

Raising Children with Special Health Care Needs and the Impact on Family Health

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Special points of interest:

- Families experience daily struggles that impact all aspects of their lives.
- Parents are not the only ones impacted by a child's SHCN. Siblings feel the impact as well.
- Physical and emotional health needs are often overlooked by parents as they focus on their child's needs.
- Having a strong support system or network can make all the difference for families of children with SHCN.

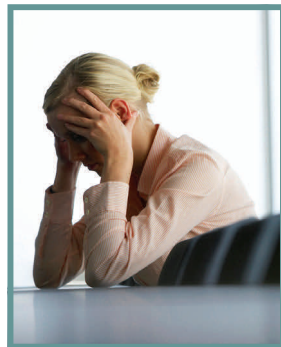
Health impacts all aspects of life. When one member of the family has health needs, such as those experienced by children with special health care needs (CSHCN), the entire family is impacted. In this paper, families describe some of the daily struggles and obstacles that they have learned to adjust to and overcome. The following stories are from families in Kansas who hope to shed light on the many impacts raising CSHCN has on the family, including parental or caregiver physical and emotional health, impact on the siblings' life, and the importance of building a support network. We hope these stories will inspire you and give you a deeper understanding of what it is like to raise a special needs child.

Overcoming Daily Obstacles

Sometimes finding a diagnosis can be the most daunting part to helping a child with a disability. Parents often ask themselves, "What did I do wrong?" The reality is, in most cases, they did everything right. If the child is diagnosed later in life, parents ask, "Why did I not realize something was different about my child?" This feeling of guilt can be difficult to overcome. Families search for answers, but this search can sometimes take years and be a very frustrating journey. This frustration felt by parents is evident in Patrick's story.

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"Our son entered young adulthood never having been treated or diagnosed as a child or an adolescent. We knew something was wrong and over the years, I grew confused, frustrated, and gradually more panicked. Finally, at age 19, he was diagnosed with paranoid schizophrenia and given the first of many medications. While I did not want my son to have a disability; the diagnosis came with a sense of relief, because we struggled for years to identify something to explain his unique behaviors."

Patrick, Parent of a Child with a Mental Illness

"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.

Daily Obstacles, continued...

There are many daily obstacles parents and families face when raising and caring for CSHCN. Parent experience many emotions when they find out they are having a child. Waiting in anticipation for what should be the most joyous day of their life is hard enough; but when something goes wrong in delivery, the emotions change to sheer fear. Julie's story describes the emotions she and her husband experienced after their son was born and shows that these emotions do not end once diagnosed.

"I felt a sense of responsibility to help my child but was unable to find answers. I worried that something important to my child's development, critical to his success in life, was going unidentified and untreated."



"I had a difficult labor and our son suffered a severe hypoxic brain injury and began having seizures. I was afraid he was going to die. We knew our journey was just beginning but we were not sure what that meant or what our future was going to be. Every developmental milestone that he misses brings us more sadness and anger with each event."

Julie, Parent of a Medically Complex Child

Families learn to adapt and adjust to their situation. They learn to face obstacles head on, think creatively to find a solution, and to navigate the hurdles they encounter. They strive to provide some level of normalcy in the midst of health crises and uncertainty. This is the reality of family life for them, regardless of how difficult or challenging it may be. Hilda's story describes the difficulties she and her son face on a daily basis.

"Life is a daily challenge and struggle for Jack; just getting out bed is difficult. His joints are stiff and he is too big for me to lift without hurting my back. His medication has to be crushed and dissolved in water before being administered. I brush his teeth for him; put his socks, shoes, glasses and his hearing aids on. For a year, I have worked with him to learn the skills needed to dress himself. It would be easier for me to just do everything for him; but he will never learn to be independent if we do not let him learn to do the things he can do for himself."

Hilda, Parent of a Child with Down Syndrome with Other Health Conditions

What About My Other Children?

Parents of CSHCN find themselves torn between the needs of one child and that of another. Many times the children without disabilities take backseat to the child with the disability, or find themselves learning to be a caregiver at a young age. This is difficult for all, and Danielle's story outlines how this has impacted her daughter.

"Our 16 year old daughter is a huge help with the boys. We try to keep her from having to take on the role of caregiver for them - it's not her responsibility! Although we have tried to not let their needs affect her social life or activities, she's still suffered a lot."

Siblings, continued...

Raising CSHCN can complicate one's relationships with other children in the household because of the care required for the child with health needs or disability. All parents have to juggle attention and time with their children, but with CSHCN that juggling act is much more demanding and difficult. Karen describes how she has overcome this challenge with her children.

*"I always told my children that I was not fair – each child would receive what he needed, when he needed it. Sometimes that meant more attention to one over the other. I would remind the child who was feeling "jilted" that allowing me to be generous to their sibling made it easier for me to be generous with them at another time, when **they** need it. We were a team, a family, and in our household there were no special considerations, or special time, given because of one's disability – only for their immediate needs."*

Karen, Parent of Multiple CSHCN



Although being a sibling with special needs can be difficult, they can also learn a lot from their experiences. Frequently, they choose career paths where they can help children like their sibling. Even at a young age, children can sense the needs of their sibling and learn to be compassionate and understanding. Julie's story is true testament to this.

"Although he is only two years old, Logan's younger brother is always aware of when Logan is sick or needs something. Of course, there is a possibility he may become resentful that a lot of time and concern is placed on Logan; but I believe having a brother with a disability is allowing him opportunities at a young age to learn acceptance and compassion for others."

Julie, Parent of a Medically Complex Child

Older siblings will often try to protect their parents from any added stressors, beyond those experienced due to their sibling's health needs. Debby's son, Tom, did just this. He feared an important school function would cause her to miss more work and add stress, so he asked a teacher to "stand in" during his National Honor Society Induction Ceremony. Debbie shares the impact this had on her.

"I learned about this on the same day of the ceremony and rushed to get to the school. His teacher saw me and happily stepped aside just as the group started to move into the school auditorium. It meant so much to me to be there and also made me very sad that my son had learned to not count on me being present for his major life milestones."

Debbie, Parent of a Medically Complex Child

"It can be very difficult to be able to spend time with our other children, but we always try to help them feel like they are also an important part of our lives."

Siblings, continued...

Siblings can find themselves torn between being a supportive family member and their desire for their own life. Having their own support network of peers and friends is important. Despite efforts to keep their friends separate and longing for when they can be themselves, they can't get away from being the brother or sister of someone with health needs. Tom shares his experience with how his sister's health needs impacted his friendships and how he interacted with others.

"The first thing people would ask when I saw them was, 'How is Abigail?' While I understood their care for how she was doing, I began to forget that I was an individual, and started seeing myself only as 'Abigail's brother.' That really wore on me. Especially as I was trying to form my own identity while progressing through my teen years. I eventually quit telling people that I had an ill sister, that way all they would know is me."



Tom, Sibling of a Medically Complex Child

My Health Matters Too!

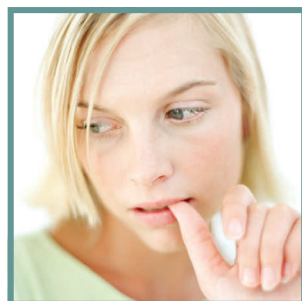
"Our son has sleep apnea and if he slept six hours a day we were lucky. He never acted tired. I, on the other hand, was exhausted."

Naturally, when their child is sick parents tend to focus on taking care of the child's needs. Many parents will admit they forget to take care of their own health. One parent provided this analogy: "You have to train like a professional athlete. An athlete has people constantly evaluating them. They eat for nutrition and endurance. They know how important their frame of mind is to their success." Nicole's story outlines how critical this can be when caring for a CSHCN.

"Over the years, I have cried happy and sad tears because of Susie's situation. I cried the most when her mother took her and we didn't have any contact. Due to the situation with Susie I became overly stressed which lead to a stroke."

Nicole, Caregiver of a Child with Cerebral Palsy

Physical health impacts emotional health, and vice versa. The process of identifying a diagnosis, the associated confusion, fear, frustration, and feelings of helplessness can have an impact on one's physical health. Patrick shares how years of resistance from both his child, and health providers, impacted his emotional and physical health.



"The frustration, disappointment, fear, and depression I experienced during our two-month stint in the hospital, and all the stress involved, contributed to a ten pound weight loss, intense suffering from fatigue during the day, and inability to sleep most nights."

Patrick, Caregiver of a Child with Mental Illness

Caregiver Health, continued...

These stories show how critical it is for parents to take care of themselves, both physically and emotionally. Help make sure they get their routine health examinations. Refer them to a therapist, counselor or a peer support network. The problems parents of CSHCN encounter are bigger than they are, and having someone to talk to about these things can make a difference. Danielle's story describes the emotions that she feels each time their son is hospitalized and the fear that accompanies these experiences.

"I am torn between taking care of our children at home and taking care of our sick child. Each time I leave the hospital to take care of things at home I wonder, is this the last time? Is this the time I am going to have to say goodbye? Will I be able to say goodbye and tell him I love him so, so much? His days are numbered and that is always hanging over our heads as loving parents."

Danielle, Parent of Multiple CSHCN

In the midst of an emotional journey, parents often find they have to remind themselves that taking time for themselves and figuring out who they are can really make a difference in their parenting abilities. Learning to advocate for their children can build confidence and boost self-esteem.

"My life slowly began to change. Isabell was transforming me into becoming a better mom, not only to her but for my other daughter. My mind began to change and I began to see life very different having a daughter with special needs. I love my daughter and I would not change her for anything!"

Maria, Parent of Child with Down Syndrome

Finding a System of Support

Life is stressful and relationships are tested. For parents of CSHCN it can be even more difficult to manage and maintain marital relationships. Despite challenges, couples often come together and become a stronger unit in their support of one another to meet the needs of their family. Danielle's story shows how adopting three boys with disabilities has strengthened their family, while also experiencing strained relationships with other family members.



"In a house like ours, it's difficult to find time with one another. After almost twenty nine years we have found that by having faith, and some humor, we have made it through the tough experiences. We chose to take on the challenges of raising children with special needs with an open mind and heart. Unfortunately, our immediate and extended families are not supportive of the life we have chosen. Many of them do not understand why we adopted children that 'no one else wants to have or keep.'"

Danielle, Parent of Multiple CSHCN

"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."

Support, continued...

Many families experience social isolation from family, friends and their community because of their child's disability. Even the closest families experience isolation and find that the challenges of raising CSHCN can strengthen or tear apart relationships with others. It is heartbreaking when contact with family ceases and you cannot rely on family for support.

"My side of the family refused to have any contact with us because we were awarded custody of Susie. Before this happened, we were very close. It was heart breaking for me to not having any contact with my family."

Nicole, Caregiver of Child with Cerebral Palsy



Conclusion

Through this paper, we hope you have learned from these families' experiences and have a better understanding of some of the barriers or obstacles associated with family or caregiver health. 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 and promote good physical and emotional health for families of CSHCN. 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 ups and downs. 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.

***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.



**Kansas Special Health
Care Needs (SHCN)
Program**

1000 SW Jackson, Suite 220
Topeka, KS 66612

1-800-332-6262

ksresourceguide@kdheks.gov

