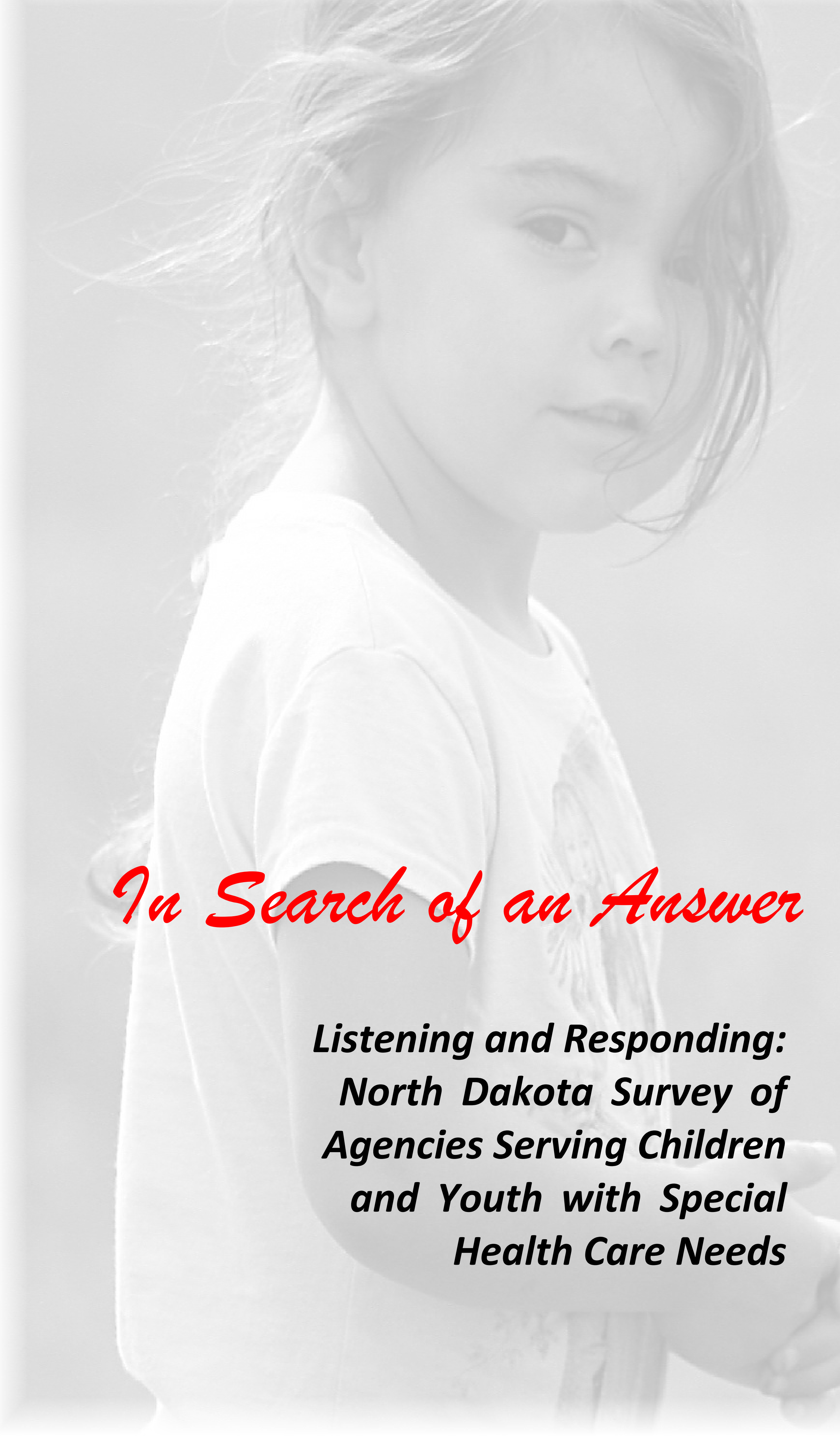

In Search of an Answer

Listening and Responding: North Dakota Survey of Agencies Serving Children and Youth with Special Health Care Needs

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In Search of an Answer

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A report of the Family Voices of North Dakota qualitative interview results to help identify the experiences that families may face as they search for resources, information, financial support, emotional support, and access to services.

Thank you to the families and professionals who provided their time and expertise on this project:

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FAMILY VOICES
OF NORTH DAKOTA

FVND was started in 1996 and became a State Chapter formally sanctioned by National Family Voices, Inc. in the first quarter of 2001. FVND aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

The FVND Health Information and Education Center:

- Assists families as they navigate public and private systems, including health systems and insurance plans;
- Provides assistance to families in accessing services and resources for their children and how to partner with providers and caregivers;
- Listens to families as they describe their encounters with systems and helps guide them to possible solutions;
- Works with families, health care providers, public and private agencies, and advocacy or support groups to promote family-centered care and medical homes for children with special health care needs; and
- Promotes discussions and linkages among families, providers, managed care programs, and government to better serve the health care and related needs of children and families in North Dakota.

ND Parent to Parent Project:

- Is a statewide network of parents supporting families of children with developmental delays, disabilities, and special health needs;
- Offers emotional support and information;
- Acts as a valuable resource to families;
- Offers assistance in learning the necessary skills to help parents face the challenges of raising their child;
- Offers moral support and encourages parents to feel comfortable and optimistic about the future; and
- Is dedicated to supporting families at their most challenging times and to celebrating each new victory.

As a component of these services, FVND offers leadership institutes, training, workshops, and resource development. They also participate as a major partner on the local, state, and national levels in system transformation, facilitating a responsive system of care for children and youth with special health care needs (CYSHCN) and their families based upon a family-centered approach.

FVND Health Information and Education Center funding is provided by a grant from the US Department of Human Services' Health Resources and Services Administration, Maternal and Child Health Bureau and the North Dakota Department of Health (Title V, Children's Special Services) and ND Parent to Parent Project funding is provided by the ND State Council on Developmental Disabilities.

> ***"We who have children with special health care needs have learned patience, joy and resilience which come from the lessons our children have taught us. Through them our lives have been enriched, learning from those lessons and sharing them with those who also have devoted their lives, partnering with parents and providers in each step. Family Voices of ND is an important connection for families not only to connect with one another but in assisting them in accessing vital information"***
>
> ***D. Feist***

Listening and Responding:

North Dakota Survey of Agencies Serving Children and Youth with Special Health Care Needs

Over the past eleven year, Family Voices of North Dakota (FVND) has utilized a qualitative interview system to gather information regarding the capacity of the system of care for families of children and youth with special health care needs (CYSHCN) to help identify the experiences that families may face as they search for resources, information, financial support, emotional support, and access to services.

This effort serves as a bridge to a better understanding of what is working well for families, barriers that families encounter, a celebration of successes and models of excellence, and opening a dialogue regarding the identified challenges that families may be facing. This paper highlights background information (including population, about FVND, about family-centered care, and need), study design (including intent and proposed outcomes, potential uses, and methodology), overall results (including data collection results, description of the response and respect scale, and interpretation), and FVND recommendations for use of results to improve the capacity of the system to be responsive to the needs of families of children and youth with special health care needs as they navigate their care and support options.

> *"Instead of depending on case workers and teachers deciding what was a need for our family, give us the choice of what our family needs and allow us to pick and choose, with assistance, what we think we need."*

Background

Children and youth with special health care needs (CYSHCN) have been defined federally as children or youth with or at risk for chronic physical, developmental, behavioral, or emotional conditions who also require health and related services beyond what is needed by children generally. This definition includes children with:

- Disabilities
- Chronic illnesses and conditions
- Health related educational and behavioral problems

Based on the information from the National Survey for Children with Special Health Care Needs (CSHCN) provided to North Dakota's Children's Special Health Services (CSHS), 12 percent of North Dakota's children (about 17,500) have a special health care need compared to 14 percent nationally. Survey data indicate that the prevalence rate of special health care needs in ND is 6 percent for children ages 0-5, 15 percent for children ages 6-11, and 15 percent for youth ages 12-17, and is 14 percent for males and 10 percent for females.

The data show that CSHCN families experience an economic impact; 18 percent of these families had someone in the family who had to quit their job, not take a job, or greatly change their job due to problems with child care for their child in the past 12 months and 19 percent experienced financial problems due to their child's health needs.

About Family-Centered Care

Family-centered care assures the health and well-being of children, youth, and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high quality services.

The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following principles:

- Families and professionals work together in the best interest of the child or youth and the family. As the youth grows, they assume a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

> *"We were alone, and I SEARCHED for resources and made calls and went to meetings and filled out paperwork. I spent more than two years searching for help, including at social services, and they never even told me about CSHS. Very sad and frustrating at how much money and stress it could've saved our family. Accessing existing programs should be a simple, streamlined process."*

Based on this partnership, family-centered care:

- Acknowledges the family as the constant in a youth's or child's life.
- Builds on family strengths.
- Supports the child or youth in learning about and participating in his or her care and decision-making.
- Honors cultural diversity and family traditions.
- Recognizes the importance of community-based services.
- Promotes an individual and developmental approach.
- Encourages family-to-family and peer support.
- Supports youth as they transition to adulthood.
- Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
- Celebrates successes.

Sources: 1) National Center for Family-Centered Care. *Family-Centered Care for Children with Special Health Care Needs.* (1989). Bethesda, MD: Association for the Care of Children's Health; 2) Bishop, Woll, and Arango (1993). *Family/Professional Collaboration for Children with Special Health Care Needs and their Families.* Burlington, VT: University of Vermont, Department of Social Work; and 3) Family-Centered Care Projects 1 and 2 (2002-2004). Bishop, Woll, and Arango. Algodones, NM; Algodones Associates.

The Needs of CYSHCN in North Dakota

The 2009 North Dakota CSHS Family Needs Assessment and Block Grant Report indicate that families varied greatly in their knowledge of community services and programs they can access. Specifically the report showed that:

- 45 percent of families did not always receive needed information from their child's doctor or other health care provider.
- 51 percent of families did not feel comfortable in their knowledge of health care financing and the various systems.

Over the past decade, national surveys have indicated that families who are informed are better decision makers for their CYSHCN. The Health Care Experiences of Families of Children with Special Health Care Needs conducted by the Heller School at Brandeis University and Family Voices also confirmed this family need. Research shows that family and child health outcomes improve dramatically when they can consistently access accurate and quality information in a timely manner.

> *"I found it very hard to learn about services for children with special healthcare needs. I was always given the run around and always had to wait for answers. For new families I would suggest sending out a packet of information containing information for all services available and support groups for families dealing with a child with special healthcare needs."*

As a reality check to assessment and survey indicators, families who have contacted FVND via phone or in person shared their lack of health care information and knowledge and available resources in ND. In addition to problems accessing medical and community based resources, families reported difficulty in locating information that is easily understood for diagnosis and treatments of their children, and in understanding public and private insurance benefits and limitations.

Study Design

Intent and Proposed Outcomes

The intent of this project was to help identify the experiences families of children and youth with special health care needs may face as they search for resources, information, financial support, emotional support, and access to services. The project sought to identify what was working well and how that was influencing the family capacity to access information. Barriers encountered by families serve as real life examples of specific challenges faced by families as they navigate the system of care for CYSHCN.

Potential Uses

The survey can enhance family capacity to seek and access appropriate services for their CYSHCN by providing a snapshot of the strengths and challenges within the information navigation trail. It will serve as a base for identifying and celebrating success and beginning a dialogue to identify barriers that families may face. The information will be used to identify areas for FVND to work as an organizational partner with the system of care to effectively improve the capacity of families to navigate, locate, and access appropriate services and supports.

Methodology

The methodology of this initiative had several stages, each serving as a progressive way of gathering information that would meet the anticipated outcomes and assist organizations, families, and systems to better meet the needs of CYSHCN.

STAGE	DESCRIPTION
Targeting Programs:	Using traditional avenues of information seeking by families, FVND developed a database of organizations and agencies across ND that serve CYSHCN to call in search of resources and information.
Notification of survey:	Before the survey was conducted, a letter was sent to administrators of the main agencies that were going to be called to let them know about the upcoming survey.
Scenario:	A family scenario was created to serve as the purpose of the call and a consistent way of soliciting information, resources, and referrals.
Seeking information calls:	A parent caller, using the scenario and acting as a parent seeking information and resources, called agencies, organizations, and providers in the database with the scenario.
Data collection:	The parent caller documented each call individually by noting the responses she received from each person (at each agency). The caller also rated each call on both responsiveness and respectfulness, based upon a subjective scale and interpretation from the vantage point of a parent of a CYSHCN.
Aggregate findings:	The responses were collated into an Excel database.
Rating responses:	A group of individuals from across the state rated each agency on a scale of 1-5, based on the data and indicated if the agency was responsive and respectful.
Disseminate information:	The results and information were shared at meetings with agency directors and partners.

Overall Results

The results yielded good responses from a variety of programs and agencies that were genuine in their willingness to help and find information, care about the situation, follow up by email, and emulate an overall desire to cover the needs of the family. Specific "helping" behaviors included:

- Referrals to county offices
- Referrals to FVND and other family support agencies
- Offers to make calls on behalf of the family
- Willingness to check back to see how they were doing
- Follow up emails
- Active listening

Some responses and behaviors that were not found helpful included:

- Multiple "baton tosses"; passing the parent caller on to other programs and services
- Referrals to other programs that were not knowledgeable or helpful
- Not referring to their own agency's programs
- Offering websites, but not asking if the family had internet access
- Offering information without the contact information
- Using incorrect names such as "Human Resource Center" instead of "Human Service Center"
- "Good Luck" wishes when they were unable to assist

Table 1. Data Collection Results	
Number of programs called	215
Number of calls completed (sometimes spoke with multiple individuals within the same program)	324
Number with wrong 800#	8
Number with wrong local number	13
Number disconnected	14
Number totally unreachable	15
Number answering to a different name	11
Number rated as responsive	235
Number rated as respectful	146

Response and Respect Scale

1. Not responsive or respectful; gave no information or help on where to go or what to do.
2. Somewhat responsive or respectful, but not both; gave no information or help on where to go or what to do.
3. Responsive and respectful, offered some information, but it was not the best or was lacking in contact information
4. Responsive and respectful, gave information, but did not give all needed information (both parent support and other needs)
5. Responsive and respectful, gave correct information on who to call or connect to or what to do.

Table 2. Rating Results

1 – Worst	65
2	73
3	44
4	26
5 – Best	7
Rating average	**2.2**

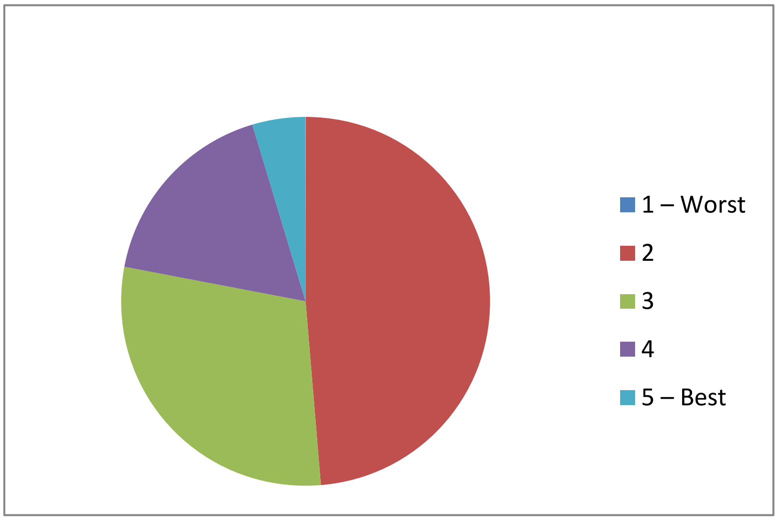

Figure 1: Response and Respect Results

Interpretation

A review of the outcomes of this exercise indicate that there are locations, agencies, and programs that are well prepared to assist families when they turn to them in search of resources, information, and assistance. Some seemed to be inclined to assist, regardless of whether it was a population that they were responsible for helping or not. Several, albeit a small number, seemed to be prepared and well organized in their approach to assisting over the phone. Because of the many barriers to communication and understanding inferred by phone conversations, those that were considered respectful are to be applauded.

While there is no current national standard to help us determine whether an average state rating of 2.2 is adequate, we feel strongly that we would like to see this number improve. This project also highlighted the plight of families as they blindly stumble through the system of care in search of resources, information, and assistance for their CYSHCN. The study suggests that there was an abundance of wrong numbers, disconnected numbers, and a general lack of available resources without "digging" from one level within a program to another. There is an obvious lack of knowledge of the system of care in general by many programs and service agencies – sometimes within their own program. The "loop" of information had many missing links such as a failure to ascertain the capacity and resources of families to follow the suggested resource or failure to offer the contact information. First contact employees (those who answer the phone) may have created a barrier by not stating the program name appropriately or not offering a clear and concise description of what they could offer families of CYSHCN.

FVND Recommendations

Transformation of the health care system for CYSHCN will be dependent upon ensuring that families have accessible, accurate, family centered and culturally competent information. With the Family to Family Health Information Center and ND Parent to Parent Project, FVND recognizes their role and responsibility in working in collaboration with other partners to create an accessible and accurate information system for families. Recommendations that warrant follow up include the following.

Training that facilitates:

- Information sharing and cross training within an agency on the various programs, including the full scope of the agency, not just a specific program.
- Orientation and ongoing training for all front line/first contact staff, such as operators, receptionists, or outreach workers.
- Cross training and sharing of information and resources between agencies, programs, organizations, and service providers within the state's communities.
- Staff that are trained on accessing family support partners, such as FVND.
- Utilization of FVND training on family-centered practices and encourage agencies to have FVND staff present at staff meetings, trainings, and conferences.

Partnerships that:

- Encourage networking opportunities between agencies and service providers.
- Promote statewide information and resource partnerships that will promote consistent and predictable methods for sharing information that ensure service agencies, programs, and organizations can be responsive to the requests and needs of families and their CYSHCN.
- Ensure that agencies and programs include families and youth on advisory boards and committees.
- Provide families with information on FVND and other family organizations with all referrals.

Tools that promote:

- Quality improvement for monitoring and improving the information and resource system.
- The use or development of a shared database of information for families and providers with accurate contact information.
- The utilization of data from family support partners such as FVND to evaluate program and agency effectiveness in supporting families.

Accountability that will:

- Identify and use regular "check points" between critical partners within the CYSHCN system of care to identify gaps in the provision of information and resources.
- Lead to a strategic plan for a family centered and culturally and linguistically competent approach to addressing the needs of families.
- Assure that family support partners such as FVND are included in the planning, implementation, and evaluation of the information and referral system.
- Utilize FVND as an outside evaluator of the information and referral system.
- Continue to discuss available opportunities for family support organizations to provide information regarding family perspective in accessing services and support.

FVND Next Steps

As an immediate response, FVND will meet with state agency directors to review the survey, results, discuss recommendations, and explore partnership opportunities for improving information and resource access. After meeting with state agency directors, FVND is prepared to follow up with staff and present the results and discuss approaches to improve family access to information and resources.

FVND is working on a "North Dakota Roadmap" to begin addressing the information gaps experienced by families. We invite partners from across the state to join in this endeavor and other approaches to develop the capacity of the health care and information system to be more responsive to the requests for information and services of families of CYSHCN.

Finally, FVND is invested in the vitality of this survey and its potential to expand the capacity of families to access accurate information and support. We will continue to seek resources to support the survey each year, hoping to document improvements in information, support, service, and resource access for CYSHCN and their families.

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