

**Petition to the State Health Coordinating Council for Adjusted Needs
Determination for an Underserved Population (African American) for
Mecklenburg County.**

Petitioner Requesting Adjusted Need Determination

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I. Statement of the Requested Adjustment

Continuum Care Hospice requests an adjustment to the Proposed 2018 SMFP to include a need determination for one additional hospice home care office in Mecklenburg County, specifically organized and staffed to serve African American patients.

Our petition is directed at one aspect of the racial disparities in health care delivery to the African American community, the underutilization of hospice care by African Americans in Mecklenburg County. If this petition is granted, Continuum would submit a CON application to develop a new hospice agency in Mecklenburg County. If approved, our services will not only benefit the lives of this target population, but will also decrease the cost of caring for them. Providing quality hospice care for African Americans will improve the quality of end-of-life care, prolong survival rates while decreasing the number of high-cost hospital admissions and needless aggressive therapeutic care.

II. Reasons for the Proposed Adjustment

Hospice is a holistic model of care for individuals at the end of life that focuses on comfort and palliation of symptoms instead of cure of disease. It is a cost-effective end-of-life care option that provides a high quality of life for dying patients and their loved ones. The goal of hospice is to provide nursing and medical care, as well as spiritual and emotional support. Utilizing compassion and an interdisciplinary

approach, hospice use decreases pain, improves patient and family satisfaction, decreases spiritual distress, offers enhanced bereavement services, and prolongs life. Continuum would like to ensure that all people, to the extent possible, have meaningful access to services that could ease the dying process for them and their families.

Despite the high quality of hospice care, many scholars have noted a significant disparity in hospice utilization by African Americans. Not only do African Americans utilize hospice less than whites but the number of African Americans utilizing hospice is shrinking. In 2013, 8.4 % of patients on hospice were African American, while the African American population represented 13.2% of the total U.S. population. In 2014, only 7.6% of hospice patients were African American, while African Americans constituted 13.2% of the U.S. population.¹ In North Carolina, the total hospice utilization of Medicare beneficiaries in 2014 was 46%. Of those, whites comprised 48.6% and African Americans 35.7 %.² In Mecklenburg County, hospice utilization among Medicare beneficiaries who died in 2014 was 51.5%. Of these, 55% were whites and 42% were African American, a 12.6% disparity.

While the disparity described is not unique to Mecklenburg County, Continuum selected Mecklenburg County for an adjusted need determination petition because there is a greater need for rectifying the disparity in Mecklenburg County than in any other North Carolina county. Mecklenburg County has the largest county population in North Carolina, and also has the largest absolute African American population in North Carolina.

Since 2000, the percentage of white residents has declined, while the percentage of African Americans has increased in Mecklenburg County. According to the North Carolina Office of Budget Management, the Mecklenburg County population as of July 2015 was 1,035,605, of which 339,523, or 32.8% were African Americans. This is comparatively a higher percentage of African Americans to the total population than for North Carolina overall. The Office of Budget Management projects the population of Mecklenburg County to grow to 1,496,762 by July 2036, with 33% being African American. These population projections indicate that by 2036 there will be roughly half a million African Americans in Mecklenburg County who, without a hospice specifically staffed and organized to serve African American patients, are likely to continue to suffer a significant disparity in hospice utilization.

¹ NHPCO/US Census Bureau

² CMS

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Proposed 2018 State Medical Facilities Plan Adjusted Need Determination Continuum Care Hospice

Year	Whites (non-Hispanic)	African- American	American Indian	Asian	2 or More Races
2017	497,529.00	358,663.00	10,268.00	59,375.00	28,216.00
2018	503,041.00	367,681.00	10,692.00	61,322.00	29,451.00
2019	508,761.00	376,435.00	11,106.00	63,225.00	30,660.00
2020	514,043.00	385,480.00	11,529.00	65,181.00	31,891.00
2021	518,686.00	395,098.00	11,971.00	67,238.00	33,172.00

OSBM 5 Yr Projection - Mecklenburg

Therefore, the greatest need for hospice services to the underserved African American community exists in Mecklenburg County. Also Mecklenburg County is well positioned to host a new hospice home agency specifically designed to serve the African American community because it is a large metropolitan area with access to supportive services.

The disparity in hospice utilization between whites and African Americans is even more glaring because one would expect the representation of African American hospice patients to be proportionately higher than those of whites since African Americans suffer inequitably higher rates of three of the leading causes of death in the county. The 2008-2012 age-adjusted rate for all causes of death in Mecklenburg County is 1.4 times greater for African Americans than whites. The three leading causes of death, which are also the most common hospice diagnoses, are cancer, heart disease and stroke.³ According to the Mecklenburg County Community Health Assessment (a survey conducted by the Mecklenburg County Health Department) African Americans have higher mortality rates for nearly every type of cancer, and they also die at higher rates than whites from heart disease, stroke and diabetes. In data from 2008-2012, death rates for African Americans were 1.3 times higher for heart disease and 1.5 times higher for stroke in comparison with whites. Cancer death rates are also higher among African Americans. In comparison with whites, death rates for African Americans are 1.4 times higher for breast cancer, 1.6 times higher for colon cancer and 3.4 times higher for prostate cancer. Yet it is clear that African Americans use hospice care at a far lower rate than whites; as mentioned previously, there was a 12.6 %

³ NHPCO

disparity among Medicare beneficiaries in hospice utilization in Mecklenburg County in 2014. This, despite the fact that 92% of African Americans who use hospice services are satisfied with their care.⁴ Disparities in hospice utilization are disconcerting because large numbers of African American patients die in hospitals and experience long periods of often futile, life-sustaining treatment, insufficient pain management, poor communication with health care providers, and increased health expenditures. These experiences are inconsistent with many African Americans' preferences to die at home, while avoiding life-prolonging treatments with uncomfortable side effects. These experiences are also counter to the mission of hospice care, which is to improve the quality of life for all patients as they near the end of life.

III. SMFP Basic Principles: Quality/Access/Value

A. Access

Continuum Care Hospice has demonstrated great success in providing access to hospice care in the African American community. In the markets we currently serve, Continuum Care Hospice serves double the number of African Americans than the state average or the other hospices in the area. We are, therefore, well positioned to provide increased hospice utilization to the African American community in Mecklenburg County as well. We will employ the same methods that have worked for us to enable the African American community to access the physical, psychological and social benefits that our hospice care offers.

The most commonly cited barrier to hospice use by African Americans is limited knowledge of hospice services, and the absence of communication about hospice care between African American patients and their family members and health care providers. In particular, studies suggest that many African Americans may be unaware of services that are available through hospice and locations where the services are provided. Studies also indicate that many African Americans are unaware of how hospice is paid for, and the role of loved ones in caring for hospice patients. Other studies have noted that African Americans are less likely to have advance health care directives that offer explicit directions regarding

⁴ NHPCO

their end-of-life care preferences.⁵ This is due to the deeply rooted mistrust of the medical system by African Americans, which often underserves this population throughout their lives.

For Continuum, the first step in the Mecklenburg County outreach would consist of overcoming the limited knowledge of hospice services and increasing the communication about hospice care between African Americans and their family members and health care providers. Our staff will educate the community about the benefits of hospice through fostering a sense of trust and open communication between the community and hospice professionals. We will partner with existing organizations and events that are important to the African American community such as the AARP, the local chapter of the NAACP, local organizations for African American professionals, seniors, educators, business leaders, church leaders, academics and students. Continuum will work with local black heritage festivals, community centers, hospital case managers, SNF's, ALF's and other workgroups on "how to talk to people about hospice". We will have targeted health campaigns and workshops not only about hospice care but also about end-of-life care generally. For example, many in the community are not aware of the true meaning of advance care planning, and therefore African Americans are significantly less likely to have advance care directives. Only 35.5% of African Americans have a living will or a DPOA, compared to 67.4% of whites.⁶ Not only will we educate the community about the benefits of advance care directives, we will also work to dispel the distrust about directives being honored by the medical profession, and emphasize the role of the family in decision making. Another concern we will address is the financial aspect, since many in the community refuse to believe that Medicaid, Medicare and most important, private insurance companies cover hospice expenses.

To improve communication and accessibility, we will locate our offices in the neighborhoods of the community that we will service. We will endeavor to dispel the confusion among members of the community surrounding hospice care. Many in the community think of hospice as a place where someone is sent away when their family has abandoned them, and equate it to nursing homes.⁷ Because nursing facilities are viewed negatively, we will emphasize that hospice care is most often provided in a person's home. Hospice staff will emphasize the role of the family, and stress that hospice supports caregivers; it does not replace family members or preclude them from playing a central role in

⁵ Dillon,16.

⁶ American Psychological Association

⁷ African American Outreach Guide 9.

care-giving and decision-making. Hospice alleviates the burden of caregivers by providing help in caring for the patient, thus enhancing the family's role rather than supplanting it.

In summary, to overcome the under-utilization of hospice care by African Americans, Continuum proposes outreach measures to educate members of the African American community about the high quality of hospice care, and to encourage them to access this important resource at the end of life.

B. Quality

Continuum Care Hospice operates with a special emphasis on the quality of patient care. It operates differently from other hospices, and its approach to the care of their patients goes far beyond what other hospices offer. It has a much more personal approach to the care of its patients, spending as much time as needed with each patient and family members. Everyone at Continuum, the nurses, the aides, the social workers, the chaplain -- not only do their medical job with the utmost skill, efficiency and compassion to ease the physical process, but they also provide the maximum emotional and spiritual support and connection that patients and their families crave. They are friends, spiritual guides, therapists and cheerleaders, referred to by one grateful family member as that wonderful "team of angels". Even before a patient formally enters hospice care, Continuum provides the Palliative Care Transition Program, sending a nurse practitioner to the patient's home to familiarize, guide and educate the patient and his family about quality care. After formal admission into Hospice care, each patient is assessed as an individual with his own unique physical, spiritual and emotional needs. A personalized care plan is then designed down to the minutest detail such as, for example, the kind of musical therapy to be provided. Because of the extraordinary quality of care that it provides, Continuum has been selected as one of the few hospices that Kaiser, the largest non-profit health care organization, contracts with to send their patients for hospice services. Please see the attached letter of support from Kaiser.

Continuum provides the highest quality of care for everyone, but has reached out in particular to the African American community with notable success. In its present market, Continuum has successfully addressed several cultural barriers to hospice use that exist in the community, and plans to do the same in Mecklenburg County. For example, studies indicate that African Americans tend to be less comfortable discussing death, more likely to want life-prolonging therapies, and more likely to agree

that those who believe in God should not have to plan for end-of-life care, than Caucasians.⁸ In addition, African American patients place utmost importance on the community and honoring the family; therefore, African American patients value the input of others, especially family members, when making end-of-life care decisions.⁹ Such family-centered values call for a departure from the patient-centered, autonomy-guided, healthcare values predominant in the American healthcare system. African-Americans usually prefer to die at home, but in fact most die in the hospital, perhaps correlating with their preference for more aggressive treatment at the end of life. Their religious and philosophical views of death and dying contribute to the low rate at which African Americans access hospice services. These religious and philosophical views have been shaped by the African American experience with slavery, segregation and racism which resulted in the attitudes and beliefs about advance directives, palliative care and hospice services. Fear and mistrust of the medical establishment seem to be logical outcomes of a century of unethical experimentation and unequal medical care. This mistrust is reinforced and magnified when healthcare providers have culturally discordant backgrounds from their patients, and do not possess the cultural insights and guidance skills to effectively address their patients' concerns. African American professionals experience less difficulty than members of the healthcare professions from other backgrounds in understanding the cultural influences operating on patients of their same racial or ethnic backgrounds. Patients requiring hospice services are more likely to interact with healthcare professional in a meaningful way if they share their own racial or ethnic background. In a recent study, 77% of African American participants said they would be more willing to use hospice if it were more racially diverse.

Continuum has addressed these cultural issues in many ways, and as a result has overcome African American resistance to hospice utilization in its present market. For example, we have African American leadership and our staff consists of diverse professionals with whom our patients identify and who understand the cultural influences operating on patients. As a result, we serve African Americans at more than double the state average and double the other area providers. We plan to use the same approach and expect the same result in Mecklenburg County. These healthcare professional who have the cultural insights to relate to the concerns of the African American community understand the end-of-life issues specific to African American communities, such as the spiritual aspects of care and the

⁸ Alina M. Perez and Kathy L. Cerminara, *La Caja de Pandora: Improving Access to Hospice Care Among Hispanic and African- American Patients*, 10 Hous. J. Health L & Policy, 279-280.

⁹ Perez, 281.

sociological and cultural perspectives on death and dying. We partner with family members and the community to better support African Americans with end-of-life issues so that patients and their families will be better served in a culturally competent way, honoring and respecting their traditions, their faith and the deeply rooted historical issues of most African Americans. We offer to support current caregivers, explaining how the team will care for the family as well as the patient's physical, emotional and spiritual needs. Sometimes a patient's illness is just one part of a bigger, highly complex family system. We emphasize the connected role of faith and medicine, and partner with clergy to educate the community about the resources of hospice, which does not mean the patient must give up faith and hope for healing. And since the members of the Continuum team look like the patients they are serving, speak the same cultural language and are equally aware of the realities of treatment differences, healthcare disparities and basic historical experiences, they are trusted and patients and their families feel comfortable with them.

There are other ways that Continuum has improved the quality of health care in the African American community through increased hospice utilization. By dispelling mistaken notions about the benefits of aggressive end-of-life care, it has encouraged the use of the more dignified and peaceful palliative care.

There are some common misconceptions about end-of-life care, some of which affect the African American community even more than the general population. People with terminal illnesses frequently believe that more therapeutic care, such as tests, procedures and drug therapies, leads to longer life and improved physical well-being. In fact, a growing body of evidence demonstrates that aggressive, hospital-based care at the end of life does not necessarily produce better outcomes; in fact, sometimes less is more. It has been shown that an emphasis on palliative care rather than aggressive therapy can improve patients' quality of life and even prolong survival. In one recent study of patients with advanced cancer, aggressive therapy, including frequent cardiopulmonary resuscitation, ventilator use and frequent admission to intensive care, was associated with poorer quality of life including iatrogenic harm and additional pain and discomfort than those receiving palliative care in the last weeks of life.¹⁰ Patients receiving palliative care reported a higher quality of life through the final course of their

¹⁰Barbara A. Noah, *The Role of Race in End-of-Life Care*, 15 J. Health Care L. & Pol'y 354.

illness.¹¹ Studies have also shown that those who received palliative care lived, on average, almost two months longer than those who received standard treatment.¹²

African Americans utilize palliative care and hospice much less frequently than white Americans. Research shows that African Americans discontinue aggressive therapy at disproportionately lower rates compared with white patients. African American patients are more likely to request expensive interventions such as cardiovascular resuscitation, mechanical ventilation, intensive care and artificial feeding regardless of prognosis.¹³ This attitude toward end-of-life care has been shaped by a history of healthcare discrimination, and a century of unethical medical experimentation so that many African Americans distrust treatment choices that may imply that less care will be provided. In fact, many African Americans believe that hospice means a denial of care. As a result, they favor more aggressive medical treatment when facing terminal illness but instead of benefiting from such treatment they end up dying sooner and in more pain. When faced with life threatening illness, African Americans reject or turn to hospice later in the course of a terminal illness in part out of fear that ceasing therapeutic treatment would be premature DESPITE the medical advice they are receiving.¹⁴ This is part and parcel of the general, deeply rooted distrust of the medical system by African Americans. Evidence suggests that this distrust is justified. Research indicates strong disparities in health care. (Racial minorities are less likely to receive even routine medical procedures and experience a lower quality of health services. For example, African Americans are less likely to receive surgery for early stage lung cancer and are less likely to receive cardiac catheterization than whites even when all other factors are equal.¹⁵ They are less likely than whites to receive kidney dialysis or transplants, undergo bypass surgery or receive state-of-art HIV/AIDS treatments.¹⁶) Through its outreach programs Continuum has succeeded, in its present market, in persuading members of the African American community that sometimes less is more and that palliative care doesn't mean giving up or denying care. Educating African Americans with terminal illnesses in Mecklenburg County on the benefits of hospice will surely increase hospice use by the African American community, and will result in prolonging life and providing a better quality of life for its users.

¹¹New England Journal of Medicine, 2010.

¹²New England Journal of Medicine, 2010.

¹³Noah, 352.

¹⁴Noah, 352.

¹⁵New England Journal of Medicine, 1999.

¹⁶IOM, 2005.

C. Value

In addition to providing high quality care, studies indicate that hospice can also address the need for cost-effective end-of-life care. Despite the demonstrated pattern of under-treatment for African Americans for various diseases and conditions, in the final six months of life, health care spending is 32% higher for African American patients compared with white patients. Among Medicare beneficiaries, 32.5% of African Americans were admitted to the intensive care unit compared to only 27% of whites.¹⁷ Yet higher health care spending at the end of life was associated with poorer quality of life in the last weeks before death. Simply put, the care African Americans receive at the end of life is more expensive and of lower quality. One recent study indicates that hospice saves the Medicare program an average of \$2,300 per decedent, with a maximum savings of around \$7,000 for patients who received hospice care for seven weeks. Access to hospice reduces re-hospitalizations by 50% in the last thirty days of life.¹⁸ Aggressive therapy with frequent re-hospitalization instead of palliative care needlessly increases costs in a health care system that is already straining to meet its obligations. Increasing access to hospice for African Americans will improve the quality of care received at the end of life and substantively reduce health care costs.

The measures outlined above to increase hospice utilization among African Americans in North Carolina are not based on theoretical, untested hypotheses. They have been used by Continuum Care Hospice with such success that in its original market, Continuum serves African Americans at more than double the state average and double the other area hospice providers. Therefore, the steps that we have outlined have a proven track record and we will duplicate them in Mecklenburg County. The proposals enumerated to educate the community about hospice and to dispel misunderstandings and cultural barriers have been employed by Continuum with outstanding results. Continuum, with its African American leadership and diverse health care professionals, has demonstrated, that despite disparities in health care, despite barriers to hospice utilization by African Americans, it is possible to raise African American hospice utilization tremendously. We are confident that we can increase African American hospice utilization in Mecklenburg County to the levels of our present market. Increasing access to

¹⁷ Noah, 358.

¹⁸ Dillon, 13.

hospice for African Americans in Mecklenburg County will improve quality of life, prolong lives, provide much needed support to families and caregivers and reduce healthcare costs exponentially.

IV. Adverse Impact

If the proposed adjustment is not made, the present disparity in hospice utilization will worsen with the growth of the African American population in Mecklenburg County. The numbers will be magnified by the higher rates of cancer, heart disease and stroke in the community. This lower utilization of hospice and palliative care will deprive the African American population of the county of the benefits of hospice care. It will result in lower quality end-of-life care, with continued frequent hospital admissions and more aggressive but futile interventions. Not only will quality of life suffer with these aggressive treatments, but instead of prolonging life, will actually shorten life. This occurs because studies indicate African Americans typically demand much more aggressive intervention at the end of life, which leads to more suffering and pain without extending the life of the patient. The tragic irony is that African American patients end up dying in hospitals hooked up to machines even though their preferences are to die at home surrounded by family. This unfortunate irony is compounded by the fact that 92% of African Americans who use hospice are satisfied with their care. Another consequence of the situation is that not only does the disparity result in poor quality and shorter life, but it is also much more expensive. The disparity in hospice utilization results in poor end of life quality, shorter life span at much higher cost. All this could be remedied by Continuum if our petition for the adjusted need determination is granted. Upon subsequent CON approval and development of a new hospice home care office in Mecklenburg County, Continuum will significantly increase African American hospice utilization, provide quality end-of-life care and prolong life, at much lower cost. Furthermore, palliative care not only treats the patient but also assists the family with the physical, spiritual and emotional burden of caring for the terminally ill. It bridges the medical and spiritual approach, and by addressing the cultural and sociological issues of the community it leads to better outcomes, better patient care, better support for the family all at a much lower cost to the system.

V. Alternatives

Continuum does not propose a change in the hospice methodology of the SMFP, which we don't consider a necessary change to address the issue. Rather, we are proposing a specific adjustment to include a need determination for one additional hospice home care office to serve an underserved group in Mecklenburg County. We believe that the standard hospice home care office methodology in the SMFP would eventually identify the Mecklenburg County need in a future SMFP. However, it would be of great benefit to the underserved population as well as to the state to deal with the disparity sooner rather than later. A significant portion of the Mecklenburg population is missing out on a humane, sociologically and culturally efficient, cost effective end-of-life option. Continuum could have proposed an adjusted need determination for another North Carolina county, but Mecklenburg County has been selected because it is North Carolina's largest county by population, with the largest absolute African American population in the state. Since the disparity has been identified and a solution available, we think that this situation should be immediately dealt with instead of waiting for the problem to get worse. Without this proposed adjustment, the underserved group will continue to suffer a disparity in hospice utilization and the financial strain on the system will increase. We are confident that when the success of our enterprise in Mecklenburg County becomes known, it will spread to other North Carolina counties as well.

VI. No Unnecessary Duplication

The request for an adjusted need determination in Mecklenburg County for one additional hospice home care office, specifically staffed and organized to serve African American patients, would not unnecessarily duplicate services. The disparate African American hospice penetration indicates there is a need for specialized hospice outreach. Continuum is ideally situated to perform this outreach since its approach has demonstrated great success in the market it currently serves. Continuum serves double the number of African Americans than the state average or the other hospices in the area.

VII. Conclusion

Continuum Care Hospice reiterates the request for a need determination for one additional hospice home care office in Mecklenburg County in the 2018 SMFP. The reason for the request is the glaring disparity in hospice utilization between whites and African Americans. In 2014, Mecklenburg County, the largest county by population with the largest absolute African American population in North Carolina, had a 12.6% disparity in hospice utilization. Continuum is confident it can correct this disparity if an adjusted need determination is included in the 2018 SMFP, thus enabling us in 2018 to submit a CON application to develop a new hospice home care office in Mecklenburg County. This confidence is based on our success in a current market where Continuum serves double the number of African Americans than the state average or the other hospices in the area. As described above Continuum's proposed adjustment is consistent with the Basic Principles that govern the SMFP. Continuum operates with a focus on and dedication to an extraordinary level of patient safety and quality of care. In addition, it facilitates improved access to care, especially for the medically underserved and it provides all this care in a highly cost-effective way saving the Medicare program an average of \$2,300 per decedent.

Continuum recognizes and applauds the valuable work the SHCC is performing, and we have full confidence in the SHCC and the SMFP planning process. We are, therefore, fully confident that the SHCC will appreciate that the Continuum team has a commitment to more than simply introducing African Americans within the community to hospice. It is more than numbers and larger than our organization. It is about social justice and ending healthcare disparities, and helping African Americans realize that hospice truly helps the living.