

Child Policy Brief



Special Health Care Needs

Issue

Children with special health care needs incur enormous health costs and use services from many state agencies in an environment with minimal coordination or accountability.

Recommendations

The state has a responsibility to monitor and report on access and quality of care, as well as a financial incentive to use funds efficiently. Critical activities are:

- Assuring the availability of services that meet children's needs
- Appropriately financing benefits, including maximizing the use of federal funds, reducing duplication of services, and coordinating payment strategies
- Convening payer, provider, and family representatives to develop a coherent strategy for care
- Developing an accessible, user-friendly guide for families and providers to navigate the existing system, and
- Establishing a statewide data collection and reporting system that measures cost, needs, services, and quality.

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 beyond that required by children generally.

Maternal and Child Health (MCH) Bureau, 1998

Changing Federal and State Expectations

In Georgia, children with special health care needs (CSHCN) rely on a wide range of state and federally funded services to maintain or improve their health and well being. In recent years, advocates, providers, parents, and agency staff have met to attempt care coordination and to simplify administrative processes. These efforts have borne little fruit, in part because of the lack of good information on which to base sound policy and lack of clear direction.

Three recent changes suggest an opportunity may exist for addressing these children's needs. First, Georgia has strengthened its commitment to children. Pre-Kindergarten programs, education reforms, Hope Scholarships, Family Connection, Medicaid expansions and PeachCare for Kids are just a few of the major initiatives that are preparing children for school and productive lives after school. Second, the Federal government has increased expectations about states' provision of services for children with special needs. The Department of Health and Human Services through maternal and child health programs, Medicaid, and CHIP, has begun asking states to demonstrate that CSHCN have access to appropriate services. The Department of Education requires states to provide special education and related services to enable all students to participate in the education system. Third, research has begun to document that access problems do exist.

Who Are Children With Special Health Care Needs?

Almost a fifth of U.S. children have at least one special health care need that may be interfering with their success in school and beyond. CSHCN miss, on average, 17 school days a year; fall behind in their school work; and at the high school level, 35% have failing grades.

Based on national estimates, over 370,000 children in Georgia can be expected to have a special health care need. Among Medicaid children, the most frequent diagnoses are mental illness, asthma, perinatal complications, and congenital disorders. Some have substantial health care needs, and cost the state over \$70,000 per year for health care needs alone.

CSHCN are served by over twenty agencies and programs. (See table next page.)

How Are CSHCN Faring In Georgia?

Federal regulations and state initiatives create a complex system of public services. In 1999, the Georgia Health Policy Center conducted interviews with providers, state personnel, families, and advocates to understand how children were faring. Our main findings were:

- Families, providers, and state personnel have difficulty identifying the services CSHCN are eligible for and how to enroll them. Once enrolled, confusion exists about benefit limits and continued eligibility.

Special Health Care Needs

| Georgia's Largest Public Programs Serving Children with Special Needs | | |
|---|---------------------------------|------------------------|
| Agency/Program | Estimated CSHCN Served Per Year | Annual Expenditure |
| Department of Community Health | | <u>\$510,780,245</u> |
| TANF, RSM, and Foster Care | 105,000 | \$304,040,680 |
| SSI | 20,080 | \$141,005,365 |
| PeachCare for Kids | 18,900 | \$ 65,734,200 |
| Department of Human Resources | | <u>\$147,102,764</u> |
| DPH, Children's Medical Services | 16,000 | \$ 30,686,580 |
| DPH, Babies Can't Wait (DoE funds) | 6,000 | \$ 18,590,928 |
| MH/SA, Community Services | Not Available | \$ 50,825,256 |
| MH/SA, Match Program | 1,100 | \$ 47,000,000 |
| Department of Education | | <u>\$741,000,000</u> |
| Special Education (all costs) | 150,000 | |
| Department of Juvenile Justice | | <u>\$ 19,200,000</u> |
| Youth Development Campuses | 59,000 | \$ 9,400,000 |
| Regional Youth Detention Centers | | \$ 9,800,000 |
| Total Annual Expenditures in the Largest Programs | | \$1,418,083,009 |

Note: Children receive services in multiple places so a sum of the children in these programs would overcount the total children served.

- Substantial numbers of CSHCN access multiple agencies with minimal coordination among the agencies. Duplication of services; inefficient use of federal, state, and local tax dollars; and a lack of accountability arise from this fragmentation.
- Providers seek higher reimbursement for care of medically complex children.
- Monitoring the quality of services and management of care are essential for improvement and increased accountability.
- Some children are going without needed services, especially specialty physician services (18%) and dental care (51%).

What Have Other States Done?

Like Georgia, most states have fragmented delivery systems and funding streams, and can provide little or no information about quality or adequacy of care. A few states have begun to identify and enroll CSHCN in special programs.

- Florida diverts CSHCN from the Medicaid and CHIP programs to the Title V program, which is a complete and separate delivery system.
- California has a specialty-care carve out. Children with special needs are simultaneously enrolled in managed care plans for primary care and in the Children's Services program (Title V) for specialty care.
- Connecticut and North Carolina established wrap-around services for children who exceed the basic benefits of public insurance programs. CSHCN receive services

through the mainstream system and are eligible for an additional package of clinical and support services.

A growing number of states are attempting to blend funding from different agencies. Their efforts have emphasized strong leadership and inter-agency collaboration to overcome problems experienced in the past.

Conclusion

Assuring comprehensive access to needed care for children with special health care needs is a major undertaking. We believe this can happen best if the State will:

- Support agencies to work together to coordinate eligibility, funding, and service delivery
- Facilitate family participation in planning and monitoring their child's care
- Assure the availability of benefits that meet children's needs
- Measure and improve the cost, delivery, and quality of services
- Coordinate financing benefits, including maximizing the use of federal funds
- Developing an accessible, user-friendly guide for families and providers to navigate the existing system.

The challenges are enormous and a strong commitment by all parties is needed. The Federal push for accountability will make it increasingly evident that our current system is inadequate. The evidence is mounting that changes must be made, and some models exist for building a more integrated system.

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