



## North Carolina Pediatric Society

### Chapter President

Deborah Ainsworth, MD, FAAP  
1206 Brown Street  
Washington, NC 27889  
Phone: (252) 946-4134  
Fax: (252) 946-2432  
drainsdl@gmail.com

### Chapter Vice President

Scott St. Clair, MD, FAAP  
Blue Ridge Pediatric & Adolescent  
Medicine  
579 Greenway Road, #200  
Boone, NC 28607  
Phone: (828) 262-0100  
wscottstclair@gmail.com

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Raleigh

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Asheville, NC

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Elizabeth Hudgins, MPP  
1100 Wake Forest Road  
Suite 200  
Raleigh, NC 27604  
Phone: (919) 839-1156  
Fax: (919) 839-1158  
Elizabeth@ncpeds.org  
www.ncpeds.org

May 18, 2016

Mr. Dave Richard  
Deputy Secretary for Medical Assistance  
1985 Umstead Drive  
Raleigh NC 27603-2001

RE: 3K-3, CAP Waiver

Dear Mr. Richard:

Thank you for the many ways that the Division of Medical Assistance works to advance child health. We are concerned that the recently proposed waiver changes to the Community Alternatives Program would adversely affect the health and well-being of some of our most fragile and medically needy children and urge DMA to reconsider some of the CAP waiver provisions.

Caring for medically fragile and complex children in their own homes through the current Community Alternatives Program for Children (CAP-C) allows quality medical care in the home for a better quality of life for the child. We understand the need for a waiver to combine the CAP-C and CAP-DA programs. However, we have several concerns about specific waiver proposals.

We recommend the following waiver modifications.

- 1) **Base care provision on well-documented medical need, not pre-determined spending caps.** It is unclear where the \$110,000 nursing and other limits originated (page 21), but for some families this simply will not cover their nursing and other needs. Furthermore, inflation will erode the purchasing power of the set sums over time. We understand the need to control costs but making it harder – if not impossible – for families to meet the medical needs of their fragile and complex children with pre-set limits is not medically appropriate. We recommend managing costs through informed medical providers familiar with the needs of the child and the family, not arbitrary limits. Increasing oversight of approved services may be appropriate, but pre-set limits that do not take the unique needs of the patient into accounts are not. Overall, care should be based on well-demonstrated medical need, not artificial caps.

- 2) Maintain 56 hours of sleep per week.** Currently, families are allowed 56 hours of sleep coverage per week. This is reduced to 40 hours per week in the waiver (page 77). Family members are called on to make exceedingly challenging decisions and provide a high level of medical care. Expecting quality health outcomes by non-health-professionals providing care with less than 6 hours of sleep per night is not in the best health interest of medically fragile and complex children. Given the consequential and challenging care needed by the patient and the training needed by the parent, it is not medically appropriate to expect untrained friends and family to help out on weekends. (Also, the sleep time allowance is the full amount of time that coverage is provided. It does not allow any time for exchanging current information and medical instructions or other logistics that families must address. Therefore, even at 56 hours of sleep per week, parents are generally operating on less than 8 hours of rest.)
- 3) Maintain \$15,000 for vehicle modifications.** The current allowable limit for vehicle modification is \$15,000. The proposed waiver reduces it down to \$5,000 (page 76). If parents cannot transport their children to appointments, they may need to call an ambulance or other specialized transportation which would incur substantial system costs. Modifying a vehicle (for example, lowering the floor and adding a ramp) often costs at least \$10,000-\$12,000. This proposed cut in funding will impact families' abilities to transport their child, including to medical and therapy appointments.
- 4) Base assistive technology on well-documented need, not set spending caps.** The waiver limits assistive technology to \$3,000 every five years. This is especially inappropriate for children. As children grow, equipment needs change. Equipment breaks or wears out despite proper care. Incidents occur such as development of contractures, bedsores, or need for trach/g-tube/ventilator. Limiting the monetary allotment over 5 years does not take into account that the conditions and needs of medically fragile patients are rarely static. Again, approval should be managed by medical professionals familiar with the child, family and history, not based on pre-set limits.
- 5) Assure adequate and flexible respite and personal care services.** Currently, families receive 1,020 hours per year (20 hours/week) of personal care time and a sliding scale between 180 and 720 hours per year of respite. Respite is currently flexible so that each family can best determine their respite needs. The new proposed waiver is for 720 hours per year for respite, which includes the personal care time (page 54). Furthermore, the proposed 720 hours of respite care limits flexibility by assigning it as follows: 420 hours for the caregiver "personal time for emotional balance" and 300 hours for caregiver or beneficiary to be away from home.

- 6) **Extend expedited care to children with limited life expectancy.** The waiver creates certain groups for expedited services (page 10). We urge the addition to other highly medically fragile children, such as those with life expectancies of less than one year. This will help avoid catastrophic events.
- 7) **Restore palliative care counseling.** Currently, palliative care counseling is offered. The waiver has no palliative care counseling service. This counseling is very beneficial for some families and should be maintained.
- 8) **Assure no waiting list for children.** Currently, adults and children are in separate programs. We are concerned that combining the programs may exacerbate wait list concerns that already exist in some parts of the state. We urge mechanisms to limit wait lists for this important service for children.

CAP-C allows children to get needed medical care in their own homes. Parents must balance that care with needs of their other children, jobs, grocery store visits and other necessary activities. Parents generally lack comprehensive medical training yet they are willing and grateful to take on the care of their high-need children. Nursing care, respite and other supports are what allow the system to work for medically fragile and complex children and their families. While we understand the need to control costs, this should be the job of medical experts in consultation with the family – not based on pre-set limits that do not take the needs and strengths of the patient and the family into account.

Thank you for your consideration. If you have any questions, please feel free to contact us.

Sincerely,



Deborah Ainsworth, MD, FAAP  
Chapter President  
NC Pediatric Society, Inc