

Ethical Case Management Issues Across the Brain Injury Continuum

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Why is this discussion important?

It is easy in abstract to say every person has the right to autonomy

But

It might be just easier to follow the rules

&

It is critical to include the personal aspects while making decisions.



Nurses Code of Ethics: What is it?

- “Ethics is the systematic approach to understanding, analyzing, and distinguishing matters of right and wrong, good and bad as they exist along a continuum and as they relate to the well being of and the relationships among sentient beings.” (Rich and Butts, 2013)
- Foundational moral document of nursing- recently updated.
- Encompasses the profession’s values, obligations, standards, aspirations and ideals.
- Ethics standards of behavior that tell us how human beings ought to act in the many situations in which they find themselves as friends, parents, children, caregivers, providers of service, etc.

Case Managers Today

- Coordinate and manage the care of ill and injured workers.
- Provide management of work-related and non-work-related injuries and illnesses, which include aspects related to group health, workers' compensation, and Family Medical Leave Act (FMLA) and short-term/long-term disability benefits.



Case Managers Today

- Counseling and crisis intervention
- Health promotion and risk reduction
- Legal and regulatory compliance
- Worker and workplace hazard detection



Ethical Standards

- Ethical Standards are standards of professional conduct rooted in the moral principles and values of society and the profession.
- Although legal rights are anchored in ethical standards, ethical standards exceed legal rights
- Regulatory boards, employers, and professional organizations establish ethical standards in professional codes of conduct and in state regulations
- Ethics in Human Research: <http://www.cdc.gov/od/science/integrity/hrpo/training.htm>



Ethical Issues Identified by Rehabilitation Practitioners

(Kirschner, APMR, 12/2001)

- Lack of financial resources for needed services
- Resource allocation: effectiveness of rehab & cost - “the essential benefit package”
- Suboptimal discharge or admission plans: funder “challenge”: unsafe or inappropriate environment; CM vs Claims Adjuster
- Decision making capacity and ability to give consent: throughout the “continuum of ‘recovery’ ”, patient or family refusal of recommendations



Ethical Issues Identified by Rehabilitation Practitioners

(Kirschner, APMR, 12/2001)

- Issues of surrogacy or second party consent
- Withdrawing life sustaining treatment for patient with disabilities
- Goal setting: team conflict, patient compliance and refusal, questionable decision making capacity
- Quality of life issues - feeding tubes, driving, social media use
- “Truth telling” regarding prognosis
- Injured worker difficulties



Models of Ethical Decision Making in Clinical Practice: using a case based approach



Jonsen's “Four Boxes”



Medical Indications: principles of beneficence & non-maleficence

- What is the diagnoses, treatment, prognosis, acuity?
- What is the chronicity, reversibility and terminality?
- What are the goals of treatment?
- What treatments are not indicated?
- What is the probability of success?
- What is the benefit to the patient?

Patient References: principles of respect for autonomy

- What is the patient's "informedness"?
- What is the patient's comprehension ?
- Is the patient participating on a voluntary basis?
- What is their mental capacity? What is their legal status?
- Do they have advanced directives and/or prior expressed preferences?
- Do they have a surrogate?

Quality of Life: principles of beneficence, non-maleficence & respect for autonomy

- What are prospects with and without treatment?
- What physical, mental, and social deficits is the consumer likely to experience if treatment succeeds?
- Are there biases that might prejudice the provider's evaluation of the consumer's quality of life?
- Might the present or future condition be judged as undesirable?

Contextual Features: principles of justice & fairness

- Are there family issues that might influence treatment decisions?
- Are there provider issues that might influence treatment decisions?
- Are there financial, economic and allocation of resources constraints?
- How does the law affect decisions?
- Is there a conflict of interest on the part of the providers?

Ethical Principlism

- **Autonomy:** one's ability to self rule and generate personal decisions
- Respect for autonomy
- Informed consent
- Patient choice for treatment options
- Confidentiality
- **Beneficence:** in nursing, nurses take actions to benefit patients and facilitate their well being.
- Putting side rails up

Ethical Principlism

- **Non-maleficence:** to do no harm; refraining from actions that might harm.
- Avoiding negligent care
- Withholding treatment; Extraordinary or heroic treatment

Justice: Fair treatment of individuals to the equitable distribution of benefits and burdens to individuals in social institutions and how the rights of various individuals are realized.

Is the decision based on need? Age? Prognosis?

Using the Process

- **Assessment/Data Collection:** Define the type of problem it is and who is involved? Collect the facts about the patient; about the values; concerns; opinions of the entire team
- **Analysis:** Look at the facts within the context of a theory
- **Diagnoses:** make a clinical judgment about the care context including points of agreement, tension, conflicts of obligation or value.

Using the Process

- **Outcomes/Planning:** What would happen if? You can identify a range of approaches.
- **Implementation:** What is the fitting answer? What is the outcome people can live with?
- **Evaluation:** What has happened? What can be learned from this?

Sticking Our Neck Out

Ethical Areas of Concern

Medical Decisions -

- Complexities of decisions
- Shared decision making
- Competency and capacity
- Where is the person coming from and what are their wishes?

Life Decisions- aging, discharge planning

Risks and Safety

Maximizing funding and resources



Certain Laws Protecting the Individual & Shaping Health Care Practice Guide Ethical Decision Making



Laws Protecting the Individual & Shaping Health Care Practice

- **Common Law** - Developed from court decisions- medical malpractice- “defensive medicine”
- **Constitutional Law** - Based on the U.S. Constitution, as well as the constitution of the state where the person lives - protects the rights of the individual (civil rights); ADA



Laws Protecting the Individual & Shaping Health Care Practice

- **Statutory Law** - Enacted by Congress or a state legislature in the form of individual statutes, which together form a code: HIPAA, Affordable Care Act, Workers Comp
- **Administrative Law** -Regulations created by administrative agencies such as the CMS, JCAHO, CARF, DPW, OSHA. Authorizes an agency to create *rules or regulations*.



Client Bill of Rights

- Generally outlines person's right to receive respectful, timely care by competent professionals; right to informed consent; privacy; knowledge of the institution's rules; ability to make decisions/refuse care; to be treated in a safe environment free of restraints.
- As a staff member, it is our responsibility to immediately bring potential violations up to the supervisor or program, or outside agency, if necessary, as they are discovered. Failure to do so may make the staff person personally liable for any violations.



Client Bill of Rights

- A written guarantee of basic rights for persons served
- A violation of any of these rights could be an unlawful act or potential grounds for a lawsuit
- Must be posted in the program/available for review at all times
- Need to review Rights w. Consumer/Guardian on admission and annually
- Must be written in the primary language of each consumer
 - Assistance must be provided to each person to assure comprehension of his or her rights



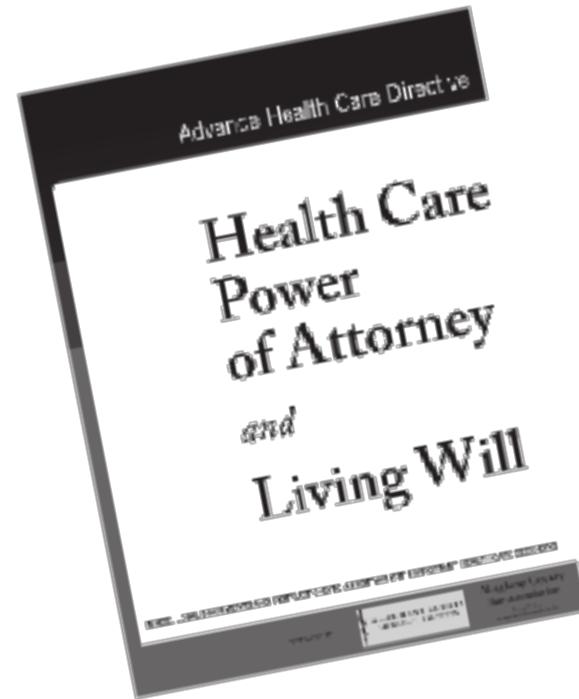
Levels of Decision Making Assistance

- Power of Attorney
 - Conduct affairs on behalf of a person a/c their wishes
 - No concerns re: person's ability to make decisions
- Representative Payee
 - Receive SSI/SSDI checks for person
 - Expected to assist w money management
- Financial Guardian
- Guardian of Person & Estate
- Advanced Directives
- Medical Power of Attorney



Medical Decisions

- Advanced Directives: A written instruction, such as a living will or durable power of attorney for health care, which guides care when an individual is terminally ill or incapacitated and unable to communicate his/her desires.
- Written by person to express his/her desires re: medical treatment; can be modified at any time.



Medical Decisions

Durable Power of Attorney for Health Care = Medical power of attorney/Health care proxy

- A competent adult, the principal, appoints an agent to make decisions about medical care in the event that the principal is unable to make those decisions. They remain in effect while person is unable to make his or her own decisions.
- It differs from a living will or advance directive because the principal is not giving specific instructions about what to do, but identifying the person he or she wants to make those decisions.
- **Most states combine durable power of attorney for health care forms with advanced directives.**

Medical Decisions & Informed Consent

Valid consent needs to be informed, voluntary and competent

Patient needs to have the:

- Ability to communicate treatment choice
- Ability to appreciate consequences of choice
- Ability to reason about different choices
- Ability to be understood



Surrogacy

Power of Attorney

- A competent person, the principal, appoints another, the agent, to act for him in ***legal and financial matters***
- The agent may have specified broad or limited powers.
- The powers of the agent may begin immediately or following an event (e.g., brain injury)
- The appointment may also be *durable*, meaning that the powers do not change when the principal becomes disabled or incapacitated
- Under most state laws, a guardian can override or revoke the power of attorney
- Staff should be aware of the consumer's power of attorney document and its specified duties



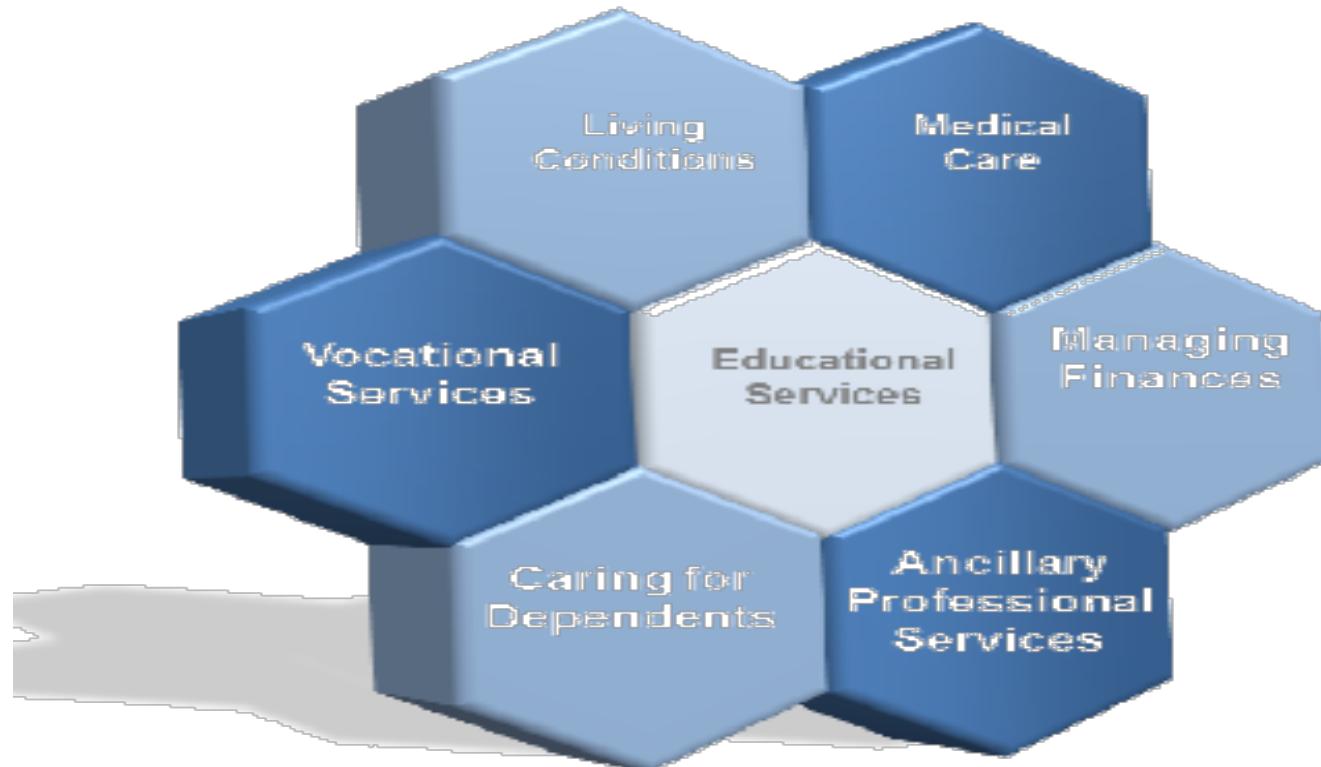
Competency or Capacity

- A legal term that describes a person's mental ability to understand the nature and effect of one's decisions and acts
- Generally, the law presumes competence unless proven otherwise; states determine legal age of competency (18 in PA)
- Only a court may determine that an individual is legally incapacitated
- If deemed incapacitated, the court will appoint a representative to make the decisions that the individual is incapable of making
- Staff should report concerns that a legally competent consumer/participant is not able to make decisions or vice versa
- Individual has the right to contest competency
- *Many (most) families avoid this step!*
- *Ethically we have to approach this together*

Guardianship

- A legally enforceable arrangement under which one person, “the guardian”, has the legal right and duty to care for another, “the ward”
- A person with a guardian does not lose basic legal rights
- Guardian of the estate – financial matters, benefits, property (conservator)
- Guardian has the right to have input re: the person’s program, medical care, release of records
- Partial - limits may be determined by court

Areas of Decision Making Where Most Guardianships are Focused



Guardianship & Protections

- Abuse - the willful infliction of injury, confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish
 - Neglect - a failure to provide for the basic needs of a dependent individual
 - Exploitation - the use of a dependent person's property illegally or without their consent
 - Poor Guardianship
 - Aging Guardian



Aging

- Quality of Life
- Medical Co-Morbidities
- Changing levels of care
- Advanced Directives
- End of Life Issues
- Final Wishes -
- Burial/cremation
- Religious/Cultural beliefs and preferences





Risks for Individuals with Diminished Capacity



- Use of social media
- Living alone
- Dating/Marriage
- Community access
- Adaptive sports
- Taking public transportation
- Driving
- Eating
- Exploitation

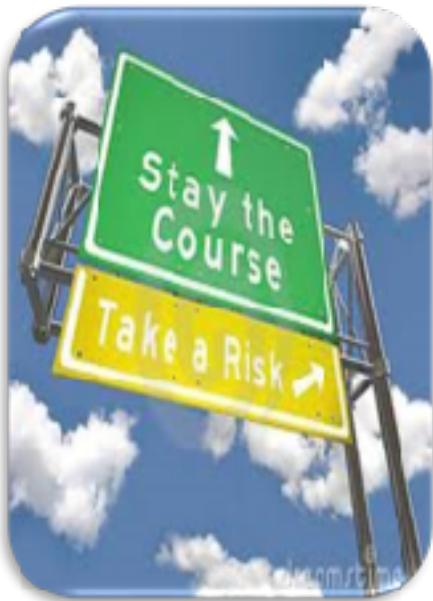


Risks for Individuals with Diminished Capacity

- Social Media/Dating - Buying Bride from Russia, sending \$\$\$ to online girlfriend
- Taking Medical Risks - Peg Tube vs Eating
- Community Access - bars, restaurants, etc.
- Financial Risks - getting \$6,000 in debt for a cruise
- Driving Risks - vehicle maintenance, who gets in the car, where are they going, etc.



Risk or Supportive Failure?



- Identify goals, strengths and barriers as well as risks, benefits and preferences with consumer and caregiver
- Define the plan; set objectives to achieve goals
- Identify supports, strategies and systems to accomplish the plan
- Evaluate alternatives
- Provide education to team, including consumer & family
- Helping the consumers and key support/caregivers to come to agreement with and reinforce the plan
- **EVALUATE & ADJUST**

Risky Business



TAKING RISK

There's a fine line between taking a calculated risk and doing something dumb.

Maximizing Funding and Resources

- Identifying state benefits and government resources
- Identifying pre-morbid issues and those related to work related injury
- Long term planning
- Special Needs Trust
- Identifying back-up/ secondary Guardians
- Long term funding for services

Planning for Care: Considerations

- Dealing with current Prognosis & Changes
- What kind of care is needed?
- Caregiver's role
- Consumer's role in the plan
- Who will provide care
- When home might not be an option
- When home must be the option
- No Home
- Paying for care
- Lifetime considerations



Think DIFFERENTLY

We need to challenge people to think
BEYOND their *Disabilities*

&

*Get Injured Workers, Providers, Funders & Families to think
outside the box and work together*



Tools & Documentation

- Policies for Clinical Decision making and surrogacy
- Educational information for Advanced directives and end of life planning-dynamic discussions
- Policies for medical decision making
- Tools to determine capacity
- Policy for competency and capacity
- Pre-scripted forms for advanced directives
- Strategies and support for community integration to support risk



Tools & Strategies

- Strategies to promote consumer centered decision making
- Written information
- Educational forums, medication classes
- Ethics Committee
- Ethics Consultant
- NIH - Protecting Human Research Participants Course
 - <http://phrp.nihtraining.com/users/login.php>
 - Additional requirements for any research concerning vulnerable populations



CASE STUDY I

- Injured worker sustained TBI over 25 years ago.
- Received large settlement; insurance continues to pay for medical/program care. Continues to get SSDI; payee attorney
- Injured worker asked his “high school” buddy to be his guardian of person, medical and finance.
- Difficulty with communication
- Difficulty with getting money monthly
- Attorney has not provided information related to trust; has not providing an accounting to IW
- Health insurance policy lapsed secondary to non-payment

CASE STUDY II

- Individual was injured over 30 years ago.
- Was in good health until about 10 years ago; dysphagia dx.
- History of pneumonia secondary to allergies
- After numerous hospitalizations, family advised he should have peg tube
- Family was guardian
- Family concerned about peg tube insertion.
- Discussions
- Conclusions

Questions and Thank You!

