

AGING AND END OF LIFE WEBINAR SERIES

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American Association on Intellectual and Developmental Disability (AAIDD)
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The Arc of the United States
American Network of Community Options and Resources
AAIDD Gerontology Division
University Illinois-Chicago Rehabilitation Research and Training Center
on Aging with Developmental Disabilities

END OF LIFE THROUGH A CULTURAL LENS

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Webinar Overview and Objectives

This webinar will explore cultural beliefs and influences that often converge when an individual is faced with end-of-life decisions within the contexts of the legal system, the health care system, community and social networks, spirituality or the faith community, and the family.

Participants will be able to:

- Define culture and describe its multiple dimensions.
- Describe examples of how cultural variables from each system may impact an individual with an intellectual or developmental disability.
- Describe how culturally competent values, policies, structures, and practices can be applied to end-of-life decision making for individuals with intellectual or developmental disability.

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What could be more universal than death?
Yet what an incredible variety
of responses it evokes.

Metcalf & Huntington, 1991, p.24

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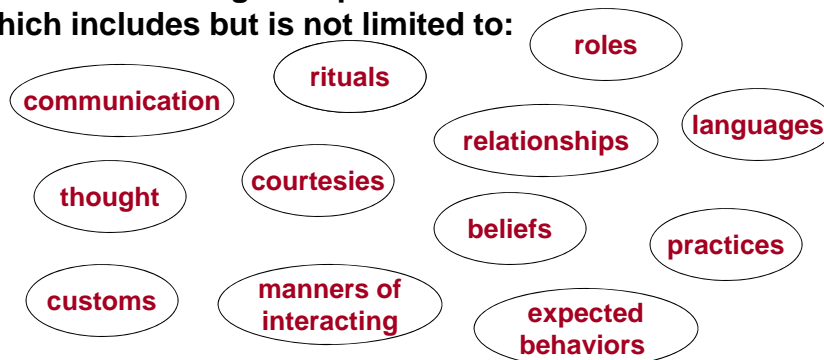
Exploring the Multiple Dimensions of Culture

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Culture

Culture is an integrated pattern of human behavior which includes but is not limited to:



... of a racial, ethnic, religious, social, or political group;
the ability to transmit the above to succeeding generations;
dynamic in nature.

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Culture is ...

- applicable to all peoples
- active & dynamic
 - changes over time
 - changes with migration
 - changes to meet new challenges to group
 - changes through interactions with other groups
 - changes based on climate



Adapted from Vivian Jackson, NCCC, 2003

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Culture is ...

- multi-layered
 - at personal, family, community level
 - home, school, work/profession levels
- malleable over time
- always considered within a context



Adapted from Vivian Jackson, NCCC, 2003

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Culture

- structures perceptions
- shapes behaviors
- is the total way of life – it tells group members how to behave and provides their identity



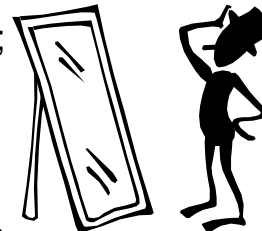
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Culture

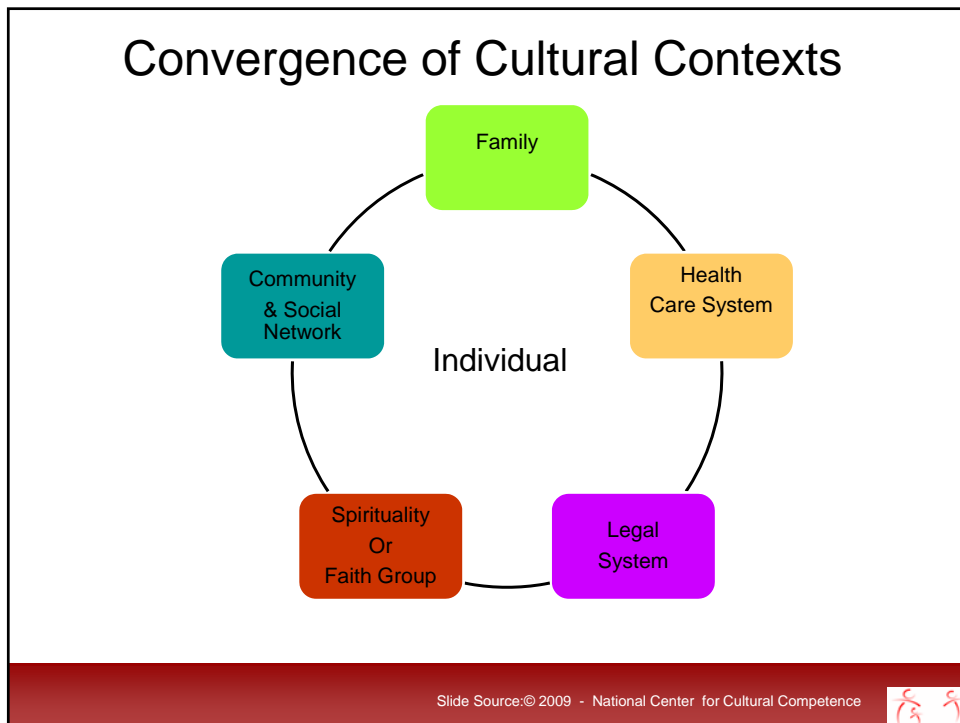
Culture is akin to being the person observed through a one-way mirror; everything we see is from our own perspective.



It is only when we join the observed on the other side that it is possible to see ourselves and others clearly – but getting to the other side of the glass presents many challenges.

(Lynch & Hanson 1992 Developing Cross Cultural Competence)

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LEGAL SYSTEM

Basic Values of the Patient Self-determination Act of 1991

- Autonomy
- Truth Telling
- Informed Consent
- Individual Control over the Dying Process



Source: Goode & Maloof (in press)
Reference: Giger, Davidhizar & Fordham, 2006

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HEALTH CARE SYSTEM

- Culture of Biomedicine
- Technology
- Institutional Policies & Structures
- Brain Death - a Cultural Construct
- Alternative Medicine



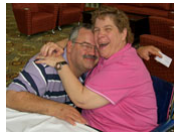
Source: Goode & Maloof (in press)

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COMMUNITY, SOCIAL NETWORK, FAMILY

- Cultural Perceptions and Beliefs about:
 - causes of illness & disability
 - people who experience disability
 - death and end of life



Source: Goode & Maloof (in press)

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COMMUNITY, SOCIAL NETWORK, FAMILY

- Language
- Mourning & Bereavement Rituals
- Grief



Source: Goode & Maloof (in press)

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SPIRITUALITY or FAITH GROUP

- Religious and Spiritual Beliefs and practices about Death and End of Life



- Religion a source of comfort & conflict



Source: Goode & Maloof (in press)

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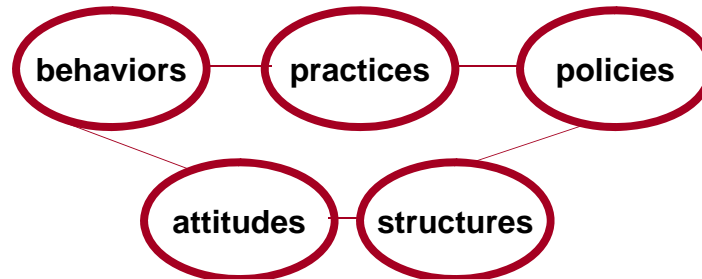


Cultural and Linguistic Competence Definitions & Frameworks

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Cultural Competence



requires that organizations have a clearly defined, congruent set of values and principles, and demonstrate behaviors, attitudes, policies, structures, and practices that enable them to work effectively cross-culturally

(adapted from Cross, Bazron, Dennis and Isaacs, 1989)

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Five Elements of Cultural Competence

Organizational Level

- value diversity
- conduct cultural self-assessment
- manage the dynamics of difference
- institutionalize cultural knowledge
- adapt to diversity
 - policies - structures
 - values - services

(Cross, Bazron, Dennis and Isaacs, 1989)

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ESSENTIAL ELEMENTS IN A CULTURALLY COMPETENT SYSTEM

These five elements must be manifested at every level of an organization including:

- policy makers
- administration
- practice & service delivery
- individual/patient/consumer/family
- community

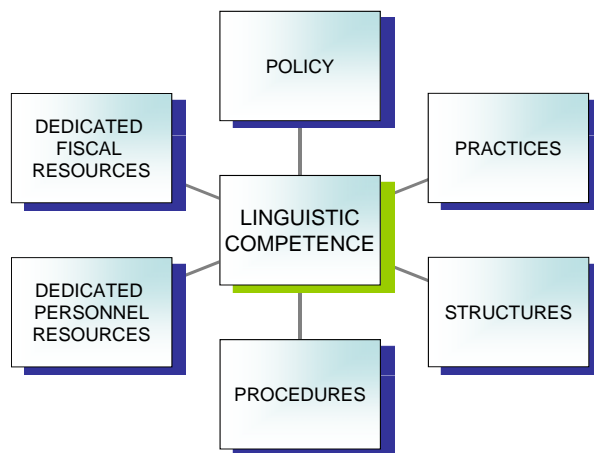
and reflected in its attitudes, structures, policies, practices, and services.

Adapted from Cross, Bazron, Dennis, & Isaacs, 1989

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LINGUISTIC COMPETENCE FRAMEWORK



Goode & Jones, Revised 2009

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Applying Concepts to Organizations concerned with Intellectual and other Developmental Disabilities

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Cultural Competence **From Conceptual Framework to Policy & Practice**

Value Diversity

- Ensure organizational philosophy recognizes the diversity of cultural expressions, traditions, and norms associated with end of life.
- Actively seek and include individuals from diverse cultural and linguistic groups as members of your organization's advisory committees and governing boards.

Source: Goode & Maloof (in press)

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Cultural Competence

From Conceptual Framework to Policy & Practice

Conduct Self-Assessment

- Assess the extent to which your organization's policies and structures take into consideration the beliefs and practices related to death and end of life for cultural groups served.
- Assess the degree to which your academic institution and faculty contribute to the body of knowledge on cultural practices related to death, end of life, and individuals and families impacted by IDD.

Source: Goode & Maloof (in press)

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Cultural Competence

From Conceptual Framework to Policy & Practice

Manage the Dynamics of Difference

- Use existing structures or establish new ones to explore and resolve ethical dilemmas associate with end-of-life decision making and differing cultural viewpoints.
- Enlist the assistance of religious or spiritual advisors and cultural brokers in problem solving and dispute resolution.
- Attend to issues associated with literacy, health literacy, and mental health literacy of individuals, families, and communities served.

Source: Goode & Maloof (in press)

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Cultural Competence

From Conceptual Framework to Policy & Practice

Acquire & Institutionalize Cultural Knowledge

- ❑ Establish policies that specifically address cultural preferences in end-of-life decisions. Ensure that all staff are knowledgeable and have received training in the procedures and practices to implement such policies.
- ❑ Offer forums for staff, faculty, and volunteers to:
 - share knowledge and experiences related to cultural practices, traditions, and norms associated with death and end of life.
 - receive training, mentoring, and consultation to enhance knowledge and skills necessary to interact with and support culturally and linguistically diverse individuals and their families.

Source: Goode & Maloof (in press)

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Cultural Competence

From Conceptual Framework to Policy & Practice

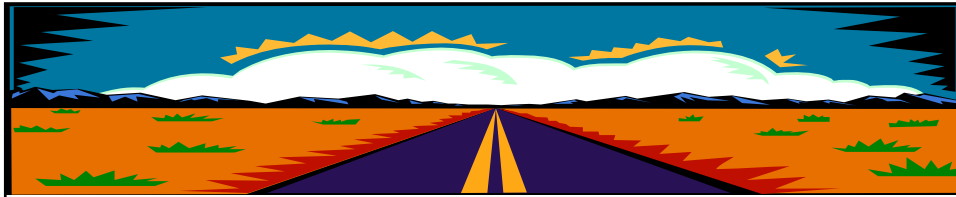
Adapt to Diversity & Cultural Contexts of Communities

- ❑ Revisit existing policies and practices related to end of life to determine if they present barriers for cultural communities served.
- ❑ Identify and modify policies and practices that promote cultural congruence in end-of-life care and support, with the exception of those that would violate legal and regulatory requirements.

Source: Goode & Maloof (in press)

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Achieving cultural
and linguistic competence
is a life's journey ...
not a destination
Safe travels!

CONTACT US

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