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## SECTION 2

# CAP/C BASICS AND KEY CONCEPTS

### Learning Objectives

1. Describe the purpose and goal of CAP/C.
2. List the services that CAP/C offers.
3. Define key terms: medically fragile; risk of institutionalization; continuous, complex, and substantial; health, safety, and well-being; recipient choice; nursing facility level of care; cost-effectiveness; medical necessity; specific unmet needs; supplement rather than replace; not for Medicaid only; EPSDT.
4. Apply these terms to decisions involving CAP/C participation and approval.

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## CAP/C.....ALSO KNOWN AS.....

- Katie Beckett program
  - medically fragile waiver program
  - in some states, TANF (Temporary Assistance to Needy Families) funds are used to provide financial assistance to families of medically fragile children
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- CAP/C programs vary among states in name, eligibility, and services offered. Some states may not have a children's waiver.

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The Center for Medicare and Medicaid Services (CMS) established Home and Community Based Services (HCBS) waiver programs because of a child in Iowa named Katie Beckett. After being hospitalized for a long time, Katie was medically ready to return home, but the cost of care prohibited her from doing so. Medicaid paid for her hospitalization, but her parents' income prevented them from paying for her home care. Thus, the Katie Beckett program was developed. In North Carolina, the Katie Beckett program is known as the Community Alternatives Program for Children (CAP/C). It was first implemented in 1983.

It is important that families moving here from other states have realistic expectations of North Carolina's CAP/C program. At the time of referral, case managers should assess what services the family receives in their home state and inform them what they can expect from CAP/C in North Carolina. This is especially true for families who were receiving TANF funds, as in North Carolina, families can not receive financial aid only – they must need nursing care and case management.

## THE PURPOSE OF CAP/C

The Community Alternatives Program for Children (CAP/C) is a special Medicaid-waiver home and community based program. It is designed to serve medically high risk children who would be at risk for institutionalization in a nursing facility or hospital without Medicaid payment for the home care available through CAP/C. With good case management, a complete package of services, and support from the parents or substitute parents, some of these children may remain safely at home at a lower Medicaid cost than institutional care.

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### Key points:

The children have to medically high-risk.

They have to need and be eligible for nursing home or hospital placement unless they receive in-home care.

They have to need Medicaid to pay for that in-home care. If private insurance covers their staffing, there is no need for CAP/C.

Case management is required.

Family/caregivers must participate in the child's care and in the CAP/C program.

The cost of home care must be less than the cost of institutional care.

## THE GOAL OF CAP/C

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To allow children needing long-term medical care to return to or remain in the community and live as independently as possible in their homes.

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CAP/C can be provided to children who are either at home facing nursing home or hospital placement, or to children in a nursing facility or hospital who want to come home.

## CAP/C PACKAGE OF SERVICES

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- Case Management
- Nursing Services
- Nurse Aide Services
- CAP/C Waiver Supplies
- Home Modifications
- Respite

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These services will be described in detail in Section 4.

Children enrolled in the CAP/C program have Medicaid; therefore, they may receive services other than those listed above. These other services are referred to as 'regular Medicaid' or 'non-waivered' or 'state plan' services. The CAP/C services are referred to as 'CAP/C' or 'waivered' services.

## LIST OF KEY TERMS AND CONCEPTS

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- Medically Fragile
- Risk Of Institutionalization
- Continuous, Complex, And Substantial
- Health, Safety, And Well-being
- Recipient Choice
- Nursing Facility or Level of Care
- Cost – Effectiveness
- Medical Necessity
- “...specific unmet needs of the child...”
- “...supplement rather than replace...”
- not for Medicaid only
- EPSDT

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These are core concepts of the CAP/C program. Understanding these concepts is essential in your role as Case Manager. They will help you as you educate and inform families about CAP/C, assess families for CAP/C participation, and develop plans of care.

# MEDICALLY FRAGILE

Medically fragile refers to children who have...

- a primary diagnosis or diagnoses that are medical – not psychological, behavioral, cognitive, or developmental.
- a serious, ongoing, illness or chronic condition requiring prolonged hospitalization and ongoing medical treatments and monitoring.
- a need for devices or care to compensate for the loss of bodily function.
- a need for physician-ordered, continuous, in-home care that requires the presence or oversight of a Registered Nurse.

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Children with diagnoses such as Down's Syndrome, autism, and behavioral disorders as their sole diagnosis usually do not qualify for CAP/C.

In addition to having a medical diagnosis, there must be nursing care that is provided in the home that relates to that diagnosis. Many children have long lists of medical diagnoses, but they require the care of a physician; there is no need for an in-home nurse or nurse aide. Examples would include some children with congenital heart defects, cystic fibrosis, or cancer. These children would not qualify for CAP/C. Conversely, a child with a minor nursing need that is related to a psychological diagnosis; for example, incontinence related to the developmental delays associated with Down's Syndrome, would not qualify for CAP/C.

The child must have an ongoing, chronic illness. CAP/C can not be provided for short-term needs such as postoperative care of an otherwise ineligible child.

Devices or care common to CAP/C children include incontinence supplies, feeding tubes, and tracheostomies.

The in-home care must not only be continuous, it must require the presence or oversight of a Registered Nurse. Some children require constant supervision, but it is due to behavioral issues such as wandering or self-injurious behavior. Such issues do not require the care or oversight of a Registered Nurse, therefore, they would not qualify a child for CAP/C.

## RISK OF INSTITUTIONALIZATION

Risk of institutionalization refers to children who...

- are prior- approved through EDS for nursing facility level of care.
- without in-home nursing care, would need to be institutionalized in a nursing facility or hospital as determined by statement of parents or responsible party.
- do not have other available resources, formal or informal, including daycare/developmental daycare or family support which can meet their needs.

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Because CAP/C is an alternative to institutionalization, children must meet the criteria for institutionalization in order to qualify for CAP/C.

The process for prior approval through EDS will be discussed in detail in a later section. This is our primary means of determining risk of institutionalization.

Since CAP/C is an alternative to institutionalization, if other alternatives exist, CAP/C is not needed. CAP/C exists to supplement rather than replace the formal and informal services and support already available to the child. So, if a developmental daycare is a valid option for a child, CAP/C could not replace that daycare.

## CONTINUOUS, COMPLEX, AND SUBSTANTIAL – CONTINUOUS

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Intervention which is performed at least every two to four hours during the hours that Medicaid reimbursed nursing or nurse aide service is provided.

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There are two important components to continuous:

1. CAP/C is designed for hourly private duty nursing or nurse aide care, not visits. Generally, a visit is of two hours duration or less. If the child's care can be completed in that time, CAP/C is probably not appropriate, and a referral to Home Health may be needed.
2. The continuous care must be provided while the nurse or nurse aide is in the home. For example, a child who receives bolus tube feedings throughout the day but no care at night, would not be eligible to have CAP/C staff in the home overnight, even if the parent worked third shift and was not available.

## CONTINUOUS, COMPLEX, AND SUBSTANTIAL – COMPLEX

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Nursing assessment requiring intervention that can only be performed by a licensed nurse. The purpose of having a licensed nurse with the recipient is NOT for observation or in case an intervention is required. 'Just in case something happens' is not covered.

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CAP/C approval is based on the presence of actual, scheduled, hands-on tasks occurring throughout the shift. CAP/C can not be approved in case a child has a seizure, in case the feeding pump alarms, in case the CPAP comes off. If the patient had very frequent seizures requiring intervention such as swiping of a VNS device or administration of Diastat, or if in addition to the CPAP there was need for oxygen which needed to be frequently adjusted based on pulse oximetry readings and nursing judgment, then CAP/C could be approved.

**CONTINUOUS, COMPLEX, AND  
SUBSTANTIAL –  
SUBSTANTIAL**

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Multiple interrelated nursing assessments requiring interventions that can only be performed by a licensed nurse, in accordance with program requirements

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The North Carolina Board of Nursing website, <http://ncbon.org>, contains information regarding the scope of practice of RNs, LPNs, and Nurse Aides.

## HEALTH, SAFETY, AND WELL-BEING

A state must provide various assurances to CMS (Center for Medicare and Medicaid Services) in order to operate a waiver program such as CAP/C. North Carolina has assured CMS that we will protect the health, safety, and well-being of our recipients. These safeguards include:

- Provider standards
- Certification/licensure requirements
- Specifications on the location of service delivery
- Case management oversight of the home and the care provided as well as parental involvement in the plan of care.

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The last bullet is the most important for Case Managers. Every aspect of your assessment and Plan of Care relates back to health, safety, and well-being.

## RECIPIENT CHOICE/ FREEDOM OF CHOICE

Case management agencies must ensure that CAP/C recipients are aware of their right to select

- between CAP/C services and institutionalization, and
- among enrolled Medicaid providers for CAP/C and other Medicaid services, and
- among individuals within those provider agencies who will provide the CAP/C and other Medicaid services

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Special care must be taken to avoid a conflict of interest when the case management agency is a home health agency. The client must be given the choice of other nursing agencies to meet the child's needs. Freedom of choice should be explained to the client at the start of care and periodically thereafter (at least annually), particularly any time a client expresses dissatisfaction with their home health agency services.

Section H of the Plan of Care is the way in which we document that the client understands their freedom of choice. It should be signed with the initial plan of care, with each CNR, and additionally as needed.

## NURSING FACILITY LEVEL OF CARE

CAP/C is an alternative to placement in a nursing facility, so the child must qualify for care in a nursing facility in order to be approved for CAP/C. The FL-2 is the way in which this is done. EDS will approve the FL-2 at one of two levels of nursing facility care:

- IC (Intermediate Care facility), or
- SC (Skilled Care facility).

(There is also a third level of care, HC (Hospital Care) which is approved by the DMA Nurse Consultants rather than by EDS, and requires that the child must qualify for care in a hospital rather than an IC or SC facility)

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For EDS' policies regarding nursing facility level of care, please refer to the Nursing Facilities Provider Manual, chapter 4, at <http://www.dhhs.state.nc.us/dma/nursingfacility.htm>. Chapter 3 of that same manual contains additional information about the FL-2 and the prior approval process, including information about Provider Link, a system which allows you to submit FL-2s electronically. Information about completing and submitting the FL-2 will be provided in another section.

Hospital level of care is a subset of skilled level of care. Hospital level of care is not approved by EDS using the FL-2; it is approved by the CAP/C Nurse Consultant after review of the assessment and plan of care.

As a GENERAL guideline:

IC children have no technology needs, or their technology has been in place for a long time and is very stable. (Child with cerebral palsy, non-ambulatory, incontinent.)

SC children have technology needs, and those needs are often new or require frequent nursing/physician monitoring and intervention. (Child with trach requiring suctioning and pulse oximetry.)

HC children require extensive nursing support and usually hourly intervention (Child with trach requiring hourly suctioning and bolus tube feedings.)

The FL-2 process and the criteria for hospital level of care will be discussed in more detail in a later section.

## COST-EFFECTIVENESS

For any Medicaid service to be approved, there must be no other as effective and less costly option available statewide.

This means that:

- the cost of CAP/C care must be less than the cost of it's alternative: nursing facility or hospital placement. For this reason, CAP/C recipients have monthly budgets.
- if another, non-waiver, Medicaid program (for instance, Medicaid Personal Care Services) can meet a recipient's needs as effectively, then that program is the one that must be provided.

*"Medicaid does not pay for a Cadillac when a Chevy will do."*

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The monthly budgets are set according to the recipient's level of care:

IC - \$2730/month

SC - \$3537/month

HC - \$28, 729/month.

## MEDICAL NECESSITY

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Medicaid coverage of a CAP/C service is available to the extent that the service is a necessary component of a Plan of Care to prevent institutionalization. The amount and duration of each CAP/C service must not exceed the amount necessary to meet the program's requirement for the health, safety, and well-being of its participants.

Convenience items or features are not covered.

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The amount and duration of services covered is individually determined, but is subject to both CAP/C and Medicaid policies and guidelines. More details will be given throughout this course. You may also refer to the CAP/C Manual.

## SPECIFIC UNMET NEEDS

Services are planned and authorized to meet the specific unmet needs of the child, not the needs or preferences of caregivers, provider agencies, or others involved in the child's care.

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As difficult as it is to do, only the child's needs can be considered in making decisions regarding CAP/C. For instance, if the parents are stressed because they are caring for their elderly parent in addition to their medically fragile child, we cannot give the child additional CAP/C hours. Instead, you should seek to put services in place for the elderly parent.

Staffing issues also cannot be a factor. We can not approve a nurse instead of an aide because a nurse is available and an aide is not.

## SUPPLEMENT RATHER THAN REPLACE

- CAP/C exists to supplement rather than replace the formal and informal support already available to a child. It is not the role of CAP/C to assume long-term responsibility for the care of the client, but rather to assist family members. CAP/C services are provided only in cases when assistance is needed by informal caregivers to meet specific unmet needs of the child.
- CAP/C is not intended to replace other sources of funding, such as private insurance.

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Formal support includes services provided through private insurance, school, or daycare. Informal support includes care provided by family, relatives, neighbors, etc.

This concept is important in terms of overall CAP/C approval, but it is of particular importance when determining the number of nurse or nurse aide hours that can be approved on the Plan of Care.

## NOT FOR MEDICAID ONLY

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An individual is placed on CAP/C because of a need for coverage of CAP/C services, in addition to CAP/C Case Management, to avoid institutional care.

A child is not placed on CAP/C solely to become eligible for Medicaid or other Medicaid services.

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Although a family doesn't have to financially qualify for Medicaid to get CAP/C, once they get CAP/C, they get Medicaid. This means that in addition to their CAP/C services, Medicaid pays doctors office bills, hospital bills, prescriptions, etc. Many people apply for or keep CAP/C in order to keep this financial assistance. However, that is NOT an appropriate use of CAP/C. CAP/C can only be approved because a recipient needs in-home nursing care and case management. CAP/C will not be approved for any other reason.

## EPSDT

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- Stands for Early Periodic Screening, Diagnosis, and Treatment
- Applies to Medicaid recipients under 21 years of age
- Medicaid must cover any service that is medically necessary to correct or ameliorate a defect, physical or mental illness, or a condition identified by screening, whether or not the state normally covers the service, if it is in the scope of services listed in federal law.
- For CAP/C recipients, the budget limit still applies. EPSDT does not allow you to exceed the budget limit.

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## CAP/C RESOURCES

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- The CAP/C Waiver  
<http://www.ncdhhs.gov/dma/capc/capcwaiver.pdf>
- The CAP/C Policy  
<http://www.ncdhhs.gov/dma/cc/capc.htm>
- The CAP/C Manual  
<http://www.ncdhhs.gov/dma/cc/capc.htm>
- The CAP/C Parent Handbook  
<http://www.dhhs.state.nc.us/dma/capc/capcparenthandbook.pdf>

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## SUMMARY

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- CAP/C programs vary from state to state.
- CAP/C is a Medicaid waiver (1915c) program.
- CAP/C is an alternative to nursing facility or hospital placement for medically fragile children.
- CAP/C offers in home nursing or nurse aide care, case management, respite, home modifications, and waiver supplies.
- With the above services, children needing long-term medical care can safely remain in their homes and communities at a cost less than that of nursing home or hospital placement.

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## SUMMARY, CONT'D.

- Because it is a waiver program, CAP/C can offer some services and supplies that regular Medicaid cannot.
- Children must be medically fragile and at risk for institutionalization to qualify for CAP/C.
- The in-home nursing care provided must be continuous, complex, and substantial.
- CAP/C providers must ensure the health, safety, and well-being of recipients.
- Recipients must be aware that they have freedom of choice.
- Recipients must need the level of care that would be provided in a nursing home or hospital.
- CAP/C and other services must be the least costly effective option available statewide.
- Services must be medically necessary and based on the needs of the child.
- CAP/C can not replace other resources already available to the child.
- CAP/C can not be authorized so the the family can receive Medicaid or items that Medicaid pays for.
- CAP/C recipients are eligible for services under EPSDT as long as those services fit within the budget limit.

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## REVIEW QUESTIONS

Please make sure you can answer the following questions before proceeding to the next section.

1. True or False: A family moving here from another state can expect to get exactly the same services in North Carolina as they had been receiving in their home state.
2. Which of the following is NOT a CAP/C service?
  - A. case management
  - B. in-home nursing
  - C. in-home physical therapy
  - D. home modifications
3. CAP/C is an alternative to \_\_\_\_\_.
4. True or False: A child who needs constant supervision due to behavioral issues would be a good candidate for CAP/C participation.
5. True or False: If a CAP/C recipient is at the budget limits but needs more nursing hours, he/she can obtain them through EPSDT.
6. The two nursing facility levels of care approved by EDS are \_\_\_\_ and \_\_\_\_
7. \_\_\_\_\_ approves hospital level of care.
8. Continuous care means that actual, hands-on nursing tasks are performed at least every \_\_\_\_\_ hours.

## REVIEW ANSWERS

1. False. Programs vary from state to state.
2. C. in-home physical therapy. CAP/C recipients can receive therapy services as part of their plan of care, but therapy is a regular Medicaid service, not a CAP/C service.
3. institutionalization, or nursing home or hospital placement. CAP/C's purpose is to enable children to remain with their families in their homes and communities rather than having to reside in a nursing home or hospital.
4. False. The child would not be a good candidate for CAP/C services. Although his needs are continuous, they are behavioral, not medical, and they do not require the care or oversight of a Registered Nurse. This child would be better served by a behavioral health program.
5. False. CAP/C recipients can obtain services and supplies through EPSDT, but those items are still subject to the CAP/C budget limit. EPSDT does not override the budget limit of the waiver.
6. IC (Intermediate Care) and SC (Skilled Care).
7. The CAP/C Nurse Consultants at the Division of Medical Assistance approve hospital level of care after review of the assessment and plan of care. A hospital level patient would be considered SC by EDS.
8. 2-4. Needs that are less frequent can typically be handled within the scope of a home health visit, or qualify as 'monitoring' or 'being there just in case something happens'.