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Services and Support for Georgia Families of Children with Special Needs: Findings from a Community Outreach Effort

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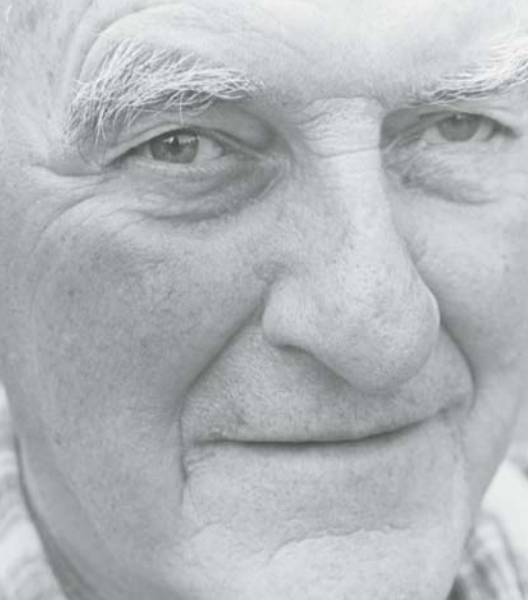
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**Services and Support for Georgia
Families of Children with Special Needs:
*Findings from a Community Outreach Effort***

prepared for

The Community Foundation for Greater Atlanta

by

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June 2007

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Executive Summary

This report details the results of a mixed-method community outreach effort conducted by the Georgia Health Policy Center (GHPC) as part of The Community Foundation for Greater Atlanta's Champions for Children with Exceptional Needs Initiative (Champions).

The purpose of this outreach effort is (1) to provide a systematic examination of the existing gaps in service and support for families with medically fragile and special needs children in Georgia and (2) to compile a list of service delivery options gathered from the community outreach efforts that could be provided to families through the funding of an appropriate nonprofit or network of nonprofits across Georgia. The report will be shared with The Community Foundation and the Champions Advisory Committee to guide them in the distribution of at least \$2.2 million that has been appropriated by the Georgia Legislature to meet the needs of this population.

Data collection for the Initiative used both quantitative and qualitative approaches to explore the experience of families with special needs and medically fragile children. The quantitative component included a Medicaid claims analysis of children eligible for the Katie Beckett Waiver program during Calendar Year 2005. The qualitative data collection methods for the community outreach effort included:

- Three focus groups with parents of special needs and medically fragile children;
- Sixteen Key Informant interviews with parents, advocates, representatives from local and state-wide non-profit agencies and medical providers;
- Two community forums structured to present data collected in the needs assessment and outreach and gather suggestions/feedback from community members regarding possible service delivery models.

Medicaid Claims Analysis

Findings from the Medicaid claims analysis of children who received services through the Katie Beckett Waiver program in 2005 exemplify the needs of many medically-fragile children in Georgia. In Calendar Year 2005 (CY2005), there were 6,572 children enrolled in Medicaid through the Katie Beckett class of assistance. The descriptive analysis of the Katie Beckett enrollees found that:

- 95% (6,130) of the Katie Beckett children submitted at least one Medicaid claim during the year. The top two diagnoses, specific delays in development and psychoses with origin specific to childhood (infantile autism, disintegrative psychosis and schizophrenia) comprise 28% of all the outpatient claims.
- The average Medicaid reimbursement per Katie Beckett recipient was \$5,033 in CY2005. The services that Medicaid paid for the most were therapeutic services, prescriptions/medical equipment, and home services.
- In addition to Medicaid, most Katie Beckett children also have some other insurance coverage. Of all the Katie Beckett children who used any Medicaid services in CY2005, 76% had at least one third party liability payment. For these children the average yearly third party liability claim is \$2,878 while the Medicaid share averages \$4,198.

This descriptive analysis of Medicaid claims data provides a snapshot of the patterns of service utilization of children enrolled in the Katie Beckett Waiver program in 2005. The findings show that even those families with private insurance relied on Medicaid to pay a significant portion of expenses related to therapy, prescriptions, medical equipment, and home-based care.

Findings from the Community Outreach Effort

As part of the community outreach effort, the Georgia Health Policy Center conducted three focus groups with parents of medically fragile and special needs children. Focus groups were held both with families still receiving benefits under the Katie Beckett waiver program and those families who lost benefits after the change to the level of care determination process in 2005.

One-on-one interviews were conducted with sixteen Key Informants. The sixteen Key Informants who were interviewed as part of the community outreach process represent a wide range of stakeholder groups who have professional and personal experiences with medically fragile and special needs children and their families. In the presentation and description of the qualitative findings from the interviews and focus groups, the term “special needs children” is used to describe the support and service needs of medically fragile children as well as children with special medical and/or therapeutic service needs.

There was significant overlap and concurrence between the key themes that emerged from the parent focus groups and Key Informant interviews. Key Informants and parents who participated in the focus group discussions see the State as providing necessary direct support for important services such as therapies, home-based care, financial assistance for co-payments, prescription medications and durable medical equipment that are not otherwise covered through private insurance or available through non-profit organizations. This assistance usually comes to families through Medicaid and Medicaid waiver programs. They see the supports provided by the State to families as essential to the survival and development of medically fragile and special needs children.

Parents and Informants alike described the myriad of obstacles that families with special needs children face in caring for their children. Trying to meet the medical needs of their children is a constant struggle for parents, both financially and emotionally. When parents seek support from government, they are met with a complex system that appears to them to be inflexible and is extremely difficult for them to navigate. Parents brought all of their frustrations in dealing with the Katie Beckett Waiver program to the discussions about their struggles to obtain care for their children and when envisioning the most appropriate way to spend the \$2.2 million allocated from the State Legislature. Their greatest hope is the decision reached regarding the expenditure of these funds will ease their burden rather than be yet another obstacle to receiving care for their children.

Key Informants and parents were asked to provide their ideas for how the funding allocated through the Champions Initiative could be best utilized to meet the service and support needs of families with medically fragile and special needs children. They provided some overarching principles they feel should guide allocation of the funding to non-profit agencies as well as more specific service and support models that should be prioritized for funding through the Initiative.

The guiding principles proposed by Key Informants and parents can be classified into the following general thematic categories:

- *Determination of need and eligibility:* The current level of funding allocated to this Initiative does not begin to come close to the level of funding that is needed to meet the service and support needs of medically fragile and special needs children across the State. In order to reach the most families, some Key Informants suggested that the funding be “reserved for parents who don’t have any other options.” They suggested that it may be necessary to limit the services or supports provided through the Initiative to a focused set of services, make services available to specified diagnoses groups, or provide support for a limited amount of time to each family served. Most of the parents who participated in the focus group discussion held a divergent view of the concept of establishing eligibility criteria for the services funded through this Initiative. Many are wary of services that require an eligibility determination process and expressed the sentiment that qualification for support should be based on the child’s need and not on the income of the family.
- *Eliminate red tape:* Informants and parents stressed the importance of making access to the services or supports offered through the Initiative easy and free of cumbersome red tape and applications. Central to this concept of a simple process for obtaining support is the commonly expressed sentiment that the funds allocated by the Legislature should not be used to “set up another bureaucracy.” The funds should go to the direct support of children, not to pay for the administration of a program.
- *Early intervention:* Early intensive and consistent intervention with special needs and medically fragile children is crucial to the development of their children and will reduce the financial supports required of the State when they become adults.
- *Equitable access:* Services and supports must be accessible to families throughout the State and through multiple channels. The non-profit or network of non-profits that are funded to support families through the Initiative must have reach and presence throughout the State.
- *Sustainability:* Key Informants feel strongly that in order for this Initiative to be successful, long-term support and sustainability must be built into the design. Children who are developmentally delayed or who have chronic medical conditions are not “cured with a year of therapy.” Their needs span a lifetime and require support across their development.

Key Informants and parents were asked to envision and describe delivery models that would meet the unmet service and support needs of families through funding efforts by an existing non-profit or network of non-profits. They suggested an array of potential options that ranged from providing direct financial support to families to intervening at the systems-level to reorganizing the way that services are delivered to children with special needs in the State. The range of potential options can be categorized into the following general service and support approaches:

- *Provision of flexible monies to parents for their children’s needs:* Many Key Informants acknowledged that the biggest need for many families with medically fragile and special needs children is expanded access to direct services. Financial assistance to obtain therapies, durable medical equipment, prescription medications and respite care are in high demand and in short supply for many families.

- *Creation of/expansion of a resource center that is a ‘one-stop shop’ for family-centered supports, information and referral:* Funds could be used to expand upon existing family resource and information centers that are currently working to aid families as they struggle to navigate the complex State system and seek out community resources for their children. An ideal resource center would provide information for families, but would also be “hands on” and provide training and skills development to families and providers.
- *Provision of case management and service coordination:* Families struggle to manage the complex medical, social and emotional needs of their children and could greatly benefit from having an individual assigned to help families navigate the public and non-profit sectors and provide case management and care coordination.
- *Expansion of programs offered through the public school system and the community to effectively transition children into adulthood:* Many stressed the importance of the public school system in the delivery of services for special needs children and see the school as a potential intervention site for the provision of services funded through this Initiative. They spoke of the need to expand the quality and intensity of the therapies and other support programs provided through the schools to effectively prepare children to live as independently as possible in the community and direct their own care as adults.
- *Establishment of local, community-based networks of support for children, parents, professionals, and community allies:* Informants spoke of the need to educate local communities about the needs of special needs and medically fragile children. Central to this concept is the principle of local communities being empowered to seek out local solutions for families. The focus of this effort would be to raise community awareness about the needs of these children and their families so that communities can respond accordingly with adequate local services and supports.
- *Coordinate advocacy for medically fragile and special needs children and their families:* Parents suggested using the funds to hire advocates to bring their concerns to the attention of State policy makers. Informants also spoke of the need to “force change” in the system by using the earmarked monies to establish a legal fund for families seeking representation to compel the State to meet its obligations to medically fragile and special needs children as mandated under State and Federal statutes.
- *Systems-level interventions:* Work at the State level to encourage increased communication and collaboration across agencies that service families and children.

One of the key themes that emerged from the Key Informant interviews and the focus group discussions was the need for change to occur at the systems-level within the State. Though this type of change process is beyond the scope of this Initiative, many parents and Informants feel strongly that the unmet service and support needs of families with medically fragile and special needs children cannot be adequately addressed in Georgia until key leaders in the political and state agency systems make significant changes to the way that services are delivered to families and children in the State. Suggested systems-level initiatives included: using the allocated funds as an incentive to bring state leaders to the table to begin talking about how to “de-silo” government’s approach to supporting families and ensure a more effective delivery of services; hiring a private firm to audit Medicaid and the Katie Beckett waiver application process to make

the process simpler for families and ensure a more efficient delivery of services; and establishing a separate unit within DFCS of case workers trained specifically to coordinate the care and provide information and referral assistance to families of children with special needs.

Though there was not one view of how best to utilize the funds allocated by the Legislature to serve and support these families, the Informants and parents were all of the opinion that whatever supports are put in place, that they be accessible to families of varying means across the State and sustainable over time. Everyone agreed that the current level of funding (\$2.2 million) cannot meet the diverse and ever expanding needs of these families, but expressed hope that these funds can begin to strengthen the capacity of families and existing non-profit agencies to empower parents and communities to ensure continuity of care for these children across their lifespan.

The data collection methods implemented by the GHPC and described in this report are part of an ongoing community engagement process being undertaken by The Community Foundation for Greater Atlanta. The findings presented in this report, along with the community feedback gathered through The Community Foundation's outreach efforts, will be presented to the Champions Advisory Committee and will be used to inform a process to develop a Request for Proposal (RFP). This RFP will define the parameters of a service and support delivery model for medically fragile and special needs children and their families in Georgia and invite non-profits and networks of non-profits to submit proposals to carry out the proposed programming model.

Background

The Katie Beckett Waiver Program (also known as the Deeming Waiver) is an optional Medicaid waiver provided under the Tax Equity and Fiscal Responsibility Act (TEFRA). Under the TEFRA, states have the option to provide Medicaid to children age 18 and under at home who qualify as disabled individuals under the Social Security Act provided certain conditions are met. The waiver allows families who otherwise have incomes too high to qualify for Medicaid to enroll by waiving parental income and assets and considering only the child's assets when determining eligibility. In order for a child to establish Medicaid eligibility under this program, it must be determined that:

- If the child was in a medical institution, he/she would be eligible for medical assistance under the State plan for Title XIX;
- The child requires a level of care provided in a hospital, skilled nursing facility, or intermediate care facility (including an intermediate care facility for the mentally retarded);
- It is appropriate to provide the care to the child at home; and
- The estimated cost of caring for the child outside of the institution will not exceed the estimated cost of treating the child within the institution¹.

In Georgia, the Department of Community Health (DCH) provides benefits through the Katie Beckett waiver to those children who meet the institutional level of care determination. In November of 2004, the process for determining the level of care for children applying for coverage under the waiver was adjusted to bring State practices in line with Federal regulations. Prior to this change, eligibility was determined using adult Activities of Daily Living (ADL) to assess eligibility of children, rather than the federally required pediatric criteria.²

This change in the eligibility determination process narrowed the group of medically fragile children and families in Georgia who are eligible to receive assistance from the State through the Katie Beckett Waiver program. In State Fiscal Year 2005, more than 6,200 families who did not meet Medicaid's income eligibility were able to receive supplementary financial assistance to cover essential expenses such as hospitalization, therapy, and adaptive instruments. Following the change in the eligibility determination process, 1,681 families lost coverage under the waiver.

¹ Source: Georgia Department of Community Health, Division of Medical Assistance. Part II: Informational Manual TEFRA/Katie Beckett Deeming Waiver. Accessed online:

http://dch.georgia.gov/vgn/images/portal/cit_1210/26/56/46098632Katie_Beckett_Manual.pdf

² Source: The Georgia Department of Community Health: A Snapshot of the Katie Beckett Program.

http://dch.georgia.gov/vgn/images/portal/cit_1210/11/4/70650170Katie_Beckett-Fact_Sheet.pdf

The Champions for Children with Exceptional Needs Initiative

In the 2006 Legislative Session, the Georgia General Assembly appropriated \$7.6 million in the supplemental 2006 budget to help transition those families who are no longer eligible for the Katie Beckett waiver as a result of the change in the level of care determination process. \$5.4 million was set aside as a one-time allocation of funds to help families purchase limited assistance. Any child that received assistance from the Katie Beckett Waiver program and was denied assistance on or after October 2005 because of a level of care decision was eligible to receive the transitional funds.³ Children whose cases were closed prior to October 2005 are not eligible. Eligible families received a card that functioned as a prepaid debit card in the amount of \$2,600 for each eligible child. The funds could be used for any medically-necessary service and could also be used to purchase respite care from participating non-Medicaid providers.⁴

In addition to the \$5.4 million allocated for transitional funding, the Georgia Department of Human Resources (DHR) committed at least \$2.2 million to one or more nonprofit organizations that will 1) provide critical services to Georgia families no longer eligible for the Katie Beckett Waiver Program as well as other families with medically fragile and special needs children; and 2) identify additional financial and other resources from the private sector and other sources to serve this population in the future⁵. Any of the transitional funding not spent by the recipient families as of June 30, 2007 will be added to the \$2.2 million earmarked by the Legislature for disbursement to a non-profit or network of non-profits.

DHR requested that The Community Foundation for Greater Atlanta assist in the development of a plan for administering and distributing these dollars. The Community Foundation convened an Advisory Committee made up of key stakeholders representing diverse constituencies within the State's disability community. This Advisory Committee will provide consultation and perspective to The Community Foundation and has been tasked with identifying the service option that will be funded by the \$2.2 million earmarked by the Legislature. This effort has been named the Champions for Children with Exceptional Needs Initiative (the Champions Initiative).

³ Source: *Georgia House Bill 1026* Accessed online: <http://legis.state.ga.us>

⁴ Source: Governor's Council on Developmental Disabilities: *Katie Beckett FAQs sheet*. Access online: <http://gcdd.org/publicpolicy>

⁵ The Community Foundation for Greater Atlanta *Champions for Children with Exceptional Needs Initiative Fact Sheet*

Community Outreach Process

In an effort to determine how to best utilize the funds (\$2.2 million) earmarked by the Georgia Legislature, The Community Foundation for Greater Atlanta contracted with the Georgia Healthy Policy Center to conduct a mixed-method community outreach effort. The purpose of this outreach effort is to provide a systematic examination of the existing gaps in service and support for families with medically fragile and special needs children in Georgia. The data gathered through this community outreach effort will be provided to The Community Foundation and the Champions Initiative Advisory Committee and will inform the creation of a Request for Proposal to fund a non-profit or network of non-profits to serve special needs children and their families. This report presents the resulting data gathered through the various outreach activities.

Data collection efforts included:

- Medicaid claims analysis of children with the Katie Beckett Waiver aid category during Calendar Year 2005;
- Three focus groups with parents of special needs and medically fragile children;
- Sixteen Key Informant interviews with parents, advocates, representatives from local and state-wide non-profit agencies, and medical providers;
- Two community forums structured to present data collected in the needs assessment and outreach and gather suggestions/feedback from community members regarding possible service delivery models.

The first section of this report presents a descriptive analysis conducted on Calendar Year 2005 Medicaid claims. The subsequent sections present qualitative analyses of key themes and perspectives gathered through focus group discussions, Key Informant interviews, and community forums. The presentation of the findings from the parent focus group discussions summarizes parents' experiences seeking out supports and services for their medically fragile or special needs children and provides their perspectives on how to best utilize the funding allocated by the Legislature for the Champions Initiative. The presentation of the findings from the Key Informant interviews summarizes Informants' views on the most significant unmet service and support needs of children and their families and presents perspectives on how to best utilize the allocated funds. Finally, the synopsis of the community forums presents participants' reactions to a set of suggested principles that should guide the allocation of the funds and their views on proposed service and support delivery options for special needs children and their families.

**Katie Beckett Kids:
Cohort Analysis Using Medicaid Claims Data, Calendar Year 2005**

The Georgia Health Policy Center conducted a descriptive analysis of the Calendar Year (CY) 2005 Medicaid claims of children who received services through the Katie Beckett Waiver. The claims data are used to describe the demographics and primary diagnoses of enrolled children as well as to study their patterns of service utilization and the associated costs to Medicaid. This analysis provides a general illustration of the services and supports that may no longer be available to those families who lost coverage under the waiver program or for those families who were never eligible for coverage under the waiver.

Demographics

In CY2005, there were 6,572 children enrolled in Medicaid through the Katie Beckett class of assistance. Exhibit 1 on the following page shows the geographic distribution of the Katie Beckett enrollees by county of residence in CY2005. The map illustrates that most of the Katie Beckett children live around the Metropolitan Atlanta area and in large cities such as Augusta or Savannah.

Exhibit 1: County of Residence

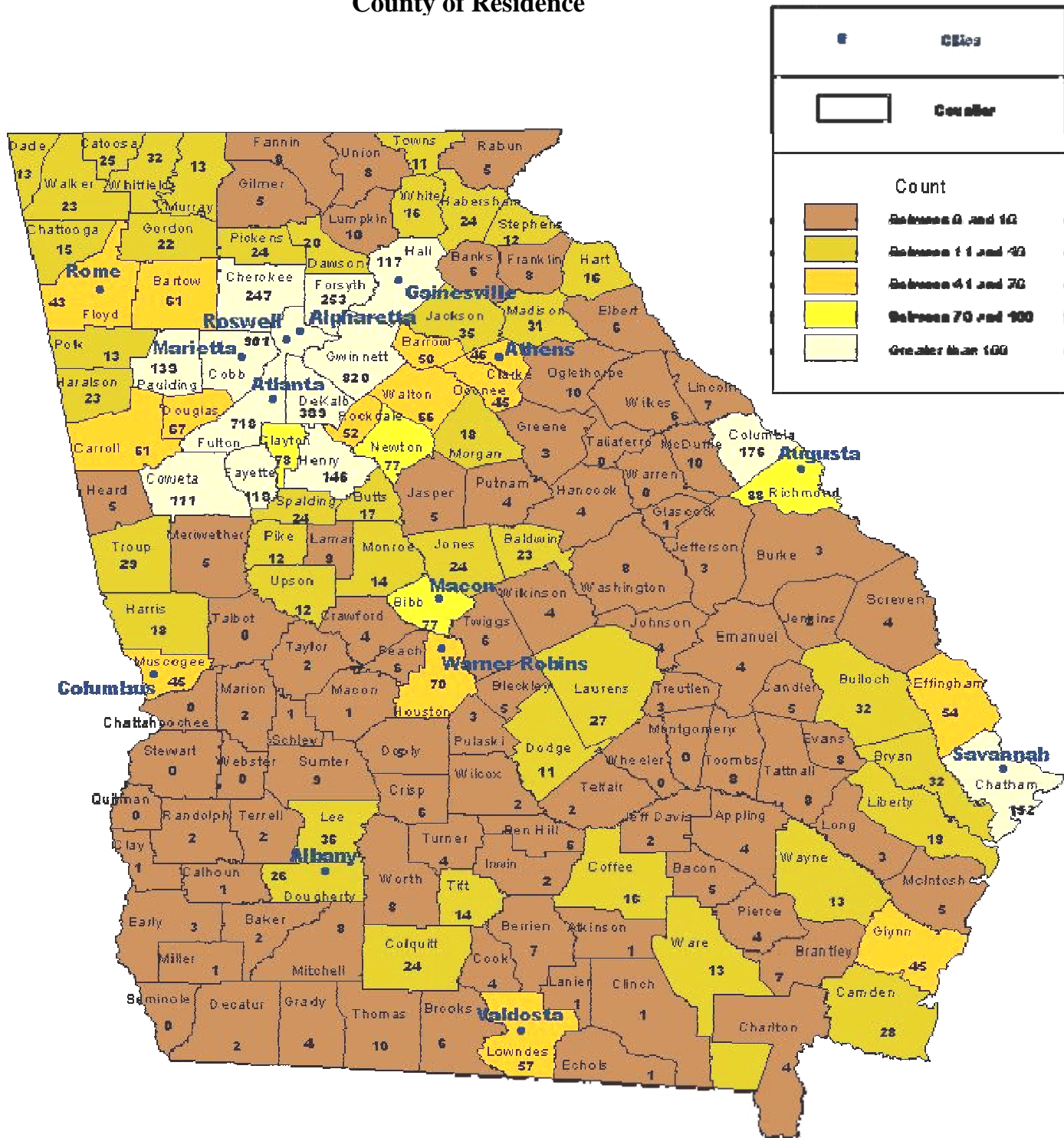
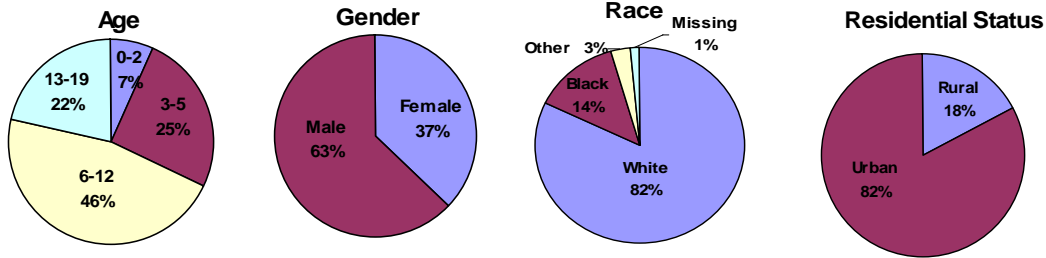


Exhibit 2 presents additional demographics. Six to 12 year-olds comprise almost half of the children enrolled in the program (46%). Males (63%) are more likely to be enrolled in the program than females (37%). A majority of the Katie Beckett children are white (82%) and live in urban areas (82%).

Exhibit 2: Demographics



Top Diagnoses

Program enrollment does not always equate to utilization. In CY2005, however, we find that 95 percent (6,130) of the children enrolled in Katie Beckett submitted at least one Medicaid claim during the year. Exhibit 3 presents the top ten outpatient diagnoses for the study year. The top two diagnoses, specific delays in development and psychoses with origin specific to childhood, comprise 28 percent of all the outpatient claims. Infantile autism, disintegrative psychosis, and schizophrenia are all conditions included in the psychoses with origin specific to childhood diagnosis grouping. In total, the top 10 diagnoses account for 63 percent of all outpatient claims.

Exhibit 3: Top 10 Outpatient Diagnoses for Katie Beckett Children

Rank	Diagnosis Code	Description	Percent
1	315	Specific delays in development	17.4%
2	299	Psychoses with origin specific to childhood	10.6%
3	343	Infantile cerebral palsy	10.4%
4	758	Chromosomal anomalies	7.6%
5	783	Symptoms concerning nutrition, metabolism, and development	5.4%
6	784	Symptoms involving head and neck	5.4%
7	781	Symptoms involving nervous and musculoskeletal systems	2.2%
8	742	Other congenital anomalies of nervous system	1.6%
9	759	Other and unspecified congenital anomalies	1.4%
10	780	General symptoms	1.2%

Medicaid Payment

Medicaid payments of children enrolled in the Katie Beckett program were also analyzed. The average Medicaid reimbursement per Katie Beckett recipient was \$5,033 in CY2005, as shown in Exhibit 4. It was approximately two and one-half times as high as the average Medicaid payment for all children in Medicaid, which was \$2,034 in CY2005. The services that Medicaid paid for the most were therapeutic services, prescriptions/medical equipment, and home services.

Exhibit 4: Medicaid Payment per Recipient

Type of Service	Children with at least one Medicaid claim (N=6,130)
	Average Medicaid Payment per Recipient in CY05
Therapeutic services	\$ 1,634
Prescription / Medical Equipment	\$ 1,348
Home service	\$ 610
Outpatient Hospital /ASC/FQHC/ RHC	\$ 459
Inpatient Hospital	\$ 304
Other Outpatient Care	\$ 169
Mental Health	\$ 149
Physician/ Nurse/ Lab	\$ 215
Case Management	\$ 140
Other	\$ 3
TOTAL	\$ 5,033

In addition to Medicaid, most Katie Beckett children also have other insurance coverage. Of all the Katie Beckett children who used any Medicaid services in CY2005, 76 percent had at least one third party payment.

For the 4,653 children with third party coverage, Medicaid paid for 88 percent of the expenses related to their therapeutic services and 99 percent of the expenses for their home care services (see Exhibit 5). Medicaid also paid for prescription and medical equipment services (41%).

Since the Medicaid reimbursement rate is usually lower than the private pay rate, if an enrollee is no longer eligible for Medicaid, the actual medical expense (and potential out-of-pocket costs) will be higher than the average Medicaid payment presented here. We may actually underestimate total payment for children with third party coverage since Medicaid claims data may not capture their complete third party payment information.

Exhibit 5: Per Recipient Payment Breakdown by Medicaid and Third Party Liability

Type of Service	Children with Third Party Liability (N=4,653)	
	Medicaid Payment	Third Party Liability
Therapeutic services	\$ 1,590	\$ 210
Prescription / Medical Equipments	\$ 1,065	\$ 1,507
Home service	\$ 590	\$ 8
Outpatient Hospital /ASC/FQHC/RHC	\$ 286	\$ 381
Inpatient Hospital	\$ 135	\$ 408
Other outpatient Care	\$ 132	\$ 72
Mental Health	\$ 114	\$ 16
Physician / Nurse/ Lab	\$ 132	\$ 275
Case Management	\$ 152	\$ 0
Other	\$ 3	\$ 1
TOTAL	\$ 4,198	\$ 2,878

Generalizability

The descriptive analysis presented here is representative of the claims filed by children enrolled in the Katie Beckett program in CY2005. While informative, they likely do not represent a complete picture of the service needs of all medically fragile children in Georgia since many eligible children may never enroll. Furthermore, the data presented in this analysis are from CY2005, reflecting service utilization reimbursed through Medicaid two years ago. For the most part, these claims occurred prior to changes in the Katie Beckett eligibility determination process. More recent claims data that would allow us to examine current utilization and compare enrollment and utilization before and after the eligibility changes are not available. As such, there is no way to determine in this analysis whether the families who continued enrollment in the waiver program had different patterns or levels of service utilization than those families who were deemed ineligible.

Focus Groups with Parents of Children with Special Needs: Summary of Key Themes

As part of the community outreach effort, the Georgia Health Policy Center conducted three focus groups with parents who have children with special needs. A focus group held in Marietta included parents whose children had received benefits under the Katie Beckett Waiver program but were recently determined to be ineligible for those benefits. Parents whose children are currently eligible for benefits as well as those who have children that are no longer eligible participated in the Athens group. Only parents with children currently on the program attended the group in Decatur.

A total of 36 parents participated in these discussions. Their children have a wide range of illnesses and conditions such as autism, cerebral palsy, mitochondrial disease, blindness, auditory disorders, Asperger Syndrome, Down Syndrome, epilepsy, and others. Their children range in age from 2 to 19 years old. All but two parents reported having private health insurance coverage for their special needs child.

The objectives of the parent focus groups were to:

- chronicle family experiences with the Katie Beckett Waiver program;
- describe families' experience seeking access to health care professionals and medical and therapeutic services for their special needs children; and
- hear parents' ideas for how best to utilize the \$2.2 million that was allocated by the Georgia Legislature to support special needs children.

The conversations were audio recorded and transcribed for the purposes of preparing this report. Interview transcriptions were coded using an inductive coding scheme that followed the objectives of the Focus Group Discussion Guide (See Appendix A- Focus Group Discussion Guide). After coding was completed, data were sorted by thematic codes and analyzed for key themes. The key themes that emerged from the focus group discussions are presented below.

Experiences with the Katie Beckett Waiver Program

Utilization of Program Benefits

As would be expected from the range of their children's needs, parents use benefits from the Katie Beckett Waiver program in a variety of ways. Many parents rely on these benefits to help with deductibles and co-pays as emphasized by the Athens mother who said, "The co-pays can put you under." Many also use Katie Beckett funds to supplement a variety of therapies for their children. A Decatur woman noted:

My son gets speech and occupational therapy. We've been on Katie Beckett for a little over four years now, and he has been having intensive therapy. We've seen tremendous improvement since we've been able to access the program.

Additionally, parents use benefits to purchase hearing aids, glasses, durable medical equipment, and pay for nursing care, among other things. For some, access to medical specialists is the greatest benefit their child derives from being on the Katie Beckett program. One mother commented:

Access to medical services themselves is part of the thing that I am incredibly grateful for with the Katie Beckett Waiver. I know my family wouldn't have the same ability to see many of the medical specialists that we are able to with waiver.

Parents whose children were determined to be ineligible for Katie Beckett received a \$2600 debit card to assist in the transition. These parents reported using the funds from debit cards in much the same way as described above. One Cobb mother voiced the feelings of many others when she made the following comment about the debit cards:

The debit card gave you a lot more liberty to really decide for yourself what your child needed. Sometimes that's a lot better than a program that allows you to get one of these or one of those or determines if you are qualified or you are not.

Many parents have been faced with making difficult treatment decisions since their children are not eligible for benefits. The following comments illustrate the hardships that many of these families are experiencing as a result of losing benefits:

We had to drop occupational therapy which she desperately needs.

Our deductible on our private insurance is so high that we couldn't really reach the deductible to even get him therapy. He's a year and a half to two years behind since we lost Katie Beckett.

My daughter has degeneration so eating certain things or smelling certain things bother her. I was able to take her to the class at Scottish Rite to work on feeding issues, but now we don't do that any more.

My child has not had occupational therapy for a year, and her hands are starting to curl up again. We do what we can do at home.

There was quite a bit that we gave up. He was getting outside speech therapy twice a week, and we had to give that up. We also had to cut back on his psychotherapy.

We have to pay between \$400 and \$500 more a month out of pocket for co-pays since we lost Katie Beckett.

Access to Services

Parents in all three focus groups reported difficulty in locating appropriate health care professionals for their children. While most have a primary care physician, access to specialists is problematic. They indicated that specialists are either not available in their area or will not accept Medicaid payment. A Decatur woman decried, “A lot of the therapy clinics are not taking Medicaid, and we have no place to go.” A second mother in that group added, “We live in Cherokee County and it is impossible to find services for special needs kids in Cherokee.” A third said, “Respite care doesn’t work for us because it is very hard to find respite care in Clayton County.”

An Athens mother observed that access to care is even more difficult for those who live in more rural areas. She said, “Because the volume is not here, a neurological pediatrician is not going to settle in Athens, Georgia.” Parents in that group reported driving to Atlanta, Cumming, Snellville, Alpharetta, and other locations to access services for their children. Program regulations also contribute to the problem of access, as explained by this comment from an Athens parent:

It’s a catch 22. If you can’t find anybody in your area that will accept your HMO, then you can’t get assistance from Medicaid because they won’t help if your insurance refuses to pay.

Parents complain that payment schedules and inefficiencies within the Medicaid system in Georgia exacerbate their inability to locate appropriate care for their children. A Cobb mother described the challenges of finding providers:

We’ve lost all of our in-home therapists because they were just not getting paid. The therapist would bill, and she would only get a percentage of what she billed. So, she decided not to work with Medicaid patients anymore.

An Athens mother echoed:

One of the main things that I have heard from doctors that my son has seen is the reason that they have dropped Medicaid is because the paperwork is so expansive, and it’s a lot less payment.

The Marcus Institute and Children’s Healthcare of Atlanta are the two institutions most often visited by the children of these parents. However, parents stated that Medicaid payments for

therapeutic services provided by these institutions are increasingly limited because of the way Medicaid reimburses tertiary care centers. Parents described how Medicaid stipulates that hospitals like Children's Healthcare may be reimbursed for therapies related to acute care, but not for long-term therapeutic services. Thus, many children have lost access to therapies provided by these institutions in-house. One parent described the loss of services provided by Children's Healthcare as a "huge setback." Parents fear that access to the specialized care their children require will get worse due to continued cutbacks and increased paperwork imposed on providers.

To help fill the voids in service access and coverage, parents seek support for their children from non-profit organizations and social service agencies. Some of these provide broad services that are relevant to most families, such as Parent to Parent of Georgia, FOCUS (Families of Children Under Stress), and Foundation for Medically Fragile Children. Others provide assistance to those with specific illnesses and conditions, such as Georgia Pines, Muscular Dystrophy Association, and Diabetes Foundation. In addition, a number of non-profit camps are available for special needs children as well as some respite programs for parents.

Bureaucratic Frustrations

These parents expressed a great deal of frustration with working through the State to obtain and maintain benefits for their children. They described a system that is bureaucratic, inconsistent in coverage, and bogged down with endless paperwork. Their many complaints include:

- Department of Human Resources employees that are assigned to assist with the application process and the Department of Community Health personnel who administer the program lack complete knowledge about eligibility requirements, coverage provided by the program and other essential information
- Forms are so complicated that physicians cannot properly complete them
- Guidelines for what is and is not covered are unclear and constantly changing
- The annual renewal process is cumbersome
- There is all together too much paper work

Here are some of their many comments about the state system that administers the Katie Beckett Waiver program:

I've got to fill out 100 pages of paper again to prove my child still has cerebral palsy.

When the State plan says we are only going to give you eight units of physical therapy or only eight units of speech therapy, that is against the law because the federal law says the State must cover whatever is necessary to correct the problem.

I think it is unfair that when you have doctors, nurses, and therapists saying that a child needs something to either make her more comfortable or improve her condition a lot, that Medicaid can turn around and say, "No." I don't think they should be given the right to deny coverage for something that a medical professional says the child needs.

Nobody is on the same page.

The providers have no idea what services they are supposed to provide, and the beneficiaries have no idea what services they are entitled to receive.

We were getting five therapies a week before the cuts. Now we get six a month.

The application process is too difficult for families.

The annual renewal process is ridiculous. My child is MR [mentally retarded] and has cerebral palsy and lung disease. Next year he is still going to have MR, cerebral palsy and lung disease.

It's very difficult to access anything on the State government website.

You have to do everything paper wise. Everything has to be documented through the doctor's office. You have to deliver the paperwork and pick it up and mail it. And, you have to pay the doctor to fill it out.

We went through the people in the county losing our application. It's a rural county, and there was one caseworker that serves three counties to help with Katie Beckett. It was just a nightmare.

Additionally, parents whose children remain eligible for the Katie Beckett Waiver program fear a loss of benefits and the subsequent impacts on their special needs children. A Decatur mother said with exasperation:

All of these changes have been horrific. We've had one child denied and reinstated. I have two more reviews at the end of this month, so it's always a guessing game.

The burden falls to the parents

It is clear from the conversations with these parents that they must assume additional roles of case managers and advocates in order to obtain services for their special needs children. Parents report having to constantly search for services and specialists for their children because information is not readily available to them. Almost all who attended the focus groups said that they had learned about the Katie Beckett Waiver program almost by accident. A mother from Athens described how she learned about the program: "The way I learned about Katie Beckett was in the waiting room at the therapy class."

Neither doctors nor hospitals provide information to parents with special needs children as illustrated by the mother who lamented:

There are no posters, no anything about disabilities in my pediatrician's office. There's no information about the organizations in Georgia that can help a parent with a child like mine.

In actuality, parents often find themselves in conflict with providers regarding diagnosis and treatment of their children. A mother explained:

I am the case manager and that is something that I tell every doctor I see. I don't have an MD behind my name, but I am this child's case manager. I understand my child much more than any doctor.

Taking care of a special needs child affects all aspects of the family's life and can have a significant impact on the parent's employment. Many reported having lost jobs or not being able to work at all so that they can tend to the needs of their child. They also express anxiety because other children in the family do not receive the attention they need and deserve because of the demands of taking care of the special needs child. A Marietta mother expressed this concern:

You know a lot of the responsibility falls to the parent to try to give therapy to your own child. I'm not qualified to do that, and I have another child too that I need to care for.

One parent summed up the sentiments of many of the parents when she said:

As parents of special needs children we are the health advocates for our children, and as such we have found ourselves in positions where we have to leap through incredible hoops and paperwork and red tape to a point that is beyond anything that you could really believe to get a proper diagnosis or to get proper care.

Suggested Guiding Principles for the Allocation of the Funding

When asked how they would utilize the \$2.2 million allocation from the Legislature, the parents' first reaction was that the money allocated is insufficient to meet the needs of children like theirs across the State. A woman from Athens stated: "That doesn't sound like hardly any money for what is needed." As they spoke about the money available, they began to articulate parameters that should be placed on the utilization of the funds that can be considered guiding principles. The principles described by parents can be categorized as follows:

- Focus on early intervention
- The child's needs should be the primary consideration for support
- Eliminate red tape when possible
- Maximize the funding that goes directly to children

Focus on early intervention

Throughout their conversations, parents commented on the importance of early intervention for special needs children. All agree that therapies and services in the earliest stages of diagnosis are crucial in the development of their children. Given the wide range of their children's needs, early intervention is the one area that all found in common, as expressed by their comments:

I like the idea of early intervention. Early intervention gave me information.

I would make sure that there was early intervention and help in getting people started on knowing what to do with the child who has special needs.

It's hard because we are so diverse. I guess if there is one thing we have in common, its early intervention, which is the only thing that really ties us.

Early intervention is the best way that you can spend that money because the State of Georgia is going to have a terrible problem when all of these kids become adults.

Base qualification for support on the needs of the child rather than the income of the family

Parents are adamant that the qualification to receive support from the Legislative allocation should be based on the needs of the child rather than family income. Caring for a special needs child can tax the incomes of low, middle and high income families due to the high cost of care and intensity of care needed to support these children. Parents believe it would be unfair to have family income as criteria for receiving assistance. One parent summed up this commonly-expressed sentiment:

You know, you reach a point where it really doesn't matter what you're making if all of your money is going to medical care for your child. You're still going to be poor. So, my only thing would be please don't put an economic standing on it. It should be based on the need of the child.

Make the process of obtaining support as simple as possible and eliminate red tape whenever possible

As previously noted, these parents are extremely frustrated with the bureaucracy that governs the Katie Beckett Waiver program. They do not want another system with unending paperwork to oversee the distribution of these new funds, as expressed by the parent who said:

If it can be simple and easy and give direct information for families, I can't think of anything that would be more refreshing.

Maximize the funding that goes directly to the children

Parents were apprehensive about the mechanism for distributing the allocated funds. They fear that too much money will be devoted to the administration of the program and not on providing services to their children. Since they are concerned that the money allocated is insufficient to meet the need, they want as much money as possible to reach the families who need the support. They especially do not want the money used to create a new non-profit organization because “there’s a lot of money and time wasted in start up.” One parent spoke for many when she said, “I think that the point is getting the money back to the children.”

Suggested Service and Support Options

Parents were asked for their suggestions for how the Legislative allocation could address the unmet needs of families like their own throughout the State. They proposed a number of service and support options that fall into five general categories:

- Provide flexible money to parents for their children’s needs
- Establish a resource center for family-centered support services
- Provide services that support transition to adulthood
- Coordinate advocacy for medically fragile and other special needs children and their families
- Make system-level changes in the State

Provide flexible money to parents for their children’s needs

Because of the varied needs of their children, parents would like access to funds that can be used at the discretion of the parent. Some may need assistance with deductibles and co-pays, others may need specific equipment, materials or supplies, and still others may want to send their child to a special camp or school or pay for respite care. Consequently, they propose either directly distributing the funds similar to the debit cards that were given to the families of children that were deemed ineligible or giving the funds to a foundation that would provide cash allocations to families. Their comments on this option included:

I would like to be able to make the choice for my daughter. If I have to make the choice between a wheelchair and medications, I can live with that because she is my child. I think you should just disburse it to the family.

I like the idea of the card because it gives you the option of choosing. You don’t have to worry about what your insurance will cover.

Establish a resource center for family-centered support services

Parents shared common experiences in seeking information about available support and programs that could be helpful to them in caring for their special needs child. While they acknowledged that a lot of information may be available, parents assert that they must be aggressive in seeking out the information because it is not readily accessible. To address this problem, they suggest a resource center that would be a clearinghouse for all families with special needs children and one that would “help people navigate through the system.” Such a resource center would not only provide information but also “organize parents who have been through it [having a child diagnosed with special needs] to help parents who are newly going through it.” While parents want a web-based information system to be an essential part of the proposed resource center, they also acknowledged that many families do not have adequate access to the technology needed for this service to be of benefit to them.

Provide services that support transition to adulthood

Parents with older children worry about the future of their children when they become adults and no longer qualify for the Katie Beckett Waiver program and other supports that are only made available to children of certain ages. These parents would like to see the allocated funding

devoted to a program that would assist them in transitioning their child into adulthood. An Athens mother explained:

I would like to see some sort of help in transitioning from Katie Beckett Waiver to adulthood. At 22, we are entering all new territory without the Medicaid waiver. We don't have any adult services. I'm looking at the fight that I have had behind me and bracing for another one to come.

Coordinate advocacy for medically fragile and other special needs children and their families

Parents do not believe that those who make decisions about program funding understand enough about the challenges of caring for special needs children. Several parents want funding earmarked for assistance with advocacy in bringing their concerns to the attention of policy makers, specifically State Legislators. Some propose using the money to train parents to be better advocates:

Let's give the money to Partners in Policy Making, and they can teach all the parents how to scream louder so the Legislators will know what our needs are.

Others proposed using the money to hire a lobbyist to advocate on their behalf. One Decatur man suggested “hiring a professional who is familiar with state and federal laws that can protect our children.”

Make system-level changes in the State

Many parents assert that special needs children will never receive adequate support until there are fundamental changes in the State-level system. They are steadfast in their belief that the available funding be used to address what they perceive to be fundamental flaws in the administration of the Katie Beckett Waiver program. Their specific suggestions on how to improve the program include:

- Research how the Katie Beckett program is administered in other states and incorporate the best practices into the Georgia program
- Hire an independent company to audit the program to simplify the application process and make operations more efficient
- Establish a training program for DFCS case workers that would provide them with a comprehensive understanding of the program.
- Assign one trained caseworker in each DFCS office to be the single-point of contact for families with medically fragile and special needs children.

Here are some of the many comments made by parents regarding these suggestions:

Bring in people from other states, and let's figure out what good things they are doing, what bad things they are doing. Let's take out all the bad things that we are doing and find out the good that we are doing and see if we can create a program that actually provides services that children need.

One of the biggest hassles with Katie Beckett is the fact that just about the time you've gone through the process; you have to do it again. Could some of this money be used to make the process easier?

Pulling a few people from the State and really educating them about Katie Beckett would be a huge, huge deal. These people are supposed to be guiding us, but they know nothing.

Let's get a private company to come in and make sure that everybody can communicate. They could find the problems and help get rid of the red tape and do some checks and balances.

I think it's real important that we get an outside person, a private company involved.

Let's go see what other states are doing because obviously we [in Georgia] are failing miserably. We don't have clue.

Key Informant Interviews: Summary of Key Themes

As part of the community outreach effort, the Georgia Health Policy Center conducted one-on-one interviews with sixteen Key Informants. The Key Informants were identified by members of the Champions Initiative Advisory Committee as individuals who were knowledgeable about, and had direct experience with, medically fragile and special needs children and their families. The Key Informants represent multiple stakeholder and key constituency groups: local and statewide non-profit organizations serving special needs and medically fragile children and their families, medical and therapeutic service providers, parents, advocates, and representatives from various State agencies that coordinate the delivery of services to medically fragile and special needs children.

The objectives of the interviews were to:

- identify existing resources and programs available to families of special needs and medically fragile children living in Georgia;
- identify and describe service gaps and critical unmet service and support needs of these children and their families;
- explore models of service provision and other supports available to families in other states in the country; and,
- gather suggestions on what types of supports and services should be funded by the Champions Initiative

Data Collection and Analysis

The Key Informant interviews were conducted in person or over the telephone. When feasible, the interviews were recorded and transcribed verbatim. Where tape recording was not possible, in-depth written summary notes were taken. Both interview transcriptions and summary notes were initially coded using an inductive coding scheme that followed the objectives of the interview guide (See Appendix B- Key Informant Discussion Guide). A second level of coding was completed using a set of deductive codes that were developed based on themes emerging from the Informant interviews. After two rounds of coding were completed, data were sorted by thematic codes and analyzed for key themes. The key themes that emerged from the series of Key Informant interviews are presented below.

The State of Our State: The Current Landscape of Support and Services Available to Special Needs Children and Their Families in Georgia

The role of the State in delivering services and support to families

Informants said that the main focus of the State delivery of medically-focused supports and services were Medicaid services like the Katie Beckett waiver and the Georgia Pediatric Program (GAPP) for medically fragile children who meet income eligibility for Medicaid. Eligible children who are developmentally delayed or disabled may receive home and community-based services through the Mental Retardation Waiver Program (MRWP).

Informants often mentioned the value of the Babies Can't Wait service delivery system for families of children with developmental delays or disabilities. Parents and providers alike see the Babies Can't Wait program as an important resource for parents as well as the children served by the program because it is designed as a family-centered model that trains and empowers the family to identify and engage services for their children. One parent interviewed described the Babies Can't Wait program as an important resource for parents who have just received a diagnosis for their developmentally delayed or disabled child:

You know, if I hadn't had Babies Can't Wait when my daughter was younger, I would have never gotten for her what she needed as quickly. Having the service coordinator come in, because when you are a parent and you find out that something is drastically not right with your child and that it is probably going to be a lifelong ordeal, you are so overwhelmed that you become so stressed, it's hard to even think. You hear so many different options. It sure is nice to have somebody come in and go, 'Here. And here is the route you take to get there.'

However, many Key Informants also expressed concern about the changes and challenges that the Babies Can't Wait program is currently facing. Parents and providers alike are worried that the program has been “dumped into a CMO (care management organization).” They perceive that the paperwork required of the participating providers is so burdensome and the reimbursements are so low that Babies Can't Wait service coordinators are leaving the program. One Informant expressed dismay over watching “service coordinators leaving the program in droves because they can't get reimbursed for their work.”

The Katie Beckett Waiver Program: Patterns of utilization and available supports

Georgia is one of 21 states in the country that opted to implement the Katie Beckett program under the TEFRA. Key Informants say that the Katie Beckett waiver is an important resource for those families that qualify for assistance and think that it is important that the State of Georgia recognizes the need for the waiver program. Key Informant perspectives on the utilization of the Katie Beckett waiver reflect the Medicaid claims analysis reported earlier in this report. The waiver is used primarily to pay for therapies (occupational, physical, and speech) that are not covered under private insurance plans as well as to help families pay for prescription medication and medical appointment co-payments.

For many families, having the Katie Beckett waiver provides them with “peace of mind” because they know that they will not go into financial ruin trying to get the medical care that their children need. One Key Informant described the program this way:

It is a very important tool on a lot of different levels – financially, medically and emotionally for parents who are dealing with these issues. It is a financial safety net for families who are a hairs breath way from a weekend of medical crisis, who have medical issues that could take the family into bankruptcy. For families of all incomes, it is a way to ensure that when they are in the midst of dealing with those unexpected medical costs that they don't have to worry about what their private insurance pays...Katie Beckett is a safety net.

Key Informants view the State as providing necessary direct support for vital services such as therapies, home-based care, financial assistance for co-payments, prescription medications, and durable medical equipment that are not otherwise covered through private insurance or available through non-profit organizations. This assistance usually comes to families through Medicaid and Medicaid waiver programs. Informants see the supports provided by the State to families as essential to the survival and development of medically fragile and special needs children.

The role of the Public School System in the provision of services and support

The public school system in Georgia was characterized by many Key Informants as the primary source of non-medical therapies for many special needs children. Through the development and implementation of Individualized Education Plans (IEPs) for children with special needs, the children are able to receive some appropriate educational therapies and learning supports. Informants who had direct experience with schools systems, either as an advocate for children with special needs or as a parent, characterized the services and supports offered through the public school system as limited in scope. Informants view mandates from the federal No Child Left Behind legislation as “rolling back” the gains previously made under the federal Individuals with Disabilities Education Act (IDEA), which mandates that public school systems provide a free and appropriate education to children with disabilities.

Informants characterized the public school system as overwhelmed with federal mandates and severely under funded to meet the needs of special needs children. Informants view the school system, at the State level, as one that has “really good people who have got really good ideas and who really know how to do it,” but where State-level ideas and approaches are not linked effectively to the local school systems’ capacity to meet all children’s educational needs.

The role of non-profit agencies in supporting families of special needs children

Non-profit agencies play an important role for many families with special needs children. Disability and disease-specific associations were mentioned by most Informants as an important support for families. These groups are often a “first line of defense” for many families after they receive their child’s diagnosis. These organizations are helpful to families by providing information about their child’s diagnosis and may provide informational support to parents seeking services for their child. One Informant said that these organizations are key for parents because they allow parents to “network with people that understand your ‘speak’ and understand

your issues.” The Informant went on to describe the importance for parents to feel connected to other parents:

Each disability has its own language. We are all alike in a lot of ways, we are more alike than we are different, but there are some things that are particular to certain disabilities. Families need that support and they need to feel connected and know that other people understand what the issues are and that they are not alone. I think that the families that really struggle the most are those that feel that they are left alone out there.

Informants described an array of services and supports available to families through non-profit agencies. Non-profits may provide information and navigational assistance to parents, parent training and education, support in the form of grants or loans to buy durable medical equipment, emotional support for families, and recreational opportunities for special needs children and their families. However, Informants described the support that non-profit agencies are able to provide to families as limited in scope because of the restricted funding landscape that exists in Georgia. Though their work is important to families, it is often smaller in scale and cannot meet the intensive and long-term support needs of families with special needs children. Informants also stressed that most of the support and services provided through non-profits are almost completely focused in the Metropolitan Atlanta area. One Key Informant described the challenges that families outside the metro area face:

I really feel for those families in the rural parts of Georgia. The metro Atlanta families have a lot more resources, but for those families in South Georgia, there is nothing, absolutely nothing. So when they lose the Katie Beckett Waiver, it is like the bottom has fallen out from under them, literally. There are just no programs available to them.

Informants say that non-profit organizations should play a role in supporting children and families. However, many Informants expressed trepidation at the idea of “outsourcing” the role that government has historically played in providing direct supports like financial support for necessary therapies and medications to families. Some Informants consider it a dangerous proposition to take the government out of its traditional role of ensuring that these key supports and services are available to families and giving that role to local non-profit agencies that do not have a steady stream of dedicated funding to sustain such an essential effort. One Key Informant described this concern:

The solution is not a one-time solution, it is long-term support, it is until the child is 22. Every year you have kids born with disabilities... It is a natural condition of the human existence. A one-shot deal is a misunderstanding of the solution. My concern is that outsourcing long-term care, expecting either private business or foundations or individuals to donate money into a fund, may be hard to sustain...The system with the most stable money is government. How do we ensure that we are not ‘shell gaming’ this and that we are not pushing the cost over to another system that has less accountability than the government?

Unmet Service Needs and Gaps in the Provision of Service and Support to Families with Special Needs and Medically Fragile Children

The need for navigational and informational supports for families

Though State programs like Babies Can't Wait and the Katie Beckett Waiver Program exist, many Informants say that State programs and services are inaccessible to many families with special needs children. Many families are unaware of the programs and do not know how and where to access information and assistance in applying for State programs. A Key Informant described one such instance:

I met a family that, for whatever reason, went through early intervention and had their child in the emergency room at the hospital with life-long developmental disabilities and was never told about Katie Beckett. They ended up having to sell their house and go into debt \$300,000 because of medical bills and now live in an apartment. They are trying to figure out what other supports that they could put in place. If they had been informed about Katie Beckett they wouldn't have lost their house.

Multiple Key Informants described the frustration that families feel as they try to navigate the maze of services for their children. Many parents and providers alike say that social workers with the Department of Family and Children Services (DFCS) are not always effective navigators for families with special needs children. Case workers are often unaware of the programs available to these families and uninformed of the eligibility criteria and application process.

There is nowhere within the State for people to call. Families may call DFCS to get a Katie Beckett Waiver application. Most of the time the families are told "What is the Katie Beckett waiver?" The case workers don't even know...

By default, parents are often forced into the role of service coordinator for their children:

One of the frustrations for families is it is almost like it is all in who you know... So if you happen to be plugged in with the right other family, that dictates what information you have. But there are a lot of unknowns. The State hasn't done a good job of community outreach themselves, of letting families know that the services are out there. So unless a parent takes an active role with it, it doesn't happen.

The “siloe d” nature of service delivery

Much parental frustration comes from what one Informant described as the “siloe d” nature of the organization of State services and programs. One Informant described the lack of continuity and communication among State agencies that provide support to families and their children:

We are not covering the landscape very well in Georgia. The services are patchworky and transition out of one program into the next is not often smooth.

This lack of continuity of care causes anxiety for parents of special needs children because they “often don’t know what the next step will be.” An Informant described the lack of communication and coordination between agencies:

I am in it and work with it and I still don’t understand the hierarchy of it... Everybody is functioning in isolation of everybody else. Nobody is sharing information, so families that could be very successful are doomed to fail. These systems are wasting tremendous time and resources. Everybody is focusing on their own process and what their department is doing, and they appear to be unwilling to come together and integrate some of those processes- first and foremost to be more of assistance [to families] and to really get down to helping the child.

Transition to Adulthood

Related to the “siloe d” nature of service delivery in Georgia is a commonly expressed concern about the lack of services and programs that transition special needs children out of the school system, off of the Katie Beckett Waiver and other programs, and into adulthood. Many Informants say that the State is lacking in training and employment support programs that would enable young adults to be trained and supported to live and work as independently as possible in the community:

There are no options for these kids after high school. Employment options are dismal at best in most communities. You could probably go into most rural communities and they wouldn’t even know what [employee supports] are, or what that means. There is no real push to get planning out to these families that can assist in that transition process out of high school and into adulthood.

Another Informant described the lack of options for young people transitioning into the adult system:

Where it becomes really stressful is that transition from the school system to the adult system, because each system is looking at the other, not knowing what to do and being overwhelmed by the amount of money and support and experience [needed]. They are pointing at each other; the schools are saying “We are getting them ready, getting them connected to work.” And the adult systems are saying that the schools are not focusing on the skills that they need to work in the community. And the adult system doesn’t have any money for them; all they have is a waiting list.

Disparities in access: The rural experience and the language gap

Many Informants expressed concern about families in Georgia who are not “networked in” with other families who can help them navigate the service maze or who do not have access to information and services that are often clustered in metro areas around the State. These Informants say that families who live in rural communities across Georgia are at a great disadvantage.

I am very concerned about what is happening outside the metro areas. There is a second, and even a third, Georgia. People who live in small rural counties have no support and no access to services. I don't know what those families who aren't hooked in, who don't have access; I don't know what they would do.

Multiple Informants observed that the lack of bilingual providers in the State poses a challenge for non-English speaking families and their providers alike. Many Informants say that the current political environment makes it difficult for State agencies to effectively serve non-English speaking families through language appropriate education and outreach efforts and through the hiring of bilingual personnel:

I really feel like some of the Spanish-speaking families are getting the shaft because there is that language barrier. I do not think that their physicians take them very seriously, and they are not being referred to whom they need to be referred to and they are not getting the tests done that need to be done. There are not bilingual providers.

Gaps in direct services to children with special needs

Informants also described some of the main gaps in available direct services for families with special needs children. Many Informants say that families are most in need of therapies for their children. Private insurance limits the number of therapy sessions for which they will annually pay. Families who are income eligible or who qualify for Medicaid through a waiver program are seeing their allowable therapies limited or are having to go through a pre-authorization process before accessing therapies that they believe are key to their child's continued development and progress.

A second area where there is perceived unmet need is in the availability of affordable and appropriate respite care. One Informant described the need for respite to allow caregivers some time away:

So we [parents] are all dedicated to keeping our kids in the home [and not in institutions], but either we try to have a job, or you need a break and you need somebody qualified to help take care of your child. If you don't have a waiver, it is really hard to get funds for respite care. I don't know of any community organization that would provide assistance to caregivers, and that is the most pressing need for parents.

A third area of concern for Informants when looking at the gaps in services and support for families with special needs children is the dearth of providers who are trained to provide specialized medical and therapeutic services and who accept Medicaid. According to Informants, the paperwork that is required of participating providers by the care management organizations places an undue administrative burden on their practices. As a result, many providers are no longer accepting Medicaid patients.

I would say that probably close to half of the providers in our area of the State have stopped accepting Medicaid. So you run into a problem when you have a kid who needs services, but you can't find anybody to serve them because they have [this Medicaid health plan] or [that Medicaid health plan]. They are making it so difficult for these providers to get the services to them that it is just not worth their while.

Other Key Informants said that there are simply not enough providers in Georgia trained to provide care and therapies for children with complex medical and developmental needs:

For example, if you look at kids with autism. We have nothing. You can go to the Georgia Association of Behavior Analysis, the behavior analysts are the ones who are certified to do Applied Behavioral Analysis [an early intervention treatment for autism], and there may be 30 people in Georgia. Florida probably has 500. We could win court cases all day long, saying these kids aren't being served and need to be, but there are no centers to send them to.

Parent Experiences: Raising Special Needs Children in Georgia

Informants described the challenges that parents and care givers face as they try to cobble together services and supports for their special needs and medically fragile children. Some Informants say that the environment in the State of Georgia makes the job of parents particularly difficult. Many Informants characterized the relationship between parents of special needs children and the “State” (i.e. elected officials, representatives from State agencies tasked with organizing and delivering services to children and their families) as an adversarial one. They perceive the attitude of State officials and parents alike as one of “us versus them.” One Informant described this contentious relationship:

I think that in Massachusetts, New Jersey, and in New York, other states don't fight families so hard. Here I have seen a parent who comes in and says to the school system, "I want Applied Behavioral Analysis." And the school system says, "No way, let's fight." The same thing happens with [other programs] too.

Informants spoke of the struggle that parents face as they work to ensure that their children get the services that they need. One Informant, who is also the parent of a special needs child, described that struggle:

As a parent, you just have to gear yourself up. You have to fight for everything that you get. It shouldn't be that way, but every year, I have to put my bullet-proof vest on and walk into that meeting at school. I am my child's only advocate, so I have to stand up for what we feel she needs. You know, that's hard to do. I wish that families didn't have to do that.

Another Informant described parents' struggles this way:

Having a child with a disability is very stressful, very, very stressful. Then you add on to it the financial burdens of it and having to advocate for everything in their life. You have to advocate in education. You have to advocate in health care. You have to advocate in community services. Nothing is easy when it comes to children with disabilities. It is not like anything is given to you, you have to fight for everything. What happens is that families get worn out, burned out. And I will be honest with you, I feel like the State almost breeds that.

Informants see the passion and dedication with which parents advocate for their children's best interests as being motivated by their desire to see their children reach their full potential and grow into adults able to contribute in some way to society. All Informants stressed the importance of early and consistent intervention as a way to save the State dollars later when children grow into adults who may require more intensive and much more expensive State intervention.

A Key Informant who is also the parent of a special needs child described her hopes for her child and her struggles to make decisions regarding her care within the context of other financial demands:

All we want for our child, as we want for all our children, is for her to be a happy and productive part of society. I think that the biggest dilemma for our family and for most families is how can you put a price on what you do for your child? If you know that your child needs something - and I am not talking about material things - I am talking about therapies or educational needs. If you know that they will need something so that they will be more functional as an adult, how can you say, "Well just because we don't make \$200,000 a year, we can't afford to do it." We just can't do that. It is just a very difficult decision, to have to put a price on what your child's future is worth.

What Is Working Well In Georgia: Foundations Upon Which to Build

When asked to reflect on what is working well in the State and existing resources for families and children, Informants often referred to the particular “quality” of Georgia’s parents and families. Many Informants described parents of special needs children in the State as singularly dedicated to providing their children with the best care that they can within their homes and communities. A Key Informant described this characteristic:

The best that Georgia has is its families. These families do amazing things with very little help; I am continuously astounded at their motivation and their heart. I think that a lot of that comes from the environment that we are in, in the Deep South, in the Bible Belt. We are in a cultural environment down here that lends itself to a people that is very caring, that is very willing to open their hearts and their homes, more so than in other areas of the country.

Other Key Informants spoke of the recent increase in funding for disability issues in the State. Informants described a trend of increasing dollars being put into adult community service programs like the Mental Retardation Waiver Program or the Independent Care Waiver Program. Waiting lists for these adult services programs have been reduced for the first time in Georgia’s recent history. One Informant described this recent trend:

If indications are right, we have had the largest increase in funding for disability issues in the history of Georgia. We are last in so many measures, and we have for so long neglected adult services, but for the first time, when you look at numbers for the waiting list for adult services, it has gone down by 1,300 because more slots were allocated.

Informants also described the creation of the New Options Waiver (NOW) which will give families access to some self-directed funds and some choice in community-based service options. Some Informants, though not all, see the recent expansion of some waiver programs as a sign of increased commitment to and understanding of the importance of family-directed community-based services for individuals with developmental and other disabilities.

Key Informants were asked to provide their ideas for how the funding allocated through the Champions Initiative could be best utilized to meet the service and support needs of families with medically fragile and special needs children. Informants provided some overarching principles they say should guide allocation of the funding to non-profit agencies as well as ideas for the structure of specific service and support delivery models that should be prioritized for funding through the Initiative.

Suggested Guiding Principles for the Allocation of the Funding

A set of guiding principles emerged from the Key Informant interviews. The suggested principles provide guidance on how the funding for the Champions Initiative should be allocated. The guiding principles proposed by Key Informants are classified into four general thematic categories:

- Determination of need and eligibility
- Family and child-centered support
- Equitable access
- Sustainability

Determination of need and eligibility

Key Informants all stated that the current level of funding allocated to this Initiative does not begin to come close to the level of funding that is needed to meet the service and support needs of medically fragile and special needs children across the State, especially if the Initiative were to provide direct supports (in the form of financial assistance for therapies, medications, respite care or durable medical equipment). Informants worked to envision a way to ensure that the limited funding would be used optimally to meet the greatest needs of those families who do not have other options or resources. Many Informants said that should the Initiative provide direct services or financial assistance to families, it should be an option only after all other avenues are exhausted. The funding should be “reserved for parents who don’t have any other options.”

Some Informants say that families should meet certain eligibility criteria in order to qualify for services through the Initiative:

The \$2.2 million will be spent very quickly. You can spend that amount easily within a couple of months. You may need to set eligibility criteria: an upper limit for family income that takes into account medical expenses and whether there are other children, etc.

You have children who need therapies, who don’t go to the doctor as often; you have children who need a lot of intensive treatment and see a lot of specialists and have surgeries. I don’t know how you would handle it because you have so many different types of children. You might want to consider some type of Support Intensity Scale as a way to even out the playing field. It has to be based on need. If you are going to give out financial assistance, I don’t think it is fair that it be the same across the board. There are some families that need more and there are families that may need less and you need to have some kind of way to capture that to even it out for all the families.

A few Informants spoke of the challenges of providing continuous supports and services to families for life-long diseases and conditions. Such intense levels of support require years of expensive intervention that is not easily sustained through a non-profit agency that does not have a dedicated stream of funding to provide such care. These Informants proposed that support be time-limited so that aid could reach more families. One Informant suggested that support could be tied to defined developmental or medical goals.

What parents need most is funding for speech therapy, occupational therapy, and physical therapy. Consider setting goals for the child to meet, like being able to say the alphabet and fund the therapies until the child reaches that goal. That way, funds can be spread out over multiple families to assist their needs instead of being spent on just a few children over a long period of time.

Key Informants recognized that limiting the Initiative supports to certain diagnoses or providing funding for a limited period of time would be met with resistance from many families and providers alike. Some Key Informants suggested that the funded effort define a specific set of services and supports for children and their families, rather than prioritize services based on diagnoses classifications:

Families are not going to want to hear “this diagnosis over that diagnosis.” That would be really tricky. It might be better to figure out what services will be provided, rather than what diagnoses you would address.

My gut reaction is that it is not enough [money], because there are no criteria. The question is what is it that people really, really need? What are the basic services that the Foundation can reasonably guarantee and the needs of those who will meet the qualifications? Because obviously we are going to have to come up with some qualifications of who is included. The \$2.2 million, or whatever they decide, it is not going to be enough, so we have to decide what is reasonable. We can't cover everything. We have to figure out the base of services.

Family and child-centered support

The idea that families should meet a set of eligibility criteria before qualifying for services was a point that many Informants struggled with. All agree that some sort of criteria for eligibility must be in place to ensure that those with the most unmet needs are being served. However, Informants were quick to stress the importance of making access to the services or supports offered through the Champions Initiative easy and free of cumbersome red tape and applications:

Whatever is done, it has to be easy for parents to access. Parents are denied SSI, then denied Katie Beckett, and if they are denied by the new foundation... Reserve the funding for parents who don't have any other options, but don't make them jump through hoops to get it and then be denied. The paperwork that is involved in these programs is outrageous.

Informants described families with medically fragile and special needs children as having significant time constraints that limit their ability to engage in long application processes or attend trainings or meetings to engage supports for their family. One Informant described the importance of easy access for families:

Now I will tell you, all of the resources out there are wonderful, but when you are a parent at home with a medically fragile child, identifying those resources and tapping into those resources is a Herculean task. A parent of a medically fragile child barely has time to go to the bathroom and sleep. Trying to get on the Internet or make phone calls to track people down to get resources is next to impossible.

Also key to a child and family-centered approach is providing supports or services that support a child throughout their growth and development. Informants say that there needs to be increased capacity to address the needs of the child as the child grows and that there should always be supports in place to move the child closer to independent functioning. Informants stress that each child's needs are different, but that early and consistent intervention that progresses as the child progresses will "save the State money in the long-term" because people will grow into adults who are able to direct their own care.

Equitable access

Related to the principle that supports and services made available through the Initiative should be easy to access for families is the principle that services and supports must be accessible to families throughout the State and through multiple channels. The non-profit or network of non-profit agencies that are funded to support families through the Initiative must have reach and presence throughout the State - not just in Metro Atlanta or other metro areas. As described earlier in this report, many Informants expressed concern about those families who live in rural communities throughout Georgia where there are few services available to them and fewer networks of support functioning in their communities.

Informants said that families must be able to access information about the programs available to them through multiple channels of communication. One informant described this multi-channel communication:

You have to give people resources and information multiple times when they touch the system, through the pediatrician, the emergency room, the therapist, within the school system.

Many families do not have access to the Internet and are not connected to existing groups or resource centers that provide information on services and supports. Information must be available through channels other than the Internet and to those families who are less "networked in":

The current process [of getting services for your child] leans towards people with a keyboard. Families who aren't as savvy or connected can get lost in the process. I worry about those parents who can't get quick and accurate information.

Central to the principle of multiple channels of delivery and communication of supports is the importance of collaboration among and between agencies at local and state levels. Many Key Informants say that collaboration must be required of any agency seeking to be funded under the Champions Initiative because it will ensure that existing resources are not reinvented, but rather expanded upon and available through multiple groups with which a parent may come in to contact.

One Key Informant described the importance of collaboration this way:

I truly believe that the only through collaboration will we ever be able to address this issue. This has to be true collaboration; getting everybody at the table to talk about what is going on. We have got to play on what we can each do and what we each do well without turf guarding what we do.

Sustainability

Key Informants say that in order for this Initiative to be successful, long-term support and sustainability must be built into the design. Children who are developmentally delayed or who have chronic medical conditions are not “cured with a year of therapy.” Their needs span a lifetime and require support across their development.

Informants are concerned that families will suffer if supports that are not sustained are put into place for the short-term:

You have to think about what will happen to the families who come to rely on the funds from the foundation. This shouldn't be a teaser that families will end up losing when the money runs out.

Informants stressed the importance of identifying and developing steady streams of funding that can support this Initiative, but many struggled to define ways to make these supports sustainable without a dedicated source of funding from a governmental source.

You are going to have the same medical costs and therapy costs next year that you do this year. So you give them a debit card worth \$2,000, but the developmental disabilities don't go away. So how do you invest that money, or mobilize a community into replenishing [the funds] over a long period of time?

There needs to be a steady stream of funding that is not dependent on fundraising. Many of these parents are in a specialized group and their needs and issues are not 'main stream' so fund raising would be a challenge. We need to think about automatic funding mechanisms that would bring in constant funding.

Suggested Service and Support Options

Key Informants were asked to envision and describe the most effective and efficient way to address the unmet service and support needs of families through funding efforts by an existing non-profit or network of non-profit agencies. Informants suggested an array of potential options that ranged from providing direct financial support to families to intervening at the systems-level, in order to reorganize the way that services are delivered to children with special needs in the State. The range of potential service and support options proposed by the Key Informants to be funded through the Champions Initiative can be categorized into six general service and support approaches:

- Provision of flexible monies to parents for their children's needs
- Creation or expansion of a resource center that is a 'one-stop shop' for family-centered supports, information, and referral
- Provision of case management and service coordination
- Expansion of programs offered through the public school system
- Establishment of local, community-based networks of support for children, parents, professionals, and community allies
- Systems-level interventions

Providing flexible monies to parents for their children's needs

Many Key Informants acknowledged that the biggest need for many families with medically fragile and special needs children is expanded access to direct services. Financial assistance to obtain therapies, durable medical equipment, prescription medications, and respite care is in high demand and in short supply for many families.

I guess that the biggest hit the families take is the therapy and I think the prescriptions. For the medically fragile children who were denied Katie Beckett, they have got the medical bills and co-pays from their primary insurance - that is a big deal.

I don't think that the State does a very good job with filling in the gaps...sometimes families need durable equipment and the main thing is therapy, therapy, therapy... There are not a lot of places that you can refer people for direct services. There are not a lot of places where you can refer families that can fill those gaps.

Though many Informants spoke of families' needs for direct support, they grappled with how to make the provision of funds to families sustainable and wide-reaching. Therapies, equipment, prescriptions, respite care, and other medical costs are very expensive, and the unmet needs of families in the State are great. Many expressed the fear that if used in this way, the funds would be exhausted in a matter of months. Some Informants suggested that part of the allocated money be used to hire a fundraiser who could grow the pot of money. Others suggested that the funds be invested and grown that way.

The \$2.2 million [allocated by the Legislature] would be start up money. That money could be invested and used in order to make a viable foundation. They could hire quality fund raisers, somebody who can keep bringing in the dollars.

Building a ‘one-stop shop’ resource center for families

Most of the Key Informants say that families of special needs children are in great need of intensive and effective navigational assistance. They suggested that the funds be used to expand upon existing family resource and information centers that are working to aid families as they struggle to navigate the system and seek out community resources for their children.

I would love to see a one-stop shop, because that is the thing that is so frustrating for parents. The information is so fractured and you feel so overwhelmed. Where do I go and what do I do? I think that there is a huge need for [information on] what are the services and where to go.

Parents and care givers of special needs children need access to information that is clear, concise, and centralized. Informants spoke of the importance of having one central “place” that parents could contact, either via the phone or the Internet, that would provide information and connect parents to resources with just one call or just one click of the mouse.

Make it quick, a one page fact sheet or something like that, something that they can look at on one piece of paper, something that is quick that says, “Here are the resources available to you, here are the non-profits, here is the contact information, here are the waivers you should consider, here are other programs like Babies Can’t Wait or the GAP Program.” There should be a number to call in, and maybe the person who answers doesn’t have the answer right away, but that person is networked in and can find the answer and get back to the family.

Informants stressed that this information center should be “more than just a phone line.” An ideal resource center would provide information for families but would also work with families and providers to provide training and skills development. The resource center should be “hands-on.” Informants see a need for educational seminars that provide skills development for parents and other care givers as their child grows and develops. Informants mentioned the need for parent training related to the Individualized Education Plans (IEPs) that are created for special needs children in the public school system – how to write an IEP and how to ensure that it is carried out within the school system; how to fill out waiver applications; how to effectively transition your child from public school into adulthood, etc. A Key Informant described such an approach:

Have educational seminars for families that are ongoing, as new families come on board, but also have educational seminars for those families that have been around a while and have new concerns and new issues. As a child crosses over from Babies Can’t Wait at the age of three into the school system. That is a very scary time for families. The whole IEP process is very intimidating for families. As the child develops, develop an education program for the families to develop with the child.

Providing case management and service coordination

A few Informants said that families' needs for navigational and informational support went beyond what a resource center could provide. These Informants advocated that the funding be used to set up case management programs for families. They described how families struggle to manage the complex medical, social, and emotional needs of their children. They feel that these families could benefit from having an individual assigned to help families navigate the public and non-profit sectors and provide case management and care coordination. One Informant suggested that the funds be used to create a case management system similar to the SOURCE Program (Service Options Using Resources in a Community Environment) which is a State program that seeks to provide enhanced primary care case management to disabled and frail elderly Medicaid beneficiaries. Through the SOURCE Program beneficiaries are assigned a case manager who coordinates community-based services and medical care with the beneficiary's primary care physician.

There should be a model like SOURCE that includes medical management. It would be a set of community-based services for families that is coordinated by one person. This would be a great model for the families that we see. They need help tapping into community resources- they don't know what is out there. These families need more than just some phone numbers. They need someone to really do it.

Expanding programming offered through the public school system

Many Informants stressed the importance of the public school system in the delivery of services for special needs children and see the school as a potential intervention site for the provision of services funded through this Initiative. Multiple Informants spoke of the need to expand the quality and intensity of the therapies and other support programs provided through the schools and build the public school systems' capacity to effectively service these children.

One Informant suggested that the funds be used to create a "model school" that could be used as a training ground for other schools across the State. This individual described a school that would develop curricula, provide training to teachers, school administrators, other school staff and parents on how to best educate special needs children, and conduct research that would improve special education approaches in the State. Other Informants suggested that the money be used to subsidize private school programs to make specialized educational opportunities for special needs children more affordable for families. Private schools and specialized programs are out of reach for many families because of their "astronomical cost."

One key area of service that is reported to be lacking is a system or set of resources that aid young adults as they transition out of the public school system and into adulthood. Informants see the need for an expanded role through public schools to provide training and transitional support. These Informants spoke of the need to build the State's capacity to meet the living and supportive employment needs of young adults so that they continue to develop skills that will facilitate more independent living after they leave public school. They suggested that funds be used to strengthen the public school system's programming to prepare youth for jobs and independent living and to set up programs that provide a bridge between the school system and community-based supports for adults.

Creating local networks of support

A few Informants talked about the need to educate local communities about the needs of special needs and medically fragile children. They see a need to “de-isolate” these children and their families from the greater community by providing training and educational opportunities for community members to have direct contact with children and their families. Informants stressed the importance of looking beyond the “typical” stakeholders and allies to bring other community members and professionals into the fold: church leaders, local government officials, neighbors, and school teachers who do not teach in special education programs.

Central to this concept is the principle of local communities being empowered to seek out local solutions for families. The focus of this effort would be to raise community awareness about the needs of children and their families so that communities can respond accordingly with adequate local services and supports and build local networks of support for families in need. One Key Informant described this effort as “funding naturally-occurring support systems” for families with medically fragile and special needs children.

[We need to] create the resources to empower families in our communities to care for themselves. Empowerment is a huge tool, if you can facilitate that knowledge and the communication. You could go to a family and have them invite some people in to do a training - their care manager, their neighbors, their friends at church, from the basketball team, whatever. And they see the child in the home and there is the ripple effect of [the community] being desensitized to the child, and learning and growing. The ripple effect is huge. It just goes and goes and goes, because you are empowering at the bottom level, at the family. You are not building bureaucracy.

Part of expanding local communities’ roles in support of special needs children and their families is providing funding to expand recreational opportunities for children that allow them opportunities to meet and play with other children. A few Informants described how expanded recreational opportunities would allow special needs children to “feel like a typical kid” and “families to feel like families” while providing other children, parents and community members the opportunity to interact with special needs children and their families.

Making the case for systems-level changes in the State

One of the key themes that emerged from the Key Informant interviews was the need for change to occur at the systems-level within the State. Though this type of change process is beyond the scope of this Initiative, many Informants say that the unmet service and support needs of families with medically fragile and special needs children cannot be adequately addressed in Georgia until key leaders in the political and State agency systems make significant changes to the way that services are delivered to families and children.

Why is it that when we get sued and we get fined and we lose millions of dollars and we have kids dying in care and we have a chaotic, dysfunctional system, why can't somebody say, "We need to sit down and look at the big picture here. What is it that we know? What are the facts? What does research show and how can we create a structure in a program that is going to be effective?" Where is the collaboration? Where is the communication? Where is the leadership? Where is that knowledge?

Most of the Key Informants expressed the belief that State leadership approaches the issue as if it were a short-term concern that can be solved with a series of "one-shot solutions," when, in actuality, it requires long-term planning and provision of consistent services that meet the needs of children across every stage of development and through their adult lives. Many Informants argued that the funds allocated to this Initiative would be most effectively used as an incentive to bring State leaders to the table to begin talking about how to "de-silo" government's approach to supporting families and ensure more effective delivery of services. One Informant described such an approach:

You know, this is not a one-time deal... We often talk about how little different systems understand each other... You have to create conversations between systems on several different levels. And the best carrot to bring those systems together is by putting money at the center of the table. You have to bring the different systems that you want to understand each other and put some incentive in the middle. You ask them to come together and create some kind of common agenda. So you are not just putting money into direct educational opportunities for individuals, you are also looking at it on a systems level. The integration should happen in multiple contexts.

Informants like the individual quoted above spoke of using money as an incentive to bring together leaders representing different service delivery systems to begin to communicate and coordinate with one another. A second approach for encouraging inter-agency communication and collaboration advocated by a few Informants was to train and empower parents to convene service providers from many different agencies to train them on meeting the educational, employment, social, and medical needs of special needs children. These Informants saw "whole system" training as a way to build a more seamless system of care across the life of a child and into adulthood. A Key Informant described such an approach:

There is a need for folks who understand how to work with people throughout their life span, folks who are not necessarily their primary [providers] but who need to have that understanding in order to better serve them. That includes DFCS and juvenile justice and the courts, attorneys, police officers, judges, school administrators, principals, para-professionals, teachers...I think that there is a real need to support initiatives that empower parents to be those teachers. And it can be on a number of different levels. I think that it is important to have programs that seek out those parents who want to put themselves in the position of gate keeping and information, referral, and leadership in their local community. The concept is that you get parents teaching service coordinators, and get in the same room - DFCS and therapists and school teachers and all those individuals that are going to play a part in the system.

Informants suggested other systems-level approaches to better meeting the needs of children and their families. Many Informants spoke at great length about the application and annual reauthorization process that families must undertake when applying for and maintaining State-financed services for their children. Informants suggested that the funds could be best used to streamline the application process and reduce the amount of paperwork required of families and their providers.

Multiple Informants spoke of the key role that case workers play in the lives of families with special needs children and described what they perceive to be case workers' lack of awareness of the programs and resources, both public and non-profit, which are available for families with special needs and medically fragile children. Many Informants suggested that the funds be used to establish a separate unit within DFCS to train case workers to specialize in serving medically fragile and special needs children. Having case workers who are knowledgeable about services and resources available to families and who are adept at helping families navigate the application and eligibility maze would take away stress from families.

Finally, one Informant suggested that systems-level changes in the State have to be forced. This Informant recommended that the funds be used to set up a fund to pay for legal representation for families:

I would have a fund to fund legal representation for families. It is the only thing... You have got to force the State to do it, and after you force them a few times, everybody will come around. There are only four attorneys in the entire State that represent disabled kids, whether it be in the educational system, with Babies Can't Wait, getting their Katie Beckett, whatever.

Don't Reinvent the Wheel: Learning How Other States Support Children and Their Families

As part of the interview, Key Informants were asked to describe service delivery and support models that have been successful in meeting the needs of special needs and medically fragile children in other states. Programs described by Key Informants as “best practices” or models that Georgia could learn from are state-financed public programs or collaborations between non-profit and government entities with a dedicated stream of funding from the State. Informants struggled to identify “model” initiatives that are community-based, funded, and managed solely by non-profits.

When asked to describe models of support and service provision in other states, Key Informants often spoke of the differences in the way that other states interact with families of special needs children. As described earlier in this report, many Informants say that “other states don't fight their families as much” and described state-funded programs that support special needs children and their families. Multiple Informants mentioned the Catastrophic Illness in Children Relief Fund Commission in New Jersey. The fund was established by the New Jersey State Legislature to provide financial assistance to families overwhelmed by their child's medical expenses. The fund is a dedicated, non-lapsing trust fund that is financed in part through a levy on employers who are subject to the State's Unemployment Compensation Law. Families who have incurred expenses related to medical care, durable medical equipment, transportation, home modifications, prescription medication or home-based care can apply for financial assistance through the Fund. The monies are allocated by a commission of appointed members. The fund has allocated over \$100 million to more than 4,000 families since its inception in 1989.⁶

A few Informants mentioned Wisconsin's approach to helping families with medically fragile children navigate the Medicaid application process. Each county in Wisconsin has a “Katie Beckett Coordinator” who is knowledgeable about the level of care determination process, eligibility criteria, and the paperwork required of families and providers. The Katie Beckett Coordinator in each county can work with families to find a waiver program or other State program that meets their child's care needs and for which they would most likely qualify. The Coordinator works with families to fill out the application and assist them through the eligibility determination process.⁷

Washington State was mentioned by multiple Informants as a model state for their success in providing supportive employment opportunities for adults. A Key Informant described Washington State's approach to providing adult transitional and employment services⁸:

⁶ For more information on the Catastrophic Illness in Children Relief Fund, see:
<http://www.state.nj.us/humanservices/catill/cicrf1.htm>

⁷ For more information on Wisconsin's Katie Beckett Program Consultant program, see:
<http://dhfs.wisconsin.gov/bdds/kbp/kbpapply.htm>

⁸ For additional information on Washington State's approach to providing employment supports see: Butterworth, J and Cohen Hall, A. Innovation in Employment Supports: Washington State's Division of Developmental Disabilities: Research to Practice. (2003). Institute for Community Inclusion. Available online:
http://www.communityinclusion.org/article/php?article_id=140&staff_id=2

We should look at other states like the State of Washington, which has policies in place that are like 'tickets to work,' policies that assume that kids with developmental disabilities in the school system should work, can work, and that they just need to be transitioned early with long-term supports from the adult system to be successful. And, they have the dollars and the experience to do it.

Informants spoke of the value in undertaking a concerted effort in the State of Georgia to learn about how other states meet the care and support needs of medically fragile and special needs children. A few Informants suggested that the funds allocated be used to convene government leaders from multiple states to share successful approaches and programs. One Informant described this approach:

The people who really know what they are doing are the ones who find out what is going on in those states where children's outcomes are the best. For example, there is research out there that says that the best state for children is Minnesota. So people would go to Minnesota and find out what they are doing there. So how does early intervention work in Minnesota? How does Katie Beckett work? How do the developmental disability service waivers work? How do the public schools work? How does the transition work?

These Informants talked about the importance of “not reinventing the wheel” and modeling programs in Georgia after successful efforts that have already been implemented and proven to work in other States.

**Community Forums Sponsored By Champions For Children With Exceptional
Needs Initiative:
Summary of Process and Results**

Two community forums were held to provide parents, advocates, providers and the general public an opportunity to have input into how the State-funded allocation should be used to support children with special needs. One forum was held in Atlanta on April 28, 2007 and one in Savannah on May 5. During the forum, participants were given an overview of the Champions for Children with Exceptional Needs Initiative and the purpose and parameters of the State legislative funding. Additionally, participants heard an overview of the findings from the focus groups and Key Informant interviews. Participants were then presented with the guiding principles and suggested options that emerged from parents in the focus groups and the Key Informants. Forum participants were afforded the opportunity to reject or accept the guiding principles and prioritize the suggested options or propose additional options for consideration.

Results

Unfortunately, both community forums were poorly attended. Six people came to the Atlanta forum: two representatives from a local camp for children with special needs, one employee of a home health company, one parent of two autistic children, and two members of the Champions for Children for Exceptional Needs Advisory Committee. Six providers from various organizations attended the Savannah forum: a nurse from a local children's hospital, two physical therapists, a representative from a hipotherapy center, a representative from a home health company and a caregiver from a daycare center that serves medically fragile children.

Because so few people attended the forums, their input cannot be considered representative of all those who are interested in the welfare of children with special needs. However, participants in both forums strongly endorsed the guiding principles that had emerged from the focus groups and Key Informant interviews and indicated that the principles were "right on." These principles are:

- Focus on early intervention
- Base qualification for support on the needs of the child rather than the income of the family
- Make the process for obtaining support as simple as possible and eliminate red tape whenever possible
- Maximize the funding that goes directly to the support of children
- Make access to support equitable throughout the State
- Use a variety of mechanisms to broadly communicate the availability of support
- Build sustainability into the plan for providing support

The following five options for spending the \$2.2 million allocation were presented to the community forum attendees:

- Provide flexible money to parents for children's needs (medications, equipment, respite care, therapies, transportation, recreational activities, etc.)
- Establish a resource center for family-centered support services, including networking and support opportunities, information and referral, and skill-development training
- Provide services that support transition to adulthood
- Provide case management and service coordination
- Coordinate advocacy for medically fragile and other special needs children and their families

Participants were asked to choose the two options they most favored. Participants from both forums coincided in their choices for the top two options:

- Provide flexible money to parents for children's needs (medications, equipment, respite care, therapies, transportation, recreational activities, etc.)
- Establish a resource center for family-centered support services, including networking and support opportunities, information and referral, and skill-development training

However, these results cannot be considered to be representative due to the small number of people who provided input into the process.

Appendix A

Champions for Children with Exceptional Needs PARENT FOCUS GROUP DISCUSSION GUIDE

I. Introduction - 5 minutes

- Facilitator introduces self and thanks those in attendance for participating
- Facilitator explains purposes of discussion:

The Georgia Health Policy Center is working with The Community Foundation for Greater Atlanta on a project to understand the needs of families who have children with special needs. The Georgia Legislature set aside \$7.6 million to assist medically fragile children and their families, including those impacted by the changes in eligibility for the Katie Beckett Waiver Program. While most of that allocation was set aside as immediate direct assistance to families, additional funds have been designated to respond to their longer term needs. We have asked you here tonight to hear your experiences, learn about your needs and get your suggestions for how to most wisely use the funds that have been allocated.

- Facilitator explains about informed consent form, reads form and has participants sign consent forms.
- Explain about focus groups:
 - ⇒ Give and take conversation
 - ⇒ I have questions I want to ask, but you will do most of the talking
 - ⇒ There are no right or wrong answers
 - ⇒ You are not expected to be an expert on the Katie Beckett program, we just want your opinion
 - ⇒ You don't have to answer any questions you are uncomfortable answering
 - ⇒ It is important to speak one at a time because we are recording this conversation
 - ⇒ Your names will not be used when the tapes are transcribed, just male or female will appear on any transcript
 - ⇒ You may decide to stop participating in the group discussion at any time. However, because we don't identify individuals when they speak, if you decide to stop participating in the focus group, we can't remove information that you have already contributed from the transcript of the focus group discussion.
 - ⇒ I want to give everyone the opportunity to talk, so I may call on some of you who are quiet or ask others to "hold on a minute" while I hear from someone else, so don't take offense

Let's go around the table and introduce ourselves to each other. Please tell us your name and something about your family.

II. Experiences Receiving Services – 30 minutes

1. Please tell us about your child with special needs.
2. What special services/therapies/programs do your child and other children with similar conditions need?
3. Are these services/therapies/program available to you in the community where you live? If not, how far do you have to travel to obtain these services?
4. What other barriers do you face in being able to access the services your child needs?
5. What, if any, resources in your community have been a support to your child and your family? Please explain.
6. What, if any, organizations in Georgia or in your area are best equipped to address the needs of your child and your family and others like yours?
7. If you are receiving assistance from others, who or what organization is providing that assistance? Is it sufficient to meet your child's needs?

III. Moving Forward – 45 minutes

21. If you had to prioritize the services that your child needs that are not covered by private insurance, what services would be the most important? Are there any that you could manage to do without coverage for? Please explain.
22. In general, how can service provision/support to children with special needs and their families be improved?
23. In the ideal world, what would a comprehensive resource and support system look like?
24. What are your thoughts about how the funds allocated by the Legislature should be spent?
25. Are there existing agencies or organizations that should be considered to receive this funding in support of families such as yours? Please explain.

26. If there were to be a process for families to qualify for support through such a nonprofit organization, what are your thoughts about what that process would be? What are the criteria that children and families should meet to receive assistance?

27. What advice do you have for those making decisions about how the funds should be spent?

IV. Closing – 5 minutes

28. Is there anything else you would like to tell me or suggestions that you have that we have not yet discussed?

Facilitator thanks participants for coming and sharing their thoughts.

Appendix B

Champions for Children with Exceptional Needs Key Informant Interview Discussion Guide

Introduction:

The Georgia Health Policy Center is working with The Community Foundation for Greater Atlanta on a project to understand the needs of families who have children with special needs. The Georgia Legislature set aside \$7.6 million to assist medically fragile children and their families, including those impacted by the changes in eligibility for the Katie Beckett Waiver Program. While most of that allocation was set aside as immediate direct assistance to families, additional funds have been designated to respond to their longer term needs.

As part of the data collection process, The Georgia Health Policy Center is conducting interviews with Key Informants- individuals who have experience with and knowledge about the care needs and service gaps of children with special needs and their families. We have asked to speak with you today because of your experience working with and your knowledge of these families.

- *Interviewer reviews consent form with informant and has participant sign consent form. Participation may be by telephone and consent will be faxed.*

Service provision and gaps in Georgia

1. What resources/programs are currently available to families with medically fragile children/children with special needs in Georgia?
 - a. Are programs statewide? Local?
 - b. Are some areas of the state better served than others?
2. In Georgia, what role do federal, state and local government agencies play in the provision of care and support of these families and their children?
3. In Georgia, what role do non-profit and community-based agencies play in the provision of care and support of families with children with special needs?
4. What does Georgia do well?
5. What does Georgia not do well? What areas of support/care are most in need of improvement?
6. What type of agency/organization/system in Georgia is best equipped to address the needs of families of children with special needs?

Models of service provision and support

7. What are other states doing to address the needs of children with special needs and their families?
 - a. Are you aware of “model” programs or resources available to these families in other states? Please describe.

8. What would a comprehensive resource and support system look like? What is the 'ideal'?
9. The Georgia Legislature has budgeted funds to assist these children and their families, including those impacted by the changes in eligibility for the Katie Beckett Waiver Program. What are your thoughts about how the funds being allocated by the Legislature should be spent?
10. Are there existing agencies or organizations that should be considered to receive this funding in support of families? Please explain.

For clinical/therapy providers *and others responsible for care management:*

11. The state is committed to addressing the service gaps and needs of families with children with special needs. How would you define a 'child with a special need'?
12. What are the service needs of these children and their families?
 - a. Do they differ by type of functionality/diagnosis?
13. In your experience, how are the medical needs of these children being met?
 - a. What about their non-medical needs?
14. How well do insurance and other publicly funded programs meet the needs of these children?
15. Where are the gaps?
 - a. Do the gaps in service differ by functional level or type of diagnosis? (Are some medically fragile children better served by existing services than others?)
16. Are there services that could be provided to these children that would improve their quality of life that are often unavailable to families? What are they? (Probe for financial issue, access issue, provider issue)
17. The Georgia Legislature has budgeted funds to assist these children and their families, including those impacted by the changes in eligibility for the Katie Beckett Waiver Program. What are your thoughts about how the funds being allocated by the Legislature should be spent?
18. Are there existing agencies or organizations that should be considered to receive this funding in support of families? Please explain.
19. How would you prioritize the medical/therapeutic services to be offered through such a nonprofit? (Are there certain services or resources that are more important?)