The Right to Self-Determination vs. The Right to be Protected and Safe
A Meeting of the Minds Dementia Conference 2011
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Objectives:
• List at least three ethical conflicts experienced when working with vulnerable clients
• List legal/professional limits to clients’ right to self-determination
• Identify legal interventions and when these may be necessary

Vulnerability? Let Me Count the Ways…
(Why are we here today?)
• “Non-compliant” with medical cares
• Hospital/nursing home: leaving AMA
• Fall risk
• Personal safety issues: household, neighborhood
• Refusing or reluctantly/tentatively accepting care
• Cognitive deficits: lack of ability to meet basic needs, impaired judgment, lack of insight
• Other
Balancing Client’s Right to Self-Determine with Client’s Right to Protection

- Recognize the ethical dilemma(s).
- Assess if appropriate to advocate for client’s right to engage in risky behaviors
- Assess if situation warrants need to intervene to protect client from themselves
- Identify your role:
  - Advocate for client’s wishes & Facilitate supports?
  - Obtain protective interventions?

Common Ethical Principles:

- **Autonomy**: Allow those who are competent to make their own choices
- **Beneficence**: Act to promote good
- **Honesty/Veracity**: Do not deceive others
- **Non-maleficence**: Do no harm
- **Paternalism**: Intervene to protect the interests of the vulnerable/incapacitated
- **Utility**: Promote the greatest good for the greatest number

Ethical/Professional/Legal Conflicts

- Safety vs. Autonomy *(Autonomy)*
- Protection vs. Happiness *(Paternalism)*
- Quantity of Life/Prolonging Life vs. Quality of Life
- Provider Liability vs. Client Rights/Choices *(Beneficence; Non-malefeasance)*
Ethical/Professional/Legal Conflicts (cont’d)

- Good of Individual vs. Good of the Group (Utility)
- Worker’s Personal vs. Professional Opinions
- Truth Telling vs. Avoiding Conflict (Honesty/Veracity)
- Social Work Values vs. Other Professions’ Values

All are potential sources of conflict in client and family relationships and/or between professions and professionals.

Right to Experience Risk & Exercise Autonomy

- Constitution of United States: “Blessings of Liberty”
- Bill of Rights – 14th Amendment prohibits deprivation of liberty or property without due process
- US Cultural Value - Independence, freedom and non-interference from Government in citizens’ lives

Clients’ Individual Rights as Determined by Professional Values and Standards for Care

- Social Work Value - Self Determination
  NASW Code of Ethics
  MN Board of Social Work
- Medical Professions – Patient Rights
  American Nursing Association
  International Council of Nurses
  Patient Self-Determination Act
- National Association of Geriatric Care Managers
  Fostering Self Determination
Limits of Self-Determination / Where Right to Autonomy Ends

- Mandated reporting
- Duty to Warn (Threatening Others)
- Threats of Suicide (Danger to Self)
- Violate rights of others
- Governmental Code/Law Violations
- Incapacity (maybe)

Capacity (Competence)

Legal Capacity

Court Determination:
- Evidentiary Standards
- Statute, Rule, Case Law

Functional Capacity

Medical/Other Professional Determination:
- Ability to give informed consent/refusal

Functional Assessment Tool: Informed Consent

Ability to:

- Understand the issue: give & receive information
- Understand available options
- Understand risks and benefits of options
- Make a decision
  - Decision not based on delusion
  - Decision not coerced
Making Informed Decisions

“Capacitated” People Have a Right to:

• Denial
• Poor decisions
• Choose to do nothing
• Place themselves at risk
• Express own unique values, lifestyle and beliefs
• Change their mind

Self-Determination / Autonomy

<table>
<thead>
<tr>
<th>Decision:</th>
<th>Low Risk</th>
<th>High Risk</th>
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</thead>
<tbody>
<tr>
<td>Capacitated/Competent</td>
<td>right to risk</td>
<td>right to risk</td>
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<tr>
<td>Informed Decision Making</td>
<td>right to risk</td>
<td>right to risk</td>
</tr>
<tr>
<td>Questionable Capacity</td>
<td>right to risk (?)</td>
<td>higher value placed on protection</td>
</tr>
<tr>
<td>Incapacitated/Incompetent</td>
<td>need for protection (?)</td>
<td>need for protection</td>
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</tbody>
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Transition: Theory to Practice

When ethical and legal conflicts exist between a client’s needs/wishes and other interests (competing values, provider liability, professional practice and standards, legal requirements) creative problem-solving is in order.

Some helpful approaches follow.
Resolution of Conflicts/Addressing Risk

• Client Advocacy
• Negotiated Consent
• Outside Resources (Tool Kit)
• Legal Intervention Tools

Client Advocacy

• Build trust
• Advocate for decisions client can make
• Accommodate for disabilities
• Give information about rights
• Help client identify needs
• Facilitate realistic goal setting (Insight Proxy)
• Identify and link to formal and informal resources
• May need to confront other professionals

Negotiated Consent

• Participation by client or surrogate
• Wide consultation with interested parties
• Decision-making process is documented as well as outcomes and dissent
Tool Kit

- Family/Friends
- Institutional Policy
- Ethics Committee
- Attorney
- Banking/Financial Tools
- City Inspectors
- Adult Protection
- Legal Surrogate Decision Maker: HCD; Power of Attorney/Trustee; Court Intervention

FYI: HCD
Health Care Directive (Principal appoints agent)
- Capacity to establish vs. capacity to make medical decision
- Nomination for Guardian
- Allows agent to make placement decisions
- Goal: every client? (answer: YES!)

FYI: POA
Power Of Attorney (Principal appoints attorney-in-fact)
- Even if check “all powers”, $$$ only
- Nomination for Conservator
- Can be effective in meeting care needs even without official personal powers
- Role of attorney
Common Myths/Misperceptions Concerning Dementia, Cognitive Capacity, and the Role of Guardianship

- All vulnerable adults are incapacitated
- All people with dementia are incapacitated
- All incapacitated people need a guardian
- Guardianship is a relatively simple process
- Guardianship will solve most problems

When to Intervene with Court Tools

- Person is a danger to self or others; or
- Person lacks capacity, and;
- Person’s basic needs are unmet; or
- Personal and/or Financial Decision needs to be made; or
- Conflict/Controversy about decision, or;
- Required by policy, or;
- Person unable to receive necessary services without intervention

Criteria for Legal Intervention: Guardianship

- When a person is incapacitated: lacks sufficient understanding/capacity to make or communicate responsible personal decisions, even with use of appropriate technological assistance and
- Has behavioral deficits which evidence inability to meet personal needs for medical care, nutrition, clothing, shelter, safety and
- No less restrictive alternatives will meet their needs
Legal Intervention: Conservatorship

- Person is unable to manage property & business affairs b/c of inability to receive and evaluate information or make decisions, even with use of appropriate technological assistance;
- Has property which will be wasted or dissipated unless management is provided or
- Money is needed for support, care, education, health, and welfare of the person or individuals entitled to the person’s support and
- Needs cannot be met by less restrictive alternatives

Legal Intervention: Commitment

- When individual has Mental Illness (includes dementing illnesses), Mental Retardation or Chemical Dependency to protect from harm and ensure treatment and
- Is a danger to self or others
- Allows individual to be held for 72 hours pending determination of grounds and need for petition
- May allows treatment to stabilize MH and avoid need for further intervention, obtain HCD.

When Not to Intervene with Court Tools

- When the person is incapacitated: maintains their right to make decisions (however poor)
- When the person’s needs can be met in any other way
- Whenever an alternative has not been reasonably tried
- When the court intervention is not likely to be effective in addressing the problem at hand
- When there is no decision to be made / no current issues (not proactive tools!)
- When criteria not met/can’t be proven
Alzheimer’s Association: Dementia and Self-Determination

1. Diagnosis alone not indication of incompetence
2. Caregivers: seek least restrictive alternatives when person incompetent in some areas
3. Competent people, and many with dementia, have right to refuse treatment
4. Reasonable indecision/change of mind does not itself indicate incompetence

5. Alzheimer’s pt. may still have capacity to make competent decisions
6. Appointment of legal guardian may allow Alzheimer’s pt. to maintain degree of independence/autonomy
7. Judgment of incompetence: reflect mental condition of dementia pt., not needs or tolerance of others

Alzheimer’s Association “Ethical Issues in Alzheimer’s Disease: Respect for Autonomy”
www.alz.org/documents/national/autonomyEI.pdf