



Advocates for Medically Fragile Kids NC

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The Honorable Eric D. Hargan
Acting Secretary
US Department of Health & Human Services
330 Independence Avenue SW
Washington, DC 20201

Re: Comments on the Proposed NC Section 1115 Demonstration Waiver Application

Dear Secretary Hargan:

Advocates for Medically Fragile Kids NC was founded in 2016 by parents of medically fragile children in North Carolina when it became apparent that our kids' needs were not well understood by those in policy-making positions. We are dedicated to advocating for the rights and needs of medically fragile children and their families. We work with legislators and other policy makers to ensure they are fully educated on the hardships and impact on families. We educate and empower families to advocate for their medically fragile children. We believe every child deserves to have all of his/her healthcare needs met.

We are deeply concerned about moving Medicaid in North Carolina from a fee-for-service model to managed care. It would reduce and complicate overall access to healthcare, add administrative burden for providers, and has not been shown in any major study to reduce costs. Moving Medicaid to managed care in NC is especially concerning with the issues surrounding unscrupulous actions of one of our current LME/MCOs (Cardinal Innovations). An uncertain future at the federal level regarding the ACA, Medicaid, and CHIP makes the move to managed care even more worrisome. Any changes to these programs will significantly impact NC and its ability to ensure the well-being of its citizens.

Nationally there is very little, if any, experience successfully providing care to medically fragile populations in managed care. It is especially risky to include children with such a complex mix of medical and developmental needs as are in NC's CAP/C program. To continue to fulfill EPSDT requirements that ensure their safety, quality of care, and access to specialists and tertiary providers, *the CAP/C program must be excluded from NC's Medicaid managed care mandate*. Excluding the CAP/DA and TBI waivers also would be wise given their medical complexity. CAP/C, CAP/DA, and TBI waiver recipients even require care managers with much more professional training and expertise than most managed care organizations offer. If these populations are included, North Carolina risks duplicating the disasters occurring in states such as Florida, Iowa, Kansas, and Texas that now include people with medically complex needs in managed care.

Greater ongoing consumer/family/beneficiary involvement is needed in all NC DHHS programs, but especially regarding Medicaid Transformation and managed care. In North Carolina, there is a tendency for more value and opportunity for input to be given to providers and industry representatives than to consumers/families/beneficiaries. For example, specific requirements for consumer/family/beneficiary (not just the vague term “stakeholder”) involvement on the Medical Care Advisory Committee (MCAC) must be written into policy, not simply encouraged or vaguely mentioned in policy. Members currently do not constitute the required makeup or rotation as defined by federal guidelines and state MCAC bylaws. Also, while call-in options to attend meetings remotely are sometimes available, DHHS fails to enable enough spaces for as many people who would like to call in to do so. Sometimes audio is so poor that it is difficult to understand what is said when joining remotely. Program workgroups (such as for CAP/C) should provide opportunity for two-way communication. NC DHHS tends to be unresponsive to questions/concerns voiced by consumers/families/beneficiaries or by providers. While DHHS holds occasional “listening sessions”, staff members refuse to respond during these meetings or even to follow-up afterwards. Additionally, meetings are usually held only in Raleigh on weekdays between 9-5 pm, which is when most parents/caregivers are at work and unavailable to participate. A plan must also be put in statute that ensures adequate engagement at the state/regional and local levels between PHPs/MCOs and beneficiaries and their families. At least one of the state’s current LME/MCOs cut off their consumer & family advisory committee. It only recently reconvened when beneficiary and their families advocated for their voices to be heard.

Incorporating the Carolina Cares program in Medicaid transformation is helpful to increase access to Medicaid. However, creating barriers to access such as imposing work requirements and/or premiums, cost-sharing, and/or lockouts beyond federally allowed levels could be counterproductive. People without healthcare tend to be less healthy and therefore less able to work or to care for their children, particularly kids with complex medical needs. In addition, pregnant mothers without healthcare are at greater risk for medical complications, which could increase the number of medically fragile children in the state.

A plan written in statute is necessary to detail how beneficiaries may go outside of managed care geographic catchment areas for care when needed. Such access is especially important for children, as there is a shortage throughout the state of pediatric primary care providers as well as pediatric specialists and subspecialists. The additional administrative and payment barriers created in a managed care environment are likely to result in an even greater shortage of pediatric providers. Adult providers are not adequately trained or experienced in pediatric care. Attempting to substitute adult providers where pediatric ones are needed puts children’s lives at risk, especially those who are already medically fragile. In addition, there are very few specialists in the state or even in the entire country for some rare diseases. Immediate access to the right care and physicians is critical. Managed care restricts access to specialty care, which can cause a significant decline in the health, safety, and welfare of already fragile children.

Tracking service denials in the managed care environment and holding PHPs/MCOs accountable for inappropriate denials is extremely important. In other states, denials significantly increased under managed care, resulting in inadequate care and sometimes patient deaths. Pediatric populations and people with complex medical needs are especially vulnerable. Including an independent, conflict-free ombudsman program is vital to address concerns and grievances as well as to help beneficiaries access needed services and ensure their rights are upheld, especially regarding due process. To best hold managed care organizations and DHHS accountable, we additionally believe that any appeals that are withdrawn should be required to include with them a reason for the withdrawal.

Thank you for the opportunity to share our concerns with about NC's 1115 Medicaid waiver. We are happy to discuss them with you further should you wish to reach out to us.

Sincerely,

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