

Community-Based Programs for Children with Disabilities

By Adrienne J. Arkontaky

As recently as thirty years ago, parents of children with severe disabilities had limited choices when faced with the challenge of raising a special needs child at home. Many physicians and other professionals believed that the only solution was institutionalization. We all remember the exposure of the atrocities of places like Willowbrook. In the years following, New York and many other states advocated for programs that would provide the necessary supports to allow families to care for children with disabilities at home with the dignity and quality of life they deserve. New programs were developed and existing programs were improved. These programs assisted families financially and emotionally. They provided such supports as nursing, respite, vocational training, case management, home and vehicle adaptations, habilitation and many other components that enriched the lives of children with disabilities and their families.



We are fortunate in New York State to have a wealth of community based programs that are dedicated to the proposition that with the proper supports, children with disabilities can become active participants in planning their futures.

However, families struggle with health care costs, uncovered therapies and drug coverage for children with disabilities. The epidemic of autism, along with a rising survival rate of at-risk infants, are two of the many reasons there are an extraordinary number of children requiring home care services.

New York State and many other states have developed “waiver programs” that allow children with severe disabilities to remain in the community. New York State provides access to health care coverage and home care under a waiver program. 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. Usually, a waiver program disregards (or “waives”) the parent’s or guardian’s income and resources in determining eligibility for a typical means-tested program. In doing so, families are able to access services that would not

generally be available to children with disabilities and their families because of income levels.

Many of these programs are funded with a blend of both federal and state dollars and are overseen by several different state agencies. This article provides an overview of the most utilized programs in New York and a description of why they are successful. Knowledge of the available supports in the community for families of children with disabilities allows for better planning using a comprehensive approach. The expense of raising a child with disabilities at home without the following programs would be unsustainable for most families.

The Care at Home Waiver Program

The Care at Home Waiver allows children with severe physical disabilities to remain at home with their families while providing access to health care, nursing and home and vehicle modifications.

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 children are 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 their parents’ income is considered for Medicaid eligibility, often deeming a 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. The child must be ineligible for Medicaid in the community because the income and resources of the responsible parent or guardian would be deemed to the child and the child would be eligible when not deemed, and 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 ("EI). 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 also 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 Medicaid and other support services in the community and 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, adaptations in the home.

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

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. Families 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. Each of the CAH programs has 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.

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.

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.

The Care at Home Program ends upon the child's eighteenth 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.

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.

The Care at Home Program may be administered by the Department of Health and/or the Office of Mental Retardation and Developmental Disabilities. 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.

Children with Special Needs Program

The Children with Special Health Care Needs Program ("CSHCN"), including Physically Handi-

capped Children's Program ("PHCP"), was developed for children from birth to 21 years who have a chronic or severe disability (including developmental, behavioral and/or emotional issues) and require health and related services in excess or those services required by their non-disabled peers. This program is administered on a county-to-county basis.

The CSHCN program provides information, evaluation and referral services and, in some instances, case management for families. This is a public health program.

The CSHCN Program also offers some financial support including the Physically Handicapped Children's Program. The PHCP provides funding for uncovered medical bills for children with severe chronic illnesses and/or physical disabilities for children between birth and 21 years of age who meet certain county medical and financial eligibility criteria.

The program may also provide families with information on community-based services such as low-cost health insurance programs, and early intervention programs that provide at-home or center based services for children with special needs. The program may also provide information on parent support.

The program assists families with obtaining orthopedic equipment, hearing aids, medication, transportation for physician appointments and clinic visits. The Diagnosis and Evaluation Program reimburses specialty providers for the diagnosis and development of a care plan for eligible children while the Treatment Program will reimburse special providers for ongoing health care and related services necessary under the care plan for eligible children. This program was developed to assist families with inadequate private health insurance and low incomes obtain necessary medical and ongoing health care for their children. To inquire about whether the CSHCN/PHCP programs are available in your county, you may call the New York State Department of Health's Growing Up Healthy Hotline at 1-800-522-5006 or call the local Department of Health.

Services for Mental Retardation and Developmental Disabilities

The Office of Mental Retardation and Developmental Disabilities ("OMRDD") is a statewide agency that coordinates and provides services for individuals with developmental disabilities and their families throughout New York State. The regional offices that administer the programs are called Developmental Disabilities Services Offices ("DDSOs").

OMRDD provides a vast number of services including family support, case management, respite,

housing, supported employment, recreation, vocational training, adaptive devices, family, education and training and day and residential long-term habilitation services.

In order to access services through OMRDD, a child must be found to be “eligible” for OMRDD services. OMRDD utilizes the New York State Mental Hygiene Law (§ 1.03(22)) as the standard for eligibility. Section 1.03 defines a developmental disability as one attributed to:

- (1) mental retardation, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia or autism: or
- (2) attributed to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded or requires treatment and services similar to those required for such persons: or (3) attributable to dyslexia resulting from a disability in (1) or (2). AND originates before the age of twenty two and is expected to continue indefinitely and constitutes a substantial handicap to such person’s ability to function normally in society.

OMRDD uses an eligibility process to determine if children are eligible to use OMRDD-funded services. Parents or caregivers usually contact the local DDSO office and an Intake coordinator assists with the completion of the necessary paperwork. A three-step eligibility process is used to determine eligibility.

During the first step review, a child may be found eligible for appropriate services or DDSO staff will advise the family that additional information is needed to determine eligibility. In some cases, the additional information is sent to DDSO personnel for review under a 2nd Step Review and a determination is made. At this point, the DDSO will send a determination notification to the family or the DDSO may send a denial letter stating that based on the information available, the child does not qualify for OMRDD services. If a family is denied services, it can meet with the DDSO staff to discuss the situation, it can request a 3rd Step Review or it can request a Medicaid Fair Hearing if the family is seeking Medicaid supports. During the 3rd Step Review, assigned eligibility determination committees will review all the documentation and make appropriate recommendations. It is important for families to provide as much information as possible, documenting the developmental disability of the child. This may include medical and psychological reports and testing and evaluations.

After a child is deemed eligible for OMRDD services, the local DDSO may assist families in determining what supports are appropriate for the child with special needs. OMRDD offers many supports and services including many of the Waiver programs listed below. In addition, an important component of pulling all these programs together is the utilization of a Medicaid service coordinator. In order to utilize the services of a Medicaid Service Coordinator, the child must be found eligible for Medicaid. This professional is an incredible resource for many families who demonstrate a need for ongoing coordination of services for the child. A good Medicaid Service Coordinator can help a family access many programs and services to allow a child to remain home and thrive in the community. Important information regarding service coordination may be found on the OMRDD Web site at www.omr.state.ny.us.

OMRDD develops and administers many of the “Waiver” Programs described in this article.

Home and Community-Based Waiver Program

OMRDD first introduced the Home and Community-Based Services (“HCBS”) Waiver in 1991 in an effort to provide community-based services to individuals with disabilities as an alternative to residential placement.

The HCBS waivers in New York State provide services and supports to children (and adults) with long-term disabilities. These waivers also provide support to families committed to keeping their children with disabilities at home. The name “Community Based” is indicative of the vision of the program to keep individuals with disabilities in their own communities. Individuals who qualify for the HCBS program are typically those who, without the supports provided by the Waiver, would require a level of care only available in a long-term care facility. The HCBS Waiver was developed to assist the individual with disabilities develop to his or her fullest potential in the community with the support of the individual’s family and local support system.

Under the HCBS Waiver, Medicaid pays for some services not typically paid for by standard Medicaid such as case management, respite and home modifications. Once again, only the child’s assets and income are examined to determine eligibility. The funding available under the HCBS Waiver is used to allow families to provide care for the child at home and in the community. The HCBS Waiver is funded by a combination of both federal and state dollars and in some cases, funded by the counties that administer the programs.

To be eligible for this Waiver, individuals must have a documented developmental disability and live in either a Family Care home, their own home, an

Individual Residential Alternative or a Community Residence.

Additional services available under the HCBS Waiver include intensive behavioral services, community habilitation, employment supports and transition planning.

Serious Emotional Disabilities Waiver

The Home and Community-Based Waiver for children and adolescents with serious emotional disabilities provides services and support for children through age eighteen diagnosed with serious emotional disturbances so that they can remain at home and in the community. The program also provides the families the resources necessary to care for their children. Children eligible for this waiver, in addition to being diagnosed with a severe emotional disability, must demonstrate complex health and mental health needs and be at imminent risk of needing psychiatric inpatient care. Components of the program include individualized care coordination, intensive in-home services, respite care, family support services, crisis response services and skill building services. Many times, children eligible under this program have attempted to utilize OMRDD services but because the child's diagnosis is not a developmental disability, they are deemed ineligible. There is a growing problem among children with a dual diagnosis of emotional disturbance and developmental disability to access services. Many counties have attempted initiatives to coordinate services between the Department of Mental Health and the OMRDD so that children receive appropriate services and supports. More information on this Waiver may be available by calling the New York State Office of Mental Health at 518-474-8394.

Home and Hospital Instruction

When discussing home care options for children with disabilities, it is important to recognize that these children are entitled to an education whether it be center-based or home-based. Part 200.6 of the Regulations of the Commissioner of Education of the State of New York allows for home and hospital instruction. Students with disabilities who because of their disabilities cannot participate in a regular classroom setting may receive educational services at home for a minimum of five hours per week at the elementary level, or a minimum of ten hours per week at the secondary level. It is important to recognize that local school districts have

an obligation to provide educational services to children with disabilities who need home-based services.

Residential Services and NYS-Cares

One additional note regarding home-care options for children in New York State. Many families desire to keep their loved ones with disabilities home for as long as possible and as long as appropriate. However, families must plan for the future and one aspect of this planning may involve seeking out group home placement. NYS-Cares assists families locate out-of-home residential services. NYS-Cares works with provider agencies to locate out-of-home supports and services for individuals with disabilities when families are in need of out-of-home placement. It is important for families to register their child with NYS-Cares even if they are not ready or have no immediate need for out-of-home placement as the waiting lists for residential placement is long and there is no guarantee of placement except in crisis situations.

While this article includes a description of many of the programs in New York State available to assist families with caring for children with disabilities at home and in the community, it is not to be considered an all-inclusive list. Parents and professionals are encouraged to explore programs in their communities. They should speak to their local DDSO, Department of Health, local educational agencies and even medical associations to determine if there are additional supports on the local level that will allow children to achieve their goals, remain home in their local communities and become productive members of society. These programs will also enable families to better face the many challenges associated with raising a child with disabilities.

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