

The North Carolina Community Alternatives Program for Children (CAP/C)

Parent Handbook



October 2010

INTRODUCTION

Welcome to *CAP/C*!

This handbook is designed for two purposes:

1. to answer your questions about the *CAP/C* program
2. to provide you with information and resources to help you become an informed and active participant in your child's care.

The handbook is divided into six sections:

1. *General Information About CAP/C*
2. *Getting the Most From Your CAP/C Services*
3. *Other Resources*
4. *Care Plans*
5. *Emergency Information*
6. *Useful Forms*

Any of the forms in this book can be copied, can be downloaded from <http://www.dhhs.state.nc.us/dma/formsprov.html#capc>, or can be provided to you by your *Case Manager*.

If you have additional questions, please contact your *Case Manager*.

We look forward to partnering with you and supporting you with caring for your medically fragile child.

Section One

General Information about CAP/C

In this section you will find a list of questions and answers about the CAP/C program, specifically:

- The CAP/C waiver
- The services that CAP/C offers
- Who is eligible to get CAP/C
- How to apply for CAP/C
- Planning your child's care
- What happens while you are on CAP/C
- Transitioning off of CAP/C
- Where to get more information about CAP/C

I. The Waiver

WHAT IS THE CAP/C WAIVER?

The Community Alternatives Program for Children (CAP/C) is a Medicaid waiver program. It allows children who need the kind of long-term nursing care provided in a nursing home or hospital to stay at home with their family instead of having to stay in the nursing home or hospital.

A waiver program is one in which certain Medicaid rules are "waived". In other words, some rules that apply to children in a regular Medicaid program do not apply to children in the waiver program. In CAP/C, one example of this is that your family does not have to meet the regular income requirements for Medicaid; only your child's income (if he/she has any) is counted when determining Medicaid eligibility. Another example is that CAP/C can offer you some services and supplies that regular Medicaid cannot.

In exchange for being able to "waive" these rules, CAP/C must make some assurances to the state and federal authorities that regulate Medicaid. The most important assurances to you as a parent are the assurances of health, safety, and well-being, and of cost-effectiveness. Health, safety, and well-being means that CAP/C must be able to care for your child in the home safely and effectively. If CAP/C can not meet this need, then CAP/C participation will not be available. Cost effectiveness means that the cost of providing care to your child at home cannot be higher than the cost of your child being in a nursing home or hospital. For this reason, each service or supply available on the CAP/C program has a limit on the time or money that can be spent on that services.

The NC Division of Medical Assistance (DMA) is responsible for approving your child's participation in the CAP/C program.

The CAP/C waiver document can be found at <http://www.dhhs.state.nc.us/dma/capc/CAPCwaiver.pdf>. Medicaid is required to send this document to CMS (the federal government) for approval every 5 years.

II. CAP/C Services

WHAT DOES CAP/C OFFER?

All CAP/C recipients are required to receive the following two CAP/C services:

- Case Management
- At least one other service from the list below, used at least once each quarter

The additional services to choose from include:

- In-Home Nursing,
- In-Home Pediatric Nurse Aide Care
- In-Home Personal Care
- In-Home Attendant care
- Home modifications/Community Transition Funding
- Vehicle modifications/Community Transition Funding
- Waiver Supplies: Reusable incontinence diapers and disposable liners, and adaptive tricycles
- Caregiver Training and Education
- Palliative care

In addition, a child receiving case management plus at least one of the above services (except Attendant Care) each quarter may receive the following:

- Institutional respite care
- In-Home Nursing respite care
- In-Home Nurse Aide respite care

Case Management is the service of a Nurse or Social Worker, called a Case Manager, to help you oversee and coordinate your child's health care as well as social, educational, and other services related to your child's health care needs.

In-Home Nursing services are for children with medically necessary, continuous, complex, and substantial skilled nursing needs. *Continuous* means that something needs to be done for your child at least every two hours during the time that the nurse is there. *Complex* means that the nurse is doing more than being there just in case something happens; there are actual tasks that she needs to do.

Substantial means that the care could only be provided by a nurse; a nurse aide would not be qualified to provide it. The Nurse is either an RN or LPN and provides direct care to your child in your home.

In-Home Pediatric Nurse Aide (NA) services is assistance for children who need help with eating, bathing, dressing, personal hygiene, ambulation, and activities of daily living due to a medical condition. The help they need requires that the staff provided be either an NA I+ or a NA II. In addition to the NA I+ or NA II

training, these Nurse Aides have undergone additional training in pediatrics and in-home care.

In-Home Personal Care Services is assistance for children who need help with eating, bathing, dressing, personal hygiene, ambulation, and activities of daily living due to a medical condition. The help they need requires that the staff provided be a NA I.

Attendant Care is assistance for children who do not meet the criteria for regular CAP/C nurse or nurse aide services, but nevertheless have a medical condition with some requirement for supervision related to that medical condition,

Home modifications are items provided to give your child safety, mobility, and independence in your home. They include such modifications as wheelchair ramps and widening of doorways for wheelchair access. These items are not available through regular Medicaid; they are only available under the waiver.

Vehicle modifications are items provided to transport the child safely within the community. They include such modifications as wheelchair ramps and tie downs. These items are not available through regular Medicaid; they are only available under the waiver.

Community transition funding is the same as home or vehicle modifications. The amount of money you may receive for home and vehicle modifications is dependent upon the length of time you are in the five year waiver cycle. Community transition funding makes up the difference for children who are coming out of a nursing facility or hospital with need for extensive modifications but who have not been in the waiver cycle long enough.

Waiver supplies are other items that are available only under the waiver; they are not available through regular Medicaid. The specific waiver supplies that CAP/C provides are reusable diapers and the disposable liners for the reusable diapers, and adaptive tricycles.

Caregiver Training and Education reimburses a parent or other informal support person for the cost of attending a seminar, training, or conference that will help that person in their care-giving abilities

Palliative Care provides counseling, music therapy, art therapy, or bereavement counseling to the child or to members of the family

Respite Care is direct care to your child, provided in your home or in an institution, in order to give you some leisure time away from your care-giving responsibilities.

Children on CAP/C also have access to regular Medicaid services, for example; physical therapy, occupational therapy, speech therapy, and medical equipment. These regular Medicaid services are subject to the rules for those services. For

instance, if a service requires prior approval, the normal procedure for prior approval must be followed; CAP/C cannot prior-approve non-CAP/C services.

III. Eligibility

WHO CAN GET CAP/C?

CAP/C is open to individuals who

- Are under 21 years of age
- Live in a private residence (children currently in a nursing home or hospital may apply for CAP/C if they want to live at home)
- Are medically fragile. Medically fragile means that your child needs to have primarily physical medical care needs, not mental health, developmental, behavioral, or social needs. Also, the care that the staff provides in your home must be a result of that medical physical care need.
- Are at risk for institutionalization. This means that your child has to require at least the level of nursing care provided in a nursing home. This level of care is referred to as nursing facility level of care.
- Are eligible for Medicaid under the waiver criteria and need Medicaid to pay for home care services.
- Are able to be cared for safely at home
- Are able to be cared for at home within the financial limitations of the CAP/C program
- Have family members that are willing to actively participate in the care and care planning for their child.

Examples of children who may be eligible for CAP/C include children with ventilators, tracheostomies, feeding tubes, severe seizures, and those children who need help with activities such as bathing, dressing, grooming, and toileting when the child, for medical reasons, is not able to do or learn to do those tasks independently.

WHAT ELSE DO I NEED TO KNOW ABOUT CAP/C?

- CAP/C exists to supplement, not replace. There are some things that you do for your child because of his or her medical needs, and there are some things you do for your child just because he/she is a child. CAP/C can only be approved to

help with the medical things; CAP/C cannot assume normal parental responsibilities.

- Medicaid is always the payer of last resort. If you have private insurance, it **MUST** be billed first. If your insurance pays the total cost of your in-home nursing or nurse aide care, you will be ineligible for CAP/C.
- The services approved must be medically necessary, and there must be no other as effective but less costly service available. For instance, Medicaid cannot pay for a nurse when the care could be provided by a nurse aide.
- You have the right to choose between CAP/C and institutionalization. If you choose CAP/C, you have the right to choose from among enrolled Medicaid provider agencies, and among individuals within those provider agencies.
- CAP/C is not a means for obtaining Medicaid or other forms of financial assistance. CAP/C is only for families who need and want a waiver service in order to prevent their child from having to stay in a nursing home or hospital.
- CAP/C can only be approved to meet the specific unmet needs of the child. It is not approved to meet the needs of parents, caregivers, or provider agencies. For example, if you want care for your child at night because you work third shift, but your child had no nursing care needed at night, CAP/C can not provide a nurse or nurse aide at night.

IV. APPLYING FOR CAP/C

HOW DO I GET MY APPLICATION STARTED?

The first step in applying for CAP/C is completing the referral form. The form is located at http://www.dhhs.state.nc.us/dma/forms/CAPC_referral.doc. Anyone may complete the form, but it is best if the Case Manager does so. You can find the Case Management agency for your county at <http://www.dhhs.state.nc.us/dma/capc/capcagency.htm>. Once completed, the referral form is submitted to the Division of Medical Assistance. The instructions for submitting the form are located on the form itself.

THE REFERRAL WAS APPROVED. WHEN WILL SERVICES START?

The referral is only a screening process. It is NOT approval for participation in the CAP/C program. An approved referral means that DMA thinks your child is likely a good candidate for the CAP/C program, and authorizes the Case Manager to collect the complete information necessary for DMA to make a decision regarding

participation. This information includes your Medicaid application, an FL-2 form and sometimes a Physician's Request Form, an assessment, and a plan of care.

THE REFERRAL WAS DENIED. WHAT DO I DO IF I DISAGREE WITH THAT DECISION?

The referral is only a screening process. It is not a denial of participation in CAP/C. A denied referral means that based on the information provided to DMA, DMA does not believe that CAP/C is the appropriate program for your child. The Case Manager is not authorized to perform the assessment (collect the rest of the data for the complete application). Your denial letter states the reason for that decision and lists any recommendations that we have for programs we think would be appropriate.

We realize, however, that the limited amount of information on the referral form may not give us a complete and accurate picture of your child. For that reason, you may request that the Case Manager perform the assessment anyway. If you make this request, be aware that if your child's participation in CAP/C is still denied, your Case Manager may bill you for those assessment activities. Whether the Case Management agency bills for those activities and how much they bill varies from agency to agency, so be sure to inquire about this up front, before your Case Manager does anything.

WHY DO I HAVE TO APPLY FOR MEDICAID? I THOUGHT MY INCOME DID NOT COUNT.

Your income does not count. But if your child has income (a social security death benefit, a trust fund...) that may count. There are also non-financial requirements for Medicaid (for instance, citizenship status). Your child must be eligible for Medicaid (under the waiver rules for eligibility) in order to be approved for CAP/C.

As you apply for Medicaid, you will be asked about your income and resources. DSS is required to look at all the ways that a child may be eligible for Medicaid. In some instances, this is an advantage to you, because it may allow your child to get on regular Medicaid before CAP/C participation can be approved.

I ALREADY HAVE MEDICAID. WHY DO I STILL HAVE TO APPLY?

There are many different kinds of Medicaid. To be approved for CAP/C, you must be eligible for one of the following four types:

Medicaid to the Disabled (MAD)

Medicaid to the Blind (MAB)

Medicaid for children receiving adoption assistance (I-AS)

Medicaid for children receiving foster care assistance (H-SF).

So if you have Medicaid that is not one of these four types, you will need to apply for one of these four types. Even if your Medicaid is one of these types, the DSS needs to be aware that you are completing an application for CAP/C.

WHAT IS AN FL-2?

The FL-2 is a form that nursing homes use to determine that a person is sick or disabled enough to require the kind of care that a nursing home provides. Since CAP/C is an alternative to being placed in a nursing home, the FL-2 form is used by CAP/C to verify that the child is indeed eligible for institutional care, and that CAP/C is being sought as an alternative to that type of care.

The form is completed by your physician, and sent for approval to the prior approval unit for Medicaid (called HP). You, together with your Case Manager, will then be able to develop a plan of care for your child.

The FL-2 is also important because it is the only written record we have from a physician regarding your child's care. The physician's input is important in ensuring that a medically fragile child's needs can be met safely within the home.

WHAT WILL BE DONE DURING THE HOME VISIT?

During your home visit, your Case Manager will assess the needs of your child and your family, and help you develop a plan of care, which will include CAP/C services as well as other services to meet your needs. Your Case Manager will discuss with you your child's physical and mental health care needs and what your family both has and needs in order to meet the needs of your child. He or she will answer any questions you have about CAP/C or about your child's care.

WHEN WILL I HEAR IF MY CHILD IS APPROVED OR NOT?

Once DMA receives the completed application, you will be notified within 15 business days of the decision (often sooner). Occasionally, DMA may need more information than was submitted, and the application could be delayed by as much as another 15 business days after that information is submitted.

WHAT IF I AM NOT APPROVED?

If CAP/C participation is not approved, you will receive a letter which explains the reason for the denial and how to appeal the decision if you disagree.

CAN I APPLY FOR CAP/C WHILE I AM ON THE WAITING LIST FOR CAP-MR/DD?

Yes, you may apply. However, in order to be approved, your child must meet the CAP/C criteria. We cannot approve CAP/C services when the child is not eligible for CAP/C, just so they can get something while they wait. Once your child is approved for CAP-MR/DD, you must choose between the two programs. You may not receive 2 waiver programs at the same time.

If your child already has Medicaid, you may apply for either Medicaid Personal Care Services (PCS) or CAP/C. More information about PCS can be found in Section 3 of this handbook.

V. PLANNING YOUR CHILD'S CARE

WHY CAN'T I GET THE SAME SERVICES I WAS GETTING IN ANOTHER STATE?

Each state designs and administers its own waiver programs. Although the goals of the programs may be similar, they may differ in the services provided or in their policies and regulations.

CAN'T I JUST GET HELP PAYING FOR THERAPIES OR SUPPLIES?

Therapies and supplies are regular Medicaid services, not CAP/C services. CAP/C has no authority to approve, deny, or reimburse for these services. CAP/C can not be approved so that the child has access to regular Medicaid services. If you need help with items such as this, but do not want or qualify for a waiver service, the case manager may be able to recommend an alternative.

WHAT DETERMINES WHETHER MY CHILD GETS A NURSE OR A NURSE AIDE?

The type of care your child needs determines the level of staff that CAP/C can provide. For example, if he/she needs help with activities such as bathing and range of motion, CAP/C will approve a Nurse Aide (Nurse Aide I). If he/she has more complex needs such as tracheostomy care and suctioning, CAP/C will approve

a Nurse (LPN or RN). Medicaid can only authorize the lowest level of staff that can meet the child's needs. Medicaid cannot honor a request for a Nurse if a Nurse Aide can meet the child's needs. For information on what tasks are within the scope of practice for a Nurse or Nurse Aide, please visit the website of the NC Board of Nursing, at www.ncbon.org.

CAN I BE THE CAP/C NURSE OR NURSE AIDE FOR MY CHILD?

No. CAP/C cannot assume normal parental responsibilities, and parents do not normally get paid for caring for their children. CAP/C prohibits parents, siblings, grandparents and most other family members from being paid caregivers.

DO I HAVE TO HAVE A CASE MANAGER?

Yes, Case Management is a required component of CAP/C participation. Your Case Manager is your liaison to DMA, ensuring that your child receives all the services he/she needs in accordance with CAP/C policies and regulations. Your Case Manager can oversee all of your child's healthcare services and can link your child and family to resources outside of CAP/C. Caregivers are expected to work collaboratively with their Case Managers. For more information about your Case Manager's role, and how to work effectively with your Case Manager, please see Section 2.

WILL MY CHILD BE ABLE TO GET 24 HOUR PER DAY NURSE OR NURSE AIDE CARE?

CAP/C will not provide 24 hour per day care on a continuous basis. CAP/C is to "supplement, not replace", meaning that parents must have responsibility for their child for at least a portion of the day. CAP/C cannot assume that normal parental responsibility. You and your family must be trained and willing to provide care for your child on a daily basis and in an emergency, such as when a nurse is unable to work her shift as planned.

24 hour a day care can be approved for limited amounts of time in special circumstances, for instance when a child first comes home with a new tracheostomy or ventilator (so that the agency nurses can teach you how to care for your child), or for respite care.

WHAT IS THE HOSPITAL LEVEL OF CARE? WHAT DETERMINES MY CHILD'S LEVEL OF CARE?

Hospital level of care is a subset of nursing facility level of care. DMA makes the decision about whether your child qualifies for hospital level. Most CAP/C children who are hospital level have high technology needs such as ventilators or are unstable in some way. From the child's and family's perspective; it makes no difference whether you are nursing facility or hospital level of care; you can receive the same services and amounts of services either way. The designation is there only for the purpose of the state's reports to the federal government.

HOW ARE THE NUMBERS OF HOURS OF NURSE, NURSE AIDE, OR ATTENDANT CARE MY CHILD RECEIVES DETERMINED?

The number of hours for which your child is approved are based on your child's care needs, the availability of informal caregivers (unpaid caregivers such as parents, relatives, and neighbors), and the child's approved level of care. Specifically, it is based on the following formula: personal time + work time + sleep time - hours that other caregivers are available = the number of hours your child may receive.

Personal time refers to a base number of hours that every child on CAP/C is eligible for. This is time for caregivers to take care of their own needs, errands, etc. A maximum of 20 hours per week of personal time may be approved.

Work time refers to the time the caregiver is absent from the home due to work or school. Actual work hours, commute time, and lunch time are included. A maximum of 50 hours per week of work time may be approved. You will need to provide verification of your employment status and schedule.

Sleep time is generally only available only to children requiring RN or LPN care. A maximum of 56 hours per week of sleep time may be approved.

No child will receive more than 126 hours per week.

The hours approved are inclusive of all formal support (school, daycare, in-home care paid by private insurance). That means that if your child is approved for 126 hours per week, and your child goes to school for seven hours per day (35 hours per week), then the 126 hours includes 35 hours at school and 91 hours at home, whether or not CAP/C is involved with the school hours. If you are approved for 70 hours per week, and your private insurance pays for 40 hours per week, then you get 70 hours per week, with 40 hours being paid by private insurance and 30 hours being paid by CAP/C.

Hours are approved based on the care needs that your child has during the time the hours are requested. For instance, if your child needs tube feedings, help with personal care, and therapy activities during the day, but sleeps through the night with no needs, CAP/C hours will not be approved for night-time use, even if you work at night.

You may use your weekly hours at your discretion, as long as there is medically-related (not age-appropriate) care needed during the times you want the nurse or nurse aide there. However, once you use your hours for the week, they are gone. There are no more available until the next week. If you run out of hours and still need care, you may use your respite time or find an alternate arrangement. It is your responsibility to plan your hours to ensure that your child is not left without needed care. If you consistently use your hours unwisely, you may be subject to a) being placed on a daily, rather than weekly schedule with the need to call your Case Manager to approve changes in that schedule, b) referral to Child Protective Services if the child is endangered by lack of care, and/or c) termination from the CAP/C program because we are unable to ensure your child's health, safety, and well-being.

HOW DOES THE CAP/C BUDGET WORK?

In order to be able to operate CAP/C as an alternative to institutionalization, we must ensure that our services are less costly than institutionalization. For that reason, each CAP/C service and supply has a limit.

The limit is not an entitlement. In other words, if your child is eligible to receive up to \$10,000 in home modifications, you don't get to buy whatever you want until you spend the whole \$10,000. It means that you can have what is medically necessary for your child, and the total cost of those medically necessary modifications must be \$10,000 or less. If the modifications cost more than \$10,000, you and your case manager will need to work to find other sources of funding.

WHAT SHOULD THE SCHOOL PROVIDE/PAY FOR?

The public school system should pay for any services that are provided as part of your child's IEP. For instance, if according to your child's IEP, a nurse must accompany your child to school, then the school should pay for that nurse.

In certain very specific instances, CAP/C may pay for the 1:1 nurse or nurse aide services your child receives in public school. Your case manager and/or IEP team can provide you with guidance. Your case manager will need to obtain

documentation from the school to verify that the criteria for allowing CAP/C payment have been met.

Please note that this applies to the North Carolina public school system. The above may not be true for students enrolled in private schools or daycares.

HOW DOES CAP/C WORK WITH MY PRIVATE INSURANCE?

Medicaid is always the payer of last resort. Your private insurance will be billed first, and then Medicaid will pay the balance of what Medicaid allows. This includes items not paid by your private insurance because of a deductible or co-pay.

Medicaid is not intended to replace your private insurance or any other source of funding. You should not drop your private insurance once you are enrolled in CAP/C. Your private insurance will actually be very beneficial in that payments by private insurance do not count toward your spending limits (they still count toward hourly limits).

WHERE CAN SERVICES BE PROVIDED?

CAP/C services can be provided

- In your home
- In someone else's home, when that home has been assessed by your Case Manager
- In school
- In a preschool or daycare with at least a one star license
- In a church-based preschool or daycare with a letter of compliance

Services can NOT be provided in the home of a paid caregiver. For example, your nurse must take care of your child in your home; you can not take the child to your nurse's home. Also, someone living in your home, even if not a family member, can not be the paid caregiver.

CAN OUR NURSE/NURSE AIDE GO WITH OUR CHILD TO AFTER-SCHOOL ACTIVITIES OR LEISURE ACTIVITIES?

This is allowed when the following factors are taken into account:

- The Nurse/Nurse Aide can NOT transport the child to or from the activity
- There must be medical care that needs to be provided to the child during the activity
- The environment in which the activity takes place must be safe - for example, adequate sanitation, and telephone access to 911.

- The Nurse or Nurse Aide must be needed to provide the care. For instance, a nurse would not be approved to accompany the parents and child to a restaurant when both the parents are available to provide the needed care.
- The leisure activity must not replace the regularly scheduled care. For example, if you have a Nurse Aide to perform bathing, dressing, and personal care to your child, the Nurse Aide may not instead accompany your child on a leisure activity in which those tasks will not be done. The Nurse Aide can perform those tasks, and then accompany the child during the remaining time.

WHAT CAN'T MY NURSE OR NURSE AIDE DO?

1. Your nurse or nurse aide cannot drive you or your child anywhere. In some cases, your nurse or nurse aide may accompany you and your child while you drive or take some other means of transportation, but the nurse or nurse aide may not do the driving. They are there only to provide the medical care your child needs, which they cannot do while they are driving.

2. The nurse or nurse aide may not provide care for other family members. If there are siblings in the home, they remain your responsibility, even while the nurse or nurse aide is there. If you must leave the home while the nurse or nurse aide is there, you must take the siblings with you or provide a separate babysitter.

3. The nurse or nurse aide may not do the family's housework . The nurse or aide is there primarily to meet the medical needs of your child. Once that has been done, it may be appropriate for the worker to do patient-related chores, such as clean up the patient care area, clean the dishes they used to prepare the patient a meal, change the patient's bed, or do the patient's laundry, if those things are in the patient's plan of care. However, they may not clean other areas of the house, clean up the family's dishes, change all the beds, or do laundry that is not the patient's.

4. A Nurse Aide may not make decisions about a patient's care. Any task that requires a judgment, such as the administration of as-needed medications or oxygen, requires a licensed LPN or RN.

VI. NOW THAT YOU'RE APPROVED

WHAT IS THE DIFFERENCE BETWEEN RESPITE SERVICES AND SHORT-TERM-INTENSIVE SERVICES?

Both respite and short-term-intensive services are 'extra' hours, but they have different purposes. Respite hours are provided for caregivers to have leisure time, away from the responsibilities of care giving. Examples of respite time include going to a movie, attending a sibling's soccer game, or going away for a weekend. There is a limit to the number of respite hours that can be used each year. Short-term-intensive hours are for when extra hours are needed for non-leisure activities. Examples of short-term-intensive hours include the child temporarily needing extra care because of an acute illness, the illness of a caregiver, or the absence of a caregiver due to work obligations or family emergencies. There is no limit to the amount of short-term-intensive services that can be provided, but each occurrence must be approved by DMA.

HOW MUCH RESPITE CAN I HAVE?

The maximum amount of respite you can have is determined by how many hours per week of regularly scheduled care you are approved for. The fewer hours per week of care you have, the more respite you may have.

SCHEDULED HOURS PER WEEK	RESPITE HOURS PER YEAR (July 1 – Jun 30)
30 or less	720
31-60	540
61-90	360
91-126	180

In-home respite hours are counted as time above and beyond what is normally provided. For example, if you need 110 hours one week, and your child normally receives 100 hours, you are only using 10 hours of respite care.

Institutional respite is counted as 24 hours for each day in the institution.

Remember, respite can not be provided to recipients of attendant care services and can not be the only waiver service provided besides case management.

IF I AM UNABLE TO USE SOME OF MY SCHEDULED HOURS, CAN I USE THEM ANOTHER TIME?

Just as your CAP/C budget is not considered an entitlement, neither are your CAP/C hours. You may change your hours within the week, but those hours are still

planned based upon your child's medical needs and your availability to provide care. For example:

You work part-time on Monday, Wednesday, and Friday. You care for your child on the days you don't work, so your CAP/C schedule is also Monday, Wednesday, and Friday. The Nurse that is supposed to come on Monday calls out sick, and you must stay home from work to care for your child. You cannot have the nurse come on Tuesday simply because she missed Monday. There is no reason for her to be there; you are available that day to care for your child. If however, you went in to work on Tuesday to make up for the time missed on Monday, then you could use your hours on Tuesday.

Your hours must be used within the same week; they cannot be carried over.

Respite hours may always be rescheduled.

WHAT IS EPSDT?

Early Periodic Screening, Diagnosis and Treatment (EPSDT) is the federal law that requires Medicaid to provide medically necessary health care services to Medicaid-eligible children through the age of 20 even if the services are not normally covered by Medicaid or the services are normally only covered for recipients 21 years of age and older.

For example, if your child needs a piece of equipment that Medicaid does not normally pay for, you may be able to get it paid for through EPSDT, as long as it is medically necessary.

MY DOCTOR ORDERED SOMETHING. WHY WON'T CAP/C PROVIDE IT?

Much like an insurance company, there are services and supplies that are covered or not covered, and there are limits to what is covered. Your Case Manager can work with you and your child's physician to find a way to meet your child's needs.

I KNOW OF A CHILD WHO RECEIVES SOMETHING THAT MY CHILD DOESN'T. WHY?

There are several "CAP" programs in our state which offer various types and levels of services.

Any time that you want to request a particular service or supply, please ask your Case Manager. While DMA tries to be as consistent and as objective as we can, we also realize that each family has unique needs. We strive to meet the needs of the child and family while being fair to all of the other families across the state. We

need to ensure that we run the program effectively overall, so that it will continue to exist for everyone for a long time to come.

WHY DOES MY CHILD HAVE MONEY AVAILABLE THAT IS NOT BEING SPENT?

The CAP/C limits are just that; LIMITS, not ENTITLEMENTS. The items on the plan of care are there because your child needs them. Your child cannot have more than he/she needs simply because there is more money to be spent. Your child's continued CAP/C services are NOT at risk if you don't use the entire budget. Your child's continued CAP/C services ARE at risk if you use them to provide unnecessary care or equipment. Your Case Manager, in conjunction with you and your child's physician, can help you determine what the medical NEEDS of your child are.

WHAT IF WE DON'T AGREE WITH A DECISION ABOUT OUR CHILD'S CARE?

Any time that DMA makes a decision to give you less services or supplies than you requested (for instance, termination of CAP/C services, reduction of hours, or a denial of a request for more services), you have the right to appeal the decision. You will receive a letter stating the decision that was made, the reason for that decision, recommendations we have for alternative services or supplies, and details describing your appeal rights and how to request your appeal if you still disagree.

CAN WE SWITCH TO A DIFFERENT STAFFING AGENCY OR EQUIPMENT PROVIDER?

Absolutely. You have the freedom to choose from amongst any Medicaid-enrolled provider agency. You can also choose among individuals within that agency. For example, if you are unhappy with your nurse, you may request a different nurse. And if the agency does not have another nurse available, you may choose another agency.

CAN I HAVE AN ADDITIONAL SET OF EQUIPMENT FOR WHEN MY CHILD IS WITH HIS/HER OTHER PARENT OR AT SCHOOL?

No, Medicaid will not approve duplicate equipment. Equipment is approved for home use only; it will not be approved for primary use in the school. If equipment is to be used outside the home, it must be transported to the alternate location.

WHY CAN'T MY NURSE/NURSE AIDE PICK MY CHILD UP FROM SCHOOL?

CAP/C prohibits staff from transporting recipients. CAP/C children are medically fragile. The Nurse or Nurse Aide is there to provide medical care to the child; she cannot do that while she is driving. In certain cases, your Nurse or Nurse Aide may accompany you and your child while in the car, or if the school allows, your Nurse may accompany your child on the bus.

WHY CAN'T MY NURSE/NURSE AIDE TAKE MY CHILD TO THE DOCTOR OR TO THERAPY?

There are several reasons for this. First and most importantly, you are the parent, you know your child and your family's needs the best, and it is important for you to attend appointments so that you fully understand and are fully involved in your child's health care. Secondly, as stated above, staff are prohibited from transporting recipients. Lastly, Medicaid will not pay for the services of your home care Nurse or Nurse Aide while you are in a medical facility; it is considered a duplication of services, both because there are trained medical professionals present and because you as the caregiver are also there to provide care.

WHAT HAPPENS IF MY CHILD IS HOSPITALIZED?

Please notify your Case Manager immediately if your child is hospitalized. CAP/C services, with the exception of Case Management, will be suspended during your child's hospitalization, and restarted as soon as your child returns home.

In some cases, a prolonged hospitalization (lasting more than 30 days) can affect your child's Medicaid eligibility. Your Case Manager will coordinate with the Medicaid eligibility worker in your county. If the eligibility worker says that CAP/C does need to be terminated because of your hospitalization, rest assured your Case Manager and DMA will get your CAP/C restarted as soon as your child is discharged.

WHAT HAPPENS IF MY CHILD WILL BE OUT OF THE STATE FOR VACATION OR TREATMENT OR DUE TO CUSTODY ARRANGEMENTS?

Please notify your Case Manager whenever your child will be absent from your county. Your CAP/C services will be suspended until you return. The Medicaid eligibility worker in your county will need to be notified of prolonged absences (lasting more than 30 days). In most cases, such absences will not require that CAP/C be terminated, and services can restart as soon as you return home.

CAN OUR NURSE/NURSE AIDE GO ON VACATION WITH US TO PROVIDE CARE FOR MY CHILD?

This request must be considered on a case-by-case basis. There are several factors to consider.

- **Licensing issues.** The Nurse/Nurse Aide may not be licensed in the state you are going to.
- The Nurse/Nurse Aide agency has regulations regarding supervision, and the agency must be able to adhere to those regulations during your vacation.
- **Monitoring and Coordination of Care.** Depending upon the length and location of your vacation, your Case Manager may be unable to safely monitor and coordinate the services you receive.
- Care must be provided in a place that meets health and safety requirements for providing care, and your case manager must be able to assess or be reasonably sure that the environment meets these requirements.
- If your vacation is out of state, the Nurse/Nurse Aide must be employed by an agency that is a NC Medicaid provider (in order to get paid). For instance, if you went on vacation to Florida, the nurse that normally takes care of your child could go with you to Florida. However, if your agency had a branch office in Florida, they could not use that branch office to provide services to you while you are there.

If you do receive Nurse/Nurse Aide services during your vacation, it will only be for the hours that you would normally get if you were at home. The Nurse/Nurse Aide can not get paid for 24 hours per day, or for more hours than you would normally be authorized to receive. If you wish to use your respite services to supplement your hours, you may do so. A single staff person should not provide more than 12 hours per day or 60 hours per week of care. Staff may not get paid for sleep time.

WHAT IF WE MOVE TO A DIFFERENT COUNTY?

Please notify your Case Manager as soon as you know you plan to move. She will contact the Case Manager in your new county and she will coordinate the transfer of your Medicaid to the new county, so that there will be no break in your child's services.

VII. TRANSITIONING OFF OF CAP/C

WHAT HAPPENS WHEN MY CHILD'S CONDITION CHANGES?

Please notify your Case Manager any time your child's condition changes, for better or for worse. Your Case Manager will reassess your child's needs and adjust his/her services accordingly. This may mean an adjustment to a different type or amount of care within CAP/C, or transitioning off of CAP/C entirely. If your child is withdrawn from the CAP/C program, you can always reapply if or when your child's condition changes and he or she would be eligible again. In the meantime, there may be other Medicaid or community services which can meet your child's needs. Your Case Manager can help you locate these resources.

WHAT SHOULD I DO WHEN MY CHILD TURNS 21 YEARS OLD?

Your Case Manager will assist you with this transition. You should start well before your child's 21st birthday. CAP/DA, PCS, and PDN are some Medicaid programs that your child may be eligible for. If applicable, you should also involve the school system in setting your child up with vocational rehab services.

WHAT HAPPENS IF WE MOVE OUT OF NORTH CAROLINA?

Once you move out of North Carolina, you are no longer eligible for the CAP/C program. Waivers vary from state to state, so the services are not transferrable. As soon as you know you will be moving, let your Case Manager know. He or she can assist you with locating and applying for services in your new state.

VIII. MORE INFORMATION

WHERE CAN I FIND MORE INFORMATION ABOUT CAP/C?

- Your Case Manager is your primary source of information for all of your questions about CAP/C.
- There is a CAP/C webpage for consumers located at <http://www.ncdhhs.gov/dma/medicaid/capchildren.htm>
- There is a CAP/C webpage for providers located at <http://www.ncdhhs.gov/dma/services/capc.htm>. This page contains
 - the CAP/C waiver document
 - the CAP/C policy
 - the CAP/C Provider Manual
- You may also contact the Division of Medical Assistance at 919 855 4380, and ask to speak to the CAP/C Nurse Consultant for your county.

Section Two

Getting the Most From Your CAP/C Services

This section contains information to help you work with your in-home staff and with your Case Manager.

- SPEAK UP
- Interviewing potential Agencies/
Nurses/Nurse Aides
- Working with your Nurses/Nurse
Aides
- Working collaboratively with your
Case Manager

SPEAK UP About Your Home Care

Speak up if you have questions or concerns, and if you don't understand, ask again. It's your child and you have a right to know.

- Your child's health is too important to worry about being embarrassed if you don't understand something that your home care professional tells you.
- Don't be afraid to ask about safety. If you're receiving medications mailed to your home, always check the label for the correct drug and dose.
- Don't be afraid to tell your home care professional if you think your child is about to receive the wrong medication or therapy, or if you have received a piece of equipment that you don't think your child needs.
- Don't hesitate to tell your home care professional if you think he or she has confused your child with another patient.

Pay attention to the care your child is receiving. Make sure he/she is getting the right treatments and medications by the right home care staff. Don't assume anything.

- Tell your home care professional if something doesn't seem quite right.
- Expect home care workers to introduce themselves when they enter your home and look for their identification badges.
- If medical equipment such as a suction machine, oxygen or wheelchair is used, make sure you and responsible family members have been taught to use and care for the equipment in the home.
- Make sure your home care organization has a 24-hour telephone number you can call when you have questions or complaints.
- Notice whether home care workers have washed their hands. Hand washing is the most important way to prevent the spread of infections. Don't be afraid to gently remind your child's caregiver to do this.
- Make sure your home care professional confirms your child's identity before he or she administers any medication or treatment.

Educate yourself about your child's diagnosis, the services the home care organization will be providing to your child, and your child's care plan.

- Gather information about your child's condition. Good sources include the doctor, the home care organization, your library, respected websites and support groups.
- Write down important facts your doctor tells you about the home care services your child will be receiving, so that you can look for additional information later. And ask your doctor if he or she has any written information you can keep.
- Thoroughly read all forms and make sure you understand them before you sign anything. If you don't understand, ask your home care staff person to explain them.
- Make sure you are familiar with the operation of any equipment that is being used in your home. If you will be using oxygen at home, do not smoke or allow anyone to smoke near you while oxygen is in use.

Ask a trusted family member or friend to be your advocate.

(In CAP/C, your Case Manager is an advocate.)

- Your advocate can ask questions that you may not think of while you are under stress.
- Ask this person to be with you during home care visits. Your advocate can help to make sure you get the right medications, equipment and treatments. (Your Case Manager will visit your home during the time that your home care worker is there, at least every three months.)
- Your advocate can also help remember answers to questions you have asked, and speak up for you if you cannot.
- Make sure this person understands your preferences for your child's care and your wishes concerning resuscitation and life support.
- Review consents for treatment with your advocate before you sign them and make sure you both understand exactly what you are agreeing to.
- Your advocate should know what to look for if your child's condition is getting worse and whom to call.

Know what medications your child takes and why he or she takes them.

Medication errors are the most common health care mistakes.

(See section 6. It contains a chart that you can complete to help you know your child's medications).

- Ask about the purpose of the medication and ask for written information about it, including its brand and generic names. Also inquire about the side effects of the medication.
- If you do not recognize a medication, verify that it is for your child. Ask about oral medications before your child swallows them, and read the contents of bags of intravenous (IV) fluids.
- If your child gets an IV, ask the nurse how long it should take for the liquid to "run out." Tell the nurse if it doesn't seem to be dripping properly (that it is too fast or too slow).
- Whenever your child is going to receive a new medication, tell his/her doctors and home care professionals about allergies he/she has, or negative reactions he/she has had to medications in the past.
- If your child is taking multiple medications, ask the doctor or pharmacist if it is safe to take those medications together. This holds true for vitamins, herbal supplements and over-the-counter drugs, too.
- Make sure you can read the handwriting on any prescriptions written by the doctor. If you can't read it, the pharmacist may not be able to either.

Use a home care organization that has undergone a rigorous on-site evaluation against established, state-of-the-art quality and safety standards, such as that provided by the Joint Commission (JCAHO).

- Ask about the home care organization's experience in treating your child's type of illness. What specialized care do they provide in helping patients get well?
- If you have more than one home care organization to choose from, ask your Case Manager which one offers the best care for your child.
- Before your child is discharged from home care services, ask about follow-up care and make sure that you understand all of the instructions.
- Go to Quality Check at www.qualitycheck.org to find out whether your home care organization is accredited by the Joint Commission.

Participate in all decisions about your child's treatment and the home care services he/she is receiving. You are the center of the health care team.

- You and your home care agency should agree on what will be done during each step of your child's care.
- Know who will be taking care of your child, what services he/she will be receiving, how long the treatment will last, and how he/she should feel.

- Understand that more treatments or medications may not always be better. Ask your child's doctor what a new treatment or medication is likely to achieve.

WORKING WITH YOUR CASE MANAGER

My case manager's name is _____.

He/She works at _____.

I can reach my Case Manager by

Phone _____

Fax _____

E-mail _____

Mail _____

The Case Manager's job is to get your child the full range of medical care and services that he/she needs. You can expect your Case Manager to:

- ◆ Guide you through the CAP/C and Medicaid application process
- ◆ Explain the rules, regulations, benefits, and limitations of the CAP/C program
- ◆ Explain to you your rights and responsibilities
- ◆ Explain to you that you have an option between CAP/C and institutionalization, and have you to sign the plan of care electing CAP/C as your choice
- ◆ Understand and manage the resources you already have, and locate other possible resources for which your child may be eligible. This includes resources both within and outside of CAP/C.
- ◆ Contact you at least monthly to review your child's needs and services
- ◆ Visit you, your child, and your in-home worker every 30-90 days in your home.
- ◆ Contact your service providers monthly regarding the provision of Nurse and Nurse Aide services, review a sample of your child's nurse or nurse aide notes quarterly, and review all of the provider's claims to ensure that services are being provided in accordance with your child's plan of care.
- ◆ Attend doctor's visits, IEP meetings, and other appointments with you as necessary or helpful.
- ◆ Conduct an annual re-assessment and revision to the plan of care (known as the CNR) to ensure your child's continued and appropriate participation in CAP/C.
- ◆ Help your child leave the CAP/C program when the child no longer needs it or becomes too old for it.

One thing your Case Manager cannot do is make decisions about or authorize CAP/C services or supplies. All requests must be submitted by the Case Manager to the Division of Medical Assistance (DMA) for approval.

Here are some of the things your Case Manager expects you to do:

- ◆ Notify your Case Manager any time your child is hospitalized

- ◆ Notify your Case Manager of any new equipment your child receives
- ◆ Notify your Case Manager any time you will be out of the county for vacations, etc
- ◆ Promptly return your Case Manager's phone calls
- ◆ Be there as scheduled when your Case Manager visits your home
- ◆ Notify your Case Manager as soon as you know of any changes you need made to your plan of care, particularly extra hours, so that there is adequate time to get approval from DMA.
- ◆ Keep your Case Manager involved in and informed about other services, particularly school-based or Early Intervention services.

INTERVIEWING POTENTIAL NURSES AND NURSE AIDES

Your Case Manager will do a lot of the work of finding an appropriate agency for you to work with, but you may also want to be involved. Many parents like to speak to a potential agency themselves, or like to interview the particular worker that will be coming into their home. Listed below are some questions you may want to ask. Ask all of them, or choose the ones that are important to you.

Please remember that due to nursing and nurse aide shortages, there may not always be workers available to cover all of the hours your child is approved for.

How long has the agency been serving this community?

What services does the agency offer?

Is the quality of care certified by a national accrediting body such as the Joint Commission for the Accreditation of Healthcare Organizations?

Does this agency accept my private insurance?

Does the agency offer a "Patients' Bill of Rights" that describes the rights and responsibilities of both the agency and the person being cared for?

Does the agency write the plan of care for the patient with input from the patient and his or her doctor and family?

How closely do supervisors oversee care to ensure quality?

How will agency caregivers keep family members informed about the kind of care their loved one is getting?

Are agency staff members available around the clock, seven days a week, if necessary?

Does the agency have a nursing supervisor available to provide on-call assistance 24 hours a day?

How does the agency ensure patient confidentiality?

How are agency caregivers hired and trained?

Can this agency staff all of the hours on my plan of care?

Will my healthcare worker have an identification badge?

Does the healthcare worker have previous experience in pediatrics? In home care? With your particular child's needs, such as a ventilator or a particular diagnosis?

If you have pets in your home, is the healthcare worker allergic to or afraid of them? Is the healthcare worker allergic to or sensitive to other things that may be in your home, such as plants, or tobacco odors?

Are the healthcare workers CPR certified? Are the Nurse Aides first-aid certified?

What is the procedure for resolving problems when they occur, and who can I call with questions or complaints?

Will the agency provide a list of references for its caregivers?

Who does the agency call if the home health care worker cannot come when scheduled?

What type of employee screening is done? How often?

Other questions specific to my child/family/needs:

GETTING READY FOR YOUR IN-HOME HEALTH CARE WORKER

You will want to have a good working relationship with your in-home workers. The following are some suggestions to help both you and them feel comfortable in your home.

1. Tell your worker where she should park her car.
2. Tell her which entrance to your home she should use.
3. Please specify which if any areas of your house are off-limits to your health care worker.
4. Please provide your health care worker with a place to put her personal belongings (coat, lunch...)
5. Provide a place for your health care worker to eat her meal.
6. Provide use of a bathroom including a soap and clean towels or paper towels to facilitate handwashing.
7. Provide use of a phone so that your worker can contact her agency, your child's physician, or you.
8. Provide a workspace so that she can write her notes.
Note: You will be asked to sign your nurse or nurse aide's notes or time sheet. Do not sign blank notes or time sheets. Before you sign, make sure that the time and date are accurate. Agencies are required to be truthful in the time they bill Medicaid for your child's care.
9. Secure animals away from the patient care area as necessary.
10. Be respectful of your worker's time. Be home a few minutes before her shift ends so that you will have time to receive report and allow the worker to leave on time.

11. Remember that the worker is in your home to give care to your child. She is not there to take care of other children or to do things that are not in her job description and on your child's plan of care.

Section Three Other Resources

This section contains information about other services and resources that you may find helpful.

- WIC
- Early Intervention
- PCS/PCS+
- CAP-DA
- PDN
- CAP-MR/DD
- Hospice
- Division of Health Services Regulation
- Program Integrity
- Local community resources identified by your Case Manager

WIC (WOMEN, INFANTS, AND CHILDREN PROGRAM)

Purpose: provides specific foods, special therapeutic infant formulas, and medical foods.

Eligibility: Children under the age of five years who are receiving CAP/C are usually eligible

WIC and CAP/C: You can have WIC and CAP/C simultaneously. Formula paid for by WIC does not count against your child's monthly budget.

Getting Services: Call your county health department, or the state WIC office at 919 707 5800, or visit <http://www.nutritionnc.com>

EARLY INTERVENTION SERVICES/INFANT-TODDLER PROGRAM

Purpose: provides therapies and other services to children with developmental needs

Eligibility: 0-3 years of age and either A) an identified condition(s) associated with developmental concern, or B) an identified need for developmental, therapeutic, or educational intervention

Early Intervention and CAP/C: Your child can be on both programs simultaneously. The cost of therapy provided by Early Intervention does count against the monthly budget if it is paid for by Medicaid. You will not be able to receive Case Management services through Early Intervention because Medicaid regulations prohibit a recipient from having two Case Managers; your CAP/C Case Manager will take over the Early Intervention Case Manager's functions.

Getting Services: Contact the local Children's Developmental Services Agency (CDSA). A list of agencies and contact information can be found at <http://www.ncei.org/ei/itp/cdsa.html>.

PERSONAL CARE SERVICES (PCS) AND PERSONAL CARE SERVICES PLUS (PCS+)

Purpose: provides in-home nurse aide care to Medicaid recipients who need help with activities of daily living (bathing, dressing, grooming, toileting, eating...) due to a medical condition

Eligibility: all ages, must have Medicaid, care must not be appropriate to child's age

PCS and CAP/C: Except in certain conditions where services are provided in school, there would be no reason to have both programs simultaneously. If the child does receive both programs, any personal care your child requires would be provided entirely by PCS, with other waiver services provided by CAP/C. PCS is recommended to some children at the time of CAP/C referral who have Medicaid

and do not demonstrate a need for case management or waiver services other than nurse aide services. When your child who has been cared for by an NA ages out of CAP/C, PCS is one of the programs you may transition into.

Getting Services: Contact a home care agency of your choice.

COMMUNITY ALTERNATIVES PROGRAM FOR DISABLED ADULTS (CAP/DA)

Purpose: provides nurse aide level care as well as waiver services and supplies similar to those on CAP/C plus some additional supplies/services

Eligibility: age 18 and over, requires in-home Nurse Aide care to prevent institutionalization

CAP/DA and CAP/C: A child can not be on both waivers simultaneously. A child who turns 18 years old can transition to CAP-DA prior to their 21st birthday so that there is no gap in services.

Getting Services: Contact the local lead agency for CAP-DA. A list of agencies and contact information can be found at

<http://www.dhhs.state.nc.us/dma.capcontactlist.pdf>.

PRIVATE DUTY NURSING (PDN)

Purpose: to provide RN and LPN services for continuous in-home care

Eligibility: all ages, must have Medicaid even if not on the waiver

PDN and CAP/C: Except in certain conditions where services are provided in school, there would be no reason to have both programs simultaneously. If the child does receive both programs, any nursing care your child requires would be provided entirely by PDN, with other waiver services provided by CAP/C. When your child who has been cared for by a Nurse ages out of CAP/C, PDN is one of the programs you may transition into.

Getting Services: Send referral information (Private Duty Nursing Prior Approval Referral Form, Physician's Request Form for Private Duty Nursing and Hourly Nursing Review Criteria Form) located at

<http://www.dhhs.state.nc.us/dma/formsprov.html#pdn>
to DMA.

COMMUNITY ALTERNATIVES PROGRAM FOR PERSONS WITH MENTAL RETARDATION OR DEVELOPMENTAL DISABILITIES (CAP-MR/DD)

Purpose: To provide in-home care and supports to prevent institutionalization of people with mental retardation and developmental delays.

Eligibility: usually age 4 or older, at risk for institutionalization because of mental retardation or developmental delay that manifested prior to age 22

CAP-MR/DD and CAP/C: A child cannot be on both waivers simultaneously.

Getting Services: Contact your local LME. A list of LMEs and contact information is available at <http://www.dhhs.state.nc.us/mhddsas/lmedirectory.htm>

HOSPICE

Purpose: To provide end of life care to individuals and their families

Eligibility: Medicaid recipient with less than six months to live as certified by a physician

Hospice and CAP/C: Both services can be received simultaneously with care taken to avoid duplication of services such as nursing care

Getting Services: Contact a hospice agency of your choice or your CAP/C case Manager.

DIVISION OF HEALTH SERVICES REGULATION (DHSR)

The Division of Health Services Regulation has responsibility for licensure and certification of home health agencies, home care agencies, hospice agencies and other health care facilities, agencies, and homes.

Their Complaint Intake Unit is available to receive complaints regarding the care and services provided to patients by these agencies. The incident must have occurred within the last year and involve an issue regulated by federal or state law.

To report a complaint, please call **1-800-624-3004 (within NC)** or **919-855-4500**. Your confidentiality is assured.

PROGRAM INTEGRITY

Program Integrity is a unit of Medicaid that ensures that Medicaid payments are accurate, and that fraud, waste, and abuse are identified. If you suspect Medicaid fraud or abuse, you may report it to **919-647-8000** or contact the CARE-LINE at **1-800-662-7030** and ask for the DMA Program Integrity Section.

Section Four Care Plans

This is a section for
your plans of care.
In this section, keep a
copy of your most recent

- CAP/C Assessment
- CAP/C Plan of Care
- IFSP,
- IHP, IEP, or 504

and any other
pertinent information
such as therapy goals,
custody or visitation
arrangements, etc.

- _____
- _____
- _____

Section Five Emergency Information

In this section, keep important emergency information such as

- insurance information
- a complete list of people involved in my child's care
- a copy of an advance directive
- the enclosed emergency information form or other documents you may need.

CHILD

First Name _____ MI ____ Last Name _____ Suffix _____

Preferred Name/Nickname _____

Date of Birth

Mo _____ Day _____ Year _____

Gender

Male Female

Race

- | | | |
|---|---|--------------------------------------|
| <input type="checkbox"/> American Indian/Alaskan Native | <input type="checkbox"/> White (not Hispanic) | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Asian/Pacific Islander | <input type="checkbox"/> Hispanic | <input type="checkbox"/> Unreported |
| <input type="checkbox"/> Black (not Hispanic) | <input type="checkbox"/> Mixed | |

INSURANCE - MEDICAID

MID number _____ - _____ - _____ Medicaid County _____

Medicaid type

MAD MAB I-AS H-SF

CAP Indicator Code

IC SC HC

EDS Prior-Approved Level of Care

Intermediate Skilled

CAPC Level of Care

Intermediate Skilled (with Aide)
 Skilled (with Nurse) Hospital

Deductible/Spend-down Information N/A _____

INSURANCE – THIRD PARTY

Company _____	Subscriber Name _____
Policy Number _____	Group Number _____
Contact Person _____	Phone () _____ - _____ ext _____
	Fax () _____ - _____

INSURANCE – THIRD PARTY

Company _____	Subscriber Name _____
Policy Number _____	Group Number _____
Contact Person _____	Phone () _____ - _____ ext _____
	Fax () _____ - _____

PRIMARY CAREGIVER

Name _____ Title/Agency (if applicable) _____	
Social Relationship to Child <input type="checkbox"/> parent <input type="checkbox"/> sibling <input type="checkbox"/> grandparent <input type="checkbox"/> other relative _____ <input type="checkbox"/> friend <input type="checkbox"/> other _____	
Legal Relationship to Child <input type="checkbox"/> legal guardian <input type="checkbox"/> joint custody <input type="checkbox"/> visitation <input type="checkbox"/> health care power of attorney <input type="checkbox"/> foster parent <input type="checkbox"/> caregiver	
Street Address Street _____ City _____ State _____ Zip Code _____ - _____	Mailing Address <input type="checkbox"/> same as street address Street _____ City _____ State _____ Zip Code _____ - _____
Phone (home) (_____) _____ - _____	Phone (cell) (_____) _____ - _____
Phone (work) (_____) _____ - _____ ext _____	E-mail _____ @ _____

PRIMARY CAREGIVER

Name _____ Title/Agency (if applicable) _____	
Social Relationship to Child <input type="checkbox"/> parent <input type="checkbox"/> sibling <input type="checkbox"/> grandparent <input type="checkbox"/> other relative _____ <input type="checkbox"/> friend <input type="checkbox"/> other _____	
Legal Relationship to Child <input type="checkbox"/> legal guardian <input type="checkbox"/> joint custody <input type="checkbox"/> visitation <input type="checkbox"/> health care power of attorney <input type="checkbox"/> foster parent <input type="checkbox"/> caregiver	
Phone (work) (_____) _____ - _____ ext _____	Phone (cell) (_____) _____ - _____ E-mail _____ @ _____

OTHER HOUSEHOLD MEMBERS

Name		Title/Agency (if applicable)	
Social Relationship to Child			
<input type="checkbox"/> parent <input type="checkbox"/> sibling <input type="checkbox"/> grandparent <input type="checkbox"/> other relative _____ <input type="checkbox"/> friend <input type="checkbox"/> other _____			
Legal Relationship to Child			
<input type="checkbox"/> legal guardian <input type="checkbox"/> joint custody <input type="checkbox"/> visitation <input type="checkbox"/> health care power of attorney <input type="checkbox"/> foster parent <input type="checkbox"/> caregiver			
Phone (work)		Phone (cell)	
(_____) _____ - _____ ext _____		(_____) _____ - _____	
		E-mail	
		_____ @ _____	
Age under 18 years <input type="checkbox"/> Yes <input type="checkbox"/> No			

OTHER HOUSEHOLD MEMBERS

Name		Title/Agency (if applicable)	
Social Relationship to Child			
<input type="checkbox"/> parent <input type="checkbox"/> sibling <input type="checkbox"/> grandparent <input type="checkbox"/> other relative _____ <input type="checkbox"/> friend <input type="checkbox"/> other _____			
Legal Relationship to Child			
<input type="checkbox"/> legal guardian <input type="checkbox"/> joint custody <input type="checkbox"/> visitation <input type="checkbox"/> health care power of attorney <input type="checkbox"/> foster parent <input type="checkbox"/> caregiver			
Phone (work)		Phone (cell)	
(_____) _____ - _____ ext _____		(_____) _____ - _____	
		E-mail	
		_____ @ _____	
Age under 18 years <input type="checkbox"/> Yes <input type="checkbox"/> No			

OTHER HOUSEHOLD MEMBERS

Name		Title/Agency (if applicable)	
Social Relationship to Child			
<input type="checkbox"/> parent <input type="checkbox"/> sibling <input type="checkbox"/> grandparent <input type="checkbox"/> other relative _____ <input type="checkbox"/> friend <input type="checkbox"/> other _____			
Legal Relationship to Child			
<input type="checkbox"/> legal guardian <input type="checkbox"/> joint custody <input type="checkbox"/> visitation <input type="checkbox"/> health care power of attorney <input type="checkbox"/> foster parent <input type="checkbox"/> caregiver			
Phone (work)		Phone (cell)	
(_____) _____ - _____ ext _____		(_____) _____ - _____	
		E-mail	
		_____ @ _____	
Age under 18 years <input type="checkbox"/> Yes <input type="checkbox"/> No			

EXTENDED FAMILY AND FRIENDS

Name _____	
Social Relationship to Child <input type="checkbox"/> parent <input type="checkbox"/> sibling <input type="checkbox"/> grandparent <input type="checkbox"/> other relative _____ <input type="checkbox"/> friend <input type="checkbox"/> other _____	
Legal Relationship to Child <input type="checkbox"/> legal guardian <input type="checkbox"/> joint custody <input type="checkbox"/> visitation <input type="checkbox"/> health care power of attorney <input type="checkbox"/> foster parent <input type="checkbox"/> caregiver	
Street Address Street _____ City _____ State _____ Zip Code _____ - _____	Mailing Address <input type="checkbox"/> same as street address Street _____ City _____ State _____ Zip Code _____ - _____
Phone (home) (_____) _____ - _____	Phone (cell) (_____) _____ - _____
Phone (work) (_____) _____ - _____ ext _____	E-mail _____ @ _____

EXTENDED FAMILY AND FRIENDS

Name _____	
Social Relationship to Child <input type="checkbox"/> parent <input type="checkbox"/> sibling <input type="checkbox"/> grandparent <input type="checkbox"/> other relative _____ <input type="checkbox"/> friend <input type="checkbox"/> other _____	
Legal Relationship to Child <input type="checkbox"/> legal guardian <input type="checkbox"/> joint custody <input type="checkbox"/> visitation <input type="checkbox"/> health care power of attorney <input type="checkbox"/> foster parent <input type="checkbox"/> caregiver	
Street Address Street _____ City _____ State _____ Zip Code _____ - _____	Mailing Address <input type="checkbox"/> same as street address Street _____ City _____ State _____ Zip Code _____ - _____
Phone (home) (_____) _____ - _____	Phone (cell) (_____) _____ - _____
Phone (work) (_____) _____ - _____ ext _____	E-mail _____ @ _____

EXTENDED FAMILY AND FRIENDS

Name _____	
Social Relationship to Child <input type="checkbox"/> parent <input type="checkbox"/> sibling <input type="checkbox"/> grandparent <input type="checkbox"/> other relative _____ <input type="checkbox"/> friend <input type="checkbox"/> other _____	
Legal Relationship to Child <input type="checkbox"/> legal guardian <input type="checkbox"/> joint custody <input type="checkbox"/> visitation <input type="checkbox"/> health care power of attorney <input type="checkbox"/> foster parent <input type="checkbox"/> caregiver	
Street Address Street _____ City _____ State _____ Zip Code _____ - _____	Mailing Address <input type="checkbox"/> same as street address Street _____ City _____ State _____ Zip Code _____ - _____
Phone (home) (_____) _____ - _____	Phone (cell) (_____) _____ - _____
Phone (work) (_____) _____ - _____ ext _____	E-mail _____ @ _____

() - ext @

COORDINATING CARE PHYSICIAN

Name of Physician Specialty

Name of Practice

Street Address Street _____ City _____ State _____ Zip Code _____ - _____	Mailing Address <input type="checkbox"/> same as street address Street _____ City _____ State _____ Zip Code _____ - _____
---	--

Office Phone () - _____	Fax () - _____	After Hours Phone () - _____
------------------------------------	---------------------------	---

OTHER PHYSICIAN

Name of Physician Specialty

Name of Practice

Street Address Street _____ City _____ State _____ Zip Code _____ - _____	Mailing Address <input type="checkbox"/> same as street address Street _____ City _____ State _____ Zip Code _____ - _____
---	--

Office Phone () - _____	Fax () - _____	After Hours Phone () - _____
------------------------------------	---------------------------	---

OTHER PHYSICIAN

Name of Physician Specialty

Name of Practice

Street Address Street _____ City _____ State _____ Zip Code _____ - _____	Mailing Address <input type="checkbox"/> same as street address Street _____ City _____ State _____ Zip Code _____ - _____
---	--

Office Phone () - _____	Fax () - _____	After Hours Phone () - _____
------------------------------------	---------------------------	---

OTHER PHYSICIAN

Name of Physician _____			Specialty _____		
Name of Practice _____					
Street Address			Mailing Address <input type="checkbox"/> same as street address		
Street _____			Street _____		
City _____			City _____		
State _____ Zip Code _____ - _____			State _____ Zip Code _____ - _____		
Office Phone		Fax		After Hours Phone	
(____) _____ - _____		(____) _____ - _____		(____) _____ - _____	

OTHER PHYSICIAN

Name of Physician _____			Specialty _____		
Name of Practice _____					
Street Address			Mailing Address <input type="checkbox"/> same as street address		
Street _____			Street _____		
City _____			City _____		
State _____ Zip Code _____ - _____			State _____ Zip Code _____ - _____		
Office Phone		Fax		After Hours Phone	
(____) _____ - _____		(____) _____ - _____		(____) _____ - _____	

OTHER PHYSICIAN

Name of Physician _____			Specialty _____		
Name of Practice _____					
Street Address			Mailing Address <input type="checkbox"/> same as street address		
Street _____			Street _____		
City _____			City _____		
State _____ Zip Code _____ - _____			State _____ Zip Code _____ - _____		
Office Phone		Fax		After Hours Phone	
(____) _____ - _____		(____) _____ - _____		(____) _____ - _____	

PHARMACY

Name _____	
Address/location _____	
Office Phone	Fax
(____) _____ - _____	(____) _____ - _____

EARLY INTERVENTION SERVICES

Case Manager Name/Title _____		
CDSA Name _____		
Street Address Street _____ City _____ State _____ Zip Code _____ - _____		Mailing Address <input type="checkbox"/> same as street address Street _____ City _____ State _____ Zip Code _____ - _____
Phone (_____) _____ - _____ Fax (_____) _____ - _____		
Email _____ @ _____		
Services Provided		
<input type="checkbox"/> Assistive Technology	<input type="checkbox"/> Audiology Services	<input type="checkbox"/> Early Identification and Screening
<input type="checkbox"/> Family Counseling/ Therapy	<input type="checkbox"/> Health Services	<input type="checkbox"/> Medical Services
<input type="checkbox"/> Multidisciplinary Evaluations	<input type="checkbox"/> Nursing Services	<input type="checkbox"/> Nutrition Services
<input type="checkbox"/> Occupational therapy	<input type="checkbox"/> Physical Therapy	<input type="checkbox"/> Psychological Services
<input type="checkbox"/> Respite Services	<input type="checkbox"/> Social Work Services	<input type="checkbox"/> Child Service Coordination
<input type="checkbox"/> Speech-Language therapy	<input type="checkbox"/> Vision Services	<input type="checkbox"/> Special Instruction (CBRS)
<input type="checkbox"/> Transportation		

CAP/C CASE MANAGER

Name/Title _____		
Name of Agency _____		
Street Address Street _____ City _____ State _____ Zip Code _____ - _____		Mailing Address <input type="checkbox"/> same as street address Street _____ City _____ State _____ Zip Code _____ - _____
Phone (_____) _____ - _____		Fax (_____) _____ - _____
Email _____ @ _____		

SCHOOL

- Daycare Preschool Before/After School School Vacation/Track-Out
 Standard Developmental Medically Fragile
 traditional modified traditional year-round modified year-round extended school year

Name of School _____

Contact Person Name/Title _____

Street Address
Street _____
City _____
State _____ Zip Code _____ - _____

Mailing Address same as street address
Street _____
City _____
State _____ Zip Code _____ - _____

Phone (_____) _____ - _____

Fax (_____) _____ - _____

Email _____@_____

SCHOOL

- Daycare Preschool Before/After School School Vacation/Track-Out
 Standard Developmental Medically Fragile
 traditional modified traditional year-round modified year-round extended school year

Name of School _____

Contact Person Name/Title _____

Street Address
Street _____
City _____
State _____ Zip Code _____ - _____

Mailing Address same as street address
Street _____
City _____
State _____ Zip Code _____ - _____

Phone (_____) _____ - _____

Fax (_____) _____ - _____

Email _____@_____

PROVIDER AGENCY

Agency Name _____	
Agency Type	
<input type="checkbox"/> Home Health	<input type="checkbox"/> Hospice
<input type="checkbox"/> Home Care	<input type="checkbox"/> Independent Practitioner
<input type="checkbox"/> Home Infusion	<input type="checkbox"/> Durable Medical Equipment
<input type="checkbox"/> Behavioral/Mental Health	
Services Provided	
<input type="checkbox"/> RN/LPN scheduled	<input type="checkbox"/> NA I/NA II scheduled
<input type="checkbox"/> RN/LPN respite	<input type="checkbox"/> NA I/NA II respite
<input type="checkbox"/> Nurse Visits	<input type="checkbox"/> NA Visits
<input type="checkbox"/> Hospice	<input type="checkbox"/> Home Infusion Therapy
<input type="checkbox"/> Institutional Respite	<input type="checkbox"/> Durable Medical Equipment
	<input type="checkbox"/> Supplies
	<input type="checkbox"/> Physical Therapy
	<input type="checkbox"/> Occupational Therapy
	<input type="checkbox"/> Speech Therapy
	<input type="checkbox"/> Respiratory Therapy
	<input type="checkbox"/> Community Support Services
	<input type="checkbox"/> Developmental Therapy Services
Street Address	Mailing Address <input type="checkbox"/> same as street address
Street _____	Street _____
City _____	City _____
State _____ Zip Code _____ - _____	State _____ Zip Code _____ - _____
Contact Person Name/Title _____	
Phone (_____) _____ - _____	Fax (_____) _____ - _____

PROVIDER AGENCY

Agency Name _____	
Agency Type	
<input type="checkbox"/> Home Health	<input type="checkbox"/> Hospice
<input type="checkbox"/> Home Care	<input type="checkbox"/> Independent Practitioner
<input type="checkbox"/> Home Infusion	<input type="checkbox"/> Durable Medical Equipment
<input type="checkbox"/> Behavioral/Mental Health	
Services Provided	
<input type="checkbox"/> RN/LPN scheduled	<input type="checkbox"/> NA I/NA II scheduled
<input type="checkbox"/> RN/LPN respite	<input type="checkbox"/> NA I/NA II respite
<input type="checkbox"/> Nurse Visits	<input type="checkbox"/> NA Visits
<input type="checkbox"/> Hospice	<input type="checkbox"/> Home Infusion Therapy
<input type="checkbox"/> Institutional Respite	<input type="checkbox"/> Durable Medical Equipment
	<input type="checkbox"/> Supplies
	<input type="checkbox"/> Physical Therapy
	<input type="checkbox"/> Occupational Therapy
	<input type="checkbox"/> Speech Therapy
	<input type="checkbox"/> Respiratory Therapy
	<input type="checkbox"/> Community Support Services
	<input type="checkbox"/> Developmental Therapy Services
Street Address	Mailing Address <input type="checkbox"/> same as street address
Street _____	Street _____
City _____	City _____
State _____ Zip Code _____ - _____	State _____ Zip Code _____ - _____
Contact Person Name/Title _____	
Phone (_____) _____ - _____	Fax (_____) _____ - _____

PROVIDER AGENCY

Agency Name _____	
Agency Type	
<input type="checkbox"/> Home Health	<input type="checkbox"/> Hospice
<input type="checkbox"/> Home Care	<input type="checkbox"/> Independent Practitioner
<input type="checkbox"/> Home Infusion	<input type="checkbox"/> Durable Medical Equipment
<input type="checkbox"/> Behavioral/Mental Health	
Services Provided	
<input type="checkbox"/> RN/LPN scheduled	<input type="checkbox"/> NA I/NA II scheduled
<input type="checkbox"/> RN/LPN respite	<input type="checkbox"/> NA I/NA II respite
<input type="checkbox"/> Nurse Visits	<input type="checkbox"/> NA Visits
<input type="checkbox"/> Hospice	<input type="checkbox"/> Home Infusion Therapy
<input type="checkbox"/> Institutional Respite	<input type="checkbox"/> Durable Medical Equipment
	<input type="checkbox"/> Supplies
	<input type="checkbox"/> Physical Therapy
	<input type="checkbox"/> Occupational Therapy
	<input type="checkbox"/> Speech Therapy
	<input type="checkbox"/> Respiratory Therapy
	<input type="checkbox"/> Community Support Services
	<input type="checkbox"/> Developmental Therapy Services
Street Address	Mailing Address <input type="checkbox"/> same as street address
Street _____	Street _____
City _____	City _____
State _____ Zip Code _____ - _____	State _____ Zip Code _____ - _____
Contact Person Name/Title _____	
Phone (_____) _____ - _____	Fax (_____) _____ - _____

PROVIDER AGENCY

Agency Name _____	
Agency Type	
<input type="checkbox"/> Home Health	<input type="checkbox"/> Hospice
<input type="checkbox"/> Home Care	<input type="checkbox"/> Independent Practitioner
<input type="checkbox"/> Home Infusion	<input type="checkbox"/> Durable Medical Equipment
<input type="checkbox"/> Behavioral/Mental Health	
Services Provided	
<input type="checkbox"/> RN/LPN scheduled	<input type="checkbox"/> NA I/NA II scheduled
<input type="checkbox"/> RN/LPN respite	<input type="checkbox"/> NA I/NA II respite
<input type="checkbox"/> Nurse Visits	<input type="checkbox"/> NA Visits
<input type="checkbox"/> Hospice	<input type="checkbox"/> Home Infusion Therapy
<input type="checkbox"/> Institutional Respite	<input type="checkbox"/> Durable Medical Equipment
	<input type="checkbox"/> Supplies
	<input type="checkbox"/> Physical Therapy
	<input type="checkbox"/> Occupational Therapy
	<input type="checkbox"/> Speech Therapy
	<input type="checkbox"/> Respiratory Therapy
	<input type="checkbox"/> Community Support Services
	<input type="checkbox"/> Developmental Therapy Services
Street Address	Mailing Address <input type="checkbox"/> same as street address
Street _____	Street _____
City _____	City _____
State _____ Zip Code _____ - _____	State _____ Zip Code _____ - _____
Contact Person Name/Title _____	
Phone (_____) _____ - _____	Fax (_____) _____ - _____

Information regarding Advance Directives can be found at the following links:

Medical Care Decisions and Advance Directives Brochure (condensed version, 4 pages) (828 KB)

<http://www.ncdhhs.gov/dma/medicaid/AdvancedDirectCondensed.pdf>

Medical Care Decisions and Advance Directives Brochure (expanded version, 16 pages) (2 MB)

<http://www.ncdhhs.gov/dma/medicaid/AdvanceDirectExpanded.pdf>

Emergency Information Form for Children With Special Needs

Last name:

**American College of
Emergency Physicians***

**American Academy
of Pediatrics**



Date form
completed
By: Wkom

Revised
Revised

Initials
Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:	Emergency Phone:		
	Fax:		
Current Specialty physician: Specialty:	Emergency Phone:		
	Fax:		
Current Specialty physician: Specialty:	Emergency Phone:		
	Fax:		
Anticipated Primary ED:	Pharmacy:		
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1. _____	Baseline physical findings: _____
_____	_____
2. _____	_____
_____	_____
3. _____	Baseline vital signs: _____
_____	_____
4. _____	_____
_____	_____
Synopsis: _____	Baseline neurological status: _____
_____	_____
_____	_____
_____	_____

*Consent for release of this form to health care providers

Section Six

Useful Forms

In this section you will find several tools to help you, your Case Manager, your physicians, and other providers track your child's health and care needs.

- Calendar
- Event Log
- Things I need to discuss with my Case Manager
- Doctor's Appointment Record
- Immunizations
- Growth Record
- Diagnosis/Problem List
- Medication List

CALENDAR - DAILY/ DAILY SCHEDULE

Use this calendar to keep track of appointments with your child's doctors and your case manager, to keep track of changes you need to make in your nurse or nurse aide's schedule, and anything else you need it for!

Date _____

7A	
8A	
9A	
10A	
11A	
12N	
1P	
2P	
3P	
4P	
5P	
6P	
7P	
8P	
9P	
10P	
11P	
12MN	
1A	
2A	
3A	
4A	
5A	
6A	

THINGS I NEED TO DISCUSS WITH MY CASE MANAGER

MY CHILD'S HEALTH

- My child has been to the doctor, emergency room, or hospital.
- My child has the following appointments or tests coming up: _____.
- My child's overall condition seems to be getting better or getting worse.
- Something about my child's medicine, diet, or treatment has changed.

COORDINATING MY CHILD'S SERVICES

- My child has an IEP coming up, or I need help with issues involving school.
- I need help with issues involving my child's therapies.
- I need help locating or applying for community resources.
- I need help with issues involving my nurse or nurse aide agency.
- I need help with issues involving my medical supply/equipment company.

MY CHILD'S EQUIPMENT

- My child has received the following new equipment _____.
- My child needs the following equipment _____.
- I am receiving too much or not enough of _____.

MY FAMILY

- There has been a change in custody, visitation, or guardianship.
- My or another adult caregiver's work schedule has changed.
- My child's school schedule has changed.
- There has been a change to my informal support system.
- I or someone in my support system needs training about _____.

IN-HOME CARE

- I have concerns about my nurse or nurse aide, or the agency she works for.
- I am having problems getting staff; the agency frequently doesn't have someone or the worker does not come.
- I need to change my nursing or nurse aide schedule temporarily/permanently because _____.

INSURANCE INFORMATION

- something has changed with my child's private insurance or Medicaid, or I have received a new card (please show the card to your case manager)

OTHER

What is the most important thing I learned at this appointment?

What do I need to do?

Why is it important for me to do this?

DOCTOR'S APPOINTMENT

Date_____

Name of doctor_____

Type of Doctor (Pediatrician, neurologist, cardiologist....)

Routine Appointment

Appointment made because_____

What is the most important thing I learned at this appointment?

What do I need to do?

Why is it important for me to do this?

Our next appointment with this doctor is_____.

IMMUNIZATIONS

	DATE	DATE	DATE	DATE	DATE	DATE
HEPATITIS B						
DIPHTHERIA/PERTUSSIS/ TETANUS						
BOSTERS						
HAEMOPHIUS INFLUENZA B						
POLIO						
MEASLES/MUMPS/ RUBELLA						
VARICELLA						
ROTAVIRUS						
PREVNAR						
MENINGOCOCCAL						
HEPATITIS A						
HPV						
SYNAGIS YEAR 1						
SYNAGIS YEAR 2						
INFLUENZA						
OTHER						

