The Health Care System for Medicaid Children with Special Health Care Needs

prepared for

Division of Medical Assistance
Department of Community Health,
State of Georgia

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Georgia
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State Medicaid programs are challenged to meet two competing goals: to provide equitable access to necessary health care services and to control spending. This tension exists when managing care for all populations, but it is especially true in covering children with special health care needs because of the breadth, complexity, and costs associated with their health care needs. Medicaid programs across the country are examining and reconsidering how they serve children with special health care needs. Some states are testing new models for serving children with special health care needs through capitated systems, while others are trying to integrate Medicaid with other public programs. It is too early to know what approaches hold the most promise.

In Georgia, policymakers, program staff, advocates, and providers have for several years discussed, without reaching consensus, how best to serve children with special health care needs. Most recently, the passage of Georgia CHIP legislation presented an opportunity for changes for children with special health care needs, but it was agreed that more information was needed before recommendations could be endorsed by all the groups involved.

Following that discussion, the Division of Medical Assistance (DMA) asked the Georgia Health Policy Center to evaluate the health care system serving Georgia's Medicaid children with special health care needs. As we conducted interviews with people who work in and around the system of care for children with special needs, we found problems with fragmentation that caused us to look beyond the existing Medicaid programs. Key informants cited a need for coordination among different programs within Medicaid and across different agencies that provided care for these children. Therefore, the study's focus shifted to a larger exploration of the publicly funded health care provided to Medicaid children with special health care needs.

We critically examine the types of services being used and the health care dollars associated with those services. In addition, we present contextual information about the system gleaned from interviews with program administrators, providers, parents and caregivers of children with special needs, and advocates. We believe that this is the first paper to examine the health care system for Medicaid children with special health care needs in Georgia.

KEY FINDINGS

We started with a broad, clinical definition of children with special health care needs drawn from the literature. The definition includes twenty conditions, has been used by several other states for identifying children with special health care needs, and was endorsed by our advisory group (see Table 1 of main paper for list of conditions.) The Health Policy Center analyzed paid Medicaid claims from FY98 to identify all children with one of the twenty conditions. We then pulled all health care utilization for those children in the one-year period.

Population and Costs

- More than one in five Medicaid children (127,942 children) were treated in FY98 for a health condition categorized as a special health care need. The most frequent special needs diagnoses were mental illness and related disorders, which includes the diagnoses for ADD, ADHD, and developmental delay (10 percent of all Medicaid children), asthma and bronchiectasis (6 percent), and perinatal complications (2 percent).

- DMA spent over $445 million for care for children with special needs in FY98, or 71 percent of Medicaid spending for all children. The average cost per special needs child was $3,478, compared to less than $600, on average, per Medicaid enrolled child without a special need.

- Hospitals were a major site of care for special needs children, more so than for other Medicaid children. About 40 percent of the amount spent on children with special needs was for inpatient care, 34 percent for outpatient physician services, 18 percent for other outpatient services, and about 8 percent for pharmaceuticals.

- The one-percent most expensive children (1,279 children) had average costs of $78,841 and had a total cost of $100,837,375 which represents 16 percent of spending for all Medicaid children.

Programs Covering Children with Special Health Care Needs

DMA has several programs or services designed for children with special health care needs:

- About 300 children with the most complex chronic conditions participate in special waiver programs giving them access to different providers or levels of service. These children are very expensive because of the type and volume of care they receive. For example, children enrolled in the Model Waiver program cost, on average, $68,000 per child in 1998.

- About 13,000 children with specific conditions received services in 1999 through the Babies Can't Wait program or Children's Medical Services (both programs of the Division of Public Health, Department of Human Resources) which were partly reimbursed by DMA.

- In FY98, 10,157 children received a limited range of therapeutic services for physical disabilities or developmental delay under the Children's Intervention Services (CIS) program. The provision of therapeutic services occurs through CIS and its school-based program, Children's Intervention School Services (CISS). These services cost DMA $11,994, 650 ($8,785,005 in CIS and $3,157,645 in CISS).

The number of CSHCN served by targeted DMA programs is much smaller than the 127,942 identified in this analysis by diagnosis. The programs specified above provide access to specialized services for children who meet each program's eligibility criteria. In addition, most Medicaid children, including children with special health care needs, are enrolled in Georgia Better Health Care Program (GBHC), which provides primary care case management. Through GBHC, children with special health care needs have the same benefits and service limits as other children, including being able to get services in excess of limits through a prior authorization process.

Problems with the System

The Health Policy Center interviewed over thirty people, including agency administrators, families, providers, and advocates about the system of care for children with special health care needs. We found several consistent themes.

- Interviews with <u>families and advocates</u> indicate major barriers to appropriate care exist, including:
  - Many families do not understand what services are covered and how to gain access to them.
  - Some families do not have access to appropriate, participating providers in their part of the state.
  - It was reported that there are not enough qualified therapists who will accept the Medicaid payment rate.

- Interviews with <u>providers</u> identified major barriers as well.
  - Providers told us that they have difficulty understanding eligibility requirements, service limits, and referral requirements.
  - Providers reported that reimbursement was inadequate to cover expenses, and thus reduced willingness to participate in the Medicaid program.

RECOMMENDATIONS:

Based on the full study which follows this section, we recommend five changes be made:

1. The current programs serving children with special health care needs contribute to the fragmentation of care for these children by narrowly defining eligibility criteria and benefits. We believe DMA should define a broader program for children with special health care needs which is needs based.

In order to identify the needs of the population, DMA should introduce a case management program including:

- an assessment of need by a multidisciplinary team, a care plan, and a case manager;
- an external authoritative body to review medical necessity appeals;
- a payment rate for this benefit;
- a list of eligible providers and provider training;
- a mechanism for evaluating the effectiveness of the benefit; and,
- enabling the case manager the authority to change the number or frequency of visits in accordance with the patient's needs.

This benefit could be phased in upon demonstration of its success for the most expensive children with special health care needs. We recommend starting with very high cost children, children who are in one of the waivers, and children who are considered "exceptional children".

2. In consideration of the cost constraints DMA faces, programs serving children with special health care needs should have to demonstrate quality and cost effectiveness. DMA should put in place a system that would measure the quality of care, including measures of structure, process, and outcome. Disease-specific measures are available for many special needs conditions and should be reviewed and approved by a provider panel for inclusion in the assessment. Cost-effectiveness standards would have to be established that conform with HCFA standards.

3. To respond to the frustration we heard from families and providers, we recommend DMA develop a manual for families, case managers, and providers that explains the Medicaid benefits available to children with special health care needs and the ways to access them. Let families and providers know what services are covered, and how to appeal when they want an exception to the rules. The manual should also identify resources external to Medicaid.

4. To reduce fragmentation for those children receiving care from more than one agency, DMA should pursue interagency cooperative agreements that clearly define the respective responsibilities of the major public programs serving children with special needs. Ideally, merge or coordinate public funding streams supporting children with special health care needs to remove barriers to the rational organization of care. The most important are agencies for these children are DMA, DPH, and DOE.

5. Involve families and providers in all aspects of the planning of these changes.

Challenges DMA Faces

DMA will face some considerable challenges to implementing the proposed changes. First, it is difficult to predict how much unmet need will be uncovered through case management, and budget constraints exist. This is why we recommend pilot testing the case management. We have interviewed some people familiar with some children in Georgia who have special health care needs, and they believe that there is some waste in the system that could offset some expansions of care.

Another option for handling the risk of a large increase in costs is to share the risk with the case management provider. Retrospective costs could be used to develop payment rates with risk corridors so that the case management providers work with families to consider trade-offs in the benefits received.

The state is losing some opportunities to maximize federal revenue drawn down for care for these children because public health and education programs do not always bill Medicaid for covered services. It may be possible to draw down some of this funding to cover the additional cost of case management. However, interagency agreements would be needed to overcome some of the existing barriers.

Additional copies of this report are available upon request from the Georgia Health Policy Center.

BACKGROUND

State Medicaid programs are pulled between two competing goals: to provide equitable access to necessary health care services and to control spending. This tension exists when managing care for all populations served by Medicaid, but it is especially true in covering children with special health care needs because of the breadth, complexity, and costs associated with their health care needs. Medicaid programs across the country are examining and reconsidering how they serve children with special health care needs. Some states are testing new models for serving children with special health care needs through capitated systems, while others are trying to integrate Medicaid with other public programs. It is too early to know what approaches hold the most promise.

In Georgia, discussions have been going on for several years about how best to serve special needs children. In 1998, many people concerned about child health access came together to discuss implementing the Children's Health Insurance Program (CHIP). They revisited the question of how to improve access to covered services for children with special health care needs but decided the deadline for designing CHIP would not allow sufficient time to consider all the issues. Following those meetings between state officials, providers, advocates, and observers came a request for more information. The Georgia Health Policy Center was asked to do a study of how well the current system was meeting the needs of children with special health care needs and make recommendations to DMA about changes that might improve the system. The group raised questions about how many children with special health care needs are served by Medicaid, what services they use, and how much their care costs.

In order to report on the current system and answer these specific questions, the Georgia Health Policy Center has reviewed the relevant literature, conducted interviews with over three dozen people who work in and around the health care system, interviewed families of children with special needs, participated in national meetings, and analyzed Medicaid paid claims data. This first report provides baseline information on the status of the current Medicaid system for children with special health care needs (CSHCN) and answers four questions:

- How do we define children with special health care needs?
- Who are the children with special needs being served by the Medicaid system?
- How does the Medicaid system serve children with special health care needs?
- What are the challenges and barriers in the Medicaid system for children with special health care needs?

How do we define children with special health care needs?

Children with special health care needs are those who have or are at increased risk of chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally (McPherson et al, Pediatrics 1998). While this definition is generally agreed upon, it casts a fairly wide net, identifying about 20 percent of children as having a special health care need.

Determining that a child meets any of the criteria embedded in the above definition requires measurement. For example, to know if a child has a chronic condition requires you ask the child or parent or look at past health care utilization for evidence of health care utilization consistent with a chronic condition. There are four main types of measures used to determine if a child has special health care needs: functional limitations, specific diagnoses, level of utilization, or eligibility for a specific federal program. Examples of different measurement tools are provided in Appendix I.

The best approach to measuring the number of children with special health care needs depends on the purpose for which it will be used. For example, we are interested in expenditures for children with special health care needs, which can only be assessed by analyzing paid claims data. Claims data do not include a risk assessment or survey data. Therefore, we have no choice but to look at specific diagnoses or children who use a lot of services. We could look at children eligible for SSI, who are known to be disabled in order to qualify for the program. However, we know the program excludes a number of Medicaid children whose incomes are above the SSI threshold or who have chronic conditions that don't meet the SSI criteria (like most asthmatics).

In reporting on Medicaid special needs children, the Health Policy Center has taken two of the approaches listed above. We have used a list of special needs diagnoses (see Table 1) and compared them to paid claims data from fiscal year 1998. The results are provided in the next section.

Table 1. List of ICD-9 codes used for Population Identification.

Codes	**Conditions**
042	Human Immunodeficiency Virus (HIV)/ AIDS
142, 147, 155, 158, 170-171, 189, 190-192, 196, 197, 200-208	Malignant neoplasms
237	Benign neoplasms
250, 277	Genetic endocrine disorders (diabetes & cystic fibrosis)
282	Hereditary hemolytic anemias (includes sickle cell)
292-296, 299	Organic mental illess and psychoses
300-302, 306-310, 312-316	Neurotic and non-psychotic mental disorders (includes ADD, ADHD, and developmental delay)
317-319	Mental retardation
330-331, 343-344	Cerebral degeneration and other paralytic syndromes
345	Epilepsy
359	Muscular dystrophy
369, 389	Blindness and hearing loss
394-396	Disorders of the mitral and aortic valves
493-494	Asthma and bronchietasis

580-581, 584-589	Structural and functional disorders of the kidney
714	Rheumatoid arthritis
741	Spina Bifida
744-747, 749-751, 754, 758	Congenital anomalies
765-766, 770-771	Perinatal conditions
800-803, 806, 940-949	Head, thorax, and spine fractures and Burns
995.5	Child Abuse

We also conducted a survey of families of special needs children using the screening questions in Table 2 to identify the children. This screening tool is very new and based on the convergence of two previous approaches to identifying special needs children (Fowler et al, 1998). Results of the survey are available in a separate report. We did not conduct a functional assessment because of the very high costs involved; nor did we look at federal program eligibility because it is extremely restrictive (identifying only six percent of children as special needs).

Table 2: Screening questions to identify children with special health care needs

1. Does your child now have any medical conditions that have lasted or are expected to last for at least 3 months?
2. In the last 6 months, has your child seen a doctor or other health provider more than twice for any of these conditions?
3. Has your child been taking prescription medication regularly for any of these conditions?

We believe that when DMA is ready to implement any changes for special needs children, decisions will be made about which children are to be affected by the changes. Depending on the nature of the changes, different methods of defining eligible children may be most helpful. We have focused on case management as a major improvement. We believe all children would benefit from case management, but that it may be most cost-effective for children who use multiple providers and have high cost conditions. To identify the right children for this benefit, DMA would want to use diagnosis or high costs to trigger an assessment by a qualified provider. The provider might then do a functional assessment to determine level of need.

To implement a program that incorporates multiple agencies and their programs, the operationalization of a definition is critical. Successful programs have incorporated several mechanisms to accomplish a coordinated method of caring for children with special needs and one of the most critical was the formalized process of making the definition operational throughout the system. Similarly, in States where a definition was developed but never incorporated into the system’s process, the programs for children with special needs have not advanced beyond a conceptual stage.

Who are the children with special needs currently being served by the Medicaid system?

We can report on children with special health care needs in the Georgia Medicaid program two ways. The first is to apply national prevalence data to the Georgia population. The second is to count Medicaid enrolled children with specific diagnoses. For each method, we have summarized what is known about costs.

National prevalence estimates applied to Georgia

The most recent prevalence estimate of children with special health care needs is 18% of U.S. children birth through 18 years old. The estimate uses the definition from the Maternal and Child Health Bureau, which includes children who have a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children generally (Newacheck, 1998). The Albert Einstein College of Medicine and the National Association of Children's Hospitals and Related Institutions have published similar estimates. By applying this estimate to Georgia's Medicaid program 1998 enrollment figures of 670,077 children, approximately 120,614 children have special health care needs.

Overall prevalence estimates mask the enormous variation among special needs children. More than half of special needs children have conditions that minimally impact their health status. A smaller group, about 1 to 2 percent have severe conditions that result in substantial utilization of health care services. Applying these estimates to Georgia's 1998 Medicaid population, we would find 1,206 have severe conditions.

Georgia prevalence estimates

The Health Policy Center used paid claims data to identify Medicaid children with special health care needs between the ages of birth to 21 years old. There is a high level of agreement about which diagnoses should be included in an analysis of this sort. Washington and Florida both have published their methodologies, and we drew our list of ICD-9 codes from theirs. (Please refer back to Table 1 for the specific codes used.) At the time we started this analysis, the most recent year for which complete data were available in Georgia was fiscal year 1998.

Using paid claims for fiscal year 1998, we found 127,942 children in Georgia, out of over 670,000 Medicaid-enrolled children, who received care for one or more health condition classified as a special needs condition. That means about 19 percent of Medicaid-enrolled children in 1998 had a special health care need. We believe the percentage is higher than in the national data Medicaid enrollees are known to be sicker than the population as a whole.

The following table provides basic demographic information about the special needs population enrolled in Georgia Medicaid.

Table 3. Characteristics of GA Medicaid Children with Special Needs

Characteristic	Number	Percent	Characteristic	Number	Percent
Total	**127,942**	100%			
Age			Eligibility Category		
< 1	18,544	14%	SSI	20,080	16%
1 - 5	35,577	28%	Low Income	99,897	78%
6 - 21	73,796	58%	Foster Care	7,284	6%
Unknown	25	0%	Other	681	0%
Gender			Race		
Female	53,613	42%	African-American	64,308	50%
Male	74,329	58%	Caucasian	49,028	38%
			Other	14,606	11%
SMA					
Urban	85,784	67%			
Rural	42,158	33%			

Source: GA DMA paid claims, FY98

National costs of health care

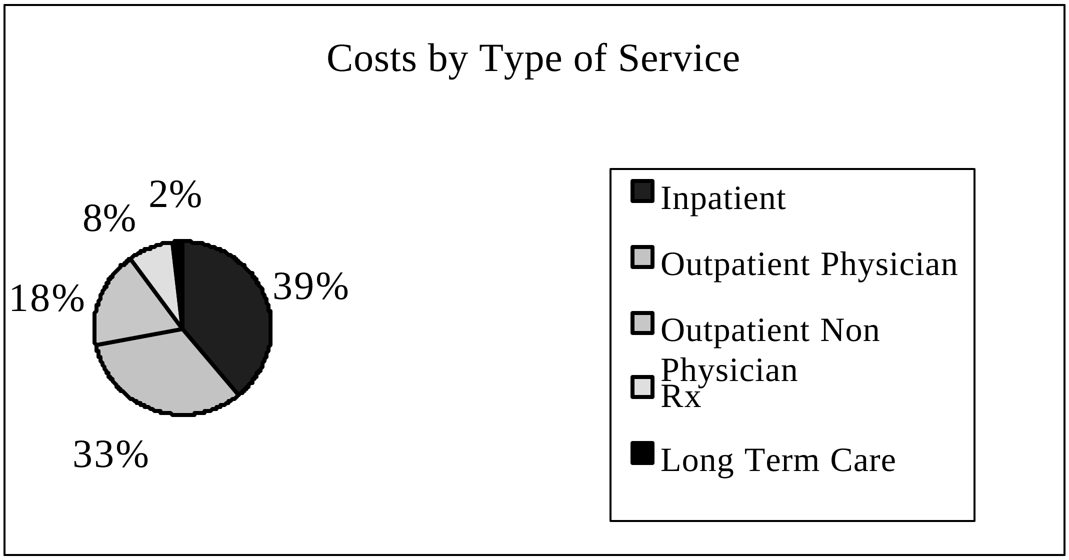
Children with disabilities are a costly population to serve. Washington State estimated its Medicaid expenditures for children with one of eight selected chronic conditions in 1993 and found that average expenditures were $3,800 per child with special health care needs (Ireys, 1997). In contrast, Washington Medicaid paid on average $955 for all other children. Average expenditures across conditions ranged from $2,359 for diabetes to $19,104 for chronic respiratory disease. Moreover, the mean expenditures within a selected condition varied substantially depending upon comorbidities and severity levels. Ten percent of the cases accounted for approximately 66% of the spending, while the least expensive 70% of cases made up only 15% of expenditures. Further research by Andrews et al. (Andrews, 1997) explored the high cost conditions and reported a range of costs expended from $31,000 on average for low birth weight infants to $197,000 on average for children with congenital and hereditary progressive muscular dystrophy.

In another evaluation of Medicaid expenditures, children who qualify for Supplemental Security Income (SSI) are more likely to have high cost, severe conditions; average expenditures from state and federal governments were $7,128 in 1995 for 955,000 children on SSI (Alliance Report, June 1997). Expenses are not predictable or consistent across conditions or within conditions. This complication exacerbates the difficulty in planning a system of care appropriate for CSHCN with predictable costs.

Costs related to other aspects of caring for a child with special needs are not well documented. Out-of-pocket expenses for co-insurance, residential living space adaptations, impact on employment of the caregiver, and the indirect costs of stress have not been quantified. However, caregivers report that these are substantial financial burdens. One study estimated that, on average, caregivers with children with special needs pay approximately 20 percent of their child's medical expenses directly out-of-pocket (Newacheck, 1990).

Georgia Medicaid Spending for CSHCN

Georgia's Medicaid program spent $445 million in FY98 for the 127,942 children with special health care needs. As Figure 1 illustrates, approximately 39% of medical care expenses were for inpatient services, with a total expenditure of $173,567,958. Outpatient physician services cost the Division of Medical Assistance $146,865,195, or 33% of expenditures for children with special health care needs. Other outpatient services, such as durable medical equipment and other providers reflected 18% of expenditures in 1998 for children with special needs, with $80,108,288 reimbursed. Pharmaceutical services represent only 8% of total expenditures for children with special health care needs, accounting for $35,603,684. Long term care expenditures account for 2% of public Medicaid dollars spent on children with special needs; $8,900,920 was expended for long term care services in 1998 for children with special needs.



On average, children with special health care needs cost $3,478 per year. Again, averages mask the wide variation in spending. The most expensive one-percent of children (1,279 children) used an average of $78,841 in health care services, or 16 percent of Medicaid spending on all children.

Table 4. Medicaid Expenditures for Children with Special Health Care Needs

	All CSHCN	Top 1% by Expenditures
Children with Special Needs	127,942	1,279
% of all Medicaid children	19%	0.2%
Total Cost	$ 445,046,045	$ 100,837,375
Average Cost	$ 3,478	$ 78,841
% of Medicaid Spending on Children	71%	16%

Source: GA DMA Paid Claims, FY98

Spending varies tremendously by diagnosis. In Table 5, we have arrayed prevalence of each special needs diagnosis and average spending per by child within a given condition. The numbers add to more than 127,942 because children are included for each diagnosis they received medical care for in 1998. Given the wide variation in costs, we also included median expenditure values, which is a measurement less sensitive to extreme values. Separately, we present the prevalence and cost of the 1% most expensive children with special needs.

Table 5. Medicaid Expenditures for special needs condition

	All Children with Special Needs			**Most Expensive Children**		
Condition Groups	**number**	**avg cost**	**median**	**number**	**avg cost**	**median**
Total	127,942	$ 3,478	$1,139	1,279	$ 78,841	$ 67,406
Mental illness and related disorders	61,210	$ 2,799	$ 1,183	330	$ 68,413	$ 56,163
Asthma and bronchietasis	40,872	$ 2,770	$ 1,031	212	$ 91,702	$ 71,882
Perinatal complications	10,674	$ 10,880	$ 3,829	643	$ 84,602	$ 74,281
Congenital anomalies	7,047	$ 10,821	$ 2,637	434	$ 86,590	$ 74,367
Blindness & hearing loss	5,942	$ 3,963	$ 1,428	69	$ 77,377	$ 60,433
Cerebral degeneration & other paralytic syn.	4,615	$ 12,120	$ 4,796	261	$ 92,085	$ 70,726
Epilepsy	3,389	$ 8,150	$ 2,970	107	$ 86,802	$ 69,110
Head, thorax and spine fractures; Severe burns	2,521	$ 4,086	$ 1,004	28	$ 97,109	$ 105,264
Mental retardation	2,511	$ 9,189	$ 2,999	148	$ 62,613	$ 53,964
Genetic endocrine disorders	1,921	$ 7,203	$ 2,389	56	$ 83,476	$ 70,239
Hereditary hemolytic anemias	1,818	$ 4,968	$ 1,419	18	$ 71,076	$ 56,102
Child abuse	1,806	$ 3,455	$ 1,263	18	$ 67,196	$ 60,783
Spina bifida	1,718	$ 16,061	$ 6,640	142	$ 92,739	$ 78,109
Disorders of mitral and aortic valves	1,697	$ 1,840	$ 665	9	$ 96,802	$ 88,322
Malignant neoplasm	858	$ 16,184	$ 3,242	91	$ 93,872	$ 80,652
Structural and functional kidney disorders	798	$ 14,859	$ 3,075	76	$ 95,982	$ 70,881
HIV	424	$ 7,886	$ 3,246	8	$ 96,088	$ 101,019
Benign neoplasms	281	$ 7,813	$ 2,345	9	$ 74,971	$ 71,845
Rheumatoid arthritis	196	$ 3,096	$ 1,649	-	-	-

Source: GA DMA Paid Claims, FY98

Table 6 shows spending for specific health care services for children with each special needs diagnosis. As would be expected, some health conditions result in greater use of inpatient services than others do, and these are the most expensive.

Table 6. Distribution of Disease-Specific Costs by Type of Service

Condition	Inpatient	Outpatient Physician	Outpatient Other	Pharmacy	Long Term Care
Neurotic and non-psychotic mental disorders	19%	41%	30%	9%	0%
Asthma and bronchiectasis	2%	58%	19%	21%	0%
Perinatal complications	75%	16%	7%	2%	1%
Congenital disorders	62%	22%	11%	4%	1%
Blindness & hearing loss	29%	38%	25%	8%	0%
Organic mental illness and psychoses	22%	33%	31%	10%	4%
Head, thorax and spine fractures and burns	49%	33%	11%	6%	0%
Cerebral degeneration & other paralytic syn.	43%	23%	26%	5%	3%
Epilepsy	13%	78%	6%	3%	0%
Benign neoplasms	39%	40%	12%	8%	0%
Mental retardation	12%	25%	37%	7%	19%
Genetic endocrine disorders	47%	16%	11%	16%	10%
Hereditary hemolytic anemias	58%	29%	6%	8%	0%
Child abuse	24%	30%	40%	5%	0%
Disorders of the mitral and aortic valves	40%	47%	8%	5%	0%
Malignant neoplasm	67%	24%	4%	4%	1%
Structural and functional kidney disorders	71%	19%	5%	6%	0%
Spina Bifida	45%	25%	27%	4%	0%
HIV	40%	20%	11%	29%	0%
Rheumatoid arthritis	34%	40%	11%	15%	0%
Muscular dystrophy	42%	18%	35%	5%	0%

Source: GA DMA Paid Claims, FY98

Costs for Children enrolled in the Model Waiver

A very small number of children with special health care needs are eligible for special health care services, so their costs are of particular interest. In this section, we look at children in the Model Waiver program. The purpose of the Model Waiver is to provide skilled nursing services to children who are oxygen dependent or ventilator dependent 24 hours per day. These children may receive care in their home or in a day care center for medically fragile children.

Analysis of the Medicaid claims data identified 140 children who received services under the Model Waiver category of service throughout 1998. Waivered services alone cost $3,662,261. Children in the waiver program cost Medicaid a total of $9,525,447 for all of their health care. As with the general special needs population, it is probable that the costs underestimate the range of medical and health care services provided to these children because of reimbursement from private insurance, other public programs, or indigent care costs.

Table 7 compares the distribution of costs for Model Waiver children and other children with special needs enrolled in Medicaid in 1998. As expected, Model Waiver children have higher expenditures, on average, for all types of service, except long-term care, when compared to other special needs children. Since the purpose of Model Waiver is to prevent institutionalization of children with complex medical needs, we would not expect to see long term care claims.

Table 7. Comparison of Cost for Model Waiver and other CSHCN

Type of service	Total Cost	Average Costs	%	Total Costs	Average Costs	%
Inpatient	$ 4,040,433	$ 28,860	42.4%	$ 173,567,958	$ 1,357	38.6%
Outpatient Physician	$ 748,881	$ 5,349	7.9%	$ 146,865,195	$ 1,148	32.9%
Outpatient Other	$ 4,398,399	$ 31,417	46.2%	$ 80,108,288	$ 626	17.9%
Pharmacy	$ 337,734	$ 2,412	3.5%	$ 35,603,684	$ 278	8.6%
Long Term Care	-			$ 8,900,920	$ 70	2.0%

In addition, the relative importance of the physician as a provider diminishes considerably among children enrolled in the Model Waiver (7.9% versus 33.9%), with other outpatient providers such as therapists and nurses and hospitals serving as the primary sources of medical care.

How does the current Medicaid system serve children with special health care needs?

In Georgia, almost all Medicaid children with special health care needs are mainstreamed with other Medicaid children. Most receive care through Georgia Better Health Care (GBHC) and smaller numbers are in traditional fee-for-service Medicaid. These children are not identified by DMA as having special needs. They enter the Medicaid program through the same intake process as other children, which is an assessment of eligibility by a caseworker at the Division of Family and Children's Services (DFCS) or a Right from the Start Medicaid outreach worker. Moreover, the special needs children, as with the rest of the Medicaid children, have their health care services managed through the primary care case management system (PCCM) operated via a contract with GBHC.

A very small number of Medicaid children do get special services. In 1999, approximately 107 children are in the Model Waiver Program and about 55 receive care through Exceptional Kids services. In addition, in 1998 about 142 children were eligible for Medicaid through the Katie Beckett waiver, which is a special provision for determining eligibility for public health insurance. Case management services are available through Targeted Case Management and Early Intervention. Targeted Case Management is available for children from birth to age 17 who are in Foster Care or are receiving Child Protective Services to protect a child from abuse or neglect. Early Intervention Case Management is available to infants and toddlers up to age 3 enrolled in Babies Can't Wait who are Medicaid eligible, about 3,360 children in FY98. These special benefits are described below.

The rest of the children with special health care needs, about 145,300, are eligible for the same services as other Georgia Medicaid children and are subject to the same service limits (described below). Most have a primary care provider (PCP) who can refer to specialists, therapy providers, and DME providers, when necessary. Our family survey, due in April 2000, will provide more details about access to needed providers, and the extent to which the PCP has knowledge of the special needs of these children.

When they need services not covered by Medicaid (or too hard to obtain through Medicaid), many children access other health care services through Children's Medical Services (CMS), a program of the Division of Public Health, Department of Human Resources. CMS administrators estimate 9,000 Medicaid beneficiaries received CMS services is FY99. An unknown number of families purchase additional services out of pocket.

In addition, health care needs related to education are identified and provided through the school districts. Although we believe there must be a high degree of overlap between the Medicaid school age children and the children served by the Department of Education, DoE does not keep records of Medicaid eligibility.

Medicaid beneficiaries may also receive health services through the Division of Mental Health, Mental Retardation, and Substance Abuse, Division of Family and Children Services, Division of Rehabilitation Services, and the Juvenile Justice System. In early discussions between the Health Policy Center and DMA, we agreed to limit the scope of our study by excluding these agencies from our analysis. Likewise, the role of private health insurance and community-based organizations are beyond the scope of our work at this time.

Even just limiting our study to looking at the role of DMA, DPH, and DOE in serving children with special health care needs, we find that children and their parents face tough challenges in obtaining assistance to meet their complex and multiple demands. Each of these agencies contains multiple divisions, which receive federal, state, and county dollars to support their programs. These agencies and programs have unique eligibility procedures, which differ from each other in terms of age limits, income level (for DHR programs), and developmental or physical conditions. Furthermore, each program has its own assessment and care plan and, frequently, its own service coordinator. The resources available vary across programs.

Agencies Have Different, Overlapping Roles

DMA, as a health insurer, provides access to medical services for the broad population that it serves: pregnant women, children, elderly people, the blind and the disabled, who otherwise could not afford such care. From the vantage point of an insurer, the agency self-identifies as a physician reimbursement source (Snyder, 1999). For the most part, the Medicaid population requires access to general and specialized medical services on an acute basis. However, for critical subsets of the population, which include the frail elderly, children with special health care needs, and chronically ill adults, ongoing medical treatments and health care interventions are required. DMA has established programs to address the needs of some chronically ill beneficiaries. For children with special health care needs, the exceptional kids program, community care waiver, early intervention program, model waiver, children's intervention services, and mental retardation waiver are the available options for accessing specialized chronic care in addition to routine physician services. Detailed descriptions of these programs follow.

DHR has a range of programs within separate divisions addressing developmental and educational services, direct physical needs for specific conditions, and mental health needs through the Division of Public Health (DPH) and Division of Mental Health, Mental Retardation and Substance Abuse (MH/MR/SA). Within the DPH, Babies Can't Wait offers care for developmental and educational concerns. Other programs for Lead Poisoning, Immunizations, and Genetics focus on specific medical concerns. Children's Medical Services (CMS) has been the traditional program for special needs children with chronic medical conditions. MH/MR/SA provides ongoing mental health services for organic and inorganic illnesses, including long-term care and community care options.

DPH has an explicit focus on population health care. The focus emphasizes chronic disease prevention, population-based disease surveillance and prevention, and community-directed care. Recently, DPH reorganized its population-based health care for children by restructuring programs around various stages in child development, with one program, Children 1^{st}, identified as a service-finding resource for the entire DPH system as well as to community services external to the agency.

MH/MR/SA also views health as a long-term process, providing both curative and maintenance services. Historically, services were provided in institutions; more recently, the vast majority of beneficiaries are in community-based settings. Approximately, 19 percent of the population are children receiving treatment for mental illness (Toal, 1998). Since 1988, Georgia has expanded community mental health services for emotionally disturbed children and teens from limited outpatient diagnosis and counseling to a range of community services including expanded outpatient services, crisis teams that go into the home, day treatment programs and respite care. Twenty-one service areas have the full network of services, including therapeutic foster care and therapeutic group homes. In FY '98, 33,772 children and teens were served in community programs.

In contrast, DoE provides access to services intended to enhance or enable the educational experience, not to resolve physical or developmental conditions. Unlike the other two agencies, DoE’s entrance into the health care arena was prompted through federal legislation as a supplement to its educational goals. Fundamentally, DoE exists to provide educational services. Any service provided to children enrolled in the public school system must enhance or enable the child’s learning potential and be directly related to a specific educational goal. Services provided include audiology, speech and language, occupational, and physical therapy as well as limited nursing services and nutritional counseling by a licensed clinical social worker. The role of health care is to support education.

Impact on Care

The differences in perception and conflicting federal mandates and incentives create the potential for miscommunication, gaps in available services, misinterpretation of service demand, underdevelopment of provider supply and duplicative processes.

Cross-agency communication about the various programs and services available to children with physical, emotional, and behavioral needs is complicated, at best. Multiple forms to facilitate communication are used. The DMA system requires that services be authorized by a licensed practitioner. The authorization can come from a physician care plan, an Individual Family Service Plan (IFSP) from DPH, or an Individual Education Plan (IEP) from DoE. For Medicaid children crossing agencies, their services must be on the required forms within each agency in order to receive care. Furthermore, services authorized on an IFSP or an IEP can be different from those services authorized on a care plan from another licensed practitioner. For example, a seven year old child may require 2 hours of physical therapy every other week for educational purposes, which would be documented on an IEP, and a physician may authorize 3 additional hours of physical therapy every other week for medical purposes.

The potential for care coordination is hampered by conflicting eligibility categories and types of care provided both across and within agencies and programs. The next section provides more detail about the various eligibility categories.

The range of available options changes by age group and agency. Children with special health care needs who are Medicaid eligible can access DMA Early Intervention Services (EI) through the DHR Babies Can't Wait (BCW) program from age 0 months to their 3rd birthday, if they meet the additional eligibility requirements of BCW. From ages 3-5, a Medicaid child who meets the developmental delay definition from the Department of Education can access services through preschool special education, Early Head Start, and Head Start. However, finding available programs in the school system that can accommodate the needs of children with special health care needs for ages 3-5 is very difficult. Once school age (3-21), a Medicaid child can receive therapeutic services identified and prescribed by the IEP. Nevertheless, some children require both an IEP and a physician plan of care to cover extensive need for therapy. As mentioned previously, Medicaid enrolled children across all age groups can receive specific therapy services through Children's Intervention Services, authorized by a physician, without interfacing with DHR or DoE.

The resulting system requires substantial investment of time and energy to decipher. Services rendered in the educational setting or by a program in DPH may be reimbursable under Medicaid. Required forms, receipt of approvals for care, and benefits limitations can be confusing with care coordination a significant burden as children access multiple agencies and programs. For example, some parents report that the negotiations across agencies about who will pay for a recommended health care service can last for several months. This places caregivers in a precarious position as the agencies negotiate payment coverage of services, leaving the caregiver financially vulnerable and jeopardizing the child's access to health care.

ELIGIBILITY

DMA

Children with special health care needs enter into the Georgia Medicaid system through a variety of mechanisms. Eligibility for children with special health care needs can fall under five main categories:

- infants born to a woman eligible for Medicaid through Right from the Start Medicaid;
- current and former cash assistance recipients (TANF and SSI),
- low-income children who do not qualify for TANF,
- the medically needy, and
- children eligible under any of a series of Medicaid expansions or waiver programs (e.g., Katie Beckett waiver).

Since January 1999, children with special health care needs with family income levels greater than those of Medicaid but less than 200% of FPL are able to gain access to public health insurance through the Georgia Children's Health Insurance Program (CHIP), PeachCare for Kids.

In the descriptions of eligibility categories below, categories that are more likely to include children with special needs are discussed.

Right from the Start Medicaid: RSM was introduced in Georgia in January, 1989 as a Medicaid expansion for pregnant women and their children with incomes slightly above the Medicaid eligibility limit. RSM used 185 percent of the federal poverty limit as the ceiling of eligibility for pregnant women until 60 days after delivery and infants up to age 1. In 1993, the State General Assembly expanded coverage to children up to age 19 who reside with low-income families and who otherwise do not qualify for Medicaid. The income level varies with age: children up to age 1 are eligible at 185 percent of FPL; children ages 1 through 5 are eligible up to 133 percent of FPL; and children age 6 through 19 are eligible at 100 percent of FPL.

RSM was initiated in Georgia as a response to federal and state legislation targeted at reducing infant mortality and morbidity. Its purpose is to conduct active outreach and case finding to enroll women who need prenatal care in order to begin the provision of services and identification of medical need from pre-delivery onward. Early detection of adverse health outcomes is believed to improve health status and prevent delays in receiving medical care. Consequences of poor health during pregnancy include low birth weight babies, complications during pregnancy and birth, congenital anomalies, and infant disabilities. Pregnant women are covered for prenatal care services, perinatal case management, substance abuse services, and post partum home visits. Children are eligible for medical and health services covered under the standard Medicaid program. In FY98, 48 percent (69,665) of children with special needs qualified for Medicaid under RSM.

Temporary Assistance for Needy Families (TANF): The TANF Program was created by the Welfare Reform Law of 1996 and became effective July 1, 1997. TANF replaced what was then commonly known as welfare: Aid to Families with Dependent Children (AFDC) and the Job Opportunities and Basic Skills Training (JOBS) programs. The program provides cash assistance to families, contains strong work requirements, places time limits on most assistance, reduces welfare dependency, and encourages two-parent families. In Georgia, a family can qualify for TANF for up to 48 continuous months and qualify for Medicaid coverage.

Since the separation of welfare benefits from automatic eligibility for Medicaid from the Welfare Reform Law in 1996, potential beneficiaries must apply separately for both programs. Moreover, a low-income family can be eligible for Medicaid without being eligible for cash assistance. Also, Georgia waives the work requirement if a child is less than 1 year of age in the household and continues Medicaid and ChildCare benefits for up to 12 months after a family transitions off of TANF.

Since the passage of the Welfare Reform Law in 1996, Georgia's welfare recipients have decreased from 330,302 in August of 1996 to 130,210 in June of 1999, representing a 61% decline in welfare beneficiaries (Administration for Children and Families, December 1999). Nationally, the number of welfare recipients has decreased by 44% in the same time period.

Supplemental Security Income: SSI was established in 1972 as a federally-mandated program to provide cash assistance and health coverage for the aged, blind, and disabled. The disability guidelines affecting children have undergone numerous revisions, with the most recent changes occurring with the Welfare Reform Act in 1996. For the first time, the assessment of disability in a child has different attributes than that of an adult. In 1998, 20,707 children from birth to age 18 were eligible for Medicaid and received SSI benefits.

A new definition of childhood disability was created under the Welfare Reform Act. Impairment(s) is considered disabling if it causes marked and severe functional limitations. Severity is defined as either (a) marked limitations in two broad areas of functioning (such as social and personal functioning); or (b) extreme limitations in one area (such as inability to walk). In addition, the condition must be expected to last at least 12 months or be expected to result in death and the child must not be working at a job that is considered to be substantial work.

Previously, a child qualified for SSI if their condition was comparable to one that would prevent an adult from working. Also, the law eliminated the individualized functional assessment process as a basis for determining childhood disability. Furthermore, the law revised how maladaptive behavior (destructive behavior towards the self, others, or animals) could be considered when assessing a mental impairment. Previously, a child could qualify if the maladaptive behavior was such that it kept the child from functioning similar to other children of the same age. Now, the impairment is only disabling if it results in marked and severe functional limitation.

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 also tightened the SSI criteria for children and immigrants to qualify for disability assistance. However, subsequent legislation modified and reversed, to some extent, the restrictions on these populations. The Balanced Budget Act of 1997 created a new Medicaid category for disabled children and immigrants who had been eligible for SSI when welfare reform went into effect, retaining their eligibility.

Ribicoff Children: Georgia provides coverage to children who would be receiving TANF (former AFDC) but do not meet the definition of a "dependent child" through the Ribicoff provision. In Georgia, this applies to children age 18 and younger who are in private foster care or in an institutional setting for mental retardation or psychiatric treatment. In 1998, 28 children with special needs received coverage through the Ribicoff provision.

Medically Needy: Medically needy persons are those who do not satisfy the financial standards for eligibility into Medicaid or SSI but who can spend down through incurred medical expenses to satisfy eligibility. Only children up to age 18, pregnant women, and aged, blind and disabled persons (according to SSI criteria) are eligible under the Medically Needy Program. The upper bound of the financial limit is 133% of the FPL in Georgia. An individual with income above the applicable medically needy income level can reduce his/her income by incurring medical expenses in the amount of the difference between his/her current income level and the required level. In 1998, 601 special needs children received Medicaid coverage through this aid category.

Deeming Waiver or "Katie Beckett provision": The Deeming waiver is a provision that allows States to extend coverage to certain disabled children age 18 or younger who would be eligible for Medicaid if they were in a medical institution (such as a nursing home, hospital, intermediate care facility for the mentally retarded). Generally, these children require 24-hour medical care. In order to qualify, these children must satisfy the following three requirements:

1. The child requires the level of care provided in an institution;
2. It is appropriate to provide care outside a facility;
3. The cost of care at home does not exceed that of institutional care.

Because Georgia elected to include this option as an eligibility indicator, Georgia is required to cover on a statewide basis all disabled children who meet these criteria. Unlike a waiver program, which is frequently limited in numbers and services, the Katie Beckett provision is an eligibility option for entrance into Medicaid. Georgia also covers disabled and blind children under home and community-based waivers, which are discussed in a later section. In 1998, 142 children were eligible for Medicaid through this waiver.

DHR: DPH and MH/MR/SA

The Department of Human Resources contains an amalgam of programs, with different eligibility categories. Several programs are very specific, limiting by age, income, and condition, while others are available to the population of Georgia.

DPH

Title V MCH Programs: MCH Title V programs have traditionally helped to assure access to needed care for women and children. Under Title V, programs offered to women, children, and youth are housed within the Family Health Branch of the Department of Human Resources. For the population of interest, the program Children's Medical Services (CMS) provides children with special health care needs access to specialized equipment, nutrition services, highly specialized hearing aids, adult diapers, and other services not covered under the State Medicaid plan. The program is available to children with specific diagnoses and family income below 250% of the FPL. Therefore, children with special health care needs within Georgia receive services from MCH Title V programs because they are uninsured or have gaps in their insurance coverage (either public or private). The Title V programs interact routinely with Medicaid and other insurers to coordinate benefits.

DoE Program within DPH: Part C of the IDEA legislation created a new option for early intervention for infants and toddlers. The purpose of the expansion of the IDEA act was to enable children in the early stages of mental and physical development to have access to critical services that would diminish or prevent the subsequent serious complications. Children from birth to their third birthday, regardless of income, are eligible for Babies Can't Wait if they are diagnosed with certain mental or physical conditions or are experiencing significant delays in their development. This program is discussed in detail in the Key Programs Section.

MH/MR/SA Programs: Most programs are available to Georgians who meet the specific diagnosis criteria, disability severity, and financial criteria. Nearly 93% of beneficiaries are at or below 200% of the FPL. One program, MATCH, treats court-ordered cases of children with significant mental disability. DMA covers the treatment portion of the cost of residential treatment for children and adolescents in the MATCH program, but not the room and board, education, or other costs.

DoE

Unlike DHR and DMA, DoE is required to provide services to all children, regardless of income, who need developmental services to participate in school and if they meet the school's definition of delayed or disabled. The Division for Exceptional Students within the Department of Education facilitates local school system compliance with the IDEA regulations for children age 3-21. The Legal Services Division within DoE administers Section 504, a federal regulation that requires schools to provide special education services to children with disabilities such that educational opportunity is comparable to non-disabled children. A child can be referred for assessment by a teacher, physician, Babies Can't Wait coordinator, parent, or school counselor. The teacher leads the assessment, in the form of an Individualized Education Plan (IEP), with input from multiple disciplines.

Services identified in the IEP provided to Medicaid-eligible children can be reimbursed by DMA if the service is covered. An informal working group has developed between DMA and DoE to enhance cross-agency communication and to refine the cross-agency billing procedures. The financial connection between DMA and DoE is very recent (in the past 5 years) and currently only operates through the Children's Intervention School Services (CISS) program. Services that the child receives outside of the IEP take place in the regular health system that the child interfaces with, whether Medicaid or private insurance.

CMS works with school based programs to meet the intentions of the IDEA Act of 1997 and the Federal District Court ruling that children must be accommodated in the classroom to enable them to learn. If the child is eligible to receive care through CMS,

CMS will work with the school–based therapist and also provide separate medical services.

KEY PROGRAMS SERVING CHILDREN WITH SPECIAL NEEDS

Despite Medicaid's enormous financial burden of caring for children with special health care needs, few specific programs serving these children exist. DMA is in the process of reorganizing. As of November 1, 1999, programs from Maternal and Infant Health in the Division of Acute Care and programs from the Office of Children's Programs under the Division of Chronic Care were incorporated into the new Maternal and Child Health (MCH) section. Additional changes within DMA may be forthcoming.

Specific special needs programs are part of the MCH section, and include Early Intervention Services, Children's Intervention Services / Children's Intervention School Services, Model Waiver, and Exceptional Kids. Formerly, these programs were housed in the Division of Chronic Care.

The information presented below identifies programs where children with special needs routinely access services. The responsibility and accountability to look across programs and to recognize how similar subsets of a population of Medicaid children are interacting with the bureaucracy is not an identified goal of any one program or any one particular office.

Early Intervention Case Management: DMA's Early Intervention (EI) Case Management Program pays for case management services for Medicaid eligible infants and toddlers with developmental delays or other specific conditions. The Babies Can't Wait program (housed in the Family Health Branch of DHR) determines eligibility. Services are not organized or identified through EI. Rather, Babies Can't Wait provides case management and access to therapeutic services for parents and children in the program, billing Medicaid for those services provided to Medicaid beneficiaries. EI is an innovative mechanism that attempts to bridge the gap between Medicaid and DHR by facilitating cross-agency communication through a parallel structure. In FY98, DMA spent $2,245,670 on EI case management services for 3,360 infants and toddlers.

Children's Intervention Services / Children's Intervention School Services (CIS/CISS): CIS/CISS provides coverage for restorative and/or rehabilitative services to children enrolled in Medicaid who are age 0-21 years in non-institutional settings. Services must be medically necessary and documented on an IFSP, IEP, or written physician plan. DMA accepts the disability designation of a child based upon the child's defined health status by Babies Can't Wait, Children's Medical Services, Part B of the IDEA Act, or education's Section 504 provision. The child must have a physical disability or developmental delay.

Services covered for children are audiology, nursing, nutrition, occupational therapy, physical therapy, counseling by a licensed clinical social worker, and speech-language pathology. Therapists and licensed practitioners must seek written prior approval for medically necessary CIS/CISS services once the service limitations have been reached. An IFSP, IEP, or written physician plan is required to document medical necessity for amount, duration, and scope of services. In FY98, CIS covered services for 10,157 children. The two programs, CIS and CISS, spent a total of $11,944,650 on therapeutic services, with most of the expenses in CIS ($8,787,005).

<u>HealthCheck/EPSDT</u>: EPSDT, or HealthCheck as it is called in Georgia, pays for a comprehensive set of preventive and health care services to most Medicaid eligible children under age 21. EPSDT is the acronym for Early and Periodic Screening, Diagnostic and Treatment services.

Under EPSDT legislation, children must receive medically necessary services as determined by the periodic assessments, even if those services are not typically available under the State plan. “However, there is nothing in the EPSDT laws that changes a State’s authority to determine medical necessity or to limit the scope, duration, or amount of service” (Congressional Research Service, 1993). Under the Medicaid definition, “medical necessity” includes services that are necessary to correct or ameliorate a medical condition.

Minimum screening services include a comprehensive health and developmental history (including assessment of physical and mental illnesses or conditions), comprehensive physical exam, appropriate immunizations according to age and health history, and laboratory tests, and health education. Minimum vision services and hearing services include diagnosis and treatment for defects including eyeglasses and hearing aids. Minimum dental services include relief of pain and infection, restoration of teeth and maintenance of dental health.

Children with chronic health conditions may not need services to correct a condition since the condition may be progressive, not modifiable, or permanent in its nature. Services needed by children with special health care needs are more likely to be developmental, maintenance, habilitative, or rehabilitative in nature and encompass a wide range of medical, health, and related services.

Interpretation of medical necessity has become a national policy debate. A broad interpretation of medical necessity incorporates multiple concepts of health and associated treatments. Some policy advocates believe that the definition put forth by the federal government can be narrowly interpreted and result in the restriction of services. In Georgia, DMA has published a statement of medical necessity in its Policies and Procedures Manual, revised July 1999, section 106.12 on page I-5 that reads:

> “Medically necessary services are those services which are reasonable in establishing a diagnosis and providing palliative, curative or restorative treatment for physical and/or mental health conditions.”

According to federal interpretation of medical necessity, case management, homemaker/home health aide services, personal care assistance, adult day care, habilitation services, respite care, day treatment and partial hospitalization, psychosocial rehabilitation, and clinic services are not considered to be medically necessary.

Waiver programs

Waivered Home Care Services (Model Waiver): Children, birth up to age 21, who require oxygen or ventilator services on a continuous basis are eligible to be enrolled in the Model Waiver program. The goal of the program is to provide the skilled critical care nursing needed to instruct the primary care giver on all aspects of the medical care needed to maintain the child at home or until the child's ventilator dependency can be minimized or eliminated. The waiver has a limited number of slots available and is designed to be transitional, with the caregiver ultimately assuming responsibility for the child.

Services otherwise available to Medicaid beneficiaries are also available to children eligible under the Model Waiver. The services available in the Model Waiver program are provided to eligible recipients in their home or in a medical day care facility. Currently, in Georgia, only one medical day care facility is licensed and serving medically fragile children.

Respite and other back-up services and home modifications, such as modifying the electricity to accommodate a ventilator, are not covered under the Model Waiver. In addition, nursing hours of sixteen to twenty-four hours per day are approved on a short term basis.

Mental Retardation Waiver: This waiver allows for home and community-based care for functionally impaired or disabled individuals who meet specific diagnostic criteria. The program is administered through DHR's Division of MH/MR/SA, with DMA paying for medical services rendered to Medicaid eligible children. The MR Waiver is managed by the Behavioral Health section of the Chronic Care Division and has a limited number of slots. This section is separate from the Office of Children's Health.

Exceptional Kids: The Exceptional Kids service provides skilled nursing services to children who are medically complex, frequently dependent upon durable medical equipment for several hours a day, and challenging for the caregiver to take care of in the home without support and education. Length of enrollment into the program is determined by the teaching needs of the family, medical condition of the child, complexity of medical treatments, and dependence on technology. The number of private duty nursing hours is incrementally reduced over time until discharged from the program.

DPH Programs

Similar to DMA, the Division of Public Health has a myriad of programs that offer health services to children. The programs have existed somewhat independently from each other, with each program developing its own eligibility criteria, based upon federal guidelines as well as its own service delivery methods.

As mentioned previously, the Family Health Branch is taking steps to correct this silo-effect in program planning by taking a population perspective with the goal of better program integration and communication. The programs identified in this section are targeted to certain groups of children with special health care needs. The impact of the redesign efforts by the Family Health Branch will become evident throughout the next year or so.

Babies Can't Wait: Georgia's early intervention program, Babies Can't Wait, is a statewide interagency service delivery system for children from birth to three years who have developmental delays or disabilities. The program's purpose is to provide services to all children with disabilities to enhance the child's development and to prevent the development of more severe and potentially disabling conditions later in the child's life. The program is funded with state and federal dollars through the Department of Education IDEA Part C legislation. Children in families with resources that are limited may be directed to enroll in Medicaid or will have services provided through other state funds. Since the program is funded through the public education system, all families are eligible for service, with costs covered through public and private insurance as well as Federal education dollars.

The intake process occurs through a referral from a physician, from Children 1st, from parents, or from a birth certificate. Intake can take place in the physician's office, public health clinic, home, or any location convenient for the family. An Individualized Family Service Plan (IFSP) is created by a multi-disciplinary team, organized by Babies Can't Wait, assessing the child. Children are assessed for their ability to turn over, crawl, walk, and talk at age appropriate levels as well as for emotional, speech, or hearing problems. Eligibility into the program is automatic for children with certain conditions, such as: Down Syndrome, Fetal Alcohol Syndrome, spina bifida, cerebral palsy, and autism.

Babies Can't Wait organizes services for approximately 6,000 infants and toddlers a year, with a caseload of about 3,000 infants and toddlers at any one point in time. As a child approaches their 3rd birthday, a transition plan to the school system is initiated. Children are discharged from the program on their 3rd birthday. Some children, however, can continue to receive limited case management until the beginning of the school year if they turn 3 during the summer.

Children's Medical Services: CMS provides medical care to low income children with disabling conditions and/or chronic diseases. For Medicaid children with special health care needs, if they have one of the listed conditions covered by CMS, and Medicaid does not cover the service, CMS will attempt to provide the necessary service. In addition, CMS bills DMA for Medicaid-covered services. CMS serves approximately

15,000 to 16,000 children a year, with approximately 9,000 of those children having Medicaid coverage.

The intake process for CMS involves a referral by the parent, a physician, or someone else to a public health clinic. Several clinics are able to conduct basic screening for eligibility over the telephone. An administrative case manager will conduct the screening to determine medical and financial need and will make the necessary referrals to Medicaid, PeachCare, SSI, or other public programs. The financial upper limit is 250% FPL. The preferred ratio of patient to administrative case manager is 200:1. Currently, the administrative case managers are handling caseloads far exceeding their capacity.

CMS will arrange to provide the service through one of the public health clinics, private physicians, or other providers. The more common services that CMS covers for Medicaid eligible children are diabetes medications, nutrition supplements, adult diapers, durable and disposable medical equipment, appropriately fitted wheelchairs, programmable hearing aids, asthma nebulizers, over-the-counter medications, and therapy services.

<u>Children 1st:</u> The purpose of the program is to identify children, age 0 to 4 years, throughout the State of Georgia who are *at risk* of health and developmental problems. Children at risk are identified primarily through birth certificate information; however, physicians, nurses, and hospitals can refer children to the program. The program is available to all families of newborns and young children in Georgia, regardless of income or insurance coverage. Focusing on community resources, Children 1st acts as a case finding program to establish linkages between hospitals, physicians, public and private clinics, social service agencies, and parents.

<u>Regional Perinatal System</u>: DMA funds this program through the Department of Public Health. Eligibility is limited to pregnant women and infants with family incomes up to 250% FPL. The program is very limited in the services and population that it will cover. The program provides tertiary care services to high-risk pregnant women and neonatal intensive care services to infants. The neonates will most likely transition into Babies Can't Wait or Children's Medical Services, depending upon their needs.

DoE Programs

The Individuals with Disabilities Education Act (IDEA) expands access to health-related services for children with special health care needs for the enhancement of their education. The Babies Can't Wait program transitions children from the Public Health division to the Education agency or other community providers.

The two agencies, DHR and DoE have different foci, as described previously. Babies Can't Wait is focused on enhancing the medical, physical, mental, and emotional development of a child. In contrast, the Education Department concentrates on the educational development of a child. In addition, DMA does not offer case management for children ages 3-21, assuming that the schools are responsible. Thus, children with special needs ages 3-21 who are Medicaid eligible enter into a new system not designed to address their complex health conditions except as they relate to education.

Exceptional Students: Based upon the IDEA Part B / Special Education legislation, the schools secure Federal, State, and local dollars to provide a range of services to special needs children. The services necessary for school-environment functioning are determined by the IEP. A range of health-related services, including therapy services, nursing case, adaptive equipment, assistive technology, psychological services, and transportation are provided by the schools for the learning environment. Currently, the public school systems are able to enhance their funding of these services by billing the CISS Medicaid program for covered services provided to Medicaid eligible children.

Section 504: Section 504 of the Rehabilitation Act of 1973 broadly requires that any program that receives Federal financial assistant cannot discriminate against a person with a qualified disability or handicap. Public schools, through their receipt of federal funds must comply with the federal regulation to provide ‘reasonable accommodations.’ In Georgia, the program is administered by the Legal Services Division of DoE. At the Federal level, the Office for Civil Rights of the Department of Education enforces the law. In the school system, children with disabilities can be assigned to separate classrooms or courses of special education when such placement is necessary to provide them equal educational opportunity and when the separate facilities and services are comparable to other facilities and services offered to non-disabled students.

Pre-K Programs: Pre-kindergarten classes for 3-5 year olds are new to Georgia and are not coordinated with DMA even to the extent other school programs are. As a result of being new and identifying enrollment and resources, not every school district has a pre-K program. Georgia’s school systems are struggling to meet the requirements of the federal law requiring schools to accommodate the needs of children with medical situations that impact their educational goals. Furthermore, in areas where pre-K programs exist, schools are having difficulty adjusting to the influx of caregivers and children needing services as programs are initiated. A challenge exists among the local school systems to provide exceptional student services for 3-5 year olds.

In addition, hoops exist within the school programs. Frequently, children with special needs who are 3 years old have no school-based option and have been discharged from Babies Can’t Wait, despite the intent to have preschool special education classrooms for 3-5 year olds. A child who is 4 years old can access HeadStart but then cycles back to special education at age 5.

A gap in the system is evident. Without coordination by an identified public program, caregivers and children are left without a specific contact area for referral or obvious entry into the public system to access needed services.

RECOMMENDATIONS

The Georgia Health Policy Center conducted over thirty informational interviews as part of this study. Interviewees consisted of representatives from the Division of Medical Assistance, Department of Public Health, physician and therapy providers, advocacy organizations, parent resource groups, and individual parents. The questions in the interviews related to the identification of children, access to and provision of needed health services, and interactions with DMA. Appendix 2 lists the specific people interviewed for this report.

Based on the interviews and the study, we recommend five changes be made:

2. The current programs serving children with special health care needs contribute to the fragmentation of care for these children by narrowly defining eligibility criteria and benefits. We believe DMA should define a broader program for children with special health care needs which is needs based.

   In order to identify the needs of the population, DMA should introduce a case management program including:

- an assessment of need by a multidisciplinary team, a care plan, and a case manager;
- an external authoritative body to review medical necessity appeals;
- a payment rate for this benefit;
- a list of eligible providers and provider training;
- a mechanism for evaluating the effectiveness of the benefit; and,
- enabling the case manager the authority to change the number or frequency of visits in accordance with the patient's needs.

This benefit could be phased in upon demonstration of its success for the most expensive children with special health care needs. We recommend starting with very high cost children, children who are in one of the waivers, and children who are considered "exceptional children".

6. In consideration of the cost constraints DMA faces, programs serving children with special health care needs should have to demonstrate quality and cost effectiveness. DMA should put in place a system that would measure the quality of care, including measures of structure, process, and outcome. Disease-specific measures are available for many special needs conditions and should be reviewed and approved by a provider panel for inclusion in the assessment. Cost-effectiveness standards would have to be established that conform with HCFA standards.

7. To respond to the frustration we heard from families and providers, we recommend DMA develop a manual for families, case managers, and providers that explains the Medicaid benefits available to children with special health care needs and the ways to access them. Let families and providers know what services are covered, and how to

appeal when they want an exception to the rules. The manual should also identify resources external to Medicaid.

8. To reduce fragmentation for those children receiving care from more than one agency, DMA should pursue interagency cooperative agreements that clearly define the respective responsibilities of the major public programs serving children with special needs. Ideally, merge or coordinate public funding streams supporting children with special health care needs to remove barriers to the rational organization of care. The most important are agencies for these children are DMA, DPH, and DOE.

9. Involve families and providers in all aspects of the planning of these changes.

Challenges DMA Faces

DMA will face some considerable challenges to implementing the proposed changes. First, it is difficult to predict how much unmet need will be uncovered through case management, and budget constraints exist. This is why we recommend pilot testing the case management. We have interviewed some people familiar with some children in Georgia who have special health care needs, and they believe that there is some waste in the system that could offset some expansions of care.

Another option for handling the risk of a large increase in costs is to share the risk with the case management provider. Retrospective costs could be used to develop payment rates with risk corridors so that the case management providers work with families to consider trade-offs in the benefits received.

The state is losing some opportunities to maximize federal revenue drawn down for care for these children because public health and education programs do not always bill Medicaid for covered services. It may be possible to draw down some of this funding to cover the additional cost of case management. However, interagency agreements would be needed to overcome some of the existing barriers.

APPENDIX 1: TOOLS TO IDENTIFY CSHCN

Children with Special Health Care Needs (CSHCN)

Defining the population:
A uniform and consistent definition for children with special health care needs does not exist. Broadly speaking, the population includes children with disability, chronic illness, functional impairment, and sensory impairment. Moreover, the conditions of CSHCN move along a continuum from mild to severe, temporary to permanent, single system to multiple systems, and treatable to non-treatable. Furthermore, the definitions that do exist are frequently applied inconsistently, making comparisons of information even more difficult.

The methodological techniques for defining and describing children with special health care needs outlined below range from the least inclusive to the most inclusive and can be grouped as follows:

I. Primarily diagnosis-based approach that qualifies a child for federally funded programs, usually contains income restrictions.
II. Functional approach that evaluates limitations in age-appropriate behavior.
III. Service-based approach that looks a levels of utilization in children with or at risk for chronic diseases to identify high utilizers.
IV. Combinations of I, II, and/or III.
V. NACHRI's diagnostic based approach that includes all ICD-9-CM codes identifying childhood illnesses.

Methodology	Feasibility for GA	Advantages	Disadvantages	Source	% of Pop. Identified
I. Disability programs from the State, waiver programs, medically needy	Retrospective and prospective	Integrates diagnostic information; already exists	Controversial; limited by a defined set of problems, income levels, and social circumstances	HCFA, Early intervention programs	
I. Title V for CSHCN	Child-specific data and claims-like data not easily avail.	Diagnostic approach identifies children who are in the system in some capacity	Does not include mental health conditions (generally); some level of income restriction; little tracking of information	Maternal and Child Health Bureau, Institute for Child Health Policy, FL	13,000 children served in GA in 1997
I. Oregon ICD-9	Retrospective	Captures broad range of	Limited in severity, duration,	ICD-9 code listing	

Methodology	Feasibility for GA	Advantages	Disadvantages	Source	% of Pop. Identified
categorization (other states use similar methods)	and prospective	childhood diseases and medical conditions	stability, or functional status info.; minimal mental health information; only captures those in the system, seeking care	compiled by State of Oregon	
II. Functional approach: Children experiencing limitations in age-appropriate activity	Not feasible retrospectively; can incorporate prospectively	Captures multiple dimensions of functional status; well-tested instruments exist	Limited in ability to capture information to identify children with special needs	Questionnaires and assessment tools	6-9%
II. Child Health Questionnaire (CHQ): ✳ Functional approach	Not feasible retrospectively; can incorporate prospectively	Captures multiple dimensions; well-tested for children; impact of child's illness on family	Not designed specific for CSHCN; limited in ability to capture adequate range of severity info children with special needs; cannot identify level of service needed; subjective	Jeanne Landgraf	
III. Top 5% or other cost-triggers: Service-based	Retrospective	Captures a defined set of children	Depends upon children being in the system and information avail.; does not identify unmet needs, at-risk children, or stabalized but chronic children	Miscellaneous	
III. MCHB definition: Service approach CSHCN are those who are at increased risk for chronic physical, developmental, behavioral, or emotional conditions	Not feasible retrospectively; Unknown prospectively	Nationally tested in the 1994 Disability Suppl. to the Nat. Health Interview Survey; do not need diagnosis or functional information	Difficult to capture information consistently; very subjective. Except for national testing, has not been applied in other settings	McPherson M. MCHB 1995	Estimates exceed 20% of all children

Methodology	Feasibility for GA	Advantages	Disadvantages	Source	% of Pop. Identified
and who require health and related services of a type or amount beyond that generally required.					
IV. SSI Criteria: Diagnosis and function based	Retrospective and prospective	Consistently applied across States; coordinated definition; only operational model with diagnostic and functional status	Very limited in scope; usually those with mental retardation and certain neurological and mental health diagnoses	HCFA, States	3-4%
IV. Eight chronic conditions: Diagnostic and service-based: Asthma, cerebral palsy, chronic respiratory dis., cystic fibrosis, diabetes, mus. dystrophy, mal. Neoplasms, or spina bifida	Retrospective and prospective	Occur frequently and have high costs associated with disease	Does not capture whether any disability is actually present; numbers are misleading since most children identified will be asthmatic	University of Alabama	6.4%
IV. High cost, low variablity in cost: Diagnostic and service-based: Neoplasms, congenital heart disease, acute renal failure, transplants,	Retrospective and prospective	Occurs infrequently, but has predictable high costs	Limited group identified, does not capture at-risk	University of Alabama	1.4%

Methodology	Feasibility for GA	Advantages	Disadvantages	Source	% of Pop. Identified
congenital anomalies, respiratory problems					
IV. Questionnaire for Identifying Children with Chronic Conditions (QuICCC): ✳ Function and service-based	Not feasible retrospectively; used for epidemiology purposes	Designed specifically for children with special needs; includes parent info.; no diagnosis required; do not have to be in the system to be identified	Does not provide types, numbers, or severity of condition; does not identify "at-risk" chronic conditions; subjective	Ruth Stein	
IV. Florida CSHCN Classification System:✗ Diagnosis and service-based	Retrospective and prospective	Considers the financial realities; designed specifically for CSHCN; Charges of $5,000 or more within 1 calendar year and/or on the ICD-9 codes	Does not include functional status, unmet needs, or at-risk children; charges from one year are not necessarily predictive of charges for the second year because of children with special needs change rapidly	State of Florida	12-13%
V. NACHRI: ✳ Diagnostic and service-based approach	Retrospective and prospective once software available – late 1999	Can use claims databases; need diagnostic and procedure codes; well tested	Only as good as the ICD-9, CPT-4 and HCPC codes; determination of severity and duration with multiple conditions is limited	NACHRI	23.2% of children

✳ Considered to be the most promising tools to identify children with special health care needs.
✗ Florida's system is pragmatic and easier to implement than other alternatives. May be the best option for now.

Georgia's suggested definition from DPH for CSHCN:

(***Source: Draft DPH memo on restructuring Georgia's CMS Program***) Children with serious or chronic physical or developmental conditions; have a need for extensive preventative and maintenance care beyond that required by typically healthy children; have increased health care utilization greater than three times the utilization of a healthy child of the same age; care requires multiple providers, rehabilitation services, special equipment, etc.; care that may be rendered in multiple settings; utilizes services such as durable medical equipment, private duty nursing or home health services with expenditures that exceed by three times or more those of the general child population per age; have been deemed eligible for public health program for CSHCN; evidence of service utilization of specified ICD-9 codes; utilizes physician services at a significantly greater rate than the general population , per age, or upon referral from a primary care physician.

Medically-fragile child:
(Source: Foundation for Medically Fragile Children) A child between the ages of birth and 18 years who is medically stable yet requires skilled nursing services, therapy (PT, OT, SP) and/or medical equipment to enhance or sustain life.

APPENDIX 2: CONTRIBUTORS TO THIS STUDY

The Georgia Health Policy Center would like to acknowledge and thank the following people for their critical input into the development of the Children with Special Health Care Needs Analysis and Reports.

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