CAP/C Waiver Renewal 30-Day Public Comments and NC Medicaid Responses

Waiver Category: Appendix A - Administrative Authority
Public comment: We notice in the description of the CIAE process that the CIAE provider will perform reassessments. We had understood that this would not be the case, and strongly recommend that reassessments be left with case managers. Perhaps this is an inadvertent error in the application. Would you please review.
NC Medicaid proposed action to the comment: The renewed application identified an independent assessment entity that would conduct all initial assessments, and the case management entity would perform annual reassessments. The independent assessment entity may be asked to complete an annual assessment when applicable. No changes will be made to the waiver application.
Public comment: LPNs should not be allowed to be case managers. Case management is an advanced nursing/social work skill. I know of no other healthcare settings in which LPNs are allowed to be case managers. It should remain that only RNs or social workers are allowed to be case managers.
NC Medicaid proposed action to the comment: The waiver application permits a licensed nurse with the required years of experience to assume the case manager role. The case manager for waiver participants are responsible for assessing needs, planning care provision, monitoring the service plan, linking to needed services and following up. The current health care workforce warrants adding this flexibility to ensure the sufficiency of available workers. No changes will be made to the waiver application.
Public comment: I have concerns about the change in requirements for case manager for Cap/C beneficiaries. Currently case managers must have the advanced clinical skills of being an RN or a social worker. The new proposed waiver would allow LPNs to be case managers too. LPNs typically don't have the advanced clinical skills needed for this responsibility. It should be noted that social worker case managers still must have parts of their case management duties performed by an RN or in conjunction with an RN because RN level skills are required to complete those tasks. To add LPN case managers would give RNs more cases they have to collaborate on. This would take away from the RNs being able to provide appropriate care to their cases.
NC Medicaid proposed action to the comment: The waiver application permits a licensed nurse who has the required years of experience to assume the case manager role. No changes will be made to the waiver application. The case managers roles and responsibilities include assessing need, care planning , linking, monitoring, and following up. The RN case manager should not provide direct care or medical consultation specific to the waiver participant. No changes will be made to the waiver application.
Public comment: Several years ago, there were numerous conversations including lots of family advocacy and involving Dave Richard, head of Medicaid, around the proposed Comprehensive Independent Assessment Entity (CIAE) not doing CNRs (reassessments) since the ongoing case manager knows the child best. An agreement was made that the CIAE would do initials only, and the regular case manager would do the annual reassessment (CNR). Despite all of this, the proposed waiver now has the CIAE doing initial assessments AND CNR reassessments. This is a huge concern. The state has not awarded the CIAE contract yet so this needs to be addressed before this becomes part of their contract, not just with the waiver application.
NC Medicaid proposed action to the comment: The renewed application identified an independent assessment entity that will conduct all initial assessments, and the case management entity will perform annual assessments. The independent assessment

entity may be asked to complete an annual assessment, which is an option that the state may exercise when applicable. No changes will be made to the waiver application.
Public comment: The other thing is that so many families experience medical trauma while seeking care for their child. Making families meet with an independent agency during the initial evaluation is fine because there is no relationship yet. Once the initial is completed, the family goes to an agency to receive services. They establish a working relationship. Then, when facing the stress of reevaluation and determining if the child can continue receiving lifesaving services, the family has to have a new provider come into their home and the family has to recount all of the trauma, not to a trusted case manager who is up to date on all the child and family has been through, but to a new person. Families should be allowed to stay with their trusted case manager during this stressful process.
NC Medicaid proposed action to the comment: The renewed application identified an independent assessment entity that will conduct all initial assessments, and the case management entity will perform annual assessments. The independent assessment entity may be asked to complete an annual assessment when applicable. No changes will be made to the waiver application.
2 Public comments: ***It is extremely important that CAP/C Case Managers perform reassessments. The CIAE provider should only perform the initial assessment, NOT the reassessment. Case managers build relationships with beneficiaries and their families and therefore can provide the most accurate information. In addition, as caregivers with limited time, we prefer not to have to repeat our child & our family's story all over again with someone from the CIAE. NC Medicaid will get the clearest picture of a CAP/C beneficiary and his/her family by having the case manager complete the reassessment, NOT the CIAE since the case manager has been keeping in touch with us throughout the year anyway. Our children and we build rapport with case managers, and that takes time. Having someone we do not know from a CIAE doing the reassessment will add additional stress for our children and our family. When we have not already built a trusting relationship with someone, it may be difficult for us to share everything needed to provide the clearest picture of our child and family's needs for the reassessment.
NC Medicaid proposed comment: The renewed application identified an independent assessment entity that will conduct all initial assessments, and the case management entity will perform annual assessments. The independent assessment entity may be asked to complete an annual assessment when applicable. No changes will be made to the waiver application.
Public comment: As a parent, I do not want to have to explain and hope that a new agency understands my complex medically involved child after one visit. Especially since the case manager who has been providing services for the year knows all the ins-and-outs of what my child has been through. There are so many clinical questions during the reevaluation, and as a family we do not always understand what the state is seeking to learn. By having a case manager who is aware of the medical complexities of our child, if we incorrectly answer a question because we don't understand the question, they can ask the question in a different way. It is important to capture accurate info during the reevaluation. The other thing is that so many families experience medical trauma while seeking care for their child. Making families meet with an independent agency during the initial evaluation is fine because there is no relationship yet. Once the initial is completed, the family goes to an agency to receive services. They establish a working relationship. Then, when facing the stress of reevaluation and determining if the child can continue receiving lifesaving services, the family has to have a new provider come into their home

and the family has to recount all of the trauma, not to a trusted case manager who is up to date on all the child and family has been through, but to a new person. Families should be allowed to stay with their trusted case manager during this stressful process.
NC Medicaid proposed action to the comment: The renewed application identified an independent assessment entity that will conduct all initial assessments, and the case management entity will perform annual assessments. The independent assessment entity may be asked to complete an annual assessment when applicable. No changes will be made to the waiver application.
Public comment: CIAE should NOT do CNR- case manager knows child best and should be continued to be allowed to do reassessment.
NC Medicaid proposed action to the comment: The renewed application identified an independent assessment entity that will conduct all initial assessments, and the case management entity will perform annual assessments. The independent assessment entity may be asked to complete an annual assessment when applicable. No changes will be made to the waiver application.
Public comment: . The proposal states (pg. 4) that "the case management entity or designated assessors shall complete a comprehensive needs assessment"-Is the IAE not going to be taking over all assessment responsibilities? Why do the proposal state "or"? Is this just to cover for the interim until an IAE is identified?
NC Medicaid proposed action to the comment: The renewed application identified an independent assessment entity that will conduct all initial assessments, and the case management entity will perform annual assessments. The independent assessment entity may be asked to complete an annual assessment when applicable. No changes will be made to the waiver application.
Public comment: Again, it is unclear based on the wording in the proposal what the IAE's role will be in the annual review specifically. At the bottom of page 13, item #5 states the IAE will "validate annual assessment and change of status assessments completed by the case management entity' which suggests that CMEs will be completing the assessment and IAE's will not. However, in other areas of the proposal, it is worded as though all assessments will be completed the by the IAE including CNRs. Additionally in previous discussions regarding completion of CNRs it has been discussed that it makes more sense for the CME to complete the CNR as the CME had had ongoing contact with the family throughout the year and has an established relationship. But from the proposal it appears that the IA will be conducting This needs to be clarified more thoroughly in the proposal/policy.
NC Medicaid proposed action to the comment: The renewed application identified an independent assessment entity that will conduct all initial assessments, and the case management entity will perform annual assessments. The independent assessment entity may be asked to complete an annual assessment when applicable. No changes will be made to the waiver application.
Public comment: Pg 14 references that IAE's will be responsible for annual quality assurance of the service plan"-what does this entail? Will the IAE be reviewing all services plans now instead of DHB?
NC Medicaid proposed action to the comment: The Independent assessment entity will be responsible for initial assessments and approving service plans for CAP/C. No changes to the waiver application will be made.
Waiver Category: Appendix B – Participant Count
Public comment: Unless these are new recipients, we are concerned that the Department is intending to transfer the majority of PDN recipients to consumer direction under Attendant Care Nurse under this waiver. In 2020, PDN served 1806 recipients, ½ of whom were children. Recommendation: Please clarify that the Department is not intending shift the majority of PDN recipients to consumer direction.

NC Medicaid proposed action to the comment: The Department does not intend to shift PDN recipients to the consumer direction program under the CAP/C waiver. Children who qualify for enrollment in the CAP/C waiver will have the option to self-direct their care, similar to other children enrolled in the waiver. All qualifying conditions must be met for individuals at a nursing skill level of care to direct their care.
Waiver Category: Appendix C – Waiver Services: In-home aide/pediatric nurse aide
4 Public Comments: CNA services - application includes CD Lite language and covid exceptions which currently pays parents as CNAs at CNA rate PNA services - application does NOT include CD Lite language but does talk about parents being paid caregivers (why this discrepancy?) Attendant Nurse Care - It also indicated parents can be paid through this service if they are RN/LPN but is this under coordinated caregiving? It doesn't specify this in this section.
NC Medicaid proposed action to the comment: This waiver renewal application supports the payment of a legally responsible person to be a paid caregiver when all qualifying conditions are met. The reimbursement methodology is through enrollment in a new waiver service called coordinated caregiving or the consumer direction option. Under the coordinated caregiving service, the live-in legally responsible person is paid a stipend to carry out the care needs of the waiver participant. No changes will be made to the waiver application.
Public Comment: As many families have discussed repeatedly in previous stakeholder groups and with CAP/C management, there are instances where children under age three who are at the aide level or the PNA level that absolutely require ADL assistance that is beyond what can be reasonably expected to be the sole responsibility of the parent or legal guardian. One example is some children with severe short bowel syndrome on parenteral and/or enteral feeds like my daughter. There is nothing "normal" or "age-appropriate" about their extreme diaper change needs. The CAP-C Clinical Policy was amended just a couple of years ago to read, "ADL care for a beneficiary under the age of three (3) years is considered age appropriate and the responsibility of the parent or responsible representative. If the needed ADL assistance includes personal care needs, the care is not for normal age-appropriate functioning." That last sentence is critical and should absolutely be put back in the CAP-C waiver application renewal. See pgs. 67 and 124 of waiver application. Another example of a child under three needing more care is a child with Epidermolysis Bullosa who requires frequent clinical decision making on wound care and taking appropriate clinical steps to make sure wounds are covered correctly to prevent infection. Another example is a two-and-a-half-year-old child with no head control who still requires total support during bathing. Typical care involves making sure the water is the right temperature and depth, assisting with washing the baby's body and hair, and supervision during baths. Bath time for a two-and-a-half-year-old with no head control who also has a g-tube and seizures involves much, much more care than a typical child requires. For these reasons we implore you to add the last sentence back into the waiver.
NC Medicaid proposed action to the comment: The waiver application will be updated to align the ADL definition with the stakeholder's vetted clinical coverage policy ADL definition.

Public comment: Non-age-appropriate ADL assistance is covered for children under 3 should be added to the CNA and PNA descriptions. I feel like this has already been discussed and agreed upon but it's not in the waiver application.
NC Medicaid proposed action to the comment: The waiver application will be updated to align the ADL definition with the stakeholder's vetted clinical coverage policy ADL definition.
Public comment: More than the current options of paycheck companies should be offered for Cd/CDL. The current ones have major issues and show little transparency when handling Medicaid money. When using CDL why do parents need to choose between getting auth for their paycheck or getting auth for a medical item for their child? If it can take Medicaid up to 120 days for auth on some items, that means that parents go 120 days without pay. Do the people making these decisions have to wait 120 days for a paycheck when ordering something their child needs?
NC Medicaid proposed action to the comment: Changes will not be made to the waiver. Only qualified providers are approved to provide Medicaid services. Two vendors qualified to render fiscal intermediary services are approved in North Carolina. These agencies follow the guidelines of their Medicaid application and the CAP policies. Medicaid will explore opportunities to add additional vendors as the use of consumer direction increases.
Public comment: Attendant care nursing: Please ask CMS for a workaround that would allow agency nursing under the waiver in addition to the consumer direct model so nurses have the option of which form of employment. This would allow nurses with less experience (less than the mandated 2000 or 1000 hours of work experience) or nurses who prefer not to work under consumer direct, to work under the agency model (under the waiver). Without moving the agency model under the waiver, and family will have to choose between consumer direct OR PDN due to duplication of services. This is done in several states and CMS could provide guidance on how the State plan would need to be altered to allow all the LTSS nursing to move under the waiver while still being EPSDT compliant. New grad nurses are a common source of recruiting but due to the hours of required, this removes this large employment pool. In order to retain and recruit experienced nurses, consumer direct is an extremely useful tool BUT if we also want to target new grads, we can't. There must be an option to use consumer direct and hire new grad nurses. Some of our very best home health nurses have been new grads. I speak as an RN. Thanks so much for considering this.
NC Medicaid proposed action to the comment: The service definition, limitations, and experience for these newly added services will not change. Due to the fragility of the CAP/C population and the independent work the hired nurse performs, knowledge and understanding of managing a crisis or unexpected medical event are essential to ensure the health and safety of the waiver participant.
Public comment: If there is some way to get better nurse care. Over the years we have been on the CAP we find the nurses that watch our son are getting paid around $15/hr. The quality of care and of people we get sent are very unreliable and we rarely get to get out and use respite. Many show up very late or decide not to show up at all. There needs to be a way to get decent quality nurses in our home.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application; comment noted. Quality of care complaints should be reported to the employing agency or to the Division of Health Services Regulation complaint line.
Public comment: Many of the extraordinary circumstances are tied to Covid which will be N/A. Please do not make Covid the only applicable extraordinary circumstance.

NC Medicaid proposed action to the comment: COVID will be one of many extraordinary conditions to qualify as extraordinary circumstances. The waiver application will be updated to emphasize that other conditions outside COVID that may qualify for extraordinary circumstances.
Public comment: change in participant services section that states "When qualifying conditions are met, legally responsible person's will be permitted to be the paid caregiver". I can't speak for others. I can only speak of my family's own experiences and situation. I can offer my opinion and thoughts of other's situations. Our CAP/C participation began March 1, 2022, which we are so very thankful for. However, we have only been provided 1 nurse since March. This nurse came for 3 weeks. Out of the 15 days she was supposed to have worked, she only showed up on 10 of those. This was in May. She never showed back up after Memorial Day. We were never contacted by her to let us know that she had quit. We have been nurse-less since. Fault cannot be placed on the nursing agency. They are trying but have no applicants. Nobody is putting in applications no matter how many promotions and advertisements they send out. This isn't just a local issue. This seems to be a statewide problem...possibly nationwide. Lack of a nurse wouldn't be an issue if a parent could be his paid caregiver. Even if there wasn't a nursing shortage, there's no guarantee that a nurse will commit. No promise they are there to stay. As parents of a child with special needs which include severe autism and severe intellectual disabilities, we cannot have a revolving door of nurses. He needs routine. He needs consistency. He will not have that if we have different nurses coming in and out of our lives. They don't all do the same things in the same ways. He needs to be able to develop a relationship and trust with his nurse. That will never happen if we don't get a nurse who is in it for the long haul. It is unfair to him to have strangers come and go constantly. Nor is it fair to him to get use to someone, other than his parents, taking care of him only for that person to never return. It truly makes it hard on him and us emotionally and behaviorally. Being his paid caregiver as his parents, he would have his routine, his consistency, and a relationship developed and we are in it for the long haul. Parents being allowed to be paid caregivers would also give nursing agencies a little bit of a "break". They would be able to switch their focus to the clients that have no other choice than outside nursing. Those that, as caregivers, are single parents, for example. They have to seek employment in order to be able to provide. In my opinion, if our nursing agency wasn't under pressure to provide us a nurse because I am the paid caregiver, then this would allow them to focus on providing for a client who has no other choice. I do realize that it's considered a parent's "responsibility" to care for their children. However, speaking for my household, most 7-year-old children can use the bathroom themselves. Most 7-year-old children can feed themselves. Most 7-year-old children have started learning how to bath themselves. They can tell you when they're hungry, thirsty, sleepy, tired, something hurts, they don't feel well. My neurotypical 5 year can do all these things with the exception of bathing. My 7-year-old child with disabilities cannot do any of it. He requires a close watchful eye. We know what his vocalizations are. We know what they mean. We already know all this. This is the life we live every single day. We already do this every day; we should be able to get paid to do it...because for

those with non-typical children...it's extra. Plus, like I mentioned above, we can't seem to get/keep a nurse due to staffing shortages. If we get one, they don't stay long enough to be able to learn his vocalizations, his likes, his dislikes, or his wants. Personally, we need the income. We are a one income family. It's becoming a struggle just to be able to survive. We don't do any extras like eating out, vacations, and such things. We don't qualify for assistance. Income limits have not changed, but yet gas and food has tripled in price. Income limits are based on gross pay, but gross pay isn't what pays the bills, buys the food, supplies the gas. What my spouse brings home is a world of difference compared to what his gross income is. We barely make it week to week. There's no room to put back into savings. So, God forbid something happen that required us to dip into savings because there is no savings. I am unable to seek employment outside of the home. I cannot be relied upon as an employee. My child gets sick too much requiring him to be home from school. He also has too many appointments to attend for me to be depended on as an employee. Being paid as his caregiver would lift this heavy burden. Please take all of this into consideration when making a decision and allow legally responsible persons, like parents, to be paid caregivers of their child.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application. In the waiver application, a proposal is being made to allow legally responsible individuals, such as parents, to become paid caregivers using a new waiver service called coordinated caregiving or consumer direction. Children enrolled in the waiver who qualify for private duty nursing service may choose to direct their care through consumer direction, permitting a legally responsible person who is a nurse to be the paid caregiver.
Public comment: We support and agree with these limitations. We recommend the waiver address how appropriateness is determined and by whom. Recommendation: The waiver application and the subsequent clinical policy governing consumer direction of Attendant Nurse should provide sufficient details and criteria by which appropriateness is evaluated and terminated.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application. Under consumer direction, the waiver application must complete a self-assessment questionnaire and other documents to evaluate the appropriateness of self-direction with the case manager's support. When a beneficiary is approved for consumer direction, guidance is provided around how to supervise your worker and the termination process.
2 Public comments: Newly proposed waiver service – Coordinated Caregiving Coordinated caregiving - This is how the state has said previously it intends to pay parents moving forward but language in the application indicates parents can be paid under each individual service, also, which would pay more than coordinated caregiving, so why would someone choose this? None of the individual services ever mention coordinated caregiving. In the proposed changes for the CAPC Waiver, It is currently listed as is a daily rate, For CNA level of care, the rate is 41.93 per day for year 1. PNA is 63.55 per day. Neither of these rates are a livable income. In many areas of the state, it is extremely hard to find a willing nurse to hire AND harder to keep them. A livable income wage would insure stability for the patients and the families.
NC Medicaid proposed action to the comment: No changes to the waiver application will be made. The rate for coordinated caregiving was evaluated and in line with other Medicaid services.

5 Public comments: Coordinated caregiving rates - Caregivers have been forced to give up jobs and careers to stay home with their medically-fragile child due to lack of available staffing, many of them single parents. We must pay them a living wage. PNA caregivers would make the equivalent of $11.12/hr. assuming a 40-hr. work week and a CNA caregiver would make the equivalent of $7.34/hr. assuming a 40-hr. work week, which are both below the federal poverty guidelines. The state employee minimum wage of $15/hr. should be the baseline. In addition, the GA passed legislation in April 2022 requesting the state move to a minimum $15/hr. rate for caregivers of those with special needs.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application. The rates included in the waiver application were publicized and approved by state and federal authorities and complies with the S.L. 2021-108.
Public comment: Coordinated caregiving - This is how the state has said previously it intends to pay all eligible parents providing care moving forward but language in the application indicates parents can be paid under each individual service which would pay more than coordinated caregiving, so why would someone choose this? None of the individual services ever mention coordinated caregiving. **Inconsistencies for parents to not be required to be CNAs or PNAs if their child is aide level to be paid to care for their children but they are required to be RN/LPN if their child is nurse level. Nursing care isn't approved for 24 hrs. in a day, so parents/legal guardians are expected to be fully trained caregivers for the other hours not provided (as well as time not covered due to lack of staffing), whether they have an RN/LPN license or not so the state is acknowledging they are capable of doing the work.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application. To ensure the health and well-being of a child with skilled needs, the CAP waiver will permit a nurse to be hired who is not working through a Home Health agency, when qualifying conditions are met.
Public comment: I wanted to comment specifically on the coordinated caregiving waiver service and express my appreciation for the inclusion of this service as a permanent part of the waiver post-pandemic. As a CAPC case manager, I have seen first-hand how this has helped a number of families who typically struggle to juggle low-wage, out-of-home jobs with caregiving and care coordination for a medically fragile child, as well as families who struggle to find employment (or are under-employed) due to the time-intensive and unpredictable nature of caregiving and care coordination for a medically fragile child. These families, in particular, have had life-changing experiences, being a part of the CD Lite program. The reduction in caregiver stress and financial instability, and the increase in caregiver confidence and self-efficacy has been a joy to witness.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application.
Public comment: Aside from my appreciation for the proposed continuation of the program, I want to note the importance of including the following groups in the coordinated caregiving waiver service: (1) Specifically, families serving as long-term/permanent CPS kinship placements (who are not receiving supplemental income to incentivize their participation) should be INCLUDED in the waiver service. I don't see a specific exclusion for this group, but with the exclusion of foster care families, I wanted to ensure that this group is recognized as separate. (2) Also, I would like to ensure that single parents with legal guardianship of adult children over 18 in the CAPC program are able to participate. Exclusion of this group would further challenge an extremely vulnerable subset of the CAPC population, who would benefit the most from this waiver service. Moreover, often the other parent is non-participatory/not living, and in some situations, there is past domestic violence complicating the family dynamic, and only one parent can serve as caregiver and legal guardian safely.

NC Medicaid proposed action to the comment: No changes will be made to the waiver application. The newly proposed service, Coordinated Caregiving, provides a stipend to a qualifying live-in relative or legally responsible person.
Public comment: The state has said previously it intends to pay all eligible parents providing care moving forward but language in the application indicates parents can be paid under each individual service which would pay more than coordinated caregiving, so why would someone choose this? None of the individual services ever mention coordinated caregiving.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application. The newly proposed service, Coordinated Caregiving, provides a stipend to a qualifying live-in relative or legally responsible person.
Public comment: Parents as paid caregivers: I think this is a wonderful option to allow for families. Many families live in very rural areas, and it is a struggle to find care. It is my understanding that with the new waiver, it is being proposed that parents of RN/LPN level children would have the option to hire their own nurses. I think that is a great option also, as nurses would likely be able to get paid at a higher rate this way vs. working through a nursing agency. I have many nurse friends and they voice to me that is one of the reasons they do not want to work home-health, the lower pay. It is also my understanding that it is being proposed that parents can be paid caregivers of their nurse-level child, but only if the parent is a RN/LPN themselves. I think it should be considered to allow non-nurse parents to be paid caregivers of the nurse-level children also. In the majority of cases, the parents are so much more knowledgeable about their child's care than nurses. They can also identify when something is going downhill with their child quicker than someone else can. I am a RN. And if my child's level of care changes to nurse level in the future, then that would allow me the flexibility to be a paid caregiver for her. But with my nursing experience, I have minimal trach experience and absolutely no ventilator experience due to the areas in which I worked. But there are many children in CAPC who have trachs, use vents, receive IV fluids/TPN, etc. and their parents are more knowledgeable about those things than most nurses, as most nurses would only have experience in those things depending on the areas in which they have worked. So, you will allow a parent of a trach/vent child to hire and train their own nurses, but not allow them to be paid? I could understand maybe not paying them at a rate equal to that of a nurse, but I think it should at least be an option.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application. To ensure the health and well-being of a child evaluated to need skill-level care, the CAP waiver will permit a nurse to work independently, with no oversight by a Home Health agency, when qualifying conditions are met.
Public comment: Why is a parent/guardian required to be an RN/LPN in order to be a paid caregiver if their child is nurse level, but a parent/guardian of a child at a lower level of care is not required to be a CNA or PNA? The state already acknowledges that parents/guardians must be fully trained in their child's care since nursing is not approved for 24 hours each day, and we are expected to provide care when nursing is not available for any reason.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application. To ensure the health and well-being of a child evaluated to need skill-level care, the CAP waiver will permit a nurse to work independently, with no oversight by a Home Health agency, when qualifying conditions are met.
Public comment: As a taxpayer in NC, I have major concerns about the CAPC changes. Please reconsider making the coordinated care giver livable income.

Under the proposed changes for the CAPC Waiver, it is currently listed as is a daily rate, that is not livable income. In many areas of the state, it is extremely hard to find a willing nurse to hire AND harder to keep them. This makes the coordinated care givers position the only option for a LOT of families. A livable income wage would insure stability for the patients and the families.
NC Medicaid proposed action to the comment: No changes to the waiver application will be made. The rate for coordinated caregiving was evaluated and in-line with other Medicaid services.
Public comment: To Whom it May Concern. I am the parent of a child in the CAP-C program. We currently use CD Lite, and my husband is the caregiver for my daughter. This has allowed our family the opportunity to have a parent caring for our daughter rather than a stranger. It has also taken the burden of trying to find quality care off of us. I recently read over the new waiver proposal and saw that the parent caregiver rate was going to be dropped to minimum wage for a 40-hour week. I would urge you to please keep the pay rates at least where they are currently and would strongly recommend raising them. With this significant drop in pay our family will no longer be able to afford having a parent caregiver for our daughter. If my husband has to go back to work, we will likely end up needing more than 40 hours a week of coverage for our daughter. I assume this was a cost-saving measure. I feel like this move will discourage parent caregivers and encourage people to hire outside staff and go back to work themselves.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application. Newly proposed services in the waiver permit a legally responsible person to be the paid caregiver when extraordinary circumstances are met. The rate for coordinated caregiving was evaluated and n-line with other Medicaid services.
2 Public comments: I would like to express my concerns with the proposed changes to the program. Going from 20 hours a week to 10 hours a week is hard enough on families, including mine. Adding the cutting of half of the income on top of it is detrimental to the well-being of the families you look to provide services and care for. $90 a week is not a sustainable living wage. This proposed change will cause families extra stress and undue burdens. It will cause families to decide between the main "bread winner" working a second job and never seeing the family they provide and protect, or cause parents like myself to have to go and look for a job and risk exposure of covid and other germs to a medically needy child. If I was to hypothetically look for a full-time job it would add multiple factors such as a nurse, risk of sickness to my son being in school full-time, finding an employer who would willingly let me leave if one of my two children got sick, amongst other concerns/issues. This is not an idealistic solution. If the parent/caretaker has no way of working it can cause risk of a place to live, utilities, heat, and food amongst other potential undue hardships. With the potential of another variant coming out with Covid, along with the upcoming cold temperatures and increased sickness for everyone I respectfully ask that you reconsider this proposal until the economy is back to normal and more stabilized. With inflation increasing to unsustainable levels and the increased cost of living, including gas prices and cost to heat a home in the coming months, along with the problems financially it could cause across the nation, adding hardship to families is unfathomable. Most other states have made positions like mine full-time understanding the need for a parent to care for their child. The state is to provide care/help for those in need, cutting hours and salaries in half is counter to this message. Families shouldn't

have to choose between paying bills and putting food on the table. Most government programs are still providing maximum benefits to recipients for these reasons. I believe this program should continue as currently formatted.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application.
Public comment: Overall, we need to support the well-being of the families to be able to provide care for their children, no matter the cost. Families did not ask for children needing skilled level care but are subjected to a system that is not designed to help them. We need to look at flexibility for parents, family members, friends, etc. Building a system that supports the family as a whole will make an impact that will save lives now and money further down the road.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application.
Waiver Category – Waiver services: Goods and Services/Modification/Training/Equipment/Supplies/Community Integration
2 Public comments: Portable generators should not be limited only to children who are dependent on ventilators. There are other medical conditions that require electricity for the safety and health of CAP-C beneficiaries. For example, my daughter is dependent upon a feeding pump to deliver her nutrition 24 hours per day. She cannot tolerate gravity feeds right now. DME companies will not provide us a backup pump, and the feeding pumps do not have replaceable batteries. While they are rechargeable, they obviously need electricity to recharge. She also needs many medications kept cold in the refrigerator that she takes multiple times each day. And she is extremely sensitive to heat and is at high risk for dehydration due to her short gut and the inability to adequately absorb nutrients. Without electricity, she would end up hospitalized. See pgs. 109-110. The need for less restrictions surrounding eligibility for a portable generator was raised repeatedly during stakeholder meetings over the past few years. There are other medical conditions that require electricity for the safety and health of CAP-C beneficiaries. For example, some children are dependent upon a feeding pump to deliver nutrition 24 hours per day.
NC Medicaid proposed action to comment: No changes will be made to the waiver application. NC Medicaid will conduct a study after the execution of the new waiver cycle to make decisions to expand the definition of the portable generator.
Public comment: Health supplements, vitamins, etc. should remain covered items under Participant Goods & Services. Although discussion implies that this service is still included, Pg 115 states that these services are not approved in the waiver renewal.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application. Health supplements and vitamins are covered when medically identified through a waiver service called nutritional services.
Public comment: Non-Medical Transportation: Does the CME need to submit and obtain an approved POC from DHB to authorize this service just as you would a home or vehicle modification? It does not appear so in the policy just that the CME verify the need “The type, frequency of tasks and number of hours per day of this CAP service is authorized by the case management entity based on medical necessity of the CAP beneficiary, caregiver availability, budget limits and other available resources.” This need to be clear that DHB must approve the hours prior to authorization or does the CME now have the authority to approve hours? “• The coverage of a tablet or smartphone for identified waiver participants to promote telephonic/electronic engagements with service providers for telehealth, monitoring, and linkage and is restricted to individuals who do not have access to tablets or smartphones through the state plan. Coverage of data plan to operationalize the smart device. Coverage is approved based on

financial need and when determined a necessary." What qualifies as financial need? What documentation would be needed to confirm this? How will this be billed? Will the phone be in the CME's name, or the family and the CME reimburses the family for charges? Can it be replaced If lost or stolen? There is a lot of room for fraud and misuse here. A phone and a plan are well over the 800 limit and will fit the "Items that meet the definition exclusions for general utility to non-disabled individuals" category.
Participant services for supplements and transportation. Will the "retail vendor" have to bill directly for this since it state the CME cannot provide the service? What vendors are able to do so? Will they have access to eCAP to obtain the SA's
Pest eradication "The cost of this service shall not exceed $1600.00 per waiver participant (July-June); $800.00 maximum for each fiscal year." Please confirm how much is allowed? Is it 1600 or 800?
Training and education "This service will advance the cost of CPR classes for the direct care worker to assist the direct care worker become financially stable. The cost for the CPR class will be deducted from the direct care worker's wages." Is this all coordinated by the FMA?

NC Medicaid proposed action to the comment: No changes will be made to the waiver application.

Public comment: Adaptive tricycles: The budget for this service is adequate for a smaller child, but a trike for a larger child (teen/young adult) often costs more than the current allotted amount. I think the budget for this service should be increased to account for this.

NC Medicaid proposed action to the comment: No changes will be made to the waiver application. The budget allocation for this service was developed utilizing a cost neutrality projection methodology.

Public comment: Participant Goods and Services: Can you please consider adding incontinence wipes to this category. My daughter is unable to utilize the majority of the items listed in this category, so it is funds that go unused. My daughter is totally incontinent of bowel and bladder and requires the use of incontinence products. Her briefs and bed pads are covered under Medicaid. However, incontinence wipes are not. And these are a necessary item in her daily care, as well as a huge expense. I buy a box of wipes at least monthly. Wipes are utilized in hospital and home health settings. I know that years ago, in those settings and in home settings, wash cloths were used to clean after incontinent episodes, but I feel that with access to wipes, using wash cloths is no longer necessary or sanitary. When using wash cloths, there is the added expense of having to frequently wash them to keep them clean. These are not items that can be washed once weekly, but daily to keep down on the odor and infection control aspect. Not every family has access to a washing machine in their home and must travel to someone else's home or to a laundromat. I think it would be extremely helpful for families to at least have the option to use this waiver service for the purchase of wipes if they feel it is necessary. *Bottom wipers are listed in the current waiver as a covered item under PGS. However, these are not wipes. In a recent discussion, I had some fellow parents of special needs children voice that they thought bottom wipers were incontinence wipes. I had to explain to them that bottom wipers are long-handled devices used to hold a wipe or toilet tissue to help someone wipe themselves, someone who may have limited mobility or range of motion. The bottom wiper is like an extension of their arm and helps them reach around to wipe, reducing/eliminating their need for assistance and increasing their independence with toileting.

NC Medicaid proposed action to the comment: No changes will be made to the waiver application. Incontinence wipes are considered an item of general utility per the glossary section in the 3K-1 CCP, page 129.

Public comment: Wound care supplies: Most of the children we care for have severely limited with mobility and are at risk

for or have pressure injuries. Wound care supplies for prevention and treatment are available only through home health agencies (not DME providers). These agencies, however, will not provide supplies unless they are also providing services, and the majority of agencies will not provide pediatric wound care services. We receive some funding for these supplies through a charitable organization to assist our most financially needy families, but many families resort to paying out of pocket for these Medicaid-covered supplies. o Consider making wound care supplies accessible through case managers in much the same was as home and vehicle modifications; the case manager would
purchase the supplies, provide them to the family, and be reimbursed by Medicaid. Even better, please work with the Medicaid staff for the DME agencies to make the supplies available similar to how diapers and incontinence supplies are available through DMEs.

NC Medicaid proposed action to the comment: No changes will be made to the waiver application. Equipment and supplies covered by Medicaid must be obtained through State Plan services.

Public comment: Expansion of environmental health services
• Mold eradication
o Consider covering mold eradication, perhaps under the home modifications budget as the pest eradication budget in most cases would be insufficient to cover the cost. This is expensive and difficult to find resources for, yet a very real health threat to medically fragile children who often have chronic lung disease with compromised respiratory and immune systems that can contribute to unnecessary and costly acute care utilization (e.g., hospitalizations).

NC Medicaid proposed action to the comment: Comment noted, and recommendation will be evaluated at a later time. Because this recommendation was not provided during the waiver renewal planning sessions, incorporating this request to add mold eradication to the waiver will not be made at this time.

Public comment: Please increase Home Mod/Vehicle mod Budget instead of cutting it. Do not separate out budget in different buckets as a family may need the entire budget for a home mod but no need for vehicle mod.

NC Medicaid proposed action to the comment: The modification budget for this waiver was conducted using a cost neutrality methodology process. No changes will be made to the waiver application.

Public comment: In regard to home modifications, I see that replacement of certain items has been added to the proposed waiver, like light fixtures, etc. I would like to see this specifically include vanities. I know of several instances where a family had a bathroom modification and in order to allow for enough room for wheelchair/shower chair access, the existing vanity had to be removed and replaced with a smaller one. The request for a smaller vanity was denied due to it not being of use to the CAPC beneficiary. My daughter is unable to utilize the sink. So, if we proceeded with a bathroom modification and the vanity had to be replaced with a smaller one, that would be an out-of-pocket expense for us. A pedestal sink would be of no use to my daughter. The current vanity in her bathroom is used for storage of her supplies. I just feel that if the contractor states that in order to complete the modification, the current vanity needs to be replaced with a smaller one, then it should be approved.

NC Medicaid proposed action to the comment: Replacement of fixtures and other items during a modification may be approved based on the design summary of the construction. No changes will be made to the waiver application.

Public comment: Because there is a lack of vendors who have the ability to make construction appropriate modifications to an existing home it would be helpful to add an option for a family to hire a licensed contractor/vendor to make an approved modification. This will help expedite the modification process and giving families the necessary safe adjustments as needed.
NC Medicaid proposed action to the comment: The requirements and limitations in the waiver application do not restrict the vendor qualified to render a modification service. No changes will be made to the waiver application.
Public comment: In regard to home modifications, two emergency exits should be fully handicapped accessible for the child if the parent feels that it is necessary. For example, a ramp at two entrances/exits of the home. If a fire were to occur in/near one exit, the other would be an option for exit. This could mean the difference between life or death for a CAPC child if a ramp only existed at one exit.
NC Medicaid proposed to action to the comment: Medicaid does not reimburse services that are considered duplicative. Approving two ramps in the home would be viewed as a duplicative service. An emergency plan is required for all waiver participants to outline steps to take during an emergency. No changes will be made to the waiver application.
Public comment: Requests requiring submission to Medicaid/EPSDT first before allowing the request to be considered under CAPC (like under Participant Goods and Services) - I think this should include some flexibility. It is proving to be more and more difficult to find DMEs, etc. willing to go through the process of submitting the paperwork to Medicaid/EPSDT for items that they already know are not covered. It's been explained to me by a couple of DMEs that it's due to them not getting enough reimbursement to cover the leg work they put into the request, which I understand. I think requests should be allowed, but maybe with documentation that case manager/family was unable to locate a provider willing to submit the request.
NC Medicaid proposed action to the comment: Medicaid beneficiaries under 21 must receive an EPSDT evaluation for all service requests, a federal mandate. All services available through traditional Medicaid and determined medically necessary must be obtained through traditional Medicaid, known as State Plan. Payment through the waiver for State Plan services is not reimbursable. No changes will be made to the waiver application.
Public comment: Please review this policy, this is absurd as any EMS Worker would walk on foot to care for those in need. Driving surfaces when existing driving surfaces leading to the primary private residence pose an access to care issue to the beneficiary with documented gaps in service provision or documented inability to render emergency services contributing to impassable path
NC Medicaid proposed action to the comment: No changes to the waiver application will be made.
Public comment: Hypertonic saline nebulized treatments Most of our children also have chronic lung disease. Many require hypertonic saline nebulizer treatments, 3% or 7% saline, that thin secretions and stimulate coughs used in addition to their chest PT vests and cough assist machines. However, these treatments are not typically covered. Consider covering hypertonic saline treatments through the waiver – perhaps in the same category as the nutritional supplements that are already covered?
NC Medicaid proposed action to the comment: All services available through Medicaid determined to be medically necessary must be obtained through traditional Medicaid, known as State Plan. Payment through a waiver for State Plan Medicaid services is not reimbursable. No changes will be made to the waiver application.
Public comment: Community integration

• To what degree – if any – will resources be provided to identify and address unmet health-related social needs when children/families are experiencing adverse social determinants of health (e.g.., housing/food insecurity)?

NC Medicaid proposed action to the comment: Services available in the waiver application address the social determination of health, such as participant goods and services, home modification, training, education and consultation, and community integration. No changes will be made to the waiver application.

Waiver Category: New waiver service Nurse Attendant Care (Nursing)

3 Public comment: Private duty nursing (PDN) is where providers deliver homecare services to a variety of different complex patient populations including many children, medically fragile, permanently disabled and wheelchair-bound patients who require extended or continuous care with treatments utilizing assistive equipment such as ventilators, tracheostomies, feeding tubes, and oxygen administration. The alternative treatment setting for many PDN patients is often a hospital, subacute facility, or other institution that can frequently be located a long distance from the patient's home and family support. PDN offers a higher quality, more comfortable and cost-effective option than treatment through a long-term hospitalization or skilled rehabilitation center coupled with the supervisory supports and structure to ensure a high quality of patient care.

While PDN is one-on-one nursing, current law requires the continuous supervision of care by a registered nurse (RN) and oversight of an HCA to ensure the safety of the patient and provide the necessary supports to the nurse while delivery acute care to the patient. Without this framework, we fear the quality of care to the patient will not be overseen and there is risk to the patient as well as the nurse. Consumer directed services are a great option for ensuring access to unskilled services and activities of daily living and should not be treated the same as skilled health care services such as PDN.

Allowing PDN care without proper supervision of nurses, oversight of HCA jeopardizes the validity of home and community-based services (HCBS) and violates the North Carolina Nurse Practice Act under 21 NCAC 36 .0224, requiring "Managing the delivery of nursing care through the on-going supervision, teaching, and evaluation of nursing personnel shall be the responsibility of the registered nurse, as specified in the legal definition of the practice of nursing…" Current law requires the RN supervisor to be continuously available to the staff and clients the RN is supervising and available to go on-site when necessary.

NC Medicaid proposed action to the comment: Directing one's care using a consumer direction model is permissible for individuals needing skilled intervention through the waiver. The proposed service does not violate the Nurse Practice Act. No changes will be made to the waiver application.

Public comment: Page 93, Appendix C-1 "Upon requesting a waiver participant to change their care from private duty nursing to attendant nurse care through consumer-directed services, the PDN provider agency must notify the assigned waiver case manager to collaboratively work together to create a transition plan, including the transition date for waiver participant." As a social worker/human service professional, I'm not sure if I'm qualified to recommend or create a transition plan for a beneficiary requiring nursing services.

NC Medicaid proposed action to the comment: The waiver application assigns a case manager to assess, care plan, monitor, refer and follow up. One core responsibility of the case manager is facilitating smooth transitions for waiver participants. No changes will be made to the waiver application.
Public comment: Currently, PDN providers are responsible for providing training and ensuring competency of any family/caregivers that will be expected to assume care from a PDN nurse. The proposed waiver renewal of Attendant Care Nurses does not provide sufficient details to ensure the same assurances. Families will need to consider how nurse callouts will be handled, as many PDN providers will likely not agree to provide "back-up" nursing. Doing so would be a financial risk for PDN providers as the requirements outlined in the state plan would be no different when only providing care on a per diem basis. In addition, consideration should be given as to how a hired live-in caregiver will ensure hours typically provided by the family are covered. Recommendation: Clinical policy for consumer direction of Attendant Care Nurse should include specific language or guidelines for Attendant Care Nurse to ensure any person who assume care of the waiver recipient when the Attendant Care Nurse as unplanned absences is appropriately trained.
NC Medicaid proposed action to the comment: The waiver application will be updated to include any person who assumes care as the Nurse Attendant in the absence of the regularly hired worker must be appropriately trained.
Public comment: Currently, transportation by a nurse is not allowed under the PDN state plan. We are concerned that the waiver application is allowing an Attendant Care Nurse under consumer direction to transport the waiver participant without requiring a primary caregiver and creating a safety risk. Eligibility for Nurse Attendant Care requires the waiver beneficiary to have substantial, complex, and continuous nursing needs. Transportation of a medically fragile recipient (specifically, but not limited to those requiring airway interventions – trach, trach/vent) is unsafe for one individual. Families are instructed by their medical providers that safe transportation includes a driver and a caregiver. If the nurse is transporting the waiver participant and the primary caregiver this would be considered a custodial service and not reimbursable as outlined in the PDN state plan. Recommendation: Align transportation requirements based on sound-medical practice and judgement. Do not create one standard under PDN and another under consumer direction.
NC Medicaid proposed action to the comment: The consumer direction model permits the waiver participant to direct care in the manner they choose. However, all safety considerations must be planned and clearly articulated in the service plan for waiver participants approved to direct care who have skilled needs. No changes will be made to the waiver application.
Public comment: We agree that care coordination at transition is critical to ensure no gap in service. When a recipient is approved for the PDN state plan services, the physician deems the client appropriate for the nursing services in the home and writes a letter of medical necessity and/or the NC DMA Physician's Request Form for Private Duty Nursing (DMA3075). We recommend a formal collaboration with the Primary Care Physician (PCP), current home care agency and family to determine appropriateness for consumer direction. Not doing so will jeopardize the quality of care for the client.

Also, we ask that consideration be given when a recipient is receiving nursing care through Managed Medicaid and wishes to move to CAP/C consumer directed (or vice versa) so that no gap in service occurs. Recommendation: Include a provision where the PCP must evaluate and deem the waiver participant appropriate for consumer direction of skilled care. It should be more than simply checking a box.
NC Medicaid proposed action to the comment: Before a waiver participant can transition to Nurse Attendant Care, the family must consult with the primary care provider or nurse to discuss care needs and the full medical needs of the child to create a care plan. No changes to the waiver application will be made.
Public comment: Attendant Nurse-care states: "Upon requesting a waiver participant to change their care from PDN to attendant nurse care through consumer-directed services, the PDN provider...must submit a request to end-date the prior approval for PDN services consistent with the transition plan." and "A live-in family member hired to render the care cannot be paid more than 40 hours per week." ****The idea that a family member gets paid 40 hours per week for the care that was provided by outside nurses for up to 112 hours/week will strain the family further than already happening. Yes, the caregiver will have income, but no other respite or care options will be offered to the families. **Many families suffer financial constraints due to inability to maintain employment due to lack of consistent staff - and then parents are threatened with less nursing hours per week because they aren't working outside the home yet will never have enough nurses to cover their hours. Allowing a family member to be able to make money to do work that they are already doing, lessening the amount of outside nurses need to cover that patient, all facilitate the end goal of more nurses for patients at need and more families living in a functional place. Recommendation: allow a mixture of paid parents who are licensed RN/LPN, consumer-direct nurses, and nursing agencies to fulfill the weekly allotment of hours.
NC Medicaid proposed action to the comment: The family will receive support about the option of waiver services to best meet their family's needs. No change will be made to the waiver application.
Public comment: **Inconsistencies for parents to not be required to be CNAs or PNAs if their child is aide level to be paid to care for their children but they are required to be RN/LPN if their child is nurse level. Nursing care isn't approved for 24 hrs. in a day so parents/legal guardians are expected to be fully trained caregivers for the other hours not provided, whether they have an RN/LPN license or not so the state is acknowledging they are capable of doing the work. Would you please review these inconsistencies.
NC Medicaid proposed action to the comment: To ensure the health and well-being of a waiver participant who requires skill intervention, a licensed nurse must be hired to render the care. This person is expected to make quick judgments during a crisis or unexpected/unusual event. No changes will be made to the waiver application.
Public comment: Why is a parent/guardian required to be an RN/LPN in order to be a paid caregiver if their child is nurse level, but a parent/guardian of a child at a lower level of care is not required to be a CNA or PNA? The state already acknowledges that parents/guardians must be fully trained in their child's care since nursing is not approved for 24 hours each day, and we are expected to provide care when nursing is not available for any reason.

NC Medicaid proposed action to the comment: To ensure the health and well-being of a waiver participant who requires skill intervention, a licensed nurse must be hired to render the care. This person is expected to make quick clinical assessments and take appropriate action during a crisis or unexpected/unusual event. No changes will be made to the waiver application.
Public comment: Attached is the most recent survey our organization conducted with PDN families. As you can see, our state has failed to improve services for nurse level of care families. While the addition of consumer direction will help some families who have the capacity to manage this service and the access to qualified nurses, the strict qualifications necessary for a nurse to act in this role and the prevention of family's members who aren't licensed from being paid caregivers make this exceedingly limiting to access and not likely to make a significant impact to the huge crisis in lack of skilled caregivers. We suggest reconsideration of nurse qualifications as well as parents as paid caregivers for nurse level of care children when physician form is completed stating parent is fully trained and capable of providing care. There could even be nursing oversight if safety concerns existed. It is noteworthy that, in the survey, over 50% of parents expressed concerns with some of their PDN nurses being able to provide safe and appropriate care for their children. And, safety concerns were brought up, they were often not addressed appropriately. We can't cite safety concerns as the reason to keep parents from being paid to provide care for their children when the state expects the parents to provide care for the hours, they haven't approved nursing and/or when that nursing doesn't show up.
NC Medicaid proposed action to the comment: To ensure the health and well-being of a waiver participant who requires skill intervention, a licensed nurse must be hired to render the care. This person is expected to make quick clinical assessments and take appropriate action during a crisis or unexpected/unusual event. No changes will be made to the waiver application.
Public comment: §90-171.20 of the Nurse Practice Act governs what is allowable for an RN and LPN. More clearly define supervision of the LPN, i.e.- how often this will be completed and how supervision will be documented. In addition, identify the reporting process when the supervising RN has clinical concerns regarding the care being provided by the LPN attendant nurse. We are concerned with the provision that indicates that the scope, nature, and supervision of an Attendant Care Nurse is different from what is required from PDN under the state plan. We agree that BON governs the scope of practice for LPNs and RNs. The self-directed model should not be excluded from working within the BON requirements, for not only does it create two standards, but also puts the waiver participant at risk. Allowing a non-medical individual to competency verify a licensed medical professional is worrisome. While the consumer is said to assume all risk, ultimately Medicaid is responsible and liable as state funds were used to cover the services. Please ensure compliance with clinical standards of practice for health and safety of waiver recipient and to protect the licensed professional. Recommendation: Specifically detail the supervision requirements of an LPN by a RN as outlined by the NCBON.
NC Medicaid proposed action to the comment: Directing one's care using a consumer direction model is permissible for individuals needing skilled intervention through the waiver. The proposed service does not violate the Nurse Practice Act. No changes will be made to the waiver application.
Public comment: We support a process included in the waiver application to confirm the Attendant Care Nurse has the needed experience to work with medically fragile individuals. However, we do not believe this process is detailed enough to outline the requirements.

Recommendation: Expand the competency verification process to outline who will confirm this experience and by what method (copies of pay stubs, letters from previous supervisors, etc.). We urge that clinical competency be completed by a clinical professional to ensure the health and safety of the waiver participants.
NC Medicaid proposed action to the comment: The financial management agency will verify hiring requirements are met. No changes to the waiver application will be made.
Public comment: Given that the state does not allow for 24-hour nursing care for Cap/C children, the state is acknowledging that parents have the skills to be a care provider for their child. Parents therefore should be allowed to be a paid caregiver for the hours they are covering. Family members should be able to bill for the hours that they cannot staff at a bare minimum, especially given that agencies are having such a difficult time staffing the cases. But they should also be allowed to bill for the hours they are not allowed to staff nursing and have to provide care because Medicaid will not allow children to be staffed 24 hours a day. So PDN families should either be allowed to staff 24 hours a day because the state does not believe they can provide an appropriate level of care for their child without having an RN/LPN degree. Or Medicaid should allow trained family members to be a paid caregiver for their child for 20-40 weeks each week.
NC Medicaid proposed action to the comment: Service plans are person-centered and are intended to meet the needs of the waiver participant and their family. Waiver services are only intended to replace the primary caregiver's caregiving tasks temporarily. No changes will be made to the waiver application.
Public comment: When a Licensed Practical Nurse (LPN) is recruited and hired, a Registered Nurse must be contracted to provide guidance and supervision to the LPN." Is this a Medicaid service or will the family have to pay out of pocket for this. Who is supervising the nurses in the home the parent? Are the parents and the employee responsible for developing and obtaining a signed 485? If no 485 is needed, then are the nurse practicing and providing care without orders? How is that possible? Who is responsible for confirming the RN's required experience? The parent/employer?
NC Medicaid proposed action to the comment: To comply with the Nurse Practice Act, an RN must supervise an LPN. Under this model of care, the employer of record will be responsible for paying the nurse supervisor. The negotiated pay for supervision will come out of the waiver participant's budget. The financial management entity will submit claims to Medicaid based on the service plan to pay the LPN and RN. A signed 485 will not be used, but a waiver consumer direction document must be completed in collaboration with the primary physician or designated personnel at that office. No changes to the waiver application will be made.
Public comment: We applaud the proposed provision to ensure a trained and competent worker under consumer direction. However, because in most instances primary caregivers/parents are not clinicians we recommend a clinician be involved with the competency verification of the Attendant Nurse. This is particularly important for waiver beneficiaries who require a tracheostomy/mechanical ventilation. For example: nurses working in a hospital rely on respiratory therapist to assist with management of the tracheostomy and mechanical ventilation. Additionally, we recommend safeguards be put into place that will ensure the PCP directs and orders all nurse care versus the parents/primary caregiver.

Recommendation: 1) Detailed guidelines for who and how competency verification be completed. And those tasks that require the skills of a nurse be verified by a clinical professional under their scope of practice. 2) Provision to ensure physician involvement is critical as the primary care professional directing and overseeing the health and welfare of the waiver recipient.
NC Medicaid proposed action to the comment: There is a detailed process of how the waiver participant/primary caregiver must work collaboratively with the physician or designated personnel at the office to initiate consumer direction for a waiver participant who needs skilled medical intervention. No changes to the waiver application will be made.
Public comment: Required experience for CD nursing: 1000 to 2000 hours of experience in x amount of time in an acute care hospital caring for individuals with the care need(s) of individuals at the levels of care specified in the waiver. **this would require, for the most part, NICU/PICU level nurses, which many do not have the experience home care nurses have because of the large pool of resources available to them in the hospital setting and the differentiation of all tasks to specific providers. Also, new graduate nurses make up a large portion of incoming home health nurses. None of these nurses would be eligible under this required experience to work at a CD skilled case.
NC Medicaid proposed action to the comment: To ensure the health and well-being of a waiver participant who requires skill intervention, a licensed nurse with extensive experience must be hired to render the care. This person will work independently without supervision and have the capacity to make quick assessments and take appropriate action during a crisis or unexpected/unusual event. The waiver application will be updated to state specific training in the area of assessed need.
Public comment: Is my understanding correct regarding the changes that we, as parents of trached children, will now be eligible to hire our own nurses (LPN and RN)? If so, how will that work? How are the nurses going to be able to chart? What is the compensation? What about liability? Etc.
NC Medicaid proposed action to the comment: This waiver application proposes adding a new service to allow children who require skill intervention to direct their care by hiring their preferred RN or LPN. All required conditions must be met, including collaboration with the primary caregiver to assist in creating a care plan. No changes to the waiver application will be made.
Public comment: Education of Primary Care Physician (PCP) Under the agency-model, PCPs rely on the professionalism and clinical expertise of the infrastructure surrounding care delivery of a licensed and an accredited provider of services. We recommend education to be provided to physicians who order care to PDN clients regarding the proposed consumer directed care option for complex care recipients under the Attendant Care Nurse. It is important for the PCP agree with the appropriateness for individual beneficiaries to elect the consumer directed model. Recommendation: Expand the eligibility process for consumer direction for Attendant Care Nurse to ensure that PCP has determined that the waiver participant is appropriate for self-direction; and there is an established process for physician orders and nursing oversight, especially when the Attendant Care Nurse is an LPN. Waiver recipients who attend school through a school district contract Local school districts contract with licensed and accredited PDN providers to provide nursing at school. Oftentimes, the nurse who provides care at school is also the home nurse. This provides continuity of care when the recipient unexpectedly does not go to school (sickness, medical appointments, etc.). Consideration should be given as to if school districts will contract with an

independent consumer-hired Attendant Care Nurse (who may or may not have their own personal liability/malpractice insurance) on an individual basis instead of an accredited PDN provider. While we agree that continuity of care is important, school districts may be concerned with risk. Recommendation: Outline specific steps for how consumer direction will operate when a child goes to school and ensure the school districts are made aware that this Attendant Care Nurse model is not under a licensed and accredited agency-model, but under consumer direction. Personal liability/malpractice insurance Under the agency-model, licensed nurses are covered under liability and malpractice insurance of the agency. Given that these individuals are medically complex and require clinical assessment and interventions, it would be prudent for the Attendant Care Nurse to hold personal liability/malpractice insurance policy. Recommendation: The care advisor should include talking points for the Attendant Care Nurse regarding personal liability/malpractice insurance. Non-routine, billable medical supplies PDN providers order non-routine medical supplies and bill them to Medicaid using HCPC codes. Examples include dressings and gauze, trach supplies, ostomy supplies, etc. Will Attendant Care Nurses need to become an approved Medicaid provider so that the ordering and billing of non-routine supplies can continue, or will the consumer take responsibility of procuring and billing for non-routine supplies? Recommendation: Outline specific steps in the consumer direction model for how routine and non-routine supplies are to be handled and include the number and frequency of what is allowed as consistent with state plan.
NC Medicaid proposed action to the comment: This waiver application proposes adding a new service to allow children/families who require skill intervention to direct their care by hiring their preferred RN or LPN. The primary caregiver assumes full responsibility for their decision to direct care. All required conditions must be met, which includes collaboration with the primary caregiver to assist in creating a care plan. The waiver participant will continue to receive medical supplies and equipment through State Plan services. No changes to the waiver application will be made.
Public comment: I truly appreciate your consideration. Many of my recommendations come from a deep knowledge of national nurse level waivers, being an RN, and being a caregiver for our son for the past 6 years. I'm hopeful that help is on the way for nurse level families
NC Medicaid proposed action to the comment: No changes will be made to the waiver application.
Waiver Category – Appendix D - Service Plan
Public comment: "An assessment will be conducted on a quarterly basis to assess average cost of care needs. When average cost of care needs are 75% of the average at two consecutive quarters, NC Medicaid will work with the family and the case manager to assess the appropriateness of waiver services, to identify alterative resources to augment expenditures. When cost of

care needs are 100% of the average cost, arrangements must be made to access appropriateness of waiver participation to assure cost neutrality of service provision. If an adverse decision is made, the waiver participant is granted an appeal." Will NC Medicaid be completing the cost assessments and notifying the CME's ?
NC Medicaid proposed action to the comment: A cost assessment will be conducted quarterly. Notification will be provided when identified.
Public comment: The service plan must be completed and approved by the 5th day of the anniversary month for an active waiver participant and within 30 calendar days of the home visit to complete the comprehensive assessment for new individuals entering the waiver. Is it reasonable to expect same day approvals from DHB now if they need to be completed and approved by the 5 days ? Typically, they just need to be submitted by the 5th day. It then contradicts itself by saying " The annual service plan must be approved by the end of a month to have an effective date to start the first day of a given month. "If an unexpected situation occurs, the waiver participant has the autonomy to utilize unauthorized waiver services by notifying the care advisor and financial management agency. The care advisor, the FI, and the CAP Business system must be notified by the employer of record and the waiver participant within 24 hours of the unauthorized service. If the service was a short-term intensive intervention, the service plan would not be updated. The care advisor would give written approval to the financial manager to reimburse the one-time short-intensive service, and the CAP Business system will send a prior approval record to NCTracks for approval of reimbursement. If the service is ongoing, the service plan and service authorizations must be updated and disseminated to all authorized providers. The care advisor would update the service plan and notify providers." How does the Care advisor have the authority to approve anything? If the service plan does not have to be updated, then how is VieBridge able to send a PA? Is there a limit to how many" unexpected situations" a family can claim? How is this different than using respite?
NC Medicaid proposed action to the comment: This comment is a process question and guidance will be provided in the waiver standard operating procedures. No changes will be made to the waiver application.
Public comment: Page 144, Appendix C-2 "The assigned case management entity will perform weekly contacts to include monthly in-person monitoring visits to ensure the services are provided in accordance with the service plan and the waiver participation business requirements, when the waiver participant elects to enroll in self-directed care." My interpretation of this section is that parents can now enroll as a coordinated caregiver or self-directed care and if they are enrolled in self-directed then I will have to make weekly contacts and monthly visits in the home. Is this correct? I think that's going to be a lot to manage as case managers. Page 176, "A home visit to be conducted at least quarterly. ….must have face to face visit as indicated per risk and monthly multidisciplinary team meeting". Is this saying that we will be required to complete home visits but the only time they're required to be in person is if there are high risks? On page 177, it's confusing because it refers face to face as "Facetime, Skype, Video chat" but then gives an example of a face to face executed during the first visit, then the 2nd visit can be conducted through technology.
NC Medicaid proposed action to the comment: This comment is a process question and guidance will be provided in the waiver standard operating procedure. No changes will be made to the waiver application.
Public comment: The multiple transition pathways (from CAP/C to another program) are individualized and complicated. Role requirements of the care managers specifically regarding transition are recommended to be included in the waiver proposal. The group proposes six months prior to the "age out" deadline to initiate and focus on transition planning.

• More specificity and clarity about criteria for case management entities is recommended. The group agreed case management expectations should be tightened on the proposal.

NC Medicaid proposed action to the comment: No changes will be made to the waiver application.

Waiver Category – Appendix E - Self-Directed Care

Public comment: Consumer Direct for unlicensed parents. This is a common occurrence now across the country which started during Covid and has now been made permanent nationally in many States. Many unlicensed parents are the sole caregivers of nurse level children due to the chronic shortage. Paying these parents doesn't make things more dangerous, in fact it very well may make things safer as stress would be relieved by having income and being able to pay bills. CAP/C only recipient families require no certifications to be paid caregivers (appendix K and draft waiver), yet nurse level parents are required to be an RN/LPN. States work around this in 2 ways: Some boards of nursing place the nurse practice act aside to allow families members to complete nurse level tasks (they are doing this anyway) and some states will pay families for the aide level tasks as not every task nurse complete is skilled.

NC Medicaid proposed action to the comment: To comply with the NC Board of Nursing, children who are determined to need skill care administered by a nurse must comply with the Nurse Practice Act. No changes will be made to the waiver application.

Public comment: Consumer-directed care: All participants in this waiver are eligible to direct their care using consumer-directed services, including children at a skill level consistent with private duty nursing care.

NC Medicaid proposed action to the comment: This waiver renewal application will permit three care options for waiver beneficiaries and their caregivers. These three options are provider-led, consumer direction, and coordinated caregiving services. No changes will be made to the waiver application.

Public comment: Consumer-directed care

• Would teenaged family members (e.g., 16-year-old older sibling) be eligible to serve as paid in-home caregivers under consumer-directed care?

• Is there information available to clarify why parents/legal guardians would not be eligible to be paid for in-home caregiving (e.g., during hours when a contracted private duty nurse is supposed to work in the home but has to cancel last-minute, thereby leaving the parents as the sole caregiver)?

NC Medicaid proposed action to the comment: Individuals over the age of 18 are eligible to become paid caregivers. A nurse is the approved professional to render services to a waiver participant who qualifies for a nurse level of care. No changes will be made to the waiver application.

Public comment: The group valued the major change to include consumer directed care and praised the use of creative funding to increase the waiver slots.

• Concerns were raised about defining consumer directed care to guide families in understanding their options. Consumer directed care needs more prominence and explanation in the waiver proposal. More use of consistent terminology and outlining the parameters to support the consumer direct care theme is recommended in the waiver proposal

NC Medicaid proposed action to the comment: Consumer-directed care is described in more details in the clinical coverage policy. The federal waiver application uses the term self-direction. The state of NC chooses to refer to this care option as consumer direction. No changes will be made to the waiver application.
Public comment: With any consumer directed care, there is increased opportunity for waste, fraud, and abuse. However, allowing skilled health care services to be provided without supervision or oversight elevates that risk. The proposed expansion to the waiver poses a significant risk to all parties involved and should not move forward as currently drafted.
NC Medicaid proposed action to the comment. Any service has a potential for fraud, waste, and abuse(FWA). There are safeguards and education for the waiver participant and hired employees about FWA. No changes will be made to the waiver application.
Waiver Category – Appendix G – QIS
Public comment: Our consensus is that, overall, the waiver program is stronger and more responsive to clients' needs than it was five years ago. We are grateful for the proposed 50% increase in slots, as well as the flexible approach to per capita limits.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application.
Waiver Category: Appendix H – Health and welfare
Public comment: We agree with the department's recommendation for consistency on compliance and oversight. It is important to ensure the health and welfare of the waiver participant.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application.
Waiver Category- Appendix I and J - Financial Accountability
Public comment: Many don't understand the costs of equipment for older participants of the waiver. Trikes for an example typically cost well under the 3k mark however for older children it they cost well over 3k. How is this fair for older participants to utilize those service. If you are gearing a program for 0-21 then the costs should be equally accessible. Grants are not always available for all that can't afford the remaining costs and to be at a disadvantage is not fair. Trike budgets should be the same as car seats. Would also be expected to train their nurse, we have safety concerns.
NC Medicaid proposed action to the comment: Services in the wavier were evaluated. No changes will be made to the waiver application.
2 Public comments: The fee schedule only indicates one universal rate for non-institutional respite instead of three, one for each level of care. It should be set by level of care as was done in the previous waiver, especially since this section was marked as "no change". For example, there is already a major nursing shortage, especially in homecare. It would be virtually impossible to find quality RN/LPNs who would work for a rate of $28.28/hr.
NC Medicaid proposed action to the comment: The in-home respite care rate is the same for its associated in-home care type . No changes to the rate structure will be made to the waiver application.
Public comment: Coordinated caregiving rates - Caregivers have been forced to give up jobs and careers to stay home with their medically fragile child/children due to lack of available staffing, many of them single parents. We must pay them a living wage. PNA caregivers would make the equivalent of $11.12/hr. assuming a 40-hr. work week and a CNA caregiver would make the

equivalent of $7.34/hr. assuming a 40-hr. work week, which are both below the federal poverty guidelines. The state employee minimum wage of $15/hr. should be the baseline. The General Assembly also recently recommended a $15/hr. minimum.
NC Medicaid proposed action to the comment: The newly proposed service, Coordinated caregiving, is a new service that pays a stipend to a live-in caregiver to support care needs as identified in a service plan. The Session Law encourages but does not mandate a minimum wage rate of $15.00. No change will be made to the waiver application.
2 Public comments: Respite rates need to match nurse level reimbursement which is 45/hour. The waiver states 28/hr. for all CAP/C recipients which doesn't make sense.
NC Medicaid proposed action to the comment: The respite nurse rate is $11.50/15minutes which is equal to the private duty nurse rate listed on the Fee Schedule dated March 1, 2022. No changes will be made to the waiver application.
Public comment: The Department has been open to working with providers and associations to ensure access to care for this medically fragile population. We appreciate your strong past support with both temporary and permanent rate increases under this and other LTSS programs; and your willingness to involve stakeholders. We hope that process will continue as we move into 2023. We urge the Department to undertake a rate modeling methodology to ensure rates are keeping up with the cost of delivering care. Recommendations: 1). Continue to work with both providers and associations. It is important to recognize that not all providers are members of an association, and as such rely on direct communication and notices from the Department of changes. 2). Utilize ARPA funding to undertake an independent rate modeling exercise for home care (personal care and nursing) to capture the cost of delivering care. We would welcome the opportunity to participate in such an exercise.
NC Medicaid proposed action to the comment: Comment noted. No changes to the waiver application will be made.
Public comment: Current PDN services pay a large amount to an agency and then the agency hires a nurse and pays them a portion of that. How is this economically and financially responsible? Yet a parent who does the same exact job cannot get paid to do that job. Paying a parent to do that job changes so much for the family and community. However, it does not line an agency's pocket, it exposes the child to less germs , less errors, and less increase in medical care. Medicaid and the country are aware of the huge nursing shortages. Many PDN families cannot find staff to cover the hours, so they lose income weekly having to stay home and care for their child anyway. Many PDN families have had to go down to an aide level to find coverage and to utilize CD so they can choose qualified people to care for their children. Many had to so they could utilize CDL during this covid crisis
NC Medicaid proposed action to the comment: No changes will be made to the waiver application.
Public comment: We agree with the metrics included in the waiver renewal application under performance measures and quality improvement strategies. It is always important to not only track progress, but also evaluate and inform future direction. We encourage the Department to also track authorized hours verses billed hours as that would help report the strength of the staffing network to identify gaps and weakness in workforce. Recommendation: Report authorized hours verses billed hours.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application.
Public comment: Calculating inflation of 9.3% since the 2021 increase to $45.00 per hour, the PDN rate would need to be $49.30, simply to keep up. • Without reimbursement rates that address inflation and wage disparities between home care, other healthcare setting, and other sectors, providers will continue to face these challenges even as the pandemic subsides.

• 81% of NC Voters feel it is important that people who want to be cared for at home, where they feel safest, have the option to do so. (Source: Morning Consult Poll, April 2022) We appreciate the opportunity to comment on the waiver renewal application. Please direct questions related to our rate request to Lee Dobson, Area Director of Government Affairs at 919-523-2992 or via email at ldobson@bayada.com. Should you have any questions related to our recommendation, my direct line is 336-413-1779.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application.
Public comment: In regard to the proposed changes to the CAPC Waiver, please consider updating the coordinated caregiver pay. It is currently listed as a daily rate. For CNA level of care, the rate is $41.93 per day for year 1. PNA is $63.55 per day. Neither if these rates are a livable income and will make it incredibly hard, if not impossible, for families. Coordinated caregiver is the best option for many families, especially during a nursing shortage, where care is almost impossible to find.
NC Medicaid proposed action to the comment: No changes will be made to the waiver application. The rates included in the waiver application were evaluated.
5 Public comment: Respite - Definition on page 74 includes things that should be approved for STI in order to save respite hours (change in beneficiary's condition resulting in additional or increased medical needs and caregiver crisis such as illness or death in the family). Respite never mentions level of care and fee schedule indicates only one rate for non-institutional respite, not one for each of the three levels of care. Nursing respite will not be possible at a rate of $28.28/hr. Respite rate must be set by level of care as done previously, especially since that section was marked as "no change."
NC Medicaid proposed action to the comment: The rates were evaluated. No changes will be made to the waiver application.