



“What is Inappropriate Treatment for
People with Developmental Disabilities?”

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MEDICAL FUTILITY:
HOPE & COMMON SENSE



Conference Objectives:

- Define futility from medical economic values, legal & professional perspectives
- Discuss past and current efforts to achieve community consensus
- Describe strategies to achieve a definition



Program Chair



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Define Futility:

- Useless
- vain, in vain
- hopeless
- ineffective
- worthless
- non-beneficial


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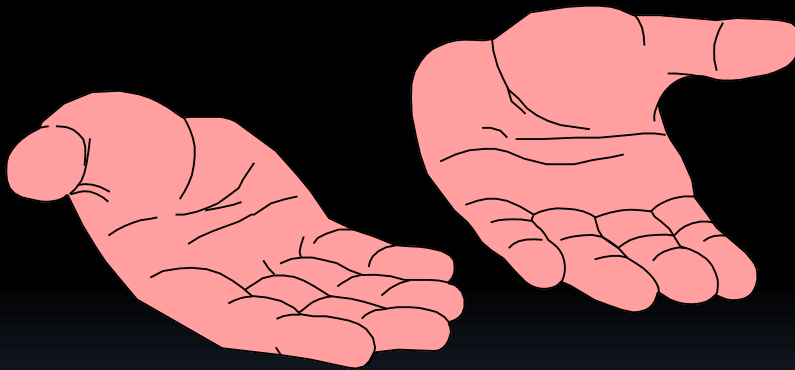
Program Chair



Efforts to Achieve Community Consensus

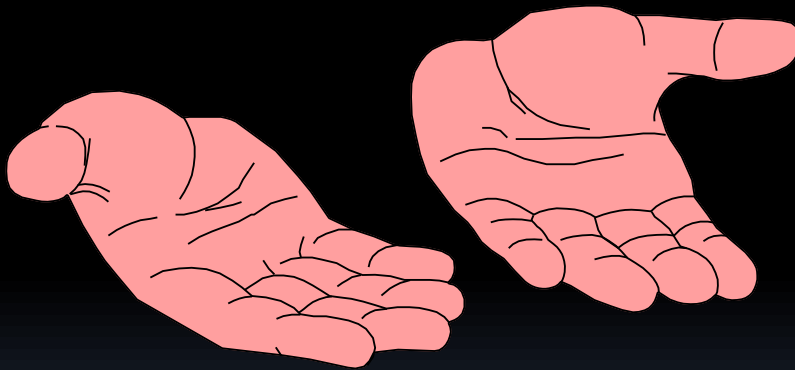
- Historic efforts to institutionalize futility in society have had **HORRIFIC OUTCOMES!**
 - Cultural differences
 - **Value driven**
 - New impetus on “Evidence Based” treatments
 - Bay Area Network of Ethics Committees
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Considerations in consensus building applied to DD



- **Minority** population
- Frequently **non-verbal**
- **Quality of life** assumptions
- Treatments are frequently **non-conventional**
- “Bottom line ” (**\$\$\$**)

Considerations in consensus building applied to DD



- In “whose best interest?”
- Diagnosis of DD is not a terminal condition
- Patient **autonomy**



CAUTION

What we need is meaningful discussions
between patient/ families and physicians



**ON FUTILITY CONSENSUS
BUILDING:**



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Necessary Considerations

- Recognize the person behind the disability
 - Disabilities are not an impediment to the pursue of happiness and meaningful lives
 - Assume competence
 - Good ethical decisions include the person with DD in the decision process
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Learning Objectives: Developmental Disability is

- Condition that affects learning,
- communication,
- self-care,
- walk and/or mobility
- Begins before birth, at birth or before 21 years old
- affects economic self-sufficiency



Although something may be determined as legal, it is not always necessarily the moral thing to do...



**DEVELOPING A DECISION
PROCESS WHERE DO YOU START?**



Relevant Laws:

- NM Uniform Healthcare Decisions Act
- NM Guardianship Statute
- NM EMS/DNR Statute
- NM Durable Power of Attorney Statute
- NM Right to Die Act
- Federal Patient Self Determination Act
- Americans with Disabilities Act



HDR

**HEALTHCARE DECISIONS
RESOURCES**

Features of the HDR group:

Interagency:


- New Mexico Arc
- Private attorney
- Protection & Advocacy
- Community Programs
- *Continuum of Care Project*

Multidisciplinary:

- Physicians
- Nurses
- Social Workers
- Guardians
- Attorneys
- Administrators
- Advocates
- Service Providers



Process to Develop Guidelines

- Seek out input from concerned parties
 - Review existing statutes and regulations
 - Interact with group developing Uniform Healthcare Decisions Act
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Process to Develop Guidelines

- Clarify role of various community team members
- Disseminate drafts for feedback
- Revise, Revise, Revise
- Make presentations & disseminate

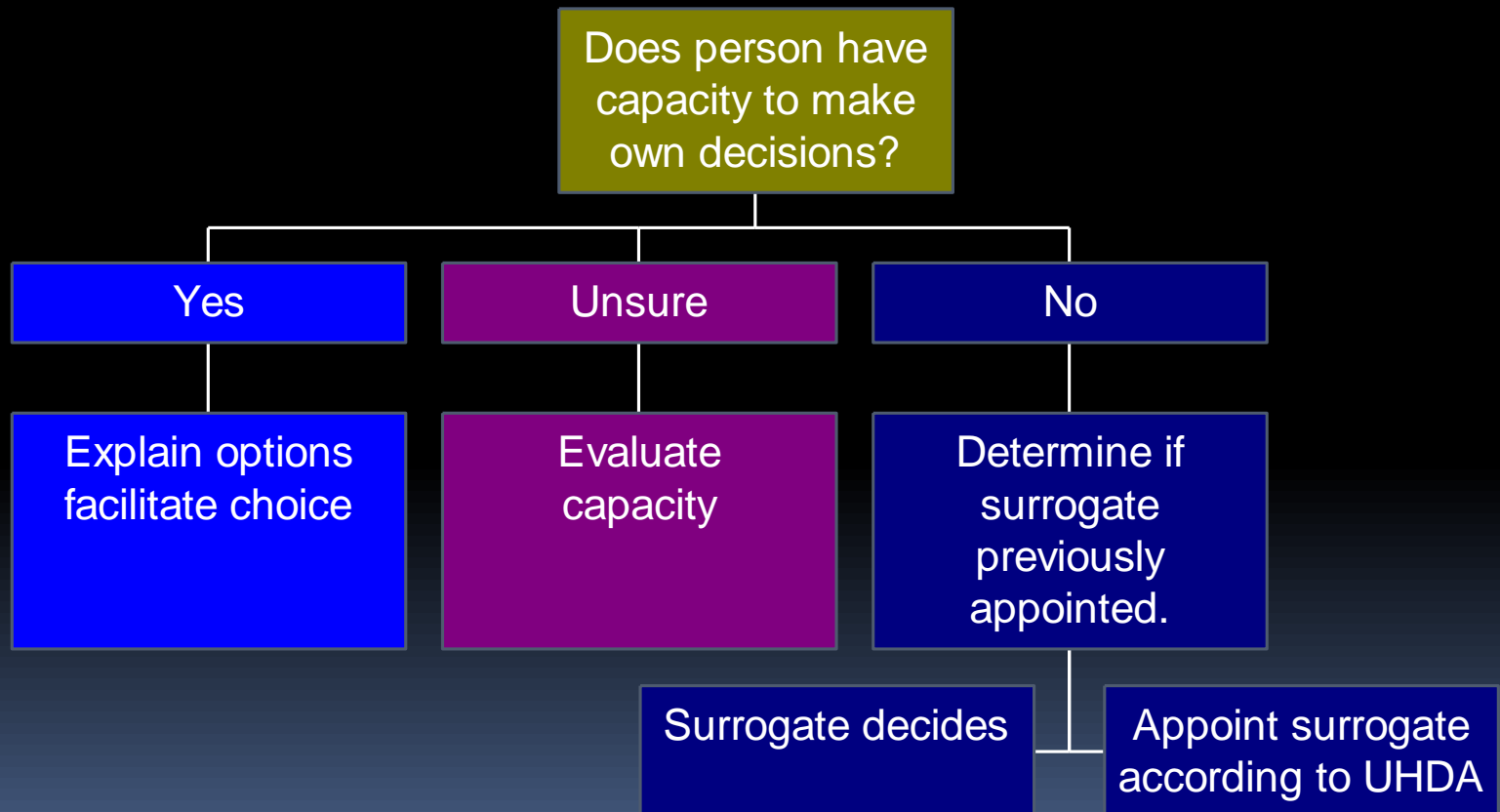
Core Values:

- individuals can make their own decisions.
- Always respect the individual's decisions.
- full disclosure of factual information.
- Health Care Decisions are value driven.
- Legal Health Care Decisions are made by the individual and or guardian; not by teams.
- Health Care Decisions can be changed or revised at any time
- CODE means full code effort.

Core Values:

- All patients regardless of the existence or content of Health Care Decisions and Advance Directives, or presence of disability, must be treated with equal dignity and respect.
- Recognize and respect cultural difference(s).
- "Do Not Resuscitate" orders, do not mean discontinuation of care.
- When in doubt provide full medical intervention

Who is the Decision Maker for Adults with DD?



Surrogate Decision Makers:

- Spouse
- individual in long-term relationship
- adult child
- parent
- adult brother or sister
- grandparent
- adult who has exhibited special care and knows patient's values

The role of the guardian

Is guardian plenary (full) or limited?

Limited

Check court order to see if specifically given authority for healthcare decisions

Plenary

Has authority over healthcare decisions

Substitute Decisions

- In accordance with patient wishes to extent known
- In accordance with patient's best interest as determined by the substitute decision maker, considering patient's values to extent known
- Decision shall not be made solely on the basis of the patient's pre-existing physical or medical condition or pre-existing or projected disability

Healthcare Decisions

Has decision already been made?

Yes

**Individual
Decision**

Advance Directive
Individual Instruction
Power of Attorney

**Substitute
Decision**

No

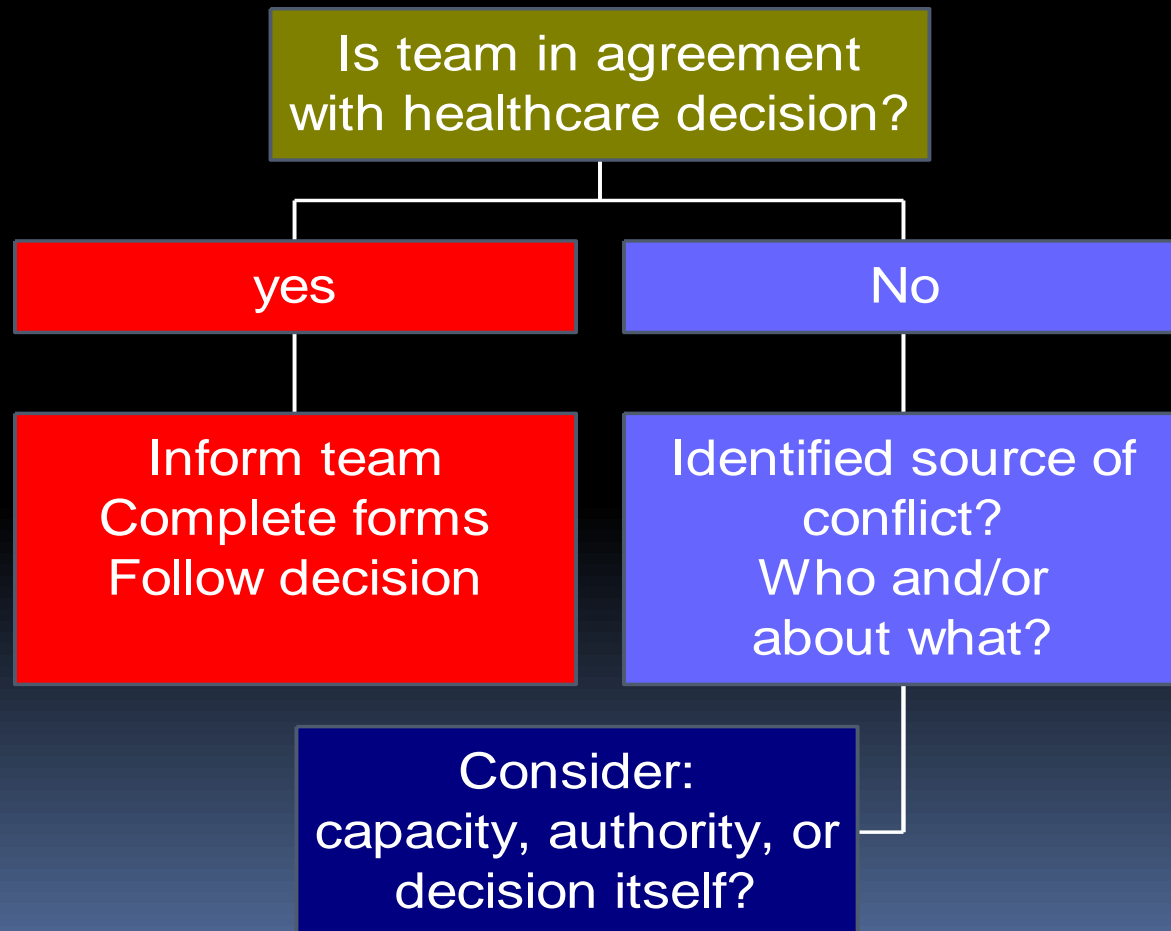
Discuss with individual
(and guardian if appropriate)

Consider: need for info
capacity, authority of decision
maker, time to think things over

Determining Capacity:

- Two qualified health care professionals, one of whom is the primary physician
- If mental health or developmental disability, one of the health care professionals must have expertise in assessing functional impairment
- Lack of capacity can not be based solely on patient's disagreement with the doctor
- An individual can challenge a determination that s/he lacks capacity. The challenge stands unless a court determines otherwise

Implementing Healthcare Decision within community



Team Member Roles:

Patient

- If they have capacity, make decisions regarding their health care & advance directives
- If they lack capacity, communicate preferences
- Learn about their conditions & treatment

Physician

- Determine capacity with professional who has expertise in DD
- Educate patient & decision maker about diagnosis, treatment options, risks, benefits etc
- Give professional advice
- Implement decision
- Coordinate with the team

Team Member Roles

Guardian or Surrogate with authority over health decisions

- Learn about diagnosis & treatment options
- Determine patient preferences
- Collect input from the team - as appropriate
- Inform team of decision

Family Members without health decision authority

- Assist in determining patient preferences
- Provide input and support to patient and decision maker

Team Member Roles:

Support Staff & Therapists

- Assist in determining patient preferences
- Support patient and decision maker
- Learn about diagnosis & treatment decided upon
- Implement decision
- Inform relevant persons of decision (such as Emergency Room)

Agency Nurse

- In addition to items at left, help decision maker interpret medical information, and
- Educate team on protocol for implementing decision

Team Member Roles:

Case Manager


- Educate patient & decision makers about UHDA & encourage fore thought
- Help patient & decision maker access supports for decision making
- Assure that all team members are informed of decisions
- Assure all team members understand how to implement the decision
- Assure that appropriate documentation of the decision is in place
- Educate patient & decision makers of the right to change a decision and/or challenge a determination of lack of capacity

Options for Resolving Conflict

- Determine capacity & preferences
- Obtain 2nd opinion
- educate team
- request ethics committee
- call HDR for support
- Talk with a pastor or social worker
- consider changing physicians
- request transfer off the case
- seek mediation
- go to court



Common Source of Conflict

- Patient's limited ability to express preferences
 - Differing views on "Best Interest"
 - Agency Policy and concern of liability
 - Assumptions about quality of life
 - Limited information available
 - Questions about "capacity"
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Conclusions

- Need to have individualized approach
- Unbiased meaningful discussions
- Awareness that healthcare decisions are value driven

In decision making consider the question of intent and the nature of the act

“religious belief is no guarantee of moral integrity” D.L..



Conclusions

Our actions will be ethical if they do no harm to
people's experience and expectations of
happiness



Dalai Lama



Continuum of Care: Mission

The mission of the Continuum of Care Project is to *increase the capacity of New Mexico's health care system to provide lifelong quality health care for people with developmental disabilities and related chronic conditions.*

We do this by:

- 
- creating learning opportunities
 - promoting best practice policies, and
 - offering specialized developmental disabilities services