Inclusion **ADD** Access Toolbox





The Architect of and Catalyst for Social Change to Advance Care at the End of Life.



Inclusion And Access Toolbox

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Guide to Using This Toolbox

WHY INCLUSION AND ACCESS?

Opening access to everyone in your community requires a commitment to inclusion. Your program, services, policies and procedures, along with all the staff and volunteers who operationalize them, must foster a culture of inclusion.

Merriam-Webster's Online Dictionary defines include as "to take in or comprise as a part of a whole or group", inclusion as "the act of being included."

In relation to access, inclusion means changing the paradigm from one of offering services and marketing them to communities to one of including members of diverse and underserved populations in hospice design and promotion. Inclusion means participating in community action. Inclusion is accomplished not by telling communities what they should do, but through establishing trusting relationships.

Inclusion and access matter because they enhance organizational culture, improve employee satisfaction and retention and increase organizational flexibility and creativity (Critical Measures, LLC, 2005.) The result is a better life for all members of your community.

USING THIS GUIDE

The NHPCO Inclusion and Access Toolbox is designed to give you new tools and resources to create an inclusive hospice organization. Foundations of inclusive care are described in each chapter to help you meet the needs of your own unique community.



As you study this guide, you'll find we have provided grounded knowledge of key principles: what inclusion means for a hospice organization, what it looks like, who it involves and how practical strategies may be used. Frequently asked questions and resources are also included at the end of each chapter.

This toolbox is a collection of suggestions and successes based on the thoughts and experiences of hospice providers in many settings

throughout the United States. Populations with diverse economic, education, sexual preference and physical and other abilities are highlighted.

You may wish to begin with the first chapter and continue step-by-step. The toolbox is also designed so that each chapter can stand on its own. You can bookmark specific chapters for focused attention. There are ample tools for you to use and share.

This toolbox is a stepping stone for exploring inclusion and access in end-of-life care. As you test strategies and learn from your colleagues, patients and families, your ability to serve new populations will grow. Our intent is for this toolbox to accelerate your learning curve.

TOOLBOX AUDIENCE

Hospice and palliative care executive directors, managers, nurses, social workers, chaplains, physicians, board members and volunteers will find essential

information designed for them. Multidisciplinary content was selected for use across these professional disciplines.



NHPCO'S INCLUSION FRAMEWORK

Patients, families and communities are the core of inclusive and accessible hospice and palliative care. Needs and strategies for their inclusion and access are articulated in four primary ways: assessment, engagement, education and evaluation.

Consistent use of this manual will guide your hospice organization to:

- 🛞 Expand board, leadership team, staff and volunteer understanding and sensitivity of inclusion and access in end-of-life care;
- 🛞 Employ new paths toward inclusion through community, staff, board and volunteer engagement;
- 🔠 Develop an organizationwide plan to increase inclusion in all areas of hospice care;
- 🛞 Demonstrate individual and collective best practices for inclusion which are cornerstones of culturally relevant and sensitive care.

The framework is held together by eight areas that are addressed chapter by chapter. These include:

- **Vision, Mission and Values**
- **Community Presence**
- **Marketing and Public Relations**
- **Board Development**

- Administration
- **Quality Assessment and Performance Improvement**
- **Workforce Development**
- **Patient and Family Care Services**

An Appendix also contains additional instruments and guidelines that will help you to implement inclusive hospice care with changing populations and audiences.

We trust these tools will guide all hospice staff, board members, volunteers and community champions toward greater end-of-life inclusion and access within all communities.



Business Case for Inclusion

WHAT OCCURS WHEN BUSINESS INCLUSION IS CHAMPIONED?

The goal of business inclusion is building a culture that removes barriers to individual and team performance and supports each employee in applying their absolute personal best efforts.

Business inclusion builds processes, systems and hospice services which meet the needs of a large local and global community.

Today's workplace is a mosaic of diverse people representing unimaginable experiences and backgrounds. Increasing workforce diversity will give you:

- A competitive business advantage
- Entrance into new markets
- Creative innovation
- Increased employee satisfaction and motivation

Those who perceive diversity as exclusively a moral imperative or a societal goal are missing the larger point.

Workforce diversity is a competitive business opportunity.

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WHAT ARE THE FACTS OF BUSINESS AND POPULATION CHANGE?

From 1990 to 2005, minority group market share and purchasing power in the United States doubled. By 2009, buying power will increase by another 50 percent. By 2050, current estimates support that 47 percent of the total U.S. population will be comprised of Asians, Hispanics, African Americans and other non-white groups (Wellner & Weisul, 1992).

Economic changes also exist among other U.S. populations. Gay, Lesbian, Bisexual and Transgender (GLBT) consumers will control 6.1% of the U.S. market share or \$608 billion. The annual buying power of women is also estimated to be \$3.3 trillion. Women also make the household purchase decisions in 80 percent of U.S. homes, as well as 80 percent of all health care decisions (The Business and Professional Women's Foundation, 2001).



WHAT DOES BUSINESS INCLUSION LOOK LIKE?

Business inclusion recognizes, respects and values differences.

Business inclusion brings together a wide range of human characteristics and experiences including communication styles, career paths, life experiences, education, geographic locations, incomes and economics, marital status, military experience, parental status and other variables that influence our perspectives of the world.

Business inclusion affects our ability to be flexible and to expand market growth. Our unique life experiences and perspectives make us react and think differently. Our different experiences shape our approach to challenges, our problem-solving capacity, how we perceive business decision-making and how we move toward technology and new market developments.

Business inclusion focuses on bringing diversity of thought to our organization.

WHAT ARE ADDITIONAL BUSINESS ADVANTAGES OF INCLUSION?

As hospices strive toward access for all, the business base of your organization will become more diverse. New populations will gain knowledge of your services. Your leaders will need increasing business expertise to meet new population and market challenges.

Multicultural populations are currently the majority communities in six of the eight largest U.S. metropolitan areas. Future-looking organizations that recognize the implications of these population shifts will become more profitable.

The case for homogeneity has ended. The business challenge of hospice care is to transform care and services to meet a more dynamic mix of people of various races, cultures and backgrounds. Improved and equitable business practices are needed to meet the needs of all hospice consumers and employees.

Hospice organizations must attract quality employees with creativity, motivation and skills. Diverse perspectives guide and enrich organizational decision making. These business decisions will shape your return on investment.

Inclusion protects the bottom line. Organizations that are not diverse are prone to employment-related lawsuits. Implementing inclusive business practices, policies and standards will help protect your organization from legal suits with costly awards.

FAQ'S

Isn't "Diversity" simply the newest term for Equal Opportunity and Affirmative Action?

No! Equal Employment Opportunity (EEO), Affirmative Action and Diversity have very different meanings.

Equal Employment Opportunity became a law through the approval of the Civil Rights Act of 1964. This act prohibits employers from making employment decisions based on an individual's race, color, religion, sex or national origin. It also requires that the granting of benefits in any federal financial assistance or health services program (such as hospice care) may not be based on race, color and national origin.

Affirmative Action is a government-initiated action to comply with the law. It is intended as a means to redress past discriminatory practices. Its goal is to eliminate under-representation of women, minorities and people with disabilities in the workplace.

Diversity is not about correcting a past imbalance, being a good corporate citizen or following the law. Diversity constructively uses the factors that make us different and unique to build a workforce where everyone can succeed and make a valuable difference. Those who perceive diversity strictly as a moral imperative and societal goal are missing an important business factor.

The following chart summarizes some differences between EEO/Affirmative **Action and Diversity.**

EEO/Affirmative Diversity Action Government-initiated Voluntary Legally driven Productivity driven Quantitative Qualitative Problem-focused Opportunity-focused Targeted Inclusive Reactive Proactive

The objective of business inclusion is not to assimilate minorities into a dominant white culture, but to create a dominant heterogeneous culture (Thomas, 1990).



9.9 Business Case for Inclusion

REVIEW OF INCLUSION AS A BEST BUSINESS PRACTICE

- ◆ Inclusion is more than demographics. Differences in gender, race, physical/other factors, sexual orientation, ethnicity, education and economics are components of inclusion. Unique perspectives, talents, insights and experiences of all people also shape business inclusion.
- ◆ Inclusion creates new systems that are equitable for all.

 These systems guide your board of directors, executive/
 management/work teams, employees and volunteers. These
 systems include diverse skills, creative talents, experiences and
 viewpoints of an emerging workforce. These systems support full
 participation of all.
- Inclusion is competence-based.
 The business goal is to gain expanded vision and competitive marketing from a diverse workforce.

"We have become
not a melting pot but a
beautiful mosaic with
different people,
different beliefs,
different yearnings,
different hopes and
different dreams."

Former President Jimmy Carter

This **Inclusion and Access Toolbo**x will guide you toward systemic changes that improve your workforce success, professional performance standards, community recognition.... *and your fiscal bottom line*.

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RESOURCES

Web

Collection and Use of Race and Ethnicity Data for Quality Improvement: http://www.ahip.org/content/default.aspx?docid=18292

The issue brief on the 2006 America's Health Insurance Plans (AHIP) and the Robert Wood Johnson Foundation (RWJF) survey highlights progress made by health insurance plans on collecting and using data on race, ethnicity and primary language to help address disparities.

Diversity Rx: www.diversityrx.org

Provides facts about language and cultural diversity in the United States; offers an overview of models and strategies for overcoming cultural and linguistic barriers to health care; reviews federal, state and organizational policies and protocols; addresses legal issues and current research; and provides networking and resources. Diversity Rx also sponsors conferences and offers training packages.

The National Institute for Jewish Hospice: www.nijh.org

The one major resource for the Jewish community, providing referrals and recognition to accredited hospices nationwide. Many helpful resources, including a patient referral guide.

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Vision, Mission and Values

People Served Staff **Volunteers** Communities

Quality Assess

WHY DOES INCLUSION IN VISION, MISSION AND VALUES MATTER?

An organization's Vision, Mission and Values - in essence its organizational culture – set its long-term direction. A thoughtful vision statement can also become a useful measure of real progress over time. To be of use, this statement should provide a definition of diversity and describe what the organizational culture will be like when diversity is understood, respected and leveraged.1

When organizational leaders and employees at many levels help to build the vision, it can become an important collective perspective that represents shared hopes, needs and common values.

Your Vision, Mission and Values are your organizational compass. They are your North Star through organizational blizzards, windstorms and hail. Your Vision, Mission and Values compass guides many travelers: your board, your leadership team, your employees and volunteers. It also informs the community where you are positioned and how you will assist those in need.

WHAT DO INCLUSIVE VISION, MISSION AND VALUES LOOK LIKE?

Together, this trio sets the stage for organizational change:

- 1. We want to create an environment where everyone is respected and included.
- 2. We want to leverage our diversity for competitive advantages.
- 3. Accomplishing this will require changing some assumptions, practices and beliefs, individually and as an organization.
- 4. These changes will not happen quickly or be done recklessly.
- 5. As our culture evolves, we will need to work together to make diversity work for us.²

A Vision statement inspires action that surpasses what may seem possible.

A Mission statement articulates the purpose of your organization. It describes why you exist and reflects your motivation for engaging in work. Mission statements are inspiring, long-term in nature and easily understood.

A Value statement identifies what is prized and supported. While a vision and mission may change as they are realized, core values rarely change.

"It is entirely possible to have great cultural diversity represented in an organization's workforce, but not value the differences or leverage the potential that greater cultural diversity offers. Valuing diversity and diversity per se are not the same thing."

Marilyn Loden, Implementing Diversity

Community Presence

Community presence means *having an impact in the communities where we live and work.* We do this by building relationships, inspiring each other and promoting positive outcomes. Community presence takes time, talent and resources.

Community presence fosters strong relationships that improve life for its members. This is accomplished not by telling people what they should do, but through *getting to know them and understanding their preferences and needs!*

As the U.S. population grows increasingly diverse, urban, suburban and rural communities are changing. Organizations that were once well-known to a particular community are shadowed by newer more visible services. If communities are to access hospice as a health care benefit, as opposed to seeing hospice as health care rationing, *hospices must demonstrate their integrity and ability to integrate into new communities*. While hospices may find themselves facing unfamiliar cultural communications and terrain, effectiveness depends on fine-tuning end-of-life care to the needs of changing communities.

- Community presence matters because hospice services must be offered in the context of community.
- Community presence matters because hospices have a responsibility to identify and meet end-of-life needs of new communities.
- ♦ Community presence matters because hospices are an asset and share in community well-being.

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WHAT DOES COMMUNITY PRESENCE LOOK LIKE?

Hospices in the United States are identifying principles to effectively meet end-of-life service needs in ethnic, religious and cultural communities. *Hospices which are successful in cultivating and expanding community end-of-life services follow these principles of practice:*

- ◆ Participate in diverse group community activities without expecting a "payback."
- Initiate dialogue and learning opportunities with leading community organizations.
- Commit to long-term development and sustenance of community relationships.
- Work collaboratively with community leaders and public health/human service/education/other organizations to promote justice and inclusion.
- Advocate for public health, human service and other policy changes to increase self-sufficiency and wellbeing of underserved populations.
- Promote staff and volunteer engagement with religious, ethnic/cultural, Gay, Lesbian, Bisexual, Transgender and other groups to demonstrate a culture of caring, giving and community service.

People Served Staff Volunteers Communities

Community Presence

The world community
is small and
interconnected.
We are all living
in one big town.

Quality Assessm

Mary Pipher,
The Middle of Everywhere

Inclusive marketing of hospice services

is a

strategic best

business practice.

Quality Assess

Marketing and Public Relations

WHY DO MARKETING AND PUBLIC RELATIONS MATTER?

Marketing and public relations with diverse audiences in the 21st century is a *best business practice*. For hospices, increasing access to end-of-life care requires community knowledge of how hospice meets patient and family caregiver needs. Culturally responsive marketing and public relations is a key strategy to communicate effective hospice messages.

Marketing and public relations strategies are part of hospice board development and strategic planning. Getting messages out to diverse communities builds new business, reaches new populations and connects hospice to the community. An impressive marketing and public relations *return on investment* results when careful planning occurs.

All hospices need a marketing and public relations business plan to communicate end-of-life services to the public. Furthermore, as services improve or change, revised messages must reach other health care organ-

izations, service organizations, faith communities and businesses. Through clear, culturally relevant marketing communications, your target audiences can learn how their needs can be met.

Marketing and public relations matter because:

- ◆ United States ethnic markets comprise approximately \$1.4 trillion annually.
- Inclusion of multicultural communities also improves your hospice culture, employee satisfaction and employee retention. Inclusion increases organizational flexibility and creativity (Critical Measures, LLC, 2005).
- Most multicultural markets have never heard of hospice care. Hospice is unknown to many community leaders, spokespersons and decision-makers.
- Achieving positive end-of-life outcomes is out of reach unless communities know how to access and benefit from culturally sensitive end-of-life care.

"If I knew hospice services existed, I would use them." — A Somali Elder

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Quality Ass

WHY DOES BOARD INCLUSION MATTER?

A changing customer base demands board diversity. Companies wishing to remain competitive in our global economy benefit from reflecting the diverse experiences and perspectives of a changing customer base. Women and minorities contribute more than \$1.5 trillion annually to the U.S. economy. Studies estimate that women make up to 70 percent of the consumer decisions in the United States.¹

Employee commitment increases with board diversity. Diverse board membership sends a clear signal to employees that an organization is committed to inclusion at the highest level of the organization.

Evidence suggests that having diverse role models on boards of directors also motivates employees by providing a concrete example of the organization's support of persons of different cultures, ethnicities and experiences.

Business relationships are strengthened with board diversity. Growing media, stakeholder and community attention to board diversity has made it imperative and fiscally effective for companies to proactively address their

board composition with regards to economics, education, sexual orientation and other perspectives.

Board inclusion impacts your organization's ability to successfully reach out to and serve new markets. With rapidly changing demographics, organizations are increasing board diversity to broaden language, educational, economics and leadership skill sets. Boards are also tapping into new recruitment sources. Strong community networks are needed to recruit, mentor and train new board representatives with more diverse resources, experiences, backgrounds and engagement styles.

Foundations pay attention to board inclusion when making funding decisions. Foundation program officers notice organizations where boards and management reflect diverse populations. Diverse boards strengthen an organization's connection to its constituency.

A diverse board brings a broader pool of ideas and perspectives. A study conducted by Booz Allen Hamilton and the Volunteer Consulting Group found that less than 14 percent of nonprofit trustees were black, Hispanic or Asian. Yet 27 percent of the total U.S. population comprises these groups. While ethnic and racial minorities are vastly under-represented on boards, diversity also means recruiting new trustees with a greater mix of skills and leadership styles.²

Research studies indicate that greater board inclusion results in superior financial returns. A 1998 study by academics Hillman, Harris, Cannella Jr. and Bellinger (2002) found that "ethnic and gender diversity on corporate boards is associated with superior stock performance." The study compared S & P 500 companies with differing numbers of women and minority directors. It concluded that companies with more diversity had better stock returns and less risk of loss for shareholders. The study found that companies with the most women and minority directors had shareholder returns 21 percent higher than companies with none.³

"A leader takes people

where they want to go.

A great leader takes

people where they don't

necessarily want to go,

but ought to be."

Rosalynn Carter

Quality Asses

WHY DOES AN INCLUSIVE ADMINISTRATION MATTER?

An open and reflective administration sets the tone for an organization's culture.

Inclusion is an organizational value. As such it must be embodied by formal and informal leaders throughout the organization. Leaders must be perceived as being genuinely committed to inclusion, otherwise the culture of the organization will never reflect the desired value.



WHAT DOES AN INCLUSIVE ADMINISTRATION LOOK LIKE?

An inclusive administration recruits and selects new leaders, retains employees and develops strategies which build vital work teams. It commits to developing systematic, objective, rational and fair recruiting strategies. It implements them aggressively and fosters a team environment that treats people fairly, regardless of their differences.

An inclusive administration challenges its employees to effectively use their talents in a cohesive way to meet business goals and objectives.

An inclusive administration creates an environment where people are able to do their best. It employs 360-degree feedback, consequences (incentives and sanctions) and performance skills, knowledge and resources.

An inclusive administration advocates for the disenfranchised, inviting and encouraging non-majority members to participate and share their experiences and knowledge. Leaders of an inclusive hospice are proactive, not waiting for people to speak up. Leaders also recognize and encourage new voices to participate in organizational activities.

An inclusive administration is intolerant of prejudicial or non-inclusive behavior. Staff who express feelings of exclusion or prejudice are not marginalized or penalized for speaking up.

An inclusive administration partners with and engages its communities in conversations on inclusion. Its leadership is visible in cultural and community activities, social action and groups. It models a community-centered philosophy of "How can we partner and support each other?" It develops and maintains long-standing relationships which are multicultural and intergenerational.

An inclusive administration builds a strong volunteer base that reflects its community and the organization. Community members of various ages, incomes, educational backgrounds and interests are invited to participate in hospice activities which promote sensitive care and access for all. Staff are encouraged to volunteer to support community organizations demonstrating the hospice's commitment to the community at large.

An inclusive administration models diversity at all levels, beginning with the executive team and continuing through all organizational branches. Promotion from within is encouraged and supported. Mentoring is offered to employees to help them achieve professional goals.

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Quality Assessment and Performance Improvement

WHY DO QUALITY ASSESSMENT AND PERFORMANCE IMPROVEMENT MATTER?

As an effective hospice provider, you must be able to measure and respond to issues concerning service value and outcomes. If hospice care is promoted for making a difference in patient and family care outcomes, your measures must accurately constitute these results. The *added value* of hospice care is much more than a slogan. It is a result of careful qualitative and quantitative measures.

When differences in end-of-life beliefs, meaning and language exist – and when decisions are based upon complex cultural factors – how do we assess quality? Has our training in the use of medical interpreters, effective cross-cultural communications and community engagement made a difference?

Your answers to these questions are based on **what you assess** and **how you measure**.

WHAT DO INCLUSION-DRIVEN QUALITY ASSESSMENT AND PERFORMANCE IMPROVEMENT LOOK LIKE?

Quality assessment and performance improvement must be based on the values of an inclusive organization.

- ◆ Inclusion is a guidepost of a quality organization.
- Inclusion is a process, not a project and therefore, ever-evolving.
- Organizations need measurable, achievable, realistic and timesensitive goals to advance their inclusion efforts.
- Inclusion is not only the right thing to do, but is essential to a sound business case.
- Providing the highest quality, most inclusive and culturally sensitive care possible requires planning, measurement and vigilance.
- Achieving quality outcomes and improving performance are about change. How well an organization can manage change is a predictor of how well it can and will achieve quality outcomes that are relevant to a particular community.
- The culture of an organization requires close monitoring if it intends to embrace newcomers enthusiastically and it must be committed to repeating whatever mechanism is employed for the purposes of comparable data over time.

Measuring Diversity Results

Workforce Development

People Served Staff **Volunteers** Communities

"Not debates or oratories,

but conversation that

welcomes the unique

perspective of

everyone there."

Margaret J. Wheatley, Finding Our Way

Quality Asse

Development Workforce

WHAT IS WORKFORCE DEVELOPMENT?

There are **six basic components** of workforce development:

- Recruiting
- Selection
- Retention
- Staff development
- Team building
- Training

How well you conduct, assess, sustain, evaluate and modify these areas will largely determine your success in developing and sustaining an inclusive hospice workforce.

WHY DOES WORKFORCE DEVELOPMENT MATTER?

An inclusive workforce is intentional. A changing labor pool that attracts educated, capable and creative people of diverse backgrounds is needed in all hospice organizations. Do you know what your community

will look like in the coming decades? How can you build your workforce now to reflect the populations and values of your community tomorrow?

In 2007, the combined buying power of African Americans, Asians and Native Americans will account for 13.8 percent of the total U.S. buying power. This is a 10.6 percent increase since 1990 (Hubbard, 2004). How you recruit, select, retain, develop, build and train your employees will impact your longevity, your community value and your retention of customers in future decades.

Workforce development involves a team with different skills and talents.

If you plan to deliver services to a new global clientele, you must develop your workforce in new and strategic ways. Your employees are excellent communicators of your organization's value. A just and inclusive reputation from the employee perspective is critical to establishing and increasing broader community awareness of organizational value.

In addition, building workforce diversity also reduces potential litigation and avoidable expensive drains on staff time and legal fees. Workforce inclusion reduces the frequency of discrimination lawsuits, voluntary employee resignations, recruitment/training costs, dissatisfied patients and lost time through mediation and bias-related conflicts.

Patient and Family Care Services

A PORTRAIT OF INCLUSIVE PATIENT AND FAMILY CARE SERVICES

As you work daily with patients and families, cultural challenges impact your care. While listening with an open mind is an important starting place, there are distinct practices that will increase your effectiveness in multicultural settings.

A key fact to remember is that **hospice has its own culture**. Some cultural beliefs and values of hospice care are:

- Providers are not always able to cure a disease.
- ◆ A "peaceful" and pain free death is a preferred outcome.
- Hospice professionals can help patients and families navigate the dying process.
- ♦ It is important to acknowledge and discuss how we wish to die.

When you work with patients and families who have different life and end-of-life perspectives, you move into the unknown. How capably do you navigate end-of-life care when:

- Family members make end-of-life care decisions to "spare" the patient from difficult decision-making?
- Patients and family members believe that discussing death brings it closer?
- The oldest son or a clan elder decides the course of action for a family?
- A patient or family member's beliefs, life-style or actions cause you discomfort?

patient and the point of need is just to sit with a family member and find a small connection you have in common."

Hospice Nurse

Cultural Brokering: A Powerful Engagement Strategy

WHO ARE CULTURAL BROKERS?

Cultural brokers are individuals who have one foot planted in their culture of origin and the other in contemporary western society. These individuals are bilingual and bicultural, with a mature understanding of the range of cultural traditions based on age, gender, economics, education, religion and ethnicity.

Cultural brokers may be teachers, spiritual leaders, health care workers, community organizers, elders, business leaders or other respected community members. They have strong communication skills and sensitivity and can interpret values and beliefs from one culture to another.

Cultural brokers bridge, link or mediate between groups or persons of different cultural backgrounds. They can help reduce conflict and increase understanding and mutual change (Jezewski, 1990).

Cultural brokers help bridge gaps in health care beliefs and understanding between persons of non-dominant and dominant communities. Engaging faith leaders, clergy, community health workers, community leaders and others in conversations on beliefs, values and preferences is a powerful way to build trust, community awareness and education about end-of-life care in diverse communities.

Acknowledgements

Appendix

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ACKNOWLEDGEMENTS

The National Hospice and Palliative Care Organization

is grateful to the

Aetna Foundation

HCR Manor Care Foundation

and

Heartland Hospice

for their generous financial support

of the Inclusion and Access Toolbox





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Inclusion and Access Toolbox Item #: 821026