Inclusion and Access Toolkit

Professional Development and Resource Series

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NHPCO
National Hospice and Palliative
Care Organization

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Guide to Using This Toolkit

Why inclusion and access?

Actively increasing access to everyone in your community requires a commitment to inclusion. To reach everyone, your program must foster a culture of inclusion.

Inclusion is accomplished not by telling communities what they should do, but through establishing trusting relationships.

Equity and inclusion must start from within an organization. These key principles will enhance organizational culture, improve employee satisfaction and retention, and increase organizational flexibility and creativity.

Using this guide

The NHPCO Inclusion and Access Toolkit is designed to provide information, resources and strategies for organizations seeking to highlight diversity and cultivate culture of inclusion. This toolkit makes the case for Diversity and Inclusion as an organizational best practice. The content and guidance included in this toolkit comes from a compilation of resources that have been curated by the NHPCO Diversity Advisory Council. This is a living document that offers a framework for all interested in diversity, equity and inclusion, and is based on the combined experience, knowledge and expertise of the committed members of the Diversity Advisory Council.

Toolkit audience

Hospice and palliative care executive directors, managers, nurses, social workers, chaplains, physicians, board members and volunteers will find essential information designed for them. Multi-disciplinary 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. Their needs and strategies for inclusion and access are articulated in four primary ways: assessment, engagement, education, and evaluation.

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

- Business Case for Inclusion
- Vision, Mission and Values
- Community Presence
- Marketing and Public Relations
- Board & Administration Development
- Quality Assessment and Performance Improvement
- Workforce Development
- Patient and Family Care Services

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

Consistent use of this manual will guide your hospice and palliative care 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 organization-wide 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.

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 and palliative care 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

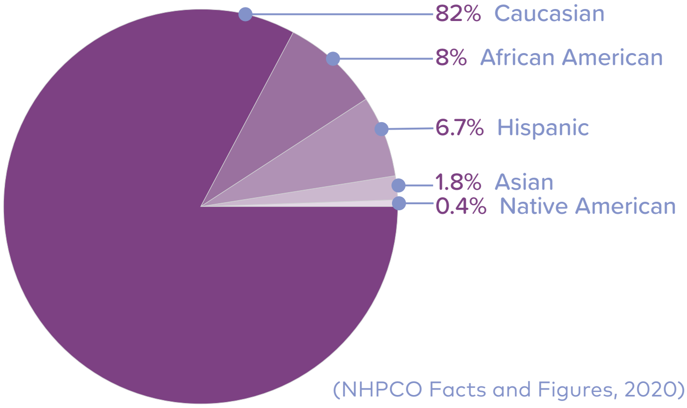
Who receives hospice and palliative care?

Addressing demographic disparities in hospice and palliative care utilization can ensure more patients receive quality care at the end-of-life as well as open untapped markets to hospice and palliative care providers.

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

2018

Medicare decedents who utilized hospice and palliative care



(NHPCO Facts and Figures, 2020).

What does business inclusion look like?

Recognizes, respects and values differences.

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.

Affects our ability to be flexible and to expand market growth.

Focuses on bringing diversity of thought to our organization.

> **Diversity is a key driver of innovation. Proximity drives empathy, and empathy provides insight which enables you to identify who's excluded, which then sparks innovation. Before Henry Ford developed the first Model T, which was produced in Detroit in October 1908, motor vehicles were only for the rich. The largest market for the car was those excluded, Ford made cars the everyday person could afford - and the rest is history. Look for those excluded and find a way of delivering what they want and need.**
>
> -Carmen Morris (2020) Founder and Managing Director of Kenroi Consulting

What are additional business advantages of inclusion?

As hospice and palliative care strives 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 community shifts will become more profitable.

Hospice and palliative care 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.

Inclusion initiatives will increase the reach of your client populations and lead to financial growth.

- Prompting inclusion will help you attract a more diverse workforce that will help you better understand and serve different cultures within your communities served.
- Improved and equitable business practices are needed to meet the needs of all hospice and palliative care consumers and employees.

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.

EEO prohibits discrimination based on protected classes defined by the law [race, color, religion, age, disability, sex (including pregnancy, sexual orientation and gender identity), or national origin. Affirmative Action seeks to comply with the EEO through promoting equal representation. Diversity constructively uses the factors that make us different and unique to build a workforce where everyone can succeed and make a valuable difference.

> **"Diverse organizations have proven to be more capable than their counterparts in attracting top talent, developing stronger relationships with customers and stakeholders, improving decision-making and innovation, and increasing employee engagement and satisfaction."**
>
> -U.S. Securities and Exchange Commission, 2020

Review of inclusion as a best business practice

Inclusion is more than demographic data. It reflects a difference in thinking that allows for more and better solutions. Inclusion promotes a hospice and palliative care organization that serves the entire community. This will ultimately improve your fiscal bottom line, driving your business forward to continue to serve the community.

> **"Our glorious diversity - our diversities of faiths and colors and creeds - that is not a threat to who we are, it makes us who we are."**
>
> -Michelle Obama (2017) Final address as First Lady

Vision, Mission and Values

Why does inclusion in vision, mission and values matter?

An organization's Vision, Mission and Values – in essence its organizational culture – establishes 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 inclusion and describe what the organizational culture will be like when inclusion is understood, respected and leveraged.

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.

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.

Values identify what is prized and supported. While a vision and mission may change as they are realized, core values rarely change.

Vision – Mission – Values Reflections

- Are your vision, mission and values inclusive?
- Are patients, employees, board members and communities included?
- Is recognition of difference honored for each patient, employee, board member and volunteer?
- Are values articulated which respect and honor all people, perspectives and cultures?
- Is there shared responsibility and accountability toward diversity?
- Is there a commitment by your board members, leadership teams, employees and volunteers that inclusion is a process, not an event or annual project?
- Does language validate all persons?
- Is the commitment to inclusion addressed as a best business practice?

> **"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

Where Do We Start?

Develop a shared responsibility and accountability for inclusion. Invite board members, employees, volunteers and community members to share their vision of end-of-life care services with you. Ensure that your organization's vision, mission and values reflect the philosophy, concepts and language of diverse contributors.

Develop organizational processes of shared responsibility and accountability toward diversity. Include all stakeholders in a visioning and accountability process. Include many points of view, situations, cultures, age groups, gender identities, sexual orientations and abilities in dialogue. If needed, budget for a skilled facilitator to help you develop inclusive dialogues and language that is inclusive and thought-provoking.

Have realistic time and process expectations for achieving diversity. Smart boards and leaders know it takes time, energy and commitment to change organizational culture. This is where careful and inclusive strategic planning that involves boards, employees, volunteers and community members is essential. A well planned and thoughtful process will move your organization ahead.

Develop processes and ways to measure changes in inclusion.

FAQ's

What are the critical questions to ask ourselves in a strategic planning process toward diversity?

- What is our organizational dream in terms of inclusion?
- What do we want to see and have realized five years from now?
- If we could have the organization of our dreams, including the type of care we aspire to, the clients we want to serve and the community partnerships we desire, what would it look like in the next five years? In the next ten years?
- What do we want to be able to say about our employees' knowledge, skills and values?
- What do we want to be able to say about patients and family responses to the care and services that we provide?
- What do we want to be able to say about the organizations with which we collaborate?

Your answers to these questions will tell you what or where your organization intends to be. Your answers will determine ways you aspire to be different than today.

Our vision, mission and value statements do not specifically use words of inclusion. Our board does not want to revise these statements again. How can organizations be time and cost effective with revisions?

If an organization strives to be inclusive and include diversity as an important element of its vision, a statement of intent must be communicated to your employees, volunteers and communities.

What happens after inclusion is incorporated in our Vision, Mission and Values?

Besides developing or revising organizational intent toward inclusion, each organization must collectively plan strategies to achieve diversity goals and objectives. Action plans with ways to measure outcome changes must be determined. All board, executive leadership, employee, volunteer and community actions must advance your inclusion goals.

FAQ's

We already address inclusion in our Vision, Mission and Values and it does not impact care. How can we make our vision meaningful?

Simply addressing inclusion will not automatically lead to optimal care or achievement. Your consistent attention to diversity in recruiting, hiring, retention and performance evaluation will gradually shape organizational culture in new ways.

Community Presence

Why does community presence matter?

Community presence means *having an impact in the communities where we live, work and serve*. 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 and palliative care as a health care benefit, as opposed to seeing hospice and palliative care 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 and palliative care services must be offered in the context of community.
- Community presence matters because hospice and palliative care has a responsibility to identify and meet end-of-life needs of new communities.
- Community presence matters because hospice and palliative care are an asset and share in community well-being.

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, including faith leaders and clergy.
- 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 well- being of underserved populations.
- Promote staff and volunteer engagement with religious, ethnic/cultural, LQBTQ+, Veterans and other groups to demonstrate a culture of caring, giving and community service.

> **"What I try to tell young people is that if you come together with a mission, and its grounded with love and a sense of community, you can make the impossible possible."**
>
> -Rep. John Lewis

Assessment: Beginning where you are

- What engagement assets and relationships do you already have? How are board members/staff/volunteers engaged in the community?
- What do you know about end-of-life beliefs, traditions, values and choices among diverse economic, and cultural communities?
- What level of community presence do you seek? What will it take to get there?
- What do you know about community and cultural barriers to hospice and palliative care? Have communities experienced recent episodes of health disparities?
- What are realistic goals for community participation by your board/staff/volunteers?

Engagement: Who do you need to involve?

Well-intentioned services sometimes result in unwanted outcomes. Many multicultural groups have experienced strong histories of mainstream betrayal. Given these histories, skepticism or mistrust of "beneficial health services" may be well-founded.

Some organizations confuse community engagement with marketing. Unlike marketing, a strong community presence continually builds long-term community relationships. Since all communities are different, you will need to prioritize what populations are most important for you to reach. Groups to consider may include:

- Faith-based organizations
- Public and private businesses
- Large corporations/small enterprises
- Youth centers
- Public health organizations
- Area agencies on aging/senior centers
- Multicultural chambers of commerce
- Multicultural education centers/schools/community colleges/universities
- Assisted living facilities

You may wish to begin these actions to increase your organization's community presence.

- Identify formal/informal community leaders, introduce your organization to them and discuss how you might work together to increase the community's well-being.
- Assess unmet end-of-life care needs within a community. Focus groups and personal interviews with community leaders/representatives are effective ways to determine community concerns. *Talk with new leaders whose voices you have not already heard*!
- Determine what community leaders your board, staff and volunteers currently have relationships with.
- Involve these community members in ongoing discussions, communications and opportunities.
- Build a public presence by advocating for public health, human services and other policy changes to increase self-sufficiency and well-being of underserved populations.
- Promote staff/volunteer engagement in diverse faith communities, ethnic/cultural groups and other organizations.

Education: What you need to know

Inclusion and access will increase as community presence grows.

- Informal word-of-mouth hospice and palliative care stories are powerful communications in houses of worship, community centers, businesses and homes.
- Staff and volunteer training in culturally relevant end-of-life care makes an enormous difference in bridging gaps that help align the values, preferences and language needs of all community members.
- Board members, staff and volunteers need ongoing education and reinforcement on the power of community presence as a business practice.
- Community engagement is continuous and never ending for all board members, employees and volunteers.
- A more diverse patient base does not occur overnight. Inclusion and access occur step by step.
- Time and consistency are essential to building trust.
- Community members are your teachers in end-of-life care. Seek direct education and staff development from diverse community trainers and leaders.
- Flexibility in hospice and palliative care services is essential to meet diverse community needs.
- Identify which community groups are not accessing services. How can you reduce potential exclusion and care barriers?

Evaluation: Have you become more inclusive?

Track your answers to these questions. Ask yourself the same questions in 6-12 months! Are your responses different? Have you become more inclusive?

- Does your hospice and palliative care have community engagement strategies that are part of a larger long-term strategic plan?
- Does your board and leaders invest time, staff and money in community participation and visibility?
- Do you assess your community presence annually to ensure active and inclusive participation?
- Do you evaluate what engagement methods are most effective in reaching new populations?
- Do you know who lives in your community? Do you keep abreast of subtle demographic changes?
- Are you current in market research, effective communications and evaluation strategies for underserved communities?
- Do you engage individuals of diverse ages, sexual orientation, education and economic backgrounds as board, staff and volunteers? Are you aware of populations who lack a community voice and begin to include them in services?
- Do you know how communities perceive your end-of-life care services? Do you identify unmet end-of-life care needs within diverse communities?
- Do you visit other community organizations and houses of worship to learn from them?
- Do you support education for your staff to increase competency in end-of-life care?

Steps toward a strong Community Presence

- Be visible and supportive in your community.
- Build long-term relationships with many community members and cultural brokers.
- Recruit and train hospice and palliative care staff and volunteers to be effective communicators across cultures.
- Open your doors – figuratively and literally.
- Know your audience. Determine your strengths and vulnerabilities. Find resources to advance your learning curve.
- Customize hospice and palliative care and end-of-life care messages to meet the needs of unique populations.
- Advertise. Build new relationships with multicultural media sources.
- Partner with other community organizations.

Who are your partners?

- Communities of faith
- Coalitions and caregiver groups
- Government entities
- Population-specific agencies (senior centers, gay and lesbian business councils, Hispanic groups, etc.)
- Recreation organizations (YMCA/YWCA, sports leagues, community, etc.)
- Specialist physician groups (oncology, internal medicine, cardiology, etc.)
- Public health, community health and human services
- Media sources (multicultural print, radio, television)
- Political/civic/grassroots organizations
- Sororities and fraternities
- Schools and education organizations
- Beauty/barber shops, pharmacies, bookstores and libraries
- Neighborhood councils and active community associations
- Neighborhood, city, or state consortiums

A Community Presence Story

A volunteer with a west coast hospice organization pointed out the lack of information on Islamic faith and culture in staff development, education and community materials. The volunteer formed a “Sisters Hospice Group” with women from four local Mosques. The volunteer also hosted a luncheon for the group in her home. Several lunch participants then contacted the hospice to begin volunteer involvement.

This group has now evolved into a “Sisters Pathways Health and Wellness Committee” to develop guidelines on end-of-life care with Muslim patients. The hospice recently hired a volunteer coordinator who is active in the Muslim community.

Three years ago, the hospice had no Muslim relationship. Today, a mutually beneficial relationship between the Muslim community and hospice care is present.

FAQ’s

Is community presence simply a marketing strategy?

No, community presence is an organizational value. It is built into the framework of your organization. Community presence begins with your board and continues through your leaders, staff and volunteers. *Community presence is demonstrated by visibility in the communities you serve*!

Who should be involved in community presence/relationship building?

Everyone! Relationship building involves all board members, staff and volunteers. As you develop new relationships, publicly recognize and emphasize your organization’s accomplishments! Create opportunities to celebrate all successes toward inclusion of faith communities, new businesses, popular neighborhood sites and other groups.

Our hospice tried to reach other communities, but no one responded to us. What did we do wrong? Are there groups whose background, values and beliefs do not welcome hospice care?

End-of-life care is a very sensitive subject for most people. A relationship involves contributing to the group – not “educating” individuals on the highlights/benefits of hospice. As your consistent presence is noticed at community gatherings and celebrations, you will have opportunities to share end-of-life services and stories more widely.

A way to approach groups with sensitivity may be to communicate your goals toward inclusion and access among all populations. Communicating your goals of care for the most vulnerable — particularly individuals with serious, life-threatening health needs — is a more appropriate way to begin a community-based conversation.

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 and palliative care meets patient and family caregiver needs. Culturally responsive marketing and public relations is a key strategy to communicate effective hospice and palliative care messages.

Marketing and public relations strategies are part of hospice and palliative care board development and strategic planning. Getting messages out to diverse communities builds new business, reaches new populations and connects hospice and palliative care 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. Through clear, culturally relevant marketing communications, your target audiences can learn how their needs can be met. Marketing and public relations matter because:

- Inclusion of multicultural communities also improves your hospice and palliative care culture, employee satisfaction and employee retention.
- Achieving positive end-of-life outcomes is out of reach for many unless communities know how to access and benefit from culturally sensitive end-of-life care.

What do inclusive marketing and public relations look like?

Inclusive marketing and public relations begin at the board level. Key discussions include:

- What are the changing demographics of your community?
- What are end-of-life needs in your community? What are the perceptions of diverse communities toward hospice and palliative care?
- What communities are most receptive to discussions about end-of-life service needs?
- What communities are more difficult to reach with end-of-life care messages? Where do you strategically wish to target your efforts?
- What are the generalized assumptions about hospice and palliative care in multicultural communities you serve?
- What current relationships do you have with multicultural communities?
- What would a five-year marketing and public relations plan look like to increase hospice and palliative care visibility and services within unserved communities?

Examples of inclusive marketing: having a hospice and palliative care booth at a city-wide Asian health and resource fair; providing blood pressure checks or other screening at a Latino community fair; and distributing give-away items and end-of-life resources as a fee-paying exhibitor at an elder care or professional conference on aging.

Examples of inclusive public relations: providing a minority radio public service announcement on end-of-life care, access and resources; holding a community forum with your LGBTQ+ community on specific end-of-life care and resources; assisting a community-based organization in developing and distributing a bilingual, culturally relevant flyer on elder end-of-life services for an immigrant community.

Marketing and Public Relations

Assessment: Beginning where you are

Begin by assessing your service and census data. Who are you serving? What communities are not seeking your services? What service opportunities are you missing from important populations? What do your demographic, ethnicity, racial and other patient/family data indicate? What trends and patterns do you notice in assessing your populations from year to year?

Assessment questions may include:

- Does your patient census reflect the racial and ethnic makeup (Latinx, African American, Native American, Hmong, Vietnamese, Cambodian, Ethiopian, Somali, Chinese, East Indian and others) of your service area?
- What percentage of your census does not speak English as their first language?
- Do you serve persons of diverse faith and spiritual communities?
- What percentages of your patients are LQBTQ+?
- What percentages of your patients have physical or developmental disabilities?
- What percentage of your patients are Veterans?

This assessment will lead your board and leadership team toward new marketing and public relations strategies and drive your business plan toward more innovative steps and inclusive actions.

Engagement: Who do you need to involve?

After assessing who you serve and what communities lack access to end-of-life care, you can begin to engage new audiences in conversations on access to care. How do you initiate new community relationships when you don't have personal contacts or knowledge of resources?

- Do your research.
- Schedule sharing and learning meetings with community leaders/decision makers.
- Join an end-of-life, caregiver or pain coalition.
- Volunteer at multicultural community events, fairs and celebrations.
- Read community newspapers or listservs for announcements and engagement opportunities.
- Ask questions and communicate your interest to learn.

Education: What you need to know

These principles will increase the success of your board and leadership team in conducting inclusive marketing and public relations:

- Each community is unique.
- Conduct focus groups to increase your understanding of diversity *within* populations.
- Age, gender, length of time in the United States, education, economics and religion are powerful influences within a population.
- Always include community leaders in creating culturally relevant messages from concept through dissemination.
- Use inclusive language, photos and graphics in marketing materials.
- Community-based word-of-mouth hospice and palliative care stories are a powerful public relations instrument.

- Educate community health, community service, faith and business leaders and business leaders on access to end-of-life care.
- Identify community members who have experienced positive hospice and palliative care and end-of-life family situations.
- Educate your board and staff on how they can provide marketing and community relations support with diverse communities.

Evaluation: Have you become more inclusive?

Evaluate your goals quarterly/annually to determine your progress and identify your next steps.

Why does board inclusion matter?

A changing customer base demands board diversity. Reaching new patrons requires new ideas and approaches. Employee commitment increases with board diversity. Evidence suggests that the board sets the expectations for your organizations.

Business relationships are strengthened with board diversity and impact your organization's ability to successfully reach out and serve new markets. Creating an inclusive organization starts at the top. Inclusion focuses on diversity of thought, background and experience.

In the McKinsey and Company 2017 report Delivering through Diversity, it was reported that "companies in the top-quartile for gender diversity on their executive teams were 21% more likely to have above-average profitability than companies in the fourth quartile. For ethnic/cultural diversity, top-quartile companies were 33% more likely to outperform on profitability."

> **"The art of life lies in a constant readjustment to our surroundings."**
>
> -Okakura Kakuzō

> **"A diverse mix of voices leads to better discussions, decisions, and outcomes for everyone."**
>
> -Sundar Pichai,
> CEO of Google

Board & Administration Development

Education: What you need to know

Stress to your board that inclusion means diversity in experience, skills, viewpoints and perspectives. This can include different temperaments and business perspectives. While this may lead to tension at times, it ultimately creates a culture of openness and allows for larger growth.

Evaluation: Have you become more inclusive?

Above all else, boards must ask difficult questions concerning the mix of people and talents that are essential. After evaluating and proposing a strategic mix of people, ideas and experiences, involve all members in ongoing recruitment.

Board members cultivate new colleagues and guide them toward positions of future hospice and palliative care leadership.

Board members develop strong relationships with community colleges, educational organizations, faith communities, community health and ethnic businesses to identify young professionals with vision.

Board members evaluate board representation for a strategic mix of consumers, persons of diverse generations and education levels, sexual orientations and community members with special physical or other needs.

Board members model openness to new colleagues and ideas. They graciously welcome new participants. They engage in communication styles that encourage greater contributions and sharing of knowledge. They are sensitive to foods, beverages, meeting times/dates and other preferences which honor dietary, prayer and other considerations.

- Does your organization cultivate new community members to serve in hospice and palliative care leadership?
- Do board members have strong and active community relationships?
- Do board members reflect the community they serve?
- Do your board members model openness?
- Do board members increase hospice and palliative care awareness?

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.

> **"Culture does not change because we desire to change it. Culture changes when the organization is transformed-the culture reflects the realities of people working together every day."**
>
> -Frances Hesselbein, Former CEO of the Girls Scouts of the USA

What does an inclusive administration look like?

An inclusive administration:

- Recruits, retains and models a work culture that treats all people fairly.
- Uses various talents to meet business goals.
- Creates an environment where people are able to do their best.
- Proactively advocates for those who are disenfranchised.
- Is intolerant of prejudicial or non-inclusive behavior.
- Engages the community in conversations on inclusion.
- Builds a strong volunteer coalition that reflects its community's diversity.
- Models diversity on all levels.

Administrative awareness

There is a need for administrative awareness of what is required to create an inclusive environment. Administrative staff must model the behavior they want to see throughout the organization. Examples of inclusive behaviors and actions include:

- Responsiveness to all needs regarding inclusion.
- Communication which builds an understanding and empathy for people's choices, values, beliefs.
- Training on how to resolve conflicts constructively that respects all parties.
- Attention to culturally appropriate language and action.
- Non-discrimination policies and procedures.

An administration inclusion assessment

Where do you stand on advancing inclusion among your employees?

- You model how to identify problems and find novel solutions, rather than allow problems to bubble beneath the surface.
- You create a heightened sensitivity to the needs, styles, values, frustrations and resentment of others.
- You energize people to use their root cause analysis skills to openly get to the heart of the matter.
- You help teams be accountable to each other and improve morale.
- You foster creative risk-taking and motivate others to come up with new solutions.
- You address problems in a direct, timely fashion.
- You use self-assessment and team analysis to identify where cultural and other barriers can impair a team's performance.
- You build strategies to work productively together.
- You pay attention to how you describe clients, employees and volunteers, both verbally and non-verbally. You pay attention to language used in same-sex or non-traditional relationships.
- You do not make assumptions about a client's means to pay or contribute to needed services. You are aware that economics is a complex area and may easily be misinterpreted.
- You demonstrate that financial ability is a matter of great pride and treat clients equitably. You do not judge by appearance and other factors.

Leading organizational change

Like any strategy, your efforts to build an inclusive administration will require creating a tactical plan, taking ownership, being accountable and measuring progress. Creating a plan is like creating a blueprint for a house. While you need a carefully planned design, the real action comes with construction. This is when your saws and levels are handy, since you will measure progress, make adjustments and achieve results.

The way to create an inclusive administration is to lead the change you want to see. This requires meaningful one-to-one interactions, increased visibility and support.

Communicating smarter and effectively. We have all seen and been part of long-winded processes and discussions. The truth is, it is not "how often" or "how long" we communicate, but "what we say."

Define issues in conflict; focus on interests, not positions. As your sensitivity and flexibility increases, a new level of maturity in discussing differences will emerge. As you create an administrative environment based on respect, new acts of trust and cooperation will emerge.

Be authentic. Your staff has heard you talk about things before and judged you by it. If you have not been supportive of diversity previously, let your administration know what things led you to your current priorities and how they can count on you in the future. Remember, everyone has the capacity to change if they really want to. To effect change, you must be authentic, convincing, consistent and visibly supportive.

Request and receive feedback. The best leaders accomplish strategies by having goals and excellent feedback mechanisms to measure progress. Effective administrations make it a point to personally find out how things are going. They use surveys, focus groups, team meetings, consultants and steering committees to stay informed.

Focus on one or two areas that you wish to improve. Begin with behavioral changes that stretch your thinking. Work toward more challenging behaviors. Give yourself permission to stumble and get back up as often as you need. Consistency will come as you continue to communicate your intent and support the actions of others.

As you articulate to others what you wish to accomplish, as you receive ongoing feedback from colleagues and as you adjust your strategies and performance, you will begin to own new behaviors and see administrative change.

Quality Assessment and Performance Improvement

Why do quality assessment and performance improvement matter?

As an effective hospice and palliative care provider, you must be able to measure and respond to issues concerning service, value, and outcomes. If hospice and palliative 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 and palliative 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 time-sensitive 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.

Assessment: Beginning where you are

Quality assessment begins by asking these questions and understanding the answers.

Where to start?

Determine the make up of your community. This goes beyond race and can include: race, ethnicity, nationality, religion, education level, income, gender, sexual orientation, age, illness, etc.

What will inclusion and access to end-of-life care look like in your community?

Do you have a process in place to obtain feedback from your customers (patients, families, physicians, etc.)? How do you know you are meeting the expectations of your customers?

If you were being interviewed on national television, how would you characterize your efforts to increase inclusiveness and the progress you have made?

In developing a framework for applying the principles of inclusion, hospices have four distinct roles: hospice and palliative care provider, employer, community citizen and economic entity. How do you see your organization addressing diversity on all four fronts?

Engagement: Who do you need to involve?

Ensure that everyone in the organization is well informed of the initiative's goals, plans and rationale through aggressive, active communications.

Frequent and varied communications with senior executives detail expectations and anticipated benefits of the change effort, including the expectation that staff are expected to learn, model and communicate the need for an inclusive workplace and inclusive business practices.

Communicate accomplishments to all internal and external audiences.

Make strong public statements to the community declaring your organization's commitment to inclusion.

Restate and reinforce to all staff the benefits of adopting a broader pool of skills, talents and perspectives to draw from for problem-solving and organizational success.

Education: What you need to know

- Create new competencies around diversity.
- Learn the new competencies.
- Practice the new competencies.
- Education for managers is critical, because they can be one of the resistance points in a culture change effort.
- Include awareness building and skill training.
- Include coaching for leaders.

Effective education moves employees toward greater competence levels. Pre and post-intervention measures can also guide education effectively.

Education in system-wide data collection/evaluation must be provided for all staff. Basic principles such as consistently obtaining demographics from the same sources (e.g. Chamber of Commerce, state statistics, census data, etc.) must be understood. An expectation of staff participation in quality assessment must be communicated.

Evaluation: Have you become more inclusive?

The following key performance items can be measured and evaluated by your hospice and palliative care organization:

- Education, which is key in moving staff from awareness to knowledge to action.
- Communications audits that examine brochures, newsletters, bulletin boards and staff interviews, etc. to determine if the diversity initiative is thoroughly and effectively communicated throughout the organization and the community.
- Staffing diversity reflects the community's diversity.
- Board diversity reflects the community's diversity.
- Staffing recruitment and retention statistics are segmented and monitored.
- Diversity is strategically included in the organization's planning.
- Leadership and employee behaviors are inclusive as determined by data collection (surveys, interviews, etc.).
- Career development initiatives are developed for under-represented groups.
- Practices are constantly evaluated and re-evaluated to make sure they reflect your organization's vision, mission and values.

- Information from ongoing benchmarking and surveys is used to reevaluate strategies and interventions as appropriate.
- Involving leadership in activities that bring fresh perspectives.
- Tracking and trending of populations served to compare with target populations identified in your access/diversity initiatives.

FAQ's

Who is the best person to ensure inclusive quality and performance improvement?

Everyone. Inclusion begins with the board and continues through the leadership, administration, staffing, volunteers, and community representation. Inclusion should be threaded and role modeled throughout all aspects of your organization.

- Know that all individuals have different styles and ways to communicate. Be aware of differences and celebrate the positive aspects of supervising and working with individuals with unique perspectives.
- Establish expectations for collaboration, team work and shared vision.
- Model inclusive learning and communication styles. Celebrate the synergy of different ideas and how they represent a more creative and inclusive group.
- Be an agent for change within your organization. Inspire others.
- Speak out when necessary. Hold the organization accountable; it is also on a learning curve and needs constructive feedback.
- Hold your direct reports and all colleagues accountable. Share learning and mentoring challenges.

Workforce Development

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 and palliative care 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 and palliative care organizations. 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.

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**.

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.

A preliminary workforce development assessment

How do you know if you have unexpected impediments toward workforce inclusion? How can you best evaluate your current workforce environment?

Assessing different levels and areas of your hospice and palliative care organization is an excellent start. Your assessment can include a review of your statistics, including demographic information of current and past employees and volunteers, employee and volunteer surveys and focus groups and discussions with your board, leadership teams, employees and volunteers.

- Does your workforce represent the community?
- Do you have a diverse leadership team?
- Does each discipline/team have diverse representation?
- What are current internal and external barriers to hiring a diverse workforce?
- Do you use inclusive verbal and printed language informally and formally in all communications?
- Who are your long-term employees and volunteers?
- Why do they stay? Why do others leave? Do you notice patterns?
- Are you tapping the unique talents, knowledge and skills of all your staff?
- Do you conduct and scrutinize exit interview data, as well as complaint patterns and grievances of all employees?
- Do you regularly review policies, procedures and job descriptions to ensure that legal requirements and organizational values are exceeded?
- Does your community recognize you as a champion of workforce inclusion? How can you analyze your workforce inclusion and development from a community perspective?

Recruiting and selecting a diverse workforce

Attracting individuals with a range of perspectives and experiences is a process. Maintaining strong community relationships also keeps your organization on the front lines of workforce inclusion. Creating both formal and informal networks for recruitment may help you find a larger, more inclusive pool of applicants.

Selecting potential employees requires a specific set of learned skills. This may include training interviewers to recognize different skills sets, potential for growth, technical abilities, emotional intelligence, and willingness to be open.

It may be helpful to develop specific selection criteria, instruments, and implement a team based interview approach that includes diverse interviewers. Make sure to develop open ended questions that focus on an interviewee's skills, competence (including cultural), training, and credentials.

Hospices seeking a greater diversity of candidates throughout the organization must:

- **Develop specific selection criteria.** All interviewers and managers must be competent and fair in using the criteria for hiring decisions.
- **Develop specific instruments to measure the criteria.** Develop a matrix with the candidates on one axis and the criteria on the other. Compare each candidate to the identical criteria.
- **Train interviewers and managers.** All interviewers must examine their own culture, values, emotional intelligence, racial and gender attitudes and other factors. They should go through the recruitment process, like any other new candidate. They should also receive feedback from recruits about their interviewing skills.
- **Use a team interview approach.** Have representatives from various departments and/or positions interview candidates and then meet as a team to review the candidates and arrive at a decision.
- **Include diverse interviewers.** Due to a tendency to hire people like ourselves, it is crucial that members of minority and under-represented communities are included in the interview and candidate selection process.
- **Always seek diversity in employees at all levels of the hospice and palliative care organization.**

Retaining a diverse workforce

The ability to retain a diverse work group once they have been recruited is a critical professional competence. Retention must focus on all levels of the organization. Employees must feel welcomed and supported at all levels. This can come via coaching, counseling, career planning, mentoring, performance reviews, compensation, and diversity friendly policies.

Staff development

In an article entitled, *On Matters of Race, Power and Privilege*, authors Brantley, et al, describe the deep-rooted and often unconscious nature of racism, classism and other "isms." "While there is no scientific evidence to support our notion of 'race,' culturally there are races because we have deemed them so. Racism is so deeply imbedded in our society, that it will take all our collective strength to rout it out" (Brantley et al, 2003).

Brantley and colleagues offer suggestions on what dominant groups can do to alleviate bias. Actions may include:

- Learn to recognize that you are a member of a group that has distinct patterns of behavior.
- Recognize group patterns that negatively impede access to employment, leadership, organizational involvement, resources and opportunities.
- Partner, collaborate and learn from others with different beliefs and views.
- Identify current organizational and community systems which increase workforce inclusion.
- Implement 360-degree feedback mechanisms for recruitment, selection, evaluation and performance analysis.
- Identify how staff can develop and reinforce strong relationships with community and faith organizations, higher education programs, community colleges, public health agencies, popular community meeting venues, multicultural media and other avenues of engagement.

Essential areas of staff development also include partial vs. full listening, indirect and direct communication, neutrality vs. empathy, superiority vs. equality, arrogant certainty vs. flexibility to learn.

Teambuilding

In the workforce, we want to be recognized for who we are. We want to be appreciated for what we do. We want to believe *our ideas and opinions are valued* and that they influence decisions that affect us and our work.

Managers must help team members understand the value of the differences that individuals bring to a team. Team members will meet and constantly work with others whose cultures may differ from their own. They will base first impressions on appearance, facial features, skin color, hair, dress, mannerisms, voice tone, etc. They may notice different behaviors that seem awkward, peculiar or difficult to understand. They might need help in bridging cultural gaps as a foundation for future learning.

Training

Shared learning is a valued component of training. All employees and volunteers should receive ongoing training in areas of:

- Individual engagement in an inclusive workforce
- The productive power of differences
- Conflict and difference resolution
- Communicating and giving feedback
- Inclusive communications
- Sensitivity to value differences that arise with a diverse workforce and a diverse client population
- Effective communication strategies across cultures

Evaluating workforce inclusion

Design workforce systems to measure inclusion. Systems may include:

- A strategic demographic review of your community.
- Annual changes in workforce diversity.
- Staff development actions. Identify outcomes of staff development that have made a difference in workforce inclusion, patient care and community relationships.
- Communicating positive changes toward inclusive behaviors and workforce differences.
- Pre- and post-evaluations of staff development and inclusion training. Use these measures to create five year perspectives and to document workforce changes.
- 360-degree evaluation procedures where employees and managers co-create performance measures and discuss shared outcomes.
- Annual review of workforce policies and procedures.
- Budgeting for workforce staff development and training.

Workforce rights checklist

Employees and volunteers have rights related to the provision of care by and for diverse populations. These rights should be articulated in the organization’s policies and procedures. Volunteers may be considered the same as paid staff, with similar rights, in some contexts. Employees and volunteer rights include the following:

- The right to feel comfortable in their work environment.
- The right to receive education and training on diversity issues.
- The right to feel safe. Relative to diversity issues, staff and volunteers have the right not to be placed in environments where they are not wanted.
- The right to receive additional support, when requested, on diversity issues.
- The right to work in an environment that values an inclusive workplace.

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 and palliative care has its own culture. Some cultural beliefs and values of hospice and palliative care are:

- Providers are not always able to cure a disease.
- A "peaceful" and pain free death is a preferred outcome.
- Hospice and palliative care professionals can help patients and families navigate the dying process.

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, lifestyle or actions cause you discomfort?

> **"Endings matter, not just for the person but, perhaps even more, for the ones left behind."**
>
> -Atul Gawande, MD, *Being Mortal: Medicine and What Matters in the End*

You bring your own culture to end-of-life care

All persons carry ethnic, racial, religious/spiritual, moral, education, economic and other values which can influence our actions. Yet, we are often unaware of our own biases and non-inclusive behaviors. Understanding our own cultural beliefs is like peeling an onion; after each layer, consecutive layers are exposed.

You can increase your cultural awareness through workshops, community discussions and other training opportunities. Yet, your strongest growth will occur in multicultural situations which challenge your knowledge and comfort.

- What are some privileges you enjoy in life? How do these privileges affect your life? Your ability to achieve your goals? Your ability to achieve success?
- Which of these privileges are unavailable to others because of the group they belong to? Beside each unavailable privilege, write the name of the group(s) that don't enjoy these privileges.
- Do you believe that the current health care system is already fair to everyone? Is everyone treated the same by all health care providers?
- Think of a time when you felt tolerated. Write a few words about it. How did it feel to be merely tolerated? How did feeling tolerated affect your relationship with the tolerant person(s)?

- Think of a time you felt appreciated. Write a few words about it. How did it feel to be truly appreciated? How did feeling appreciated affect your relationship with the appreciative person(s)?
- Do you incorporate inclusion and diversity into your organization and your life?
- Do you continually ask yourself whether you are making a value judgment about others, rather than recognizing that others might simply have different ways of reaching their goals?
- Do you listen actively; paraphrase what the other person has said and then ask her/him whether your paraphrase is an accurate version of what she/he was trying to convey?
- Do you consider talking less and thinking and listening more?
- Do you read publications that express viewpoints that differ from your own?
- Do you seek out situations, both at work and outside of work, that induce discomfort; then find ways of raising your comfort level?
- Is there any group of people for whom it would be difficult for you to work with or care for (LGBTQ+, specific faith tradition, homeless, drug user, convict, etc)? What would you do if you encountered someone from that population in your work?

How do I engage multicultural patients and families?

As a provider, you must be able to interact with others who are different from you. This requires that you:

- Recognize and adapt to the variety of listening behaviors you will encounter among diverse people.
- Listen for value-based cultural assumptions and expectations.
- Observe behaviors and monitor your interpretations and meanings.
- Learn about other views, work styles, assumptions and needs. Encourage others to do the same.
- Be comfortable in asking questions about the proper or preferred terminology, pronunciations, customs, etc.
- Be comfortable in asking if you have caused harm or offended and find out how to correct and avoid it.
- Ask people to explain such things as goals, objectives, instructions and directions to ensure common understanding.
- Develop a collaborative ("win-win") problem-solving process.
- When talking with non-fluent English speakers, speak clearly and avoid jargon and slang.
- Ensure that the person understands your meaning.
- Let others know, verbally and non-verbally, that you are willing to interact with them.
- Learn to feel and exhibit comfort with groups and individuals different from yourself.
- Respect the right of people to have beliefs, life-style choices or behaviors that you do not believe in or ascribe to.

How do I evaluate my own patient and family multicultural competence?

- Test your own language for inclusiveness.
- Become aware of your own reaction to change, as well as your ability to interact with others who are different from you; your adaptability to alternative solutions and unstructured situations; your mental flexibility and your intellectual curiosity.
- Choose a colleague to meet with regularly who also wishes to provide care with more sensitivity to differences. Share goals, set milestones and report on progress.
- Learn about differences in end-of-life care through reading, attending workshops, fostering relationships with people who are different and participating in activities that are diversity related.

- Ask questions of people who are different from you. Ask them what it is you don't understand. Listen to others as they describe diversity issues. Seek clarification, rather than making hasty judgments.
- Develop concrete measures to evaluate patient care and patient satisfaction among diverse populations
- Strengthen patient and family decision-making by providing choices and offering visible support.
- Document family values, religious and spiritual beliefs and caregiver roles.
- Learn about the history and beliefs of other racial, religious/spiritual and national groups. Keep informed on current challenges that face these groups in your community.

What factors contribute to high levels of patient and family care satisfaction?

Hospices throughout the United States are learning that specific practical actions have a positive impact on patient/family satisfaction. These include:

- Care providers acknowledge that a wide variety of beliefs, traditions, values and choices exist within all populations. Care decisions are personal, vary widely and change based on religious, spiritual and other patient/family preferences.
- Families sometimes feel more comfortable with providers that reflect their own cultural or socio-economic background. And sometimes not.
- Line-item budgets are needed for patient/family interpretive services, including purchases of language and culture specific resources.
- Audio/visual patient and family materials in non-English languages are important communication aids. Graphical representations of people that reflect the diverse community in which you live are more inclusive.
- A gracious welcome and sincere smile always help to create a welcoming presence.
- Allow time to develop a trusting relationship, particularly when families have experienced significant distress with the health care system.
- Always document information about the beliefs, traditions, values and choices of each patient and their family. Ensure that documentation is available to all team and on-call staff.
- Rephrase and say your message again if you feel you are not being understood. Use pictures and diagrams when appropriate. Frequently ask open-ended questions to check for the other person's understanding.
- Do not rely on family members to translate for you. Family translation can put the family member in an uncomfortable position.

Guiding patient/family care

Care Assessments: What you should ask patients and families

People are diverse in many different ways. While outward manifestations may be more noticeable, our inner worlds are equally significant.

The only way to learn what is important to a patient is by asking honest questions and listening carefully. Completing a patient/family care assessment is as important as completing a physical exam. In asking sensitive care-related questions, you will learn how a patient prefers to be treated, cared for and honored.

Hospice and palliative care organizations can develop a patient/family assessment which meets their specific provider, organization and patient needs. Examples of important patient-centered assessment questions include:

- Where was the patient born? If an immigrant/refugee, how long have they lived in this community and in this country? Is their family living with them or is there geographic separation or isolation?
- Does your patient maintain a strong ethnic or cultural affiliation? Is their ethnic/cultural community important in providing end-of-life caregiving and support?

Additional factors to consider include:

- Conversational style and pacing
- Non-verbal communication
- Personal space
- Eye contact
- Appropriate use of touch
- Time orientation or time values
- Use of interpreters

> **"When we listen and celebrate what is both common and different, we become a wiser, more inclusive, and better organization."**
>
> -Pat Wadors

Conclusion

The NHPCO Inclusion and Access Toolkit is designed to provide information on basic strategies to promote inclusion and provide resources to help promote a culture of inclusion. We have faith and confidence in all hospice and palliative care professionals to hold diversity and inclusion as an imperative and best business practice. This toolkit is aimed at supporting all in their efforts to build a framework and sustainable yet flexible model. For additional information on how your organization can be more inclusive of diverse patient populations, please see the Multicultural Guide included as an appendix in this document.

Please visit nhpco.org/diversity to learn more about NHPCO's Diversity Advisory Council, including other resources and inclusion activities that are available to your organization.

Resources

For additional resources, including outreach materials and guides, please visit:
https://www.nhpco.org/resources/outreach-tools/

- Boucher Nathan A., Raghavan Mythili, Smith Alexander, Arnold Robert, and Johnson Kimberly S..Journal of Palliative Medicine.Feb 2016.ahead of print http://doi.org/10.1089/jpm.2015.0523
- Brantley, Carol; Frost, Delyte; Pfeffer, Charles; Buccigrossi, Joan; Robinson, Marcus. *On Matters of Race, Power and Privilege*. wetWare, Inc., 2003.
- Bridging the Cultural Divide in Health Care Settings: The Essential Role of Cultural Broker Programs: https://nccc.georgetown.edu/culturalbroker/Cultural_Broker_EN.pdf
- https://www.nhpco.org/wp-content/uploads/2019/08/Chinese_American_Outreach_Guide.pdf
- Chen Stokes, S, RN, MSN & Pan, C, MD, AGSF, FACP: Health and health care of Chinese American Older Adults https://geriatrics.stanford.edu/ethnomed/chinese.html. In Periyakoil VS, eds.eCampus Geriatrics, Stanford CA, 2010.
- Chinese-American Coalition for Compassionate Care: www.caccc-usa.org Encouraging open dialogue about end-of-life issues so that they are viewed as a natural part of community life, giving attention to the importance of insuring that people die with dignity and respect.
- https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2010.1117
- Could Emotional Intelligence Make Patients Safer? Codier E[1], Codier DD. Am J Nurs. 2017 Jul;117(7):58-62. doi: 10.1097/01.NAJ.0000520946.39224.db.
- 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.
- Escarce JJ, Carreon R, Veselovskiy G, Lawson EH. Collection of race and ethnicity data by health plans has grown substantially, but opportunities remain to expand efforts. Health Aff. 2011;30(10):1984–91.
- https://cejce.berkeley.edu/geneq/resources/lgbtq-resources/definition-terms
- Houben, L.M (2012) Counseling Hispanics Through Loss, Grief and Bereavement. New York Springer Publishing Company Rosa, Dr. & Vazquez, C (2011) Grief Therapy with Latinos: Integrating Culture for clinicians, New York, NY Springer Publishing Company
- Kalbfleisch, N & Schmidt, T. (LGBT Cancer Project). "Cultural Competency on Lesbian, Gay, Bisexual or Transgender (LGBT)",Retrieved from https://www.med-ed.virginia.edu/courses/culture/PDF/marcuschapter008lgbtrevisedgc.pdf
- Lee M, PhD, MS, RN, CPHN: Journal of Gerontological Nursing (2015). Engaging Chinese American Adults in Advance Care Planning.
- LoPresti, A, BS: American Journal of Hospice & Palliative Medicine (2016). End-of-Life Care for People With Cancer From Ethnic Minority Groups: A Systematic Review.
- Pew Research Center. Asian Americans: A mosaic of faiths 2012;. Available at: https://www.pewforum.org/2012/07/19/asian-americans-a-mosaic-of-faiths-overview/
- Sage, a national advocacy and services organization that's been looking out for LGBT elders since 1978. https://www.sageusa.org/what-we-do/sagecare/

Appendix: Multicultural Resource Guide

Understanding attitudes and beliefs related to serious illness varies across culture and faith. Discussing care options such as hospice and palliative care, often referred to as comfort care at the end of life, can be a difficult subject to approach. But it can be a lot more challenging to have this discussion with a population group that has cultural beliefs dissimilar from our own. Perhaps you had an experience where you didn't understand how your words or actions were so offensive. Or maybe there was a moment when you had a hard time understanding how someone could believe what they believed.

This guide is helpful for anyone who is seeking to understand how the perception of comfort care at the end of life may vary across cultures. It will provide you with information specific to various populations including those of various race, ethnic and socioeconomic populations, those within different religious communities, those with different lifestyle choices, and those that identify themselves as a member of the military community. For example, did you know that many people of African American descent believe that healing can occur, even up to the point of death?

In addition to discussing these cultural values, we will offer you practical steps on what to do, what not to do, and how to best respect others. Even if you aren't quite sure what questions to ask, this guide will help to improve your awareness and sensitivity to care needs of diverse groups. It is also helpful for those who work in health organizations and would like to become advocates in their department and a resource for other staff members.

Together, with more education and awareness, we hope to foster open dialogue to remove cultural barriers and ultimately promote equal access to comfort care.

Important Note: This guide is a living document and will be continuously updated. Additional information for each of the populations discussed in this Appendix will be available in the NHPCO Outreach Guides being released in early 2021.

Purpose

- Foster an approach to care that is informed by cultural and religious norms
- Break down barriers to comfort care at end of life; promote equal access to comfort care
- Promote/Provide/Increase diversity awareness and sensitivity to care needs of diverse groups
- Support caregivers and open the dialogue around discussion of comfort care at end of life

Universal Concepts

This guide is designed to assist clinicians in improving interpersonal relations, increasing understanding, and furthering culturally competent care for our diverse patient population. The Guide was developed to foster a heightened awareness of the impact of cultural beliefs on patient and caregiver decisions, and to enhance communication between clinicians and diverse peoples. The Guide is a resource that can aid clinicians in responding appropriately to people of varying cultures, ages, races, religions, sexual orientations, abilities, and ethnicities in a way that recognizes difference; and that allows individuals to feel respected and valued. Cultural humility is the commitment to viewing each patient and caregiver as unique; and to learning how that uniqueness shapes their world.

Intersectionality Crossover

The NHPCO Diversity Advisory Council (DAC) recognizes that cultural and religious values are not definitive for any population. There are many instances where an individual may feel that he or she identifies with more than one cultural or religious group. Nevertheless, evaluating other cultures through *their* cultural lens, rather than our own, will help to build trust and reduce anxiety.

African Americans

Traditions & Health Beliefs:

- AA may believe that healing can occur; even up to the point of death (a strong belief in faith & prayer may be present).
- Talk to the client! Don't assume anything. Multiple religious affiliations exist within the AA community and this fact requires enquiry.
- Be careful how you bring up the subject of hospice; Pastoral support may be critical for hospice discussion.
- Do not stereotype that hospice will automatically be in conflict with the spiritual beliefs of the client.

Communication Preferences

Greeting:

- Address adults as "Mr., Mrs., or Ms." and add their last name. It may be considered to be disrespectful to call an individual by their first name if you have not been given the invitation to do so.
- If the individual has a professional title or position in the community, address them using that title (i.e. "Doctor" or "Pastor").
- Do not address anyone as "Honey," "Baby," or "Sweetheart;" these greeting are perceived as condescending.
- Introduce yourself, tell who you are and explain how you are related to your organization

Verbal:

- Open, honest communication
- Verbal interaction should come before written communication (written information should be available as "back up," "take home" information).
- AA communities want informative conversations and don't speak over them.

Nonverbal:

- African Americans will be "studying" the individual who is speaking to determine truthfulness, trustworthiness.
- Sit down to talk, eye level; relaxed body language; active listening.
- Eye contact should convey honesty.
- Maintain a level of respect without making any assumptions (especially the assumption that what you are saying is being accepted or is even acceptable).
- Do not use gestures that convey stereotypes.

Socioeconomic Factors

Rural:

- There may be a smaller support system.
- Explain who pays for hospice services (i.e. Medicare & Medicaid; non-profit hospices can provide care regardless of ability to pay).
- Explain hospice is provided in the home (decreases the potential worry about using resources to travel to visit the patient).

Urban:

- Multi-income families may be the norm (no stay at home caregiver).
- What supports are in place (is it feasible for the caregiver to give up their job; is the caregiver able to take paid/unpaid time off)?
- What community resources are available to the patient & caregivers?

Language

- May speak English, Spanish, Creole, African dialect, French, etc.
- Educational material must be culturally diverse based on local populations to be served (i.e. photos; brochures translated into the languages of the target populations).

Family Structure & Dynamics	• A variety of family structures & dynamics are found in the African American community (i.e. a dual parent home, a single parent home, there may be grandparents who are raising their grandchildren; etc.).
Expression of Pain & Treatment Preference	• May want to use “natural” treatments like rubs and ointments for pain relief • May believe pain is part of the disease process and cannot be controlled (education on pain relief, possible side effects of medication, benefits of medication must be ongoing)
Veracity in Diagnosis & Prognosis Disclosure	• Focus on debunking the myths within the AA community about hospice (i.e. “Hospice” does not mean you are dying tomorrow; hospice is not a “place” where they must go; morphine is not given to kill the patient or to hasten death).
Decision Making & Advance Directives	• Family is usually very involved in the care of the patient and will want to be consulted about health care decisions. • Verify who the designated Healthcare Proxy and/or Power of Attorney really is; but realize that there may be many other voices that shape the decision making process. • Address everyone in the room. • Make eye contact throughout the room with everyone present.
Imminent Dying & Death Rituals	• Family, friends, church members may stay with patient around the clock • Pastor may be called in for prayer; often believe faith healing is possible even up to death
Funeral Planning Beliefs	• It is important to clearly message that emotional and bereavement support is available for the entire family (not just the immediate caregiver).

Chinese Americans

Traditions & Health Beliefs:

- Some Asian Americans believe that the family should interact with health professionals on behalf of the patient (preference for family-centered care)
- Asian Americans are more comfortable discussing illness with family or friends than with health professionals.
- People from East Asia (China, Japan, Korea) and Southeast Asia (Vietnam, Cambodia) share many cultural similarities influenced by Confucianism. This includes respect of elders and strong value of family ties.
- Chinese has had great influence in Asia, so there are some similarities between Chinese culture and the cultures of Japan, Korea, Vietnam, and Cambodia.
- The largest Chinese American populations in the US are concentrated in the major metropolitan areas of NY City, SF, LA, Houston, Seattle, Chicago, Philadelphia, and Portland.
- 70% of Chinese Americans are foreign born, therefore, traditional culture remains very important.
- Diseases are believed to be either hot or cold. Each one is treated differently.
- It is a common belief that injections are the most effective way to treat illness.
- Patients may independently reduce prescription dosage because of the belief that western medicine is too strong for their smaller bodies.

Communication Preferences	Greeting: • Older Asian Americans prefer to be addressed more formally by their surname and title. They rarely use their first name alone, but prefer "Mr. Fong, Professor Chen, Doctor Wang." In friendly and more intimate interactions, they may appreciate being addressed by family names, even if not directly related by blood, such as "Uncle Phil, Grandma Sandy." Nonverbal: • May not ask doctors questions because of fear that asking may be viewed as a challenge to authority.
Urban/Rural Socioeconomic Factors	• Asian Americans living in urban communities are less likely to receive hospice care in the last 6 months of life.
Language	• Asian Americans' country of origin may be in any of the following geographic areas: East Asia, Southeast Asia, South Asia, Central Asia and even the Middle East. • Over 70% of Asians speak a language other than English at home. • There are many Chinese languages. Mandarin is the official language, but many speak Cantonese, Taiwanese, Shanghainese and other languages. However, they share a common written form, which has two variants: Traditional and Simplified, which has been used on the Mainland since the 1950s. • American born Asian Americans, compared to foreign born Asian Americans, tend to use hospice more.

Family Structure & Dynamics	• In Mainland China, religion has not been freely practiced for many years due to government policies. • Confucianism (which is an important moral philosophy that emphasizes ethical behavior) is often mistakenly viewed as a religion. Yet, the teachings of Confucius have greatly influenced beliefs about the appropriate way to live one's life. • Chinese and other Asians may be reluctant to place parents in long term care facilities out of respect and filial piety. The primary relationship in society is that between parent and child; an adult child is expected to care for the parent physically, emotionally, to honor the parent's memory after death, and engage in good conduct outside the home that brings a good name to one's parents and ancestors. • Daughters and daughter-in-laws bear the primary responsibility of caring for elders. There is a general taboo against talking about death and dying. • Even bringing up end of life issues can be viewed as placing a curse, encouraging death to come. • Children may advocate for aggressive treatment out of a sense of filial duty.
Expression of Pain & Treatment Preference	• May refuse pain medication and not complain of pain for fear of morphine addiction. • Family concerns about opioid analgesic use have been correlated with inadequate analgesic use in patients. • Chinese may use acupressure or acupuncture to treat pain or disease without notifying doctors. • Asian Americans of all subgroups are less likely than white patients to use hospice. • Asian Americans are more likely than whites to experience intensive therapy at end of life, such as aggressive use of feeding tubes, ventilators, IVs, and critical care and the emergency room. If they enter hospice, it is typically quite late. • Families often insist on feeding tubes and CPR even when the patient has only days/hours to live, because they don't want to abandon their parents.
Veracity in Diagnosis & Prognosis Disclosure	• Asian Americans have reported greater discomfort and less participation than whites when making EOL treatment decisions. Asian Americans are less engaged than Caucasian American adults in ACP, despite a 45.6% increase in the Asian American population in the US within the past decade. Many Chinese are reluctant to discuss Advanced Directives and end of life issues. Resistance to organ donation may result from the concept of keeping the body whole for the afterlife and showing respect by not harming or disfiguring the deceased. Attitudes vary depending on degree of acculturation. Chinese often lack information on EOL issues, and say they would have made different decisions if they had had more complete information at the time of the loved one's death. Many thought their choices were essentially to insist on aggressive care or do nothing.
Decision Making & Advance Directives	• In the United States health care system, the decision-maker is the patient. In many other cultures, family members make major health care decisions for the patient, because the family is considered central, not the individual. Most families want doctors to talk with the family first. • Most families insist that the doctor not tell the patient their diagnosis and typically insist on aggressive treatment.

Imminent Dying & Death Rituals	• Most Mainland Chinese identify themselves as "no religion" and are not open to chaplaincy services. A Chinese definition of a "good death" not only includes dying peacefully in old age, without regret (after family duties are fulfilled) and surrounded by family members; but also dying with a full stomach. A full stomach is needed for the long journey of the soul in the afterlife in preparation for reincarnation. People who starve to death are considered cursed to becoming a hungry ghost. • Rituals for illness, death and body care, and bereavement vary, depending on religious beliefs, country of origin, age, education, and family culture. Following rituals and religious ceremonies can produce a better death. Greater availability of culturally and linguistically appropriate materials will increase the likelihood that EOL issues will be discussed. • Popular belief that Chinese prefer not to die at home. Culture or ethnicity may not be the reason. Recent studies show fundamental differences in how patients understand palliative care (educational needs). No existing home care services in Hong Kong and China; beliefs that the support needed will not be received at home; fear of burdening the family
Funeral Planning Beliefs	• Formerly, Chinese believed the patient must die at home. Now, dying in the hospital is preferred because a death in a house is considered bad luck, and the children will have to lower the price when they sell the house to a Chinese person.

Latinx and Hispanic Americans

(The terms Hispanic and Latinx are used interchangeably in this guide. Latinx is a term used to describe people who are of or relate to Latin American origin or descent. It is a gender-neutral or nonbinary alternative to Latino or Latina.)

Traditions & Health Beliefs:

- Hispanics hold tight to customs and to how they were raised: the general belief is "You honor traditions."
- Patients and families tend to leave decision-making to the physician.
- It is important to actively engage family in caregiving decisions.
- The patient may depend on natural remedies such as "botánica" practices.
- Spirituality/ Religious beliefs are very important to this population and will likely be a factor in their health care decisions. Trust is placed in pastors and priests as they will pray for a miracle to cure illness. "Santeros," which are healers and/or spiritual guides may be involved as well.

Communication Preferences	Verbal: • Open and expressive communication is important to most Latinx. • Variations in communication styles can vary according to national origin, the hospice practitioner should be aware of national origin of the patient. • Introduce yourself to patient and family members. • Clarify your role and the various members of individuals in the room/home with patient. Ensure patient and family member understanding regarding the reason for your visit. • Encourage questions from the patient and family members. Nonverbal: • It is important to be at eye-level; if the family is standing, stand with them. If the family is sitting, sit down; and maintain eye contact • Latinx or Hispanic clients may be very expressive with their hands and facial expressions. **Urban/Rural Socioeconomic Factors:** • Ensure that patient has support systems at home and access to primary care provider.
Language	• For many the primary language is Spanish; however, they may use indigenous languages or other languages to communicate. Always ask! • It is important to ensure that hospice team and providers speak Spanish. • If the team and/or provider do not speak Spanish then a translator, who is not a family member, must be used. • It is critical to have information on programs written in Spanish. • Ask if patient and family have a preference about language as many are fluent in English and Spanish.
Family Structure & Dynamics	• Families are very engaged with patients. • It is common to have large family systems including connections to origin of birth. • "Familiarismo" is a value that influences the way health care decisions are handled by many families as well as the interaction of family members when a relative has a terminal disease. It is important to clarify who is the designated health care proxy for the family. It is relevant to mention that Familiarismo also refers to how patients and families feel of those coming into their home, like they are part of their family.

Expression of Pain & Treatment Preference	• Generally, patients will outwardly express pain and discomfort when asked. • "Fatalismo" is the view of many Latinos who express not having control over the illness. This keeps them from making decisions that alter the outcome: "Que sea lo que Dios quiera" is an expression that when translated means "God's will." However, at the same time is common to pursue aggressive treatment to "fight" the illness. • The hope for a miracle may prompt the request for aggressive treatment to show they haven't given up!
Veracity in Diagnosis & Prognosis Disclosure	• Talking about terminal illness and life-threating diseases is a taboo among many Usually adult children "protect" or shelter their parents from knowing about their diagnosis and prognosis. • Relatives will ask not to have discussion about the progression of the illness with the patient.
Decision Making & Advance Directives	• Often this population will not have Advance Directives in place but reluctantly are willing to discuss if engaged. • It is important to engage key family members identified by the patient in this process through family meetings. • Constant education is needed to reinforce the importance of POA, advanced directives and funeral pre- arrangements.
Imminent Dying & Death Rituals	• These populations often oppose active euthanasia. Death, dying and the dead are held in great reverence and respect. Many believe that one's attendance at and participation in funerals represents an important social obligation. • Many prefer in-ground burial for final disposition and may struggle with the concept of cremation.
Funeral Planning Beliefs	• Funerals in the country of origin mainly take place in the home: the viewing of the body is for 24 hours with the family and community. Then the body is taken to the church for a mass or service, then to the cemetery. • This time is not seen as a celebration; it is a grieving time. That means no music is played and one must abstain from engaging in any activity that brings joy. • Usually, a "Novena" is planned for those who were of the Catholic faith. The family participates in nine days of prayers for peace of the soul of the deceased loved one. • Others may have the pastor to preach to and pray for the family. • Sorrow may be demonstrated by crying and screaming out loud; some faint ("ataque de nervios") due to all the emotional charge.

LGBTQ+ Community

Traditions & Health Beliefs:

- Can be very skeptical of medical system. Overall, less likely to receive preventative screenings (some screens specific to their sexual orientation and/or gender identity may not even be offered by providers who don't know their sexual orientation and/or gender identity or are not up to date on LGBTQ+ care).
- Many older LGBTQ+ individuals remember the AIDS crisis acutely and have been exposed to hospice through the death of many members of their community.
- Insensitivity to LGBTQ+ issues is largest barrier to care; may seek alternative care or care from within their community instead.

Communication Preferences	Greeting: • Let the person guide you. Ask them what name and pronouns they'd like you to use when addressing or referring to them. Don't assume the person identifies with the sex they were assigned on their birth certificate. Nonverbal: • Body language can express health care provider's attitude towards LGBTQ+ individuals
Language	• Varies as all cultures have LGBTQ+ communities.
Family Structure & Dynamics	• Family structure is highly variable and with less defined roles than in straight and cis relationships. • Agency forms should be updated to include relationship options such as "partner" and "significant other." Create opportunity for clients to designate who they consider family or supportive. • May consider non-biological friends as "family" or "family of choice" • Legal status of children may be complicated; children often need to be formally adopted by the non-biological parent. Fostering prior to adopting is also common.
Expression of Pain & Treatment Preference	• May have increased anxiety due to fear of homophobia or transphobia. Anxiety may increase the perception of pain. • Those who have a history of overcoming addiction, who are "sober," or "in recovery," may be very hesitant to accept narcotics.
Veracity in Diagnosis & Prognosis Disclosure	• Highly variable. As is the case with all other populations, some LGBTQ+ patients may prefer to appoint a surrogate to receive information for them. • Patients may or may not "out" themselves to the provider; using inclusive language is important. You may not know a patient is LGBTQ+ until after several interviews, or sometimes you won't know at all.
Decision Making & Advance Directives	• Building a sense of trust is important to allow clients to share honestly regarding their relationships and who they want to be decision makers. • Loss of bodily autonomy may be particularly hard for trans and gender non-conforming individuals as they may lose their ability to present themselves in accordance with their gender identity.
Imminent Dying & Death Rituals	• Faith group may be different than that of biological family and hence a potential source of conflict. • May only want religious visits from the pastor/priest/rabbi/imam that knows them well (due to concerns about acceptance).
Funeral Planning Beliefs	• LGBTQ+ people may be more likely to fear that their wishes will not be granted after death

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