Support Planning Professional Learning Community (SPP LC)
January 25, 2017

Diane M. Marshall | Case Management Policy Lead | Disability Services Division
To ask a question during the presentation use the Q&A Panel in WebEx

Select “All Panelists”, type your question, and click Send.
Provider Signature Requirements

Risk and Informed Choice Resource Guide

Ethical Dilemmas: Right to take risk versus right to be safe

Questions: Use Q&A Panel and send to “All Panelists”
Provider Signature Requirements

Elizabeth Siewert
MnCHOICES Policy Planner
Provider Signature Requirements

Lead agencies are now required to have each home and community-based service (HCBS) provider sign the recipient’s HCBS support plan.

• This change applies regardless of plan format, including:
  • MnCHOICES Coordinated Services and Supports Plan (DHS-6791B)
  • Community Support Plans (DHS-4166)
  • Collaborative Care Plans
  • Other health plan support plan formats.
Provider Signature Requirements

Who:

• The person who develops the support plan with the person is responsible for obtaining signature(s)

When:

• Signatures are not needed for existing plans until those plans are updated or renewed

How:

• Signatures can be documented on:
  
  • [Coordinated Services and Supports Plan Signature Sheet, DHS-6791D (PDF)](https://example.com)
  
  • [Community Support Plan (DHS-4166)](https://example.com) on the Coordinated Services and Supports Plan Signature page
  
  • For the Collaborative Care Plan or other health plan formats, the Health Plan will direct you on how best to obtain signatures
Important to remember:

• The person only needs to sign the full support plan, not each individual provider section

• The case manager, certified assessor or care coordinator should work with the person to determine if they would like the entire plan sent out to providers or only the sections that are applicable. The person has a choice of which providers receive a copy of the plan.

• Both the case manager, certified assessor or care coordinator and the provider should keep a copy of the signed form for their records

• The case manager, certified assessor or care coordinator should record the request for signature in the person’s record.
For more information:

• Community Based Services Manual (CBSM)-Assessment applicability and timelines page

• CBSM- FAQ for the provider signature requirements for support plans
Risk and Informed Choice Resource Guide

Raukiya Smith-Binns
MnCHOICES Program Administrator

Jill Tilbury
Public Guardianship Administrator
Ethical Dilemmas: Right to Take Risks v. Right to be Safe

Anita Raymond | Program Manager | Volunteers of America MN & WI
Objectives

What are the ethical issues when considering whether to intervene when a person’s actions demonstrate questionable judgement or place the person at risk of harm?

• List at least 3 ethical conflicts experienced when working with vulnerable people

• Understand self-determination as a constitutional, legal, and cultural right, as well as limits to the person’s right to self-determination

• List 3 interventions to address the person’s unsafe decisions and how to decide whether to focus on the person’s right to self-determination or the need for protection
Ethical/Professional/Legal Conflicts in Daily Work Life

- Safety/Protection vs. Self-Determination / Happiness
- Quantity of Life (Prolonging Life) vs. Quality of Life
- Provider Liability vs. Person’s Rights/Choices
- Good of Individual vs. Good of the Group
Ethical/Professional/Legal Conflicts (cont’d)

• Worker’s Personal vs. Professional Opinions

• Law/Policy vs. “What’s Right”

• Truth Telling vs. Avoiding Conflict

• Social Work Values vs. Other Professions’ Values

• The Way We’ve Always Done it vs. Person Centeredness
Common Ethical Principles

- **Autonomy**: Self-determination, making own choices
- **Beneficence**: Act to promote good
- **Honesty/Veracity**: Do not deceive others
- **Non-maleficence**: Do no harm
- **Utility**: Promote the greatest good for the greatest number
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

- U.S. Cultural Value - Independence, freedom and non-interference from Government in citizens’ lives
Individual Rights:
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/MN Medical Associations, American Nursing Association
  • Patient Self-Determination Act

• Aging Life Care Association (professional care managers)

• Olmstead Decision and Person Centered services
Vulnerabilities of the People We Serve

- “Non-compliant” with medical cares / professional recommendations
- Health care settings: leaving AMA
- Fall risk
- Engaging in risky relationships
- Being victimized
- Personal safety issues: household, neighborhood
- Refusing or only reluctantly/tentatively accepting care
- Cognitive, psychiatric, or intellectual deficits: lack of ability to meet basic needs, impaired judgment, lack of insight
- Other ...
Common Ethical Principles

- **Autonomy**: Self-determination, making own choices
- **Beneficence**: Act to promote good
- **Honesty/Veracity**: Do not deceive others
- **Non-maleficence**: Do no harm
- **Utility**: Promote the greatest good for the greatest number
- **Paternalism**: Intervene to protect the interests of the vulnerable/incapacitated
Vulnerable Citizens’ Right to Protection

- From harm
- From exploitation, abuse, neglect
- From personal dignity being robbed by incapacitating illness / injury /condition
But What About the **Dignity of Risk?**
What if you never got to make a mistake?

What if your money was always kept in an envelope where you couldn’t get it?

What if you were never given the chance to do well at something?

What if your only chance to be with people different from you was with your own family?

What if the job you did was not useful?
Dignity of Risk

What if you never got to make a decision?

What if the only risky thing you could do was to act out?

What if you couldn’t go outside because the last time you did it rained?

What if you took the wrong bus once and now you can’t take another one?

What if you got into trouble and you were sent away and you could never come back because they always remember you are trouble?
Dignity of Risk

What if you worked and got paid 46 cents an hour?

What if you had to wear your winter coat when it rained because it was all you had?

What if you had no privacy?

What if you could do part of your grocery shopping but were not allowed to because you couldn’t do all of your shopping alone?
Dignity of Risk

What if you spent three hours each day just waiting?

What if you grew old and never knew adulthood?

What if you never got a chance?

~Author Unknown
To deny the right to make choices in an effort to protect the person with disabilities from risk is to diminish their human dignity.”

– Robert Perske
Vulnerable Citizens’ Right to Protection

- From harm
- From exploitation, abuse, neglect
- From personal dignity being robbed by incapacitating illness/injury/condition
Our Ethical Duty

Advocate & Support or Intervene & Protect

Right to

Self-Determination vs.

Right to

Protection

(Autonomy)

(Paternalism)
Limits to Self-Determination

- Mandated reporting
- Duty to warn (Threatening Others)
- Threats of suicide (Danger to Self)
- Violate rights of others
- Governmental code/law violations
- Personal and Caregiving relationships
- Incapacity (??)
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
Capacity Varies

- Throughout a time period (course of illness, hospitalization, time of day, etc.)
- May deteriorate or improve
- Capacity is not global: Depends on decision or issue
- Is *NOT* determined by a test/screening score

Q: Who decides?
A: Who needs the decision?
Capacity Determination as a Practical Matter

• Benefit vs. Burden of Determination:
  • What would a determination change? What opportunities will be lost? (positive and negative consequences)

• When is a determination necessary?
Incapacity: Medical Designation

• MD/Psychiatrist/Psychologist/Neurologist’s Determination of the person’s capacity

• Based on ability to give informed consent/refusal

• Should not be based *solely* on:
  • diagnosis
  • test/screening scores
  • behavior

• Is not LEGAL determination
Incapacity: Legal Designation

Court Determination:

• Evidentiary Standards: substantial due process protections in obtaining legal determination of incompetence/incapacity/removal of right to make own decisions

• Attorney Determination/Opinion (making will, POA, etc.)

• Physician declaration: triggers agent authority in Health Care Directive
Decisional Capacity Requirements

Patient able to communicate choice

*clearly indicates chosen tx. option*

Understands relevant information

*grasps meaning of info. given*

Appreciates situation & consequences

*acknowledges condition, consequences*

Reasons about treatment options

*engages in rational process of manipulating relevant info.*

Assessment of Patients’ Competence to Consent, Paul S. Appelbaum, MD
Functional Capacity Assessment Tool: Informed Consent

• Understands the issue: give & receive information
• Understands available options
• Understands risks and benefits of options
• Makes a decision
  • Decision not based on delusion
  • Decision not coerced
Balancing Right of Self-Determination with Right to be Safe

- Recognize the ethical dilemma(s)
- Assess if appropriate to advocate for capacitated person’s right to engage in risky behaviors/self-determination: Advocate for person wishes & Facilitate supports
- Assess if situation warrants need to intervene to protect incapacitated person (limit self-determination): Pursue protective interventions. (But, in least restrictive manner with least restrictive tool)
### Self-Determination / Autonomy

<table>
<thead>
<tr>
<th>Person:</th>
<th>Decision:</th>
<th>Low Risk Outcome</th>
<th>High Risk Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capacitated/Informed Decision-making</td>
<td>right to risk</td>
<td>right to risk</td>
<td></td>
</tr>
<tr>
<td>Questionable Capacity</td>
<td>right to: risk</td>
<td>Higher value placed on protection/right to be safe</td>
<td></td>
</tr>
<tr>
<td>Incapacitated/Incompetent</td>
<td>right to: risk (maybe?)</td>
<td>Safety/protection is goal</td>
<td></td>
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</tbody>
</table>
Resolution of Conflicts: From Advocating for Right to Take Risks to Addressing Safety Concerns

- Intensive person Work
- Advocacy with Person
- Supported Decision-Making
- Negotiated Consent
- Outside Resources (Tool Kit)
- Legal Intervention Tools
Self-Determination / Autonomy:

Advocating for, and supporting, the person’s Right to Take Risks
Advocacy

- Confront your own risk tolerance
- Build trust; joining
- Advocate for decisions people can make
- Accommodate for disabilities
- Give information about rights
- Help person identify needs
- Facilitate realistic goal setting (Insight Proxy)
- Identify and link to formal and informal resources
- May need to confront other professionals
Supported Decision Making: An emerging model

• “A way people can make own decisions, stay in charge of their lives while receiving help they need to do so.”

• Making decisions with the person vs. others making decisions for them: “…cutting through the jargon to understand what’s going on and what you need to do…”

• “I don’t need a guardian. I just need a little help!” -- Jenny Hatch
Negotiated Consent

• Participation of the person ideal, not required (if person is incapacitated, others acting in best interests)

• Wide consultation with interested parties

• Decision-making process is documented as well as outcomes and dissent
Intervene and Protect

Intervening to protect the person’s Right to Protection and Safety
Tool Kit

- Influence of family/friends, authority figures
- Private Pay Care Manager or County Case Manager
- Institutional Policy, Ethics Committee
- Attorney
- Banking/Financial Tools
- Evictions/Discontinue Services
- City Inspectors
- Adult Protection
- Voluntary legal decision making tools: HCD, POA
Tool Kit: It Takes a Village...

- Influence of Family/Friends, Authority Figures
- Private Pay Care Manager or County Case Manager
- Institutional Policy, Ethics Committee
- Attorney
- Banking/Financial Tools
Tool Kit: Applying Pressure, Seeking (influencing?) Natural Consequences as Pathway to Resolution

- City Inspectors
- Housing Evictions/Discontinue Service Provision
- Adult Protection
Tool Kit: Legal Surrogate Decision Makers

- Voluntary (some capacity required):
  - Health Care Directive
  - Power Of Attorney

- Involuntary:
  - Rep Payee; Guardianship, Conservatorship
• Health Care Directive (*principal appoints agent*)
• Capacity to establish vs. capacity to make medical decision
• Nomination for Guardian
• Allows agent to make placement decisions
• Not just for older adults/end of life

*Goal: every person?*
FYI: POA

• Power Of Attorney (*principal* appoints *attorney-in-fact/AIF*)

• Even if check “all powers”, $$$ only

• Nomination for Conservator

• Can be effective in meeting care needs: *power of the purse-strings*

• Role of attorney
Representative Payee

- Voluntary Or Involuntary

- Excellent tool when governmental benefit is only income/asset

*Never under-estimate the power of controlling the purse-strings!*
Intervening with Court Tools

- Patient is a danger to self or others; or
- Patient lacks capacity, and;
- Patient’s basic needs are unmet, unable to be met with LRAs; or
- Personal and/or Financial Decision needs to be made; or
- Conflict/Controversy about decision, or
- Required by policy.

When person is incapacitated and unable to receive necessary services without this intrusive 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

(AND Guardianship appointment will actually address the identified problem)
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

- Person is mentally ill, developmentally disabled, chemically dependent and
- Danger to self (including self-neglect) or others and
- No less restrictive alternatives exist
Avoid Court Intervention:

- When the patient is capacitated: maintains their right to make decisions (however poor)
- When the patient’s needs can be met in any other way
- Whenever alternatives have not been reasonably tried
- When court intervention is not likely to be effective in addressing the problem
- When there is no decision to be made / no current issues
- 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
Autonomy, Decision-Making Supports, and Guardianship

All individuals with intellectual and/or developmental disabilities (I/DD) have the right to recognition as persons before the law and to enjoy legal capacity on an equal basis with individuals who do not have disabilities in all aspects of life (United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), 2006). The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.
AAIDD & The Arc Joint Position Statement

• Current trends presume the decision-making capacity of individuals with I/DD and the preservation of legal capacity as a priority for all people needing assistance with decision-making.

• Like their peers without disabilities, individuals with I/DD must be presumed competent; they must also be assisted to develop as decision-makers through education, supports, and life experience. Communication challenges should not be misinterpreted as lack of competency to make decisions.

• Individuals with I/DD should have access to supports and experiences to learn decision-making skills from an early age and throughout their lifetimes in educational and adult life service systems.
AAIDD & The Arc Joint Position Statement

• Families should have access to information about all options for assisting their family member to make decisions over the life course.

• All people, with and without disabilities, have a variety of formal and informal processes available to enact their decisions and preferences, including healthcare proxies and advance directives.

• Less restrictive means of decision-making supports (e.g., health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual’s decision-making capacity before use of guardianship[2] as an option is considered.
AAIDD & The Arc Joint Position Statement

• Where judges and lawyers lack knowledge about people with I/DD and their human rights, poor advocacy and tragic legal outcomes often result. Financial incentives frequently benefit professionals and guardianship corporations, often to the detriment of individuals with I/DD and their families.

• Serving in the dual roles of guardian and paid service provider or paid advocate creates a conflict of interest or the appearance of a conflict of interest. Such conflicts must be mitigated or avoided.

• Some statutory privacy measures have made it more difficult for those assisting other individuals to have access to their records, make decisions, or both. Thus, to obtain or modify needed medical care, services, and supports, an individual with I/DD may be adjudicated to be incompetent and subjected to guardianship. This result conflicts with the legal presumption of competence and with principles of autonomy, decision-making supports, presumption of competence, and the use of less restrictive alternatives.
The appointment of a guardian is a serious matter for three reasons:

(1) It limits an individual’s autonomy, that is, the individual’s agency over how to live and from whom to receive supports to carry out that choice;

(2) It transfers the individual’s rights of autonomy to another individual or entity, a guardian; and

(3) Many individuals with I/DD experience guardianship as stigmatizing and inconsistent with their exercise of adult roles and responsibilities.
RESOURCES

MAGiC
www.minnesotaguardianship.org
• Standards of Practice: G/C, POA, Rep Payee, Trusts
• Ward & Protected Person Bill of Rights

Volunteers of America MN WI  www.voamnwi.org
• Estate & Elder Law Services: HCD forms and more
• Protective Services: links to articles, G&C FAQ and more
State Courts website
http://pa.courts.state.mn.us/default.aspx Case Status

General information, forms, training video

Supported Decision Making
www.supporteddecisionmaking.org

American Association on Intellectual and Developmental Disabilities and The Arc Joint Position Statement

Center for Excellence in Supported Decision Making

A Program of VOA MN, funded by Administration for Community Living, in partnership with LSS MN, DHS, MN Elder Justice Center

* Assessments * Phone Consultation * Surrogate Decision Maker Support * Facilitation of Supported and Surrogate Decision Making Legal Tools

952-945-4174  1-844-333-1748 toll free

CESDM@voamn.org
Thank you!

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952-945-4172
Where to find help now

- **Person Centered Thinking 2-day Trainings**

- **Person Centered Practices Webpage**

- **Olmstead Plan Webpage**

- **Bulletins**
  - [http://www.dhs.state.mn.us/main/id_000305](http://www.dhs.state.mn.us/main/id_000305)

- **Lead Agency Review Website**
  - [http://www.minnesotahcbs.info/](http://www.minnesotahcbs.info/)

- **E-List Announcements**
  - [http://www.dhs.state.mn.us/main/id_000677#](http://www.dhs.state.mn.us/main/id_000677#)

- **CBSM Main Page**
  - [http://www.dhs.state.mn.us/main/id_000402](http://www.dhs.state.mn.us/main/id_000402)

Questions: Use Q&A Panel and send to "All Panelists"
Please take a moment to let us know your thoughts.

• Take our Survey:

http://surveys.dhs.state.mn.us/snapwebhost/s.asp?k=148527822045
Audio from today’s session will be available beginning tomorrow morning by dialing:

855-859-2056
Conference ID:
51654321

If you have questions following the session, email to DSD.responsecenter@state.mn.us