Aging/End of Life
Crisis or Opportunity
For Individuals and Service Providers
Our Talk: Values We Hold Dear

- Independence (Identity?)
- Productivity (Purpose?)
- Inclusion (Community?)
- Self Determination (Power and control?)
End of Life/Death
Does it end the talk?

- Destroyer of independence, return to dependence, loss of identity
- Why am I? question of purpose replaced by the Why? of death?
- End of community as we know it.
- Often even less control and power
In Old Systems of Care

Aging and Death a “Key Indicator” of

- Loneliness and loss of connection
- Injustice, no power, at hands of family and/or system
- Abandonment
- Family wounds
In “New” Systems

- Loneliness often still there: Who are the unpaid friends?
- Evidence of disconnection even while living in “the community”
- Disconnect between family and staff often still there
- Routine medical care can become end of life issue—quality of life assumptions
New Challenges and Crises

Death as “double injustice”
Disability enough to deal with, why this?
Aging, disability, death=curses
Anger by staff and others at
- Family
- Other staff
- Losses
Challenges and Crises (cont.)

Processing of Grief and Loss:
- By families and friends
- By transitions and change, including turnover. Turnover increased by unrecognized grief
- By stigma and stereotypes
Challenges and Crises (cont)

Pressures and Paradoxes

- “They don’t understand” vs. “Move on quickly.”

- Importance of relationships, not program or plan.

- Pressure to fill the empty slot, bed, or place at the table
Ambivalence and Preparedness

Don’t need a plan yet” vs. Clients’ age range 59 to 85

“In our care” VS. “Not on my shift”

“Comfort of hospital care” vs. Questioning hospital care

“We’re his family” vs. Family: nursing home plan

Michelle Wiese. (2007) End of Life Care and Dying in Place: Choices and Needs of People with Intellectual Disabilities and their Carers. IASSID.
### Ambivalence and Protectionism

<table>
<thead>
<tr>
<th>Statement</th>
<th>vs</th>
<th>Counter-Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you talk about it?</td>
<td><strong>vs</strong></td>
<td>“He couldn’t comprehend it”</td>
</tr>
<tr>
<td>Client asking about death</td>
<td><strong>vs</strong></td>
<td>“I change the subject”</td>
</tr>
<tr>
<td>Client queries body change</td>
<td><strong>vs</strong></td>
<td>“You’re getting old, forget it”</td>
</tr>
<tr>
<td>“They [clients] talk about death all the time”</td>
<td><strong>vs</strong></td>
<td>“…I don’t want to upset her”</td>
</tr>
</tbody>
</table>

Antithesis

- Of Growth and Life
- Of Power and Control (“theirs” and “ours”)
- Of Presence, Participation, and Membership
The Perfect Storm

Currents in DD systems and care is toward growth, development of potential, new life.
End of life not in the plans

Currents in health care toward healing, cure, fix, death too often enemy and disability evidence of failure.
The Tiny Boat

God bless this tiny little boat
And me who travels in it
It stays afloat for years and years
And sinks within a minute.

And so the soul in which we sail
Unknown by years of thinking,
Is deeply felt and understood
The minute that it’s sinking.

A BUNCH of POESY
12
God bless this tiny little boat
And me who travels in it.
It floats and floats for years and years
And sinks within a minute

And so the soul on which we sail
Unknown by years of thinking
Is deeply felt and understood
The minute that it’s sinking.

-Michael Leunig
Opportunity

- To be “faithful” to our values rather than “successful.”
- To remember connections to past, present, and future
- To re-member connections to communities of which people have been a part
- Build new communities of care and meaning.
- Build new partnerships and collaborations
Faithful Practice

Faith:

“A process of hoping backwards and remembering forwards.” Paul Lehman.

Choices and Advanced Care Planning are not just about treatments, DNR’s and AD’s, but what has given life meaning. Move that forward, front and center, in the final journey.
Remembering

- Remember is more than paying attention.
- Remember: Connections with past and future.
- Re-Member: Connecting to communities of which I have and have been a part
- Re-menting: Holding memories for others
- That that person’s life mattered, and every life matters.
Personal and Professional Faith as Capacity to Embrace Paradox

Paradoxes of Aging and End of Life

- Honor and Indignity
- Blessing and Curse
- Growth and Decay
- Wisdom and Senility
- Engagement and Renunciation
Paradoxes of Roles

- Staff, family, and/or friend
- “Be with” as well as “do for”
- “Care for needs” as well as “celebrate gifts.”
- Specialized supports vs. “give it away”
- Know what we don’t know, and use that to invite others in.
Opportunity

Revision not as decline but as journey.

How can we help that to be as self determined as possible? What is really important to you now? Retirement and endings.

To build new networks of care and support for both people with developmental disabilities, staff, and families.
Opportunity to Revision

Independence: “Who am I?” to “Who have I been?”

Productivity: “Why am I?” to “What difference can I make now, and have I made?”

Inclusion: “Whose am I?” to “Who remembers me?” “Whose have I been?”

Self Determination: “Choices heard and honored in my final days.”
“Unique” Tasks of Aging

- Reaffirm covenant obligations to community
- Blessing...how have you been that, done that, and give that?
- Honor in aging, dignity, respect, appreciation
- Faith in face of loss
- Reconciliation of discordant experiences, e.g., letting go, reunion, forgiving

- The Challenges of Aging: Retrieving Spiritual Traditions. The Park Ridge Center.
Challenges to People with Disabilities and People who are Aging and Caregivers

- Who is their community? Family, work, staff, other consumers?
- Where do they have, receive, and give the blessing?
- How are their journeys and survival stories honored and respected?
- Is grief/faith practice honored and supported?
- Can we look back with them, and support remembering, reconciliation, reunion?
Covenant Obligations to Community

- What communities have they (and we) been part of?
- What do you want to do with them?
- Who’s been important to you?
- What have been my favorite activities?

Thru pictures, revisiting, place to volunteer, membership rituals (it’s never too late)

Giving and Receiving Blessing

What have been someone’s key strengths and gifts?

How could they give them to others, including young workers and professionals, families, and friends?

What do you want others to have that remind them of you?
Blessings in the IHP Process

You Make a Difference!

Awarded to

Alex

In recognition of his God-given gifts of friendship, curiosity & service and the positive contribution that he makes in the lives of many people at the Eastern Christian Children’s Retreat.

Thank you for offering your gifts!

September 8, 2006
Restoring Honor in Aging

- How do we as professionals and caregivers ask for their blessing?
- Turn charts and records into stories.
- Revision “consumers” as “survivors” and “veterans.”
- Telling “them” what “they” have meant to “us”
Maintaining Faith in Face of Loss

Help people prepare.

Help people participate in the rituals of loss and mourning.

New efforts to honor practices of spirituality and build supports that will be there at the end.

Rationales for Paying Attention to Spiritual Supports

- Tapping the power of the sacred in people’s lives
- Ways that people find meaning and cope
- Cultural competency/cultural humility
- Self Determination
- Quality of Life
- Impact on Health
Reconciliation

- Telling their story, in pictures and words, e.g., supported writing, life stories.
- Re-membering connections with families, friends, old staff.
- Reunion with others or places
- Return home, to the people I know
Anticipatory Grieving by Providers

- Moments to teach and talk about death and loss with those we support.
- Build relationships with local resources so the comforters are not strangers.
- Address and honor spirituality.
- Staff in-service
- Grief and Loss Response Team
- Loss assessments, planning ahead with family and guardians.
Key Strategies for Grieving

- First, recognize it and welcome it. “Grief delayed is grief denied and grief denied is grief delayed.”
- Create a safe place for it. A sanctuary.
- Be alert for behavioral expressions.
Key Strategies for Grieving

- Accurate and honest information and support to process it.
- Enable maximum involvement in the social and spiritual activities surrounding death.
- Keep connected with key supportive relationships.
- Maximize opportunities for expression of grief and condolences.

- Jeffrey Kaufmann, Helping Persons with Mental Retardation Mourn.
At the End of the Journey

- Caring for and with the whole community
  Families, friends, staff, connections
- Creative rituals of loss and celebration
- Honoring individual differences and community as a whole.
At the End of the Journey

“I forgive you”

“Please forgive me”

“Thank you”

“I love you”

“Goodbye”
Recovering the “Profess” in Professional Capacity

- Capacity to journey with others: loyalty, fealty
- Capacity to deal with the tough ethical and spiritual questions that disability and end of life so starkly raise for us
- Capacity to recognize and celebrate those holy moments and miracles of accomplishment and growth
- Capacity to give thanks for discovery, meaning, and gift to us
- Capacity to sacrifice, give up, for sake of others
Resources

Three page listing of good resources, including those mentioned, on The Boggs Center website (under Health in the Projects area) and AAIDD.


Powerpoint of Presentation:

www.aaidd.org
Pax and Shalom

Rev. Bill Gaventa
The Boggs Center on Developmental Disabilities
Robert Wood Johnson Medical School/UMDNJ
P.O.Box 2688
New Brunswick, New Jersey 08903

732-235-9304
Email: bill.gaventa@umdnj.edu