# CONSUMER SAFETY, RISK AND RISK-TAKING:

# A GUIDE FOR COMMUNITY LONG-TERM CARE

*In 1996 Wisconsin's Department of Health and Family Services began an ambitious project of redesigning its long-term care system for frail elders and people with disabilities. The result is a capitated managed care program called Family Care, which combines Medicaid card and home and community based waiver-funded services into one flexible benefit package that includes long-term care (including nursing homes) but excludes acute and primary health care. Family Care is currently being piloted through contracts with five counties serving as Family Care "care management organizations" (CMOs)—Fond du Lac, La Crosse, Portage, Richland, and Milwaukee County Department on Aging. For more information see www.dhfs.state.wi.us/LTCare.*

This is a guide for case managers and other professionals dealing with consumers' choices to take risks. This document was developed with the Family Care case management workgroup, with help from advocacy lawyer Roy Froemming, Adult Protective Services (APS) expert Jane Raymond of the WI Department of Health and Family Services (DHFS), staff of the Bureau of Developmental Disabilities Services and the Bureau of Aging and Long Term Care Resources, and numerous case managers and APS workers throughout Wisconsin. It is meant to articulate the process by which community services experts negotiate the conflict between ensuring health and safety and respecting "the dignity of risk," i.e., consumers' rights to refuse services or to engage in risky behaviors, for the following purposes:

- To clarify the expectations of community-based consumer-focused services in which agencies do not have full control over consumers' choices –particularly in the context of managed care
- To provide a standardized process that allows for individualized focus but guides staff to prevent oversights or other mistakes
- To facilitate discussions among all parties (consumers, professionals, guardians, advocates) and to help clarify expectations, responsibilities, and consequences
- To reduce staff "burn out" by providing more constructive ways of perceiving and dealing with behavioral issues including substance abuse and non-adherence to professionals' advice (i.e., "noncompliance")
- To train new case managers and nursing staff
- For retrospective quality improvement reviews after significant harms have occurred ("Did we follow this process, and if not, where not?")

Feedback on this guideline is welcome and may be sent to:

Ann M. Pooler, RN, PhD
Center for Excellence in Long-Term Care
UW-Madison School of Nursing
H6/ 154 Clinical Science Center
Madison, WI 53792-2455
Ph. 608-263-5195 Fax 608-263-5332
ampooler@facstaff.wisc.edu

# CONSUMER SAFETY, RISK AND RISK-TAKING: A GUIDE FOR COMMUNITY LONG-TERM CARE

*This guide can be used by any provider. The discussion on this introductory page retains references to Family Care CMOs because their very narrow disenrollment criteria make them ideal laboratories for negotiating consumer self-determination and risk-taking with elders and adults with physical disabilities, developmental disabilities, and/or mental illness or substance use problems.*

Family Care presents new challenges for CMOs dealing with consumers who choose to take risks and/or resist needed services. On the one hand, federal laws require that CMOs ensure the health and safety of their consumers. On the other hand, CMOs must respect consumers' right to refuse some services, to take risks, and to live in accordance with other values besides optimal health and safety. In addition, Family Care CMOs cannot disenroll a consumer for any reason except physical assault—no matter how much the consumer rejects recommendations by CMO staff. The following are key points to consider:

- As important as the question, "Did the provider make the right decision about the risk?" is the equally important question, "Did the provider do everything it should have to respond to the situation?"

- "Courts recognize that an assessment or choice or action can be professionally acceptable and can also turn out to be wrong or to have harmful results….Courts have recognized that providers' liability is not whether a risk-taking resulted in harm so much as whether the provider followed an accepted standard of care and took "**reasonable steps to prevent foreseeable harm**." [1]

- "Professionally acceptable" means meeting "standards of care defined as the degree of care and skill exercised by an average provider of similar services." [2]

- If the "similar services" are programs that value self-direction (i.e., consumer preferences and liberty rights), then the "standards of practice" applied must do the same.[3]

- The "standards of practice" do include **comprehensive assessments** and **noticing** conditions that could lead to risk. It is extremely important to note that Family Care's emphasis on consumer choice only increases providers' responsibility to notice risk factors.

- The reasonableness of "reasonable steps to prevent foreseeable harm" can be determined only with consideration of all these factors:
  - The person's decisional capacity--the ability to make decisions in accord with her/his own values
  - The nature of the harm that might result
  - The level of risk, or likelihood that the harm will occur
  - The person's acceptance of suggested steps

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[1] Roy Froemming, WI DHFS discussion paper on "Liability Issues in Self-Directed Supports," December 1999.

[2] *ibid*.

[3] Consumers define quality care as an adaptation of professional standards to the individual--not an imposition of same upon them: "Providers cannot rely on generic provider standards and assumptions. The providers' ability to [not] do this is confounded by the frequent belief that standards of practice, safety concerns, or what the proxy decision maker considers sensible are acceptable substitutes for personal/biographical sensitivity" (Barbara Bowers, Quality in WI Partnership Program, 1996, p. 21). "A focus on safety, a lack of provider awareness about the general impact of medical regimens and side effects, and the fear of litigation act in concert to keep the providers' gaze away from the relationship between managing an illness and managing a life. **For all of the consumers interviewed, life was infused with a constant balance between following useful treatment plans and having a meaningful life**" (*ibid,* p.81, emphasis added).

# PART 1: RISK REDUCTION

## Step 1—Notice and Assess the Risk

***Do a <u>full</u> assessment and <u>notice</u> elements that create risk.***

**A. Identify and assess the risk:**

**What harm may result?**

*Non-adherence to professionals' recommendations is not in itself a risk; professionals must identify actual harms that could result.*

**How serious is it?**

**How likely is it to result?**

**B. What is the source of the risk?**

**1. Is it abuse or neglect by others?** If yes, go to "Guidelines on Abuse and Neglect."

**2. Is it a provider's responsibility?**

- If yes, contact provider for correction (with consumer's permission as needed). Follow up with quality improvement or other channels of feedback including reporting provider to authorities if appropriate.
- If no, continue.

*Inadequate services are not –cannot be excused as-- "consumer's choice."*

*Providers have legal and ethical responsibilities to avoid negligence and to uphold contractual obligations of services and products.*

**2. Is there any harm to other persons involved? How serious and how likely is that harm?**

Identify risk of harm to others, and to respond according to the probability of harm and severity of the possible harms, and vulnerability of likely victims (such as children or vulnerable adults).

*Personal liberties are far more restricted when there is risk of harm to others not just to oneself. Government agencies and providers have special obligations to prevent risk of harm to others, even if the consumer is competent and objects. After that harm is eliminated, though, the general process outlined here could still be followed to compensate for losses of liberties.*

When working with people with severe cognitive impairments, our responsibility is to figure out what their potentially harmful behavior is communicating, and to do what we can to avoid stimulating the behavior (to reduce harm to others) while maximizing the person's liberties.

**Other people's comfort levels do not justify discrimination based on disability.** (Example: Persons with frequent seizures or other evidence of a medical condition or disability should not be denied access to public spaces for that reason alone.)

# Step 2 -- Understand the Consumer's Choice

*"Decisional capacity" is a more complex concept than legal competence. It is a person's **ability** to make a choice on a **particular** matter that fits her/his overall values. (Decisional capacity is thus context-specific.) Even persons labeled legally incompetent may have decisional capacity on particular matters.*

**A. Does consumer have "DECISIONAL CAPACITY"?**[4]

→ **If no: Is consumer under court orders for guardianship, protective placement or services, or commitment for severe and treatable mental illness?**

⇒ **If yes, substitute decision-maker has responsibility for ensuring health and safety on behalf of consumer.** Continue with below to explore substitute decision-maker's reasons for the choice and to negotiate and problem-solve as needed to balance the consumer's liberties and preferences against risk of harm.

⇒ **If no, does consumer appear to have cognitive impairment (for any reason, including mental illness or substance dependency ) that is putting them at immanent risk of harm?**

→ If yes, assess for causes and procure treatment of cognitive impairments. Ensure consumer's safety and refer for APS or court orders (e.g.,Chapter 51 or 55).

→ If no, continue.

*Sometimes cognitive impairment can result from acute problems such as dehydration, electrolyte imbalances, or medications or drugs. These should be assessed and treated to improve cognitive functioning.*

→ **If yes, consumer has decisional capacity:**
**Is consumer under court orders for guardianship, protective placement or services, or commitment for mental illness?**

⇒ **If yes: Consider whether the consumer's liberties are being unnecessarily restricted.**

Consider whether the court orders should be amended to allow consumer the right to make this type of choice, since s/he has decisional capacity for it. Continue with the process outlined below, and negotiate with guardian with the goal of preserving consumer's liberties and preferences. Court intervention may be necessary to **reduce** the level of restrictiveness, e.g., changing a protective order to allow the person to choose services, or limiting a guardianship to make clear that the person makes their own decision about, e.g., choice of residence, mobility, or freedom of association.

⇒ **If no, continue.**

[4] Examples: An adult with developmental disability may have a guardian but should be allowed to make whatever choices s/he can, e.g., to choose friends, leisure activities, clothes and routines. An old woman may not correctly name the president or month, but her desire to stay in her beloved home of 40 years is longstanding and reflective of her past values and should not be ignored just because she is legally incompetent.

**B. What are the consumer's (or substitute decision-maker's) reasons for this choice?**

**1. What values or outcomes is the consumer trying to preserve or get?**

**Keep asking "Why?**" You need to understand the **reasons** for their choice and the **details** -- in order to **problem-solve** and to have something to **negotiate** with them.

**2. Does the risk relate to the consumer's support needs, or is a risk typically taken by people in our society—such that the consumer has a right to take the risk as the rest of us do?**

This includes the right to try things and make mistakes.
It also includes the right to **practice** decision-making to develop that as a life skill. provider staff should help the consumer practice this skill and can do so as part of this process.

**3. What are the emotional reasons that might be at play?**

Self-harming behavior is commonly a manifestation of despair, self-hate, depression, anger, unresolved grief, or post-traumatic stress syndrome. Apathy about risk may reflect similar feelings and losses— loss of meaning, of key relationships, loss of feeling valued or having control in one's life. Perceiving and addressing such issues are the heart of best practice and are intrinsic to the process outlined here.

Follow the "Motivating Change" guidelines in Part 2 in addition to (not instead of) continuing with the "Risk Reduction" steps here.

**C. Is this choice fully informed?**

**1. Does consumer understand the nature and likelihood of the harm that may result from the choice?**

**2. Does consumer fully understand the options that could be made available?**

Explain it in terms s/he can understand. Adjust your communication. Try using the same words and expressions the consumer tends to use. Let different people try.

The problem may be that they don't trust you in general, or that they think you're wrong or exaggerating. Find out and adjust your approach as necessary.

Explore alternatives such as trying some options on a trial basis, talking with others with similar experiences, or visiting people with alternative forms of support.

**D. Is it a truly voluntary choice, or is there some kind of coercion?**

If there is significant coercion by others, consider use of separate guidelines on abuse and neglect.

## Step 3: Explore Options, Weigh Benefits and Costs

With consumer's permission, involve anyone who might have ideas (direct care workers, friends, neighbors, etc.)[5] Be creative, focus on the individual's outcomes, not on services and system norms.

**A. What are the possible ways of eliminating the risk or minimizing the harm?**
This could be a "brainstorming" session in which together you list all possible options.

**B. What are the benefits and costs of those options? What are the costs to the consumer in terms of her/his liberties, values, preferences, and learning opportunities?**

This step is a "cost-benefit" analysis, but the important costs to be considered are costs to the consumer, not cost in resources.[6] A person's liberties cannot be restricted without justification based on health and safety.

This focused analysis will clarify **values conflicts** among interested parties. The consumer's human liberties have precedence over other people's values or comfort level. The analysis **must** incorporate the consumer's perspective; it is not something for professionals to weigh from their perspective alone.

**C. Try to find or create options that best balance safety and the consumer's liberties and values.**

Do cooperative problem-solving around the details you have discovered together in this process.

## STEP 4: Negotiate

Negotiations center on balancing risk and safety with the consumer's liberties, values and desired outcomes. Reconsumer it is costs to the consumer, not to other people's comfort level or values.[7] (See discussion below on referral to ethics committee.) When a guardian is involved, the consumer's liberties and preferences should be set as the goal for negotiations (not just the guardian's wishes). Negotiation may include making compromises and trying different things until something works; it may include making "deals" (informal contracts) with the consumer.

**A. Compensate for losses in liberty.**

**B. Negotiate for short-term alternatives.**
This may include verbal or written informal "contracts" with the consumer.

[5] Or, seek advice from others without violating confidentiality.
[6] This guide focuses on balancing risk and safety with consumer rights and preferences. The Family Care "resource allocation decision method" can be used to seek the most cost-effective way to meet individual outcomes, but those outcomes always include the person's liberties and desired outcomes. Put differently, restricting a person's liberties can be justified by health and safety considerations but not by provider costs.
[7] The thought process here bears repeating: We must counter our paternalist desire to keep consumers safe with the legal and ethical mandates to preserve consumers' personal autonomy, that is to say, consumers' right to make choices that make us uncomfortable and that fail to match professional—particularly medical or nursing—standards of practice. Within that context, providers must take reasonable steps to prevent foreseeable harm.

**C. Always consider principle of "least restrictive environment" and consumers' right to freedom from unnecessary physical or chemical restraint.**

1. Consider alternate strategies to accommodate consumer's choices and behaviors
2. Provide training and follow-up for all persons involved
3. Regularly review for need for help in decision-making and opportunities to practice
4. If restrictive safety measures are required, the following must be addressed and documented:
   - Plan for reducing or eliminating restrictive measures, with timeline
   - Informed consent is obtained when restrictive measures are applied
   - Schedule and process for regular reassessments and alternatives on on-going basis

**D. Stay involved: Repeat all 4 steps of this process as needed over time.**
Don't give up on someone because they're refusing some services or not "complying" with your service plan. Supplement this Risk Reduction process with the "Motivating Change" guidelines.

**If negative results do occur as a result of a consumer choosing to take risk, it is very important for the agency to make time to help staff deal with emotions of anger, guilt, self-doubt, and grief.**

## DOCUMENT THROUGHOUT

Documentation is critical to show that the provider was not negligent in noticing or responding to elements of risk. Documentation should include the following:

- Nature, severity, and likelihood of the harm that may result
- Source(s) of the risk
- Brief statement about person's decisional capacity, follow-up if person seems to lack decisional capacity, or assistance person needs to develop decision-making abilities
- Person's understanding of the risk and her/his reasons for making this choice. Include the consumer's own words. In case of substitute decision-makers, document their reasons.
- Key options explored with summary of cost-benefit analyses (costs to consumer's liberties and preferences)
- What was done to minimize risk, especially concerning providers' responsibilities
- Consultations or advice you sought from experts
- On-going follow-up

## "HARM REDUCTION" AND LIMIT-SETTING

This "Risk Reduction" process does incorporate the "harm-reduction" approach to alcohol and other drug abuse (AODA). The harm reduction approach to AODA can be used with people for whom traditional AODA approaches of confrontation, diagnosis, and abstinence do not work. In the harm reduction approach, abstinence can be suggested but is not the only goal. Even if the consumer continues to misuse substances, the harm reduction approach creates a "middle ground" for staff to have some successes with minimizing the harm and costs. The "Risk Reduction" steps in Part 1 should be supplemented by the "Motivating Change" guidelines in Part 2. Both parts can be applied to AODA and to any other risk-taking choices that consumers make.

**Repeated** negotiations for harm reduction should occur at least several times (and may go on for years in community settings). The suggestions for harm reduction should always reflect a balance of liberty rights with the extent, likelihood, and immediacy of harm. The harm-reducing suggestions can entail **a step-wise progression of interventions** that involve more restrictions to the consumer's liberties. This step-wise series of interventions allows the provider to recommend more restrictive settings to ensure

the consumer's health and safety. For example, after numerous attempts at negotiating harm reduction, provider staff might recommend that a consumer move to a CBRF or nursing home where abstinence can be imposed. The step-wise progression of interventions can function as **limits** set well in advance to help the consumer to make **responsible** choices to preserve her/his liberties. The step-wise interventions of suggesting more restrictive residential settings to ensure consumer's safety will be the basic "limit-setting" in the PROVIDER.

Some traditional AODA treatments hold that the individuals must be allowed to "hit bottom," to suffer the consequences of their behavior to stimulate self-motivation for change. But because PROVIDERs are mandated to ensure consumer health and safety, they cannot withhold assistance needed due to consumer's relapses or "non-compliance." Nor can CMOs counsel consumers to disenroll. CMO staff can honestly discuss resource limitations (such as staff time) as part of the negotiation process of Step 4. While some limits can and should be set, and consumers should be encouraged to take responsibility for their own health and safety, demanding that they do so is usually not as effective as following both Parts 1 and 2 of this guideline.

## REFERRAL TO ETHICS COMMITTEE

Dealing with risk is an intrinsic part of daily case management practice, especially in community settings. The decisional body of the CMO is the interdisciplinary team that includes the consumer and those who know the person best. Ethics committees can no more solve every risk situation than they can decide every resource allocation decision. Ethics committees can be valuable resources if a team feels "stuck" or if someone– the consumer, family or advocate, or staff—feels upset or confused with the way risk was or is being addressed. Ethics committees can be especially helpful in clarifying the values conflicts at play, and in presenting recent literature on decisional capacity, levels of competence, and risk negotiation.

# PART 2: MOTIVATING CHANGE [8]

*This section provides some approaches that have proven helpful in working with people who continue to make harmful choices. It focuses on helping people develop the self-motivation to change.* ***The process outlined below assumes that Part 1 "Risk Reduction" Steps have been followed.*** *"Negotiated Risk Agreements" may be done at any time as well.*

Research has shown that in making behavioral changes (including abstinence from addictive substances) people go through six "stages of change." The stages are Pre-Contemplation, Contemplation, Determination, Action, Maintenance, and Relapse. The Stages of Change are cyclical or spiral, not linear--meaning that people cycle through them usually several or many times before making permanent change.

The basic approach is to adapt your interventions to where the consumer is in the cycle of change. While you cannot control someone's behaviors, you can assess which stage of change they're at and help them move to the next stage. Some of the helpful interactions described here can be done in just 5 or 10 minutes and can be taught to anyone who works with consumers.

**For all stages: Express <u>empathy</u> and <u>respect</u>. Avoid being judgmental.**
**Reinforce consumer's strengths and successes.**
**Acknowledge how hard it is to change.**

## 1. PRE-CONTEMPLATION STAGE: Consumer does not recognize problem

a. If it's because of **lack of information**, go back to Step 1 of Part 1 "Risk Reduction" guidelines.

b. If it's because **consumer is content with the present:**
Explore positive aspects of current behavior
Explore less positive (negative) aspects of current behavior
Explore consumer's long-term goals
Prompt the consumer to compare present behavior with goals

c. If it's due to **low self-confidence** regarding ability to make this change (i.e., "self-efficacy"):
Explore earlier failed attempt to change
Reframe past experiences to focus on strengths, survival
Explore other sources of low self-efficacy
Explore ways to boost self-efficacy and to treat causes of low self-efficacy

## 2. CONTEMPLATION STAGE: Consumer is beginning to recognize problem

Same as for Pre-Contemplation Stage.

## 3. DETERMINATION STAGE: Consumer has decided to change

(a) Explore what's worked in the past
(b) Explore things that "trigger" the behavior: internal (feelings, moods, thoughts (especially negative self-talk) or external (friends, places, time of day, week, month or year)
(c) Explore the consumer's ideas for strategies to cope with triggers and to replace the benefits of the behavior.

[8] This section adapted by Ann Pooler from Stephen Rollnick and William R. Miller, "What is Motivational Interviewing?" *Behavioural and Cognitive Psychotherapy*, 23, 324-334 (1995), and Insoo Kim Berg & Scott D. Miller, <u>Working With the Problem Drinker: A Solution-Focused Approach</u> (1992).

*You might need to make suggestions, but present them as a "menu" of options from which consumer can choose. Options might include self-rewards, social supports, change of environment, etc.*

(d) Goals must be **positive**, i.e., stated as the presence of something, not the absence of something. (Anything denied becomes an obsession.)
(e) Goals must be **concrete and specific**, not vague.
(f) With questions and gentle advice help consumer see possible weaknesses in the plan.
(g) Review the plan by reflecting it back and asking if you got it right, thus eliciting consumer's corrections and approval.
(h) If you encounter resistance, back off to steps for Contemplation Stage.
(i) Set a timeline for checking progress and arrange follow up together.

**Throughout: Reinforce benefits of change, bolster self-efficacy, express empathy and respect.**

## 4. ACTION STAGE

(a) Same as Determination Stage
(b) Help person to access resources to implement plans
(c) Identify strategies that are working well and reinforce consumer's efforts
(d) Explore any disadvantages of change: What is missing, and how can it be replaced without resuming the behavior?
(e) Explore the most difficult times, relapses and near-relapses

**Throughout: Reinforce benefits of change, bolster self-efficacy, express empathy and respect.**

## 5. MAINTENANCE STAGE

(a) Ensure that the behavioral change is stable.
(b) Help consumer identify personal goals and relevant plans as consumer desires.

## 6. RELAPSE STAGE

(a) Relapse is **normal** and **common**.[9] Bolster self-efficacy and self-esteem. Avoid judgmentalism.
(b) Reframe relapse as a learning experience: What did you learn, what worked until then, what could work next?

Remember, the stages of change are cyclical, not linear: People move among them numerous times, and relapses are normal. While it is frustrating to watch someone continue to engage in self-harming behaviors, it is important for staff and consumer to keep focusing on successes --however small—and on the smaller steps of moving from one stage of change to the next.

**Exception: "Contracting"**

Sometimes the consumer **cannot find internal motivation** and you **do** set the goals and ask the consumer to "contract" with you—to make promise to you. The "contract" approach sets them up as an active equal party. It also expresses your empathy, respect and concern for them. Contracting relies on the consumers' commitment to you more than to themselves. This kind of contracting is usually used in short-term crisis situations and so is included in Part 1 "Risk Reduction" (Step 4). It might also be done as a "Negotiated Risk Agreement." In the long run you'll want to continue to try to help the consumer find internal motivations to change.

[9] Over 85% of people who quit smoking or drinking relapse--smokers an average of 5 times—before quitting permanently.