

Guardianship and Aging in Intellectual Disability Case Studies Part II

Prepared by the Center for Developmental Disabilities Evaluation
and Research (CDDER) on behalf of the Massachusetts
Department of Developmental Services (DDS)



Case Examples

- * This is a companion training to **Guardianship and Aging in Intellectual Disability, Part I**

These cases are examples only. Please contact the DDS Legal Area Office with any specific questions.



Case Examples

- * Cases presented will provide medical information
- * Guardianship status
- * Determine whether or not the designated person may consent to the treatment – and why



Margaret



- * Aged 60
- * Dementia
- * Group home and day program
- * Social withdrawal
- * DNR in hospital
- * Brother and sister are co-guardians



Margaret

- * Involved sister wants DNR to continue
- * Brother, not involved, wants DNR discontinued

DISAGREEMENT BETWEEN CO-GUARDIANS

Can Margaret's sister sign re-authorization of DNR if her brother disagrees?



Margaret

Answer: NO

- * Margaret's sister may not insist that the DNR be continued
- * For the DNR to be extended, the court would need to make a substituted judgment due to the disagreement between the co-guardians



Jim

- * Aged 72
- * Lives in his own apartment
- * Competent
- * Brother is health care agent
- * Colon cancer metastasized



Jim

- * Decided against invasive treatment due to advanced stage of disease
- * Has MOLST

BROTHER DISAGREES

Does Jim's brother have legal authority to over-ride Jim's treatment decisions, so that Jim's wishes are not implemented, as laid out in the MOLST form?



Jim

Answer: NO

- * His brother has no authority as a Health Care Agent because the Health Care Proxy is not yet in effect because Jim is still competent
- * If Jim has a disagreement with his brother, he can tear up the health care proxy and name another person who will carry out his wishes should he become incapacitated
- * If he has no one else to name as a HCA, he has created a Five Wishes document and MOLST, which should act as safeguards of his medical treatment wishes



Esther

- * Aged 64
- * Non-verbal and requires assistance in all aspects of daily living
- * Very involved family
- * Mother was guardian, but passed away



Esther

- * Brother is very involved, visits Esther regularly, and had planned to petition the court for guardianship
- * Pneumonia not responding and bacterial infection has entered Esther's bloodstream
- * Doctor has asked family to consider DNR

NO GUARDIAN, BUT LOVING FAMILY INVOLVED

Question: Can Esther's brother sign a DNR order if he is not yet appointed guardian?



Esther

Answer: YES

- * In Massachusetts law, involved loving family member may consent, even if they do not have guardianship
- * Under a Massachusetts case, the court held that “(a DNR) is a question not for judicial decision, but one for the attending physician... in light of the patient’s history and condition and wishes of her family.”

---In the Matter of Shirley Dinnerstein, 6 Mass App Ct, 466, 475 (1978)



Irma

- * Aged 76
- * Lived and worked on her family's farm until her parents died
- * Only sibling lives out of state and is uninvolved
- * Supervised apartment
- * Legally competent
- * Never completed an advanced directive or health care proxy



Irma

- * A stroke left her partially paralyzed and with significant memory loss
- * No longer able to make informed treatment decisions

NO LONGER CAPABLE, NO ADVANCED DIRECTIVE, NO HCA

Question: Who can make treatment decisions on Irma's behalf?



Irma

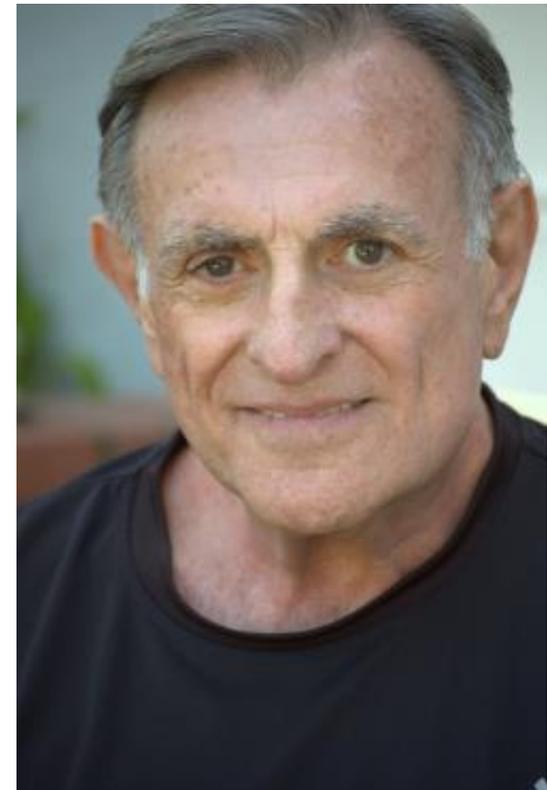
Answer: This is complicated.

- * If capable of making informed decisions, she may sign her own forms
- * If not, a clinical review team would evaluate her need for a guardian, and if so, what kind
- * If recommendation is for guardian, then support team would petition the court for a guardian to be appointed
- * Reach out to the sister to see if she could be involved in an emergency situation, either as health care agent if Irma were competent, or as guardian, if not



Donald

- * 67 year old man with moderate ID
- * Lives in a supervised apartment with roommates
- * Works in a day program, but wants to retire like his roommates
- * Wants to spend time with friends and pursuing activities in his community



Donald

- * Donald's brother is his guardian
- * He wants Donald to keep working as long as he is able
- * Donald's case manager thinks he would enjoy social opportunities in his community if he retired
- * She believes Donald wouldn't get into trouble, and has urged Donald's brother to honor Donald's wishes

CONFLICT BETWEEN DONALD AND HIS LEGAL GUARDIAN

Question: Can Donald's brother prevent him from retiring?



Donald

Answer: Yes

- * His brother has the authority to decide whether or not Donald may retire
- * Everyone under guardianship is entitled to representation from a court appointed attorney
- * Under Massachusetts Uniform Probate Code, guardians must act in the best interests of the individual
- * If court appoints an attorney, he or she can question whether or not guardian is acting in Donald's best interest. If not, court may override the guardian's decision
- * Furthermore, Donald can look into the possibility of removing the brother as guardian, and replacing him if a guardian is indicated
- * Or a new determination could be made that Donald does not need a guardian



Mavis

- * 57 year old woman with Down syndrome
- * Has diabetes, dementia and heart disease
- * Lives in a group home
- * Physician has recommended visiting nurse
- * Mother is legal guardian



Mavis

- * Mother wants Mavis to move to a nursing home
- * Treatment team disagrees:
 - * Benefit from routine and social support of her living situation
 - * Visiting nurse will provide adequate medical support
- * Mavis incapable of expressing her wishes

CONFLICT BETWEEN GUARDIAN AND TEAM

Question: Can Mavis' mother/guardian over-ride recommendations of treatment team?



Mavis

Answer: Unlikely

- * Mother would have to contact an Aging Service Access Point (ASAP) to request an evaluation
- * Because Mavis is receiving services from DDS that her clinical team believe are the best option, and are less restrictive than placement in a nursing facility, it is unlikely that the ASAP would recommend placement in a nursing facility



William

- * 76 years old and lives in his own apartment with a roommate
- * Experienced recurrent pneumonia and has been intubated twice in the past year
- * Legally competent
- * Signed a MOLST order with his physician
- * MOLST indicates that William does not want to be intubated again, but would accept less invasive breathing assistance



William

- * One night, William had difficulty breathing, and the area office nurse arranged for him to be transported to the hospital by ambulance
- * The emergency responders wanted to intubate him, but William refused and the nurse handed them the MOLST form

THEY AGREED TO USE CONTINUOUS POSITIVE AIRWAY PRESSURE – A LESS INVASIVE WAY TO ASSIST SOMEONE IN RESPIRATORY DISTRESS

**Question: Were they correct
in their actions?**



William

Answer: Yes

- * William is competent and has a signed MOLST form in place stating that he does not want to be intubated
- * It was his right to refuse intubation, and the nurse was correct in sharing the MOLST form with the EMTs
- * Because William is willing to accept a less invasive treatment, the emergency responders were correct in using Continuous Positive Airway Pressure



Additional Webinars

- * Guardianship and Aging in Intellectual Disability, Part I & Guardianship and Aging in Intellectual Disability, Case Studies Part II
- * Life Sustaining Treatment Policy
- * Massachusetts Medical Orders for Life-Sustaining Treatment (MOLST)
- * End of Life Definitions



Additional Resources

Massachusetts Department of Developmental Services (DDS)
www.mass.gov/eohhs/gov/departments/dds/aging-with-id.html

Center for Developmental Disabilities Evaluation & Research
http://shriver.umassmed.edu/cdder/aging_idd_education



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