

Financial Impact of Raising Children with Special Health Care Needs

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Special points of interest:

- Raising CSHCN can impact employment opportunities and options.
- The high cost of health care services, medications, insurance premiums and other medical costs impact all aspects of family life.
- Insurance coverage impacts care options, service utilization and family stress levels.
- Financial planning for a child's future can add stress and relief at the same time.

One of the greatest challenges families of children with special health care needs (CSHCN) face is financial struggles. While there are many different services available to help, many families are unaware that they exist and rely on medical and community service providers for valuable and relevant referrals to these services. One's finances impact decisions related to employment, cost and utilization of health care services, insurance coverage needs, and planning for the future. The following describes real-life experiences families in Kansas face on a daily basis.

Work: Challenges, Barriers, and Obstacles

Having a child with special health care needs or disabilities can affect a parent's ability to find and maintain employment, particularly if their child's health impacts the need for flexibility in work schedules. The National Survey of Children with Special Health Care Needs (NS-CSHCN, 2009/10) indicates that 23% of families in Kansas report that their child's health condition caused them to cut back, both in time and/or pay, or stop working completely. The decision to change jobs or start their own business was impacted for Julie's family because insuring their son was too costly and no one would provide coverage. We hope these stories will give you a deeper understanding of what it is like to raise a special needs child and inspire you to learn more about the individual financial needs of those you interact with.

"When Logan was about eight months old, I decided to leave my job and focus on his needs. We did not qualify for any programs due to income; even though we were now a one income family.



For my husband, insurance benefits limit his ability for movement with his career. He has to keep a job that has good insurance coverage. This prevented us from being able to own our own business because we could not find affordable insurance or someone to cover him."

Julie, Parent of a Medically Complex Child

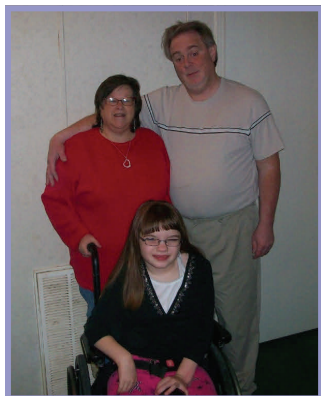
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"Children with special health care needs (CSHCN) are those who have, or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required 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.

Work, continued...

The need for quality insurance can cause some families to make difficult choices with regard to their jobs and careers. Often families report accepting a job below their desired pay and insurance benefits. According to the 2009/10 NS-CSHCN, nearly one-fifth (19.8%) of families describe avoiding changing jobs due to concerns of maintaining adequate health insurance, as was the case in Linda's story.



“Our need for quality insurance has definitely impacted my employment. I stayed with a very low paying job for much too long because the insurance was excellent. But health insurance doesn't pay bills or buy groceries. As a nurse I could make a lot more money working night shifts or commuting to a larger, more urban community. I am very hesitant to leave town with our home situation and my son's needs. I tried working nights at our local hospital for a year. Although the pay was great, finding someone dependable to stay with the kids at night was difficult.”

Linda, Parent of Child with Autism

“I know I can't work outside the home and take proper care of my children. I just don't have the energy to do that.”

Nearly 14% of CSHCN missed 11 or more days of school due to their health or illness (NS-CSHCN, 2009/10). Often, this causes parents to miss work, which can put their job in jeopardy. Maria describes how finding a job with a flexible work environment was necessary for their family.

“I was working and able to make a living before my daughter was born. Once I had Isabell, my job was determined by her disability because I needed a job that was flexible so I could attend her numerous medical appointments. The job I have now is very flexible, but I do not make a lot of money.”

Maria, Parent of Young Adult with Down Syndrome

High Medical Costs Impact Living

The combination of the costs of medical care, medication, durable medical and other life saving equipment, and insurance premiums and co-payments can cause extreme financial hardship for many families. Approximately 22.1% of Kansas families of CSHCN reported paying \$1,000 or more out-of-pocket in medical expenses in the last year (NS-CSHCN, 2009/10).

“When our son began having trouble eating and needed to get a feeding tube in his nose, our local doctors felt it was time to seek more specialty care at a children's hospital. This brought many co-pays, coinsurance, and gas traveling back and forth to the hospital, about 60 miles away.”

Julie, Parent of a Medically Complex Child

Medical Costs, continued...

While there are services available to help families of CSHCN, many families are unaware that they exist or they do not qualify for those services. For those who are able to access those resources, they are not nearly enough when you look at the deep financial burden most families experience.

“We lived in overdraft, thank goodness for our overdraft protection! Our goal was not exceeding our limit and getting checks bounced. Learning to make choices as to what meds we considered optional and could go a day or two without and asking the pharmacy to process a “partial refill” between paydays were skills developed from necessity. We paid two insurance premiums and struggled to not exhaust our flexible medical spending accounts (we took out the maximum amounts for both my husband’s and my employee benefits). If we couldn’t make it to August, we knew it was going to be a rougher than usual fall and winter.”

Debby, Parent of Child with Significant Health Needs

Karen’s story illustrates how having the right attitude can help overcome barriers and obstacles and make the best of situations when things look bleak.

“I believe that wealth is a perceived state of mind. Money was always tight, but we had a roof, food, clothing and education. It is just a matter of priorities. Using the library, shopping at thrift stores, using day old grocery products and not eating out is not poverty – it is being financially smart.”

Karen, Parent of Multiple Children with Special Health Care Needs

Over 26% of families of CSHCN reported that their child’s needs caused financial problems for the family (NS-CSHCN, 2009/10). Families have many factors to weigh when trying to fund basic needs. Danielle’s story describes what families go through on a daily basis.



“The equipment needs for a child like Charlie is overwhelming. It is intimidating to figure out how to fund basic, life-changing needs, such as medical equipment. Will insurance deem it necessary? What will my out of pocket cost be? How quickly will he grow out of it? If he grows too quickly, does that change the cost effectiveness of obtaining the equipment? Weighing all these factors can be daunting and exhausting. Multiple funding sources and supports are needed to ensure these things happen.”

Danielle, Parent of Multiple Children with Special Health Care Needs

“Money has always been extremely tight due to medical costs and necessary equipment.”

Waiver Services Make Living Possible

Home and community based services (HCBS), a program that provides in-home services as well as a medical card for participants of the program, can be life altering. In Kansas, eight waiver programs serve an average of nearly 25,000 individuals each month, totaling over \$306 million of services to Kansans in need (Kansas Department for Aging and Disability Services, 2011). Families often express how valuable these services can be to them and their child.

“When Logan was four years old, we qualified for the technology assisted (TA) waiver program. This waiver is for children who are dependent upon intensive medical technology and who are medically fragile. This program has been lifesaving. It provides us with respite care for Logan, a medical card that will cover what our primary insurance does not – including co-pays for medications, co-insurance costs, special chairs, syringes, tape and other equipment and supplies. I am not sure where we would be today without it.”



Julie, Parent of a Medically Complex Child

The uncertainty and fear that their child will no longer be eligible for these services can cause great stress for families. Hilda’s story expresses this fear and what it would mean for her and her family if these services were not available.

“I am fearful every year with Jack’s annual assessment that he will no longer qualify for the I/DD waiver. Without it he would not have health insurance coverage. I cannot afford to purchase private insurance and he would not qualify for Medicaid without the waiver. Although there are programs in place to assist those without health insurance, I have found very few programs that will assist a middle class family. Jack’s medication is almost \$600.00 a month, if he did not have Medicaid I do not know how I would pay for the medications and his physician’s visits. I know Jack’s illnesses well and I don’t take him to a physician unless I am sure it is something I cannot manage on my own.”

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

Families of CSHCN report having an unmet need for health care services, 20.5%, and family support services, 7.2% (NS-CSHCN, 2009/10). Changes in health status can cause a change in insurance providers or insurance coverage, as Molly describes here.

“Changes in Bobby’s diagnoses put his services in jeopardy and we were unsure if we’d be able to stay on his current waiver. It was determined that we may be eligible through another waiver program, however there was a very long waiting list for that waiver. If services were not available, this could have led to many more problems for Bobby. We felt like we were in a no-win situation.”

Molly, Parent of Multiple CSHCN

“In reality, all the time and effort in seeking resources leads families to stop and think, “Why do all of this? Maybe we should just pay for it and go without food or clothing or electricity?” Or the alternative, just simply sit down and have a good cry.”

Insurance Coverage Challenges

Approximately 32% of Kansas families of CSHCN report inadequate health care coverage and 10.7% of families reported having a period of time during the last 12 months where their child was not insured at all (NS-CSHCN, 2009/10). Commonly, families may have either public or private insurance coverage, or both, however this is not always adequate to cover all health care costs and needs. Additionally, standard insurance policies or protocols can determine individualized care.



“According to the insurance company, my son’s doctors were expected to diagnose and develop a plan for therapy after spending several minutes each day with him during his hospital stay. This was during the time my son was suffering the biggest deficits from his illness and he was the most uncooperative with his treatment plan.

The expectations by the insurance provider for my son seemed to be similar to any patient that had full mental capacity, not based on his individual needs at that moment.”

Patrick, Parent of a Child with Mental Health Needs

Even when families have medical coverage, they are challenged with justifying each and every service or need. Filing appeals, explaining medical necessity to people who do not understand or know the child, maintaining coverage, obtaining annual assessments, and coverage limitations are all things that families of CSHCN encounter when working to get their child’s needs covered. Danielle’s story, as well as the previous stories in this section, help to understand how this impacts families.

“The MOST frustrating thing for us is when the insurance makes decisions based on protocols or procedures. They do not know my child, what does he look like, what is he capable of, what are his needs, or what is medically necessary or just a safety measure? These life or death decisions affect my child directly and I have had to appeal many decisions made by the insurance company.”

Danielle, Parent of Multiple CSHCN

Finances for the Future

Transition to adulthood for CSHCN can be a very trying time. There are many things to arrange or assure is in place for the future. Families have much to consider and multiple legal decisions to make. This includes preparing for and obtaining guardianship, if applicable. Julie describes how they have prepared for their son’s future.

“Logan will be with us for his entire life. He needs total support and that is not likely to change. Because of his needs, we have set up a special needs trust to ensure he is cared for if something were to happen to myself or my husband.”

Julie, Parent of a Medically Complex Child

“I felt great stress because we were reaching our inpatient hospital stay maximum and a solution had not been identified yet. We weren’t sure what we were going to do.”

Future, continued...

"It never occurred to us that a Power of Attorney would be needed. There was no guardianship in place when the time came."

A recent survey shows only 38.7% of youth ages 12-17 in Kansas were reported as having received anticipatory guidance for their transition to adult health care, which should include planning for the future and the financial need for the child or young adult (NS-SHCN, 2009/10). It's important to ensure youth are prepared for adult life. For those that are not able to be fully independent, it can be especially challenging for the parent as most future planning requires legal involvement and with a high cost.

"I do worry about what will happen to him in the future. I can't afford an attorney for financial planning, which causes additional guilt because I think he will be lost when I am gone. "

Linda, Parent of Child with Autism



Conclusion

As you can see, the financial burden on families of CSHCN can be extensive. Increased stress, grief, fear, and worry can be detrimental to the health of the family, including the child. It is encouraged that providers consider these financial strains and work with families to help them meet their needs, in the most affordable and cost-effective manner. 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 the financial struggles in order to better partner 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.



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