

Partner and Communicate with Families of Children with Special Health Care Needs

2013 Series

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Special points of interest:

- **Treat families with care and compassion to open lines of communication.**
- **Learn about ways to support families as they overcome challenges to build partnerships.**
- **Provide medical home services, such as care coordination and culturally competent services to support partnerships.**
- **Encourage family advocacy skills and acknowledge the family voice.**

Navigating the health care system can be challenging for anyone. For families of children with special health care needs (CSHCN), it can be even more challenging. By partnering with providers, families have experienced fewer frustrations, increased satisfaction with providers, and comfort in knowing that their child's care is being coordinated by caring and compassionate providers. Families should be recognized as experts and engaged as active participants in their child's care. When this is done, providers and families gain mutual respect and trust for one another. By increasing provider's understanding of the child's and family's needs, meaningful partnerships are developed.

Compassionate Communication

When families are experiencing emergent health needs and are fearful for their child's health and safety, it is critical for providers to understand the extreme stress surrounding that and be compassionate to the families needs and feelings. Families of CHSCN are familiar with what is typical for their child and when something is not right, providers who acknowledge the family perspective and work in partnership with the family can be a blessing. Unfortunately, this was not the experience in the following story.

"After four years of poor eating and multiple life threatening episodes, my son was diagnosed with delayed gastric emptying. Even after many doctors appointments and multiple hospital stays,



I still never felt like they were listening to me. They would tell me he wasn't eating because I was not preparing his food correctly. They made it out to be MY fault, when in reality it was because of a physical abnormality. I went to them for guidance, looking for answers on how to help my son. Instead, I was made to feel like I was an inadequate mother."

Danielle, Parent of a Medically Complex Child

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"Children with special health care needs (CSHCN) are those who have, or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (Maternal and Child Health Bureau). Conditions affecting CSHCN may be permanent or temporary, chronic or acute, visible or invisible. Regardless of the conditions, the impacts and affects are felt in all aspects of family living.

Compassionate, continued...

According to the 2009/10 National Survey for Children with Special Health Care Needs (NS-CSHCN), 11% of Kansas families reported feeling that their health care providers sometimes or never listened to them. Many families have shared their experiences and frustrations when this occurs. Through partnerships, compassionate listening, and a little understanding, more families can report feeling like their providers listened to them.

“After surgery to have a baclofen pump placed, we noticed many sores and puss coming out of the wound. We went to the doctor’s office hoping to see the doctor. His receptionist told us everyone had already gone for the day or were too busy to see us. I showed her the wound and she even said she could



see the pump trying to come out. She still refused to do anything to help us! I was so afraid the pump would pop out of my niece and she would die in my arms. The receptionist just ignored us.”

Nicole, Caregiver of Child with Cerebral Palsy

When parents first learn that their child has special health care needs, many emotions arise. Emotions can create barriers to effective listening. Having a provider who takes time to explain the situation and allows time to process the information being provided can make all the difference. Ensuring families understand what is being shared and feel prepared to take on these unexpected needs is critical to building effective partnerships.

“At six weeks old, Jack came home from the hospital with a heart monitor, medication, orders for early childhood services, and much more. We had to be trained on CPR and how to feed him. I did not have anyone to help me understand his diagnosis and what it meant for his future. Luckily, I found an online forum and did lots of research to help me understand his needs.”

Hilda, Parent of a Child with Down Syndrome

Communication between families and providers can be complex and if families feel they are not receiving the information they need to address for their child’s needs, partnerships can be negatively impacted. Communication can be especially challenging for families from different cultures or who might speak another language. In the 2009/10 NS-CSHCN, 8% of families reported their doctors or health providers are not sensitive to their family’s values and customs. Maria experienced first hand what these families reported.

“At first, I did not understand what Down syndrome was and what it meant for my daughter. The fact that my English was very limited made it very difficult to understand and I felt my health professionals were too busy to explain it to me. I was feeling overwhelmed with the news and did not know how I was going to take care of my baby.”

Maria, Parent of a Child with Down Syndrome

“I always ask a lot of questions. Some doctors are a great help. However, I have felt discouraged because some did not listen to me. That makes it hard to help these children.”

Support Disability and Understand Needs

Families look to providers for information, guidance, and support. They desire open communication and want to know their provider cares about their child's health and well-being. They want their providers to be open-minded and optimistic, although realistic, when planning for long-term outcomes. According to the 2009/10 NS-CSHCN, only 64.5% of parents reported their provider always discusses the range of options to consider regarding the care or treatment of their child.

"Although doctors always treated my son okay, one provider in particular did not like for me to ask questions. When we were considering applying for the Deaf/ Blind Project and asked for his recommendation, he accused me of asking him to falsely document Jack's condition. Fortunately, we found a provider who was willing to follow Jack's vision care and assist in determining his eligibility. Now that Jack has been diagnosed as legally blind his school district is able to purchase equipment to assist in his education."



Hilda, Parent of a Child with Down Syndrome

Parents desire compassion, understanding, and partnership. Reactions of providers may not have a great impact on parents, especially after receiving the news that their child has a disability. The hope (or lack of hope) a provider displays can build the dreams a parent has for their child. In Karen's story you will learn how her provider's lack of knowledge and negativity empowered her to help her child have the best life possible.

"When Michelle was diagnosed with autism, the first thing her doctor said was "I don't know anything about autism." When I asked about follow up care, he said that there was no need to do developmental checks as she would not progress beyond infantile communication. I remember thinking to myself, "I can sit in the corner and sulk, or I can try to help Michelle as much as I can." I decided my doctor needed to get more involved, so I signed him up and paid a five year membership to the Autism Society of America. I wanted no other mother to hear "I don't know anything about Autism" from this doctor."

Karen, Parent of a Young Adult with Autism

Families and providers must share a mutual respect and trust to partner effectively. Families need to feel they are heard or valued. Families desire individualized care and consideration for their child's needs. Hilda's experience shows how critical this can be.

"By teaching myself to read lab results my son was diagnosed with hypothyroidism and anemia. Things his physicians missed when they read the lab results. I have learned that I cannot have blind trust in my son's providers; I have to continue to educate myself on his medical needs and be proactive with physicians."

Hilda, Parent of Child with Down Syndrome

"Walking for Charlie may be unrealistic, but that doesn't mean we can't dream about it. He has met every other goal, even things his providers said he would never be able to do."

Medical Homes + Care Coordination = Successful Partnerships

All families struggle to find enough time for all of the things they want and need to do. With all of the daily responsibilities and activities, it can be challenging to coordinate the entire family's annual preventive or primary care visits. For families of CSHCN, many also have to coordinate with multiple specialty care providers, therapists, medical tests, medications, and more. Families desperately need assistance in coordinating these various types of care. The 2009/10 NS-CSHCN shows that only 17% of families of CSHCN reported having a health provider, or their staff, who helped in coordinating their child's health care needs. Debby's story outlines the relief having a provider like this can bring to an extremely stressful scenario.

"Imagine your process to take a child to the doctor: you must take time off work, notify the school, obtain notes for extracurricular activity sponsors, etc. When Abigail's new physician took over her care, he began directly communicating with the many subspecialists involved in her care. He would arrange to run tests the specialists were interested in and report directly to them. Not only were the specialists relieved because now their colleague was taking responsibility for every aspect of Abigail's care and keeping them informed of any relevant changes in her condition, but so was I. We could visit just one doctor rather than three to five specialists at a time. Can you imagine what it meant to a very sick girl to know that her physician was 'all in'? I know it meant the world to me as her mother."



Debby, Mother of a Medically Complex Child

Having someone to assist with this coordination can reduce the stress associated with navigating our complex health system. The benefits for the family are numerous; they spend less time on the phone with doctors and more time attending to the emotional and physical needs of their child. Often, families report they spend less time being a parent, instead their time is consumed as a healthcare provider. Care coordination can improve family relationships, as well as reduce the amount of time parents miss work and the child misses school. For families in rural communities, this is even more critical. For those that must travel long distances and spend multiple hours to get to medical appointments, such as Maria, care coordination can be the difference between positive health care experiences and negative ones.

"Many times I have arrived at the health provider's office, to find that the appointment has been canceled. I'm not sure they realize how much time and effort families put in just to get to that appointment. Driving over three hours, missing work, taking my child out of school, and so much more, just for the appointment to not even happen? This is difficult and causes added stress."

Maria, Mother of a Child with Down Syndrome

“Over the years
he has seen
several specialists.
It is very time
consuming to
coordinate his
care and take him
to appointments.”

Successful Partnerships, continued...

A medical home team with a care coordination component can alleviate confusions, missed opportunities for improved care, and reduce the gaps in service delivery and health care coverage. Within the medical home, high value is placed on family involvement as the expert in the care of the child. In Kansas, less than 50% of families reported receiving coordinated, ongoing, comprehensive care within a medical home. Carrie's story shows how she was included as part of the team, in turn supporting effective communication among the provider and the family. This shows the importance of open communication and balanced responsibility with regards to directing health care.

"I built relationships with physicians on behalf of Jennifer. Being a reliable reporter of symptoms was important in building trust and our ability to be partners in Jennifer's care. At times, the doctor and their staff deferred to me because they did not know how to communicate with Jennifer. Although I was appreciative of their willingness to involve me, I sometimes felt they let me dictate the care to a degree that was not comfortable for me."

Carrie, Parent of Young Adult with SHCN

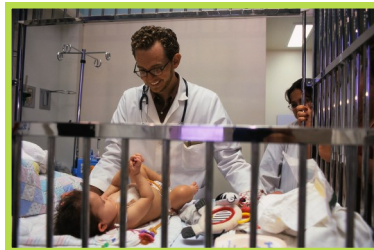
By allowing families to ask questions, and providing appropriate feedback, mutual trust and open communication can be established. Less than 30% of Kansas families who responded to the 2009/10 NS-CSHCN reported that their providers did not always encourage them to ask questions or raise concerns. In the next story, what Molly's doctor did may seem small, but for families of CSHCN, this level of open communication was very important in helping her family prepare for what was in store.

"Prior to our appointment, the doctor called to ask some follow up questions and tell me the test results were leading him to diagnose my son with Childhood Disintegrative Disorder. He wanted to prepare me in advance, so that I could research and put all my questions together prior to our appointment."

Molly, Parent of Child with Mental Illness

Families desire to work with providers who have their child's best interest in mind and treat their child and family with respect. Debby shares below how their doctor showed the ultimate level of compassion for her daughter.

"Abigail was fortunate to have one doctor step up to the plate to care for a medically fragile and complex child whose condition intimidated many skilled providers. These providers often referred to my daughter as the 'sickest child they ever cared for' or the 'most complicated child at the children's hospital'. Her doctor cared for her as though she was his own child."



Debby, Parent of Medically Complex Child

"Learn to recognize the most subtle signs of progress and know that every small optimistic sign may seem fleeting, but does have a long-term favorable effect."

Families As Advocates and Resources

“Getting connected to other parents helped me learn to advocate for my child, as well as myself and my beliefs.”

Many families struggle to find support, assistance, and guidance as they navigate the various services systems they encounter. Often overwhelmed, families reach out and seek partnerships with their providers. Families come to a point when they have to decide, “Do I wallow in this diagnosis, or do I use this to motivate me to find support and answers?” It is important to encourage families to find support groups, or reach out to organizations that help parents learn to navigate these systems, like Karen did.

“I decided early on that this situation would not get better with ‘tears and why me’s’. So I chose to look forward with a pragmatic approach. I didn’t have much of a support network when the kids were first diagnosed so I reached out to advocacy organizations for their help in understanding the law and solving specific problems I was facing.”

Karen, Caregiver of Multiple CSHCN

Conclusion

Through this paper, we hope you have learned from these families’ experiences and have a better understanding of some of the needs families have with regard to effective communication and partnerships. As you reflect on these stories please take a moment to think about how different your life would look if your child had a special health care need or a disability. Think about ways you can support these families. Additionally, we hope you consider:

- Learning more about the needs of families of CSHCN;
- Share this paper and resources with families colleagues;
- Advocate for CSHCN and their families; and
- Become knowledgeable about and connect families with community resources.

Raising CSHCN can be a unique experience with many joys and challenges. While it is hard for parents to share these challenges and the emotions they invoke, it is important for others to understand their daily struggles in order to be better partners in the provision of services for these individuals and their families.

***This document was developed by the
Kansas SHCN Family Advisory Council (FAC).***

The FAC consists of parents and family members of CSHCN who work together to provide guidance to the Kansas Special Health Care Needs Program, with support and in partnership with Families Together, Inc.

The FAC strives to promote opportunities for CSHCN to be independent, be productive, and be integrated and included in all facets of community life.

Your input is important to us. To take a short survey about this white paper, please go to www.surveymonkey.com/s/HQS22SV.



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