

Champions for Children: Lifeline to Families with Medically Fragile Children



About the Community Foundation for Greater Atlanta

Since 1951, the Community Foundation has been connecting donors, nonprofits and community leaders to strengthen the 23-county Atlanta region through philanthropy. By uniting the passions of donors with the missions of nonprofits, the Community Foundation serves as a conduit for change by providing quality services and innovative leadership on community issues. Visit cfgreateratlanta.org for more information.

About Champions for Children & the Community Foundation for Greater Atlanta

Thousands of Georgia families who earn too much to qualify for Medicaid rely on the TEFRA/Katie Beckett Medicaid program to help them afford care for children with medical needs. In 2004, the process for determining the level of care under Katie Beckett was adjusted, reducing the number of qualifying families by 1,681. The Legislature appropriated \$7.6 million in 2006 to help these families. The Community Foundation of Greater Atlanta was asked to oversee \$4.3 million, which was to be distributed to nonprofit organizations. The Foundation partnered with Easter Seals of Southern Georgia and four other affiliates to provide financial assistance and support to qualifying families of medically fragile and special needs children. The effort was called Champions for Children with Exceptional Needs, known simply as Champions.



State and local nonprofits prove working together benefits children in need

The narrowing of a federal program for families with disabled children led to an opportunity for the Georgia Legislature to strengthen local support for families. Today, the Champions for Children program, administered by Easter Seals Southern Georgia, provides reimbursement for therapies, supplies and respite care. The program also helps families access other community resources, closing gaps in coverage and lessening the stress families experience while raising their exceptional child.

Champions for Children is an example of state government and local nonprofits working together to fill a pressing need and improve the lives of children.



Loss of Katie Beckett

Families with medically fragile children face obstacles every day. They must determine their child's needs, find the right program to address those needs and figure out a way to pay for services. In addition to insurance and money paid out of pocket, many families rely on the Katie Beckett program, established in 1982 to provide Medicaid benefits to disabled children, regardless of parents' income.

In 2004, a change in eligibility requirements caused 1,681 Georgia families to lose coverage under Katie Beckett. The average annual reimbursement under Katie Beckett was \$5,000, a significant sum for parents already stretched thin by the cost of caring for their exceptional child.

Georgia legislators responded to these families' cries for help, appropriating \$7.6 million in the supplemental 2006 budget. Of this allocation, \$5.4 million was used to carry families over for one year as they adapted to the loss of coverage under Katie Beckett. The remaining \$2.2 million was set aside by the Georgia Department of Human Resources to be awarded to nonprofit organizations. Recipients would use the funds to provide critical services to Georgia families deemed ineligible for Katie Beckett as well as other families in need and to connect families with additional local resources.

Katie Beckett is a federal program established in 1982 to provide Medicaid benefits to disabled children, regardless of parents' income. In 2004, a change in eligibility requirements caused 1,681 Georgia families to lose coverage. The state of Georgia partnered with the Community Foundation as part of their solution to those left in need.

“The language, expectation and culture are different between sectors... we had to navigate these differences, all while keeping children and families as our first priority. Everyone brought their particular expertise to the effort, and the result was amazing.”

—Lesley Grady, senior vice president, community, Community Foundation for Greater Atlanta

Families exasperated by red tape

The Community Foundation was brought in to provide leadership in the enlisting of nonprofit organizations to provide services for these children and their parents.

“Partnering with government requires open, honest dialogue,” said Lesley Grady, senior vice president of community at the Community Foundation. “The language, expectations and culture are different between sectors and we had to navigate these differences, all while keeping children and families as our first priority. Everyone brought their particular expertise to the effort, and the result was amazing.”

An examination of the issue, which included focus groups, interviews and forums with parents of exceptional children, revealed a constant financial and emotional struggle in trying to access therapies and services their children desperately needed. Parents expressed frustration at the red tape involved in accessing public funds. They longed for a simple process that would ease their burden rather than place additional obstacles in their already difficult paths.

The Community Foundation used this feedback to create a Request for Proposal. In 2008, a \$4.87 million, multi-year grant was awarded to Easter Seals Southern Georgia (ESSG), an affiliate of Easter Seals Inc.

ESSG was chosen for its deep understanding of the needs of families of exceptional children. Easter Seals has been helping people with disabilities nationwide for almost a century. ESSG has been serving residents of 39 counties since 1957. Its Family Support Program has a simple, quick determination of need and eligibility process.

A partnership was formed among ESSG and four other Georgia Easter Seals affiliates, known as the Georgia Coalition. Parent to Parent of Georgia, the state’s primary resource network for Georgia families impacted by disabilities, was another key partner that joined the coalition. This coalition was charged with administering a statewide program known as Champions for Children.



Champions for Children

The goal of Champions for Children was to allow families to continue to care for their exceptional children at home. This was achieved by providing some of the reimbursement for services and supplies previously provided by Katie Beckett while requiring less red tape to access the reimbursement. Additionally, the program connected families with other services offered by nonprofits, lessening families' dependence on public funds.

Reaching out to families shut out of Katie Beckett proved challenging because of privacy restrictions. An aggressive marketing effort was launched to reach families and inform them of the new program. Over the course of the five-year grant, 357 children were served. The average expenditure per child served over the five-year period was \$4,908. Of the children enrolled, autism was the most common diagnosis, followed by cerebral palsy and Down syndrome.

The most common services funded through the program were various types of therapy, including speech therapy, therapeutic riding, recreational therapeutic activities and memory therapy. Many families received coverage for diapers and other medical supplies.



Brix's Story

When Brix was born four years ago with Down syndrome and a heart condition, he needed therapy for feeding issues and referrals to various specialists. He was hospitalized several times with pneumonia.

His parents were overwhelmed with medical bills. Champions for Children stepped in to cover some of the costs not covered by insurance. That support also enabled Brix to continue horseback riding, swimming, as well as occupational, physical, speech and feeding therapy.

Today, Brix is a fun-loving child who enjoys dancing, riding four-wheelers and wrestling with his six-year-old brother.

Support from Champions for Children enabled Brix to continue horseback riding and swimming, as well as occupational, physical, speech and feeding therapy.

“We will always be grateful for the people who make up Easter Seals and the Champions for Children program,” his mother said. “Brix has been given many opportunities to be successful, and that is the best gift anyone could give our precious Brix.”

“Champions has provided support and hope,” one client said. “Without their help, our child would not be able to function to the best of his ability. Without the therapy, services and equipment provided by this grant, he may never have spoken or had movement.”

“This program has been outstanding in terms of fulfilling the legislative intent,” said Nicki Wilson, director of respite and family support services at Easter Seals Southern Georgia. “I identify with these families. They are working, middle-class families who don’t want help but find themselves desperate to meet the needs of their child.”

As an added benefit, many families were referred to Parent to Parent of Georgia, a partner program that provides one-on-one emotional support, referrals and Spanish language assistance. Parents especially appreciated referrals to parents who have experienced living with a disability, a connection that helped parents feel less alone.

“This is about more than meeting immediate needs,” said Beth English, executive director of Easter Seals Southern Georgia. “It’s a tool kit to be better able to care for their kids, to be better able to navigate the system.”

Brooks’ Story

Brooks, an active nine-year-old and aspiring actor, needed eye drops for glaucoma and growth hormone therapy because his pituitary gland was damaged as a premature baby in the NICU. His family faced additional bills for eye glasses, doctor visits and special needs camps.

Champions for Children stepped in to help cover some of these expenses, a service that offered Brooks’ family assurance that their son would get the care he needed.

Glaucoma is a progressive disease with no cure, so Brooks, who is legally blind, learned to read Braille in school. His parents hope it’s a skill he won’t need to use, but they want him to have that proficiency, should he lose his vision completely.

Champions for Children is a partner for families dealing with complex medical needs. These families make decisions big and small every day to ensure their child the opportunity to live life to the fullest. They need support, empathy and help covering costs.

Champions for Children support helped Brooks’ family pay for growth hormone therapy, eye drops for glaucoma, eye glasses and special needs camps.

“The Champions for Children program has been such a blessing in our lives,” Brooks’ mother said. “We are very thankful for Champions for Children, and all those who work so hard to help families like ours.”

Praise for Champions

Families enrolled in Champions for Children consistently praised the program. Ninety-eight percent of clients surveyed said the Champions program allowed choices of services, and 97 percent said they felt empowered. While only 21 percent had an easy time accessing services before they became a Champions client, 86 percent had an easy time after getting help from Champions.

Ninety-two percent of clients surveyed said Champions had continued or extended their ability to care for their children at home. One family reported relief from having to choose between food and medical procedures for their son.

Said a parent of triplets: “The support we’ve received from Champions for Children has helped tremendously. It has allowed us to focus on their needs without having to worry about the financial implications of the medical costs not covered by our insurance.”

Looking ahead

Champions for Children continued after the grant expired in 2012, using \$980,000 in unspent funds from the Community Foundation grant along with funds raised by the Coalition.

Today, the Easter Seals affiliates are still working together to serve these families, even though funds for administering the partnership have been fully expended.

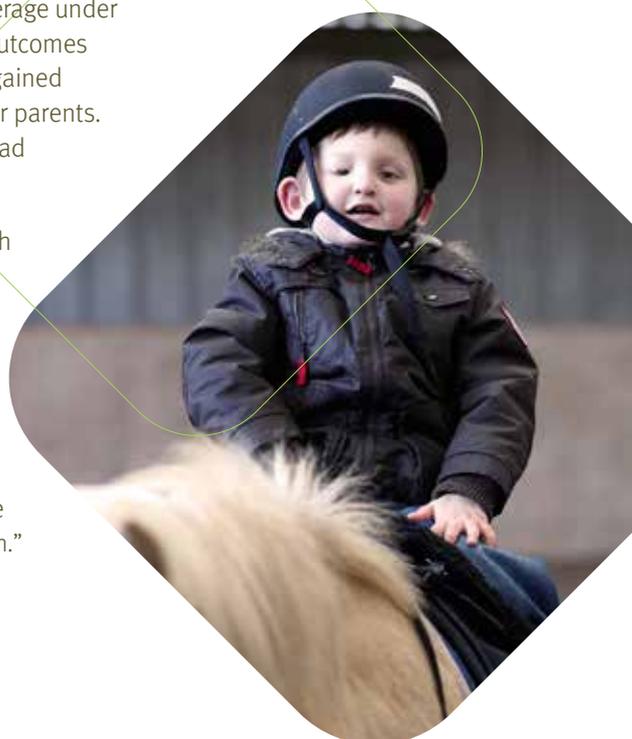
“It’s a testament to the strength of the program that these affiliates, who had never before worked together on a statewide initiative, are continuing their important work,” said Lita Pardi, senior program officer at the Community Foundation. “The program taught us that individuals, nonprofits and government agencies can identify solutions that work for everyone.”

Champions for Children began as a way of helping families denied coverage under Katie Beckett. The program met or exceeded its goals and intended outcomes in alignment with legislative intent. Along the way, service providers gained a greater understanding of the needs of exceptional children and their parents. A group of nonprofit affiliates learned to work together in ways they had not attempted before, all for the common good of families.

The program was more than a coordinated effort to assist families with exceptional children. Champions for Children became a model for how the nonprofit community can come together and responsibly carry out the goals of the Legislature to improve lives for a specific constituency.

“Champions for Children seems to me to be a well-run, well-managed program,” a recipient of services said. “It seems to require accountability on the families’ behalf and at the same time be truly accessible to those who need and apply for it. Our family cannot thank you enough.”

In an additional effort to ensure continuity of care, the Foundation set up a \$1.5 million fund at the Community Foundation of Central Georgia in Macon to support Champions for Children families in need of ongoing support. The fund generates up to \$70,000 a year, which goes directly to these families.





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