

May 20, 2016

Dave Richard, Director
Division of Medical Assistance
N.C. Department of Health and Human Services
1985 Umstead Drive
Raleigh, NC 27603
dma.webmedpolicy@dhhs.nc.gov

SUBMITTED VIA EMAIL

Re: Comments on Proposed CAP Waiver Policy 3K-3

Dear Mr. Richard,

Disability Rights NC is our state's federally mandated protection and advocacy organization. We work to protect the legal rights of North Carolinians with disabilities. We are a non-profit agency providing legal services and advocacy to North Carolinians with disabilities in a broad range of matters related to their disabilities, including employment, education, housing, abuse, and health care. In particular, Disability Rights NC provides advocacy and representation to many North Carolinians seeking access to services through Medicaid, including the CAP-C and CAP-DA Waivers. Disability Rights NC welcomes the opportunity to comment on the proposed combined CAP Waiver Policy 3K-3.

Budget Limits and Due Process

To date we have been supportive of the State's efforts to combine the CAP/C and CAP/DA waivers into a unified waiver, because we anticipated it would allow more seamless transitions for children entering adulthood and provide additional services to adults. There are several aspects of this proposal that appear to expand available services to adults, such as some nursing and nurse aide services. In order not to restrict what is currently available to children under CAP-C for medically fragile children, we understand that participants in the new CAP waiver will not be limited to requesting and receiving services under both the CAP waiver and the State Medicaid State Plan, such as Private Duty Nursing. With this in mind, based on the proposed Clinical Coverage Policy 3K-3, we still have some concerns and questions about the budget limits and due process contained in the policy and underlying waiver. The stated maximum budget of \$110,000 is a drastic reduction from the current \$265,000 maximum in the CAP-C waiver. The \$110,000 cap appears problematic because it is significantly lower than the cost of serving waiver participants in an institutional setting. The current maximum budget is more comparable to the cost of serving waiver participants with facility-based care. In comparison, the \$135K cap in Innovations is arguably comparable to the cost of an ICF institutional placement. The waiver application and proposed clinical coverage policy 3K-3 both describe a budgeting process and screening tool that will be used to determine the intensity of support need and an acuity level of care to which a recipient will be assigned (Intermediate: \$32K, Skilled \$42K, Nursing \$110K). This budgeting process sounds similar to the Supports Needs Matrix used in the Innovations waiver, but there do not appear to be procedural safeguards included to protect participants' rights in the CAP waiver. For example, an Innovations Waiver participant may request a new Supports Intensity Scale (SIS) assessment, and importantly, she is permitted to request medically necessary services that exceed the assigned budget.

The proposed clinical coverage policy 3K-3, section 5.7.3 CAP Budget Limits, outlines a process to develop a 90-day transition plan to realign budgets to assure they are kept within the service limits. The waiver (p. 127-28) describes finite time limit to reach this goal: "Each waiver beneficiary is given a total of 6 months to align within their cost limit upon the discovery of exceeding the budget." Ultimately, if the cost is not reduced to a specific budget limit of the particular category, the recipient will be "transitioned to other community services." The clinical coverage policy (pp. 20-21) provides the State will "transition the participant to comparable Medicaid program or community service that can meet some or all needs." The prospect of losing waiver services such that only "some" needs are met raises the risk that institutionalization will be more likely. To the extent that the \$110,000 waiver limit does not approximate or come close to what the institutional cost would be for someone on the high end (nursing acuity level), we see Olmstead implications for this upper limit. To the extent that there is no process to request medically necessary services above the internal limits of intermediate and skilled acuity levels, there are due process problems, especially in light of the protections the State recently agreed to follow in the *L.S. v. Brajer* settlement. There must be allowances and clear instruction to beneficiaries that they are entitled to request medically necessary services that exceed the cost of the assigned budget acuity level, without facing the prospect of losing waiver services entirely. It is also not clear whether the process, as outlined, to permit 6 months to align the budget applies only to changes in status and to all acuity levels or on only to the highest, nursing level. The timing of implementation may implicate provisions from the *L.S.* settlement. The process by which the State rolls out the new budgeting process and limits must be done on a rolling basis, at the beginning of each plan year, as opposed to mid-plan year, and appeal rights must be given. This is necessary to avoid any reduction or termination of services approved in an annual plan without due process.

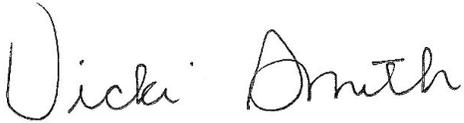
Other Areas of Concern

- Restrictions on Nursing- The changed criteria for qualification for nursing services exclude many children for whom there is no other feasible services besides nursing, creating risk of institutionalization.
- Unmet Need and Waiting Lists- It is unclear from the proposed policy what the unmet need for this waiver might be and how long the wait for services could be as a result. While all people with disabilities should be able to access appropriate services without unreasonable delay, for medically fragile children, even short waits can be developmentally detrimental. Expedited services are one way to mitigate the problem of unmet need. We encourage the inclusion of children for whom life expectancy is less than one year on the list of categories of participants eligible for expedited services.
- Reduction of Allowances for Sleep- The reduction from 56 hours to 40 hours per week seems ripe for the development of long term stress and, ultimately, increased risk of institutional placement. This equates to less than 6 hours per night and is not adequate to sustain the health of caregivers. The very nature of the care needed by participants in this waiver makes informal caregiving impractical.
- Respite- The reduction in respite hours to 720 hours per year and other limits to the use and allocation of hours will increase stress on family caregivers and, ultimately, increase pressure to seek an institutional placement.
- Unrealistic cuts to modify vehicles to \$5,000 every 5 years. The cost to modify a car to fit a wheelchair and other needs is significantly more than \$5,000. Lack of access to transportation will result in greater utilization of ambulance services that are unnecessarily costly and impractical.

Given these concerns we are unable to continue to support the plan to merge the CAP-C and CAP-DA waivers into a single waiver without significant revisions.

We appreciate the opportunity to comment on this policy and thank you for your attention to the needs of the population served by this waiver. We are available to discuss our concerns and proposals. If you have any questions or concerns, please contact me or Corye Dunn, our Director of Public Policy, at 919-856-2195 or corye.dunn@disabilityrightsnc.org.

Sincerely,

A handwritten signature in black ink that reads "Vicki Smith". The signature is written in a cursive style with a large, looped initial "V".

Vicki Smith
Executive Director