

## **WHO'S SAFE? WHO'S SORRY: THE DUTY TO PROTECT THE SAFETY OF HCBS CONSUMERS**

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In Holstein, MB & Mitzen, PB (eds) (2001). Ethics in Community-Based Elder Care New York: Springer Publishing

First, do no harm. This is a major tenet in medical ethics. It is also the first statement of the ethical principle of beneficence, that is, doing good, which holds that ethical professionals act so as to benefit their clientele and, at the least, so as to do no harm.

The laudable goal of doing no harm has been extended to the ideal that the care and service plans developed for home and community-based services (HCBS) for older people be designed to maximize those consumers' physical safety and protection and to minimize the likelihood of preventable negative events, such as falls, injuries, or relapses. The social workers, nurses, and others who hold up safety as a goal may be striving to do no harm. But, such professionals may have lost perspective on the nature of their own agency in helping individuals plan their lives, and they may be assuming too much responsibility for their clients' lives. They may have also lost perspective on the facts, that is, what actually constitutes safety and what actually constitutes risk.

HCBS have sprung up as alternatives to nursing facilities and are popular for the very reason that they offer clientele the care they need in environments that are more homelike and less restrictive than a nursing facility. Older people choose these options and they remain popular alternatives, in part, because of a desire to manage and direct their own care and lives, and in part because of a desire for privacy, continuity, and familiarity in lifestyle. Protecting HCBS clients ultimately may mean declining to serve them in their own homes because the plan seems unsafe. Protecting HCBS clients ultimately may mean reshaping assisted living settings through regulations until they mirror more restrictive settings like nursing homes, or (in a continuation of the impetus that encouraged placement in assisted living settings) declining to retain a person in assisted living because he or she seems to be unsafe without the greater protection of a nursing home. Paradoxically, therefore, the desire to do no harm and hold safety above all may actually result in harm for consumers, at least in the sense of disrupting their lives.

### **DEFINING HARM**

Harm comes in different forms. One type of harm is physical, affecting one's health and physical safety. The jury is by no means out that all efforts now made on behalf of physical safety are justified in their own right. Harm may also be done to psychological well-being, creating anxiety, depression, a sense of being bereft and without hope. Harm may also be done to social well-being, cutting people off from relationships and activities that are valued and creating difficulties for those who wish to form new relationships. Those who argue for safety above all tend to emphasize

physical safety. The very act of constricting freedom and choice for individuals and preventing them from taking risks may create psychological harm. Less subtly, the environments and programs favored because they appear to be safe rarely nourish the spirit, the psyche, or the intellect. In this chapter, we consider the full range of harm that may occur to people needing long-term care, namely physical, psychological, and social harm. We also consider that removing the right to take risks from other human beings may in itself be a harm that should not be lightly undertaken. Two justifications for restricting individual's rights to take risks are sometimes made: 1) without that restriction, harm is likely to come to others; 2) without that restriction people are likely to harm themselves (typically because cognitive impairment or mental illness have rendered them unable to make a judgment). Both justifications can be valid in some instances, but, we argue, are used too readily and with insufficient evidence to restrict people who receive long-term care.

The most exquisitely difficult ethical dilemmas that arise in HCBS concern the proper boundaries between promoting freedom for older people and avoiding interference with their life goals versus acting responsibly to promote the older person's health and safety. These are anguishing dilemmas for professionals. The case files of ethics committees that have sprung up in HCBS are littered with examples wherein professionals wrestle consciously and conscientiously with the problems of striking the right balance between safety and freedom. Often, the professional has the painful sense that he or she is joining the forces pushing unwilling clients towards nursing homes, yet it seems to be for their own good.

These ethical dilemmas are exacerbated by the profound ambivalence that so many people feel about tradeoffs between their freedom and safety. Older people like people of all ages want to be *both* free and safe. Older HCBS consumers, who often are aware of their increased risks and diminished capabilities, can have great difficulty making a forced choice between the two values. In one study of more than 800 elderly HCBS clients, about a third chose freedom, a third chose safety, and a third vacillated indecisively between the two (Degenholtz, Kane, & Kivnick, 1997). Professionals express similar ambivalence. In one such study, care providers, advocates, and public officials showed respondents overwhelmingly agreeing with the proposition that older HCBS clients should be free to act against professional advice regarding risk-taking without the program withdrawing from the scene. When asked to elaborate the circumstances under such client risk-taking would be permissible, almost all responded with a variant on when it does not jeopardize their own safety and those of others (Kane, 1995). Professionals endorsed informed risk-taking, but apparently only when it was risk-free!

In this article, we further dissect the concept of consumer risk-taking and professional responsibility in HCBS. We, then, turn to possible ways for professionals to negotiate these ethical mine-fields, including an exploration of the relatively new concept of *managed risk contracting* or *negotiated risk*. We argue that active steps need to be taken to preserve and promote the right of competent older people to make decisions about their care in general not just narrow decisions about specific procedures. (Currently, it is easier to refuse a recommended amputation than a recommended nursing home placement.) However, some safeguarding procedures

and perhaps even some regulation needs to be in place to govern any contractual mechanisms for risk-taking of older HCBS clients.

### **Rights to Risk-Taking**

One ethics source book defined risk as an adverse future event that is not certain but only probable (Shone-Seifert, 1995). People who are competent decision-makers ordinarily make autonomous decisions about the risks they wish to take based on the magnitude and the likelihood of expected harms and benefits associated with each course of action. There may, of course, be limits to a person's right to take informed risks. Obviously, one should not implicate other third parties in one's risk-taking. For example, the person who wishes to risk smoking around his or her oxygen cannot properly endanger others in a living setting by choosing to incur the risks. The insulin-dependent diabetic who fails to stick to a diet, on the other hand, may injure only herself. Yet, some would argue that this noncompliant individual has no right to repeatedly drive herself into diabetic coma, if, in so doing, she harms others by drawing resources away from them. Without getting into the more abstract arguments about finite resources for health care, we could certainly argue that a person who has a weekly health crisis in an assisted living setting takes valuable and often limited staff time away from others.

Let's assume a consumer's desired risk-taking can cause no harm to others. Let's further assume that the consumer has decided, after thoughtful decision-making, that the benefits of following the risky course of action outweigh the potential harms to the self. They may yet not be free to follow their preferences. Care providers might still argue that they cannot allow people under their care to assume certain risks because they, themselves, would, then, be negligent in their duties. For this reason, home care agencies or HCBS case managers sometimes terminate cases rather than manage them at lower intensity of service than they think proper (Kane and Caplan, 1993). For certain technical procedures, for example, administration of intravenous fluid or treatment of wounds, the consumer has no privilege to waive technical standards of competence for performing the procedures. The provider is not off the hook for negligence because the consumer has consented to, say, reusing a needle. What about the quadriplegic consumer who cannot take his own medicine and prefers to have his housekeeper administer the medications rather eat up the resources for his HCBS plan by expensive visits from a licensed nurse? This may become hotly debated by providers struggling to define the boundaries of their negligence versus the consumer's informed risk-taking. Or, the ethical tension may be, at least temporarily, resolved at a policy level by rules that require certain training to perform certain tasks.

To take another example, regardless of a resident's informed choice, staff of an assisted living program often obsess over whether they would be negligent to retain someone in their setting whose needs seem to exceed the service capability in the setting. Such a dilemma typically involves a risk, not a certainty. The resident *might* fall, and *if* she were to fall at night, the staff would be insufficient to transfer her back to bed. The resident *might* wander out because of insufficient staff supervision and, if so, *might* sustain an injury, which *might* be serious. However, in jurisdictions where assisted living programs are legally required to eject anyone who reaches a certain level of need, the consumer's prerogative to take certain risks has been preempted.

The great variety of prohibitions and permissions that govern licensed HCBS entities suggests that conventional wisdom is in flux and confusion about how much protection should be built in programmatically. We need to build in safeguards to ensure that autonomy not be legislated or regulated out of long-term care altogether. Because the regulation arena for both home care and assisted living is changing rapidly, it is important to ensure that these options remain viable. Individuals with care needs have a strong desire to stay in their own homes. If this is not possible, most will choose to enter the least restrictive long-term care facility possible. This is why assisted living facilities have become a very popular alternative in the United States today. Home care and assisted living are alternatives that frail elders choose knowing that they will not be completely safe, but these are risks they are willing to take in order to retain a certain degree of autonomy. There is the potential in developing rules and regulations that these types of popular alternatives will be regulated away and all that will be left are nursing facilities which are the most regulated types of health care institutions in this country.

Thus, the rights of a consumer to take informed risks are modified by the moral, legal, and regulatory responsibilities of health professionals and care organizations. However, the moral foundation for the legal and regulatory constraints on consumer risk-taking needs constant examination. Professional orthodoxy, risk-aversion, and guild motivations may all conspire to reduce the freedom of the consumers to take changes in the interests of their own goals.

### **Deconstructing Consumer Risk-Taking**

The slogan better safe than sorry covers a wide range of circumstances. A certain amount of deconstruction is needed to parse what is encompassed in the concept of risk. Also useful would be a common language for discussing risks and risk-taking. We argue that the following should be considered in any appraisal of risks to an HCBS consumer:

**Type of risk to be avoided.** As stated above, risks may be physical, psychological, or social, including financial. For the most part, physical risks are the ones that care providers bring to consumers' attention while psychological and social risks tend to be discounted. Even when considering physical risks, we should surely view differently the risk of having a particular health indicator become elevated (which, in turn, is a risk-factor for a health problem) versus the risk of a specific disease or injury. For example, preoccupation with maintaining cholesterol levels in people over 85 with no history of cardiovascular disease may be short-sighted.

In the psychological or social sphere, risks may be more than trivial. For example, some care plans may be accompanied by a high risk of painful depression, loss of role, loneliness, and lack of purpose. Usually, however, care providers are in the business of presenting risks to physical health and safety and rarely would review risks social or psychological risks and advise people, for example, to avoid a nursing home because they seem at high risk for substantial human misery.

What about the risk of death, to some the ultimate harm. Viewing death as the result to be avoided at all times belies the fact that most people receiving HCBS of the intensity where these freedom-protection tradeoffs are likely to surface are often very old and have shortened life expectancies. Perhaps a 99 year old brittle diabetic would

rather taken her chances with a double chocolate brownie once a week. However, chocolate brownie or not, her expectancy for further years of life is limited.

**Severity of risk.** Some risks are severe, even life-threatening, whereas others are relatively trivial. Surely, the severity of the condition or circumstance being risked must be taken into account. For example, taking some risks—for example, crossing a busy, wide intersection alone despite severe macular degeneration and a slow gait carries with it risk of serious injury or death. Insisting on walking to the bathroom alone despite the same circumstances carries a much lesser risk, though for people with some health conditions a fall can begin a serious decline. Being in a bathroom with an internal locking door carries with it the risk that the individual thus protected may be less quick to receive help should they suffer a fall, a heart attack, or a spell of dizziness. It seems quite unlikely that the bow to normal life and privacy occasioned by the locking bathroom door creates an unacceptably severe risk.

**Likelihood of the risk.** Some severe risks are, fortunately, quite unlikely. Perishing in a fire is one such unlikely risk, as is being hit by lightning, though in both cases the consequences of the adverse event are dire. Often, professionals and, for that matter, family members of the older person with the disability, concentrate on the severity of consequences, say, if an older person with some dementia is alone in the home and becomes prey to a dangerous criminal rather than on the likelihood, which is often slight.

**Risks to Others.** What if the risks are to others in the housing setting, community, assisted living building, or nursing home. A risk to others is typically taken more seriously than a chosen risk to the self. The archetypal risks to others are fire (caused by unsafe smoking or unsafe use that concerned with unsafe use of cooking equipment) and driving. Thus, there seems to be a good justification for restricting smoking and cooking to times and places where the individual can be observed and assisted and prohibiting use of an automobile for those whose memories and judgment are impaired. In contrast, using a shower may put the same individual in danger of being scalded or injured but is unlikely to harm others. The important considerations here are the likelihood and severity of the risk, and the possibility of mitigating both the likelihood and severity of the negative event (controlling the water temperature and flow and non-slip surfaces to reduce likelihood and pull-cords for summoning help to reduce severity). The chocolate brownie for the diabetic apparently carries no risk to others at all, though some might argue that if he or she is truly courting diabetic coma with each slice, he or she will be using resources that could have better been allocated to others. This argument about harming others by using too many resources is often applied in a facile manner, however. Unless, this particular person had experienced a few recent crises that demanded the attention of staff, the risk seems altogether too hypothetical to be given much weight.

**Quantifying risk.** Risks associated with HCBS plans are notoriously difficult to quantify. In contrast, the difficult matter of advising patients about risks of medical procedures is almost easy. Although science is far from exact, it is often plausible to provide the potential consumer with information about death and complication rates following a surgical procedure or a drug intervention and even to elaborate on the circumstances that exacerbate or minimize the likelihood that the particular person will

experience a bad outcome. Similarly, it is often possible to provide information about the likely course of action if the surgery is rejected or the medicine not taken.

In contrast, long-term care typically deals with many small consecutive or repeated decisions rather than one big decision. For example, the likelihood of falling, difficult to predict at best, is related to each decision involving independent ambulation or transfer in all their differing circumstances. The consumer who is advised to curtail activities to prevent falls may adopt a partial strategy, perhaps with less risk avoidance than providers prefer but more caution than they would normally adopt. The likely consequences of highly individualized strategies to entertain or avoid health risks are almost impossible to calculate with any precision.

**Negative effects of avoiding the risk.** These effects, like the original risk itself, are also not a certainty, but merely a prediction. They too can be classified in terms of type of effect, for example, physical, psychological, social, financial. They too can be examined in terms of their likelihood and their severity. Negative effects of avoiding the risk can limit the freedom of the individual and may also cause additional strain or decrease quality of life. If an individual in her own home or in an assisted living facility is not allowed to bathe alone because her providers fear that she may slip and fall, this can potentially cause her emotional harm. She may lose dignity by having to ask for assistance. She and her family members may also be strained financially because she will have to pay a provider to assist her with bathing. Especially if this woman has no prior history of falling in the bathtub, the negative effects may be greater than allowing the risk. Another negative effect in this situation may be that the woman will have to burden her family members or friends in order to receive the assistance that the provider believes she needs. This burden can be the physical burden of the family member or the psychological burden of having to ask for assistance. There is risk at every moment in every individual's life. How do we know where to draw the line?

Case managers, hospital discharge planners, and home-care providers are often in the role of recommending nursing home placements as the safest bet for an individual who seems to be at risk. Seldom, however, do they evaluate the risks associated with the recommended placement. Rather they concentrate on the observable risks in the current home situation or if the person were to return home from the hospital. There well may be physical as well as other kinds of risks associated with the more restrictive alternative that have not been considered. For example, there may be dangers of losing functional abilities through disuse, or of the resident being hurt by a combative resident, or of institution-borne infections. Truly assessing the risks involved in a nursing home placement requires particularization regarding the particular risk factors to which the individual referred to a nursing home is prone, regarding the nature and track record of the nursing home, and even regarding the particular unit and room where the individual will be housed. Nobody making a placement has time or knowledge to consider such risks, nor does he or she usually learn about the results of the placement. The individual moved to a nursing home because of fear that she might fall in her apartment could have fallen and been severely injured in the nursing home within weeks of admission but this event would not help inform the discharge planner's decision-making formulas.

**Role of providers.** Long-term care choices differ from choices about many discrete health decisions because the providers may still be active in the case after their advice is ignored. In this sense, HCBS resembles primary care, but with much more intensity and intimacy of involvement than is usually the case between patient and physician. If home care providers, care coordinators, or assisted living providers are present on an almost daily basis, they may find themselves impelled to renew the subject of their own concerns regularly. It is always easier to honor autonomy in the abstract than when one must confront a client who is in a dangerous situation. Providers have a real sense of responsibility and experience a real tension between respecting autonomy and being negligent. Where do we draw the line? How should we draw the line? For example, a client in her early seventies who has difficulty seeing because of complications of diabetes has been in her bed for over a week when a case manager stops by to check on her. The visiting nurse who monitors the situation believes that the woman is in danger of losing her foot because the small sores that she has had for the past month have been left untreated and have turned into large open wounds. The older woman refuses to seek medical treatment from a health care professional because she believes only in herbal remedies. Because the woman is in severe pain caused by what is perhaps an infection in her open wound, she has not been able to get out of bed for over a week. She has been lying in her own feces and urine and the visiting nurse wants her to go to the hospital. The woman refuses, which puts the nurse in a very difficult situation. She does not want to simply abandon her client, but sees that she is in real danger. Health care providers are often placed in these difficult situations and there are no clear cut rules governing what it is they should do.

### **Ingredients of Informed Risk-Taking**

Almost as a tautology, informed risk-taking requires a source of trustworthy information. The consumer may also require time to digest that information and consider the implications. At issue is whether and under what circumstances care providers are a good source of information about the riskiness of various courses of action. And, if not the care provider, who should provide such information? Should it be provided in writing? With a witness? Will all those trappings create such an aura of dread and fear that it unduly influences the deliberations of the consumer? Yet, without such a process, how is it clear that the consumer has been informed and how do professionals and care organizations protect themselves from legal liability?

Informed risk-taking also requires a competent individual who is capable of understanding the trade-offs and making the choices. Many older adults are capable of making certain decisions, but not others. Just as with any informed consent, a client must be given information and decisions should be made on an individual basis. There is a danger that when older adults disagree with their providers, this can be taken as incompetence when all it really is is a disagreement. A first step that needs to be taken when considering any type of risk is an assessment of the possible negative effects as well as the alternatives.

Many long-term care consumers suffer from some degree of impaired memory or judgment that may render them incapable of making a decision to take chances in the

name of autonomy. It still may be feasible to develop a process by which an agent weighs the benefits and harms of various courses of action on behalf of the individual with severe dementia, but the rationale for such a process is based on a different set of assumptions than respect for autonomy, such as a desire to promote happiness. However, just as we examine risk on a continuum, cognitive impairment must also be seen as a progression. There is reason to believe that people with mild cognitive impairment can appreciate some risks and accept them knowingly. Unfortunately, however, probably because of the propensity to protect, little research has been done to examine the nature of the tradeoffs people with early Alzheimer's would make and the reliability of their decisions.

### **Managed Risk Contracting**

Managed risk contracting is a term that has come into vogue in the 1990s as many state HCBS programs have given explicit recognition to notions such as dignity of risk in their supporting legislation or program rules. In the state of Oregon, the concept has had the most widespread application. As developed there, managed risk contracting is an orderly process for examining and resolving issues that arise when providers become concerned about the risks that their clientele are assuming (Kapp and Wilson, 1995). Managed risk contracting as it has evolved in Oregon has several steps:

- defining risks and provider concerns;
- defining probable consequences of the consumer's behavior or condition;
- identifying the preferences of everyone involved, which includes the at-risk; consumer, one or more care providers, and possibly one or more family members;
- identifying possible solutions;
- choosing a solution.

Ultimately, the person incurring the risk is perceived as the ultimate decision-maker (assuming competency and no inordinate risks to others, but the search is always for compromise solutions). The plan is documented in writing and signed by the consumer and other relevant parties to the agreement.

Managed risk agreements in Oregon have evolved particularly in the assisted living setting, which, by law, is a congregate care setting that is expected to maximize values of privacy, dignity, choice, independence, and normal lifestyles. It is structured so as to encourage people with nursing-home levels of disability to live in their own self-contained small apartments with features and amenities that encourage independence but also court danger, for example, because of roll-in showers, refrigerators and cooking appliances, and locking doors. Assisted living programs in Oregon charge less than do nursing homes and receive less in public payment and are not staffed for constant attention even if the environments were conducive to such surveillance. As individual residents are perceived to be at some risk because of their own behavior not waiting for bathroom assistance, violating special diets, going out on their own recognizance, imperfectly managing a self-medication regimen, formal managed risk contracting is sometimes considered. At times, the managed risk contract is out into effect because the consumer's preference counters the providers. For example, the provider might prefer to administer all medications whereas the consumer prefers to self-medicate



either to keep independent or to avoid extra costs associated with accepting more help. At other times, the managed risk contract clarifies what kind of assistance can be expected in the setting. For instance, the consumer might be content to be accompanied on all walks, but the provider may not have the staff to do so.

In an ongoing study, we asked about 60 assisted living providers to comment on their views of managed risk contracting as a mechanism for clarifying and perhaps resolving some of the ethical conflicts arising over safety-freedom tradeoffs. We found vastly differing enthusiasm for the concept, ranging from high to unwillingness to touch it with a 10-foot pole. Regardless of the respondent's stance, few providers believed that a managed risk agreement is a legally binding document. Indeed, we have not identified any case law that is directly on point to clarify the topic and suspect that a managed risk agreement would provide little protection in the case of a legal challenge.

Proponents of managed risk contracting believe that the very act of identifying the issues is salutary and may, in fact, lead to creative compromise solutions. Managed risk contracts are a tool that encourages and structures discussion among all parties involved. Oftentimes family members, residents, and providers have not all sat down to discuss the issues. This is one way of getting the discussion started that allows each party to voice their preferences. Opponents believe they are not worth the paper they are written on. Some opponents indicated that they saw formal managed risk contracts as a failure in care planning. They would assert that managed risk contracts are unnecessary because discussions of risks and preferences should be a regular and ongoing part of care planning. We also identified a small subset of providers who were using the mechanism to clarify the risks *providers* were willing to take. For example, the managed risk agreement might read that the consumer would be permitted to smoke in a defined area of the building but, if he dropped the cigarette, he would need to smoke outside. Certainly, the establishment of the progressive steps in a provider's willingness to tolerate the risky behavior and the ultimatum approach (three strikes and you're out!) distorts the original consumer-empowering intent of managed risk contracting.

### **Examples of Managed Risk Contracts**

At present, no official legal format exists for managed risk contracts, and there are few models circulating in the community. Individual providers and public payment programs have created approaches to managed risk contracts that suit their specific needs. Some assisted living facilities have managed risk policies or declarations in their resident handbooks or as part of the orientation material that prospective residents receive (Table 1). Most create individualized managed risk agreements as situations come up, and some use both devices. That is, they include general language to alert residents and families that risks may be taken in this facility, but if the risks go beyond normal, they execute a managed risk agreement.

Table 1: Language from Admissions Material at An Oregon Assisted Living Setting

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Assisted Living Facilities in Oregon operate on the principle of MANAGED RISK. Managed risk allows elderly or disabled persons the choice of living more independently than allowed in some institutional settings such as nursing facilities. With the increase in independence, comes some risk to the resident. Listed below are some of the features at \_\_\_\_\_ and the risk each may present.

- 1) locked and keyed private apartments where staff members do not interrupt residents unless a resident calls for assistance or a planned intervention has been arranged; hallways and doorways are not monitored
- 2) non-restraint policy increases the risk of falling for those residents who are unsteady on their feet
- 3) unsupervised snack area which allows residents who are on restricted diets the chance to stray from their diets
- 4) concludes with a statement that the resident is the final decision-maker unless there is a guardian

Table 2 shows a hypothetical managed risk agreement based on some that we collected from Oregon Assisted Living Facilities. This particular firm has developed a pattern for managed risk agreements that identify the problem or issue, identify the resident's concerns, the provider's concerns, the list of possible solutions generated, and the chosen solution.

Table 3 shows an example of a managed risk contract developed by a free standing case management organization in Illinois. The agency has developed a format that includes a standard statement on the top that explains the nature of a managed risk agreement, followed by a specific managed risk agreement for a particular client. The specific document makes it clear that the doctor would prefer a different plan and also specifies specific risks to the individual. In this particular agency, the risks are often articulated generally as the risks of staying at home rather than accepting a nursing home.

## Table 2. Example of a Managed Risk Agreement in Assisted Living

**Resident's Name:** Henrietta \_\_\_\_\_ **Date:** \_\_\_\_\_

### Parties involved in discussion:

Henrietta \_\_\_\_\_, Henrietta's son, the AL nurse, and Henrietta's case manager.

### Managed risk issue/problem.

Henrietta is an insulin dependent diabetic with physician's orders to follow the American Diabetic Association's recommended diet. Henrietta however, loves to eat candies such as gum drops and peppermints in her room as well as cake with white frosting in the dining room. Henrietta asks staff members to purchase sweets for her outside the facility. She frequently requests dessert after meals. Henrietta refuses to eat diabetic desserts stating that they are not made for human consumption.

### Resident's concerns:

Henrietta wishes to be allowed to eat candy in her room and desserts in the dining hall.

### Consequences of the risk/providers' concerns:

Refusing to follow the diabetic diet can place Henrietta at severe health risks including possible diabetic exacerbations, coma, and even death.

### Possible alternatives to minimize the risk:

1) Henrietta could refrain from asking for non-diabetic desserts in the dining hall; 2) Henrietta could refrain from eating sugar candy in her apartment; 3) the facility could increase the variety of diabetic desserts offered in order to find one that Henrietta likes; 4) Henrietta can get special diabetic candies from the local market; 5) Henrietta could be permitted to do as she desires after being informed of the health risks involved with being non-compliant with the ADA diet.

### Agreement:

The AL will offer more varieties of diabetic desserts including diabetic candies. Henrietta will try diabetic desserts and will help the cook find new recipes for diabetic desserts that look more appealing. If Henrietta insists on eating a particular dessert that is not on her diet at a meal, the dining staff will remind her that it is not recommended, but will not prevent Henrietta from eating the dessert. This agreement will be reviewed by \_\_\_\_\_.

### Signatures:

\_\_\_\_\_  
Resident

\_\_\_\_\_  
Date

\_\_\_\_\_  
Representative of facility

\_\_\_\_\_  
Date

\_\_\_\_\_  
Family (if applicable)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Other (as applicable)

\_\_\_\_\_  
Role

\_\_\_\_\_  
Date

Source: Adapted from a variety of corporate tools with an emphasis on approaches used by Assisted Living Concepts, Portland, Oregon.

**Table 3. Example of Managed Risk Statement Used in Home Care**

Some clients choose to make decisions that are contrary to the recommendations of the physician, the family, the care providers, or the case manager. Such decisions may put the client at risk of injury or harm. This Risk Statement has been developed to highlight the client’s impairments and the particular risks that may occur if the client chooses to remain at home against the doctor’s, family’s, or case manager’s recommendations. The client’s signature indicates informed consent; that he/she understands the risks and consequences that his/her decisions may have, and that he/she is willing to accept the risks.

**RISK STATEMENT FORM**

I, \_\_\_\_\_, understand that I have the right to self-determination. I have chosen to remain at home and refuse to go into a nursing home. I understand that Dr. \_\_\_\_\_ has recommended a nursing home that provides 24-hour care and supervision but that s/he has agreed to home care at my preference.

My care manager has discussed the following risks, which I understand and am willing to accept:

1. My dizziness may result in a fall.
2. Not being able to see clearly to take my medications by myself may aggravate my congestive heart failure and result in hospitalization. I understand that my daughter is no longer able to continue medication set-up as she has previously done.
3. Not being able to easily prepare food may result in a loss of nutritional status.
4. Not being able to use my oxygen when I need it may result in hospitalization.

\_\_\_\_\_  
Client signature

\_\_\_\_\_  
Case manager signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

Client’s functional and cognitive assessment status attached.

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Source: Based on a form developed by Alternatives for the Older Adult, Rock Island, Illinois. Client describes is also fictional but based on real situations.

## **When Things Go Wrong**

Everybody can congratulate themselves on being sensitive to consumer preferences as long as no untoward events occur. When things go wrong, especially in publicly funded programs, there is a natural tendency to seek someone to blame (Kapp, 1997). The true test of an approach where consumers can make decisions to take chances comes after the negative event. When the fall occurs, does the consumer get a chance to rise and fall again. And in the worst possible scenario, when the consumer dies as a result of the course of action pursued, will providers be held culpable. Even if they are not blamed, will they feel responsible in a way that detracts from their effectiveness.

The more long-term care mirrors normal life, the more things can go wrong. Depressed people will have more access to weapons that could potentially harm them. Die-hard smokers on oxygen will have the opportunity to become human torches (an event that is more likely to kill them than injure others nearby). People may leave their homes or assisted living setting, suffer a health event (a fall, a stroke) and die unattended. Should care providers be held responsible for each such negative event regardless of its rarity and the fact that the possibility had been discussed with the consumer?

## **Cognitive Impairment and Surrogate Risk-Taking**

The most difficult scenario concerns cognitive impairment, the very scenario where most risks occur. Some family members express confidence that they know what kind of risks their relative would prefer to take, and some lay claim to greater freedom for their relatives with Alzheimer's disease. Do family members have the right to assert that mother would rather be at home, even if at times alone and unsafe, than in an unfamiliar institution? Do they have the right to assert that they would rather have that independent experience for mother? Do they have the right to say dad should remain in an assisted living setting where he might at times wander out and accept the consequences? Should a family member be allowed to negotiate an agreement that the assisted living setting will check the whereabouts of a wandering parent at intervals and call 911 if the parent is missing? Does such an agreement get the facility off the hook if the worse happens? What if family members appear to have a conflict of interest? For example, the more protective plan may make a greater erosion into an expected legacy from the older person.

## **Towards Clarity**

Resolving the problems that arise when perceived safety and freedom conflict will require new organizational and perhaps legal vehicles. It will be necessary to determine who has a stake in the outcome and who deserves to be part of the deliberations. It will be necessary to develop better ways of engaging consumers in genuine and ongoing consideration of the risks they want to take and the way they want to live. We will need to learn how to distinguish between negligent care and care that respects autonomous risk-taking, between protecting consumers and coercing them into conforming lifestyles. Most ethical problems in home and community-based care revolve around the safety-protection tradeoffs and consumers and providers alike are anguished about what to do.

We have already tried making safety (in the eye of the provider) the default position without guaranteeing either safety or other sorts of well-being. A cautious effort to develop a new approach seems worth the risk.

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## Acknowledgment

The work that led to this manuscript was supported by The Retirement Research Foundation.