

Preface

Care at Home: A Handbook for Parents is a guide that is intended to help parents/guardians meet some of the challenges of caring for a physically disabled child at home. It includes information about programs and resources that can help meet the medical and social needs of the child.

There are four parts to the Handbook:

Part I explains the Care At Home (CAH) Program, including the purpose of the program, the eligibility rules, how to apply, how Medicaid works, what Medicaid does and does not cover, and how Medicaid rules apply to the CAH Program.

Part II provides other important information for parents:

- Answers to questions that many parents ask about how the CAH program works
- Helpful advice from other parents who have children in the CAH programs
- Guidelines for working with the case manager, budgeting, and dealing with private insurers and home-care providers
- Descriptions of CAH waiver services, including home adaptations and vehicle modifications

Part III includes useful reference materials:

- Explanations of important terms used in the handbook
- Specific descriptions and facts about the CAH Waiver Programs
- Phone numbers to call to get more program information
- Sample forms used in the CAH Program

Part IV includes helpful forms that can be copied and used to create a notebook for your child's home care information. It includes separate pages for:

- listing important phone numbers that parents or care givers may need to call often or in an emergency
- the child's daily schedule
- current medications
- general information for caregivers

When the term "parent" is used throughout this manual, it will also include the child's legal guardian.

Contents

Preface

Part I: An Introduction to the CAH Program

What Is the Care at Home Program?	3
Who Is Eligible for the Care at Home Program?	3
How Can CAH Help Our Child?	4
What If We Already Have Insurance that Pays for Homecare?	4
How Does the Application Process Work?	6
Are There Any Other Requirements?	6
Will Anything Else Be Needed?	7
What is the CAH Budget Cap?	8
Who Will Put Together My Child's Plan of Care?	9
What Will Happen Next?	10
What Else Do We Need to Know?	11
How Do We Get Medicaid Services for Our Child?	12
What Are Prior Approval and Prior Authorization?	13
What Services Will Medicaid Cover?	13
Are There Services That Medicaid Won't Cover?	14
What If We Don't Agree With A Decision About Our Child's Care?	15
What is a Fair Hearing?	15
Can We Bring Someone to the Fair Hearing?	15
How Should We Get Ready for the Fair Hearing?	16

Part II: Additional Information

Frequently Asked Questions	19
Advice from Other Parents	24
Facts, Tips, and Guidelines	26
Working with the Case Manager	27

Caring for Your Child at Home: The Real Costs	29
Creating a Family Budget	30
Dealing with Private Insurers	31
Using Home Care Providers	32
CAH Waiver Services	35
Getting Home Adaptations/Vehicle Modifications	37

Part III: Reference Materials

Key Terms	41
CAH Waiver Descriptions	44
CAH Waiver Fact Sheet	45
Local Departments of Social Services	47
Sample CAH Program Forms	52

Part IV: Helpful Forms

Notes for Caregivers	59
Daily Schedule	60
Current Medications	61
Important Information/Telephone Numbers	63
Nurse Information	64

Part I: An Introduction to the CAH Program

What Is the Care at Home Program?

The Care at Home (CAH) program is a special Medicaid waiver program. It is designed to provide certain medical and related services to families who want to bring their physically disabled child home from a hospital or nursing home. Families who have already brought their child home can also apply.

The CAH program is for families who would not normally be eligible for Medicaid. CAH Medicaid helps to pay for medically necessary in-home services to make it possible for physically disabled children to live in their own home with their families.

The CAH program is for families who would not normally be eligible for Medicaid.

Who Is Eligible for the Care at Home Program?

Two types of CAH programs are administered by the New York State Department of Health (NYSDOH):

CAH I is for physically disabled children who require a level of care provided in a skilled nursing facility.

CAH II is for physically disabled children who are technology dependent and require the level of care provided in a hospital.

Both CAH I and CAH II require the child to have had a 30-day institutional stay.

There are several other Care at Home programs for children with both developmental disabilities and complex health care needs who have not had a 30-day institutional stay. Those programs also help families with children who require special services to stay at home. Other Medicaid home- and community-based services waiver programs address the needs of children and/or adults who are mentally ill or who have suffered traumatic brain injuries.

Each family's situation is different. It is important to speak with the local department of social services (LDSS) CAH Coordinator for advice about which program is right for your child and family. For those living in New York City, the Human Resources Administration (HRA) CAH Coordinator should be contacted for advice.

More information about the CAH Medicaid programs is included in Part III of this handbook, along with important contact phone numbers.

Each family's situation is different. It is important to speak with the local department of social services (LDSS) CAH Coordinator for advice about which program is right for your child and family.

More information about the CAH Medicaid programs is included in Part III of this handbook, along with important contact phone numbers.

How Can CAH Help Our Child?

CAH children get Medicaid coverage.

If your child is eligible for the CAH program, he or she will be enrolled in the New York State Medicaid Program. Once enrolled, he or she will have access to all medically necessary services covered by Medicaid so long as services are obtained from health care providers who participate in the NYS Medicaid program.

The Care at Home program also has available, when medically necessary, three special waiver services that are not available through the regular Medicaid program:

Special CAH services:

- respite
- case management
- home adaptation
- vehicle modification

1. Respite Care – This service provides short term, periodic care for your child when your family or the primary caregiver cannot provide necessary care.

2. Case Management – These are services to assist and enable your child and family to access the full range of services and resources for which they are eligible.

3. Home Adaptations/Vehicle Modifications – Home adaptations and vehicle modifications services are available to improve movement and/or safety for your child within your home and to improve your child's access from the home to the community.

More information about these services can be found in Part II of this handbook.

What If We Already Have Insurance That Pays for Homecare?

Telephone numbers and addresses for LDSS offices and the NYC HRA office are included at the back of this handbook.

You can still apply for CAH Medicaid for your child even if you already have health insurance coverage. Many families have health insurance, but often it isn't enough to cover all of the costs of keeping a physically disabled child at home.

The CAH program is designed to work with other insurance plans so your child's coverage can be as complete as possible. For example, if a doctor isn't a Medicaid provider, your child's health insurance can be billed. In addition to

doctors who don't accept Medicaid, there are also some services that Medicaid does not cover. Your child's health insurance may be able to pay for those services.

Also, sometimes your child's insurance plan may not pay for as many hours of in-home nursing care as your child needs each day. In some cases, Medicaid may be used to pay for additional hours that the insurance won't cover.

But remember, an important Medicaid rule is that all other insurance available to your child must be billed before Medicaid will pay for services for your child.

Any other health insurance available to your child must be billed before Medicaid will pay for services for your child.

How Do We Apply for the CAH Program?

To apply for the CAH program, you should contact your local department of social services (LDSS) or the Human Resources Administration (HRA) in New York City (NYC) and ask to speak to the Care at Home (CAH) Coordinator. Each local department of social services office has a CAH Coordinator who will help parents apply for the CAH program. You can do this in person or by phone.

You will have to fill out a simple, two-page form in order to start the application process. If you ask, the CAH Coordinator can mail it to you.

The CAH Coordinator can also assist you in finding a case manager. Your case manager can help you with the application process.

More information about the role of the case manager can be found on page 27 of this handbook.

The CAH Coordinator will ask you some questions to see if CAH is the right program for your child.

How Does the Application Process Work?

The first step is for you to apply for Medicaid.

Remember, the Medicaid application must be completed for all members of your child's household, even though only your child is applying.

The CAH application process brings together all of the information about your child to see if he or she meets the participation guidelines for CAH eligibility.

The CAH Coordinator will set up a file for all of the information needed to make a decision about your child's application. The Coordinator will let you know exactly what information is needed.

The first step is for you to apply for Medicaid. The Medicaid application must be completed including all members of your child's household, even though only your child needs coverage.

- Your child must be **ineligible** for Medicaid when parental income and resources are counted.

– and –

- Your child must be **eligible** for Medicaid using only income and resources belonging to your child.

If your child is found to be eligible for Medicaid when parental income and resources are counted, then your child (and possibly other family members) will be able to get regular Medicaid and will not be enrolled in the CAH program.

If your child is denied Medicaid when parental income and resources are counted, your child may be enrolled in the CAH program if he or she meets the other requirements.

Are There Any Other Requirements?

In addition to Medicaid eligibility, your child must also meet several other requirements in order to participate in the CAH program. You will need to show certain papers to prove that your child meets those requirements. The requirements and the papers you will need are listed below:

1. Your child must be under 18 years of age. In order to prove your child's age, you must provide your child's birth certificate. If you don't have your child's birth certificate, you can use another form of proof, such as a baptismal certificate or adoption record. If necessary, ask the CAH Coordinator for help.

*under 18 years
of age*

2. Your child must have had a continuous, 30-day hospital stay (in some cases, 30 days within a 90-day period). You will need to show a letter from the hospital or a bill with the admission and discharge dates to prove that your child had a 30-day stay in the hospital.

*30 day hospital
stay*

3. Your child must be determined physically disabled based on Supplemental Security Income (SSI) rules. An LDSS worker will complete a disability interview (DSS 1151) for your child with information you supply. Another form (DSS 486-T) will be sent to your child's physician in order to get information about your child's disability. If those forms and other medical information show that your child has a physical disability based on SSI criteria, another form (DSS 639) will be completed for your child's file.

*SSI physical
disability*

4. Your child must require the level of care provided in a skilled nursing facility (CAH I) or in a hospital (CAH II). A copy of the Pediatric Patient Review Instrument (PPRI), completed as part of the Home Assessment, should be used to show the level of care needed at home.

*facility level of
care*

5. Your child must be able to be cared for safely at home and at no greater cost to Medicaid than in the appropriate facility. A copy of the estimated monthly budget for home care should be used to show all of the costs of caring for your child at home, including those to be paid for by Medicaid.

*monthly budget
limit*

Will Anything Else Be Needed?

In addition to the paperwork, the CAH application process also includes special assessments and reviews. These are used to see what services your child and family need and whether the CAH program can meet those needs.

The Home Health Assessment

An important part of the application process is looking at your child's medical needs at home. An agency is asked by the CAH Coordinator to complete a home health assessment for each CAH applicant. This assessment is used to determine if the program can meet your child's health care needs and if your child can be cared for safely and cost effectively in the family home.

*A home
assessment is
needed to see if
CAH can meet
your child's
health care
needs and to see
if your child can
be cared for
safely and cost
effectively in the
family home.*

A nurse from the agency will visit your home to complete the home assessment and fill out the necessary forms. The home assessment will provide a picture of the health care and services your child needs and how those needs can be met in your home. The nurse will look at your home to see how safe it is for your child. For example, the assessment will note things like how easy or hard it is to get your child in and out of your home. It will also note if your home has the right electrical service for any special medical equipment that your child needs.

The CAH Plan of Care

After the home assessment is completed, a preliminary Plan of Care will be written. The Plan of Care should show all of the services needed by your child. It must include all of the following information:

A Plan of Care needs to be completed for your child.

Descriptions of all services needed, including the Physician's Orders that show the medical necessity of the services

How often the services are to be provided

Names of all the service agencies and/or providers

Unit costs of services provided

Payment sources (Medicaid, private insurance)

Case management information

What Is the CAH Budget Cap?

When your child's Plan of Care is developed, an estimate of monthly home care costs for your child will be made.

Only the care paid for by Medicaid is looked at under the monthly cap.

There is a monthly budget limit (sometimes called a "cap") for Medicaid costs for each CAH program. The budget caps are based on the type of care your child needs and are different for each CAH program:

- The monthly budget cap for **CAH I** is based on the monthly Medicaid costs for care in a skilled nursing facility. It is currently set at \$9,000./month.
- The monthly budget cap for **CAH II** is based on the monthly Medicaid costs for care in a hospital. It is currently set at \$14,500./month.

A final budget is developed to show all of the monthly costs for care and services at home. The budget must also show who will pay for each item of care or service. For example, your private insurance may pay for necessary medical equipment, and Medicaid may pay for the hours of nursing care provided each month.

Only the care paid for by Medicaid is looked at under the monthly cap. It is important to remember that all other insurance must be billed before Medicaid is billed. Using the other insurance available to your child will also help to make sure that your child's Medicaid costs for care at home do not exceed the monthly program cap.

Only the care paid for by Medicaid is looked at under the monthly cap. All other insurance must be billed before Medicaid is billed.

Who Will Put Together My Child's Plan of Care?

The last step in the application process is to set up a final Plan of Care for your child. It will show all of the services needed by your child, who will provide the services, and how the bills will be paid.

The final Plan of Care includes all of the following:

The Home Health Assessment – the report that lists the services and supports needed at home for your child

The Pediatric Patient Review Instrument (PPRI) – the report that shows the medical needs of your child

The Physician's Orders – the papers that show the medical necessity of the services listed

The Case Management Plan – the report that shows how your child will get services

The Monthly Budget – the report that shows the total hours of each service your child will receive, the costs of each item and service, and who will pay for each.

The final Plan of Care is the responsibility of the CAH Coordinator, the assessing agency, your child's case manager, and you, the child's parent or guardian. You will want to look at the Plan of Care very carefully to make sure that all of your child's needs will be met. If you have any questions or concerns, you should discuss them with the case manager.

When you sign your child's Plan of Care Services Form, your signature(s) indicates that you understand what services will be provided for your child and who will pay for each service. If you disagree with the Plan of Care as it is written, possible changes and other options should be discussed so agreement is reached before you sign.

What Will Happen Next?

When all the paperwork is completed, there are two final steps:

1. NYS Approval

The LDSS CAH Coordinator will send the completed information package to the NYS Department of Health for review and approval.

2. Implementation

Following approval from the NYS Department of Health, the Care at Home program will be implemented for your child. Your child's enrollment will begin at that time.

How Will the CAH Program Start?

As soon as approval is received from the State, a telephone call or meeting with you, your child's case manager, and the LDSS CAH Coordinator will occur. The purpose of the call or meeting will be to discuss program implementation and to go over the Plan of Care for your child. During this call or meeting, the roles of each caregiver will be clarified so that you will know what to expect.

By the end of the call or meeting, you should:

- Understand the roles of the CAH coordinator and your child's case manager.
- Be familiar with your child's Plan of Care.
- Know the monthly Medicaid expense cap (limit) for your child, including which care and services are to be billed to Medicaid.
- Understand the role of your child's physician in the approval process required for the services to be provided.
- Understand the re-assessment process and have a copy of your child's reassessment schedule.
- Understand the process of Medicaid eligibility recertification for your child.

(More information about the role of the case manager can be found on page 27 of this handbook.)

You will be sent a copy of the CAH approval letter for your child. The approval letter will show the monthly budget cap for your child.

In some cases, if you disagree with the amount or type of service that your child will be getting, you can ask for a fair hearing. (More information about fair hearings can be found on page 15.)

What Else Do We Need to Know?

After your child has been enrolled in the CAH program, some things will have to be done on a regular basis. They are explained below.

Reassessments

The Plan of Care, which lists the services your child needs and shows how the bills are to be paid, must be reviewed and updated every 120 days. This means that a home visit (called a “reassessment” visit) by a nurse will be made about every four months. The visit is to make sure that the services being provided continue to meet your child’s needs.

In instances when there are frequent changes in your child’s situation, the assessing nurse and case manager may decide that more frequent visits should be made. At the time of reassessment, a new or revised Plan of Care must be written, based on any changes in the services your child needs.

You must review and approve any changes in your child’s Plan of Care. The LDSS CAH Coordinator must also approve the changes.

A new assessment may also be conducted whenever there is a change in your child and/or family’s situation. Such assessments are referred to as “event-based” reassessments.

Some of the conditions or situations that might call for an event-based reassessment that may result in a completely new Plan of Care and/or new budget are listed below:

- Loss of a primary caregiver through illness or new employment

- A medical crisis involving your child (such as hospitalization)

- Major changes in your child’s physical or mental health

Physician’s Orders

The Physician’s Orders must be renewed at least every 60 days.

Pediatric Patient Review Instrument (PPRI)

A new PPRI must be completed every year.

Your child’s Plan of Care needs to be reviewed every 120 days.

Physician’s Orders for services for your child need to be renewed every 60 days.

How Do We Get Medicaid Services for Our Child?

Be sure to bring your child's Medicaid and other insurance cards with you whenever you take your child for medical care.

If your child is in the CAH program, your child will have Medicaid available to pay for needed medical care and services, but only when the care and services are received from Medicaid-enrolled providers. The LDSS (or HRA in NYC) will order a Medicaid card for your child's coverage to be sent to you.

Keep the Medicaid card with you whenever you take your child to medical appointments. Medicaid providers (such as pharmacists or clinics) will ask to see your child's Medicaid card every time they provide a service. (This is done to be sure that they will be paid for the services for your child.) If your child has other insurance that will pay for some services, you should bring those insurance cards and information with you too.

Services must be medically necessary.

In order for Medicaid to pay for care and services for your child, the care and services must be medically necessary. In most cases, this means that your child's physician must order the care and services.

Some Medicaid services must have prior approval or prior authorization before they can be provided. As your child's Plan of Care is being set up, those Medicaid services that require prior approval or prior authorization can be discussed. (See page 13 for more information about prior approval and prior authorization.)

Be sure you know what the rules for payment are for each program.

The Plan of Care will show what services your child needs each month and who will pay for those services. The CAH Coordinator will help make sure that you and your child's case manager know what the rules for payment are for each service.

What are Prior Approval and Prior Authorization?

When a child is enrolled in the Medicaid program, requests for certain services and supplies must be referred to a health or social services official for review and prior approval or prior authorization.

Prior Approval

Prior approval involves a review to determine the medical necessity for a service. Listed below are some of the services and supplies that **always** require prior approval:

- Expensive medical supplies (IV, sickroom and miscellaneous supplies)
- Durable medical equipment (wheelchairs, etc.) as well as equipment repairs
- Prosthetic or orthotic appliances (artificial legs, etc.)
- Some repairs of hearing aids
- Some brand-name medications
- Some services provided by dentists and physicians
- Some vision services such as contact lens fittings

Prior Authorization of Services

Prior authorization means that the local commissioner of social services (or his/her designated representative) agrees to pay for a service or a series of services to be rendered by the provider. If approval is given, Medicaid will pay for the services.

Non-emergency medical transportation services and personal care services are two services that **always** require prior authorization.

Requests for prior authorizations must be submitted to the local department of social services (or the HRA in NYC).

The child's medical provider must submit all requests for prior approval and prior authorization to the appropriate NYS or local DSS office (or the HRA in NYC).

What Services Will Medicaid Cover?

The New York State Medicaid Program covers a broad range of medically necessary health care and services when provided by practitioners and institutions enrolled as New York State Medicaid providers.

Listed below are some of the kinds of care and services that your child may access through the Medicaid program:

Hospital inpatient and outpatient services, as well services from clinics

Laboratory tests and X-rays

Care in a nursing facility

Home health agencies services such as nursing, home health care, and personal care

Services of physicians and dentists and other health care providers including eye care, hearing aides, and podiatry

Physical, occupational, and speech therapies

Transportation to Medicaid-covered medical services as needed

Medications as well as medical supplies, medical equipment, and appliances such as wheelchairs

Early intervention and most health services in the Individualized Educational Program (IEP) of preschool and school-age children

Hospice services

Are There Services That Medicaid Won't Cover?

The Medicaid program **will not cover** payment for services in certain situations. For example:

1. When services are not requested or approved by a physician
2. When services are provided by individuals, agencies, or facilities that are not enrolled as New York State Medicaid providers
3. When services are experimental in nature

Medicaid will pay for services for your child only when they are provided by Medicaid-enrolled providers.

What If We Don't Agree with a Decision About Our Child's Case?

If you think that a decision concerning your child's care is wrong or if you don't understand the decision, you can ask to have that decision explained during a meeting with the CAH Coordinator. Sometimes the fastest way to solve any problems is to ask for a meeting.

If you meet with the CAH Coordinator and still disagree or if you don't want to speak with the CAH Coordinator, you can ask to have the decision reviewed at a fair hearing.

You can have a meeting even when you ask for a fair hearing. However, for your child's services to stay the same while you wait for an answer, you must ask for a fair hearing within 10 days of getting the decision.

What Is a Fair Hearing?

A fair hearing gives you a chance to explain why you think a decision about your child's care is wrong. New York State holds the fair hearing. If you ask for a fair hearing, the State will send you a letter that will tell you the place and time of the hearing.

During the fair hearing you, your lawyer, or other representative will have a chance to explain why the decision about your child is wrong. You will also be able to give the hearing officer any papers, such as medical bills and Physician's orders that help explain why the decision is wrong.

A fair hearing gives you a chance to explain why you think a decision about your child's care is wrong.

Can We Bring Someone to the Fair Hearing?

When you go to the fair hearing, you can bring someone with you, like a lawyer, family member or friend who can help you explain why you think that a decision about your child's care is wrong.

If you can't come to the fair hearing yourself, you can send someone to represent you. If you send someone who is not a lawyer to represent you, you will have to give that person a letter that tells the hearing officer that you want the person to represent you and your child at the fair hearing.

You can bring someone with you to a fair hearing.

How Should We Get Ready for the Fair Hearing?

A list of LDSS (HRA in NYC) CAH Coordinators with their addresses and phone numbers is included in Part III of this Handbook.

Before you or someone representing you and your child attends the fair hearing, you should get copies of any papers that will help support your case. Supporting papers could include medical bills, Physician's Orders, and letters that explain your child's needs.

If you need more information about your child's case or about how to arrange to see your child's file and/or get copies of it before the fair hearing, or if have any questions about which papers you should bring to the fair hearing, you should call your LDSS (or in NYC the HRA) CAH coordinator.

If you need more information about how to ask for a fair hearing, you should call your LDSS (or in NYC the HRA) CAH Coordinator.

Frequently Asked Questions

These questions are often asked by parents caring for a child at home. The answers shown will explain many important points about the CAH program.

How long will the application process take?

1. How long will we have to wait to be notified of our child's acceptance into or denial of acceptance into the CAH program?

The CAH application packet must be complete before the LDSS (or HRA in NYC) can submit it to the NYS Department of Health. It must include all of the following papers:

- A completed, signed CAH application form

- A copy of your child's social security card

- Proof of your child's Medicaid eligibility without parental income/resources

- Proof of your child's age

- Proof of your child's physical disability (DSS-639, based on other required forms as mentioned on page 7)

- Proof of your child's length of institutional stay (such as an inpatient bill or insurance statement)

The application packet must also include these important papers. Your child's CAH Coordinator will be sure that they are all there.

- The Home Assessment Abstract with results of the home visit

- The Pediatric Patient Review Instrument (PPRI), which shows your child's need for health care services

- The Plan of Care (POC)

- The Physician's Orders

- A completed budget sheet

It usually takes 4 to 6 weeks from the time a referral is made to the acceptance/denial of the case. The process may be longer or shorter depending on how long it takes to get information for the application. Once received at the NYS Department of Health, the application is acted upon promptly.

Will we be able to change case managers?

2. Is it possible to get a different case manager for my child?

Families are always free to choose a different case manager or agency at any time. If you move within a particular county or within New York State, it may be necessary to change agencies. You may also request a change if you feel that you don't have a good relationship with your child's current case manager or case management agency.

Keep in mind that in some areas of the state there are fewer agencies from which to choose. You should first contact the LDSS CAH coordinator to get a list of agencies in your area. Then you should call to find out if the agency you are considering is taking new cases. If there is an opening, you should discuss the needs of both your child and your family with the new case management agency.

Once a new agency is chosen, you must notify both the CAH Coordinator and your child's current case management agency that you are changing case managers. It may take up to a month to change from one agency to another. The goal is not to interrupt any services that are in place for your child.

All case management agencies must follow the same CAH rules. If you want to change agencies to get a service that your present case management agency is not able to get for you, you must keep in mind that a new agency may not be able to get that service either. That is why it is important to discuss your concerns with the CAH Coordinator as well as with your case manager.

Can we apply for more than one waiver?

3. Can we apply for a different waiver program?

A child can be enrolled in only one waiver at a time. The CAH programs also have different eligibility rules. If you want to apply for another waiver, your child must meet the qualifications of that program. It is important to remember that some waivers may have long waiting lists. If you want to apply for a different program, it is very important that you talk to your case manager and your CAH Coordinator in order to get information and help. More information about the other CAH programs and contact names and phone numbers are included in Part III of this handbook.

4. What will we have to do if we move to another county or state?

Waivers are different from state to state, and enrollment is NOT transferable when you move (out of or into NYS). You should contact the state that your family plans to move to for more information. Your case manager and LDSS (or HRA in NYC) can provide the names of agencies in other states for you to contact for information. If you are moving to NYS from outside the state, you should contact the LDSS in the county to which you are moving.

If you move from one county to another county within NYS, CAH Program eligibility goes with your child. You will need to contact the LDSS CAH Coordinator in the new county to begin the transition process.

Each LDSS has CAH staff who can help. Your current case manager will also help you with the process. It is important that you notify your case manager as soon as you know when and where you will be moving. Often, a move from one county to another means that you will need to find new providers for the services that your child needs.

What happens if we move to another county or to another state?

5. Can we travel out of our local area?

Of course you can travel! However, some services may not be available in other areas. The CAH program will only reimburse for services provided in the United States, Canada, Puerto Rico, Guam, the American Virgin Islands, and American Samoa. Services must be from providers enrolled in the New York State Medicaid program. When you make travel plans, be sure to notify your case manager and LDSS as soon as possible in order to arrange for your child's medical needs to be met. CAH will try to help arrange for services when your child is traveling with you or when you travel and your child remains at home with another responsible adult. Contact your case manager and LDSS for more information.

Will we be able to travel with our child?

6. What should we to do if our child needs health services from an out-of-state provider?

When traveling out of state with your child for necessary medical care, it is important that you contact your case manager and/or LDSS as soon as you know when and where you will be going. If New York State Medicaid will be requested to pay for all or part of the medical care and/or transportation, then special prior approval or prior authorization may be required.

7. Will CAH pay for home care services while my child is in the hospital?

No, Medicaid will not pay for skilled nursing or aide services for your child when he or she is an inpatient.

What happens if we disagree about the services our child needs?

8. Is there a way we can appeal a reduction in services or denial of services?

Yes. If your child's services are reduced or if a Medicaid service is denied, as a NYS Medicaid recipient, your child has a right to a fair hearing. When there is a reduction in services or denial of services for your child, you should receive a written notice from the LDSS that says that the service has been reduced or denied. If you receive such a notice, you may request a fair hearing to explain why the reduction or denial is wrong. Contact your case manager or LDSS CAH Coordinator for more information on fair hearings. In NYS the contact phone number to call to request a fair hearing will depend on where you live, but fair hearings are always held in the LDSS of the county where you live.

It is important that you request a fair hearing as soon as possible. If you do not receive a notice of denial of services, you still may request a fair hearing if you feel that your child is being denied access to a medically necessary service.

More information about fair hearings is on page 15.

9. What happens when our child's condition improves?

When your child's condition improves and he or she no longer requires the level of care in the respective waiver, your child will be transitioned off the waiver. CAH eligibility slots are limited. The waivers were created to help families care for their child in their own home instead of being forced to place them in an institution.

Qualified nursing professionals do home assessments to determine each child's required level of care and any other medical needs that he or she may need. It is important to remember that if your child is disenrolled from the waiver, he or she child can be still reenrolled if his or her medical condition changes and skilled care is again required.

What happens if our child improves?

10. What should we do when our child reaches 18 years of age?

The day that your child turns 18 years old, he or she will no longer be eligible for the CAH waiver, including waiver services such as case management.

At least six months before your child turns 18 you, your case manager, and the LDSS should begin to transition your child out of the CAH program. This transition process will include finishing any necessary adaptations to your home or vehicle prior to your child's eighteenth birthday.

When your child turns 18, only your child's income and resources will be counted when he or she applies for SSI or recertifies for SSI-related Medicaid. Eligibility depends on meeting both disability and financial criteria.

When your child reaches age 18, he or she may be eligible for a different waiver program. Therefore, it is very important to look at all options. Again, talk to your case manager and LDSS. (More information about the other home- and community-based services programs and the special services each offer is included in Part III of this handbook, along with contact names and phone numbers.)

*What happens
when our child
reaches 18?*

11. Will our child be able to get 24 hours a day nursing care?

The CAH program will not support 24 hours/day nursing care. You, as well as other family members or friends, must be trained and willing to provide direct skilled care for your child on a daily basis. You must also be able to provide care in an emergency such as a nurse not showing up for a shift.

Advice from Other Parents

Be your child's advocate at all times!

Don't be afraid to ask questions!

Be prepared to have other people (nurses, therapists) in your home.

Listed below are some helpful tips offered by parents with experience caring for a child at home:

1. Be ready to be your child's advocate at all times.
2. Be aware of your own role as your child's informal caregiver.
3. Keep in mind that applying for the CAH program takes time and may seem difficult—you will have to visit your local department of social services, complete a lot of paperwork, make all kinds of information about your personal finances available to others, and so forth. Doing all those things will seem like a lot at first, but later on it will get easier. The time and effort you put into the application will turn out to be very worthwhile, because both your child and your family will benefit from the program.
4. Remember that it may take time to get an answer regarding your application. If you have questions, be sure to call and ask them. Don't be afraid to call back if you don't get an answer the first time.
5. Keep in mind that the CAH program is not a source of cash assistance for paying bills. Instead, the CAH program simply makes Medicaid available as a means of paying for medical care and services for children. Medicaid providers can bill Medicaid for medically necessary care and services provided to the CAH-enrolled child. This will allow a disabled child's family to care for their child at home. **Remember: Medicaid will not pay for expenses such as utility or telephone bills.**
6. Be patient, and remember that it may take longer than you expected to get approval of certain services—sometimes that happens because there is more than one insurance company involved in the approval process, in addition to the Medicaid program itself.
7. Be sure you know your child's correct waiver program title (CAH I or CAH II).
8. Be ready to accept the fact that once your child is enrolled in the Care at Home program there will frequently be other persons (such as nurses and therapists) in your home.
9. Welcome nurses and other caregivers by providing a warm, safe environment for them and your child.

10. When you have questions about your child or the kind of care and/or help your child is getting, talk to more than one source. Sometimes information about a new resource or treatment may come up as you talk with different people.
11. Make a list of all the medications, medical supplies, and special equipment that your child needs. Be sure to keep the list up to date and on hand for easy reference. (For example, if your child is hospitalized you should bring the list with you to the hospital.)
12. Write down your child's daily schedule, including any special procedures that your child needs. Also, be sure to include the things that your child likes and dislikes. Then, whenever a new nurse or caregiver cares for your child, you'll have something in writing to give to that person. This will be a good way of introducing your child and explaining your child's needs. It will also help to make the time they spend together more pleasant and productive.
13. Remember that parent support groups and/or networks can be very helpful. They can be important sources of emotional support and useful information for parents. Most parents caring for a disabled child at home find it very helpful to be part of (or at least in contact with) such groups.
14. Always keep a vision of your child's future.
15. Don't give up!

Remember to keep lists for quick reference.

Consider joining a support group.

Facts, Tips, and Guidelines

When you speak with people about your child's care, be sure to take notes. Write down names, dates and what was said.

Keep extra copies of identification cards and other important papers.

1. Once a provider agrees to accept your child as a Medicaid patient, that provider must accept the amount that Medicaid pays as payment in full for all Medicaid-covered services. In other words, you should not receive a bill, be asked to make a co-payment, or have to pay a deductible.
2. If a service is not covered by your child's insurance or by Medicaid, the provider must tell you, before the service is provided, that you'll be expected to pay for that service yourself.
3. If you are not satisfied with the help provided by your child's case manager, you may ask for a new case manager. You may be able to get a new case manager from the same agency or from a different agency (if there are other agencies available in your local area).
4. Due to nursing shortages, there may not be nurses available to cover all of the hours that your child needs, even when your child is approved for nursing hours.
5. It is important that your child's doctors list every service that your child needs. The doctors should write a medical summary with specific technical reasons for each needed service, along with how often the service is needed by the child and for how long each day or week.
6. You should keep copies of all bills you receive. You should also keep copies of all receipts for services for your child that you have paid for yourself.
7. Whenever you speak with an employee of an organization or agency about your child's care, be sure to write down the date, the person's name, his or her title, and the name of the agency. Be sure to make notes of what was said. Also, ask the person who spoke with you to send you a letter confirming the major points discussed.
8. Keep extra copies of the identification cards and important papers that doctors and medical offices ask to see, including these:
 - Your child's birth certificate
 - Insurance cards
 - Medicaid identification card/number for your child
 - Documents that verify your income (such as pay stubs)
 - Copies of all bills received and/or paid
9. When you send information or documents, always send them by registered mail, and be sure to keep a copy for your own file.

Working with the Case Manager

Most families need help when they bring their disabled child home. Often, no single program or agency can provide all of the care and services that the child and family need.

When you bring your child home, you may have to ask for help from more than one source. One of the first things you should do is choose a case manager for your child. The case manager will help you do many of the things that need to be done.

The Role of the Case Manager

The case manager's job is to help you get your child the full range of medical care and related services that he or she needs. The case manager will begin by helping you:

- List all of your child's needs and their costs.
- Identify new household and family costs related to your child's needs.

After seeing what is needed, the case manager will also help you:

- Understand and manage the resources you already have.
- Look for other possible resources for which your child may be eligible.

Your child's case manager will work with you to set up the goals that will best meet the needs of your child and family. The case manager will make sure that the goals are written down in a case management plan.

The first case management plan will do all of the following:

- List all of the services your child needs, including how much, how often, and for how long, along with the cost of each service.
- Show the providers of services.
- Show which needed services you and your family will provide.
- Show your family's informal support group (grandparents, aunts, uncles, and family friends) who can help provide care.
- Show what things need to be worked on, who will work on them, and when those things will get done.

A case manager will help you do many of the things that need to be done in order to keep your child at home.

When you sign the case management plan along with the case manager, doing that means that you agree with the goals as they are written in the plan.

It is important to remember that your child's case management plan will change over time, as some goals are met and new ones are added.

The case manager will help keep track of all of the things that need to be done to keep your child's services and funding in place, including all of these:

- Home assessments and reassessments
- Updates on the Physician's Orders
- Prior approvals for services
- Medicaid recertification

The case manager will also keep a file for your child. That file will include copies of home care assessments, CAH budgets, and notes that show how the case manager has been helping you and your child.

Finally, the case manager will also help you and your child leave the program when your child no longer needs CAH program help or becomes too old for the program.

What To Look For When Choosing A Case Manager

Choosing the right case manager is important.

Case managers can work for different types of agencies—a LDSS or other State or private agencies. You will be able to choose your child's case manager from any agency enrolled as a CAH case management provider doing business in the district where you and your child live.

The case manager you choose must be able to work well with you and your child. This is the person you will trust to help you with forms and paperwork, to speak with officials on behalf of you and your child, and to help solve problems that come up. A good case manager must also be able to do all these things for you and your child:

- Be able to work with service providers and program officials to get help to meet your child's needs.
- Know about entitlement programs (like SSI) and other funding sources.
- Know about different types of services (medical, social, and educational) available where you live.
- Be able to help identify problems and help solve them.
- Be a good advocate for your child.

Caring for Your Child at Home: The Real Costs

In addition to basic living expenses, parents caring for disabled children at home may have other expenses related to the child's disability. Those expenses may not be covered by insurance or Medicaid.

Such additional expenses might include any or all of the following (and may include items not listed):

- Higher telephone and utility (electrical, heating, and/or cooling) bills
- Additional transportation costs including car or van replacement
- Special supplies and equipment (both portable and permanent) needed for the child
- Baby sitting services for siblings
- Day care
- Special foods and/or nutritional supplements
- Home repair or moving expenses
- Specially designed clothing and/or alterations

There are other non-medical expenses related to a child's disability.

Creating a Family Budget

Try to estimate all of the costs – not just the medical costs.

It is important to try to take into account and plan for the full financial needs of the family and child. There are two major steps in this process.

1. Determine the financial needs.

The first step before looking for financial help is to list the child's medical care and services needs. Once the needs are listed, try to determine how much the care and services will cost. You should work with your child's case manager to develop a family budget. The family budget should include at least the following:

Total costs for all services needed for the child

Basic living costs for the household

Estimated increases in basic living costs

2. Identify possible sources of financial support.

The following guidelines may be helpful when trying to develop a family financial support plan:

- Begin by listing all of the possible sources of financial help to meet each of the needs listed in the family budget.
- Next, try to see what limits or eligibility rules must be met for each possible funding source. When looking at each funding source, be sure to see whether or not using one funding source will have any impact on the benefits available from another source.
- Finally, try to match possible sources of financial help with each of the listed needs.

Look for possible sources of financial help.

Dealing with Private Insurers

If your disabled child is covered by private insurance, you will need to carefully examine your health insurance policy. As you review the policy coverage, you should ask the following questions in order to identify key information:

What are the specific benefits provided in your existing policy?

Is there a lifetime maximum benefit and/or are there any other financial caps in the policy (particularly if your child is expected to require long-term hospitalization or frequent periods of hospitalization) and, if so, what are the caps?

Is the coverage included in the policy adequate to cover the costs of caring for your child at home?

It may also be necessary to consider whether purchasing an additional policy or finding a new carrier might help to better meet your child's service needs and strengthen your family's financial plan.

Sometimes it may be possible for parents to negotiate what is called an "exception to policy" with their insurance company. In order to be successful in getting an exception to policy, it is necessary to show the insurance carrier that there will be a financial advantage for the insurer to make a change to the policy.

For example, your policy may have a yearly limit on nursing services that will only cover nursing care in your home for 10 months. However, your policy may have no limit on hospital care. You may be able to show that payments for additional home care will be less costly than if your child were to stay in the hospital.

Continuous home care, even on a long-term basis, is usually less expensive for the insurer than paying for numerous intermittent hospitalizations for your child.

Remember that Medicaid is the last payor for services. That means that all other insurance available for your child must be billed before Medicaid. Using other insurance will help keep your child's Medicaid expenditures under the CAH program cap.

Using Homecare Providers

Other people will be coming into your home to care for your child.

Caring for a physically disabled child at home often means that other people will be coming into your house or apartment to care for your child. Listed below are some of the important things that you should be aware of when choosing homecare providers. You will also have to think about making preparations for them to be in your home.

Hiring Homecare Providers

Most homecare providers come from homecare agencies that are certified or licensed. You'll want to know how each agency does business before any of their workers come into your home.

Although your case manager will do a lot of the work of finding out about the agencies for you, you may also want to be involved. If you decide to call some of the agencies yourself, be sure to keep a notebook. Write down the questions that you want to ask, and then write down the answers you are given by each agency that you call. You and your child's case manager will want to compare notes before you choose an agency.

Have your list of questions ready when you call each agency.

1. Begin by making a list of the care and services that your child needs, and then ask each agency these questions:

What services can the agency provide?

Can the agency provide all of the services on your list?

Does the agency accept your insurance and Medicaid?

Once you find an agency that can provide the services your child needs and that will take payments from your insurance and Medicaid, then go on to your next questions.

2. Remember that homecare agencies have rules that all their employees/workers must follow. You will need to find out what those rules are and what they mean to you. Ask the agency questions such as these:

How long has the agency been in business?

Do all workers carry identification cards?

Who will supervise the workers?

Will the supervisor come to your house to check on the worker?

How will the workers get additional training if they need it?

Will you have to sign time cards?

3. You will also want to know about the worker who will be caring for your child, so you should ask questions such as these:

Who should you call if there's a problem with your child's care or if a worker doesn't show up?

Will you get the same worker every time?

Can you ask to have the same worker every time?

4. You will also want to know about worker qualifications. You should ask the agency about worker training. For nurses, both those employed by an agency and those who are self-employed, you should ask for the following things:

a copy of the nurse's current license,

proof of the malpractice insurance coverage,

proof of CPR certification.

5. Finally, you'll want to know the answers to questions such as these:

How will the agency and worker make sure that your child's and family's information is kept confidential?

Will the agency and worker give you a list of client and professional references?

How soon can services be started?

Ask questions about the workers who will be caring for your child.

Be clear about what you expect when workers are in your home.

Getting Ready For Home Care Workers

All families have their own ways of doing everyday kinds of things such as cooking meals, cleaning, homework, listening to music, or watching television. Your family's ways may not always match the ways of others.

It is important for you to be clear about what you expect when other people are in your home. You may not always find a perfect match, but the most important thing is that your child gets the best care possible.

Be sure to keep a list of the medication your child needs to take – with the times and dosages. Be sure to write down who is responsible for making sure your child takes the medication.

Keep an emergency contact list.

You will also need to make some space for your home care workers to use.

Taking Care of Your Child's Needs

Write down your child's daily schedule, and be sure to include any special procedures or therapies needed. Include a list of the medication(s) that your child needs to take, along with the times and dosages. Be sure to write down who will be responsible for making sure that the medication is given to your child.

Include a list of important names and phone numbers—your child's doctor, the pharmacy, and any emergency numbers where you can be reached when you're out. Also be sure to make a list of names and phone numbers for all emergency back-ups that you may have. If another family member or friend will fill in for you at certain times or for certain reasons, be sure to write down that information too.

Writing things down and making lists will help to make things easier and clearer whenever a new nurse or caregiver comes into your home to care for your child. Having things in writing is a good way of helping new people get to know your child and the kinds of care that your child needs. (A handy form that you can copy and fill out is included on pages 47-49 of this manual.)

Taking Care of Home Care Worker Needs

When a new caregiver starts caring for your child, you may have to give the caregiver information such as the directions to your house, bus routes, or where to park. You will also have to arrange for the following for the caregiver:

- A place to put personal belongings (such as coats, hats, lunches)

- A place to eat meals

- Use of a bathroom

- A place to write notes about your child and your child's care

- Use of a phone

Remember that caregivers work a set number of hours and may not be able to start early or stay late unless you work it out ahead of time. They are in your home to give skilled care to your child. They are not there to take care of other children or to do things that are not in their job description and that are not included in your child's plan of care.

CAH Waiver Services

Respite Care

Respite care is periodic and can be a short-term option for your child when the family member or the primary caregiver cannot provide necessary care. However, out-of-home respite care cannot exceed 30 days per calendar year.

Home Adaptation and Vehicle Modification Services

The CAH program can also help with financing for certain home and vehicle modifications. These services are covered to ensure the welfare and safety of your child and to permit your child to move about within your home, and/or to provide access between the home and the community.

Covered Adaptations and Services

Examples of changes that can be made to a home or vehicle that may be covered by Medicaid include (but are not limited to) the following:

- Purchase of a backup generator for needed medical equipment
- Installation of wheelchair ramps
- Widening of doorways
- Modifications to permit independent use of bathroom or modifications to facilitate bathroom use with assistance
- Installation of stair glides
- Modification to a parent-owned vehicle to accommodate the needs of a child

Adaptations That Are Not Covered

There are some home adaptations that will not be covered, including all of these:

- Any new housing construction or portion of any new housing construction
- Room extensions or construction of additional rooms or spaces beyond the existing structure of a dwelling
- Renovation of existing rooms or construction of new rooms intended for physical therapy equipment storage and use
- Purchase of therapeutic equipment or supplies, personal computers, etc.

CAH can help pay for some home and vehicle adaptations to make them safer and easier for your child.

Some adaptations are not covered.

Purchase or installation of a swimming pool, hot tub, whirlpool, steam bath, or sauna for either indoor or outdoor use

Driveway paving

Purchase and installation of elevators

Purchase of items that primarily benefit members of the household other than the CAH participant

Purchase of service or maintenance contracts

Other Important Considerations

Home adaptations are only approved for the child's primary residence.

All maintenance and repair costs of home and vehicle adaptations are the responsibility of the owner.

1. Home adaptations to accommodate a child in the CAH program will only be approved for the child's primary residence. The cost of any home adaptations must fit within your child's annual CAH budget. The total costs of all home adaptations cannot exceed \$20,000 for the duration that your child is enrolled in the CAH Program (unless there is a significant change in your child's needs or capabilities).
2. Vehicle modifications to accommodate a child in the CAH program will only be approved for one parent-owned vehicle. Vehicle modification costs must be included within your child's annual CAH budget. Total vehicle modification costs cannot exceed \$14,000 for the duration that your child is enrolled in the CAH program (unless there is some significant change in your child's needs or capabilities).
3. Items purchased through the program become the property of the home or vehicle owner. All maintenance and repair costs become the responsibility of the owner. Owners must maintain proper insurance coverage on their property and/or modified vehicle. The costs of restoring the home or vehicle to their original state are the responsibility of the owner.

Getting Home Adaptations/Vehicle Modifications

To get home adaptation and vehicle modification services, you will need to work with your child's case manager, who will help prepare the necessary paperwork. You or the case manager can get a copy of the administrative directive from the local district CAH Coordinator (NYSDOH 00 OMM/ADM – 4), which lists the steps and necessary paperwork.

The decision to approve or deny a home adaptation or vehicle modification is a joint process that includes both the NYS Department of Health and the LDSS (or HRA in NYC).

The following documents are required:

- 1. Physician's Statement** – You must get a written document from your child's doctor stating that the home adaptation or vehicle modification is medically necessary.
- 2. Plan of Care** – You must include the need for the home adaptation or vehicle modification in your child's Plan of Care.
- 3. Permission of Building Owner** – If the adaptation is planned for rental property, you will need to get written permission from the owner of the building.
- 4. Evaluation Document** – You will also need a written report documenting all of the following:
 - The need for the home or vehicle modification
 - The safety of the proposed home or vehicle modification
 - The expected benefit(s) to your child
 - The most cost-effective way to fill the need

Your child's case manager must contact the LDSS (or HRA in NYC) to arrange for an evaluation of your child's needs for any home or vehicle modification(s).

When you ask for a vehicle modification, you will have to pay the cost of the basic vehicle and equipment available from the dealer through factory installation. You should contact the vehicle manufacturer and/or dealer for information about possible rebates and warranty information on factory-installed adaptive equipment.

Your child's case manager will help with the necessary paper work.

Home adaptations and vehicle modifications must be medically necessary.

The LDSS (HRA in NYC) will arrange for an evaluation of your child's need for any home or vehicle modifications.

Three cost estimates or bids for the services to be provided must be submitted to NYSDOH.

Evaluations for vehicle modifications must be done by an evaluator approved by the Office of Vocational and Educational Services for Individuals with Disabilities (VESID). The evaluation, which will include any vehicle modification recommendations, must be submitted to the LDSS (or HRA in NYC). You must sign the Parent Agreement showing that you understand your responsibility for maintenance and repair costs. The LDSS or HRA will send copies of the agreement and evaluation to the NYS Department of Health for review and approval.

5. Estimate – After modification is approved, you and the case manager must get three cost estimates or bids for the services to be provided. These bids must be submitted to the NYS Department of Health, along with the form described below.

6. Home Adaptation and Vehicle Modification Form – The CAH Coordinator will complete a CAH Home Adaptation and Vehicle Modification Form whenever a home or vehicle modification is requested. The reason(s) why the request is either approved with a bid chosen or denied by the LDSS or HRA must be included. The form, the bids, and the LDSS- or HRA-recommended action must be submitted to the NYS Department of Health. The NYS Department of Health will make the final decision to approve or deny the request.

The Home and Vehicle Modifications Request Review

NYS Department of Health staff will review the request and notify the LDSS or HRA of their decision. The CAH Coordinator will then notify you and the case manager about the Department's approval or denial.

Fair Hearing Rights

If the Home or Vehicle Modification request is denied completely or in part by both the LDSS or HRA and the NYS Department of Health, you have the legal right to ask for a fair hearing if you don't understand or disagree with the decision. (More information about fair hearings can be found on page 15.)

You can request a fair hearing if you don't agree with the decision about the home or vehicle modification request.

Part III: Reference Materials

Key Terms

Parents with a child enrolled in the CAH program will find this listing helpful in understanding the meanings of special terms as they apply to their child and their child's right to receive certain services:

Advocacy the actions taken by a child's parent(s) or guardian to be sure that the child has access to the services and/or financial help for which he or she is eligible

Budget Cap the limit on the monthly costs that will be covered by Medicaid for each child enrolled in the CAH program

Budget Sheet the document that shows a child's monthly expenses, including special items and services necessary for caring for the child at home

CAH short for the Care at Home Program, a special Medicaid program designed to help pay for medical and other services for families who want their physically disabled child to live at home rather than in a hospital or nursing home

CAH I a special Medicaid program for physically disabled children who require care in a skilled nursing facility, but who are not eligible for regular Medicaid

CAH II a special Medicaid program for physically disabled children who are technology dependent and who require hospital care, but who are not eligible for regular Medicaid

CAH Coordinator the person at each local department of social services whose job it is to help families apply for the CAH program and then to provide help in arranging for needed medical care, supplies, and equipment for children being cared for at home

Case Management the services that help a child and his or her family to access the full range of services and resources for which they are eligible

Case Management Plan the report that lists a child's needs, the providers of various services, the payment sources, and the issues that must be addressed while the child is being cared for at home

Case Manager an agency person whose job it is to help families caring for a CAH-enrolled child get the services and financial help they need

LDSS short for local county department of social services

Event-Based Reassessment the type of reassessment of a child's Plan of Care or Case Management Plan that occurs whenever there is a big change in the child's home or health situation

Fair Hearing a legal meeting held by New York State staff in order to give the person(s) advocating for the child a chance to explain why they think a decision about the child's case is wrong and should be changed

Home Adaptations/Vehicle Modifications the necessary adaptations and/or modifications that are made to improve safety and to permit a child to move about within the family home and/or to give better access between the home and the community

Home Assessment the process that is used to see if the CAH program can meet the child's health care needs and to see if the child can be cared for safely in the family home.

Home Health Assessment Abstract the report that lists the findings of the home assessment

Home Health Care Worker/Provider a skilled person who will come into the family home to care for a child

HRA short for the Human Resources Administration, which is the agency in New York City that is responsible for Medicaid

PPRI short for Pediatric Patient Review Instrument, the report that is completed as part of the home assessment to show the medical needs of the child

Physician's Orders the report written by the child's primary physician(s) in order to show the medical and support services and equipment that the child needs

Plan of Care the report that shows all of the services needed by the child, how often the services are to be provided, the names of service agencies and/or providers, the costs of services, payment sources, and the name and phone number of the case manager

Prior Approval a Medicaid review process that is used to determine if certain medical services or supplies are needed by a child enrolled in the CAH program

Prior Authorization the process that approves payment by a local department of social services for certain services (such as personal care or non-emergency transportation) that are needed by a CAH-enrolled child

Reassessment the process of looking at the different parts of the child's Plan of Care every few months in order to determine the child's continuing need for CAH services

Respite Care short-term, periodic care provided for a child enrolled in the CAH program when the family or primary caregiver cannot provide necessary care or needs to take a break from caregiver responsibilities

SSI short for Supplemental Security Income, the Social Security benefits that are paid based on disability and financial need as determined by the federal government.

VESID short for the Office of Vocational and Educational Services for Individuals with Disabilities, which is the agency that approves vehicle modification(s) for CAH children

Waiver Program special programs such as the CAH program that provides payment for Medicaid services that would not normally be covered by the regular Medicaid program for recipients who would not normally be eligible for Medicaid

Waiver Services certain services that are provided to a child enrolled in the CAH program but which are not normally covered for a child enrolled in regular Medicaid

New York State Department of Health

Home-and Community-Based Services (HCBS) 1915(c) Medicaid Waivers

For more information about any of these programs, speak with your case manager or call the NYS DOH Helpline at 1-800-541-2831.

Waiver Name	Waiver Description
*OMRDD HCBS Waiver	Administered by DOH and OMRDD for adults and children who are developmentally disabled and who require intermediate care facility level of care.
*OMH HCBS Waiver	Administered by DOH and OMH for children who are seriously emotionally disturbed and who require psychiatric-hospital level of care. (Available in selected counties in NYS)
*Traumatic Brain Injury (TBI) Waiver	Administered by DOH for persons age 18 and over who have experienced a traumatic brain injury and who require nursing facility level of care.
*Care at Home (CAH) I, II Waiver	Administered by DOH for children under age 18 who are physically disabled and who have had 30-day inpatient stay but who are not eligible for MA due to parental income and resources.
*Care at Home (CAH) III, IV, VI Waiver	Administered by DOH and OMRDD for children under the age of 18 who are developmentally disabled, have complex health care needs, and require intermediate care facility level of care but who are not eligible for MA due to parental income and resources.
*Long-Term Home Health Care Program (LTHHCP) Waiver	Administered by DOH for persons who are elderly or disabled and who require nursing home level of care.

***Key:** **MA:** Medical Assistance (Medicaid)
 DOH: Department of Health
 OMH: Office of Mental Health
 OMRDD: Office of Mental Retardation and Developmental Disabilities

New York State Medicaid CAH Waivers

(Care at Home I, II, III, IV AND VI)

There are currently five Medicaid CAH Waiver Programs operational in New York State:

Program	Administering Agency	Monthly Medicaid Expenditure Cap
Care at Home I (CAH I) (for nursing facility level of care)	NYSDOH	\$9,000
Care at Home II (CAH II) (for hospital level care with technology dependence)	NYSDOH	\$14,500
Care at Home III, IV, and VI (for ICF/MR level of care)	OMRDD	\$9,000

Eligibility Requirements

The CAH programs have both general and specific eligibility requirements:

General Eligibility Requirements

The following requirements apply to four programs, and all five of these requirements must be met in order for a child to be considered eligible:

1. The child must be under 18 years of age.
 2. The child must be determined disabled according to the standards specified in the federal Social Security Act.
 3. The child is ineligible for Medicaid due to the parents' excess income and/or resources.
 4. The child is Medicaid eligible when parents' income and/or resources are not counted.
 5. The child can be cared for at home safely and at no greater cost than in the appropriate facility
-

Specific Eligibility Requirements

Program	Requirement(s)
CAH I and II	The child must have had an institutional stay of at least 30 consecutive days. The SSI disability must be physical in nature. CAH II enrollees must be technology dependent.
CAH III	A written request for institutional placement must be submitted.
CAH III, IV, and VI	There is no institutional stay requirement. The child must have a developmental disability. The child must have complex health care needs* *Complex health care needs are defined as needs for medical therapies that are designed to replace or compensate for a vital body function or avert immediate threat to life; that is reliance on medical devices, nursing care, monitoring, or prescribed medical therapy for the maintenance of life over a period expected to extend beyond 12 months.

Contact Information:

CAH I and II – DOH State: (518) 486-6562

CAH III, IV, and VI – OMRDD State: Susan Grasso (518)-473-6256

Local Departments of Social Services

(Addresses and Phone Numbers for the Care at Home Program)

Albany County DSS

162 Washington Avenue
5th Floor
Albany, New York 12210
(518) 447-7271

Allegany County DSS

County Office Building
Belmont, New York 14813
(585) 268-7661

Broome County DSS

36-38 Main Street
Binghamton, New York 13905
(607) 778-2707

Cattaraugus County DSS

1701 Lincoln Avenue
Suite 6010
Olean, New York 14760-1158
(716) 753-8060 (ext. 480)

Cayuga County DSS

County Office Building
160 Genesee Street
Auburn, New York 13021
(315) 253-1110

Chautauqua County DSS

Hall R. Clothier Health and
Social Services Building
Mayville, New York 14757
(716) 753-4447

Chemung County DSS

Human Resources Center
425-447 Pennsylvania Avenue
Elmira, New York 14904
(607) 737-5454

Chenango County DSS

P.O. Box 590
Norwich, New York 13815
(607) 337-1590

Clinton County DSS

13 Durkee Street
Plattsburgh, New York 12901
(518) 565-3363

Columbia County DSS

25 Railroad Avenue
P.O. Box 458
Hudson, New York 12534
(518) 828-9411 (ext. 172)

Cortland County DSS

County Office Building
Central Avenue
P.O. Box 5590
Cortland, New York 13045
(607) 753-5085

Delaware County DSS

111 Main Street
Delhi, New York 13753
(607) 746-2325

Dutchess County DSS

60 Market Street
Poughkeepsie, New York 12601
(845) 486-3353

Erie County DSS

Statler Towers, Suite 1800
107 Delaware Avenue
Buffalo, New York 14202
(716) 858-2318, (716) 858-2322

Essex County DSS

P.O. Box 217
Elizabethtown, New York 12932
(518) 873-3550

Franklin County DSS

Court House
Malone, New York 12953
(518) 481-6770 (ext. 856)

Fulton County DSS

County Services Complex
P.O. Box 415
Johnstown, New York 12095
(518) 762-0718

Genesee County DSS

3837 West Main Road
Batavia, New York 14020
(585) 343-5429

Greene County DSS

457 Main Street
Catskill, New York 12414
(518) 943-4154

Hamilton County DSS

White Birch Lane
Indian Lake, New York 12842
(518) 648-6131

Herkimer County DSS

301 North Washington Avenue
Herkimer, New York 13350
(315) 867-1222

Jefferson County DSS

250 Arsenal Street
Watertown, New York 13601
(315) 785-3008

Lewis County DSS

Outer Stowe Street
P.O. Box 193
Lowville, New York 13367
(315) 376-5400

Livingston County DSS

Livingston County Campus, Bldg. 3
Mount Morris, New York 14510
(585) 243-7300 ext. 225

Madison County DSS

P.O. Box 637
Wampsville, New York 13163
(315) 366-2270

Monroe County DSS

111 Westfall Road
Rochester, New York 14620
(585) 274-6000

Montgomery County DSS

County Office Building
Fonda, New York 12068
(518) 853-8276

Nassau County DSS

County Seat Drive
Mineola, New York 11501
(516) 571-0939

New York City Human Resources Administration (HRA)

Home Care Field Operations
309 East 94th Street, 3rd Floor
New York, New York 10128
(212) 360-5444

Niagara County DSS

301 Tenth Street
P.O. Box 865
Niagara Falls, New York 14302
(716) 278-8612

Oneida County DSS

Oneida County Office Building
520 Seneca Street
Utica, New York 13502
(315) 798-5982

Onondaga County DSS

Onondaga Long-Term Care
Resource Center
5065 West Seneca Turnpike
Syracuse, New York 13215
(315) 435-5600 (ext. 135)

Ontario County DSS

3010 County Complex Drive
Canandaigua, New York 14424
(585) 396-4150

Orange County DSS

Quarry Road, Box Z
Goshen, New York 10924
(845) 291-4308

Oswego County DSS

100 Spring Street
P.O. Box 1320
Mexico, New York 13114
(315) 963-5341

Otsego County DSS

County Office Building
197 Main Street
Cooperstown, New York 13326
(607) 547-7574

Putnam County DSS

110 Old Route 6 Center
Carmel, New York 10512
(845) 225-7040 (ext. 1241)

Rensselaer County DSS

1801 Sixth Avenue
Troy, New York 12180
(518) 268-4005

Rockland County DSS

CASA – Yeager Health Care Center
Building C, Room 103
Sanatorium Road
Pomona, New York 10970
(845) 364-3557

Saratoga County DSS

152 West High Street
Ballston Spa, New York 12020
(518) 884-4140

Schenectady County

Long Term Care Unit
107 Nott Terrace, Suite 202
Schenectady, New York 12308
(518) 386-2253

Schoharie County DSS

P.O. Box 687
Schoharie, New York 12157
(518) 265-8173

Schuyler County DSS

County Office Building
P.O. Box 169
Watkins Glen, New York 14891
(607) 535-8338

Seneca County DSS

1 DiPronio Drive
P.O. Box 690
Waterloo, New York 13165
(315) 539-1800

St. Lawrence County DSS

Harold B. Smith County Office Building
Judson Street
Canton, New York 13617
(315) 379-2185

Steuben County DSS

3 East Poultney Square
Bath, New York 14810
(607) 776-7611

Suffolk County DSS

Medicaid Chronic Care
P.O. Box 18100
Hauppauge, New York 11788
(631) 854-5896

Sullivan County DSS

P.O. Box 231
Liberty, New York 12754
(845) 292-0100 (ext. 420)

Tioga County DSS

TASAP
231 Main Street
Owego, New York 13827
(607) 687-8550

Tompkins County

320 West State Street
Ithaca, New York 14850
(607) 274-5369

Ulster County DSS

1001 Development Court
Kingston, New York 12401
(845) 334-5026

Warren County DSS

Municipal Center
1340 State Route 9
Lake George, New York 12845
(518) 946-4881

Washington County DSS

Washington County Municipal Center
383 Upper Broadway
Fort Edward, New York 12828
(518) 746-2342

Wayne County DSS

77 Water Street
P.O. Box 10
Lyons, New York 14489
(315) 946-4881

Westchester County DSS

270 North Avenue
New Rochelle, New York 10801
(914) 813-5312

Wyoming County DSS

466 North Main Street
Warsaw, New York 14569
(716) 786-8838

Yates County DSS

County Office Building
110 Court Street
Penn Yan, New York 14527
(315) 536-5183

**New York State Department of Health
Care At Home Program**

Choice of Care

I, _____, am the parent of _____, who is or was a patient at _____. I understand that _____ Department of Social Services has determined that my child is eligible for services under a federal waiver program authorized by Section 1915(c) of the Social Security Act. I understand the availability to my child of case management and other Medicaid services offered by New York State. I have indicated, in the appropriate space below, my decision whether or not to bring my child home to receive these Medicaid services under the waiver program. My decision is voluntary and does not result from coercion or pressure exerted on me by the Department or by the medical institution where my child now resides.

_____ I have decided to bring my child home to receive Medicaid services under this waiver.

_____ I have decided not to bring my child home at this time. I understand that my decision not to bring my child home at this time does not affect my child's eligibility for Medicaid services in the institution where my child now resides. I also understand that I may later reapply for services under the program if I should change my mind.

Parent's Signature

Date

Witness

CARE AT HOME (CAH) I & II PROGRAM

Application Form

The New York State Department of Health's Care at Home I and II Programs, authorized by Section 1915(c) of the Social Security Act, are federal waiver programs that extend Medicaid eligibility to children with certain disabilities who have been in a hospital or in a skilled nursing facility (SNF) at least 30 days; are eighteen years of age or under; physically disabled, according to SSI program criteria; require the level of care provided in a hospital or skilled nursing facility; be capable of being care for in the community when provided with waiver services in addition to all other services under Medicaid; be ineligible for Medical Assistance and be capable of being cared for at no more cost in the community than in the appropriate institutional setting.

It is necessary but NOT sufficient for admission to the Care at Home II program to require frequent or prolonged device-based respiratory, nutritional, or other vital body-function support, with skilled nursing care for the medical disability.

The primary purpose of these waivers is to enable children who would otherwise remain in medical institutions to return to their own home and community by providing comprehensive case management and other Medicaid services.

Please print or type:

- | | |
|---|--|
| 1. Child's Name: _____ | 10. Address to which child will be discharged: |
| 2. D.O.B.: ____/____/____ | _____ |
| 3. Diagnosis: _____ | Number, Street |
| 4. S.S. #: ____-____-____ | _____ |
| 5. Facility where child is/was a patient: | City, State Zip Code |
| _____ | _____ |
| 6. Date Admitted: ____/____/____ | County |
| 7. Discharge Date: ____/____/____ | _____ |
| 8. Receiving Medicaid while in facility? | (____) _____ |
| ____ Yes ____ No | Telephone Number |
| 9. If Yes, Medicaid Number: _____ | |

Name(s) of Parents: _____

I (we) will assist in making any required assignment of health or accident insurance benefits.
I (we) will file any claims for health or accident insurance benefits to which my child is entitled.

Date: _____

Parent Signature

Parent Signature

CLIENT'S NAME: _____ *** CARE AT HOME PROGRAM *** CAH Group I _____

CAH Group II _____

☐ New Application

For Physically Disabled Children

☐ Reassessment: Period (_____)

BUDGET SHEET

☐ Amended Budget Sheet

Date: _____

(5)

PAYMENT SOURCE AND AMOUNT
Enter \$ amount from column (4)
in appropriate column:

Services	(1) Provided By Agency/ Person	(2) How Often Hrs./Days/ Week	(3) Hr./Trtmt. Cost Per (2) x (3) x (4.33)	(4) Cost Per Month (2) x (3) x (4.33)	(A) (B) (C)		
					MA \$	Self \$	Other \$ (Specify)
Physician							
Supervisor Nursing							
Shift Nursing							
Home Health Aide							
Physical Therapy							
Speech Pathology							
Personal Care Svcs.							
Other:							
Medical Supplies							
1.							
2.							
Medical Equipment							
1.							
2.							
Transportation							
Case Management							
Ancillary Service							
1.							
2.							
(6) TOTAL OF CARE: _____ (7) TOTALS A+B+C _____					Total: (A)	Total: (B)	Total: (C)

(8) Case Mgt. Agency: _____

Comments: _____

(9) Signature: _____

Date: _____

CARE AT HOME (CAH) Case Management Plan
Plan of Services

INITIAL ASSESSMENT
REASSESSMENT PERIOD
TO
CAH WAIVER: I II III IV VI
DDSO/LDSS:

CHILD'S NAME:
DOB:
MEDICAID #:
PRIMARY DIAGNOSIS:

ISSUE(S) OF CONCERN TO BE ADDRESSED IN THIS PERIOD:

- 1A. ASSISTIVE TECHNOLOGIES (OMRDD) 5. Medical/Health/Physical Development 10. Fire Safety/Emergency Planning 15. Family
- 1B. HOME ADAPTATIONS/VEHICLE MODIFICATIONS (SDOH) 6. Financial/Guardianship/Trust Planning 11. Transition 16. Mental Health
2. CASE MANAGEMENT 7. Educational/Vocational Training 12. Social/Leisure 17. Other (Specify)
3. RESPITE 8. ADL's/Independent Living 13. Communication
4. Skilled Home Care 9. Religion/Faith 14. Community/Home Accessibility

ISSUE #	Goals/Objectives	Date Need Identified:	Need/Problem to be Addressed:	Actions to be Taken: Frequency/Duration Of Services If Applicable:	Responsible Person(s): (Name, Title, Agency,Phone#)	Target Date for Resolution/ Date Resolved

Comments:

I verify that I have participated in the development of this plan to the extent I have requested and that I agree with this document, I consent to the sharing of all information necessary to the carrying out of this plan with the service

PARENT: PARENT SIGNATURE: DATE: NEXT REVIEW DATE:

CASE MANAGER/AGENCY: CASE MANAGER SIGNATURE

ADDRESS:

PHONE#:

Part IV: Helpful Forms

Feel free to make copies of the forms in this section
to create a Care Notebook for your child.

For more ideas and helpful forms use the internet.

Go to www.cshcn.org to see what some other families are using.

Also look at Tools on the American Academy
of Pediatrics website at www.medicalhomeinfo.org

Notes for Caregivers

Date _____

Child's Name: _____ Age: _____

Personality: _____

Special Likes/Dislikes: _____

Services Required: _____

Special Procedures/Therapies Required: _____

Daily Schedule

Date _____

Time

Task

Comments

Morning:

1. _____

2. _____

3. _____

4. _____

5. _____

Afternoon:

1. _____

2. _____

3. _____

4. _____

5. _____

Evening:

1. _____

2. _____

3. _____

4. _____

5. _____

Current Medications for _____

(child's name)

(include over the counter medications)

Medication	Date Started	Dosage	Delivery Route	Times	Given By
_____	_____	_____	_____	_____	_____
Notes/Side Effects	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
Notes/Side Effects	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
Notes/Side Effects	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
Notes/Side Effects	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
Notes/Side Effects	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
Notes/Side Effects	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
Notes/Side Effects	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
Notes/Side Effects	_____	_____	_____	_____	_____

Emergency Phone Numbers

Parent(s) at Work: _____

Other Family Member(s): _____

Physician(s): _____

Pharmacy: _____

Emergency back-up(s)/Caregiver(s): _____

Other: _____

Additional Notes

[illegible]

Other Important Information/Telephone Numbers

Child's Name: _____

Date of Birth: _____

Social Security Number: _____

Providers/Contacts

Telephone Numbers

Insurance Company: _____

Policy Number: _____

Contact Person: _____

Medicaid ID Number: _____

Case Manager: _____

LDSS CAH Coordinator: _____

Primary Doctor: _____

Specialists: _____

Clinics: _____

DME Provider: _____

Pharmacy: _____

Home Care Agency: _____

Individual Nurses/contacts for emergencies _____

Transportation: _____

School: _____

Fire Department: _____

Police Department: _____

Emergency Caregiver(s): _____

Nurse Information

Nurse _____ Tele. No. _____ Emergency Availability _____

Days/Hours Available _____ RN / LPN Lic. # _____

Comments _____

Nurse _____ Tele. No. _____ Emergency Availability _____

Days/Hours Available _____ RN / LPN Lic. # _____

Comments _____

Nurse _____ Tele. No. _____ Emergency Availability _____

Days/Hours Available _____ RN / LPN Lic. # _____

Comments _____

Nurse _____ Tele. No. _____ Emergency Availability _____

Days/Hours Available _____ RN / LPN Lic. # _____

Comments _____

Nurse _____ Tele. No. _____ Emergency Availability _____

Days/Hours Available _____ RN / LPN Lic. # _____

Comments _____

Nurse _____ Tele. No. _____ Emergency Availability _____

Days/Hours Available _____ RN / LPN Lic. # _____

Comments _____

Nurse _____ Tele. No. _____ Emergency Availability _____

Days/Hours Available _____ RN / LPN Lic. # _____

Comments _____

Nurse _____ Tele. No. _____ Emergency Availability _____

Days/Hours Available _____ RN / LPN Lic. # _____

Comments _____

Notes: