



North Carolina Pediatric Society

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November 18, 2016

Secretary Rick Brajer

Department of Health and Human Services
101 Blair Drive
Raleigh, NC 27603

RE: CAP/C 1915(c) Waiver

Dear Secretary Brajer:

On behalf of the NC Pediatric Society, thank you for pausing and reconsidering the CAP/C waiver. In particular, we appreciate the thoughtful and inclusive stakeholder process to develop the revised application. By including parents – deep experts – DMA was able to create a much stronger, more responsive plan.

We applaud the many strong improvements you made to the waiver, such as

- increasing the number of slots to 4000;
- increasing the average child “budget” to \$129,000 per year;
- increasing flexibility for many key services, such as the combining of home and vehicle modification allowances to permit families to make choices best suited to their needs or combining respite services.

However, we have concerns that the language of the waiver may not always exactly match what we understood the summary documents and discussions to reflect. We urge DMA to carefully review the entire application towards resolving ambiguities. For example, the “average” service budget is sometimes presented as an average but at other times appears to be a maximum. Some discussion language implied that waiting lists would be statewide but the waiver seems to suggest wait lists would be regional. (Please see for example, pages 25 – 35; page 90)

We also urge you to take great care in developing transition plans, improving services in rural communities so that children across the state have access to a full range of needed services, and in assuring that the needs of families with limited English proficiency are met.

Other specific concerns include the following:

1. The application process has become more complicated with substantially more documentation during the referral stage. While this information will help evaluate the need for services, we worry that it will delay the process for families who may already be in crisis.
2. In terms of services (page 6 of the Stakeholder Engagement document), it will help if the process of children receiving hospice care (Concurrent Care of the Affordable Care Act) in addition to CAP/C is made easier. According to the ACA, children are entitled to hospice care services. Currently, it is very cumbersome for a child with CAP/C to get hospice services.
3. With regards to the Waiver Fact Sheet, pages 1 and 2: the eligibility criteria are not clear
 - a. Will eligibility based on criteria listed be determined at the initial application process or will it be assessed at every renewal?
 - b. Criterion c: replace endotracheal tube with tracheostomy tube; include non-invasive ventilation, all feeding tubes - nasogastric tube, transpyloric tube, gastrostomy tube, gastrojejunostomy tube and feeding pumps, vagal nerve stimulator, catheterization and central line management. This will help Consultants evaluate the needs of children better.
 - c. Criterion c: Also, there are some children who do not have technology, but need constant medical assessment and management of intractable symptoms. Examples include seizures necessitating medication administration, secretions needing constant suctioning, and autonomic storming necessitating assessment of need for medication use.
 - d. Criterion c: There are children who have extensive medical needs at home but do not meet the criteria above. For example, an adolescent with Duchene Muscular Dystrophy who needs a lift system at home cannot receive this service now because he is not eligible for CAP/C with the current system.
4. Current policy states that to receive vehicle modification through CAP/C, the vehicle should be no older than 5 years. This restricts many families to modify their vehicle to transport the medically fragile child. It will help if this restriction is relaxed to 10 years. Alternatively, mileage instead of number of years can be used as a criterion.

Finally, we echo the concerns already expressed by parents about the proposal to move in-home services such as CAP Nursing and Personal Care Services to the State Plan. Since there are differences in CAP rules and State Plan rules, it appears that the differences in quantity of service allowed, as well as the qualifications of the providers, might lead to reduced services for many children. DMA staff has verbally committed to maintaining each child's service level, but it is not delineated in the waiver application. It appears that the problem might be resolved through the clinical policies under development, as well as the careful use of EPSDT accommodations. Given this uncertainty and the need to protect medically fragile children and their families, we recommend that, if at all possible, in-home services remain under the CAP/C waiver.

Thank you again for the many strong improvements. We look forward to continuing to work with DMA on the implementation of the new waiver cycle and development of policies as needed.

Sincerely,



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North Carolina Pediatric Society (NCPeds)