

# Health Care and End of Life Issues for People with IDD

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# End of Life

- Components:
  - Chronic disease(s) or symptoms or functional impairments that persist and may fluctuate; and
  - Symptoms or impairments resulting from the underlying irreversible disease that require formal (paid professional) or informal (unpaid) care and can lead to death.

(NIH 2004)

# Living Longer

- 1996: only 10 years difference in life span between people with and without IDD
- 1960's: increased attention paid to people at the end of life
- Due to societal attitudes this did not include people with IDD
- They are entitled to the same services and supports as others throughout their life span

# Ethical Frameworks and Principles

## Topics

1. Medical indications – goals of care and benefit to patient
2. Patient preferences – patients have right to make decisions
3. Quality of life – varies, perceived differently by patients and HCP.
4. Contextual issues – influences on HCDM, financial, religious, cultural, confidentiality, resource allocation, legal, research, conflict of interest

## Principles

1. Beneficence, nonmaleficence
2. Respect for autonomy
3. Beneficence, nonmaleficence, respect for autonomy
4. Justice: loyalty and fairness

# Last Passages Project

- Base end-of-life care decisions on lifelong process of making choices, experiencing rituals and ceremonies around death in your family, culture and country.
  - Include children and adults with IDD
  - Respect everyone's opinions
  - Include children in the DM process
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- SUNY-Albany, funded as Project of National Significance by ADD

# Last Passages Project

- Barriers to delivery of quality EOL care to people with IDD
  - Overlook DMC of person with IDD
  - Make choices without legal authorization
  - Neglect asking for the person's preferences
  - Life sustaining technology seen as futile at EOL for people with IDD

# Last Passages Project

- HCP and family:
  - Have a pro disability attitude/advocate
  - Learn about issues related to EOL care, pain management, hospice, medicaid/medicare regs, in-home care, nursing care, HCDM in your state, etc.
  - Communicate about issues with HCP
  - Plan for EOL : advance directives, Five Wishes
  - Guardians must make decisions based on the values and beliefs of the person as known to them

# ***Decision Making Capacity (DMC)***

- Presumed unless proven otherwise
- Not determined by age or diagnosis
- Actual functioning in a specific decision-making context
- Cognitive abilities and affective states
- **Grisso & Appelbaum, 1998 *Assessing Competence to Consent to Treatment***



# 5 Maxims of Legal Competence

1. Related to, but not the same as impaired mental states
2. Refers to functional deficits
3. Depends on functional demands
4. Depends on consequences
5. Can change

*“The idea that serious mental illness, mental retardation or cognitive impairment renders a person incompetent to make decisions, is obsolete.”*

- Grisso & Appelbaum, 1998 *Assessing Competence to Consent to Treatment*

# Decision making capacity

- Understand information
- Appreciate personal significance
- Reason with information
- Express voluntary choice
  
- Give informed consent!
  
- Grisso & Applebaum, 1998

# Palliative care

- Prevention and relief of suffering
- Meticulous management of symptoms
- Prepares for death
- Through final stages of illness
- Emotional, spiritual and practical needs of patients, family, close friends
- Curative and life prolonging treatment
- Care includes bereavement counseling
- Hospice programs, bereavement support groups
- Communication about people's goals and preferences

# Palliative Care for Children

- American academy of pediatrics:
  - maintenance of QOL in remaining time
  - Give children information about their condition and tx choices
  - Ask for their opinions in developmentally appropriate conversations
  - Parents have the final say.

# Culture of People with IDD

- Different values and perspectives
- May be difficult communicating
- Environmental barriers
- Life sustaining treatments used as life long supports
  - E.g. Ventilators, artificial nutrition and hydration, tracheotomy
  - Curative treatments include chemotherapy, radiation, antibiotics and surgery, etc.
  - Base decisions re: curatives on harm vs. benefit, not only on IDD.

# Best Interests Decision Making

- For people who never made wishes known
- Lack of capacity to understand
- Assume that they want the same quality of life as any other person

Jonsen, et al 2006

# Withholding and Withdrawing

- Agreed by ethicists and general public that withholding life support is morally acceptable when death is inevitable
- Is artificial hydration and nutrition morally or medically different than other life supports
- May be more burdensome than beneficial at EOL
- Ethicists and judges: no difference between withholding and withdrawing tx if palliative care provided.

# Futility

Process:

- Careful consideration, weighing of options, harms benefits to each individual
- HCP, patient, family members
- Can be influenced by HCP bias regarding value of people with IDD

Pellegrino, 2000



# Dying Well

- Applies to children and adults, with IDD or not
  - Focuses on the process as well as the outcome
  - Very individualized
  - Consistent with autonomy or self determination
  - Respects unique beliefs, values and preferences, culture, etc
  - Communication during the caring process, reminiscing, personal and spiritual matters
  - Resolve and complete relationships
  - Get affairs in order
- Byok, I. (1997) *Dying Well*

# Decision Making Resources

*“Are you traveling without a map?”*

A Layperson’s Guide to Advance Care Planning. (Caring Connections, a program of the National Hospice and Palliative Care Organizations)

Advance directives, *Five Wishes* Health Care Power of Attorney , conversations with physicians, family and friends, consultation from ethics or patient care advisory committees.

*Caring Conversations*, developed by the Center for Practical Bioethics

# Other Resources

- *Approaching Death: Improving Care at the End of Life* (Institute of Medicine, 1997)
- *When Children Die: Improving End-of-life Care for Children and Their Families* (Institute of Medicine, 2002)