BAKER DONELSON

100 LIGHT STREET • BALTIMORE, MARYLAND 21202 • 410.685.1120 • bakerdonelson.com

HOWARD L. SOLLINS, SHAREHOLDER
Direct Dial: 410.862.1101
Direct Fax: 443.263.7569
E-Mail Address: hsollins@bakerdonelson.com

June 21, 2017

VIA ELECTRONIC MAIL AND FEDERAL EXPRESS
Kevin McDonald
Chief, Certificate of Need
Maryland Health Care Commission
4160 Patterson Avenue
Baltimore, MD 21215

RE: **P-B Health Home Care Agency, Inc.**
Prince George's County Hospice CON Review
Docket No. 16-16-2385
Response to Interested Party Comments

Dear Mr. McDonald:

On behalf of P-B Health Home Care Agency, Inc. ("P-B Health"), I am hereby submitting our Response to Interested Party Comments in the above-referenced matter, for review and consideration by the Maryland Health Care Commission. We will also provide electronic and Word copies as appropriate.

Please let us know if any additional information is needed.

Sincerely,

Howard L. Sollins

HLS/tjr
Enclosures

Certificate of Service

I HEREBY CERTIFY on this 21st day of June, 2017 a copy of the P-B Health Home Care Agency, Inc.'s Response to Interested Party Comments was sent via Electronic Mail and Federal Express to:

Kevin McDonald, Chief
Certificate of Need Division
Maryland Health Care Commission
4160 Paterson Avenue
Baltimore, Maryland 21215
kevin.mcdonald@maryland.gov

Suellen Wideman
Assistant Attorney General
Maryland Health Care Commission
4160 Patterson Avenue
Baltimore, MD 21215-2299
suellen.wideman@maryland.gov

Marta D. Harting
Venable, LLP
750 E. Pratt Street, Suite 900
Baltimore, MD 21202
mdharting@Venable.com

Timothy B. Adelman
Hall, Render, Killian, Heath & Lyman, PC
180 Admiral Cochrane Drive, Suite 370
Annapolis, MD 21401
tadelman@hallrender.com

Lena M. Woody
2535 Saint Paul Street
Baltimore, MD 21218
woodyl@p-bhealth.com

Jonathan Montgomery, Esquire
Gordon Feinblatt, LLC
223 E. Redwood Street
Baltimore, MD 21202
jmontgomery@grflaw.com

Andrew Solberg
5612 Thicket Lane
Columbia, MD 21044
asolberg@earthlink.net

Pamela Brown-Creekmur, RN
Health Officer
Prince George's County
1701 McCormick Drive, Suite 200
Largo, MD 20774
pbcreekmur@co.pg.md.us

Howard L. Sollins

BEFORE THE MARYLAND HEALTH CARE COMMISSION

IN THE MATTER OF *
P-B HEALTH HOME * **Docket No. 16-16-2385**
CARE AGENCY *

* * * * * * * * * * * * *

P-B HEALTH HOME CARE AGENCY, INC.
<u>RESPONSE TO INTERESTED PARTY COMMENTS</u>

P-B Health Home Care Agency, Inc. ("P-B Health"), through undersigned counsel, responds to the comments filed respectively by Bayada Home Health Care, Inc. ("Bayada") and Montgomery Hospice, Inc. ("MH") (collectively, the "Comments"). The process for responding to the Comments has been a helpful process, leading to improvements in the P-B Health certificate of need ("CON") application to extend its longstanding, successful track record as a home health agency, to establish a hospice in Prince George's County (the "County"). We also note, at the outset, that P-B Health did not challenge any of the other applications. P-B Health does not object to the approval of all of the pending CON applications.

The backdrop for the County's CON review for hospice services is a finding of need for two of Maryland's jurisdictions, Prince George's County and Baltimore City. This is no coincidence. In the plan development process leading to the adoption of the Hospice Services Chapter of the State Health Plan at COMAR 10.24.16 (the "Chapter") it was expressly and repeatedly noted that the African American community accesses hospice services at a lower use rate than the population as a whole. This is the case, notwithstanding that African American hospice patients comprised, respectively, 60% and 57.3% of all hospice patients in Prince George's County and Baltimore City in 2014.

The Maryland Health Care Commission ("MHCC") website posts an October 14, 2014 presentation by Linda Cole of the MHCC staff to the Prince George's County Department of Health (the "Cole Presentation") (Exhibit 1). The presentation confirmed that, in the period studied, hospice utilization by African Americans in Prince George's County was disproportionately low in relation to utilization by the White community, even though the number of African American Medicare decedents was significantly higher than Medicare decedents from the White community. Use rates were correspondingly lower among African Americans. The Cole Presentation summarized barriers identified from the research literature, including, for example, an expectation that hospice employees would not be from the minority community.

The Cole Presentation was consistent with findings in other materials used by the MHCC in the development of the Chapter. The MHCC posted the attached Washington Post article (Exhibit 2) reporting on reasons why the African American community has been slower to accept hospice as an alternative care model. The African American Outreach Guide the MHCC posted (Exhibit 3) is devoted to ideas and solutions for addressing this disparity. The attached summaries of MHCC meetings of presentations (Exhibit 4) to the MHCC are replete with references to the need for cultural competence and a diverse hospice workforce.

The plan development process resulted in the adoption of the Chapter which states, in part:

> The use of hospice services nationally and within Maryland varies by population groups. It has been shown that some individuals and groups are reluctant to access hospice services based on religious, ethnic, cultural and other factors.

It is abundantly clear from the plan development record that this refers, to a significant degree, to the reluctance of the African-American community to access hospice services.

These findings are relevant in a related context, as applicable to the P-B Health CON application. While there were, historically, Maryland health care facilities that were either owned by African-Americans or were not for profit health care facilities founded by African-American community leaders, nearly none of these exist any longer. For example:

All of Maryland's hospitals are now not-for-profit institutions. Provident Hospital in Baltimore City, founded in 1894 by African-American physicians, no longer operates. We believe that there are zero principally owned African-American comprehensive facilities in Maryland, with only one owned by a church within the African-American community. There are zero hospices in Maryland owned by African-Americans. There is, today, only one African-American owned home health agency in Maryland, which is P-B Health.

Attached is a comparative chart (Exhibit 5) confirming that P-B Health served the largest percentage of Black Home Health Clients/Total Clients of all the home health agencies serving Baltimore City. Along with its ownership and leadership, its culturally competent team has precisely the sort of expertise and experience the MHCC has identified as needed.

This is not to say that other health care providers discriminate against African-Americans or do not seek to serve this community. Neither does it mean that African-Americans do not lead and provide a wide range of professional, clinical and other services at health care facilities. It does not mean that only an African-American hospice can serve this community.

At the same time, the MHCC has identified a disparity problem with lower numbers of African-Americans accessing hospice services, leading to the Chapter identifying a need in Prince George's County and Baltimore City. Moreover, the MHCC has heard repeatedly from experts that key parts the solution to this disparity in utilization is the provision of culturally competent services that reflect an understanding of the history, needs and concerns of the African-American community and the importance of a diverse work force. In light of that MHCC determination, the MHCC could not possibly be sending a message that, in the face of these concerns and solutions, there is no place for P-B Health, a longstanding, qualified and high quality provider to be both a home health provider and hospice provider.

Of course, were Bayada and MH to have identified fatal flaws in the P-B Health CON application, it should be denied. Moreover, if only one hospice can be approved, it is incumbent on the MHCC to choose the best applicant, which is P-B Health based on its track record of success and quality. However, in this CON review, not only have the other applicants not identified fatal flaws in the P-B health CON application, it is also the case that more than one applicant can be approved, providing an opportunity to select several highly qualified applicants, including P-B Health.

In reply to the Comments, P-B Health specifically responds as follows:

1. Contrary to the allegations of MH, P-B Health's project is financially feasible under COMAR 10.24.01.098G(3)(d).

The regulation cited by MH is:

> The Commission shall consider the availability of financial and nonfinancial resources, including community support, necessary to implement the project within the time frames set forth in the Commission's performance requirements, as well as the availability of resources necessary to sustain the project.

MH failed to identify any flaws in the nonfinancial resources available to P-B Health. It solely challenged P-B Health's financial viability. It does so notwithstanding P-B Health's 30 year history as a successful, viable health care facility providing home based services.

Regarding MH's flawed financial arguments, MH claims that P-B Health must provide audited financial statements. This is wrong. As a family owned, private business there is no such requirement. Moreover, there is no CON regulation or provision of the Chapter requiring an audited financial statement. The sole reference is guidance in the MHCC's application form. There, either an audited financial statement or a letter from an independent accountant suffices, and P-B Health provided the latter. An updated accountant's letter is attached as Exhibit 6. It attests to the available resources P-B Health has at its disposal.

To bolster the P-B Health application further, two letters from separate lenders were submitted on June 14, 2017 as part of P-B Health's CON Application Modification, expressing willingness to loan funds to P-B Health. These may not be needed but it is supportive for the MHCC to know that independent lenders are comfortable with P-B Health's creditworthy status.

Also submitted as part of the CON Application Modification was a letter from an independent real estate agent, advising on the market value of the property in which P-B Health operates, under common ownership with P-B Health, documenting that the owners of P-B Health have substantial equity to support current operations and hospice services.

MH observes that P-B Health showed losses in 2014 and 2015. First, the CON Application Modification contained restated financials for 2015, correcting an accounting error, showing a profit for that year. Second, revised financials for 2016, also submitted with the CON Application Modification documented that P-B Health did have a loss in 2016. This performance, in the context of a 30 year operating history demonstrate that P-B Health is able to manage its financial resources and succeed. To be sure, P-B Health does not have the advantage available to MH as an organization that does not pay taxes and can benefit from tax-exempt charitable contributions. P-B earns, pays taxes on and prudently uses very dollar it is reimbursed, all while delivering more charity care than any other home health agency in Baltimore City (*see* Exhibit 7), as a percentage of visits. It does so while achieving a 4 out of 5 star ranking for quality on the Centers for Medicare and Medicaid Services website.

MH claims that $120,000 in cash "outside of payroll" is problematic and reflects a lack of viability. Yet, there is no requirement for more cash. Moreover, we have augmented the record with accountants letters, confirmation of equity in real estate, and expressions of interest from lenders. We agree that P-B is not as well-off as MH, but it meets the standard, is financially viable, highly charitable and has a strong record of quality.

In addition, P-B Health will have access to a working line of credit, as it has demonstrated. It has an operating history, receivables and equity to back it up.

Finally, we agree that updated budget and operating projections are warranted and are providing them in a modification to the application being submitted under separate cover.

2. P-B Health complies with Section .05B of the Chapter. MH identifies no noncompliance.

It is correct that P-B Health does not plan to care for pediatric hospice patients. This is not a requirement, and therefore is not a flaw in the application. The MHCC should not turn down the application on this basis.

As for using a 35+ population we respond as follows:

- P-B Health will accept adult hospice patients of any age.
- The MHCC itself uses a 35+ age distinction in its hospice statistics. *See* Exhibit 8, African-American Hospice Patients as a Proportion of Total Hospice Patients.

- 2014 Hospice Data show that 99.12% of hospice patients were age 35 and older.

Age 0 to 34	0.88%
Age 35-64	15.75%
Age 65-74	16.87%
Age 75-84	25.55%
Age 85+	40.96%
Age Total:	100.00%

Source: MHCC Hospice Public Use Dataset, 2014.

Therefore, P-B Health's assumption that its patients will be age 35 and older is understandable since 99.12% of all hospice patients are age 35+.

MH's comment is effectively without substance, and P-B Health agrees to admit all adult hospice patients in any event. The volume increase in adults under 35 years of age is immaterial.

3. P-B Health complies with Section .05E of the Chapter, concerning volunteers.

We would expect MH to have a robust volunteer program as it states. But, this does not mean P-B Health will lack one if it follows a different course of action. P-B Health recognizes the essential need for volunteers in Hospice care programs and how they play a vital role in enhancing the quality of care that will be delivered to the patient and family. We have sought the leaders of the Maryland Chapter for Volunteers of the following sororities and fraternities as community participators in the overall hospice care program for P-B Health's Hospice: Omega Psi Phi, Alpha Kappa Alpha, Alpha Phi Alpha, Zeta Phi Beta, and Kappa Alpha Si.

P-B Health has also contacted and continues to contact church ministerial staff in the Prince Georges County community to develop an additional core group of volunteers for our hospice program.

Further, we note that P-B Health has previously submitted materials indicating how it will effectively meet this standard, and reserves the right to continue to supplement the record to keep the MHCC informed of P-B Health's program refinements in this regard. See original CON application submitted on October 7, 2014, pages 23-24, and Certificate of Need Response to Questions submitted December 15, 2016, pages 30-34.

4. P-B Health complies with Section .05C(2)(h) of the Charity standard concerning bereavement services.

Here too, it is no shortcoming of the P-B Health CON application simply because MH currently provides bereavement services as it is required to do as an existing hospice. P-B Health will effectively meet this standard as established by the following portion from its CON application.

For state licensing purposes, COMAR 10.07.21.10 provides:

> "H. Bereavement Plan.
>
> (1) The hospice care program shall initiate a written plan of bereavement intervention at the time of admission to the hospice which shall be incorporated into the patient's plan of care.
>
> (2) The bereavement plan shall be based on an assessment of the needs of the family and shall recognize the family's social, religious, and cultural values.
>
> (3) At a minimum, the bereavement plan shall include the:
>
> (a) Scope and frequency of bereavement services; and
>
> (b) Family's acceptance of bereavement services."

According to the Centers for Medicare and Medicaid Services, State Operations Manual, Appendix M, implementing the federal hospice conditions of participation:

"§418.54(c) (7) - Bereavement. An initial bereavement assessment of the needs of the patient's family and other individuals focusing on the social, spiritual, and cultural factors that may impact their ability to cope with the patient's death. Information gathered from the initial bereavement assessment must be incorporated into the plan of care and considered in the bereavement plan of care.

Interpretive Guidelines §418.54(c)(7) Although a bereavement plan is initiated after the death of the patient, prior to the death, the hospice must assess any grief/loss issues of the patient’s family through an initial bereavement risk assessment that is incorporated in the plan of care. Bereavement issues continue to be part of the ongoing assessments, and the bereavement plan of care after death is based on all these assessments. Bereavement services may be offered prior to the death when the initial assessment, comprehensive assessment, or updates to the assessment identifies the need for the patient/family. Social, spiritual and cultural factors that may impact a family member or other individual’s ability to cope with the patient’s death would include, but not be limited to:

- History of previous losses;
- Family problems;
- Financial concerns;
- Communication issues;
- Drug and alcohol abuse;
- Health concerns;
- Legal and financial concern;
- Mental health issues;
- Presence or absence of a support system; and
- Feelings of despair, anger, guilt or abandonment.

> These issues may not be readily apparent during the initial bereavement risk assessment, but should be incorporated into the hospice plan of care if they become evident, and must be considered in the bereavement plan of care."

P-B Health will comply with these federal and state standards, using contracted staff.

5. P-B Health is a strong provider of charity care and will continue to do so, in compliance with Section .05J of the Chapter.

As Exhibit 7 shows, P-B Health provides more charity care than any other home health agency in Baltimore City, as a percentage of visits. It is a complete mischaracterization for MH to suggest otherwise. As a not for profit organization not paying taxes and raising money through charitable contributions, MH certainly is required to provide charity care. It does not deserve extra credit for doing what is required. By the same token, P-B Health provides substantial charity care, as a family business, in comparison to other home agencies. It will continue this tradition in the County as a hospice provider.

Bayada is wrong to imply that only a large, national existing hospice provider is qualified to serve the County. P-B Health has not suggested there is no place for Bayada in the County and it is wrong for Bayada to seek to block P-B Health's application. If there were a prohibition against new "first time" providers, the MHCC would have included the restriction in the Chapter. It did not do so.

6. Bayada is not a more cost-effective alternative under COMAR 10.24.01.08G(3)(c).

P-B Health identified an error in its ALOS calculation. It has submitted new tables in its CON Application Modification. These bolster its application's cost-effectiveness.

7. In response to Bayada's comments on financial viability:

- New capital budget figures and operating projections were included in the CON Application Modification submitted separately.
- The projections are solid and realistic, showing a financially feasible hospice service. In rebuttal to Bayada's allegations, P-B's Health was profitable in 2015. Notwithstanding a loss in 2016, P-B Health has a longstanding history as a financially viable, quality provider of home health services. It will perform in strong manner as a hospice provider.
- As documented in reply to MH, there is support from an independent accountant, making the attestations that the MHCC has routinely accepted in the CON process, augmented by expressions of lender interest.
- Bayada questions P-B Health's financial performance and touts its own, yet P-B Health provided more charity care than any other Baltimore City home health agency in the same year that Bayada's reported charity are was nil.

In summary, P-B Health responded above on the topics of pediatric hospice patients and its agreement to take all adult hospice patients, its volunteer program, and financial viability. In addition, P-B Health further represents that:

- It will accept patients with communicable diseases.
- It will not require patients to have advance directives and will assist patients who wish to have them.
- It will not require patients to authorize DNR (Do Not Resuscitate) orders.
- It is contracting with Seasons Hospice to provide support for home hospice patients in need of respite care.

- It has reached out to pharmacies experienced in working with hospice providers for hospice pharmacy services.

CONCLUSION

For these reasons, P-B Health respectfully requests that the Comments of other parties in this review be disregarded, and that the P-B Health CON Application be approved.

Howard L. Sollins

Howard L. Sollins
John J. Eller
Baker, Donelson, Bearman, Caldwell & Berkowitz
100 Light Street
Baltimore, MD 21202
(410) 685-1120
hsollins@bakerdonelson.com
jeller@bakerdonelson.com

Certificate of Service

I HEREBY CERTIFY on this 21st day of June, 2017 a copy of the P-B Health Home Agency, Inc.'s Response To Interested Party Comments was sent via First Class Mail and Electronic mail to:

Kevin McDonald, Chief
Certificate of Need Division
Maryland Health Care Commission
4160 Paterson Avenue
Baltimore, Maryland 21215
kevin.mcdonald@maryland.gov

Suellen Wideman
Assistant Attorney General
Maryland Health Care Commission
4160 Patterson Avenue
Baltimore, MD 21215-2299
suellen.wideman@maryland.gov

Marta D. Harting
Venable, LLP
750 E. Pratt Street, Suite 900
Baltimore, MD 21202
mdharting@Venable.com

Timothy B. Adelman
Hall, Render, Killian, Heath & Lyman, PC
180 Admiral Cochrane Drive, Suite 370
Annapolis, MD 21401
tadelman@hallrender.com

Lena M. Woody
2535 Saint Paul Street
Baltimore, MD 21218
woodyl@p-bhealth.com

Jonathan Montgomery, Esquire
Gordon Feinblatt, LLC
223 E. Redwood Street
Baltimore, MD 21202
jmontgomery@grflaw.com

Andrew Solberg
5612 Thicket Lane
Columbia, MD 21044
asolberg@earthlink.net

Pamela Brown-Creekmur, RN
Health Officer
Prince George's County
1701 McCormick Drive, Suite 200
Largo, MD 20774
pbcreekmur@co.pg.md.us

Howard L. Sollins

EXHIBIT LIST

1. October 14, 2014 presentation by Linda Cole of the MHCC staff to the Prince George's County Department of Health

2. Washington Post Article: "A Higher Power will Deliver Me," November 21, 2015

3. African American Outreach Guide, published by Caring Connections in collaboration with Duke Institute on Care at the End of Life (2008)

4. MHCC Meeting Summaries

5. Comparative Chart: Black Clients - Home Health Agencies – Baltimore City, 2014

6. Updated Accountant's Letter

7. Comparative Chart: Charity Care Visits – Home Health Agencies – Baltimore City, 2014

8. MHCC Chart: African-American Hospice Patients as a Proportion of Total Hospice Patients

9. Affirmations

EXHIBIT 1

MARYLAND
HEALTH CARE
COMMISSION

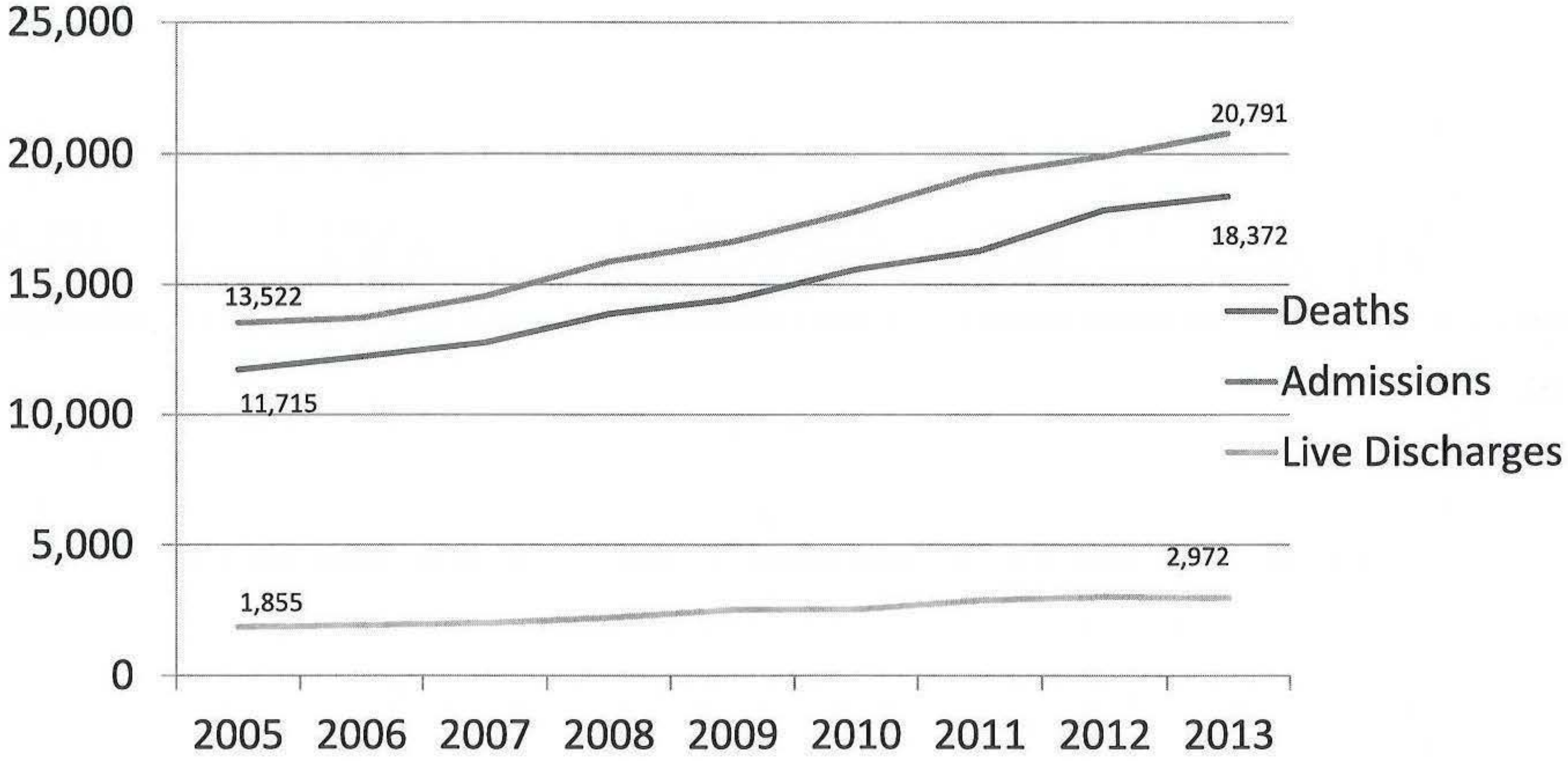
Hospice Education and Outreach Work Group

Prince George's County Health Dept.
October 10, 2014
Linda Cole, MHCC

Review of Preliminary Prince George's County Hospice Meeting

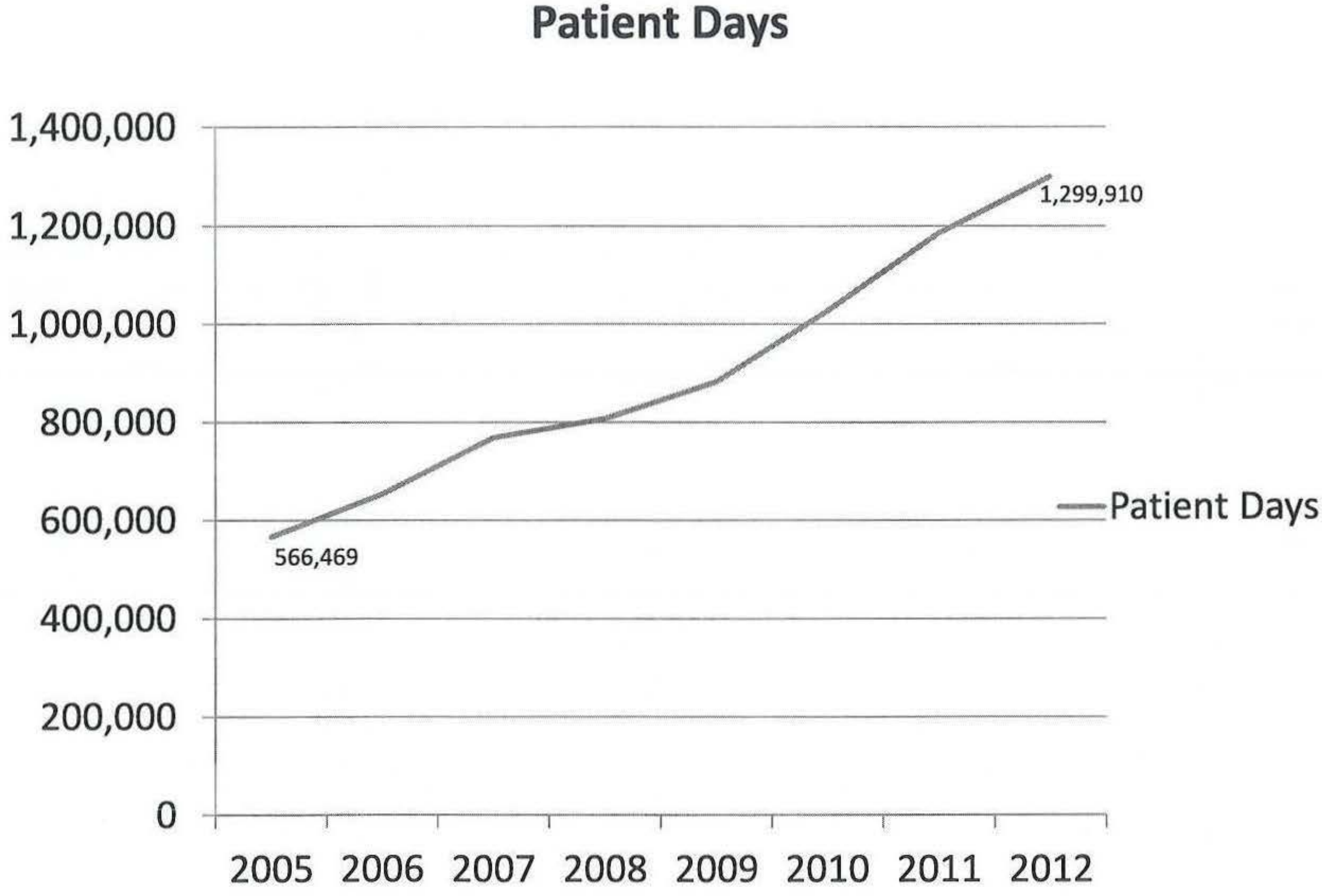
- Themes:
  - Programs need to be advertised through community outreach
  - Need to work with local clergy
  - Physicians are reluctant to refer to hospice; lack of time for end of life discussions
  - MOLST is a way to start conversations
- Recommendations for Programs:
  - Should address religious and ethical issues
  - Should use panel format with different disciplines

Trends in Maryland Hospice Utilization (FY2005-2013)



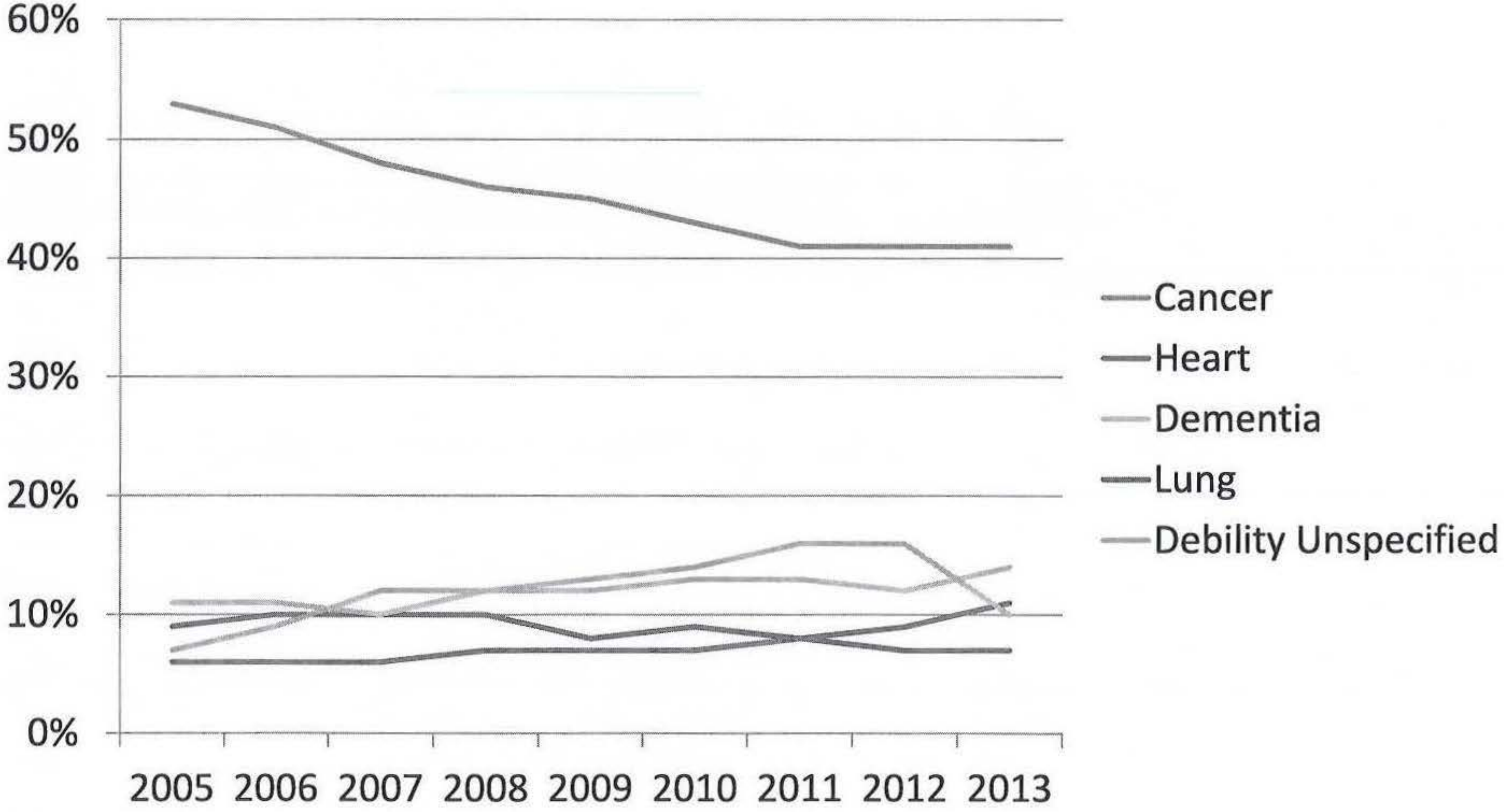
Source: Maryland Hospice Surveys (FY 2005-2013). Note: 2013 data is preliminary

Trends in Maryland Hospice Patient Days (FY 2005-2012)



Source: Maryland Hospice Surveys. (FY 2005-2012)

Percent of Maryland Hospice Admissions by Diagnosis FY 2005-2013



Source: Maryland Hospice Surveys (FY 2005-2013). Note: 2013 data is preliminary

Maryland Hospice Use Rates (2007-2013)

Maryland Hospice Use Rates* (2007-2013)

Region	Jurisdiction	2007	2008	2009	2010	2011	2012	2013
Central Maryland	**Anne Arundel**	0.4	0.41	0.45	0.47	0.47	0.51	0.52
	Baltimore City	**0.21**	**0.28**	**0.26**	**0.24**	**0.25**	**0.32**	**0.31**
	Baltimore County	0.37	0.38	0.44	0.49	0.54	0.56	0.54
	Harford	0.34	0.33	0.36	0.42	0.41	0.49	0.47
	Howard	0.38	0.36	0.4	0.41	0.42	0.6	0.49
Eastern Shore	**Caroline**	0.31	0.22	0.28	0.27	0.18	0.24	0.22
	Cecil	0.37	0.44	0.32	0.5	0.54	0.54	0.46
	Dorchester	0.2	0.18	0.16	0.19	0.19	0.18	0.22
	Kent	0.2	0.27	0.28	0.33	0.31	0.36	0.34
	Queen Anne's	0.31	0.37	0.43	0.42	0.44	0.47	0.4
	Somerset	0.22	0.32	0.25	0.26	0.38	0.39	0.32
	Talbot	0.32	0.33	0.34	0.37	0.39	0.39	0.46
	Wicomico	0.3	0.37	0.36	0.43	0.44	0.43	0.45
	Worcester	0.27	0.27	0.32	0.36	0.42	0.46	0.42
Montgomery	**Montgomery**	0.36	0.36	0.39	0.43	0.43	0.45	0.47
Southern Maryland	**Calvert**	0.31	0.38	0.33	0.37	0.35	0.37	0.37
	Charles	0.24	0.28	0.22	0.29	0.29	0.3	0.33
	Prince George's	**0.2**	**0.23**	**0.22**	**0.24**	**0.22**	**0.26**	**0.26**
	St. Mary's	0.45	0.43	0.36	0.43	0.47	0.48	0.41
Western Maryland	**Allegany**	0.19	0.2	0.21	0.19	0.22	0.24	0.18
	Carroll	0.43	0.48	0.5	0.5	0.53	0.54	0.52
	Frederick	0.3	0.26	0.3	0.34	0.34	0.37	0.47
	Garrett	0.27	0.23	0.28	0.27	0.3	0.25	0.25
	Washington	0.3	0.32	0.33	0.34	0.38	0.44	0.48

•Use rates are the ratio of 'All Hospice Deaths' to 'Population Deaths - Age 35+' to be consistent with the Hospice State Health Plan (COMAR 10.24.13)

•Source: Hospice Deaths-MHCC Annual Hospice Surveys. (2007-2013) Note 2013 data is preliminary. Pop. Deaths-MD Vital Statistics Administration Data (2007-2013, released 2014 with preliminary 2013 data.)

Hospice Use among Medicare Decedents, Baltimore/Washington Metro Jurisdictions, 2012

Jurisdiction	Race	Number of Medicare Decedents	Number of Hospice Users	Use Rate
Anne Arundel	African American	403	145	0.36
	White	2,668	1,268	0.48
Baltimore	African American	1,088	428	0.39
	White	4,863	2,386	0.49
Baltimore City	African American	2414	805	0.33
	White	1,971	814	0.41
Harford	African American	110	42	0.38
	White	1,409	685	0.49
Howard	African American	155	69	0.45
	White	759	410	0.54
Montgomery	African American	581	193	0.33
	White	3,686	1,640	0.44
Prince George's	African American	2,168	677	0.31
	White	1,303	523	0.40
Frederick	African American	75	23	0.31
	White	1,144	462	0.40

Source: Medicare Master Beneficiary Summary File Cost and Use Segment (2012)

Minority Utilization of Hospice

Hospice Use Rates by Medicare decedents using hospice care, U.S.

Population	2000	2011	2012
Total	0.23	0.45	0.47
White	0.24	0.47	0.48
Minority	0.17	0.35	0.36

Source: MedPAC June 2014 Data Book: Health Care Spending and the Medicare Program, Chart 11-9

Themes from Literature

Barriers to hospice use:

- Conflicting values with hospice philosophy
- Lack of information on hospice
- Concerns about burdening the family
- Financial access concerns
- Mistrust of the healthcare system
- Preference for caring for loved one at home
- Expectation that hospice employees would not be minority
- Hospice means "giving up"

Source: Medicare Hospice Payment Reform: A Review of the Literature:
Abt Associates Inc.

Sources of Hospice Data

- **Maryland Hospice Survey: Public Use Data Set***
  http://mhcc.maryland.gov/public_use_files/index.aspx
- **Medicare Data:** http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Geographic-Variation/GV_PUF.html
- **Med Pac Report:**
  http://medpac.gov/documents/publications/jun14databookentirereport.pdf?sfvrsn=1
- **National Hospice and Palliative Care Organization:**
  http://www.nhpco.org/

*Note that MHCC Website will be changing during October, 2014

EXHIBIT 2

THE WASHINGTON POST

By Cathy Lynn Grossman | Religion News Service, Published: November 21

WASHINGTON — "A higher power will deliver me."

"If Jesus suffered, I'm going to suffer."

"I have a daughter, why would I need an advance directive?"

That's what elderly African-Americans have told Karen Bullock, a medical sociologist and social worker.

Race, religion and a sense of the role of the family all play into end-of-life decisions for African-Americans, "and you cannot disentangle them," said Bullock, a professor and head of the department of social work at North Carolina State University in Raleigh, N.C.

A new survey on end-of-life issues, released Thursday (Nov. 21) by the Pew Research Center's Religion & Public Life Project, bears this out: Blacks and Hispanics are twice as likely as white Protestants, Catholics and people of no religious identity to insist that doctors do everything possible to stave off death, even in the face of incurable disease and great pain.

What's more, the most recent statistics from the National Hospice and Palliative Care Organization show hospice service is overwhelmingly used (83 percent) by non-Hispanic whites. Less than 9 percent of hospice patients were black, and less than 7 percent were Hispanic.

Bullock, who is an African-American Southern Baptist, has tried to address end-of-life issues with a faith-based approach. She's partnered with churches to talk about advance directives and decisions about aggressive treatment, palliative care (shifting from efforts to cure to pain management in incurable cases) and hospice.

Even that didn't work.

"I could talk about a good death, but I couldn't convince them that medical providers were truly going to act on their behalf," she said. Hospice may be the "gold standard of care at the end of life," but minorities are not easily convinced, she said.

Bullock points to elderly African-Americans' historic experiences for one reason they insist on aggressive treatment even in severe pain with an incurable disease.

This is the generation that lived through segregation and that remembered the infamous Tuskegee experiment, in which black men were injected with syphilis and studied but not treated, she said.

People who overcome adversity by relying on their faith in God are unlikely to change that in their last days, she said. "They believe death is not the end for them and they will pass on to a better place."

They also have a different understanding of suffering.

"Suffering is not being able to feed your family," Bullock said. "Lying in a hospital bed is not suffering."

George Eighmey made a similar observation during his 12 years as executive director of Death with Dignity in Oregon, the first of four states that have legalized physician-assisted dying for terminally ill patients.

Eighmey, who retired in 2010, said he saw no black, Hispanic or Asian people inquire about the law before it was enacted, or after when it allowed people to obtain a lethal prescription from a physician and choose the day of their death.

He began an educational outreach program to all three communities to learn their concerns. Eighmey found Asians and Hispanics often rejected physician-assisted dying because they believe it is up to family members to "care for someone to the end."

Hispanics and blacks, he said, also brought their deeply religious faith in miracles to their end-of-life views. They believe God is in control, not human beings.

Those few minorities who did, eventually, avail themselves of the Oregon law, he said, were largely "upper-income, highly educated, fiercely independent individuals who are accustomed to having things their way — pretty much like white people who have used the law."

These are not people waiting passively for a miracle, said the Rev. Tarris Rosell, an ethics consultant at the Center for Practical Bioethics in Kansas City and an associate professor at the University of Kansas Medical Center, School of Medicine.

"If the patient or the patient's family is praying for God to intervene, then everything must be done to keep Grandma or Grandpa going."

Rosell, who was ordained in the liberal American Baptist tradition, said arguments over whether someone should continue aggressive treatment or turn to palliative care are a major reason he's called in for ethics consultations.

Once, he said, a family came to him when their grandfather was already sedated, on a ventilator and unable to speak for himself. Their question: "Is it permissible to stop treatment, or is that a lack of faith?"

By stopping aggressive treatment, they feared they were saying that they didn't believe in the power of God to heal.

"The miracle may be a release from suffering in this world," he told them. "If God intervenes in the world to bring another kind of healing, wonderful! But then you don't need doctors and machines. Maybe it would be best to turn them off and let God do what God is going to do.

"Faithfulness does not require us to keep someone in a state of suffering, to prolong the natural dying process. It's our job as pastors to explain that at a certain point, the optimal level of care, which they always deserved, may be in letting go."

This is not easy to convey to people accustomed to prayers such as, "Lord, be with the doctors," said the Rev. Elree Canty, pastor at Grace and Mercy Christian Church, a nondenominational church in Lenexa, Kan.

"You will hear people say, 'Lord, bless the surgeon's hand and guide his mind to find a cure.' If you shut that down, many feel you are closing the doors to a blessing," Canty said.

"Everyone knows somebody who was on the verge of death and held on and kept fighting and, guess what, they bounced back!"

His mother did. Eight years ago, she was fighting breast cancer. "She was very aggressive about living."

But, Canty said, his mother, now 60, also has written down all her desires for care if she falls ill again. Just in case.

EXHIBIT 3

African American
OUTREACH GUIDE

Caring Connections

In collaboration with

DUKE INSTITUTE ON CARE AT THE END OF LIFE

Table of Contents

I. Overview

> *"Hospice offers the best hope not to be alone, to be with family, to have pain controlled, and to be connected to your faith and beliefs. We are as entitled and deserving as anyone else to have these hopes fulfilled."*
>
> — Richard Payne, MD
> Professor of Medicine and Divinity
> Esther Colliflower Director
> Duke Institute on Care at the End of Life
> Durham, NC

Harlem Renaissance author, poet and playwright, Langston Hughes (1902-1967) once said, *"There is no color line in death."* Mr. Hughes understood that however we reach the end of life, our mortality is universal; there is no color line in death and there should not be one in life either.

With that thought in mind, it is interesting to note that while the African American population accounts for over 12% of the overall U.S. population, fewer than 10% of those entering hospice programs across the country are African American. Conversely, the white/Caucasian population comprises 80.1% of the U.S. population (U.S. Census estimate for 2006)[1] and accounts for more than 80% of hospice admissions.[2]

Within Medicare decedents ages 65 and older, the disparity is even more pronounced. Researchers have found that in the last year of life, black decedents were less likely to use hospice than white decedents (22% vs. 29%, respectively).[3] Hospice utilization has also been shown to be "lower among African-Americans than among white decedents, across all age groups," "across all causes of death except Alzheimer's disease" and "in 31 of 40 states." The researchers theorize "that racial disparities in hospice utilization decrease in areas where hospice utilization is more common" and that "one promising strategy to help reduce white/African American disparity in hospice use appears to be to increase access to hospice care for all eligible individuals".[4]

Given the inequalities described above, the purpose of this Guide is to provide outreach strategies and resources for providers and coalitions to better support African Americans with end-of-life issues.

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[1] *http://quickfacts.census.gov/qfd/states/00000.html*

[2] NHPCO Facts and Figures, 2007. *www.nhpco.org*

[3] Connor SR, Elwert F, Spence C, Christakis NA. Geographic variation in hospice use in the United States in 2002.J Pain Symptom Manage. 2007 Sep; 34(3):277-85.

[4] Connor SR, Elwert F, Spence C, Christakis NA. Racial disparity in hospice use in the United States in 2002.Palliat Med. 2008 Apr; 22(3):205-13.

The Guide specifically provides you with a review of significant end-of-life issues relevant to African American communities, and detailed strategies and tools gathered from hospice programs and experts. The "Resources" section offers many suggestions for continuing your research and outreach efforts. We encourage you to focus on taking time to get to know your community and fostering meaningful relationships, growing together as you reach out. In addition, the Caring Connections team has a wealth of materials that can assist you with virtually all aspects of your outreach, located at *www.caringinfo.org/community*.

We hope that this Guide will help highlight the importance of improving outreach and access efforts with African Americans in your community, as well as provide practical tools so that ultimately patients and their families will be better served in a culturally competent way, honoring and respecting their traditions.

A. DEMOGRAPHICS

There are over 300 million Americans living in the U.S. today, 39 million of whom are African American (just over 12 percent of the total population). One out of every four African Americans lives in New York, Florida or Georgia, with the largest concentration in the South (55 percent). The highest proportions are in the District of Columbia (57 percent) and Mississippi (37 percent), and the lowest are in Montana, Idaho and Vermont (less than one percent each). 52 percent of all African Americans live within metropolitan areas, with only 13 percent in nonmetropolitan areas.[5]

Most African Americans are high school graduates, and one in six has a college degree. Median income is about $32,000, one in four live below the poverty level, and about nine percent are unemployed (double the national average). African Americans are less likely to be married than non-Hispanic whites, and a larger proportion of their households are maintained by women. African Americans are more likely to live with and care for grandchildren.

B. HISTORY

Many African Americans remember the days of segregation, Jim Crowe laws and violence towards their people. And many African Americans are deeply distrustful of the government and the healthcare system, a distrust that is rooted in both historical and present day experiences. For example, while emancipation from slavery was achieved in 1865, many African American families are only three generations removed from slavery. And as recently as 40 years ago, African American men with syphilis were purposely left untreated and studied to determine the long-term effects of the disease; many died in excruciating pain, all unnecessarily. In addition, a survey of African Americans conducted from 2002-2003, reported in the *Journal of Acquired Immune Deficiency Syndrome*, found that nearly half of the respondents believe that the U.S. government created HIV/AIDS, in part, as a plot to exterminate blacks.[7] So when African Americans do seek care for their health, particularly at the end-of-life, it is little wonder that many worry that hospice is just another way to hasten death.

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[5] U.S. Census Bureau. (2004). The American Community – Blacks. *www.census.gov/prod/2007pubs/acs-04.pdf*.

[6] U.S. Census Bureau. (2004). The American Community – Blacks. *www.census.gov/prod/2007pubs/acs-04.pdf*.

[7] Bogart, L.M., Thorburn, S. (2005). Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans? Journal of Acquired Immune Deficiency Syndrome, 39 (2), 213-218.

"Black people still don't believe in the political process, because the process has never served us. We've been betrayed by the political process, betrayed by the medical process, betrayed by each and every process in America, and it's all based on racism. That distrust affects our entire personality in a great many ways."

— AFRICAN AMERICAN FOCUS GROUP MEMBER,
NEW YORK, NEW YORK, 2005
(SEE FOCUS GROUP REPORT IN SECTION II)

C. HEALTHCARE DISPARITIES

"Among African Americans, non-acceptance of advance directives appears to be part of a much broader pattern of values regarding quality of life, as well as a historical legacy of segregation. [Do Not Resuscitate] DNR orders may be viewed as a way of limiting expensive healthcare or as cutting costs by ceasing care prematurely. Historically, this perspective may stem from a long history of distrust of the white-dominated healthcare system."[8]

Population-specific differences in the presence of disease, health outcomes and access to healthcare are all part of the healthcare disparities conversation. A 2002 Institute of Medicine (IOM) study found that "a consistent body of research demonstrates significant variation in the rates of medical procedures by race, even when insurance status, income, age, and severity of conditions are comparable. Research further indicates that U.S. racial and ethnic minorities are less likely to receive even routine medical procedures and experience a lower quality of health services."[9] This comprehensive report entitled, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, basically reveals that African Americans are dying from treatable and preventable illnesses with more frequency than other ethnic groups.

For example, African Americans are more likely to develop cardiovascular disease and HIV/AIDS, and are twice as likely to die from diabetes. Cancer incidence rates are ten percent higher overall, with a 25 percent greater chance of dying from it than whites. African Americans have higher infant mortality rates, and are more likely to live with a cognitive disability. Seven million African Americans do not have health insurance, and life expectancy is nearly ten years less than for whites.[10]

Peer-reviewed medical journals cite countless examples of African American patients experiencing discrimination, from the refusal to administer appropriate medications (most notably opiates), to inferior care. The IOM report specifically found that African Americans are less likely than whites to receive kidney dialysis or transplants, undergo coronary bypass surgery or receive state-of-the-art HIV/AIDS treatments.[11]

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[8] Searight, H. R., Gafford, J. (2005, February 1). Cultural diversity at the end of life: Issues and guidelines for family physicians. *American Family Physician*, 71(3), 515-522.

[9] Institute of Medicine. (2002). Report Brief: What Health Care Providers Need to Know about Racial and Ethnic Disparities in Healthcare. Retrieved from *www.iom.edu/Object.File/Master/4/175/Disparitieshcproviders8pgFINAL.pdf*.

[10] Centers for Disease Control. (2008). National Center for Health Statistics: Health of Black or African American Population. Retrieved from *www.cdc.gov/nchs/fastats/black_health.htm*.

[11] Institute of Medicine. (2005). Addressing Racial and Ethnic Health Care Disparities. Retrieved from *www.iom.edu/Object.File/Master/33/249/BROCHURE_disparities.pdf*.

While the reasons for these disparities are numerous and frequently directly correlated to lower socioeconomic status, African Americans do not seek healthcare as often, and when they do, it is often with a physician they may see only once. The healthcare system in America and its many services have made incredible strides over the years, yet much work is to be done with regard to differences in quality of care and treatment options based on ethnic background.

D. AFRICAN AMERICAN ORIGINS

For purposes of this Guide, we have limited our focus to US-born African Americans (unless otherwise specified). However, it is important to be aware that eight percent of the total black population is foreign-born, and most came to the U.S. after 1990. The highest percentages live in New York, Massachusetts, Minnesota and Florida, and nearly all were born in Africa or Latin America.[12]

Recent immigrants may present with advanced disease that has gone untreated, either because of lack of care or a preference for alternative (and potentially less effective) treatments. Others may have undergone extreme trauma as part of their immigration experience or in their home countries, including illegal flight, genocide and extreme poverty. Take the time to learn where the family is originally from and ask about specific healthcare traditions that are important to them; then integrate these treatments into the plan of care. Be sensitive to the special customs of these groups, particularly with regard to traditional medicine.

> *"I have seen more young people who are immigrants diagnosed with advanced cancer. It's not that unusual for those from a foreign country to present with illness that is further along. And when the patient is young, they're often hesitant to call back home to tell their parents how very sick they are. I have to encourage and facilitate those calls. What's wonderful, though, is that these are often tight communities that provide a network of support. In many cases groups of strangers from the same country immigrated together in search of employment, so their "community" came with them, and it is built on a shared place of origin, culture and tradition."*
>
> — Lyla Correoso, MD,
> Attending Physician with the Visiting Nurse Service of New York, NY

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[12] U.S. Census Bureau. (2007). The American Community0Blacks. Retrieved from *www.census.gov/prod/2007pubs/acs-04.pdf.*

E. RELIGION

Historically, African American slaves in the U.S. were denied religious freedom, and racial segregation led to the development of separate, organized religious denominations. While African Americans practice a number of religions, Protestant Christianity remains the most popular with a nearly 76 percent following, the majority of Baptist and Methodist tradition. Seven percent identify themselves as "Other", six and a half percent are Catholic, less than one percent are Jewish and about ten percent do not identify with any religious group.[13]

Further, a profile of African American religious participation reveals that 70 percent attend religious services at least a few times a month, and 80 percent pray nearly every day. 27 percent read religious books and 21 percent watch or listen to religious programming on television or radio daily. Overall, 80 percent consider themselves to be either very or fairly religious.[14]

In African American faith communities, members seek out everything from spiritual guidance, to relationship counsel, to adult vocational education programs. Each African American religious tradition takes great pride in its ability to hold together its congregation even in the gravest of times. From native Africans initial embracing of Western religions while retaining elements of their own native traditions, the evolution of the Black church into today's modern religious practice remains the backbone of African American communities.

Note that because of the popularity of Christianity among African Americans, Christian themes and spirituality predominate throughout this Guide, and many of the strategies tie into a Christian faith base. However, we recognize that not all African Americans are involved with a church, nor are all Christian.

"[Healthcare] decisions and actions taken are often based on religious traditions, such as fasting, prayer, seeking God (specifically God's will) and even asking a doctor to pray with or for the patient and family."

— STACIE PINDERHUGHES, MD,
CHIEF, DIVISION OF HOSPICE AND PALLIATIVE MEDICINE,
NORTH GENERAL HOSPITAL, NEW YORK, NY

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[13] Religion Newswriters Foundation. (2007). A Guide to African Americans and Religion. Retrieved from *www.religionlink.org/tip_070108.php#stats*.

[14] Mamiya, L. (2006). *Pulpit & Pew: Research on Pastoral Leadership*. Section II: Profiles and Studies of African American Laity. Durham, N.C.: Duke Divinity School. p. 24.

Section II. African American Focus Group Findings

In May 2006, NHPCO's Caring Connections conducted two African American end-of-life focus groups in St. Louis, Missouri. Men and women were interviewed separately. Group participants discussed their general feelings and issues regarding end-of-life thinking, talking and planning. Participants were then asked to read and react to topics such as advance care planning, end-of-life caregiving and hospice. Key findings are below.

A. DEATH, DYING AND ADVANCE CARE PLANNING

Group participants were divided on their comfort level on the topic of death and dying – some seemed at ease, while others felt that it was culturally taboo to even discuss it. Older participants indicated that they talk about it more as they themselves are aging. Generally, there is a conflict between wanting to be informed medically, but being culturally bound to privacy and wanting to turn to and rely on faith first and foremost.

"It interests me now. There was a time when I used to kind of shy away from that, because... there's just something about it that you just don't want to talk about. You don't want to hear about it. But as you get older, it comes to the forefront of your mind and so it's like you want to go and find out things about it."

— African American focus group member commenting on death

Most participants were unaware of the true meaning of advance care planning, using it interchangeably with end-of-life care, which they connected with life insurance and funeral planning. Many misinterpreted the materials they were given, and thought that advance care planning referred to an agency or organization where all advance directives are stored. Hospice staff, therefore, should emphasize the role of the family, and that it is possible to name the person who would make decisions on a patient's behalf. There was significant distrust that even if preferences are specified in writing, that the medical professional in charge would not honor them.

"What I sense that you're leading at is, a person fills out a document and then you get this document notarized or something and this goes to some agency and then when the person is ill then the hospital had the responsibility to contact this agency and see if this person has a document ready and the document says or the person says, 'This person wants to be kept alive by all means possible,' then the doctors are going to be bound by that document. I don't think it's going to happen like that."

— African American focus group member commenting on Advance Directives

Many said they would not want to be kept alive on life support indefinitely because of a fear of being a burden on their loved ones, but would want a few weeks to be given a chance at recovery. While most feel that advance care planning is a wise idea, concerns were expressed; some even stated that the very idea of writing your wishes down was quite strange, especially "pre-crisis."

B. CAREGIVING

The African American family structure is usually tightly-knit, extended, matriarchal, and includes many close friends who are considered kin. While families are more dispersed today, it is still expected that family members will find a way to care for loved ones in their own homes. This choice is always preferred to someone coming 'from the outside.' Therefore, caregiving provides the strongest foundation on which to begin a discussion of end-of-life issues. Participants repeatedly stated, "We take care of our own." It is important to stress that hospice supports caregivers; it does not replace family members or preclude them from playing a central caregiving and decision-making role.

> *"I think we talk about mostly caring for each other or our loved one at the end, during the end of their life on earth other than just their dying. Blacks seem to be concerned with taking care of their people."*
>
> — African-American focus group member

C. UNDERSTANDING OF HOSPICE

About half of the participants had heard of hospice care, although there was much confusion over what hospice really is. Some recognize that hospice is for when "they run out of things to do medically; they can't do anything to cure you." Yet many think of it as a place someone is "sent away to" when their family has "abandoned" them, and equate it to nursing homes.

Because nursing facilities are viewed so negatively, it is important to emphasize that hospice care is most often provided in a person's own home. The most frequent concern was the financial aspect, and an inability to believe that Medicaid, Medicare and most private insurance companies cover hospice expenses. Some were still doubtful even after reading NHPCO handouts explaining the Hospice Medicare Benefit.

Section III. Strategies for Reaching Out to African American Communities

There are many ways to conduct outreach that meets the needs of your organization and your community. By showing yourself as a true partner who wants to give, you engender goodwill and open the doors to all members of your community. The most successful outreach programs have been patient, and have taken time to simply observe and listen. We suggest that you be very creative and pursue opportunities that you wouldn't ordinarily consider. Above all, remember the deeply rooted historical issues for most African Americans, and be sensitive to these in your interactions.

A. GET ORGANIZED

Before implementing any strategies in your outreach, it is important to critically assess your existing resources, survey your community, formulate a plan and gather support. This foundational analysis is critical to any outreach effort, no matter which community you are targeting. While it is always noble to want to expand and diversify your clientele, you must be prepared to serve them adequately, should your outreach be successful!

- **Evaluate resources.** As you begin, your first step should be an assessment of your existing financial and personnel resources. Will the overall financial health of your organization be able to support the special requests and additional expenses that will arise as you conduct your outreach and your census increases?

  Visit the Caring Connections Web site at *www.caringinfo.org/community* for resources that can get you started. For instance, "The Golden Rules of Outreach" outlines essential elements of outreach, and "Community Assessment Guide" helps you evaluate the specific end-of-life needs in your community.

  Additionally, do you already have a staff person who is designated as outreach coordinator? Can you afford to hire new staff? Perhaps you have someone who is already engaged in community outreach, but his/her work is focused on a different ethnic population. Conceivably, this person might be able to take on additional duties, or assume a new role. (We will explore this point in more detail in "Find the Right Fit" section of this Guide.)

- **Survey your community.** Gather local demographics as well as your own organization's current trends. Learn what African Americans in your community already know (or don't know) about hospice and palliative care. Some may be well aware but choose other options, while others may be misinformed and not understand the true benefits.

  The focus group findings summarized previously in this Guide offer some insight, and you might consider conducting your own one-on-one informational interviews or organizing small focus groups to gather data specific to your community. Or, hold a town hall meeting to open a wider dialogue.

The structured conversations in this type of gathering provide opportunities for community members to share their concerns, needs and questions about end-of-life care and services. See Caring Connections "Convening Town Hall Meetings" at *http://www.caringinfo.org/Community/Outreach-StrategiesAndTools.htm* for details.

With the knowledge gained during these groups and/or meetings, you will have targeted, detailed and intimate information that gives you the most personal perspective on how African Americans in your own community truly think and feel about end-of-life care. Your staff will be better educated and your ability to serve the community will be infinitely greater.

- **Gather support and form a planning team.** Be certain that your senior leadership and all levels of staff are on board with your outreach plans. The entire organization should be engaged and share the same vision of inclusiveness and growth. The key element is forming a planning team, which should include staff as well as a wide range of community members. These individuals will ensure that a core working group is in place to support the hard work of your primary outreach liaison, and provide reassurance that he/she is part of a larger team working together to build lasting links between your hospice (or coalition) and African American community members. (More suggestions for team planning and building will be discussed in the "Build Partnerships" section of this Guide).

- **Develop a plan.** As you gather your data and support, decide where you want to start. Discuss short and long-term goals and expectations. Develop a plan of action, one that is linked to any existing marketing strategies for hospice access in your service area (see the "Consider Marketing" section of this Guide). Tap into existing networks, particularly the African American hospice outreach programs operating across the country that are highlighted in this guide.

Lyla Correoso, MD has found that there is a great lack of understanding among both the African American as well as the general population regarding end-of-life care options and treatment. She describes some specific examples:

- Encountering many caregivers who simply quit their jobs to take care of a parent, spouse or other loved one, not knowing about the Family and Medical Leave Act (FMLA).

- Little to no understanding of the concept of palliative care. Hospice home care statistics for the organization revealed there were 5,000 patients who could benefit from the palliative care model but were not getting referred accordingly. So it is not only the patients themselves who are un-informed, but many healthcare professionals, as well.

- A suspicion of hospice even among nurses, who in some cases also had very little understanding of advance directives (a particular problem in the state of New York because patients are required to have healthcare proxies). In response to this, a special hospice teaching program was initiated designed specifically for nurses. And to help those nurses who were struggling to find the right words with their patients, the organization developed a card with talking points for use when interacting with patients and families.

- **Train your team.** Make sure your hospice incorporates diversity training into your staff orientation or ongoing in-service education. Train all of your staff, including administrative and clinical personnel, as they are all part of the team. Emphasize the following end-of-life care issues specific to African American communities: healthcare history, healthcare disparities, spiritual aspects of care, and sociological and cultural perspectives on death and dying.

Cassandra Cotton, CNA, CHPNA, of Nathan Adelson Hospice, shares the following story that illustrates the need for staff to be culturally sensitive. "You need to start by asking, 'What's in your basin?' This refers to the contents of the personal care kits that patients in her program receive upon admission. Many people don't know that fine-tooth combs are difficult to use and can be damaging to African American hair. And so if you present a welcome packet with items that are not suitable for them, it gives the impression that the organization doesn't really know or care about patients. It also misses an opportunity for deeper understanding and connection. Give your staff the right tools to care for patients, and make sure they know how to use them correctly."

An excellent resource is the Duke Institute on Care at the End of Life's APPEAL (A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End) training. Designed specifically for healthcare providers working with African Americans facing serious illness, the curriculum (accredited CEU's) includes a wide range of topics: spirituality, cultural beliefs, values and traditions of African Americans that may influence end-of-life care, the impact of racial disparities throughout the healthcare continuum, and barriers to quality care for African Americans with serious illness and strategies to improve their care. For more information about APPEAL, visit *www.iceol.duke.edu*.

B. FIND THE RIGHT FIT

As you begin your outreach to African American communities, your planning team must be led by the right messenger. This messenger is the one who serves as the primary point of contact and organizer for all African American outreach activities. It is a big job, and hopefully one made more manageable by the support of your entire planning team. In addition, consider the diversity of the team itself. While it is not absolutely necessary and will not guarantee success, if your staff reflects the community you are seeking to serve, your ability to connect may be enhanced.

- **Select a messenger.** As introduced in the "Get Organized" section of this Guide, if you do not already have a point person, perhaps one can be hired, or another position can be adapted to fulfill the role. Alternatively, you might find a current hospice volunteer or another community member who would be willing to take on these responsibilities in a volunteer capacity. If you can make this happen, we suggest that you clarify how this person will serve as an official representative of your hospice and speak on your behalf.

  In filling this position, there are some important skills the person must possess. Personality matters more than anything else. *Is this person open-minded and creative? Is he/she the type of person who can develop and maintain relationships? Is he/she comfortable with public speaking? What about offering prayers?* In many settings at which African Americans will be present, it is expected that a prayer will begin and end a meeting, so he/she must be both comfortable in prayerful environments, as well as saying prayers him/herself. *Is he/she able to engage with diverse groups of people? What level of commitment does he/she bring? Can he/she be patient and commit for the long term? Does he/she have a willingness to work after hours and to attend a variety of functions across town?* Finding the right fit for that individual who will share your primary message with the community is of the utmost importance, so try to make your match carefully and appropriately.

- **If you can, hire diversely.** Making staff diversity a priority is simply smart and forward thinking – it enriches your organization and ensures that you remain vibrant and growing. For the specific purpose of outreach to African Americans, many hospice programs expressed that it can help if some members of the team look like the patients they serve. So if your staff is not already diverse, consider targeted recruitment to build a team that more accurately mirrors the wide range of people represented in your community. As mentioned in the "Get Organized" section of this Guide, be sure to provide diversity training for all of your staff, especially for those engaged in direct patient and family contact.

> *"I don't think necessarily you have to be an African American to provide good care to African Americans, but it you're not, you really need to be aware of the culture and some of the issues in that culture, and really look at how you feel about dealing with people from that culture,"*
>
> — AFRICAN AMERICAN NURSE [15]

C. EDUCATE, SUPPORT AND LISTEN TO YOUR COMMUNITY

Informing, caring for and genuinely hearing the needs of the African American community are essential elements in your outreach, and enrich the opportunity for positive community-building. Simply meet the community where it is. Try to do more listening than talking in your growing relationships. Yet be sure to focus on education, show your support for the family systems that are already in place caring for loved ones, take your time, ask questions and listen to the answers. We suggest that you leave behind any preconceived ideas and stereotypes and don't make assumptions.

- **Address what hospice is and is not.** Be sure to focus on the "mis-facts," and don't assume that everyone is accurately informed. Learn what misconceptions are prevalent, and address the common misunderstandings. One of the biggest barriers to hospice use among African American communities is that they associate hospice with a "place" as opposed to a concept, and that "place" is where they go to die, so it's definitely not a "place" they want to go. There is also the view that suffering is part of hospice because traditional medicine is no longer allowed, or that pain is actually encouraged based on faith beliefs. Clearly, awareness among caregivers is a key to building true understanding.

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[15] From an interview for the Institute of Medicine's "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care" report, 2002.

So wherever you are, whenever given the opportunity, explain hospice benefits clearly. The ability to pay should not be a deterrent for anyone, and particularly African Americans who are more often uninsured. Explain the Hospice Medicare Benefit, and how re-certification works, if needed. Patients and families, and even some healthcare providers themselves, are often unacquainted with the benefits available should the patient live past six months; they are also sometimes unaware that some patients "graduate" from hospice.

Cassandra Cotton, CNA, CHPNA, of Nathan Adelson Hospice shares this perspective on the need to educate families about pain and suffering. "Education is a huge component – for patients, families and faith leaders. No one should die in pain. Alleviation of pain does not mean that prayers and hope for healing are discontinued. Pain and suffering are not necessary for atonement of life's indiscretions. Yet my own mother viewed her suffering as necessary for past sins. She died believing that if she had had just a little more faith she would have been healed."

- **Support the caregiver.** Recognize and respect the strong history and tradition in African American communities of "taking care of our own." African Americans have done so for centuries, and so effective outreach activities should not include a "we'll come in and do it for you … because we can do it better" message. Offer to support current caregivers, explaining how the interdisciplinary team will care for the family, as well as the patient's physical, emotional and spiritual needs. Explain different options for care, from home-based to inpatient facilities.

- **Take your time and be patient.** Because many African Americans are suspicious of hospice and the entire healthcare system, and prefer to keep their illness to themselves, you must be patient throughout this process. Be prepared to make multiple visits, with many family members present, sometimes even with the pastor involved (see the "Embrace the Faith Community" section of this Guide), acting as a family liaison. This won't be a one-time conversation, and you may not get buy-in the first time. You must be willing to go through many rounds with the family so they know you're committed and that you truly have their best interests at heart.

- **Listen to their story.** As healthcare professionals, you have an incredible wealth of information – both from your clinical training as well as your professional experiences, and the natural inclination is to want to share all of it. Yet many African American families are not going to be interested in hearing from you just yet – they would rather be heard themselves, first. Sometimes it's best to listen. Many patients and families want someone to take the time to hear about their life's journey.

Gloria Ramsey, RN, JD, a nationally recognized expert in bioethics, nursing education, and health disparities, as well as a professor with the Uniformed Services University of the Health Sciences in Bethesda, Maryland, shares the following observations about the need to respect privacy and how differently African Americans deal with crisis. "What's of concern, from a deeply rooted cultural belief, is that African Americans are very private about diagnoses. The whole notion of people coming to the house, driving the vehicle with the hospice logo on it – these are difficult things for African Americans to accept. The concept of it being 'my business, and I don't want people in my business' can be a struggle, as well, because in an effort to keep people out of 'my business,' families are keeping out the very people who could be of great help."

You and your team members may need to adjust your approach. Currently, your preferred style for initial consults might be to say, "Here's what *hospice* can do for you." Instead, begin the conversation with, "What can we do for *you*?" A frequent comment made by African Americans under hospice care is that they would actually like to be asked what they think, what they know and how you can help. A common statement is *"If only we had been asked."* So ask the questions and go from there. Eventually, the time will come to share the benefits and support that the hospice team will be able to provide.

D. FIND YOUR VOICE AND LET YOUR MESSAGE BE HEARD

Whenever and with whomever you engage, do so consistently, with a clear voice that sends the same message every time — we care, and are here to support you in all of your needs. Be mindful of the actual language used in personal conversations, and if appropriate, integrate faith-based language as you are comfortable. Your words and messages are critical as you strive to be heard.

- **Be genuine.** This is a simple, yet profoundly important element in your outreach. Be sincere and transparent. Connect deeply, and seek to genuinely empathize with the range of end-of-life issues your African American community is facing. You and your colleagues must be willing to devote time and energy to making lasting changes that support your outreach. With your staff embracing this intention, it is one that your community will eventually buy into. Anything less is disingenuous and will be quickly dismissed as staged efforts to gather people in without true substance.

- **Use the right words.** Try to use simplified terminology. Palliative sedation, end-of-life care, DNRs, advance care directives, opioids, artificial hydration and nutrition – while these are all used frequently in hospice settings, for someone unfamiliar with the healthcare system and facing crisis, these terms can be very confusing and even frightening. Consider focusing on the term "comfort care," especially in the beginning.

  When simplifying your language, however, be careful to not do so in a patronizing manner. Many healthcare professionals, who use medical jargon in everyday speech, should be reminded that using less technical language is a basic courtesy to patients and families who are just learning how to navigate the system.

  In addition, be sure to recognize the connected role of faith and medicine when having conversations with the African American community (see the "Embrace the Faith Community" section of this Guide.) Steer clear of scientific and medical absolutes as much as possible, and if you're comfortable, include references to faith when you engage African Americans in dialogue.

- **Rely on word of mouth.** Your commitment, your passion and your high standards of care will speak for themselves, and your personal relationships will inspire confidence. Within African American communities, personal testimony and word of mouth are among the most meaningful ways to share trusted information and get your message out. Rely on the good that you do being shared verbally within the various community systems that exist. While this shouldn't preclude some targeted marketing as discussed in the "Get Organized" and "Think About Marketing" sections of this Guide, it is a frequent method of information sharing within the African American community, and one that can be relied on.

- **Remember that it's not just business.** Regardless of how your planning team is structured or who is in charge, it is critical to operate within more of a social work frame, and less from the bottom-line business perspective. While building the numbers will be vital as you seek to maintain support and justify your outreach efforts, it is not the only thing that matters.

Dr. Bernice Catherine Harper, MSW, MSc.PH, LLD, one of the original leaders of the African American hospice movement, a former Medical Care Advisor to the Department of Health and Human Services (HHS), founding president of the Foundation for Hospices in Sub-Saharan Africa (FHSSA), and a former Board member of the National Hospice and Palliative Care Organization (NHPCO), emphasizes the importance of recognizing the role that "Dr. Jesus" plays for African American Christians facing serious illness. "Among African Americans, there are those who will be suspicious of anyone who purports to have medical answers that are best left to 'Dr. Jesus.' Be careful with any comments that begin with, 'The doctor said …' or 'The experts all say …' These statements of medical absolutes will not go over well. Instead, consider saying, 'While only God can really know when it's your mother's time, the best medical information tells us that …' or 'We really can't know for sure, but with God's will and what medical science tells us …' This manner of explanation is presented in a culturally appropriate manner and takes in the role of faith, and will be 'heard' best."

E. LOOK AND THINK BEYOND HOSPICE

There must be a commitment to more than simply introducing African Americans within your community to hospice. It's more than numbers and larger than your organization. It is about social justice and ending healthcare disparities, and helping African Americans recognize that hospice truly helps the living. As you reach out, simply consider the big picture.

- **Consider more than the illness.** Sometimes a patient's illness is just one part of a bigger, highly complex family system. It's one thing to struggle with physical pain, but altogether another to be so overwhelmed by medical expenses that there simply isn't enough money to buy groceries for the family. Ensure that your staff is aware of the community resources available to help with a wide range of issues, some completely removed from the patient's physical needs, and be certain that they share this information in detail with patients and families. Above all, an environment should be created in which a patient or family member feels comfortable enough to bring these kinds of problems to anyone on the team.

Stacie Pinderhughes, MD, of North General Hospital, New York, NY, reminds us that, "Blacks and Latinos don't want to 'embrace your dying.' So in communities of color the discussion can't be about the dying, it has to be about the living. Initiatives must answer the question, 'How does this palliative care help my living?'"

- **Recognize disparities and remember history.** In this Guide's overview and focus group summaries, a very brief review is provided of African Americans views and experiences with regard to healthcare and death and dying. Additional research reflects that many African American doctors themselves treat their own patients differently, too, and are often inclined to treat disease more aggressively, and turn to hospice later, rather than sooner. This attitude is driven both by the patients, who prefer the treatments for longer than is necessary or beneficial, and by the doctors, who want to "do right" by their African American brothers and sisters. Be mindful of the realities of treatment differences, healthcare disparities and basic historical experiences.

Lyla Correoso, MD explains, "Sometimes death is not the biggest factor. Sometimes staff has to focus on concrete services, such as paying for the electric bill and securing guardianship of children and/or parents before they can deal with issues of death and dying. Many homes are in need of additional support prior to the onset of illness, that is, there was dysfunction before, so there is no reason to expect that these problems will go away when tragedy strikes."

F. CONSIDER MARKETING

Marketing is just one aspect of outreach and community engagement along with education, public/community relations and sales. If you don't get your message out, who will? Remember that there are many misconceptions about hospice within the African American community. This is an opportunity to dispel those myths and spread the word about what hospice is, and is not!

- **Revise existing collateral or create new materials.** Collaborate with your communications team, and be sure that all of your public relations and marketing materials – brochures, newsletters, annual reports, and training manuals – anything that the public will see – offer an accurate representation of your demographics and a thorough understanding of the population you seek to serve. Images that African Americans will connect with include extended family gathered around the bedside of a loved one, families sitting together and holding hands, and a faith leader praying over a patient with family present.

  Consider revising/re-thinking *all* of your collateral, including everything from the display boards you set up at area events to welcome packets for patients and families. Some hospices include coupons from local restaurants and hand-made quilts –anything that makes a personal connection and expresses warmth and concern. If you don't have the resources or time to create or re-create your own marketing materials, Caring Connections offers a variety of brochures that you might consider utilizing.

- **Work within your systems.** If your hospice is part of a wider healthcare system in which all public relations and marketing are managed by a separate department, communicate well before any advertising is submitted. Don't let anything go out until many eyes have viewed it, especially your own, checking for accuracy of language and appropriateness of images. Since you are the one delivering the message, be sure that the actual materials are ones that are suitable and present the right ideas to draw in the African American community.

Sally Sharpe, RN, with Pike's Peak Hospice & Palliative Care in Colorado Springs, CO, serves as palliative liaison for communications and marketing. Revising existing collateral was a key part of her outreach strategy. "We formed a coalition to help look at our existing materials. We found that most only included images of white people, which wasn't an accurate representation of our community at all, and they missed an opportunity to target and address the specific fears and needs of the African American community. So we created a new brochure and video that includes images of African Americans, Hispanics, Asians and Caucasians. Basically, the pictures in the outreach materials have to look like your community, and having a specific handout just for the population you're targeting is critical. It should also include the right buzz words, which, in this case, are: relief of suffering, comfort, family and faith, and overall, less of a focus on death and more on 'transition.'"

G. BUILD PARTNERSHIPS

The foundation of all outreach is relationships, built over time on deep trust and understanding. Seek them out in both obvious and obscure areas. Commit to fostering meaningful, life-long partnerships with a wide variety of African American groups in your community. Nurture them and continually re-examine them to be sure they are thriving and mutually beneficial. This section lists a number of ways and a wide range of organizations that you can turn to, to get your community-building underway and your partnerships established for vibrant, mutually beneficial, long-term engagement.

Stacie Pinderhughes, MD, offers the following suggestion for connecting with area businesses, specifically local restaurants. "Food is very important in African American culture. It is life. It is nurturing. So building a relationship with Sylvia's, a well-known restaurant in our area, has been vital. Sylvia's agreed to provide meals to hospice patients and their families once a week. Having a restaurateur of this caliber come in with food that is familiar, is key. Offering families the opportunity for table fellowship is important. Theologically it is very Eucharistic, and this brings great peace to all who are with us."

- **Engage the entire community.** As discussed in the "Get Organized" section of this Guide, it is imperative to gather support. Your planning team can be comprised of staff and volunteers (with all interdisciplinary team members represented), as well as a wide range of African American community leaders. Don't leave anyone out! Invite local faith leaders, healthcare professionals, business leaders, academics and students to be a part of the team that will guide your outreach. Invite members to attend meetings, and encourage them to consider committing to meeting regularly to provide guidance, suggestions, focus and oversight.

- **Learn about African American organizations.** There are numerous groups, committees, organizations and coalitions within your community geared specifically towards African American interests and needs. Some are nation-wide, and others are based right in your own community and serve the needs of your population. Gather this information by simply asking anyone in a position to know, scouring local media, noting community events, surfing the Internet and checking your local Yellow Pages. When you have a fairly comprehensive list, and have done the necessary research to learn about their priorities and interest, start reaching out. (Suggestions for how to do this may be found in the next two sections, "Embrace the Faith Community" and "Participate in and Host Community Events.")

Some of these groups include:

- Professional organizations, such as the National Medical Association (www.nmanet.org), National Black Nurses Association (*www.nbna.org*), and the National Association of Black Social Workers (*www.nabsw.org*)
- Local chapters of the NAACP (*www.naacp.org*), National Urban League (*www.nul.org*) and National Black Chamber of Commerce (*www.nationalbcc.org*)
- Multi-cultural centers, both within the community and on college campuses
- Health-related organizations, such as HIV/AIDS, child/maternal health, diabetes, heart disease, and others
- Sororities and fraternities on college campuses, and their related alumni groups and members through the National Pan-Hellenic Council (a coalition of the nine largest historically African American Greek-letter fraternities and sororities with over 1.5 million members)
- Men's organizations, like 100 Black Men of America (*www.100blackmen.org*) and the Masons (*www.freemasonry.org*)
- Women's organizations, including the National Council of Negro Women (*www.ncnw.org*) and Sisterhood Agenda (*www.sisterhoodagenda.com*)

Cheryl Gilkes, a professor of sociology and African-American studies states: "Throughout history, black churches have shielded African Americans from the harmful effects of personal and structural racism and their worship services have also functioned as a therapeutic community where people can sing with joy and exuberance or cry out in pain among those who care and understand."[16]

- **Join them.** While you may be asked to attend a specific group meeting as a result of the relationships you build, also be proactive and join them, showing your commitment and passion for their cause. Contact their leadership first, and ask whether they have any topics they would like you to address at one of their upcoming meetings (see the "Participate In and Host Community Events" section of this Guide.) If they don't have something in mind, offer your own presentation ideas, and set aside a singular agenda of promoting your own hospice. Instead, use these opportunities to get to know the members themselves and to learn about their needs. Promoting your program and welcoming new consumers will come in time.

Caring Connections offers a Faith Community Outreach Guide that can serve as a supplement to this section. It provides a very comprehensive review of why reaching out to faith communities is so important and detailed strategies for how to do so. Visit *www.caringinfo.org/Community*, then click on "Faith Outreach" to download the Guide for free.

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[16] Gilkes, C.T. (1980). The Black Church as a therapeutic community: Suggested area for research into the black religious experience. Journal of the Interdenominational Theological Center, 8, 29-44.

- **Link up.** Hospice can be linked to so many causes in your community, presenting perfect partnerships for collaboration. An example is the Balm in Gilead programs, which focus primarily on African American HIV/AIDS awareness and cervical cancer (ISIS Project). Often, their events will be co-sponsored by local churches. (See the "Embrace the Faith Community" section of this Guide.) By pooling resources on projects and events, the benefits can be enormous.

- **Involve and engage young people.** Young adults, teenagers, even 'tweens' have the energy and enthusiasm of youth, and an excitement and passion about causes that can invigorate families, schools and communities. Many are often seeking to fulfill community service hours, either through their school or their church, and will eagerly take on a variety of tasks within your hospice, providing diversity through ethnicity and age! Young people will be eager to help spread the word about you and what you do, especially if they're engaged in a project that excites them. So don't leave this pool of potential participants out when seeking opportunities for partnership-building.

Gloria Ramsey, RN, JD, relates, "You want to go into a place where you're building upon existing and already established relationships and infrastructure. You can't build that capacity and do the work, too. There needs to be great give and take between both parties. After you've made your assessment (because you need to know your baseline), let them assess if they want to work with you, too. Build on the knowledge you gather about community, culture and church — all these must go together."

H. EMBRACE THE FAITH COMMUNITY

Within African American communities, faith can carry more weight than medicine. As discussed in the "Religion" section of this Guide, many African Americans are deeply connected to their faith community and will turn there for support before seeking help from other agencies. The church serves as the bedrock of spiritual activity, a center of social engagement, an indispensible source of information on all topics and a critical foundation of support in times of crisis.

- **Faith is "It."** Studies suggest that African Americans are willing to participate in health education programs such as smoking cessation, blood pressure and cancer screenings when they are held at their churches, mosques, and synagogues. And since the place of worship is often the primary source of information on a wide range of subjects, it offers one of the best ways to reach the widest audience in a safe, trusted environment.

> *"If I can't have cure in my body, at least let me have healing in my soul."*
>
> — Bishop Simon Gordon,
> Triedstone Full Gospel Baptist Church,
> Chicago, Illinois

- **Find your "In."** Begin by identifying the person who handles health-related issues. This might be a lay leader, member of the Diaconate (deacon or deaconess), parish nurse, the head of the congregational care ministry or a social worker who serves as bereavement coordinator. He/she can be your conduit to the pastor (unless you are able to meet with the pastor from the outset). Set up a time to meet and find out the needs of the congregation. If appropriate at the first meeting, offer to host an advance directive or a hospice session. If the church holds its own health fairs, ask to set up an exhibit.

  Consider attending services regularly. Come early and stay late for personal introductions and to distribute materials if appropriate. Become a presence in the church. In time, congregants will know you as the hospice contact, and may start coming to you with their needs.

  Research shows that there are more than 1,700 church-sponsored outreach programs providing for the spiritual and physical well-being of African Americans. These programs cover basic needs such as food, clothing and shelter; financial aid and counseling for personal problems; health-related concerns such as HIV/AIDS and substance abuse; and recreation and fellowship for youth and families.[17] So within this spectrum of faith-based support, be aware that you may be competing with many requests from other groups and simply emphasize that hospice can also be a part of those conversations.

Sally Sharpe, RN, involves pastors as intimately as possible in all familial interactions, particularly in the very beginning. "We ask pastors to be present when the initial meeting takes place with a family, or at a minimum, to call in from their offices while we're meeting with the family. The best strategy is to try to make sure that the pastor is actually there in the home. We have developed a great relationship with our African American community and church. If the pastor is pro-hospice, it makes the process much easier, and infuses it with trust and security."

- **The Pastor's role is a critical one.** Not all clergy and faith leaders have the skills to advise families on end-of-life decisions. Be aware that many families will keep their pastor intimately involved in discussions and decisions about their care. Some families will even ask their pastor to be present for at least the initial meeting with hospice admissions staff. Welcome his/her presence and encourage the family to keep that relationship strong.

  Generally, pastors emphasize the duality of spirituality and proper medical care, and when serious illness is involved, it is important that he/she understands the wide range of hospice services, and how they can support his/her congregants. Be aware that some families see the pastor's job as praying for healing, first and foremost. While the pastor him/herself will acknowledge that he/she cannot work miracles, the mere suggestion of hospice might be of concern to a family who will perceive it as a pastor turning away from faith and more towards medicine.

  Pastors often find themselves negotiating the delicate balance between continuing to pray for hope and healing, but also encouraging the supportive network and resources of hospice.

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[17] Billingsley, A. (1999). Mighty like a river: The Black Church and social reform. New York: Oxford University Press.

- **Celebrate life and living, and the role of faith and hope!** Explain that hospice is not about giving up and ending life prematurely, but instead about celebrating life and making the time remaining as meaningful as possible. Hospice's focus is appropriately on life and living, with the ever-present acknowledgment of the role that faith plays. Because faith and healthcare are inextricably linked within African American communities, your team will be unsuccessful if you avoid spirituality and talk only about medicine. But do emphasize that accepting hospice does not mean the patient must give up faith and hope for healing. Hope is always a part of hospice.

Dr. Bernice Catherine Harper, MSW, MSc.PH, LLD, shares this perspective on the need to recognize death and dying and views on hospice within African American communities: "Be aware that African Americans, like most of us, are not into death and dying; they are into life and living! As a general rule, they see death as going home, and going away from a world of discrimination and hardship. So they can't get too excited about hospice. To them, hospice is a white middle class movement, and not one they view as personally applicable. So we need to help them understand it and be aware of it and present it to people of color in the appropriate cultural context. Be prepared to address the underlying concerns of the patient and family who will respond with, 'Where have you been my whole life? When I needed clothes? Or food? Now you come when I'm dying. But I'm going home. I don't need this now.' We need to break those barriers to healthcare and hospice for African Americans."

Check out Caring Connections' *It's About How You LIVE* campaign toolkit and NHPCO's 2008-09 Outreach Guide which uses the theme of Hope, Dignity, Love…It must be hospice. Both resources contain a collection of ideas, suggestions and materials to help you with your outreach efforts.

The Duke Institute on Care at the End of Life, and the Duke Divinity Office of Black Church Studies developed the Proctor Covenant Statement on End-of-Life Care. The covenant serves as an initial pledge signed by faith leaders from across the country to support initiatives to improve end-of-life care in the black church. The Proctor Covenant statement is available to view and download in the Appendix of the Guide and can be used as a theological statement on quality care at the end of life and a defining statement, standard and guide for African American clergy. For more information, visit www.iceol.duke.edu.

I. PARTICIPATE IN AND HOST COMMUNITY EVENTS

To help make hospice a household word in your community, participate in local community events, especially ones organized by and for African Americans, or ones that target issues of interest to the African American community. Organize events and invite everyone to participate. These can be held in conjunction with existing events or independently. Either way, find the appropriate focus and work collectively to plan successful gatherings that energize and inform and bring your diverse groups together.

As with many other elements of your outreach, the key is to take your time and do your research before rushing into things. Excellent tools and resources are available at *www.caringinfo.org/event_planning_toolkit*, where you will find checklists for planning your event, sample flyers and posters, even how to publicize your event. While most event planning strategies can be effective regardless of your audience, some will be more successful depending on the specific community you are trying to reach. The following essential elements are geared specifically for participating in and hosting events for African American audiences.

- **Come to my house!** Look for opportunities to invite folks to "your house." Welcome all potential partners and interested parties to an inaugural event to initiate your outreach (see the "Build Partnerships" section of this Guide). Community or prayer breakfasts are often very successful and can be incorporated into a workday. Ask one of the attending faith leaders to offer a blessing before the meal, thereby acknowledging the integral role that spirituality plays from the very beginning.

  Think very creatively about opportunities to gather. For instance, an event scheduled around the birthdays of Charles Drew (the father of the modern blood bank) or Daniel Hale Williams (the physician who performed the first successful open heart surgery) is an excellent way to honor the contributions of prominent African Americans, built around a creative celebration that also focuses on wider healthcare/hospice topics. In conjunction with your coalition or planning team, select a prominent community figure to host the event.

- **Can I come to your house?** As your relationships grow, invitations to "go to them" may come. If you sense reticence, spend more time getting to know one another, and in time, as trust is established, the call may happen. If appropriate, bring copies of your collateral materials to distribute.

- **Make your message relevant.** Don't waste your new partner's time or yours by trying to guess which topics will be of most interest. Ask your contacts which issues are important to them. Combine this with the data from your community surveys. (See the "Get Organized" section of this Guide.) You can serve as a clearinghouse organizer for a variety of topics, all with specified relevance to that community group. Hospice, advance care planning, caring for the caregiver, and how to pay for healthcare may be topics to offer depending on your initial assessment.

- **Team up.** Don't try to do it alone! As mentioned in the "Build Partnerships" section of this guide, there are many other organizations with whom you can partner and host joint events. Hospice can play a role with health prevention groups focusing on HIV/AIDS, diabetes and cancer, or offering bereavement support to families of accident, suicide or homicide/gang-related victims.

  Families affected by homicide or gang violence are a natural outreach for hospice since staff members are experts at loss. Bereavement support to families experiencing loss bridges a gap and shows hospice as an inclusive caring group of experts who seek to help all those who are facing death and dying. However, when referring to what might be perceived as a stigmatizing topic for African American communities, be sure to avoid the suggestion that the issues are solely African American problems; homicide, gang violence and crime are universal societal concerns.

- **Go everywhere, attend everything.** There is rarely a lack of African American-focused community events to attend. Go to as many as you can, and invite staff members with you, particularly if it's to a high profile event, such as a gala or an awards banquet. Include a diverse representation of staff disciplines and ethnicity. And, if appropriate, bring your table-top displays and handout materials.

  Examples of events include:

  - Black History Month
  - Martin Luther King, Jr. Day
  - Kwanzaa (usually celebrated by younger families in addition to Christmas)
  - Juneteenth celebration (*www.juneteenth.com*)
  - Women's and men's group meetings and conferences
  - Fashion shows
  - School productions
  - and more ...!

Toula Wootan, Director of Community Relations for Community Hospice of Northeast Florida in Jacksonville, turned her outreach into a special initiative on community relations, targeting everyone who might be in need. She says, "It's all about relationship-building, and the overall goal should be one of community building. You must be patient and take time to build trust, particularly around healthcare. You need to show that you care about the health and welfare of the community. Show your sincerity by taking things a step further. For instance, we've partnered with one of our city hospitals for indigent care. We reach out by providing preventative care to local churches. In addition, we have the largest murder rate in the state of Florida. So to address a broad community concern, we launched an initiative called 'Operation Safe Street.' We involved many community groups, particularly African American churches. The focus was on gun control. We're experts in loss and bereavement, but can offer our support in ways other than hospice. We try to show that we care about the community, holistically. Our message is that we're here to care for you, and we're concerned about the same issues that you're facing."

See the Appendix section of the Guide to download PowerPoint templates for Hospice and Advance Care Planning presentations that you can adapt for your community education needs.

"You should always ask to participate in health fairs or other community events, such as Juneteenth celebrations. These events are a part of the community, and you should absolutely be there to help support the event and the occasion itself. Some will be invitation-based, so your goal, as part of relationship-building, is to be the one invited. If you've built the right kind of relationship, one that is focused on more than death and dying, they'll see you as a resource and want to include you. So if you've been the first to reach out and trust has been built, you will be seen as a true partner."

— Sally Sharpe, RN
Pike's Peak Hospice & Palliative Care
Colorado Springs, CO

J. CONNECT WITH AFRICAN AMERICAN MEDIA

The opportunities to get your message out are plentiful and consider the media outreach as an extension of your outreach plan. Research your local media, and determine which are targeted to African Americans. There are often daily, weekly or monthly periodicals, published by and for the African American community, as well as radio and television stations (both secular and religious) geared specifically to the same.

- **Research media outlets.** While you may have already done a good amount of market research on your community, as described in the "Get Organized" section of this Guide, do some specific digging to gather all of the information you can on your local media, learning which demographics they target. Turn on your radio and television and tune into their stations. Listen to the advertisements and make lists of popular topics and personalities. This may give you some insight into what's being advertised – by whom and to whom.

  However, because many people not of African descent rely too heavily on the media for research into the African American community, be appropriately cautious of the information you come across. Many African Americans will tell you that their community is much different than even the black media portrays them. A good comparison is the representation of Italian-Americans in literature and film, where an almost fantasy version is concocted with its emphasis on mafia ties. The best way to research real African Americans is to go into their communities and participate in their everyday activities.

- **Make contact.** As you have with all other groups or individuals, make formal and sincere introductions. Explain your intent. But before asking about advertising or articles, get to know key staff members – reporters, publishers, DJs. Invite them to join your advisory group, or come to a specific event. As with all of the strategies, a personal relationship will take you much further than throwing collateral at a media representative and expecting it to lead to a prominent feature.

- **Get your advertisements and articles printed.** Buy advertising space and submit articles - and don't necessarily propose something that solely features your hospice, at first. Instead, help celebrate a traditional African American holiday (see the "Participate in and Host Events" section of this Guide). While "Hospice X honors Topic Y" is getting your name out, it's being done in a more subtle and gracious manner. In time, you might present a specific ad or article on your hospice or coalition – and make sure that it is appropriate to the African American community, featuring images and language that are relevant and fitting.

- **Find your own spokesperson.** There may be an African American celebrity, local or national *(e.g., music industry representative, civic leader, local business owner)* who would be interested in becoming another voice for hospice. If a high-profile personality lives in your own community, or someone you know has a personal contact that could be promising ... pursue it!

Sharon Latson, Senior Director of Access Initiatives, VITAS Innovative Hospice Care® of Chicagoland, suggests that it's wise to link up with ethnic-specific media, but to be subtle in your advertising with them. "Historically, African American businesses weren't able to advertise or be employed by some local media, so they created their own. This has built a rich pool of African American media specialists who know how to reach their audience. While our objective is to get VITAS' name out, we try to do it in a way that is not just about hospice. We submit ads that convey a message of 'When you may need us the most.' This way, we create a presence and an awareness of VITAS in the community in an understated way."

As all of these strategies suggest, one of the most important things that your organization must do when working with any cultural community for the first time is to build trust. Gaining the trust of a community takes time. Developing trust must be your main goal when seeking new partnerships and relationships. In our goal-oriented society, it is all too easy to focus on project goals rather than relationships. However, meaningful relationships are the best path to long term accomplishments. This is the best guarantee to successfully build partnerships and implement outreach activities with the African-American community.

For more information and resources on outreach to diverse communities,
visit *www.caringinfo.org/community*, and click on 'Diversity Outreach'.

IV. Model Outreach Programs and Initiatives

A. BRIDGING THE HEALTHCARE GAP: A TOUCH OF GRACE HOSPICE, INC., CHICAGO, ILLINOIS

After working in the hospice field for many years, Dr. Jennifer Moore knew she wanted to help decrease healthcare disparities among minorities, and specifically, increase the use of hospice services among African Americans.

Her solution? Founding and directing her own hospice, one that would focus on serving African Americans in the inner city. With a mission of bridging the healthcare gap among minorities and improving the overall quality of care to the local population, A Touch of Grace Hospice, Inc. focuses on the highest standards of care and cultural sensitivity, and provides extensive and ongoing diversity education and training for its staff, serving a census that is comprised of 97% minorities.

Moore understood what the barriers were from the outset – primarily distrust and misunderstanding. She found that increasing minorities' use of hospice must begin with healthcare provider education, and how hospice itself is presented. She advises professionals to stay away from typical "med-speak" and to present information in a culturally appropriate manner. The role of faith must be emphasized, not in a sense of giving false hope, but relating to their fears, and acknowledging the need to pray for hope and healing.

Another large obstacle is re-informing the community on what hospice truly is, and dispelling myths, especially those pervasive among African American communities. So education is a key component – in all of her outreach, with individual patients and families, as well as staff. Moore has found that once the community is well informed, residents become more receptive to the hospice dialogue. And the fact that her staff mirrors the community it is serving (94% are African American) is a particularly beneficial aspect.

Moore's key outreach strategies include the following:

- Create and make available culturally sensitive material
- Acknowledge the faith of the community
- Address what hospice is not
- Strive to have healthcare staff that looks like the community you're serving
- Meet with people one-on-one and be genuine
- Rely on word of mouth
- Consider more than end-of-life needs, because for some families, you have to start there before you can even talk about hospice

B. CONNECTING THOUGH FAITH:
NATHAN ADELSON HOSPICE, LAS VEGAS, NEVADA

It's personal for Cassandra Cotton, CNA, CHPNA, Community Relations and Outreach Coordinator at Nathan Adelson Hospice. After making a career switch to hospice after her own mother became ill, Cotton found fewer African Americans being served, and set out to change that. So she turned to her faith community, and with the support of her supervisor and pastor, established *The Caring Touch Ministry* at her church, one the largest congregations in the state. The ministry's goals are to support those who have been diagnosed with a life-limiting illness or are experiencing a debilitating disease, and to provide ongoing education about hospice services and continue the dialogue on end-of-life issues with the wider community.

Cotton says, "The education process begins with identifying the role of both the faith community and hospice. For centuries, faith communities have been the epicenter of caring. Hospice providers must find ways to educate faith communities and engage faith leaders in end-of-life care conversations. The congregation must have an informed, trained leader who has an understanding of the range of hospice services and how these services are delivered."

Cotton's first steps with *The Caring Touch Ministry* were to create a task force that helped spread the word throughout the congregation, and conducting a survey of the congregation to learn what they knew about hospice. She found great misunderstanding about hospice and a reluctance to discuss death and dying. So her strategies focused on hospice education, and training a core team of congregants to serve as members of the hospice ministry. Members now serve as hospice educators, spiritual caregivers and important referral sources.

Her next and ongoing initiative was setting up a workshop as part of a wider church health fair, entitled, "Getting Your House in Order." The focus was on advance care planning, presented in a scripture-based way so that the message of "preparing for your home-going" was one the community would hear. She emphasized the importance of building partnerships for the event, and linked with other churches, local Social Security and Medicare offices, the Nevada Center for Ethics and Policy, elder-law attorneys and notaries, nurses and hospice aides, volunteers, and funeral directors. She made sure that other community partners, such as local eateries and entertainers, would provide in-kind donations, and make the event fun and interactive. "Getting Your House in Order" events provide ongoing education and are well received by the entire community. And *The Caring Touch Ministry* serves as a solid link between its congregation and Nathan Adelson Hospice.

C. EMPHASIZING COMMUNITY-BUILDING: PIKE'S PEAK HOSPICE & PALLIATIVE CARE, COLORADO SPRINGS, COLORADO

In 2001, One Voice At a Time (OVAT) was begun as an initiative by Pike's Peak Hospice and Palliative Care (PPHPC) to address the under-utilization of hospice services by African Americans in Colorado Springs/El Paso County. Led by Sally Sharpe, a nurse who serves as palliative liaison and director of communications and marketing, OVAT quickly turned into a community-building endeavor as well. Recognized locally and state-wide for its innovative ideas, OVAT has received multiple awards, including the Outstanding Achievement Award from the Colorado Hospice Organization in 2003, and the Urban League Community Outreach Award in 2004.

The OVAT advisory committee was formed with the intention of not simply informing the community of what PPHPC does, but also listening to what the community's needs were. OVAT staff focused on spreading that message. Within a year of its inception, OVAT had reached out to other prominent organizations in the African American community such as the Black Leadership Forum, NAACP and the Urban League. From the initial support a coalition was created, including staff, ministers of local congregations, prominent African American leaders and a wide range of community members simply interested in supporting the cause. Recent events include healthcare conferences and fairs, Urban League Elder gatherings, and an NAACP-sponsored Freedom Fund. And as a part of bereavement outreach, an OVAT committee member suggested "Barber Shop Gatherings," which has turned into a popular way to support local African American men in one of their most comfortable settings.

In 2003, OVAT released new brochures and a video geared directly towards end-of-life care for African Americans and other minorities. PPHPC credits its success to building strong relationships, initiating community gatherings and always making face-to-face contact (as opposed to direct mailings). While promoting OVAT events, it also sought to build the initiative beyond hospice. OVAT has become a community-building and enriching program, and together with the strong ties built with both the African American and other minority communities, continues to spread the message of hospice and palliative care.

D. FOCUSING ON CHILDREN: HOSPICE AND PALLIATIVE CARE OF GREENSBORO, GREENSBORO, NORTH CAROLINA

Kids Path, a unique children's hospice program developed by Hospice and Palliative Care of Greensboro, is the most diverse program of all those offered by the organization, serving well over fifty percent minorities in both North and South Carolina and West Virginia. Housed in its own facility, it cares for children ages 3 – 18 who are living with serious, progressive medical conditions. In addition, it provides support for children and youth experiencing the grief associated with the illness or death of a loved one.

The goal of Kids Path is to enhance the quality of life for children and those who share their lives while regaining a sense of normalcy. Ursula Robinson, Vice President of Clinical Services, explains that "the program is unique in that it targets all sick children, not only those with a six-month prognosis and eligible for Medicare, but situations where the doctor does not believe they will reach adulthood. It is palliative care in the truest sense." Currently serving 40 children, it also reaches out to grieving children whose parents are in hospice. Kids Path is the only vendor allowed in the Guilford County school system.

While the demographics of the area show a majority of Caucasian residents, Hospice and Palliative Care of Greensboro and Kids Path serves a very high percentage of African Americans in the community, more than the average hospice. Robinson works with families and the wider community, emphasizing education. "For those who are eligible for hospice benefits and services, it is their right to receive them. We find that far too many don't utilize hospice simply because they don't understand what is available and what they are entitled to." For African American families with terminally ill children, Kids Path serves a community need that offers quality care to minorities, while building trust, faith, hope and understanding.

V. Resources for African American Outreach

A. PROFESSIONAL ORGANIZATIONS

- **Bureau of Labor Statistics (BLS),** *www.bls.gov/news.release/empsit.nr0.htm*, is the principal fact-finding agency for the federal government in the field of labor economics and statistics. The BLS is an independent national statistical agency that collects, processes, analyzes and disseminates essential statistical data to the U.S. public, Congress, other federal agencies, state and local governments, and the business and labor sectors.

- **Caring Connections,** *www.caringinfo.org*, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. Caring Connections provides free resources and information that address end-of-life issues such as advance care planning, serious illness, caregiving, grief and more.

- **Duke Institute on Care at the End of Life,** *www.iceol.duke.edu*, is a catalyst for growth and transformation, a global resource to improve care for those at life's end. The mission of the Institute is to create and promote the growth of knowledge and to encourage the application of that knowledge in caring for the whole person at life's end.

- **Institute of Medicine of the National Academies (IOM),** *www.iom.edu/?id=33252*, provides a vital service by working outside the framework of government to ensure scientifically informed analysis and independent guidance. The IOM's mission is to serve as adviser to the nation to improve health. It provides unbiased, evidence-based and authoritative information and advice concerning health and science policy to policy-makers, professionals, leaders in every sector of society and the public at large.

- **National Center for Cultural Competence (NCCC),** *www11.georgetown.edu/research/gucchd/nccc*, provides national leadership and contributes to the body of knowledge on cultural and linguistic competency within systems and organizations. Major emphasis is placed on translating evidence into policy and practice for programs and personnel concerned with health and mental healthcare delivery, administration, education and advocacy.

- **National Center for Health Statistics (NCHS),** *www.cdc.gov/nchs/fastats/black_health.htm*, is the nation's principal health statistics agency and operates as a part of the Centers for Disease Control and Prevention. The NCHS compiles statistical information to guide actions and policies to improve the health of US citizens. It serves as an excellent public resource for health information and a critical element of public health and health policy.

- **National Hospice and Palliative Care Organization** (NHPCO), *www.nhpco.org*, is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end-of-life and their families.

- **Office of Minority Health** (OMH), *www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=51*, seeks to improve and protect the health of racial and ethnic minority populations through the development of health policies and programs that will eliminate health disparities. It advises the federal government on public health program activities affecting American Indians and Alaska Natives, Asian Americans, Blacks/African Americans, Hispanics/Latinos, Native Hawaiians and other Pacific Islanders.

- **Robert Wood Johnson Foundation**, *www.rwjf.org/reports/grr/046134.htm*, seeks to improve the health and healthcare of all Americans. Its efforts focus on improving both the health of everyone in America and their healthcare – how it's delivered, how it's paid for, and how well it does for patients and their families.

- **U.S. Census Bureau**, *www.census.gov/prod/2007pubs/acs-04.pdf*, serves as the leading source of quality data about the nation's people and economy. This link is to a 2004 report that present a portrait of the African American population in the U.S. It provides a wide range of information on demographic, social, economic and housing characteristics of the population.

B. EDUCATIONAL TOOLS

- **APPEAL (A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End) Training, Duke Institute on Care at the End of Life**, *www.iceol.duke.edu/events/2008appealtraining.html*, is designed for healthcare professionals working with African American patients and families facing serious illness in hospitals, hospices, outpatient clinics, nursing homes and office-based settings and covers a wide range of issues pertinent to end-of-life care, from cultural issues to healthcare disparities. Participants include physicians, nurses, social workers, medical chaplains and other clergy, psychologists, counselors, hospice and hospital administrators, pharmacists and family caregivers.

- **Key Topics on End-of-Life Care for African Americans**, Duke Institute on Care at the End of Life, *www.iceol.duke.edu/resources/lastmiles/index.html*. Topics covered in this on-line book range from the impact of health disparities on end of life decision-making to spiritual aspects of care at life's end, to sociological and cultural perspectives on death and dying and finally, even to health policy considerations. The information is provided for individuals and organizations interested in increasing their understanding of African American perspectives on end-of-life care that influence important questions such as access to hospice and palliative care, and the quality of care delivered in those settings.

C. WEB SITES

- **African Americans.com**, *www.africanamericans.com/Demographics.htm*, has over 750 web pages on the African American community. The site covers many topics, including black history, the civil rights movement, slavery, African American art, and black gospel music. It also includes profiles of famous African American historical leaders such as Martin Luther King Jr., Muhammad Ali, Frederick Douglass, as well as current black celebrities, like Tiger Woods, Michael Jordan, Serena Williams, and more.

- **Black Demographics.com**, *www.blackdemographics.com*, provides interesting facts and statistics about the African American population nationwide.

D. LITERATURE

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VI. Acknowledgements

Author:

Juliette Marchioli
National Hospice and Palliative Care Organization
Alexandria, VA

Contributors:

Lyla Correoso, MD
Visiting Nurse Service of New York
New York, NY

Cassandra Cotton, CNA, CHPNA
Nathan Adelson Hospice
Las Vegas, NV

Bernice Catherine Harper, MSW, MSc.PH, LLD
Former Medical Care Advisor, HHS
Founding President, FHSSA
Former Board Member, NHPCO
Rockville, MD

Sharon R. Latson, BA
VITAS Innovative Hospice Care® of Chicagoland
Chicago, IL

Jennifer Moore, PhD
A Touch of Grace Hospice, Inc.
Chicago, IL

Stacie Pinderhughes, MD
North General Hospital
New York, NY

Gloria Ramsey, JD, RN
Uniformed Services University of the Health Sciences
Bethesda, MD

Ursula Robinson, MSW, LCSW
Hospice and Palliative Care of Greensboro
Greensboro, NC

Sally Sharpe, RN
Pike's Peak Hospice & Palliative Care
Colorado Springs, CO

Toula Wootan, MSH
Community Hospice of Northeast Florida
Jacksonville, FL

NHPCO Staff:

Melanie Abijaoude
Philip Banks
Kathy Brandt, MS
Helen Ennis
Gwynn Sullivan, RN, MSN
Emil Zuberbueler, BS

Duke Institute on Care at the End of Life:

Tracey A. Adams, M Div
Richard Payne, MD
Jeanne Twohig, MPA

VII. Appendix

Click on links below to view and download the documents. All documents may be accessed at

www.caringinfo.org/community

then clicking on "Diversity Outreach".

Proctor Covenant Statement on End-of-Life Care (pdf)

Advance Directives and End-of-Life Decisions (ppt)

Understanding Hospice, Palliative Care and End-of-Life Issues (ppt)

EXHIBIT 4

MARYLAND
HEALTH CARE
COMMISSION

Hospice & Palliative Care Network
OF MARYLAND

Hospice Education and Outreach Work Group Meeting

June 9, 2015

MEETING SUMMARY

Attendees:

Jennifer Belgarde, Seasons Hospice
Reggie Bodnar, Gilchrist Hospice

Phil Carpenter, Community Hospices
Kelly Fields, Heartland Hospice (Beltsville)
Sue Fortuna, Holy Cross Hospice
Altonia Garrett, Capital Caring
Sharon Garrick, Seasons Hospice
Leslie Gee, Carroll Hospice
Heather Guerieri, Compass Regional Hospice

Millie Higgins, Montgomery Hospice

Linzy Laughhunn, Calvert Hospice
Ben Marcantonio, Hospice of the Chesapeake
Linda Maurano, Holy Cross Hospice
Mark McKenzie, Heartland Hospice
Ann Mitchell, Montgomery Hospice
Joy Sexton, JSSA
Joe Shannon, PHRI
Mary Ellen Shea, Talbot Hospice
Shelley Steiner, Hospice of Washington Co.
Lisa Stone, Stella Maris

Speakers:

Cozzie King, Diversity Council, NHPCO
Christina Puchalski, George Washington Institute for Spirituality and Health
Diane Hill Taylor. NHPCO

MHCC:

Linda Cole
Erin Dorrien
Bruce Kozlowski
Paul Parker
Ben Steffen

Hospice & Palliative Care Network of Maryland:

Peggy Funk

Welcome and Introductions:

This meeting was jointly sponsored by the Maryland Health Care Commission and the Hospice & Palliative Care Network of Maryland. For the Commission, Paul Parker thanked everyone for coming to the meeting. He explained that this is a follow-up to meetings held last fall in Baltimore City and Prince George's Counties for hospices serving those jurisdictions. The goal of this meeting is to open the discussion to all hospices. Peggy Funk welcomed all participants on behalf of the Hospice Network.

As part of the introductory portion, Linda Cole presented data to the group. One table (see attached), which included trends in hospice use rates from 2007-2013 had been previously distributed. In this table, hospice use rates are defined as hospice deaths divided by total population deaths for those aged 35+. This table will be updated as soon as 2014 utilization and death data become available.

The second table (see attached) entitled "African American Hospice Patients as a Proportion of Total Hospice Patients, 2013-2014, Maryland", is a new table. This measure is African American hospice patients as a proportion of total patients served during the year. She offered several caveats about the data: some hospices have very small numbers of patients; some serve other minority groups not represented here; only hospices serving 10 or more African American clients were counted, unless they were the sole provider for the jurisdiction; and the final column is intended to provide context, not as a standard. With these caveats, overall there is an increase in the proportion of African American patients served; the exception is the small counties served by a single hospice.

Inclusion and Access: Engagement, Education, Evaluation, and Assessment:

The NHPCO presentation was done jointly by Diane Hill Taylor and Cozzie King. Ms. Taylor started the presentation by stating that there is no magic bullet to solve health care use by minorities. It takes time to build trust and to develop cultural competency. She also stated that the black church, which is central to the community, is based on hope, which is inconsistent with hospice.

Ms. Taylor then explained the structure and divisions of NHPCO and how they can serve members. She stated that the African American population is about 8.4% of hospice patients, and that nationally less than 1/5 of hospice patients in 2013 were minority patients. She stated that the Diversity Council is helping hospices to serve minority patients.

Ms. King then explained the Diversity Council and its work. She stated the view that "we speak to our own", and that there is a need to see diversity in staff and course presentations. She cited the work of Dr. Kimberly Johnson at Duke University on barriers to reaching African American patients. NHPCO's work on awareness will focus on a public awareness campaign.

Ms. Taylor then discussed the work on engagement. NHPCO is working with Morgan State University on continuing education programs to educate the African American community. They are also working with both undergraduate and graduate Hispanic students to engage younger people. They also work with the faith-based community. She stated that she would like to hear from hospices what has worked and not worked for their programs.

There is Going to be a Miracle-Decision When Religious Beliefs and Medical Realities Conflict:

Dr. Christina Puchalski explained her various roles as an internist, a palliative care physician, a professor, and director of the George Washington Institute for Spirituality and Health. She focuses on inpatient geriatric patients, a population not yet ready for hospice. She said that they all want to live longer. Palliative care needs to be about living well.

There is often a conflict between religious beliefs and scientific evidence. Patients are defensive if they feel that you do not take their belief system seriously. Physicians fear that religion will block their work. Dr. Puchalski said that chaplains need to be involved early in the process. Conversations need to focus on physical, social, emotional, and spiritual factors. A clinician can share hope without offering unrealistic expectations.

Dr. Puchalski then asked the hospices about their experiences. All hospices stated that they have adequately trained chaplains.

Reggie Bodnar, Gilchrist, stated that caring for children is much harder. They use a team approach, involve the chaplain in the care plan, and include debriefing after the case.

Joy Sexton, JSSA, said that hospice providers often want to reframe hope, but people do not want it reframed. Hospice providers do not want to give up hope, but do need to offer a plan.

Phil Carpenter, Community Hospices said that a question that works to open conversations is "what is keeping you up at night?"

Jennifer Belgarde, Seasons, stated that you need to ask and talk to the patient to fully understand. You cannot make assumptions.

Ben Marcantonio, Hospice of the Chesapeake, suggested that hospice providers need to let patients have the conversations that they need to have.

Sue Fortuna, Holy Cross, said that physicians often do not take the time to walk with patients before the handoff. They often dump patients on hospice and then do not respond to calls.

Dr. Puchalski said that we are still not good at communications. We need to find a balance and offer individualized care. This affects the level of trust. She then discussed communication strategies including the AMEN protocol. An important statement is: "no matter what happens, I will be with you every step of the way."

Wrap-up and Next Steps:

Ben Steffen, Executive Director of the Commission, then summarized the meeting. He stated that the Commission has sponsored various hospice education and outreach meetings and now it was up to hospices to engage residents in Prince George's County and Baltimore City. He asked participants what else is needed. Mr. Steffen asked what engagement hospices have with hospitals and the broader community to support the new hospital payment model that requires hospitasl to operate under fixed global budgets.

Peggy Funk replied that she had done a survey asking hospices about new initiatives. She noted that Coastal Hospice has a community foundation grant to do outreach to the African American community, and to work with media partners on the Eastern Shore. Hospice Caring has a Montgomery County Council grant to use bilingual volunteers for outreach and to do a community needs assessment.

Mary Ellen Shea, Talbot Hospice, said that they are working with Dr. Johnson at Duke to learn about barriers African American patients face in accessing hospice. They are doing a pilot program with six churches.

Reggie Bodnar stated that the Annual Hospice Conference will focus on transitions in care. Every hospice gets calls from the ER of hospitals. These are people who have no relationship with the hospice. Hospice should not be an emergency, but hospitals are under pressure to reduce readmissions. She also stated that Gilchrist received an Innovations Grant from CMS to offer choices for concurrent care.

Leslie Gee, Carroll Hospice, spoke about the need to reach out to the faith-based community to offer choices. She also spoke about ERs transferring patients to hospices. All the participants agreed that more needed to done to inform hospitals and physicians about the benefits of an early referral to hospice. Ms. Gee said that there is need for community-based talks about quality of life early on.

Ann Mitchell, Montgomery Hospice, said that this is a tenuous time in health care and it is difficult to measure improvements in utilization by minority patients. She noted that Montgomery Hospice serves a very diverse community and offers many educational programs. Increased competition from large national chains could diminish the ability of Montgomery Hospice and other community hospices to continue education program that had proven valuable in the past.

Ben Marcantonio, Hospice of the Chesapeake, said that hospices need to access late referrals and identify processes that would support earlier intervention and referral to hospice.

Shelley Steiner, Hospice of Washington County, said that they have one hospice and one hospital. They have a good relationship. However, younger physicians (hospitalists) who come under contract do not understand the role of hospice.

Mr. Steffen suggested that hospices describe their position to hospitals and explain what they need to serve patients. He also asked what hospices have done to work with Med Chi to explain the need for early referral and to educate physicians. He also stated the need for health care literacy and to promote advanced directives.

Ms. Bodnar said that the Network would like to be part of the discussion on advanced directives and that they have submitted comments to Delegate Morhaim.

Regarding next steps, Mr. Steffen said that use of hospice has increased in some areas. He emphasized that the Commission is open to new ideas and could foster new approaches that offered benefits to patients. He reiterated that the Network and the community hospice members would have to take the lead in implementing the new approaches.

Maryland Health Care Commission

Hospice Education Initiative Work Group

September 24, 2013

Meeting Summary

Work Group members in attendance:

Ben Steffen, Paul Parker, Bruce Kozlowski, Linda Cole, Cathy Weiss, Philip Carpenter, Arnold Eppel, Dr. Pat Fosarelli, G.I. Johnson, Maureen McNeill, Ann Mitchell, Diane Owen, Ingrid Redway, Mary Ann Rishebarger, Christine Ruch, Madeline Shea, Jessica Talley.

Work Group members in attendance via teleconference:

Ted Meyerson and Nicole Stallings.

Paul Parker, Maryland Health Care Commission (MHCC)

Mr. Parker explained that due to the reorganization of the Maryland Health Care Commission (MHCC) staff, the work on long term care health planning and development is now part of the Center for Health Care Facilities Planning and Development. Bruce Kozlowski is Co-Director of the Center for Quality and Reporting.

Mr. Parker also discussed why the work group was convened and gave background information on when a Certificate of Need (CON) is required for hospice services. It is required for: 1) establishment of a new hospice; 2) expansion of an existing hospice into a new jurisdiction; and 3) a change in the bed capacity of a hospice

Mr. Parker informed the Work Group that the Commission has now taken final action to approve the new State Health Plan Chapter for hospices services, and that hospice education and outreach is an important component of the plan chapter.

Mr. Steffen stated that the importance of education does not diminish the total update of the State Health Plan. The 2014 budget has limited funding for outreach. However, Mr. Steffen indicated that the Commission serves as a facilitator; it does not launch educational initiatives.

Mr. Parker informed the work group that MHCC has published a schedule for CON review of projects for hospice services beginning in mid-2015. He stated that the MHCC will re-examine use rates as one measure of the success of education and outreach.

Linda Cole, Maryland Health Care Commission

Ms. Cole reviewed the themes that have emerged from previous meetings:

Hospice services:

- There is a need for education about hospice.
- There are religious, cultural, and ethnic barriers to the use of hospice.
- The use of minority staff for outreach helps to build trust and rapport.
- There is a need to overcome myths and erroneous cost perceptions.
- There is a need to intervene before there is a crisis.
- Patients need help, generally, in navigating the health care system.
- There is a need for education about program eligibility and resource availability.
- The role of the educator is to offer information, not to push for specific action or a particular choice by the patient.
- The audience needs to be carefully identified for educational efforts; what works with one audience might not work with others.
- There is a need to include the faith-based community in public education and outreach and to work with churches, particularly in the African American community.
- The educational message should be "life transitions" and not "end of life care."

Staff training:

- There is a need for cultural competency training.
- There is a need to train doctors on how to share bad news and to ascertain that the patient/ family has accurately received the information.
- Social workers should also be included in end-of-life training.

Resources:

- MedChi and Monumental can distribute materials, arrange CMEs, and do outreach to physicians.
- MHA has efforts underway in patient-centered care, staff education, palliative care, and partnering with hospitals.
- MOTA (Minority Outreach and Technical Assistance) is working to address health disparities.

At this point, meeting attendees were asked to share ideas and news of interest to the group.

Maureen McNeill, Coastal Hospice

Ms. McNeill presented the efforts of Coastal Hospice in outreach. She stated that Coastal Hospice will be producing TV ads, and evaluating their effectiveness by conducting surveys on the likelihood of using hospice services before and after the ads have run. She stated that the use of hospice services is lower for African Americans in Coastal Hospice's Eastern Shore service area. She discussed the possible reasons for this disparity and myths on why hospice services are not utilized by the African American community

Dr. Pat Fosarelli

Dr. Fosarelli also talked about the low use of hospice services by African Americans. She asked her seminary students what hospice means. They used phrases like "giving up", or "being disloyal to your loved one." The family should be the caregiver; that it is the family's responsibility.

Dr. Fosarelli also stated that maybe a change in language may help. The word "transitioning" may help, but it is important to recognize that the word "dying" is part of the Judaeo-Christian tradition. She also stated that congregations in the African American community feel that they should care for their own, and that may be another reason for lack of using hospice services. Conveying the message that hospice care providers are responding to a "calling" may be perceived more positively.

Jessica Talley, Hospice of the Chesapeake

Ms. Talley stated that since hospice is a medically prescribed service, Hospice of the Chesapeake has begun to market its services directly to physicians, case managers, and nurses to encourage the use of hospice services. She stated that Hospice of the Chesapeake works at reaching the community by being present at health fairs. Ms. Talley stated that she felt access is not a problem, but a skill set to meet the needs of the African American community is needed.

Madeline Shea, Delmarva Foundation

Ms. Shea stated that she felt the term "end of life" is a big issue in choosing hospice services culturally. She felt that more skill building on cultural competency and health literacy may help increase hospice usage. She will be working with CMS on Quality Improvement for Disparities and will be happy to share the results of her research.

Diane Owens, Gilchrist Hospice

Ms. Owens informed the work group about the activities that Gilchrist Hospice has undertaken to increase use among the African American community. She stated that Gilchrist is conducting interviews for a diversity council to help guide Gilchrist in cultural competency and better ways to reach out to the community.

Mary Ann Rishebarger, Joseph Richey House

Ms. Rishebarger stated that hospices need to educate the public that hospice is a service that takes care of the family and not just the patient. She stated that Joseph Richey was doing outreach by visiting hospitals and talking to case managers and directors of nursing about hospice services. She also stated that she had a concern about the way in which some hospitals choose to have an exclusive relationship with a single hospice. Patients should be informed about the availability of all hospice options. She said she also offers tours of Joseph Richey House to members of the community.

Ann Mitchell, Montgomery Hospice

Ms. Mitchell stated that Montgomery Hospice has a long history of working to address the diverse needs of its community. She said that it has been working on outreach for many years with the goal of having the use of hospice services match the percentage of deaths by minorities. For Asians and Latinos, the use rates now match the percentage of deaths. For the African American community, the percentage of deaths is 14% but the use rate is 10%. . She stated that a diverse staff helps in outreach to the African American community. She also stated that Montgomery Hospice is bringing diversity to the leadership of the hospice and this also helps bring patients to hospice services. She stated that Montgomery Hospice strives for a presence in the Latino and Asian communities.

Ingrid Redway, Seasons Hospice

Ms. Redway stated that Seasons' national office in Chicago has a formal process for outreach. They are trying to apply this at a local level to reach diverse segments of the market. She stated that building trust is an important aspect. Seasons hospice has been marketing at health fairs to get information out about hospice before hospice services are actually needed. She stated that information aimed at the family helps overcome cultural barriers to choosing hospice services among the African American population. Based on her experience with the Seasons inpatient unit at Northwest Hospital, she deals with families who say "we take care of our own", but then come to realize that they just cannot do it all.

Phil Carpenter, Washington Home and Community Hospices

Mr. Carpenter stated that he did not think outreach would significantly increase services in the African American community in the near future, and that it will take much more time. He also stated that he felt that diversity in the staff of the hospices was an important part in choosing hospice services in the African American community. Washington Home and Community Hospice participates in local health fairs. It also offers holiday grief workshops at no cost.

Christine Ruch, Washington Home and Community Hospice

Ms. Ruch stated the work of Community Hospice focuses on quality improvement. It plans to offer training in palliative care to nurses in the community free of charge. Their goal is to have nurse trainers in assisted living, nursing homes, and other settings.

G.I. Johnson, Baltimore City Health Department

Mr. Johnson stated that he feels that people, mainly pastors, in the African American community do not have information or firsthand knowledge of hospice services and what they provide. He stated that if pastors had a better understanding or more knowledge concerning hospice care that their advice in the community would be an important factor in encouraging their congregation's members to seek hospice services. When pastors use hospice themselves, they provide a great role model for the community.

Ted Meyerson,

Mr. Meyerson stated that he felt that even people who have been in hospice just don't understand hospice care. The physicians should take the first step in discussing hospice with patients. He stated that he felt that physicians were just as important as the church for getting information on hospice services out in the community. Mr. Meyerson felt that some palliative care legislation should be passed.

Arnold Eppel, Baltimore City Health Department

Mr. Eppel stated that more education on hospice can increase the use of the services in the African American community. He said that he thinks we can make a significant difference in two years. He stated that he felt assisted living managers should be required to learn about hospice services as part of the training required by OHCQ. He also stated that more education is needed with case managers about the availability of hospice care. He is working with the bullet points that Dr. Pat Fosarelli drafted for pastors; he likes the phrase "hospice can be a gift." He mentioned the November 6th program at Morgan State University for religious leaders.

Nicole Stallings

Ms. Stallings stated that the Health Delivery Reform Subcommittee of the Health Care Reform Coordinating Council has a focus on hospitals' partnerships with long term care, and end of life and hospices issues should be discussed. She stated that the Subcommittee was not aware of this Work Group. The work group should connect with Dr. Herrera in DHMH. Ms. Stallings discussed relevant data and the reasons that hospice patients are readmitted to hospitals. Ms. Stallings also questioned the targeting of marketing efforts about hospice, based on reported experience with mailings received. She feels that more mail marketing may need to be targeted to less affluent households, which are probably the households with the least familiarity and receptivity to hospice.

Other Comments

Ms. Rishebarger stated that one reason for readmission of hospice patients to hospitals may be that loved ones call "911" when they can't handle the changing condition of the patient, because that is what they are used to doing. "Panic" is a cause for the "911" calls.

Ms. McNeill questioned the purpose of the Work Group. Ms. Cole stated that the work group was for sharing information so everyone can benefit.

Dr. Fosarelli stated that education is important for increasing the use of hospice services. She felt that the heads of dioceses should encourage hospice education for pastors, etc. She said that the Central Maryland Ecumenical Council needs speakers on hospice services. She also stated that Med Chi should see that hospice is discussed at any of its meetings with physicians. She stated that people whom the family trusts, which are often pastors or doctors, but could be other persons, should be able to discuss hospice services with them.

Ms. Talley stated that she felt there was a physician bias against hospice (mainly older physicians) because of lack of information and that more education to physicians may help in increasing the use of services.

Dr. Fosarelli stated that she felt medical schools should require hospice education for medical students and residents. She also stated that seminaries and religious schools should require hospice education.

Ms. Stalling asked the work group if there were models outside of Maryland for hospice education.

Meeting Summary:

Ms. Cole summarized the meeting discussion:

- Hospice is a "calling"; hospice is a gift;
- Need to educate front-line health care workers;
- Need to address and dispel myths about hospice;
- Need to look for tools and share information;
- Hospice team needs to work with the family unit;
- Need to get physicians as well as church leaders educated.

Next Steps:

Mr. Parker discussed what should be done in the future regarding hospice education. He said that he did not think that additional meetings of this type were necessary, given the three that had already occurred. He discussed ideas on how to proceed and asked the work group what they would like from the MHCC.

Ms.McNeill asked about how to measure attitudes and what measures to use. She stressed the need for focus groups.

Ms. Mitchell asked about other areas in the US that are similar, demographically, to Prince George's County and Baltimore City and what measures may be working or not working in these areas. Ms. Cole said that we can look at use rates in other states. Mr. Parker talked about tracking use rates by race or ethnicity and whether the hospices are currently tracking this. There was discussion about push-back on collecting racial data. However, Ms. Ruch indicated that the new Hospice Item Data Set has race as a mandatory variable. Nicole Stallings asked for a report to summarize the ideas submitted.

Mr. Parker suggested that we might need another group to determine how best to measure progress in education and outreach. Mr. Parker stated that the Work Group would not hold another meeting next month. He recommended that the Work Group would gather information on a quarterly basis from the hospices on what they have done and post it on the Commission's website, which would include a Hospice Education and Outreach page. He suggested that the Work Group reconvene in the spring of 2014 to discuss progress and share information about the education and outreach activities they engage in over the next six months.

Maryland Health Care Commission

Hospice Education Initiative Work Group

July 29, 2013
Meeting Summary

Work Group members in attendance:

Danelle Buchman, Linda Cole, Arlee Gist, Larry Gourdine, Rev. M. Luther Hill, Terrie James-Taylor, G. I. Johnson, Steve Johnson, Bruce Kozlowski, Ted Meyerson, Maureen McNeill, Diane Owen, Paul Parker, Ingrid Redway, Mary Anne Rishebarger, Dr. Madeleine Shea, Caroline Silva, Nicole Stallings, Cathy Stasny, Jessica Talley.

Work Group members in attendance via teleconference:

Dr. Pat Fosarelli, Dr. Carlessia Hussein

Bruce Kozlowski, Maryland Health Care Commission (MHCC)

Mr. Kozlowski thanked the Work Group for providing their summaries following the April 29, 2013 meeting. There were several alternates attending this meeting, as well as new members joining the Work Group. The Work Group welcomed its new members and alternates.

The focus of the July Work Group meeting is to review with each participant their upcoming plans for outreach to minority and underserved populations in Maryland on issues related to transition at end of life, whether through aging or illness, with the goal of determining measures of success. New members are welcome to share their ideas during the meeting if they have not done so prior to the meeting. Mr. Kozlowski provided some background on the genesis of the Work Group, which was initiated at the request of Chairman Middleton and Senator Delores Kelley. Senator Kelley laid the ground work and established the focus. The underutilization of hospice services by the African-American community was of primary concern, with the belief that aggressive outreach and education would provide the necessary tools and information for the underserved to make informed decisions consistent with their beliefs regarding transition of life care and hospice.

Dr. Madeleine Shea, Delmarva Foundation for Medical Care, Inc.

The Delmarva Foundation has been working with CMS on looking at disparities in Medicare with end of life care. Dr. Shea is attending the Work Group to learn what the current best practices are and she is looking for direction in working with organizations across the country.

Jessica Talley, Hospice of the Chesapeake

Ms. Talley previously shared Hospice of the Chesapeake's liaison efforts working directly with patients and families to better understand the patient and family relationship; they also provide crisis intervention. Working directly with the community they assist with communication between patients and doctors, identify lack of access to care, and identify where need exists for other interventions to occur to facilitate better access to services and increase use of existing partnerships.

Hospice of the Chesapeake recently conducted a model of care focused on cancer care from the African-American perspective. CMS produced a video on communicating end of life care.

Maureen McNeill, Coastal Hospice and Palliative Care (Coastal Hospice)

Coastal Hospice is working on a measurable outcomes survey. It is an unscientific attitude survey that will be presented to African-American members of their community, collecting feedback, making revisions and then resurveying. They will share these results with the Work Group when complete.

Coastal Hospice is challenged by the CMS eligibility for coverage guidelines, particularly guidelines for hospice services and discharges for extended diagnoses. Medicare has become rigorous in scrutinizing hospice bills and has been denying coverage. Coastal Hospice is sensitive to not overselling services that they can't deliver on because of CMS oversight. They are ready to talk to patients and families about end of life care, what hospice has to offer families, but are concerned about being undermined by CMS when coverage is denied.

Reverend M. Luther Hill, Coastal Hospice

Reverend Hill has the access to the African-American church community. Prior to being a chaplain he was a part of Minority Outreach and Technical Assistance (MOTA). Dr. Hussein has a great model to reach out to any minority member of the community. Timing is key – it is important not to wait until a crisis to provide education. Most churches have health education conferences, which present an opportunity to provide hospice and end of life information. Some individuals don't want their pastors or reverends to know their health issues or to intervene for privacy reasons. Funeral homes provide another opportunity to get the hospice message out. Some people are more receptive in that environment to discussing what their end of life expectations or wishes are. Some pastors are also funeral home directors.

Bruce Kozlowski, MHCC

In a July 2013 meeting with Delegate Tarrant and Dr. Reverend Hathaway, the question did arise of who is responsible for payment of hospice services under Medicare and Medicaid. They have since received current copies of reimbursement regulations for Medicare and Medicaid plus copies of the CDs "Reaching Out to the Underserved Populations" and "How Do I Pay for This?"

Larry Gourdine, Monumental City Medical Society

Monumental places messages and materials in physician offices so they can have conversations while taking care of patients and when they are in direct communication with family members. Physicians are in a good position to have these discussions. Monumental works with MedChi on educational materials, improving messaging materials and resources provided. Physicians are constrained by the "15 minute" rule per patient, yet end of life conversations take more time. Monumental seeks input to develop ways to provide more education to physicians.

Arlee Gist, Office of Minority Health and Health Disparities (OMHHD)

OMHHD works with all minorities and underserved populations in Maryland, not just African-Americans. Targeted groups include underserved Asian-Americans, Hispanics, and Native-Americans, all of whom have similar underutilization of these types of services.

The African-American mindset is "we take care of our own." Hospitals who serve the African-American communities often have not verbalized to loved ones and caregivers that it is end of life. The African-American community is not receiving enough education about what is happening medically. Family members take a dying patient home without receiving end of life information and without knowing what services they are eligible for and what resources are available. The education process needs to starts with the hospital staff at the onset of the patient entering the hospital. Physicians know the care and conditions of the individuals, and can provide information to hospices and families on who is likely to be eligible for hospice and/or end of life care. Training needs to be done for the front end staff (hospital, medical staff, chaplains at medical facilities) to provide information to patients and family upon entry, not just when close to end of life.

OMHHD staff goes into underserved communities and offers focus groups to minority populations. It is important to bring in people who look like the audience to provide services, and take recommendation from key leverage groups in a whole way. Messaging regarding death and dying should be the same for all; OMHHD does not want feedback saying that the messaging provided or what is offered to the African-American community is different than that provided to another community.

Dr. Carlessia Hussein, OMHHD

Dr. Hussein noted that her office is particularly interested in focusing on cultural competence. To her, this is a key word that means better identification of the provider of service (whatever service that is) to the individual client. They focus on greater training to do that and how to relate to the client. There is legislation in Maryland that encourages all sectors of the healthcare delivery system to become more culturally competent. OMHHD is working with the MHA and others to provide support, training and technical assistance in promoting cultural competency. It is important to build greater trust in the healthcare system through cultural competency with end of life issues with all clients, not just minority clients.

Ted Meyerson, State Advisory Council on Quality Care at the End of Life

Mr. Meyerson suggested that the OMHHD include the frail and elderly among the other categories of minority populations. The average length of hospice stay in Maryland is at most 21 days. This lack of utilization indicates that either no one knows about hospice services or that no one is being referred to it. HB 30 (education regarding End of Life Services) was met with resistance by churches, the medical community and hospices, equating giving information about end of life as pushing people to make a decision about end of life. The Advisory Council sent out 30,000 cards to nursing home ombudsmen and physician offices across the state in an effort to bring attention to end of life rights. Everyone participating in this Work Group has outreach in place, but there is no coordination between the participants. Mr. Meyerson believes this Work Group could lead the way to make a coordinated, centralized effort to unify the message and get information out to people. Without coordination of effort there is no political power. He would like to see consensus from the group, and move one piece of legislation forward.

Mr. Meyerson noted that there is a sharp divide between the education of the healthcare providers and the education of the population being served. He sees the biggest opportunity in educating the population being served, as they are on the receiving end for end of life services. Patients need to know what their rights are and be able to pursue hospice or whatever service is available, without having to wait for the professional to tell them that they are at the end of life. Physicians are not prone to want to tell patients that they can no longer treat them.

Diane Owen, Gilchrist Hospice

Gilchrist has recently partnered their volunteer outreach program with churches in Baltimore City. Volunteers go into people's homes. This partnership has increased community and family awareness of hospice services. It is a grassroots effort, but as more volunteers make outreach with families, awareness is increasing.

Gilchrist believes that hospitals should be providing information on hospice and end of life care options. There is an enormous need to change the mindset of hospitals and physicians, beginning in medical school. Hospice education should be in the curriculum and part of the clinical rotation. Gilchrist has medical students who rotate in the hospice program. One obstacle is changing the "I am here to heal" mindset of physicians before they begin their training.

Terrie James-Taylor, Montgomery Hospice

Montgomery Hospice offers one on one educational conferences for doctors in the hospitals to share all the concepts about hospice. Doctors have a difficult time telling patients that they are at the end of life. Doctors need to be educated about the procedures for following a hospice patient.

Steve Johnson, MedChi

MedChi is the largest physician organization in the state, so they are well situated to communicate with the physicians. MedChi looks forward to an opportunity to partner with the hospices, and is willing to distribute articles on the topic of hospice education. They have a very large continuing medical education (CME) department that has the means to electronically reach out to a wide audience. Every Monday MedChi sends out a lengthy newsletter to members via electronic ListServ, as well as sending Twitter feeds. Each county and Baltimore City has a local medical society. The largest counties meet monthly or quarterly. The small counties have more localized information, and do not meet as frequently. Primary contact is made through the State MedChi office, which holds two annual meetings as well as specialty meetings.

Ingrid Redway, Seasons Hospice

The medical director at Seasons Hospice reaches out to the medical and physician community, particularly in July when the new medical residents begin. Seasons Hospice physicians hold education sessions for the medical residents and attend grand rounds in order to meet large groups of physicians. Ms. Redway is also a community member of the Sinai Ethics Committee, in which capacity she can provide education and outreach to the hospital staff.

Mary Anne Rishebarger, Dr. Bob's Place and Joseph Richey Hospice

Dr. Bob's Place and Joseph Richey Hospice serve a unique population, primarily the underserved in Baltimore City (Joseph Richey) and children (Dr. Bob's Place). They accept anyone into their hospice regardless of ability to pay for services. They also provide home-based services.

Danelle Buchman, Hospice and Palliative Care Network of Maryland (Hospice Network)

Ms. Buchman thanked the members of the Hospice Network who are attending the Work Group meeting and for their tremendous work in Maryland providing direct hospice services. She expressed concern about the bigger goal of the Work Group. Ms. Buchman sees the need for better coordination of efforts by the various organizations and hospices in the Work Group in order to promote the work currently being done and to identify best practices already in place.

The annual Hospice Network conference has been moved to November 2013 to coincide with National Hospice Month. In addition, Hospice Network has smaller educational programs throughout the year. They have monthly webinars and in the past have shared hospice best practices. Education and advocacy is the primary focus of the Hospice Network, and they are willing to tailor a webinar with an outreach specific to diverse populations.

Nicole Stallings, Maryland Hospital Association (MHA)

Ms. Stallings previously provided an overview of how the MHA has the ability to communicate with their 66 members across the state. She is very experienced with getting messages and best practices communicated; she does not have as much experience with core messaging around hospice and particularly how to reach underserved individuals. Ms. Stallings wants to help push these resources out, but is not sure that these resources are yet available. If there is consensus about what specific materials (best practices, standards, etc.) are to be distributed, she can help the MHA members get the information distributed, and offers her assistance to other members of the Work Group. The MHA will produce a hospice related webinar within six months.

Ms. Stallings expressed concerned about what kind of training currently exists in hospitals, and how comfortable staff is talking with patients and families about hospice and palliative care. Many hospitals have strong relationships with community hospices and others are looking to grow relationships. From the MHA standpoint, they look toward creating purposeful partnerships; for example, the day after the November Hospice Network annual meeting, the MHA is holding a meeting in the same location to market together the work that the MHA does with the work of the Hospice Network.

The MHA has a steering committee that is focused on care transitions, which is comprised of many of the groups on the Work Group.

Maureen McNeill, Coastal Hospice

Addressing the broader issue of getting physicians to make referrals to end of life care, Coastal Hospice subscribes to a national newsletter publication that they customize for their hospice and distribute to physicians. They are launching an end of life education program for nurses, in collaboration with Peninsula Regional Medical Center, and invite nurses from medical practices to participate. Coastal Hospice's ongoing outreach with the healthcare community includes participation in physicians' meetings, and meeting with physicians and staff in their offices. When working with the faith based community, it is important to have a presenter who looks like the audience.

G.I. Johnson, Baltimore City Health Department, Office of Aging and CARE Services

Mr. Johnson provided an overview of the efforts of the Baltimore City Health Department (BCHD) to provide hospice outreach to the black community. Experience has found that in the black communities there is a lack of knowledge about hospice. In previous years his office attempted a hospice outreach program with the black church community in Baltimore City that failed, primarily due to starting at the "bottom" i.e., they started at the individual (congregant) level and tried to work their way up. BCHD learned from their mistake that they have to start at the top, establishing contact with the pastor of the church, in recognition that the pastor is the leader of the community. Mr. Johnson's office is hosting a conference on November 6th that will bring together all the faith based leaders.

The churches are well positioned to identify elderly people who are at risk or in need of assistance, as elderly people form the largest body of the church community. Many of these elderly members do not know what assistance is available or where to turn for help. BCHD is putting together materials for the churches, and will meet with church leaders to develop dialogue to communicate a clear understanding of what hospice is, to help their seniors utilize the programs. Church leaders essentially want to know if and how the hospice materials will benefit their congregation. A pastor who has a personal connection with hospice can increase the exposure in the black community. Most congregants rely on their pastors or ministers to provide guidance, so it is important to teach the pastors and ministers a better way to talk about end of life options and provide accurate information. Most churches need a program because so many senior members need an opportunity to be informed of and discuss end of life options. Arnold Eppel has a very good relationship with the churches and Mr. Johnson bridges the connection between a hospice professional and the churches. Two major issues in the black community are trust and attitude.

Terrie James-Taylor, Montgomery Hospice

Montgomery Hospice has found it is effective to get buy in from the church community, beginning with the pastors, elders, deacons and deaconesses. Then you can utilize the different ministries within the church, such as those who deal with death and dying, those who visit the sick and shut-ins, and the health and wellness ministries. Everyone in the church has experienced a loss, but someone might not necessarily want to go to the church leader, yet is comfortable seeking assistance from within one of the ministries. Ms. James-Taylor recommends checking the calendar of events at the churches, to see what programs are scheduled where you can target education to seniors, on topics such as Caring for the Caregiver or Alzheimer and Dementia issues.

Ms. James-Taylor said that she does not start off conversations by talking about death and dying; rather, she discusses Hospice 101 in broader terms of what services they offer, explaining their different programs, sharing what the volunteers do, and explaining how care is provided, such as by a nurse or home health aide.

Caroline Silva, University of Maryland School of Medicine

Ms. Silva noted that there are many factors that play into any patient or family's decision to choose hospice. A patient or family member might be resistant to using hospice. It might be a lack of knowledge about hospice services, lack of trust in the medical community, lack of strong family support, worry about the economic cost (will Medicare/Medicaid pay for it?), as well as personal, cultural or religious reasons. Many physicians are resistant to suggesting hospice care.

Dr. Pat Fosarelli, Central Maryland Ecumenical Council

"Best Practices" for hospice are continually evolving, particularly with pediatrics and special needs patients. For those for whom faith is important, it is important to link to that community, as no faith tradition says you have to "go it alone."

Bruce Kozlowski, MHCC

It is important to note that we want to educate the underserved about their transition of life choices, not convince people what to do.

The African-American faith based community in Baltimore City is now well represented on the Work Group, but we still lack representation from the African-American faith based community in Prince George's County. Mr. Kozlowski requests Ms. Stasny's assistance in finding a representative from that county.

Summary

The Work Group is intended to be a short-term commitment; to document what is currently being done with outreach and education of the underserved, and what the member organizations plan to do prospectively; to learn from each other; to recognize the diversity of the underserved and the differences in the approach necessary to have a conversation about transition in life and hospice; and to recognize that while there is value in some unity of approach, there is also value in diversity since not all providers or audiences respond the same.

It is important to:

- educate the underserved about their transition of life choices, not convince them as to what they should do
- educate the community about transition of life issues and hospice services before a crisis occurs

- bring in the faith-based community leaders to assist in outreach efforts
- provide education to the healthcare providers about how to have a discussion on transition of life choices
- provide resources and educational materials to the healthcare community and churches
- identify the audience before you get the message out; what works in one setting might not work as well in another; what works with one audience may not work with another
- utilize the outreach and education opportunities that already exist to the fullest

EXHIBIT 5

2014 Home Health Data show that P-B Health served the largest percentage of Black Home Health clients/Total clients in Baltimore City.

Black Clients
Home Health Agencies
Baltimore City
2014

Agency	Total Clients	Total Black Female	Total Black Male	Total Black	% Black
Visiting Nurse Association of Maryland LLC A/K/A VNA of Maryland LLC	1,975	451	238	689	34.9%
PHR of Baltimore	362	77	69	146	40.3%
Amedisys Home Health	34	8	2	10	29.4%
Personal Touch Homecare of Baltimore Inc	684	179	106	285	41.7%
MedStar Visiting Nurse Assocation Inc.	2,846	984	504	1,488	52.3%
Gentiva Health Services	379	152	82	234	61.7%
Stella Maris Inc.	557	280	107	387	69.5%
Johns Hopkins Home Health Services	1,090	449	209	658	60.4%
Amedisys Home Health	159	60	33	93	58.5%
Bayada Home Health Care	1,211	354	261	615	50.8%
HomeCare Maryland LLC	1,361	354	224	578	42.5%
Amedisys Home Health	272	85	48	133	48.9%
Community Home Health of Maryland Inc	677	155	190	345	51.0%
HomeCall Inc. d/b/a HomeCall	344	171	89	260	75.6%
Johns Hopkins Pediatrics at Home	357	96	107	203	56.9%
P-B Health Home Care Agency Inc.	824	411	236	647	78.5%
Comprehensive Nursing Services Inc DBA Comprehensive Home Health Services	75	22	30	52	69.3%
Total	13,207	4,288	2,535	6,823	51.7%

Source: MHCC Home Health Public Use Raw Dataset, 2014

2014 Hospice Data show that 99.12% of hospice patients were age 35 and older.

Age0to34	0.88%
Age35-64	15.75%
Age65-74	16.87%
Age75-84	25.55%
Age85+	40.96%
AgeTot	100.00%

Source: MHCC Hospice Public Use Dataset, 2014

EXHIBIT 6

RONALD M. KATZEN, CPA

101 Schilling Road, Suite 30 • Hunt Valley, Maryland 21031 • Direct Line 410-852-1861

June 20, 2017

Mr. Kevin McDonald
Chief, Certificate of Need
Maryland Health Care Commission
4160 Patterson Avenue
Baltimore, MD 21215

Re: P-B Health: Hospice Certificate of Need Applications for Hospice Services in Prince George's County and Baltimore City

Dear Mr. McDonald:

We are the independent accountant for P-B Health, Inc., a longstanding provider of home health care. We are aware P-B Health has applied separately for certificate of need approval to provide hospice services in Prince George's County and Baltimore City. We are knowledgeable about the finances of P-B Health. We can advise you that P-B Health is a solvent, going concern and has the funds sufficient to cover the capital costs of both certificate of need applications.

Sincerely,

Ronald Katzen CPA

Ronald Katzen CPA

cc: Jackie D. Bailey

EXHIBIT 7

2014 Home Health Data show that P-B Health served the largest number of Charity Care Home Health visits in Baltimore City. Bayada served none.

Charity Care Visits
Home Health Agencies
Baltimore City
2014

Agency	Jurisdiction	Total Visits	Charity Visits	% Charity
Visiting Nurse Association of Maryland LLC A/K/A VNA of Maryland LLC	Baltimore City	34,260	81	0.24%
PHR of Baltimore	Baltimore City	6,515	-	0.00%
Amedisys Home Health	Baltimore City	561	4	0.71%
Personal Touch Homecare of Baltimore Inc	Baltimore City	12,978	-	0.00%
MedStar Visiting Nurse Assocation Inc.	Baltimore City	36,742	-	0.00%
Gentiva Health Services	Baltimore City	8,045	-	0.00%
Stella Maris Inc.	Baltimore City	10,038	2	0.02%
Johns Hopkins Home Health Services	Baltimore City	19,003	-	0.00%
Amedisys Home Health	Baltimore City	3,060	-	0.00%
Bayada Home Health Care	Baltimore City	18,316	-	0.00%
HomeCare Maryland LLC	Baltimore City	15,607	50	0.32%
Amedisys Home Health	Baltimore City	4,414	-	0.00%
Community Home Health of Maryland Inc	Baltimore City	10,803	-	0.00%
HomeCall Inc. d/b/a HomeCall	Baltimore City	9,237	-	0.00%
Johns Hopkins Pediatrics at Home	Baltimore City	2,634	-	0.00%
P-B Health Home Care Agency Inc.	Baltimore City	15,305	98	0.64%
Comprehensive Nursing Services Inc DBA Comprehensive Home Health Services	Baltimore City	368	13	3.53%
Total		207,886	248	0.12%

Source: MHCC Home Health Public Use Raw Dataset, 2014

EXHIBIT 8

MHCC | MARYLAND
HEALTH CARE
COMMISSION

African American Hospice Patients as a Proportion of Total Hospice Patients:

2013- 2014, Maryland

Jurisdiction	2013	2014	African American Population 35+ Total Population 35+
Allegany County	1.6%*	2.4%*	6.0%
Anne Arundel County	10.8%	15.0%	14.8%
Baltimore City	46.8%	57.3%	64.8%
Baltimore County	21.6%	22.0%	24.2%
Calvert County	13.6%	10.1%	13.5%
Caroline County	7.7%*	0.0%*	13.7%
Carroll County	2.3%	2.1%	3.3%
Cecil County	3.7%	5.1%	5.8%
Charles County	27.0%	28.3%	41.1%
Dorchester County	30.8%	15.0%	24.8%
Frederick County	3.6%	5.2%	8.0%
Garrett County	0.0%*	0.0%*	0.5%
Harford County	5.5%	7.1%	11.4%
Howard County	11.9%	12.9%	17.2%
Kent County	11.3%*	14.3%	14.8%
Montgomery County	12.3%	13.8%	16.9%
Prince George's County	48.9%	60.0%	68.6%
Queen Anne's County	3.0%*	7.1%	6.7%
Somerset County	28.4%	26.4%	31.7%
St. Mary's County	12.4%	12.8%	13.8%
Talbot County	3.0%*	5.5%*	11.8%
Washington County	2.8%	2.8%	8.3%
Wicomico County	16.4%	14.1%	22.8%
Worcester County	11.9%	11.3%	11.6%

Source: Maryland Hospice Surveys: 2013-2014. Note: 2014 is preliminary data; not yet posted.
Population data: Maryland Vital Statistics Report, July, 2013.

Notes:

Hospices authorized to serve jurisdictions were not counted, if they served fewer than 10 African American patients in the selected year.

An asterisk (*) indicates that only one provider is authorized to serve that jurisdiction, but fewer than 10 African American patients were served.

EXHIBIT 9

I hereby declare and affirm under the penalties of perjury that I participated in the development of the P-B Health response to comments and provided information included in the response and that the facts stated in this response and its attachments are true and correct to the best of my knowledge, information, and belief.

Jena M. Wardy

Signature

6/14/17

Date

I hereby declare and affirm under the penalties of perjury that I participated in the development of the P-B Health response to comments and provided information included in the response and that the facts stated in this response and its attachments are true and correct to the best of my knowledge, information, and belief.

M.S.J. [illegible]

Signature

6/14/17

Date

I hereby declare and affirm under the penalties of perjury that I participated in the development of the P-B Health response to comments and provided information included in the response and that the facts stated in this response and its attachments are true and correct to the best of my knowledge, information, and belief.

Jackie Bailey, RN, CEO
Signature

6/14/17
Date

I hereby declare and affirm under the penalties of perjury that I participated in the development of the P-B Health response to comments and provided information included in the response and that the facts stated in this response and its attachments are true and correct to the best of my knowledge, information, and belief.

	6/14/17
Signature	Date