Nothing About Us, Without Us.

## North Carolina State Consumer and Family Advisory Committee

C/O Community Engagement and Empowerment Team 3001 Mail Service Center | Raleigh, NC 27699-3001 Phone: 984-236-5000 | Fax: (919) 733-4962

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September 15<sup>th</sup>, 2023

To: Deputy Secretary Jay Ludlam Cc: Director Kelly Crosbie

Happy Friday Deputy Secretary Ludlam. First and foremost I would like to thank you and your teams work with Medicaid Transformation and Expansion over the last several months. Due to the <u>Urgency</u> of the following matter, I am writing this letter to support some significant concerns with the Appendix K flexibilities.

In the last 30 days and most recently at our last SCFAC meeting public comments portion a major concerns from families and parent caregivers of consumers was identified that this committee would like to bring to your attention both which are related to Relative as Provider/Relative as Direct Support Employee's and EORs. (These could be either contracted with provider or employees.)

During COVID Appendix K was allowed certain flexibilities, which included to allow family members to work as paid caregivers, as well as provide these services to minor children under the age of 18. It is understood that these flexibilities will end on November 11<sup>th</sup>, 2023. On behalf of SCFAC we are requesting that the Appendix K flexibilities be extended ASAP and at least through February 11<sup>th</sup>, 2024 in order to give families and parent members of consumers deeply affected more time to transition; and/or provide an opportunity for the Department to produce an improved alternative to this challenge. It is <u>estimated</u> that as much as 45% of all care and services are provided by family members.

One example of this issue with no Appendix K flexibilities, exists with family members or parent caregivers not being able to attend day programs with their child, even if child needs assistance. This causes unneeded isolation for those needing care and prevents participation in social networking or events, resulting in a decrease in health and may even result in unnecessary institutionalizations.

The ripple effect also creates financial instability due to the loss of hours of care as well as the inability for the parents to work. In addition, this will cause increased anxiety and may lead to additional mental health crisis for our families and consumers.

SCFAC is requesting a written response no later than Friday 9/23/2023 to this letter and our concerns regarding Appendix K.

Respectfully, on behalf of the State Consumer and Family Advisory Committee,

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Brandon L. Wilson Chairman State Consumer and Family Advisory Committee

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