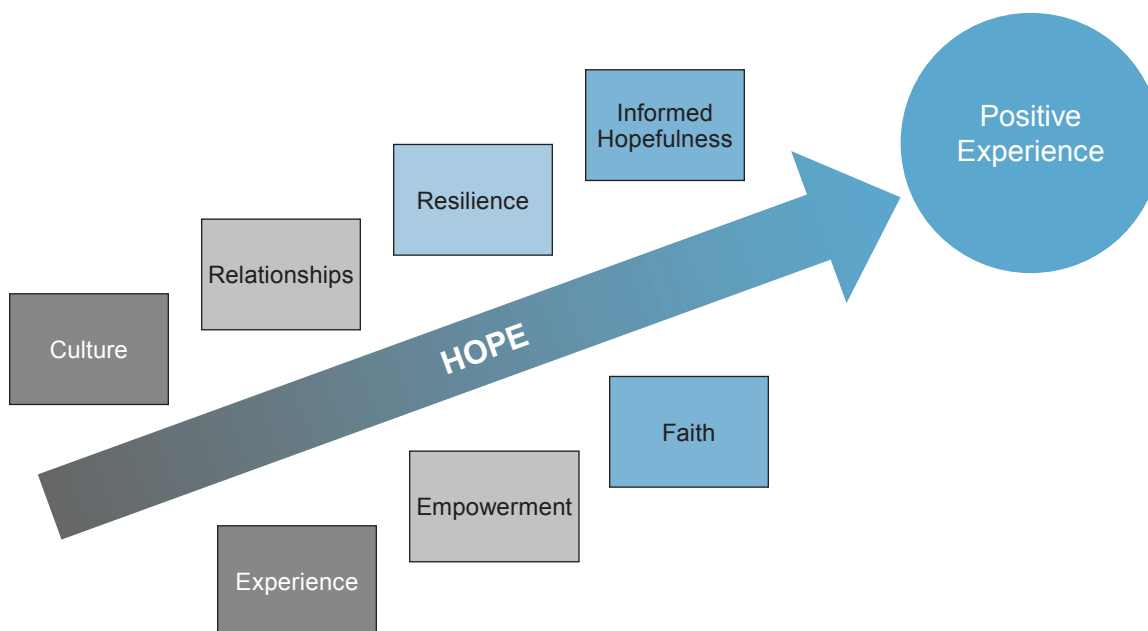
## Model 6

### Hope

The sixth model deals with the power of hope in the lives of families with children with serious health conditions. Coping with a seriously ill child is enormously difficult for parents, and having hope that they can meet their child's needs and that their child's health and well being will improve is vital to managing day to day. Hope also is a powerful motivator and source of energy and determination.

Families find hope from a number of sources.

- Some cultures have a world view that is optimistic and hopeful.
- Previous experience with health care provides knowledge and helps families' anticipate next steps.
- Overcoming prior adversity and difficult times helps create resiliency that enables people to cope with new problems.





- Relationships and the material and social support they provide are important to families going through difficult times. Families that feel that they can make a difference, and can identify actions to take, are empowered and thus hopeful. In the case of children with special health care needs, the system of care is a powerful force and can give families hope by engaging them in the care process.
- Spirituality and religion is a source of hope and strength for many people
- From health professionals who can provide informed guidance on those aspects of the child's health and well being for which parents can be hopeful

**Hope can allow something as simple as believing that tomorrow is going to be a better day.**

The positive outcome shown at the right of the illustration does not necessarily imply a complete cure for a child. But hope can allow something as simple as believing that tomorrow is going to be a better day. That expectation can be enormously important for children with special needs and their families.

## Conclusions

This model indicates that care providers should be sensitive to the importance of hope for the families in their care. Health care providers should be educated about their role in helping families draw on the resources they have and help families be realistically hopeful for their child's health and comfort.



## Looking Ahead

Families with children who have special health care needs face many challenges, some created by their child's increased or different needs and some due to shortcomings in the existing care systems. Families frequently must struggle to obtain appropriate treatment and services for their children. They face ongoing issues as they attempt to develop a normal life that incorporates a child with special needs. The emotional toll can be high as they navigate through the highly complex health care system, and the financial demands also can be significant.

These six models describe key experiences that seem to be common among many families. Looking across the six models, they suggest the need for a range of responses.

1. Families need education on both the nature of the challenges they are facing, and the most effective ways for them to navigate the system.
2. Care providers should be educated about these models and their consequences for children and families, to enable them to deal more effectively with the interpersonal dynamics of the care process and provide truly family-centered care.
3. Financing schemes, both public and private, to pay for services for children with special health care needs should be simplified and, ideally, consolidated to promote integrated systems of care.
4. Reimbursement policies that assure each child has a medical home that includes care coordination and case management services, as well as adequate access to medical specialists, would be highly beneficial to children and families, and might lead to cost savings.
5. Gaps in communication between hospital staff and community providers and gaps in resources for these children outside the hospital setting must be filled.
6. Systems of care and care standards should be designed that do not require families to argue, advocate or lobby for appropriate care for their children.

These models and recommendations, which focus on the family perspective, should be taken into account as policymakers and funders consider how to improve the health care system for children with special needs.