

# Special Needs Forum: Waivers in New York

By Adrienne Arkontaky

Each year, families of children with severe disabilities struggle to meet the needs of their children. Families are faced with mounting health care costs, uncovered therapies and drug coverage. Families cannot find or afford nurses, aides or respite workers to help with the care of children with severe disabilities. Years ago, when it became difficult for families to care for their medically fragile children, in many instances, the only option was institutionalization. Today, fortunately, there are viable alternatives to residential placement. Many states, along with New York State, have developed "Waiver Programs" which allow children with severe disabilities to remain in the community. New York State provides many supports and access to health care coverage under "Medicaid Waiver" programs. A "waiver" is a federally approved deferral of the regular Medicaid rules to allow children with disabilities to remain at home and still obtain Medicaid coverage.



As a parent of a child with severe disabilities, I understand the importance of adequate health care coverage. My sixteen-year-old daughter, Jordan, has undergone nine orthopedic surgeries since birth. Her customized wheelchair cost over \$7,000, and the nursing coverage she receives would be unaffordable without the coverage under the Waiver program. The costs of Jordan's care are covered by a combination of private insurance coverage and a Medicaid waiver program known as the "Care at Home program." This program allows children with severe physical disabilities to remain at home with their families. The Care at Home Waiver is only one of many programs that assist families in caring for children with disabilities in the home. In this issue of the "Special Needs Forum," I decided to take a look at this important program available to families in New York who have children with severe disabilities. There are other programs such as the Home and Community Based Services (HCBS) Waiver and the Traumatic Brain Injury (TBI) Waiver. I believe Elder Law practitioners should have at least a basic knowledge of these programs as they offer supports to families who struggle with the everyday stresses of caring for children with severe physical and mental challenges. These programs also allow the families of children with disabilities to be an important

part of the decision making process when determining what type of care is needed.

## The Care at Home Waiver Program

The New York State Department of Health administers five Care at Home (CAH) Medicaid Waiver programs. Started in 1985, the program enables families to obtain Medicaid coverage in order to care for children with disabilities at home instead of in an institutional setting. When the CAH Waivers were first developed, there were many children in intermediate care facilities (ICF), hospitals and nursing homes. Many of the children could return home if there were support services available in the community to attend to their needs and the children could maintain their Medicaid eligibility. When a child is placed in an ICF, nursing home or hospital, their Medicaid eligibility is determined without parental income. However, once they leave the facility, they usually lose their eligibility because the child's parents' income is considered for Medicaid eligibility, often deeming the child ineligible. The waiver allows community access to Medicaid using the child's income. The CAH programs are designed for families who would not normally be eligible for Medicaid.

The Department of Health operates CAH I/II for children who require a very high level of care similar to nursing home or hospital care. These children may require frequent device-based respiratory, nutritional or other intensive support such as suctioning, g-tube feeding and/or oxygen support. CAH III, IV and VI are available for children who require an intermediate care facility level of care. All CAH programs provide case management, respite and home and/or vehicle modification services.

CAH I/II participants must be younger than 18 and have had a continuous 30-day hospital stay or 30 days within a 90-day period. The child must be physically disabled by the Social Security Act standards (if the disability is physical in nature). There must be a determination that the child can be cared for safely at home with supports. Also, the child must be 1) ineligible for Medicaid in the community because the income and resources of the responsible parent or guardian would be deemed to the child, and 2) the child would be eligible when not deemed, and 3) the cost of caring for the child in the community must not be more than the cost of caring for the child in an appropriate institutional setting.

CAH III, IV and VI participants have the same requirements as above except they do not have to have had the 30-day hospital stay. They must be developmentally disabled and have complex needs.

Many families learn about this waiver from the child's school, physician, social worker or Early Intervention Program (EIP). The application process usually includes completion of a Medicaid application, a level-of-care screening, a home assessment, a disability determination, physician orders, care plan and a budget.

The Care at Home Waiver provides case management services. A case manager is a very important source of information for families of children with disabilities. The case manager helps families gain access to the Medicaid and other support services in the community. The case manager usually develops a care plan for the families, taking into consideration the unique needs of the child with disabilities. There is no better advocate than a well-versed and passionate service coordinator. The case manager can assist families with respite, nursing, medical equipment, and adaptations in the home. It is important that the case manager be in regular contact with the family to ensure that the child and family feel well supported. A family can change case managers at any time.

CAH also pays for durable medical equipment such as wheelchairs, orthotic appliances, bath chairs, diapers and in many cases supplemental nutrition such as Ensure. The program may also cover the cost of therapies such as physical, occupational and rehabilitative therapies.

One benefit of the CAH programs is the option of home adaptation and vehicle modification. Many children can remain at home only if changes are made to the structure of the home to assure that the children are safe. These changes also allow the families to care for the children and provide a better quality of life for them. The budget of the specific waiver program must be evaluated to be sure that the adaptations fit into the budget accordingly. Vehicle modifications are also available to families. Once again, the budget must be considered. The parents must purchase the vehicle and the CAH Waiver pays for the adaptations. There are guidelines for modifying a vehicle and home that must be followed. It is important for families to discuss these needs with a service coordinator to be sure they are following the procedures. Some examples of adaptations that can be made are the purchase of a backup generator for needed medical equipment, installation of wheelchair ramps, widening of wheelchair ramps and bathroom renovations.

There is also a respite component to the CAH Waiver Program. Respite can be provided in the home

by a nurse or health care professional. These caregivers will care for the child while family members are out. This support gives family members a break from the challenges of caring for a child with disabilities. Children may also be cared for on a short-term basis in a hospital or skilled nursing facility. Usually the service coordinator will work the additional care needs into the child's care plan.

Nursing services are probably the most needed support service and may be the most difficult to access. This is due in part to the shortage of nurses available. Nursing services can be provided by different level professionals according to the child's needs. LPNs, RNs and agencies can provide the appropriate care depending on the needs of the child. When speaking with families of children served under the CAH program, one hears that the biggest problem is finding nurses to fill the hours. It becomes difficult to locate nurses who are available at odd hours such as weekends and holidays. Many families take ads in newspapers or use word of mouth to find nurses.

It is also important to remember that CAH should generally not be a substitute if private insurance is available for the child. Medicaid is always the payor of last resort and if possible should act as a supplemental insurance policy if families can access private insurance coverage. A family may still apply for CAH Medicaid for a child even if they have private insurance. Many families have private health coverage but often there is not sufficient coverage to pay all the costs of keeping a medically fragile child at home. Many times, Medicaid will pick up costs that insurance does not. At times, private insurance will pick up a portion of the cost of nursing coverage but Medicaid is needed to provide the additional hours that are needed to keep a child safe at home. Caring for a child with severe disabilities can be physically and emotionally challenging.

The application process is also not as complicated as one might think. The CAH coordinator obtains all the necessary medical and financial information about the child. The first step is for the child to be "Medicaid eligible." The child must be ineligible for Medicaid when the parental income and resources are considered and the child must be eligible for Medicaid using only income and resources belonging to the child. There is usually a home health assessment done. An agency usually visits the home to determine the needs of the child and assess whether the child can be managed at home. The Service Coordinator develops a care plan and lists all the services needed to keep the child at home including medical equipment and any other supports that need to be in place. The care plan usually lists how many hours of nursing are required and how often the services will be provided. The plan will include the names of all the service agencies and/or

providers that are available to the families. The Service Coordinator will also monitor the budget developed for the child to be sure that it is cost effective. All of the CAH programs have budget caps which are based on the type of care the child needs. It is also important that the child's physician provide documentation that reflects the medical necessity of the services listed on the care plan developed. It is important that the family review the Plan of Care carefully to make sure that the child's needs will be met.

Once an approval is received from New York State, the case manager usually meets with the family and reviews how the program is administered. The case manager should discuss the recertification process and the eligibility requirements to be sure that the family maintains the child's eligibility. Of course, it is important that the child maintain limited assets for the purpose of maintaining eligibility. Many times problems occur when the child is deemed eligible for CAH and subsequently receives a medical malpractice settlement. It is very important for the practitioner to consider establishing a Special Needs Trust for the purpose of protecting the government benefits.

It is also important to remember that a child can only be enrolled in one waiver at a time. However, if the child's needs change, a service coordinator should consider whether the child would be better served on a different program. It is also important to remember that CAH generally will not pay for private nursing care while a child is hospitalized. Twenty-four-hour nursing care is also not generally available.

This particular waiver also ends upon the child's 18th birthday. At least six months before the child turns 18, the case manager and the local social service agency should begin to transition the child out of the CAH program. At that time, the family should consider applying for Supplemental Security Income-related

Medicaid. Eligibility of course will depend on meeting both disability and financial criteria.

It is also important to remember that if a family has a problem with any determinations under the CAH program, the right to a fair hearing is available as with other Medicaid programs.

Each family's needs are very different. It is important to speak with the local department of social services about what program is correct for a family's needs.

This is a very unique and important program for families of children with severe disabilities. Parents who utilize the program are thankful that it is available. Parents must remember that once the child is enrolled in the program, there are frequent visits from outside agencies and caregivers in the home on a regular basis. This may be somewhat intrusive for some families but the benefit is that children remain in a warm, safe, loving environment where their families can provide a good quality of life for the child and entire family.

For more information on the Care at Home Waiver, families can call the New York State Department of Health or their local Department of Social Services.

**Adrienne Arkontaky is an attorney with Littman Krooks LLP. Ms. Arkontaky's practice focuses on special needs planning, special education law and guardianship. Ms. Arkontaky was recently appointed to the Board of Trustees of the John A. Coleman School and the Board of Family Ties of Westchester. Ms. Arkontaky frequently lectures and writes on topics affecting families of children with disabilities. She resides in Westchester with her husband and three children, one with special needs.**

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