

HONORING CHOICES:

Balancing Rights, Self-Determination and Risk

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State of Wisconsin

Board on Aging & Long Term Care

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Living a Self-Determined Life

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Program Objectives



1. Participants will discuss individual choices that have aspects of risk, identifying approaches that are empowering, that consider "point of view," and that mitigate risk.
2. Participants will be challenged to consider alternatives to traditional and sometimes paternalistic ways of thinking about quality of life and choice.
3. Participants will explore how collaboration between individuals, decision-makers, staff and external resources can effectively facilitate self-determination and honor choice.

State of Wisconsin Board on Aging and Long Term Care

Long Term Care Ombudsman Program/Helpline

1-800-815-0015

Medigap Helpline

1-800-242-1060

Medicare Part D Helpline

1-855-677-2783



Ombudsman Program Authorization

- ▶ Congressional authorization through the Older Americans Act, providing for unrestricted access to persons eligible for Ombudsman services.
- ▶ Additionally, provides unrestricted access of Ombudsman to clients “at any time and without notice.”
- ▶ Independent advocate for clients in resolving concerns relating to providers, individuals, regulators or other parties.

Source: 45 CFR 1324 & § 16.009(4)(a), Wis. Stats.

Role of the Ombudsman

- ▶ Focus on the rights of long-term care consumers, to assure quality of life and quality of care. Emphasis on the right to self-determination. In WI, clients are persons over age 60, residing in licensed LTC communities, members of or participants in WI managed long-term care and self-directed supports programs (Family Care, PACE, Partnership or IRIS).
- ▶ Investigate and resolve complaints of rights violations, inadequate care and services, issues related to access to supports and services.
- ▶ Resolution of issues, striving toward positive outcomes for the client who is always and only the resident, tenant and/or member/participant. "Client" is never the provider, family member, MCO, ICA, etc.

Top 10 Reasons to Call an Ombudsman

- Substitute decision-makers “protect” beyond boundaries
- Other individuals attempt to deny rights, disrespect rights
- Client wishes to decline specific care and treatment
- Others disrupt client care and/or well-being
- Clients and/or others remain dissatisfied
- Issues related to involuntary discharge, program disenrollment
- Client wants to live somewhere else
- MCO wants to move client due to care, rate dispute
- Residents wish to engage in sexual relationships
- Persons are unsure of who to call about their long-term care services



Relevant R's to Balancing Choice & Risk – For Individuals

Recognize (rights of others impacted by the choice, expectations, point of view)

Request (information about expectations, concerns large or small, how success will be measured)

Respond (listen and share respectfully, consider point of view, respectfully debate for balanced decision-making)

Resolve (collaborate on a resolution, be open to reasonable alternatives, consider point of view about risk)

Resource (know who or what else may be available to achieve resolution, don't be afraid to reach out – call an ombudsman)

Reflect (check back – more than once - to make sure the resolution is the right one)

Record (write it down, record it: document care conferences, conversations, reflections and expressions)



Relevant R's to Balancing Choice & Risk – For Facilitators

Recognize (rights of this person and others, expectations, point of view)

Request (information about satisfaction & expectations, concerns large or small)

Respond (listen more than talk, be objective and respectful, consider point of view, inform for balanced decision-making)

Resolve (collaborate on a resolution, explore reasonable alternatives, consider dignity of risk of all aspects of choice)

Resource (know who or what else may be available to achieve resolution, don't be afraid to reach out – call an ombudsman)

Reflect (check back – more than once - to make sure the resolution is the right one)

Record (write it down: document care conferences, conversations, client reflections and expressions)



What is a Right?

“A right is not what someone gives you.
A right is what no one can take from you.”

Ramsey Clark
US Attorney General 1961-1968

Dignity & Respect

Privacy

Grievances


Access

Transfers & Discharges

Self-Determination, Choice



What's your most
valued right?



What if you lost that right; if the right was removed by another without your input?

What do you think you would you do to try to get that right restored?



Rights...

- Are the foundation for all of “our” work, but also the foundation for all of life’s choices, regardless of who you are or where you live.
- Are guaranteed by state and federal laws
- Direct that everyone – staff, families, volunteers, visitors – are required to respect, protect and promote an individual’s rights.
- Guarantee that every person has the right to exercise all of her or his rights free from interference, coercion, discrimination or retaliation.

The foundation of Resident Rights states that each person has the right to be treated as an individual, with courtesy, respect and dignity at all times and under all circumstances.



Point of View

Point of view is essential to building relationships, collaborating, communicating and getting along with others, understanding where we “fit.”


Point of view is derived from life experience, culture, influences, education, social inclusion, defines a person’s values and opinions, and is the lens through which a person views the world.

Recognizing and respecting point of view is essential when striving to meet expectations, resolving complaints and collaborating on choices.




Point of View

- Client point of view
- Family/significant other/decision-maker point of view
- Provider, contractor point of view
- Community/Corporate point of view
- Regulatory point of view




Balance Rights, Protections & Choice

- Recognize individual life history, life choices, expectations for the present and the future (point of view)
- Create success and resolve challenges by emphasizing strengths vs. threats of losses
- Encourage change and harmony by consensus, mediation, conciliation vs. by order or “house rule”



Balance Rights, Protections & Choice

- ➔ Conclusion: Success is best insured by building relationships and trust vs. by mandates, threats or “house rules”



Balance Rights, Protections & Choice

The right to make decisions is not contingent upon the quality of decisions made, the process by which they are made, or the ways in which decisions are communicated.

Some of the toughest choices are those in which the individual decides to choose freedom over safety. Appropriately negotiated risk can accomplish both.

DOCUMENTATION TOOL
HONORING RESIDENT CHOICE AND MITIGATING RISK

Resident Name _____ Date(s) _____

| I. IDENTIFY AND CLARIFY THE RESIDENT'S CHOICE | | Date/Initial |
|---------------------------------------------------------------------------|--|--------------|
| What is the resident's preference that is of concern? | | |
| Why is this important to the resident? | | |
| What is the safety/risk concern? | | |
| Who was involved in these discussions | | |
| II. DISCUSS THE CHOICE AND OPTIONS WITH THE RESIDENT | | |
| What are the potential benefits to honoring the resident's choice? | | |
| What are the potential risks to honoring the resident's choice? | | |
| What alternatives or "compromises" were discussed as alternative options? | | |
| What education about the potential consequences of the choice alternative | | |

Adapted by Karen Schoeneman from "A Process for Care Planning for Resident Choice," Rothschild Person-Centered Care Planning Task Force February 2015

Medical Model Approach vs. Person-Directed, Person-Centered Approach

- Medical Model: Approach based on mitigating negative outcomes related to “problems,” losses. Focus can appear to be problem or incident-based. Mistakes are made by assuming that persons are satisfied until or unless they complain, which leads to the first break in trust.
- Person-Directed, Person-Centered Model: Approach based on the “whole person,” self-determination, planning based on acceptance of risk based on life history, mutual goals for satisfaction, supports. Focus on quality of life as determined by the individual vs. by systems. Success is enhanced by strong, proactive communication and planning.



Medical Model Perspectives

- Person may be viewed as a diagnosis, problem list, care card assignment. Little or no consideration for point of view, importance of relationship, with focus on provision of “care.”
- Strengths may be missed that could be effective in overcoming or mitigating undesirable outcomes, or that could help influence decisions that meet both clinical outcomes and client desires.
- Decisions or directives by others may be made in the interest of best medical practice, cost-effectiveness, and may be in conflict with decisions or directives made by the client in consideration for lifestyle, life history, life expectations. Concerns rise to complaints.
- Client may feel diminished, de-valued, at worst may engage in “fight or flight” behavior to cope. Complaints rise to crises.



Person-Directed, Person-Centered Perspectives

- Client viewed as the whole person, who she or he was, contrasting and blending with who she or he is, point of view strongly considered.
- Approaches build on strengths and are used to promote satisfaction, overcome challenges, make decisions, respect decisions and personhood.
- Rights related to self-determination are honored and upheld, outcomes are planned for as choices vs. responded to as complaints or crises.
- Client feels validated, empowered, respected, supported, and enjoys a high degree of trust and collaboration with care partners.



Rights vs. Risk Examples

- Client(s) wish to engage in a sexual relationship
- Client wishes to control her own alcohol use, keep alcohol in her room
- Client wishes to smoke marijuana in the long-term care community, wishes to consume marijuana-laced food products
- Client's family wishes to decorate client's room with antique weapons
- Client wishes to smoke, even though community is non-smoking
- Client wishes to smoke, against doctor's advice and orders
- Client wishes to obtain scooter for mobility when team wants him to use a walker in order to maintain mobility skills

Guidelines in determining ability to consent to intimacy

- The person understands the distinctively sexual nature of the conduct...the acts have a special status as “sexual”.
- The person understands that their body is private and that they have the right to refuse.
- The person understands there may be health risks associated with the sexual act.
- The person understands there may be negative societal response to the conduct.

Ability to consent is very complex and has basis in case law. This is a brief overview. A more detailed handout is available from the Ombudsman Program at <http://longtermcare.wi.gov>.

Risks and Benefits

Using your “R’s,” discuss lifestyle and alcohol preferences, history.

➤ NIAAA* recommends alcohol consumption for adults 65+:

1 standard drink/day or 7 standard drinks per week, not to exceed more than 3 drinks on one occasion.

➤ Risks

Falls

Drug: Alcohol interactions

Depression

High Blood Pressure

Behaviors

➤ Benefits

Quality of life perceptions related to “home”

Stimulate appetite

Support healthy lifestyle/social choices

Source: <https://www.niaaa.nih.gov/alcohol-health/special-populations-co.../older-adults>



Rights Issues Related to Decision-Makers

- Attempts to restrict or ban preferred foods, control hours of sleep and activity, how money is spent
- Attempts to restrict or ban intimate and/or sexual relationships regardless of the client's assessed ability to consent
- Threats of further restrictions, denial of choice, associations



Rights Issues Related to Decision-Makers

- Attempts to restrict or ban visits, social participation, religious or cultural participation
- Attempts to influence the use of prescribed medications to manage pain or emotional distress in favor of alternative medicine approaches
- Attempts to control end-of-life decisions contrary to the wishes of the client



POA's and Guardians

- Health Care POA's make health care decisions only, and agree to serve according to the desires of the principal (individual).
- Guardians make decisions in the best interest of the ward (individual), but must still also consider the ward's personal preferences and desires.
- A guardian must promote the greatest possible integration of the individual into her or his community.



Rights & Surrogate Decision-Makers

- POA Health Care Agents clearly have a legal obligation to do what the principal would do or wants
- Guardians are charged with making “best interest” decisions, but the statutes specifically direct the guardian to consider what the ward wants
- Absent a Guardianship or Activated Health Care Power of Attorney, family or others have no authority to dictate care and treatment

One More Thing about Rights & Surrogate Decision-Makers

- Clients have rights
- Decision-makers, care providers, MCOs and ICAs have responsibilities
- All must respect and protect rights
- “Nothing about me without me:” the client always has a voice that must be heard above all others



About Self-Determination

- Self-determination and surrogate decision-making should not be either/or, but should work in collaboration to preserve and respect the individual's autonomy.
- All persons have fundamental rights that only a judge can remove.
- Substitute decision-makers must be aware of the rights and preferences of the individual, and must know the parameters of their roles. Providers must insure that rights are respected, including by substitute decision-makers.

Older Adults and Self-Determination

- Older adults in institutional care seem to defer many decisions, and sometimes even expressions of self-determination relative to quality of life and end-of-life care, to an adult child, trusted friend, caregiving staff.
- Some that do attempt to actively self-determine are sometimes labeled as “challenging,” “unrealistic,” or “lacking insight,” particularly in facilities or within MCO/health care structures that have a medical model or paternalistic view of their roles to “protect.”



Negotiating Risk


A request or choice should not be denied simply because risk exists.

Ask:

- Has everything possible been considered?
- What reasonable steps can be taken to prevent foreseeable harm?
- Has there been a comprehensive assessment and notation of conditions that could lead to risk, as well as things that motivate toward choices of less risk?

Collaborative Communication



- Brainstorm ways of eliminating the risk or minimizing the harm related to risk.
 - Consider not only the “hard” costs, but also the costs to the individual in terms of choices and rights, values, ability to learn.
 - The rights of the individual have precedence over the values or comfort levels of others.
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Collaborative Communication



- Create options that balance both safety and individual rights.
- Negotiate short term opportunities as opposed to denying the entire choice.
- Always consider the principle of “least restrictive,” but remember that least restrictive may depend on point of view.

Final Thoughts on Negotiating Risk

- Don't give up on a person's expressed preference because the individual declines to comply with a process or a service. This can feel like retaliation for making a different choice and breaks trust.
- Start small, move slow, if that's all that can be done in the moment.
- Provide and ask for feedback often.

Final Thoughts on Negotiating Risk

- Ask whether the risk exists because of the behavior of the individual, or because the appropriate and empowering supports and services are not created, or because current supports are inflexible or created to minimize systems risk vs. actual personal risk.
- Reflect, re-visit, re-try, re-negotiate.



Why Risks Fail

- Complacency
- False buy-in, unrealistic goals, incomplete planning and execution
- Stakeholders (client, decision-makers, family, staff, MD's) fail to recognize and act on unintended consequences of the decision
- New risk factors emerge due to changes in the client's condition or status
- Stakeholders fail to do a root cause analysis of the now emergent issues
- Stakeholders fail to take measures to appropriately modify the decision




For providers: Questions to Ask



- How do staff know what a client wants or expects?
- How do staff respond when a client's wishes conflict with those of family members, other clients or regulations?
- How do staff know, on a day to day basis, if a client's wishes are being honored?
- How are changes in a client's status or wishes noted, assessed, care planned and honored?
- What knowledge and support do staff need to provide for every step of meeting a client's wishes and supporting choices?

Benefits to Balance

- Ensures the most basic of rights: to be treated with dignity and respect
- Trust, mutual respect
- Increased interest in participation, communication, self-advocacy. *Informed decision-making.*
- Empowerment, recognition and acceptance of risk, associated benefits and consequences. *Exercise self-determination.*
- Increased satisfaction with relationships that are also partnerships: *This is my home. This is my home.*
- **Best** care, not just better care



“You have to know who I was in order to understand who I am. I am not a disease, a diagnosis. I’ve lived my life making choices, not always good ones, but they were mine. I intend to continue to do so until the day I leave this earth.”

From an older adult, newly-diagnosed with a potentially life-threatening chronic disease, to his physician.



Credits

Credit information about Negotiated Risk to:

- Ann M. Pooler, RN, PhD
- Roy Froemming WI DHFS discussion paper on "Liability Issues in Self-Directed Supports," December 1999.
- Barbara Bowers Quality in WI Partnership Program, 1996, p .21
- "A Process for Care Planning for Resident Choice," Rothschild Person-Centered Care Planning Task Force February 2015

Resources

■ **Board on Aging & Long Term Care**

Advocacy agency for LTC consumers age 60 and older

1-800-815-0015/longtermcare.wi.gov

Medigap Helpline 1-800-242-1060 for questions about LTC insurance, Medicare Advantage and Supplement plans, Medicaid

Medicare Part D Helpline 1-855-677-2783 for questions about Plan-Finder, Med Part D choices

■ **Disability Rights Wisconsin**

Protection & advocacy agency for persons with disabilities, ages 18 – 59

1-800-928-8778/disabilityrightswi.org

■ **Division of Quality Assurance (DQA)**

Regulation and licensing agency for WI LTC facilities

608-266-8481

■ **State of WI Department of Health Services (DHS)**

Website for information about long term care services, ADRC's, Family Care/COP/IRIS, reporting abuse and neglect, licensing, requirements

www.dhs.wisconsin.gov



Resources



WCCEAL

Wisconsin Coalition for Collaborative Excellence in Assisted Living



Alzheimer's Association

Resources for persons diagnosed with dementia and their families and communities, 24-hour helpline/care consultation, connection to local resources

1-800-272-3900/www.alz.org



SAGE

Services and advocacy for gay, lesbian, bisexual and transgender elders

www.sageusa.org