



U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy



# **A STUDY OF NEGOTIATED RISK AGREEMENTS IN ASSISTED LIVING:**

## **FINAL REPORT**

February 2006

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This report was prepared under contract #HHS-100-03-0025 between HHS's ASPE/DALTCP and RTI International. For additional information about this subject, you can visit the DALTCP home page at [http://aspe.hhs.gov/\\_/office\\_specific/daltcp.cfm](http://aspe.hhs.gov/_/office_specific/daltcp.cfm) or contact the ASPE Project Officer, Gavin Kennedy, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. His e-mail address is: [Gavin.Kennedy@hhs.gov](mailto:Gavin.Kennedy@hhs.gov).

# **A STUDY OF NEGOTIATED RISK AGREEMENTS IN ASSISTED LIVING: Final Report**

Robert Jenkins  
NCB Development Corporation

Janet O'Keeffe  
RTI International

Paula Carder  
University of Maryland, Erickson School of Aging Studies

Keren Brown Wilson  
Jesse F. Richardson Foundation

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# **EXECUTIVE SUMMARY**

## **Background**

Balancing the need to assure both autonomy and safety is a major challenge when providing long-term care services to older persons who reside in licensed group settings, because provider policies and state regulations intended to ensure safety can conflict with individuals' ability to make the choices they prefer. One approach proposed to achieve a balance is the use of a negotiated risk agreement (NRA), which was developed as a practical strategy to operationalize resident autonomy in this environment.

Processes and documents similar to NRAs exist in health care settings--for example informed consent--but the specific process and structure of NRAs are unique to assisted living (i.e., written documents that list):

- the behavior or resident preference of concern to the provider;
- the potential or actual risk;
- the resident preferences and potential provider accommodations or suggested alternatives to the behavior that reduce risk while meeting resident preferences;
- a negotiated resolution; and
- the resident's acknowledgement and acceptance of the potential negative consequences of his or her actions.

NRAs were conceived to help assisted living meet its goal of providing a residential alternative to institutional care that provides frail and cognitively impaired older persons an option that maximizes privacy, independence, choice, and the maintenance of a normal lifestyle--qualities that are generally lacking in institutional long-term care settings. Over the past decade, many assisted living providers have adopted NRAs, and several states have regulatory provisions regarding their use. However, their use is not without controversy.

## **Purpose of the Study**

The use of NRAs is a new topic in a relatively new long-term care setting. This study is designed to inform state policy makers, assisted living providers, and key stakeholders about NRAs and issues related to their use. The study's major objectives are to:

- Describe states' statutory and regulatory provisions related to NRAs and analyze the policy objectives that NRAs are designed to meet.

- Analyze and better understand the debate surrounding NRAs.
- Gain an understanding of how assisted living providers, staff, and residents view and use NRAs.

## Methods

We used standard policy analysis and qualitative research techniques, including a review of the published and unpublished literature; a review of statutes, regulations, and case law for all 50 states and the District of Columbia; discussions with over 50 experts and key stakeholders in long-term care law, policy, and practice; and in-depth interviews with 46 staff and residents of seven assisted living facilities in three states--Florida, Oregon, and Wisconsin.

## State Regulations Regarding NRAs

Forty-one states have regulations that govern residential care settings called assisted living. The majority of states have no provisions related to NRAs in either statute or administrative code, leaving their use to the discretion of providers unless they are prohibited under other state statutes. Fourteen states and the District of Columbia have NRA or closely related provisions related to managing risk (*hereafter*, the states). No state explicitly prohibits the use of NRAs, though several place restrictions on their use.

Alaska	Arkansas	District of Columbia
Delaware	Florida	Hawaii
Illinois	Iowa	New Jersey
Ohio	Oklahoma	Oregon
Vermont	Washington	Wisconsin

State regulations regarding NRAs and related concepts vary in their provisions and specificity, but all states view NRAs or a similar process as a means to support residents' choices that conflict with medical advice or facility norms while managing the risks associated with their choices. Most states link NRAs with service planning.

Wisconsin is the only state that requires all persons entering a specific type of assisted living--Residential Care Apartment Complexes--to have an NRA at admission. Of the 15 states with NRA provisions, four do not reference NRAs as a distinct document that is written or signed, instead referring to risk discussions as part of service planning or provisions for managing risk.

## **The Debate Surrounding NRAs**

### ***Purpose of NRAs***

Views about the purpose of NRAs are polarized. The 15 states that reference NRAs or similar processes in their assisted living regulations and the majority of proponents believe NRAs have several purposes, providing: (1) a tool for identifying and reducing risks, (2) a communication tool for discussing risks and setting expectations, and (3) a method to support residents' rights to make choices that entail risk. Some states and proponents also view NRAs as a method for assigning responsibility and limiting provider liability.

The strongest opponents tend to view NRAs as having a sole purpose--an attempt to avoid liability for negative outcomes resulting from negligence. Others recognize that "good" providers may use NRAs to identify and reduce risks, but fear that "bad" providers will use them to force residents to accept substandard care because they have no practical alternative or fear discharge to an institutional setting. Several argue that residents are in an unequal bargaining position due to frailty, lack of acceptable alternatives, and the difficulty with relocation.

Furthermore, opponents believe consumers should not be required to negotiate to exercise autonomy in assisted living because they already have the right to make the choices NRAs are designed to foster. Proponents counter that the rights of residents in licensed facilities are constrained and that providers worried about their potential liability for the negative outcomes of residents' choices often overtly curtail residents' autonomy or apply subtle coercion to restrict it.

Both proponents and opponents were divided regarding the ability to mitigate the potential negative consequences of NRAs through law and regulation. Opponents believe that prohibiting NRAs altogether rather than risking abuse best serves the public interest; proponents believe the public is best served by allowing NRAs and implementing regulatory protections. If a state allows or require NRAs, opponents also believe that regulatory protections are needed.

### ***Liability Waivers***

Liability waivers--specific or implied--are the main issue that polarizes views about NRAs. Some proponents claim that NRAs are not and never were intended to limit provider liability while others argue that they were always intended to create a balance within a regulated setting, allowing resident autonomy by providing an appropriate amount of liability protection for providers. Many argue that without limiting provider liability that could result from residents' risky choices, providers will continue to restrict residents' autonomy in favor of safety. Most proponents note, however, that blanket waivers of liability are never appropriate.

An interesting feature of the debate about NRAs and liability waivers is that few proponents or opponents believe that NRAs can effectively limit legal liability, whether or not they include a specific liability waiver. The legal status of an NRA as a contract has yet to be determined, yet virtually no one believes that broad liability waivers are enforceable or that specific liability waivers are enforceable if negligence resulted in harm to a resident or if providers violated express regulatory requirements.

### ***NRAs and State Admission and Discharge Requirements***

Several opponents believe that providers will use NRAs to allow residents to remain in a facility after their needs exceed regulatory discharge requirements--sidestepping regulations in an effort to maintain their census without increasing staffing. The consensus of legal experts was that NRAs or any private contracts, as a general rule, can not overrule regulations or law because deregulation by private contract is not enforceable. Nor can NRAs supplant a provider's fulfillment of a statutory duty.

Some states explicitly prohibit the use of NRAs to override state-mandated discharge requirements. Nonetheless, it appears that NRAs and similar agreements can be specifically included in regulations as a mechanism to allow residents to accept risks within parameters established by regulations or as a defined mechanism with which to override state discharge requirements under certain circumstances. In other words, residents do not have a right to use NRAs to enforce their choices in opposition to the state's (or, generally, the provider's) rules unless the state explicitly provides in law or regulation for NRAs to do so.

### ***Limitations on the Use of NRAs***

When asked about specific issues related to the use of NRAs--for example, what topics are appropriate, whether providers should determine residents' decision-making capacity through a formal assessment prior to executing an NRA, and whether third parties should be allowed to execute an NRA on a resident's behalf--there was a lack of consensus. Many said their position on these issues would depend on the circumstances. Some providers said that more guidance on such issues would be helpful.

In sum, stakeholders and experts disagree about the advantages and disadvantages of NRAs. The meaning of "risk" and views regarding the relative importance of protection and autonomy varies among the many disciplines involved in assisted living practice--providers, consumer advocates, regulators, nurses, social workers, attorneys, and insurers. Even among advocates, especially between traditional advocates for the elderly and advocates for persons with disabilities, views on the need for NRAs and implementation standards vary widely.

## How Assisted Living Providers, Staff, and Residents View and Use NRAs

Most of the experts and stakeholders we interviewed had strong views about NRAs, but few had firsthand experience with them. The primary purpose of our site visits was to get a sense of how NRAs are actually used and the views of those directly involved.

- With the exception of Wisconsin, which mandates NRAs for all residents admitted to a specific type of assisted living (Residential Care Apartment Complexes), NRAs appear to be used infrequently and selectively, generally only when informal discussions have not resolved an issue that has arisen more than once.
- Staff view NRAs primarily as a complement to service planning and a useful method for addressing residents' behaviors or choices that they believe pose risks to their health and safety. In particular, they foster discussion about difficult issues that providers, residents, and families might otherwise avoid. All staff agreed that behaviors that place staff or other residents at risk are not appropriate for negotiation.
- While some staff believe that NRAs could provide some liability protection in the event of a lawsuit over a negative outcome, they do not view this potential protection as the sole or primary purpose of the NRA. All management and professional staff agreed that an explicit discussion with residents and families about risk and of measures that can be taken to reduce risk can reduce providers' liability exposure.
- In no case, with the information available to us, did we determine that NRAs were being used to pressure residents into accepting inadequate care, the primary concern of NRA opponents. None of the NRAs we reviewed supported the view that providers are using NRAs exclusively as a liability "dodge" to allow them to admit and keep residents beyond the facility's capacity to care for them--or for poor quality care. However, some standardized NRAs were overly broad and inappropriate for persons with cognitive impairment (e.g., one facility had a standard NRA form that included a statement that a resident accepts responsibility for risk of injury due to wandering).
- All residents believed strongly that they should be able to make lifestyle and personal decisions that may place them at risk. Several residents did not remember signing the agreement or the specific details of their agreements.
- No facility uses a formal method to determine decision-making capacity prior to executing an NRA. In most cases, staff assess this capacity through informal observations of memory loss and poor judgment. Many staff do not appear to be

knowledgeable about the cognitive domains and other factors that affect decision-making capacity.

- Some facilities are allowing surrogates to sign NRAs without knowledge of their legal standing to accept risk on behalf of the resident.
- Some staff expressed frustration with the need to assure residents' autonomy based on two concerns: (1) fear that residents might get hurt when staff have a moral obligation to protect them, and (2) concern that staff are held responsible for all negative outcomes.
- Often, direct care staff did not have much familiarity with the concept of NRAs, know that an individual resident had an NRA, or, if they knew a resident had an NRA, they did not know what impact it had on service delivery or a resident's ability to assume risk.
- Some NRAs were used for issues other than specific risks. For example, to note a general risk factor like blindness or obesity, or as a behavior modification agreement, stating that unless a resident ceased a particular behavior, like smoking or disturbing the peace, they would be discharged from the facility.

## Conclusions

Assisted living providers, policy makers, aging advocates, and long-term care experts have defined NRAs as a mechanism to enhance resident choice by providing a rigorous process designed to balance autonomy and risk for residents and providers in assisted living. While our sample is small and not representative, our findings suggest that NRAs can be a useful tool to help residents and providers achieve a balance between desires for autonomy and concerns about safety. At the same time, they suggest that the NRA concept is proving difficult to broadly and consistently operationalize.

- NRA processes and purposes are not well understood and appear to vary widely across states, providers, and even staff in the same facility. While this may not be surprising given that assisted living varies widely within and across states, it does raise significant concerns about standards for the process. As identified in this study, the appropriate use of NRAs requires at a minimum, guidance in their use, as well as education and training.
- NRAs are not being used uniformly to maximize resident autonomy by balancing specific risks and consumer preferences as supporters advocate. Few of the NRAs we reviewed adhered to a form, process, or guidelines appropriate for the practice concept or to the recommendations in the Assisted Living Federation of America's report on NRAs. While some NRAs fit advocates' concepts, others that we reviewed addressed appropriate issues but did not include a discussion of

alternatives or a negotiation, instead presenting topics in an either/or framework. Some NRAs simply identified the risk, stated that the resident should not do what staff identified as risky, and then noted that the resident planned to continue and accepted the risk.

- The enforceability of liability waivers has not been tested in the courts but most experts do not believe that NRAs with such waivers provide any more liability protection than those without them. NRAs can be structured to address provider and consumer concerns without using formal or even an implicit liability waiver. Most experts agreed that the availability of a signed document recording formal discussions between the facility and resident regarding risky choices, staff attempts to reduce risk, and the residents' acknowledgment of their choice despite the risks could be comparable in protection to a formal waiver of liability in the event of a law suit. Given this, proponents would be advised to give less attention to liability waivers and more to assuring that providers follow recommended practices when executing NRAs. In particular, issues related to executing NRAs with individuals who may lack decision-making capacity should receive more attention.

Whether NRAs should be used or continued with residents who have cognitive impairment is unclear. If an individual includes the authority to enter into an NRA in a power of attorney or if a court has granted a guardian this power, legal concerns about the use of surrogates are lessened. In most states, guidelines regarding NRAs and surrogates are either completely lacking or do not adequately address this issue. Additional state guidance regarding appropriate and inappropriate use of surrogates would be helpful to providers and would afford protection to persons with cognitive impairment.

It may be possible to address certain risk topics found in our review of NRAs using a process that is more closely tied to service planning, particularly to address areas of risk that are typically dealt with in service plans, such as prescribed diets, medications, and use of bedrails. For example, to obtain the primary advantages of fostering communication and documenting discussions and choices, providers could use forms that address "specialized service planning issues" as well as forms that are treated as addendums to the service plan. This approach would have the advantage of being part of initial and ongoing service planning while avoiding the legal complexities of an NRA. However, an enhanced serving planning approach would not afford the benefits of negotiation and risk assumption that many proponents believe are the primary value of NRAs--both to enhance resident autonomy and protect providers from liability for the consequences of residents' choices.

While many advocates and opponents characterize the debate as absolute for or against NRAs, the debate is better characterized as an attempt to determine acceptable limits to choice and what process best achieves a balance between autonomy and safety. It seems likely that with increasing attention to the rights of persons with disabilities to exercise choice and assume risk in both long-term care settings and

independent housing, strategies for enhancing older persons' autonomy will become increasingly important.

NRAs or similar processes show some promise in providing a practical approach to enhancing resident autonomy in a living environment where a regulatory emphasis on safety and concerns about liability are salient factors affecting provider behavior. However, if NRAs are the correct tool for striking a reasonable balance between safety and autonomy, states, consumer advocates, provider associations, and the legal community need to give more detailed attention to how their use should be operationalized so they can play a significant role and to prevent potential abuse. Stakeholders also need to examine what role NRAs' can or should play in providing a process for "reasonable accommodation" when state or provider proscribed admission and discharge limits conflict with residents' preferences.

# I. INTRODUCTION

In May 1980, 83-year-old Harry Truman refused to leave his home on the side of Mount St. Helens despite predictions that the volcano was about to erupt. He was described at the time as a “crotchety” but “rugged individual” who stood “true to himself.”<sup>1</sup> Truman’s act of independence resulted in his death (and that of his 16 cats) and the creation of a song, a memoir,<sup>2</sup> a hiking trail, and a memorial at the entrance to the nearby town of Castle Rock, Washington.

Truman’s instant status as a folk hero demonstrates the value Americans place on independence, autonomy, choice, and home, even when the individual making the choices is very old and taking great risks.<sup>3</sup> However, if Truman had resided in a licensed long-term care (LTC) setting, as many 83-year-olds do, he would likely have found his ability to make choices and assume risks greatly restricted based on concerns about his safety. It is a certainty that he would not have been allowed to stay by Mount St. Helens or have 16 cats.

Balancing the need to assure both autonomy and safety is a major challenge when providing LTC services to older persons who reside in licensed group settings, because provider policies and state regulations intended to ensure safety can conflict with individuals’ ability to make the choices they prefer.<sup>4</sup> One approach proposed to achieve a balance is the use of a negotiated risk agreement (NRA), which was developed as a practical strategy to operationalize resident autonomy in a litigious LTC environment.

NRAs were conceived to help assisted living meet its goal of providing a residential alternative to institutional care that provides frail and cognitively impaired older persons a residential option that maximizes privacy, independence, choice, and the maintenance of a normal lifestyle--qualities that are generally lacking in institutional LTC settings.<sup>5</sup> Advocates of the assisted living philosophy believe that residents and providers share the responsibility to develop individualized plans to meet the residents’ needs and preferences, including preferences that entail risk, in order to maintain or improve the quality of residents’ lives. Basically, an NRA documents a process designed to assure that residents maintain control over their lives while acknowledging provider and state responsibility to assure quality and safety within the context of resident preferences.<sup>6</sup>

Over the past decade, many assisted living providers have adopted NRAs, and several states have regulatory provisions regarding their use. However, their use is not without controversy. Supporters believe they foster documented discussions that allow providers to become comfortable with risks that residents want to assume, thereby helping to prevent situations where providers, in an effort to assure safety and reduce liability risk, limit residents’ choices through facility policies.

Opponents believe consumers should not be required to negotiate to exercise autonomy in assisted living because they already have the right to make the choices

NRAs are designed to foster. Additionally, some believe that providers may abuse NRAs by using them as a liability dodge for insufficient or poor quality care.

## **Purpose of the Study**

The use of NRAs is a new topic in a relatively new LTC setting. This study is designed to inform state policy makers, assisted living providers, and key stakeholders about NRAs and issues related to their use. The study's major objectives are to:

- Describe states' statutory and regulatory provisions related to NRAs and analyze the policy objectives that NRAs are designed to meet.
- Analyze and better understand the debate surrounding NRAs.
- Gain an understanding of how assisted living providers, staff, and residents view and use NRAs.

## **Methods**

To conduct this study, we used standard policy analysis and qualitative research techniques, including a review of the published and unpublished literature; a review of statutes, regulations, and case law for all 50 states and the District of Columbia; discussions with over 50 experts and key stakeholders in LTC law, policy, and practice; and in-depth interviews with 46 staff and residents of seven assisted living facilities in three states--Florida, Oregon, and Wisconsin. Appendix A contains a detailed description of the study's methods.

Some proponents of NRAs use the term "shared responsibility agreement" rather than NRA to emphasize that the resident and the provider are sharing risk. Some states use the term managed risk agreements. In this report, we use the term NRA as the generic term for risk agreements. We will use other state-specific terms for risk agreements when discussing those states.

## **Organization of the Report**

The remainder of this report is organized in four sections. Section II discusses NRA concepts and use. Section III discusses the wide range of legal and policy issues related to the use of NRAs, including liability waivers, the role of NRAs in the discharge process, and residents' mental capacity to enter into an NRA. Section IV presents our findings from site visits to assisted living facilities in Florida, Wisconsin, and Oregon. Section V presents our conclusions regarding policy issues that need to be addressed and suggestions for future research and policy analysis.

Several appendices provide additional information. Appendix A provides detailed information about the methods used in this study. Appendix B provides the text of states' regulatory provisions regarding NRAs and summary tables of states' NRA regulatory requirements. Appendix C provides the names of experts and key stakeholders consulted or interviewed for this study. Appendix D provides information on the characteristics of the assisted living residents we interviewed. Appendix E provides examples of organizations' policy positions on NRAs and Appendix F provides a sample NRA form from a national provider. Individual citations and additional technical information are provided in endnotes.

## **II. NEGOTIATED RISK AGREEMENTS: DEFINITION, CONCEPTS, AND USE**

The right to assume risk has long been an important topic for disability advocates, LTC service providers, and policy makers. The “normalization” movement promoted by persons with developmental disabilities and their advocates warns against overprotection, defining adults’ right to take risks as a form of human dignity. Over 20 years ago, a report on mental handicap, nursing, and care noted that the world is not always safe, secure, and predictable and that “mentally handicapped people too need to assume a fair and prudent share of risk.”<sup>7</sup> Yet, choice and risk tolerance are fairly new concepts in LTC settings, with consumers of LTC services seeking more control over their lives by controlling the services they receive. At the same time, the impact of litigation in LTC and health care settings has made efforts to reduce or “manage” risk an important political, economic, and social policy issue.

NRAs were developed in this advocacy and litigation environment as a mechanism to enable older persons residing in regulated assisted living settings to make preferred choices, even when they entail some risk. Processes and documents similar to NRAs exist in health care settings--for example, informed consent--but the specific process and structure of NRAs are unique to assisted living (i.e., written documents that list):

- the behavior or resident preference of concern to the provider;
- the potential or actual risk;
- the resident preferences and potential provider accommodations or suggested alternatives to the behavior that reduce risk while meeting resident preferences;
- a negotiated resolution; and
- the resident’s acknowledgement and acceptance of the potential negative consequences of his or her actions.

The concept of allowing residents to assume risk to promote autonomy in assisted living is widely recognized. The Centers for Medicare and Medicaid Services’ definition of assisted living outlined in the standard Home and Community Based Services waiver application includes the following statement: “The consumer retains the right to assume risk, tempered only by the individual’s ability to assume responsibility for that risk.”<sup>8</sup> This definition recognizes in principle the right to assume risk while acknowledging that mental capacity is an issue in risk assumption.

In 2000, the Assisted Living Federation of America issued the first manual for providers interested in using NRAs, which includes advice on how to structure NRAs, as well as their potential impact on a provider’s liability if an injury occurs as a result of the risk assumed.<sup>9</sup>

Over the past decade, NRAs have gained prominence in policy discussions surrounding assisted living, as evidenced by three significant legal articles,<sup>10</sup> and an extended debate on their merits by the Assisted Living Workgroup in 2003. (See Appendix E for additional information on the Workgroup.) Two prominent organizations that provide voluntary accreditation to assisted living facilities--the Joint Commission on the Accreditation of Healthcare Organizations and the Rehabilitation Accreditation Commission--describe risk agreements as part of the service planning process.<sup>11</sup>

The AARP has a policy position supporting NRAs (see Appendix E) and *Consumer Reports* considers NRAs to be “one issue you will need to consider” when looking for an assisted living residence.<sup>12</sup> In 2001, the Institute of Medicine recommended increased access to consumer-directed LTC and a related research agenda that included studies to examine the effectiveness of NRAs in addressing the need to balance desires for autonomy with concerns about safety.<sup>13</sup>

## State Regulations Regarding NRAs

Forty-one states have regulations that govern residential care settings called assisted living. The majority of states have no provisions related to NRAs in either statute or administrative code, leaving their use to the discretion of providers unless they are prohibited under other state statutes. Fourteen states and the District of Columbia have NRA or closely related provisions (*hereafter*, the states).<sup>14</sup>

Alaska	Arkansas	District of Columbia
Delaware	Florida	Hawaii
Illinois	Iowa	New Jersey
Ohio	Oklahoma	Oregon
Vermont	Washington	Wisconsin

Of the 15 states with NRA provisions, only Alaska, Florida, Hawaii, and Iowa do not reference NRAs as a distinct document that is written or signed. Alaska requires a discussion of risks as part of service planning, while Florida regulations simply define managed risk as a process that can be used during service planning. Hawaii requires facilities to apply a “principle of managed risk,” defined as a formal process of negotiating and developing a plan to address resident needs, decisions, or preferences to reduce the probability of adverse outcomes for the resident and others. Iowa requires that providers have a process for managing risk, which must be disclosed prior to occupancy.

Iowa also requires a managed risk “statement” that tenants sign acknowledging “shared responsibility for identifying and meeting needs and the process for managing risk and upholding tenant autonomy when tenant decision making may result in poor outcomes for the tenant or others.” Thus, although these four states’ regulations do not specify the content or format of a risk agreement, they do specify that risk management be part of the service planning process in assisted living.

Wisconsin is the only state that requires all persons entering Residential Care Apartment Complexes (RCACs) to have an NRA at admission, even one that simply states that no specific risk issues have been identified.<sup>15</sup> Arkansas regulations require the facility to “negotiate a compliance agreement” if the resident assessment indicates a “high probability” that the resident’s choice or action places that person or others at risk of adverse outcomes. Oklahoma and Vermont require facilities to initiate a negotiation *process* when they determine that a resident’s decision, behavior, or action places the resident or others at risk of harm; under the same circumstances, Washington requires providers to develop a formal, written negotiated plan. No state prohibits NRAs. See Appendix B for a summary of the 15 states’ regulatory provisions regarding NRAs. Assisted living industry representatives play an important role in interpreting state regulations on NRAs, including developing model NRA forms and providing training sessions for their provider members.

## Use of NRAs

Two of the largest assisted living companies use NRAs as part of their standard operating procedures. However, no data regarding the frequency of use in actual settings is available, nor do we know why administrators do or do not choose to employ NRAs. As noted, Wisconsin mandates that all residents of RCACs have an NRA in place, but apart from Wisconsin, the prevalence of NRA use is not well known because no states monitor their use.

Two recent studies indicate that they may not be widely used. A recent survey of 200 Florida assisted living facilities with seven or more residents found that 6 percent use NRAs as a matter of corporate policy and 22 percent use them optionally.<sup>16</sup> A 2000 study of NRA use within a national company’s 159 facilities found that while 50 percent of managers reported using risk agreements, only 3 percent of current resident files included such a document.<sup>17</sup> A national study conducted in 1998, using a broad definition of assisted living, found that 29 percent of facilities use NRAs but did not examine the rate of NRA use within those facilities.<sup>18</sup>

Experts and stakeholders in Florida and Oregon said that NRA use is low in their states. Some attributed the low use in Florida to provider uncertainty about their legal status, most likely because the state’s regulations do not define NRAs as a document, but rather identify “managed risk” as a process connected to service planning. Some experts suggested that in Florida, NRAs are most likely used by larger facilities and corporate chains that have a policy mandating them.

Based on interviews with experts, NRA use may be low in other states as well. Both experts and providers in Oregon indicated a low rate of use. They suggested that possible reasons may include: (1) most residents not making choices that have a high risk for negative outcomes; (2) a policy and practice climate that treats the NRA as a route of last resort; and (3) uncertainty over the legal status of NRAs. One legal expert commenting on this latter concern observed that ultimately, the legal status of any

contract is unknown unless and until there is a breach and an enforcement of the contract via judicial process.

The experts and stakeholders we consulted for this study varied in their views regarding provider awareness and use of NRAs. A little over half thought that assisted living providers' awareness of NRAs is moderate to high but that their interest in using NRAs is somewhat lower.<sup>19</sup>

### **III. THE DEBATE ABOUT NEGOTIATED RISK AGREEMENTS**

As assisted living has grown in popularity, NRAs have generated a great deal of debate among consumer advocates, providers, regulators, and LTC policy and legal analysts--some of it contentious. The debate includes not only the legal concepts underlying NRAs and the policy issues related to their use, but also how they should and should not be used in practice. At the most basic level, proponents see NRAs as a tool that is paired with assessment and service planning to accommodate resident choice in regulated settings, while opponents see it as a strategy for assisted living providers to avoid liability for poor care.

#### **Purpose of NRAs**

States and the majority of proponents believe NRAs have several purposes, providing: (1) a tool for identifying and reducing risks, (2) a means for assigning responsibility and limiting provider liability, and (3) a method to support residents' rights to make choices that entail risk.

In this section, we review the competing views regarding each of these conceptual purposes. It is important to note that while we discuss "proponent" and "opponent" views in the aggregate, not all proponents or opponents share each of the views ascribed to the larger group.

We also summarize and analyze the current legal and policy debate over the use of NRAs as presented in the literature and by the experts and stakeholders we interviewed. We begin with a discussion of views regarding the purposes of NRAs, followed by a discussion of liability waivers--the central issue that polarizes views about NRAs. We also discuss the potential role of the service planning process to provide some of the perceived advantages of NRAs, the relationship between NRAs and regulations, appropriate and inappropriate risks to address in an NRA, and issues related to the use of NRAs with cognitively impaired residents.

#### ***NRAs are a Tool for Identifying and Reducing Risks***

Proponents believe that NRAs can reduce risks and lead to better overall outcomes by: (1) helping to identify potential risks, (2) fostering discussions about risk issues by residents and families, (3) looking for creative alternatives to lessen risks, and (4) formalizing what is usually an informal exchange between the provider and resident and/or family by documenting the facility's awareness of and efforts to address identified problems.

A review of the regulations in the 15 states that address NRAs indicate that states also perceive NRAs as a means to identify and reduce risks. For example, New Jersey states that the purpose of “managed risk” agreements is to avoid or reduce the risk of adverse outcomes through a process that balances resident choice and independence with the need to assure the health and safety of the resident and other persons in the facility. The District of Columbia states that the purpose of “shared responsibility” agreements is to provide a process to deal with disagreements, wherein the resident or their surrogate and the facility together determine an acceptable balance between the resident’s desire for independence and the facility’s legitimate concerns for safety.

The strongest opponents tend to view NRAs as having a sole purpose--an attempt to avoid liability for negative outcomes. Others recognize that “good” providers may use NRAs to identify and reduce risks, but fear that “bad” providers will use them to force residents to accept substandard care because they have no practical alternative or fear discharge to an institutional setting. Several argue that residents are in an unequal bargaining position due to frailty, lack of acceptable alternatives, and the difficulty with relocation.

While both proponents and opponents of NRAs expressed concerns about unequal bargaining positions, they were divided regarding the ability to mitigate the potential negative consequences through law and regulation. Opponents believe that prohibiting NRAs altogether rather than risking abuse best serves the public interest; proponents believe the public interest is best served by allowing NRAs and implementing regulatory protections.

### ***NRAs are a Means to Assign Responsibility and Limit Provider Liability***

Some experts believe NRAs are a strategy for implementing the assisted living philosophy of resident autonomy, rather than the traditional model of “imposed protection” by mitigating “law-related anxiety.”<sup>20</sup> They see them as a practical strategy for working within an “intimidating malpractice and regulatory climate that pervades health care delivery” to overcome provider policies--some legally imposed--that limit resident choice and risk assumption in order to assure safety. NRAs help give providers the comfort they need to allow exceptions to these policies when they conflict with a resident’s preference. Some also assert the need and right of providers for liability protection if residents are afforded the autonomy to choose not to follow staff’s advice and, as a result, experience a negative outcome. However, none believe that NRAs should ever include a blanket waiver of liability.

Only a few experts believe that NRAs, even with explicit waivers of liability, can limit provider liability if negligence is involved. Nonetheless, even if the potential liability limitation is more a perception than a reality, some see it as an advantage because without it providers will not be comfortable tolerating behavior that they have identified as risky. Several people we interviewed referred to a culture of “liability anxiety” in LTC settings as a major force driving provider activities. One provider commented, “The reality in this industry is lawsuits.”

Several attorneys we interviewed specifically discussed NRAs as a valuable liability reduction tool whether or not they include liability waivers. They noted that family members are less likely to sue for bad outcomes if they are included in an NRA process and, as a result, have a good relationship with the provider and understand the provider's efforts to minimize risk and maximize safety while at the same time honoring their relative's desire for autonomy.

A policy expert suggested that residents and their families would be unlikely to sue if they believed the provider was genuinely working with them to provide care the way they and their relative wanted it delivered. He also noted that juries would see the NRA document as evidence that the provider cared about outcomes and acted responsibly to alert the resident to risks, provide alternatives, and respect the resident's preference. Despite evidence that early discussions about negotiated risk included liability relief as a component of the negotiated risk concept,<sup>21</sup> there appears to be a recent shift among some proponents away from including liability waivers in the agreements.<sup>22</sup> It is not clear how the absence of liability waivers will impact provider adoption of NRAs.

Concerns about liability waivers are the primary reason consumer advocates from the legal profession oppose the use of NRAs, though they are joined by other consumer advocates, regulators, and some providers. Several claim that the sole or primary purpose of NRAs is to provide a mechanism--through a waiver--for facilities to avoid liability for substandard, inadequate, or negligent care. They see NRAs as a dangerous and unfair practice through which older persons are pressured or tricked into waiving the facility of all liability and fear that proponents are naïve when they argue otherwise.<sup>23</sup> They believe NRAs will be abused to allow providers to under-staff facilities and retain inappropriate residents in an effort to boost profits.<sup>24</sup>

These views are based in part on the published statements of providers (e.g., a trade association publication referred to NRAs as "one piece of a liability reduction strategy,"<sup>25</sup> and a recent article on NRAs asserted that "at bottom," NRAs are a way "of releasing facilities from liability.")<sup>26</sup>

Ohio specifically addresses whether a resident can choose to remain in an assisted living facility that does not offer services the resident needs, stating "if a resident requires certain personal care services that the residential care facility does not offer, the facility shall comply with paragraph (G) of rule 3701-17-58 of the Administrative Code,<sup>27</sup> and the facility or the resident shall arrange for the services to be provided; or the facility shall transfer the resident to an appropriate setting or discharge the resident...; or the facility and the resident may enter into a risk agreement...if the facility has a policy of entering into such agreements."

Opponents do not accept that abuse of liability waivers can be limited through regulation and oversight. Most oppose NRAs even if they do not include any reference to the provider's liability, believing NRAs will suppress lawsuits for negligent provider actions because residents and their families will feel that they have given up their right

to sue. This perspective is reflected in a recent policy statement from the National Senior Citizens Law Center that opposes any use of NRAs in assisted living.<sup>28</sup> Proponents have countered that unscrupulous providers could attempt to inhibit residents from pursuing lawsuits regardless of whether NRAs had been used.

Some state regulations use language regarding residents' assumption of risk, which suggests that the provider is afforded some liability protection in the event of a negative outcome. Wisconsin's regulations express this most clearly, by requiring that every resident in a RCAC have a signed, jointly NRA at the time of admission "as a protection for both the individual tenant *and the residential care apartment complex*" (emphasis added). Nonetheless, Wisconsin specifically states that a risk agreement may not waive other regulatory provisions or "any other right of the tenant," presumably including the right to sue in the event of a bad outcome.

Only four of the 15 states with NRA regulatory provisions specifically prohibit the use of NRAs as a liability waiver in some or all instances. Vermont states that "negotiated risk does not constitute a waiver of liability." Delaware states that facilities "shall make no attempt to use the managed/negotiated risk portion of the service agreement to abridge a resident's rights or to avoid liability for harm caused to a resident by the negligence of the assisted living facility and any such abridgement or disclaimer shall be void." Washington prohibits facilities from requiring or asking residents or their representatives to sign any contract or agreement, including a negotiated service or risk agreement, "that purports to waive any rights of the resident or that purports to place responsibility or liability for losses of personal property or injury on the resident."

New Jersey has the strongest language, stating that "any provision or clause waiving or limiting the right to sue for negligence or malpractice in any admission agreement or contract between a patient and a nursing home or assisted living facility, whether executed prior to, on or after the effective date of this act, is hereby declared to be void as against public policy and wholly unenforceable, and shall not constitute a defense in any action, suit or proceeding."

### ***NRAs Provide a Means to Support Residents' Rights***

Proponents, including some consumer advocates, believe that the defined negotiation process contained in NRAs, and any training that accompanies their use, raises staff and families' understanding of residents' rights to assume risk. They also feel that NRAs create a process that facilitates residents', their families', and staffs' advocacy for residents' choices even when others may view their choices as risky. Several experts thought the NRA process could encourage providers to support resident choice because the process itself might help them realize that some of their concerns are vague and do not warrant the restrictions imposed on the resident.

NRAs are seen as a useful process to help residents and providers come to agreement when a resident's desired course of action or continued occupancy is

allowed by regulations but seen as risky by the provider. Experts also noted a potential role for NRAs in enforcing the Americans with Disabilities Act (ADA) and Fair Housing Amendments, such as when courts require a provider or the state to craft a “reasonable accommodation” for a person with disabilities (young or old) to a broad admission or discharge requirement. The role that NRAs could play would be either to:

- provide a process for addressing specific concerns once a court rules that a reasonable accommodation is required, or
- provide a process within state law or regulations that gives residents the ability to supersede provider or state-ordered admission or discharge requirements under certain circumstances.

As one legal expert noted regarding “reasonable accommodation,” NRAs could help resolve the inherent conflict in the law between a desire to protect individuals’ with disabilities rights to choice and autonomy and the government’s interest in implementing minimum standards for LTC providers through enforceable uniform requirements and proscribed processes and procedures.

The experts we interviewed believe that the two main advantages NRAs offer are a formal process that educates consumers and staff about residents’ rights to assume risk, even when staff and families disagree, and a mechanism for residents to document and enforce risk-taking decisions without fear of being asked to move out. An expert in LTC policy and nursing home litigation interviewed for this paper explained that in a “litigation-charged atmosphere,” NRAs are a tool that can both protect the facility through documentation of an agreement or, potentially, an explicit waiver that allows greater autonomy for residents. She emphasized that NRAs are not about “shirking responsibility” but rather are a realistic approach to working within what another expert described as an “ageist” social and policy culture that thinks older persons need to be protected.

Some proponents believe that NRAs are a necessary strategy to allow residents to maintain autonomy in residential care settings that are intentionally different from heavily regulated nursing facilities. Specifically, while they recognize that assisted living is a licensed setting with expectations for quality of care that protects the well-being of residents, it is conceived and embraced as a consumer-driven model that attempts to balance the rights of older adults to retain the autonomy to make their own decisions.

Opponents give little credence to the fear that providers will limit choice in the absence of a risk agreement. Many believe that residents in regulated care settings should not be allowed to choose to remain in a setting that cannot meet their needs. These opponents maintain that residents should not have this choice even if the resident is prepared to forego the services or find alternative ways to meet their needs because they cannot make good decisions in these situations due to a variety of factors, including emotional and financial distress, provider manipulations, and a lack of appropriate information and expertise.

Predictably, NRA proponents view this attitude as paternalistic. One legal expert noted that the logical extension of this reasoning could be to deny all potentially vulnerable persons or their surrogates the right to choose because of a perceived risk of a negative outcome or abuse.

When asked about the potential role of NRAs in assuring residents' ability to assume risk in pursuit of preferred choices, some opponents stated that residents do not lose legal rights when they enter assisted living or other LTC settings. Instead, they expressed strong opinions that NRAs were not the answer to protecting or expanding the rights of consumers in LTC; rather better enforcement of existing rights is needed (e.g., the right to refuse treatment or a recommended plan of care). In fact, these advocates expressed deep concerns that NRAs provide a vehicle to limit the existing rights of residents by creating an atmosphere that suggests that residents must negotiate a compromise to follow a preferred course.

Proponents do not accept this argument and observe that providers have traditionally limited residents' choices or preferences through legally enforceable program policies enumerated in the contract, and through subtle or not so subtle coercion (e.g., by telling residents if they do not comply with facility policy they will be discharged). These limitations are driven, proponents argue, by well-meaning paternalism, liability concerns, and measures providers believe to be necessary to comply with state regulations. One legal expert noted that residents' rights in assisted living and other LTC settings depend to a great degree on state law. If the state does not apply landlord-tenant law to assisted living, the provider may, in effect, be the law and absent an NRA, residents may have no way to insist that their preferences be honored.

Several states believe that one of the primary purposes of an NRA is to assure residents' rights. For example, Oregon's rules state that residents are to be given "informed choice and opportunity to select or refuse service and to accept responsibility for the consequences." Washington states that a resident has a right to "take responsibility for the risks associated with decision-making" and that residents are permitted to refuse any particular service "unless adjudged incompetent or otherwise found to be legally incapacitated to direct his or her own service plan and changes in the service plan," and "so long as such refusal is documented in the record of the resident."

Illinois has the strongest statement of a resident's right to assume risk, stating a resident has the right "to direct his or her own care and negotiate the terms of his or her own care," and "to refuse services unless such services are court ordered or the health, safety, or welfare of other individuals is endangered by the refusal, and to be advised of the consequences of that refusal."

## Ability of NRAs to Limit Liability

As mentioned previously, the inclusion of liability waivers in NRAs--specific or implied--is the main issue that polarizes views about NRAs. Some proponents claim that NRAs are not and never were intended to limit provider liability while other proponents argue that they were always intended to create a balance within a regulated setting, allowing resident autonomy by providing an appropriate amount of liability protection for providers. The early literature on NRAs includes discussions of the importance of limiting liability in order to accommodate resident choice.<sup>29</sup> Many continue to argue that without limiting provider liability that could result from residents' risky choices, providers will continue to restrict residents' autonomy in favor of safety.<sup>30</sup> Some proponents note that while it may be appropriate for providers to ask residents to waive liability specific to outcomes connected to a defined resident choice, blanket waivers of liability are never appropriate.

An interesting feature of the debate about NRAs and liability waivers is that few proponents or opponents believe that NRAs can effectively limit legal liability, whether or not they include a specific liability waiver. Virtually no one believes that broad liability waivers are enforceable due to several legal precedents and principles, including the duty to provide an acceptable standard of care, the inability to waive liability resulting from negligence, and certain principles of contract law (e.g., unequal bargaining power).<sup>31</sup>

The enforceability of a liability waiver regarding a specific behavior is also questioned, with the majority believing "it depends." In the course of our interviews, we heard about only four legal cases involving NRAs or related issues. An expert cited a Florida case involving an NRA, but was not able to provide details. Of two cases identified in Virginia, one had a sealed settlement that could not be discussed. The other involved an NRA that addressed the risk of falls and a bad outcome, and was dismissed because of the written NRA, suggesting that the NRA did afford some liability protection.

When NRAs follow a carefully designed process and include a narrow liability waiver based on residents' explicit choices, some experts believe they could be enforceable and limit provider liability for negative consequences stemming from the named choice.

*"Taken together, the well established legal principles of informed consent, assumption of risk, and comparative negligence suggest that a resident or his legal representative who is able to understand and express his preferences, and who has been fully informed of and understands the attendant risks, would be held to the choices he made, including the decision to assume the risks of a negative or harmful outcome. Adding support to the prediction that negotiated risk agreements, when properly used, will be supported by the courts is the fact that a number of states expressly refer to negotiated risk agreements in their licensing regulations for assisted living."<sup>32</sup>*

Those who believe NRAs could mitigate liability acknowledge that this view is untested in case law.<sup>33</sup> One legal review article concluded that NRAs are not inherently unenforceable contracts but that their enforceability depends on state law (e.g., assisted living regulations, public policy, legal treatment of negligence and assumption of risk, and contract law), as well as the particular facts and circumstances addressed in the NRA and the process used to execute it. Given this, the enforceability of NRAs could be enhanced by constructing and implementing the agreement in accordance with the specific principles underlying enforceable contracts in that jurisdiction.<sup>34</sup>

While their enforceability may be in question, some believe that NRAs can still serve a useful function in defending against a lawsuit, by demonstrating that staff had identified and addressed risks with the resident, provided options, and honored the resident's choice. An attorney who advises assisted living providers commented that, though NRAs remain untested in the courts, if it came to a lawsuit, the NRA would be "exhibit number one." Clearly, the use of an NRA as a defense would necessitate an examination of the specific circumstances. A situation in which the provider had adequate staff and offered assistance that the resident refused would likely be viewed differently than one where the provider was incapable of meeting the resident's needs and the resident signed a liability waiver to avoid being discharged.

None of the experts believe that liability waivers would be enforceable when negligence resulted in harm to a resident or if providers violated express regulatory requirements. Several NRA opponents did note, however, that even if unenforceable, liability waivers could dissuade residents and their families from initiating valid legal actions when they believe that the provider has been negligent.

## **NRAs and State Admission and Discharge Requirements**

Several opponents believe that providers will use NRAs to allow residents to remain at the facility after their needs exceed regulatory discharge requirements--sidestepping regulations in an effort to maintain their facility's census without increasing staffing. The consensus of legal experts was that NRAs or any private contracts, as a general rule, can not overrule regulations or law because deregulation by private contract is not enforceable. Nor can NRAs supplant a provider's fulfillment of a statutory duty.<sup>35</sup>

Some states explicitly prohibit the use of NRAs to override state mandated discharge requirements. For example, Arkansas prohibits the use of an NRA to permit residents to remain in a facility if their condition violates a state-mandated discharge trigger. Delaware prohibits the use of a risk agreement as a means "to retain residents whose needs the facility cannot meet, or to supersede any other regulatory requirements."

Nonetheless, it appears that NRAs and similar agreements can be specifically included in regulations as a mechanism to allow residents to accept risks within

parameters established by regulations or as a defined mechanism with which to override state discharge requirements under certain circumstances. In other words, residents do not have a right to use NRAs to enforce their choices in opposition to the state's (or, generally, the provider's) rules unless the state explicitly provides in law or regulation for NRAs to do so.

For example, Ohio's assisted living regulations specifically allow residents to use NRAs when they meet state residency criteria and want to remain at the facility but the facility does not offer services to meet some of their needs or they choose to decline services. Ohio regulations state that a provider must "provide personal care services to its residents who require those services, unless the resident and the facility have entered into a risk agreement...or the resident has refused services." Furthermore, "if a resident requires certain personal care services that the residential care facility does not offer, the facility...or the resident shall arrange for the services to be provided; or the facility shall transfer the resident to an appropriate setting or discharge the resident; or the facility and the resident may enter into a risk agreement if the facility has a policy of entering into such agreements."

A Michigan law goes further, allowing assisted living residents to assert their choice to remain in assisted living under certain circumstances, even if they exceed state-mandated discharge requirements. Enacted in 2001, in response to an ADA lawsuit, the law specifically gives consumers the ability to override state discharge requirements for assisted living if they can reach agreement with the provider, their physician, and their family about how they will receive necessary services.

*Sec. 21325. If a resident of a home for the aged is receiving care in the facility in addition to the room, board, and supervised personal care specified in section 20106(3), as determined by a physician, the department shall not order the removal of the resident from the home for the aged if both of the following conditions are met: (a) The resident, the resident's family, the resident's physician, and the owner, operator, and governing body of the home for the aged consent to the resident's continued stay in the home for the aged. (b) The owner, operator, and governing body of the home for the aged commit to assuring that the resident receives the necessary additional services.<sup>36</sup>*

Texas and Louisiana have passed similar legislation. However, none of these three states defines NRAs in regulation.

### ***Conflicts Between Discharge Regulations and Federal Anti-Discrimination Laws***

Several experts believe that while NRAs cannot override regulations without explicit state authority to do so, they may serve a useful role in crafting "reasonable accommodations" settlements when state and provider admission and discharge criteria are successfully challenged using federal and state disability law; for example, the ADA of 1990, the Fair Housing Act (FHA) of 1968 and its subsequent amendments, Fair Housing Amendments Act (FHAA).<sup>37</sup>

Case law establishes that, under specific circumstances, individuals with disabilities and their surrogates can successfully challenge state or provider-mandated

admission and discharge requirements when they are overly broad and found, as a result, to be discriminatory. NRAs could play a role in settling these suits, providing a tool to address residents' and providers' concerns about autonomy, safety, and liability.

On the other hand, NRA opponents argue that when regulations limit choices protected by the ADA, FHA, and FHAA then the regulations need to be changed rather than using an NRA to override them. This argument assumes that regulations can be modified in ways that will protect residents who do not want to take risks while allowing choice for those who do--without the use of NRAs. NRA proponents question whether such an approach is feasible.

The core concern that opponents express regarding the use of NRAs to override discharge criteria is that this practice would allow residents to stay in a facility with less service capacity than they need while releasing providers from any obligation to meet their needs. Opponents fear that some residents lack an understanding of what services they need and the consequences of doing without them. Opponents also worry that some residents will make bad decisions to avoid a move.

Opponents worry that this lack of understanding or a strong reluctance to move (especially to a nursing home) will embolden providers to use NRAs to increase profits by cutting staffing and services without risking liability or a loss in occupancy. With NRAs potentially relieving providers of the general regulatory requirement to ensure residents' health and safety (i.e., meet all the needs of an individual resident), opponents believe that many providers will use their unequal bargaining power to threaten discharge if a resident will not accept fewer services than they need and waive the provider's liability. They also worry that the use of NRAs will leave even surveyors powerless to ensure quality care and safety. For example:

*"When surveyors threaten state sanctions [due to inadequate staffing and services to meet residents' needs], the facilities cite [NRAs] as justification for residents' rights to choose inadequate care and concurrently to release facilities from liability from any harm which may befall the resident as a result of such inadequate care...As mentioned above, negotiated risk puts residents' health and safety at risk."<sup>38</sup>*

States have an option other than NRAs to allow residents to stay in a facility after they exceed discharge requirements: they can issue a waiver allowing the resident to remain if certain conditions are met. However, since these waivers are provided at the discretion of state regulators, many argue that they do not replace the need for measures to enhance residents' ability to challenge state or provider mandated discharge.

## **Service Plans as an Alternative to NRAs**

States' views vary regarding differences between NRAs and service plans. Nine of the 15 states that include NRAs or similar concepts in regulation define them as a component of service planning or create some linkage between them and service plans.

Most states, however, do not reference NRAs or require a similar process in regulations prescribing the service planning process.

NRA opponents believe that any potential benefits NRAs offer can be obtained through the use of comprehensive and thorough service plans or a specialized service planning process as an addendum to the regular service plan. Even some NRA proponents believe NRAs will not provide any greater liability protection than would a comprehensive service plan that included the same information.

Others disagree, stating that risk agreements are not synonymous with service plans, serving complementary but distinct purposes. They believe that service plans are based on a physical, medical, and social assessment of the resident and specify services deemed necessary by a physician and/or nurse to be delivered in accordance with resident preferences. In contrast, NRAs are used when a resident wants to deviate from the service plan or to address “lifestyle” issues not typically covered in service plans. They also believe that NRAs offer a unique process that requires providers and residents to discuss the consequences of choosing to take a risk, a discussion not typically present in service planning.

Legal analysts also argue that if the NRA is to be an enforceable contract it needs to be a distinct agreement: “To the extent that a resident and provider intend to reach a definitive agreement concerning a certain risk, the typical service plan is not designed to be an enforceable contract by itself and often lacks necessary elements for a binding contract such as mutuality of consideration.”<sup>39</sup>

Several experts noted that nothing precludes a facility from using specialized forms as addendums to service plans to document discussions about risk issues that pertain to services--for example, dietary noncompliance--and to record providers’ suggestions and residents’ choices. The key differences would be that such forms would simply document that the resident is aware of the risks and chooses to assume them without addressing liability and the elements of a distinct negotiation would be absent. NRAs on the other hand, when viewed as a *contract* would require the resident to either implicitly waive provider liability by stating she assumes responsibility for the consequences of her action, or explicitly waive provider liability for any negative result of her choice.

## **Types of Risk Considered Appropriate for NRAs**

An important issue for both proponents and opponents is whether residents should have an unfettered right to choose to do what they want while living in an assisted living setting. While competent residents have the legal right to refuse treatment and the advice of a provider concerning safety concerns, providers are obligated to maintain standards of care and may, under certain circumstances, legitimately curtail or discharge residents if the provider feels their behaviors pose too great a risk. Wisconsin’s regulations uphold this right, stating that while neither the tenant nor the facility shall refuse to accept reasonable risk, neither shall they insist that the other party

accept unreasonable risk (no guidance is provided on what constitutes reasonable or unreasonable risk.)

Proponents and opponents also question whether there are certain behaviors that should never be the subject of negotiation. We asked the experts and stakeholders consulted for this study about their views on appropriate and inappropriate types of risks to be included in an NRA. In general, most indicated that a determination of whether a risk was appropriate or inappropriate would require a consideration of the physical and mental condition of the resident, the type and degree of risk, and the severity of potential negative outcomes.

About a third believed that any type of risky behavior that residents could pursue in their own home would be appropriate for an NRA.<sup>40</sup> Some identified one or more areas that they believed were always inappropriate for an NRA, including behaviors that put other residents and staff at risk of harm and those prohibited by law or regulation. However, some experts indicated that minimal risk to others or those entailing only minor consequences might be acceptable.

Within the category of risks that might affect others, views on smoking varied. Some believed it is a non-negotiable topic and should not be allowed if it poses any risk, while others felt that it could be addressed in an NRA under certain circumstances, for example, specifying that a person is allowed to smoke only in designated areas or under staff or family supervision. Some felt smoking restrictions should be specified in a facility’s rules, in which case they would not be an appropriate topic for an NRA since all residents are expected to comply with them.

We asked the experts to provide their views on using an NRA in three hypothetical cases: overriding discharge criteria regarding ability to self-evacuate, refusing medications, and refusing to use a walker. The response categories and number of experts in each are listed in Table 1.

<b>Response</b>	<b>Override Discharge Criteria Regarding Self-Evacuation</b>	<b>Refuse Meds</b>	<b>Refuse Walker</b>
Appropriate	5	12	17
Inappropriate	9	7	5
Depends/maybe	10	4	2
Uncertain/no response	2	3	2

**Overriding Discharge Criteria Regarding Self-Evacuation.** While many believe that NRAs should not and could not be used to allow residents to remain in a setting when they no longer meet regulatory discharge requirements, a little less than half said “it depends.” Potential solutions proposed to address such a situation include revising regulations that are overly prescriptive and allowing regulatory waivers. For example, states that require residents to be able to self-evacuate might issue a waiver allowing an individual to stay as long as the facility could demonstrate that the staff could evacuate him (e.g., by placing him in a room on the first floor closest to an exit).

***Refusing Medications.*** Experts were divided on whether an NRA should be used if residents refuse to take prescribed medication. Some felt that refusing any type of care, including medications, was an appropriate issue for an NRA while others stated that residents have a right to refuse medications and so an NRA is not necessary. Others believed that the appropriateness of an NRA would depend on the type of medication, physician input, and the severity of potential negative outcomes. For example, a refusal to take insulin should not be allowed, whereas a refusal to take blood pressure medications might be allowed, depending on the circumstances.

***Refusing to Use a Walker.*** Most experts agreed that an NRA would be appropriate if a resident refused to use a walker even though her physician and physical therapist stated that she was at high risk for falling if she does not. A few disagreed, noting that all health care settings, including hospitals and nursing facilities, grant patients the right to refuse medical advice, and a resident should not have to negotiate or release a facility from liability to exercise this right. Three state LTC ombudsmen argued that this issue is best addressed in service planning.

In summary, the only behaviors that everyone agreed would be inappropriate were those that posed a significant risk to others. In other cases, opinions were divided. Most agreed that a determination of appropriateness depended on unique circumstances. Florida is the only state that specifies an appropriate/permitted topic--residents' refusal to comply with prescribed diets. Several providers noted they would welcome more guidance from states on this issue, particularly Wisconsin providers who are mandated to use NRAs with all residents.

## **Determining and Reassessing Cognitive Function and Capacity**

Three studies of the prevalence of dementia among assisted living residents found rates of 12-66 percent.<sup>41</sup> It is likely that a significant portion of residents without a diagnosis of dementia also have cognitive impairment. The high prevalence of cognitive impairment among assisted living residents raises a number of policy issues related to the use of NRAs with this population, including: (1) whether providers are accurately identifying individuals with impaired decision-making capacity; (2) whether informal assessments underestimate or overestimate a resident's capacity to assume risk; (3) whether mandatory assessments of competence should be required for assisted living residents prior to executing an NRA and what the civil rights implications of such a requirement are; (4) whether guardians and powers of attorney should have the authority to enter into NRAs on residents' behalf; and (5) whether an NRA should remain valid if a resident subsequently loses the mental capacity to understand the consequences of their actions.

Only seven of the 15 states' regulations specifically address residents' capacity or ability to understand an NRA. Oregon's rules specify that facilities may not enter into or continue a risk plan with or on behalf of residents who are unable to recognize the

consequences of their behavior or choices. Wisconsin prohibits persons with cognitive impairment from moving into a RCAC unless that person moves in with a spouse or relative who is formally designated to sign an NRA on his or her behalf.<sup>42</sup>

Wisconsin's regulations state that "incapable of making care decisions" means that individuals are unable to understand their own needs for supportive, personal, or nursing services; to choose what, if any, services they want to receive to meet those needs; and to understand the outcome likely to result from that choice. The regulations specifically clarify that the term "incapable" refers to the ability to make a decision and not to the content or result of the decision.

The other five states reference capacity but do not provide specific guidance. For example, Alaska and New Jersey require that NRAs be explained or written in "understandable language." Arkansas requires facilities to have written proof that residents or their "responsible parties" are making an informed decision, but do not specify how that proof is to be obtained. Florida's rules permit the admission and retention of persons with dementia in Extended Congregate Care (ECC) facilities, but have no provisions for written NRAs. None of the 15 states with regulations pertaining to NRAs or related concepts specify or require a method for assessing residents' capacity to make decisions.

We asked experts and stakeholders a number of questions related to mental capacity: (1) whether facilities should perform a formal assessment to determine residents' mental capacity to participate in an NRA process, and if so, whether they should use a uniform method for determining and reassessing mental capacity; (2) how capacity is currently assessed; (3) whether an NRA should be invalidated if a resident declines cognitively after signing it; and (4) whether family members and legal surrogates should be able to negotiate and sign on a resident's behalf.

Experts and stakeholders were uncertain if or how assisted living providers assess residents' capacity. Most believed that a combination of methods and sources of information, mostly informal, are likely used, including a physician or other health care provider's assessment and observations by the resident's family and staff. Several noted that capacity could vary based on time of day, as well as physical and psychological factors. Florida regulators noted that a physician's assessment is required for all ECC residents on an annual basis and that part of the required assessment is the physician's opinion regarding the resident's cognitive capacity.

Several agreed that providers should assess the resident's capacity to understand the nature and consequences of an agreement, particularly if staff suspect a resident is incapable of consenting. Several consumer advocates object to assessing decision-making capacity before executing NRAs, citing the legal principle of presumed competence unless there is evidence to the contrary. They view the assumption of competence as critical to preserving residents' rights. However, given the high prevalence of cognitive impairment among assisted living residents, others argue that a presumption of competence may be a flawed approach.

Studies of informed consent that used global measures of capacity demonstrated a range of capacity among the study population based on the setting, suggesting that subsets of older populations may need a formal evaluation of decision-making capacity before entering into agreements requiring informed consent.<sup>43</sup>

One provider noted the lack of a formal process for determining mental capacity, but said that staff members “can tell” if a resident is not capable of understanding the consequences of a choice. If the resident is deemed not capable, this provider includes family members in discussions of choice and potential risk.

Of the 26 experts and stakeholders asked whether facilities should use a standard method to assess residents’ capacity to participate in an NRA process, eight said yes, 13 no, and five were uncertain. Several referenced barriers such as the lack of universally accepted assessment tools and practical realities such as cost, staff training, and reliability across different settings. Many felt that even without a formal method, providers “should know” if a resident is cognitively impaired and if the resident has the capacity to make a decision in a specific area. Several noted that residents with cognitive impairment can retain decisional capacity in some areas, and so a determination of cognitive impairment should not preclude the use of NRAs in all situations.

### ***Allowing Third Parties to Negotiate a Risk Agreement***

Eleven of the 15 states with regulatory guidance on NRAs indicate that a “responsible party” may sign a risk agreement as a proxy for the resident--Alaska, Arkansas, the District of Columbia, Florida, Illinois, Iowa, New Jersey, Ohio, Oklahoma, Oregon, and Wisconsin. None prohibit proxy signatures for NRAs. Some states require that this person be a guardian or an individual with an activated power of attorney. The others do not specify legal requirements for responsible parties. Some states reference surrogate decision makers but do not define them.

Other states include provisions regarding the involvement of third parties such as guardians or “legal representatives” but do not give them authority to sign an NRA. For example, Vermont’s regulations state that the provider shall initiate the negotiated risk process by notifying the resident and, if applicable, the legal representative, verbally and in writing. New Jersey requires the resident to agree to involve the resident’s family or representative in the NRA process but does not require that anyone sign the NRA document.

Most experts believed that if residents exhibit behavior that raises concerns about their competence, a legal surrogate, including both family and non-family representatives, should be allowed to sign an NRA on their behalf as long as the surrogate has been designated in advance and is acting in the resident’s best interest. When legally responsible parties are allowed to sign for an impaired resident, some attorneys caution that providers will need to determine if the third party is acting in the

resident's best interest and intervene if they believe the decisions are motivated by other considerations. For example, a family member could insist on an NRA to allow a refusal of medication administration services because of their cost, not because the resident wanted to self-administer medications.

Others said the appropriateness of involving surrogates depends on the severity and imminence of the risk posed. For example, the guardian of a resident with severe dementia who wanders and has gotten lost many times should not be allowed to sign an NRA that allows the resident to take unaccompanied walks. A state agency employee felt strongly that allowing another person to sign an NRA for an incompetent resident "nullifies the entire point of the managed risk concept as a way of making choices and accepting consequences." Some agreed, stating that the NRA philosophy precludes third-party involvement.

Others felt that family members and other designated representatives should be allowed to sign an NRA accepting risks regarding behaviors that they know are important to their relative's quality of life, especially if the responsible party was familiar with the resident's preference before he or she became impaired. For example, a daughter might decide that since her diabetic mother had regular ice cream each night before becoming cognitively impaired she should be able to continue after she becomes impaired. Another example might be if a husband knows that his cognitively impaired spouse becomes depressed if she cannot take walks outside the facility, he may want to sign an NRA that allows her to continue, accepting the risk that his wife might fall or get lost. Knowing his wife well, the husband may view the negative impact of depression for his wife as a greater and more imminent risk than the risk of falling or getting lost.

Experts varied in their opinions about who should be involved if no legal representative has been designated or is available.

### ***Should an NRA be Invalidated if the Resident's Mental Capacity Later Declines?***

Seven states specify when or how to review NRAs. Alaska requires that risks associated with resident choices be documented in the service plan, which must be reviewed quarterly for residents who receive health-related services and annually for those who do not. Similarly, Washington rules link risks to the service agreement, which must be reviewed semiannually. Oregon requires assisted living providers to review risk agreements "at least quarterly." Arkansas, Delaware, and Illinois rules do not specify a specific time frame, instead stating that the agreement should include the review schedule, if any.

In Wisconsin, providers must update the risk agreement "when the tenant's condition or service needs change in a way that may affect risk" as indicated in the resident's comprehensive assessment or service plan. Many experts and stakeholders agreed with Wisconsin's approach, but also felt that NRAs should also be reviewed at regular intervals.

Nearly all agreed that providers need to determine whether or not an NRA should remain valid when residents experience a cognitive decline or a change in condition that increases the imminence or severity of potential consequences. However, their opinions regarding what providers should do varied considerably. Some felt the NRA should not remain valid when a resident no longer recalls the agreement or understands the consequences. Others felt it would depend on several factors, including the resident's physical and mental condition, the issue covered in the risk agreement, and the type, likelihood, and severity of potential harm. For example, an NRA requiring a woman with diabetes to alert staff when she eats sweets so staff can adjust her insulin should be invalidated if the woman is no longer able to alert staff.

Oregon is one state that explicitly addresses this issue in its regulations, stating that a managed risk plan shall not be entered into *or continued* with or on behalf of residents unable to recognize the consequences of their behavior or choices. However, it is possible that a resident could sign an NRA and specify that she wants it to remain in force even if she declines cognitively and is unable to make an informed decision.

In sum, views regarding a range of issues related to residents' capacity to execute NRAs varied considerably and in some cases, opposing views were quite contentious. Some believe that residents with diminished capacity should not execute an NRA, while others believe that residents with diminished capacity, or their legal representatives, should be able to make decisions regarding risks and preferences, at the very least in situations where the risk of harm is not imminent and the potential harm is not severe.

## **IV. SITE VISIT FINDINGS**

### **Introduction**

Most of the experts and stakeholders we interviewed had strong views about NRAs, but few had firsthand experience with an NRA or had participated in an NRA process. The primary purpose of our site visits was to get a sense of how NRAs are actually used and the views of those directly involved. To see firsthand how people use and think about NRAs, we visited seven facilities in three states--Florida, Oregon, and Wisconsin--and spoke with 20 assisted living residents with NRAs, two family members, and 24 staff, including staff at the management level who had direct experience with NRAs and at least one direct care employee. We also reviewed the written NRAs for the residents, totaling 31 (some residents had more than one). See Appendix A for detailed information about study methods and Appendix D for a brief description of study participants.

In preparation for the site visits, we talked with 26 stakeholders and experts in the three states, including state agency staff, consumer advocates, assisted living industry representatives, attorneys, insurers, and ombudsmen. See Appendix C for a list of those interviewed. These discussions provided important information about the legal, regulatory, and policy environments in each state. A summary of each state's regulations pertaining to NRAs can be found on the next page. See Appendix B for more detailed information about these regulations.

We next present our findings regarding how providers are using NRAs, the issues they address, and what residents and providers think about them.

### **Factors Affecting the Decision to Initiate an NRA**

In all three states, potential and actual risks were typically identified by a facility employee--generally either a direct care worker or a nurse--and brought to the attention of a supervisor or the person responsible for administering risk agreements. In no case did a resident or family member initiate the risk agreement. NRAs were generally not initiated after a first report of a risky behavior, but rather after a second or third occurrence. In all cases, a senior staff member such as an administrator or registered nurse first initiated a discussion with the resident about the issue causing concern. If after discussing the facility's concerns, a resident voluntarily discontinued the risky activity, then a formal NRA process was not implemented.

Once a senior staff person determines that an NRA is necessary, the person responsible completes the facility's standard NRA form and presents it to the resident for review and discussion. An Oregon assisted living manager described it this way:

*“Once I or the staff identify a concern, we sit down with the tenant, explain the concern, give them a chance to meet in their unit or in the office, and then we discuss it and I ask them to sign it...I’ll say, ‘I’m going to be doing an [NRA] because of some reason, and we’re afraid you or someone else will be hurt.’”*

Another Oregon manager said she modifies the language of the NRA until the resident is satisfied with it. Similarly, an assistant manager explained that if the resident refuses to sign the agreement, they renegotiate to find out what they will agree to and that if the resident continues to refuse, he or she will be asked to sign a form indicating refusal to sign the NRA.

#### **Summary of Regulatory Provisions Related to Risk Agreements**

**Florida** licenses three residential care categories under the term assisted living; the three types of licenses--standard, limited nursing, and ECC--permit progressively greater levels of care. The three facilities visited for this study had ECC licenses. Florida’s ECC regulations do not specify that a NRA process must include a signed document. Rather, they define “managed risk” as a process by which facility staff discuss the service plan with the resident (and, if applicable, the resident’s representative), to assure that consequences of a resident’s decisions, including any inherent risk, are explained to “all parties” and reviewed periodically in conjunction with the service plan, taking into account changes in the resident’s status and the ability of the facility to respond accordingly.

The state defines “shared responsibility” as a method for exploring the options available to a facility resident and the risks involved with each option when making decisions pertaining to the resident’s abilities, preferences, and service needs, thereby enabling the resident (and, if applicable, the resident’s representative) and the facility to develop a service plan that best meets the resident’s needs and seeks to improve the resident’s quality of life.

The Florida regulators we spoke with did not interpret these provisions as allowing providers to use managed risk agreements to allow resident autonomy to decline needed services or pursue risky behaviors. Rather, they stated that providers are expected to find creative approaches to deliver needed services and avoid risks. If an approach that satisfies the resident cannot be found, and the resident continues to refuse needed care or provider advice, Florida regulators expect the facility to discharge the resident.

**Oregon** defines “managed risk” as a process by which the facility and a resident discuss the resident’s high-risk behavior or choices, alternatives to and consequences of the behavior, and the resident’s decision to modify the behavior or accept the consequences is documented. If a managed risk plan is developed, the agreed upon actions must be included in the service plan. Facilities are required to identify the need for and develop a managed risk plan following the facility’s established guidelines and procedures.

Managed risk plans must include an explanation of the cause of concern, possible negative consequences to the resident and/or others, a description of resident preferences, possible alternatives to minimize potential risks associated with the resident’s preferences, a description of the services the facility will provide to accommodate the resident’s choice or to minimize the potential risk, and the final agreement reached by all parties. Facilities may not enter into or continue a risk plan with residents who are unable to recognize the consequences of their behavior or choices. The managed risk plan shall be reviewed at least quarterly. Residents’ rights are defined to include the right to be given informed choice and the opportunity to select or refuse service and to accept responsibility for the consequences.

**Summary of Regulatory Provisions Related to Risk Agreements (continued)**

The state does not permit involuntary discharge from assisted living facilities; providers must request state approval before asking a resident to move. Oregon considers NRAs to be an important mechanism for providers to address and resolve conflicts with residents regarding behaviors that place the resident or others at risk of potential harm, thereby enabling residents to remain in the facility.

**Wisconsin** developed its apartment model of assisted living--a RCAC--to provide a congregate care setting that would meet residents' needs while letting them live independently and respecting their autonomy. It is a model that is minimally regulated; even though RCACs may provide a nursing home level of care, they are not licensed. Facilities that serve Medicaid clients must be certified; all others must register with the state. Whether certified or registered, both are subject to the same requirements.

Wisconsin requires RCACs to establish with each resident a signed NRA, as a "protection for both the individual tenant and the RCAC." The state requires that NRAs include a description of any situation, condition, or action taken or desired to be taken by the tenant contrary to the practice or advice of the facility and which could put the tenant at risk of harm or injury; the tenant's preference as to how the situation is to be handled and the possible consequences of acting on that preference; what the facility will and will not do to meet the tenant's needs and comply with the tenant's preference relative to the identified course of action; alternatives offered to reduce the risk or mitigate the consequences relating to the situation or condition; the agreed upon course of action, including responsibilities of both the tenant and the facility; and the tenant's understanding and acceptance of responsibility for the outcome from the agreed upon course of action.

NRAs must also include any needs identified in the comprehensive assessment that the facility will not provide, either directly or under contract. The regulations state that "a risk agreement may not waive any provision of this chapter or any other right of the tenant," and that neither the tenant nor the facility shall refuse to accept reasonable risk or insist that the other party accept unreasonable risk. Risk agreements must be updated when the resident's condition or service needs change in a way that may affect risk or at the request of the tenant or facility.

Persons with dementia or other cognitive impairments that preclude individuals from understanding the consequences of and accepting responsibility for their choices are not permitted to move into an RCAC unless they live with a significant other who is not cognitively impaired. Because the state promotes "aging in place," residents who develop cognitive impairment while residing in an RCAC are not required to move out, though the facility has the right to discharge residents whose needs exceed their staff's capacity to provide needed services. To handle situations where residents may develop cognitive impairments, all residents are required to execute a durable power of attorney form that can be activated if necessary.

Managers in Florida described a similar approach focused on explaining the concern, suggesting alternatives, and asking the resident to accept responsibility for his or her choice to continue an activity that has been identified as risky. Staff and administrators in Florida and Oregon said NRAs were not often used.

In contrast, because Wisconsin requires all RCAC residents to have NRAs, they are initiated as one of many standard forms the resident is asked to review and sign as part of the admission process. Typically, the nurse conducting the preadmission assessment identifies any potential risks, which are then addressed in an NRA. The Director of Nursing at one of these facilities said she does not use the word "risk"

because it frightens family members; instead, she makes statements such as “there is a potential that the resident may fall.” In one facility, staff noted that about 25 percent of residents have no risk issues at admission, in which case they write “none” on the executed NRA form.

We heard from both stakeholders and one assisted living manager that many RCACs have an attorney prepare a standard NRA form. One manager said she would have an attorney review NRAs before they are presented to a resident, particularly if they were addressing a situation the facility had not previously addressed.

## **NRA Processes and Formats**

Florida rules do not specify an NRA process, format, or required topics. Oregon’s and Wisconsin’s rules have almost identical process requirements, including an identification of the issue, resident preferences, possible consequences, alternatives to minimize risks, final agreement, and signatures of assisted living staff and the resident. Additionally, Wisconsin requires that the NRA must include any needs identified in the comprehensive assessment that will not be provided for by the facility, either directly or under contract.

In general, most of the forms we reviewed included the core topics specified in Wisconsin’s and Oregon’s regulations.

In the facilities we visited, some of the NRAs included a standard introductory paragraph explaining the rationale for the risk agreement (e.g., the facility hopes to promote choice, but decisions residents make may put their health and safety at risk, or, if the resident’s decision conflicts with facility care practices a risk agreement is warranted). One NRA stated that though the facility attempts to manage risk incurred by residents, the nature of the environment and program does not allow for the complete elimination of risk, and the facility will make every effort to communicate with the resident regarding those risks and make suggestions to remove or minimize risk.

One Wisconsin facility uses an NRA form with a checklist of several potential risks and associated responsibilities, including: (1) residents who are able must agree to report changes in their medical or physical status to facility staff or accept responsibility for negative outcomes related to the condition; (2) resident has a history of falls, declines one-on-one supervision, knows that future falls might occur, and accepts responsibility for injury; (3) resident has history of wandering/elopement behaviors, is likely to continue this, refuses one-on-one supervision, and accepts responsibility for risk of injury, and (4) identification of all services identified during a comprehensive assessment, which the resident needs, but that will not be provided directly or under contract by the facility. To cover risks not enumerated, the form has an “other” option. A staff person in this facility said that if a member of her family were a resident, she would like the NRA to be “more customized.”

Florida does not require a written risk agreement and the agreements we reviewed in the three Florida facilities did not always follow the NRA requirements defined in Oregon and Wisconsin, including offering less risky alternatives and the potential for a compromise agreement. For example, one Florida NRA dealing with a diabetic resident's desire to eat regular desserts stated that eating regular desserts could lead to unstable blood sugar levels and that the alternative was not to eat regular desserts. The "final agreement" stated simply that the resident would like to continue eating regular desserts, rather than suggesting other options, such as eating smaller portions of regular desserts or having staff monitor blood sugar after consumption.

One Florida facility requires all residents to sign a standard managed risk form as an addendum to the residency agreement. This form addresses the risks of wandering, falls, skin breakdown, and loss of personal property. The form ends with the statement: I have been informed of these risks and understand that other risks may exist based on each individual resident's concerns.

### ***Liability Waivers***

In only one facility did the NRA form include liability waiver language:

*"I do, hereby, agree to take responsibility and assert no liability against [name of facility], its employees, management firm, administrative officers, staff members and practitioners practicing therein, of (sic) any accident, injuries or death as a result of my refusal to comply with their express and/or written provisions listed above, which I, as evidenced by this document, hereby refuse to comply with."*

A senior staff member at this facility believed that a blanket waiver should not be signed at admission, but a limited waiver was appropriate when "issues arise." This facility also differed from others by using NRAs only for cases of noncompliance, typically related to diet and medications. While no other facilities we visited had NRA forms with liability waivers, one facility, as noted above, included standard language in its NRAs regarding the risk of wandering, falls, skin breakdown, and loss of personal property. Including this general language in an NRA appears to be an attempt to approximate a general liability waiver for the areas noted.

In Florida, although the state's regulations do not address liability waivers and the state exercises no oversight over NRAs, several stakeholders said that the state would not "approve" NRAs with liability waivers.

### **Family and Other Third Party Involvement**

In all three states, the resident and the staff member responsible for completing NRAs meet to discuss the issue(s) and additional staff members are involved, depending on the topic (e.g., a nurse if the issue being discussed is health-related). Nearly all residents and staff we spoke with said that residents with full cognitive

capacity have the right to exclude family members from the NRA process, and to tell the facility not to inform family members about the NRA.

At the same time, most staff believed that it was preferable to involve or at least inform family members. One manager noted that over a 9 year period, practically all resident placements were initiated by the family and many family members continue to be involved in the resident's ongoing health care and service decisions. A few managers and several experts noted it was important to involve family because, in most cases, it is the family who will have concerns or sue the facility if a bad outcome occurs. One staff person said they involve family members even if the resident doesn't want them involved because it "helps with resident compliance."

Staff noted additional individuals whom they might involve in the risk discussion or inform about a completed NRA, such as case managers for Medicaid clients (in Oregon), or the resident's physician if the NRA concerns treatment noncompliance such as refusal to take medications.

## **Use of NRAs with Cognitively Impaired Residents**

Many staff members said they would not use NRAs with residents who do not understand the consequences of their actions, yet none of the facilities had standardized procedures to determine residents' decision-making capacity prior to initiating an NRA. Instead, they rely on staff's professional judgment and, occasionally, formal assessments to make this determination. Staff in Florida and Oregon stated that they know residents well enough to recognize whether they understand the potential outcomes of their choices. In addition, several Florida staff noted that the state requires an annual physician assessment that includes the physician's opinion of the resident's capacity, and that they use this information in their determination of whether a resident is appropriate for an NRA.<sup>44</sup>

When we asked staff how they determined a resident's capacity to make decisions, some staff mentioned the resident's ability to understand issues and risks, others mentioned a resident's ability to remember, and a few mentioned judgment. Several staff said that an NRA was appropriate unless informal assessment indicated memory or judgment impairment (e.g., observing that the resident often forgot their room number or what time it was). Several noted that memory loss is easier to identify than judgment problems, though many staff noted that impaired decision-making ability in one area (e.g., money management) does not necessarily preclude the ability to make decisions in other areas.

One noted that if she had doubts about a person's capacity to consent to an NRA she would administer the Mini-Mental Status Examination or a Clock Drawing test. Another said she uses the mini-mental test but has no hard and fast rules about when to use it, instead relying on judgment: "if you feel they understand then okay. If anyone is confused--involve family." One manager said it was acceptable for a family to sign an

NRA, but noted that issues related to activating powers of attorney were unresolved. One staff person said she would consult with a physician if they had questions about a person's competency to sign an NRA.

While most staff believed residents needed to be able to understand the consequences of their decisions, some felt it was all right to use NRAs with residents who had memory and judgment problems. One manager said that if the family of a resident with memory problems said they could not pay \$290 a month for medication administration, then she would initiate an NRA dealing with the risks of medication self-administration. Another said he had used an NRA with a resident who'd been adjudicated incompetent but had "involved the family." Several said they would allow a family member, power of attorney or a guardian to sign an NRA on a resident's behalf. Another said that decision would need to be made by the facility's corporate attorney.

Most of the facilities review NRAs either on a quarterly basis or following a change in resident status. Many staff were uncertain of the validity of an NRA if the resident experienced cognitive decline after signing it. One said that if a person had freely chosen to assume risk when competent, then the NRA should remain in force.

## **NRA Topics**

Of the 31 risk agreements we reviewed, the majority dealt with behaviors that the facility believed posed a risk for a poor health or safety outcome for the resident. These include noncompliance with diabetic diets, refusing a prescribed pureed diet, refusing monitoring of vital signs (pulse and blood pressure), refusing to use a walker or wheelchair, choosing to use bedrails, taking unaccompanied walks, self-managing medications, refusing housekeeping, and assisting another resident who uses a wheelchair.

Three NRAs identified a specific condition as a general risk factor. One was for a resident who was blind and another for a resident with spinal stenosis. Both were perceived as being at risk for falls due to these conditions. The third was for a morbidly obese resident who was not able to wear shoes; her NRA identified risks that included falls, skin breakdown, and infection due to injury to the feet. The NRA included several "possible alternatives" for the resident to consider: (1) research weight reduction programs; (2) wear foot protection; (3) Xenical; (4) surgical intervention; and (5) possible skilled nursing facility placement. The document also listed several "actions" that were taken, the dates, and by whom.

One resident's NRA addressed a risk for falling due to general weakness after surgery; in her NRA, she agreed to use a wheelchair if she had to go a long distance. One facility in Wisconsin conducted a fall risk assessment for every prospective resident and those at high risk were required to sign an NRA addressing falls at admission.

In Oregon, several managed risk plans involved smoking in prohibited areas--a behavior that presented a risk to both self and others. Most others involved behaviors that did not pose risks but were offensive to others, such as being drunk, playing loud music, yelling at staff and other residents, and watching pornography while staff cleaned the apartment.

While many of the topics listed above fit within the NRA conceptual framework (i.e., a resident's behavior or choice poses potential risks to health or safety and the facility and resident work out an agreement that will protect the resident's autonomy), several do not. The major risk identified in several of the managed risk plans in Oregon was the risk of eviction if the resident did not comply with facility rules. These risk agreements were more like behavior modification plans, since the agreement was basically "comply or goodbye."

Because Oregon does not allow involuntary discharge from assisted living facilities without state review, it appears that some Oregon providers are using managed risk forms to document problem behaviors and providers' attempts to correct them should an eviction become necessary. Interviews with experts in that state indicated that the managed risk agreement is used in this way, though not all agree that this is an appropriate use. In such cases, the "risk" is that the resident will be asked to move out rather than the more commonly understood risk to health or safety. Additionally, a primary purpose of these NRAs is to try and secure the residents' compliance with rules not to increase options for residents' autonomy.

In Wisconsin, in addition to specifying what actions the facility would take to reduce risk, some NRAs specified what the facility would not do to address the risk. For example, in the case of noncompliance with a diabetic diet, the NRA stated that the facility can not supervise dietary intake on a 24-hour basis, prevent purchases at the facility gift store, and remove candy from the resident's apartment. In another NRA addressing the facility's concern about a resident who took long unsupervised walks, the NRA specified that the facility will encourage the resident to ask another resident to walk with her; that she will sign out when she leaves the building; that she will not walk beyond where she can see the building; and that 24-hour monitoring of whereabouts and an escort for outdoor walks are not available services.

Overall, in Oregon, the agreements dealt more with problem behaviors than risky behaviors. In Florida, they were primarily used for dietary noncompliance, and in Wisconsin they were used both for general conditions that were perceived as risks--for example, blindness--as well as specific risks, such as the use of bed rails against the facility's advice.

## Resident, Family, and Staff Views about NRAs

In addition to reviewing NRAs, we also asked residents, family members, and staff how they felt about NRAs, as well as their views on their purpose and specific issues such as whether persons with cognitive impairment should have NRAs.

### *Awareness of NRAs*

**Staff.** A clear distinction emerged between management staff and direct care staff when asked about residents' NRAs. Management staff were almost always aware of residents' NRAs and their content. On the other hand their understanding of the general principles of NRAs as established in the assisted living literature or in corporate policies varied widely. Where the principles were understood, some facility staff disagreed with the risk taking allowed under corporate policies.

In Oregon, direct care staff were aware of NRAs; in Florida and Wisconsin most were not aware that a resident had an NRA and in some cases, did not know what an NRA was. Some direct care staff had been briefed by management about issues addressed in residents' NRAs as well as the agreement reached, but they were unfamiliar with the NRA concept or process. Those who were not aware of the NRA stated that it was their responsibility to continually encourage residents to do what was best for the resident and report concerns to management.

The lack of direct care staff's awareness of NRAs appeared to be a system failure in most facilities and deliberate in some. One manager explained that she did not want direct care staff making decisions about how to implement the NRA. Rather, she wanted the direct care staff to alert her to all risky behavior and leave it to her to resolve. Direct care workers in this facility did understand that their responsibilities included informing the manager and/or a nurse about problem or risky behaviors, such as refusing medication, dietary noncompliance, or smoking. Overall, Florida direct care staff had the least knowledge of NRAs.

**Residents.** All of the Oregon residents knew they had a risk agreement, remembered signing it, and were able to explain its content and purpose. The residents in Florida and Wisconsin were aware of the issues in their NRAs, but many did not recall discussing them or having signed an agreement. Most Florida residents interviewed had a difficult time understanding the concept of risk assumption and the purpose of an NRA. Many noted that they should be able to do what they wanted but also believed the facility should not allow residents (other than themselves) to assume risks. Because Wisconsin requires that all RCAC residents have an NRA at the time of admission, for many residents, it was just one of many forms they signed when moving in. However, while most of the Wisconsin residents knew the general issues addressed in their NRAs, some could not articulate the specifics of the agreements.

## ***Purpose of NRAs***

**Staff.** Most managers and a few direct care staff saw NRAs as having two primary and related purposes: (1) to allow residents independence while affording the facilities some protection against liability for negative outcomes related to the NRA topic, and (2) to foster communication with residents and their families about important health and safety issues by providing a formal mechanism for doing so. As noted above, many direct care staff did not know what an NRA was or its purpose, and one manager said, “People are not clear about the purpose.”

In general, the Florida management and other staff seemed somewhat uncertain about the purpose of NRAs and how to use them; in contrast, their corporate staff were well versed in the concept. This may, in part, reflect the uncertain regulatory treatment of NRAs in Florida. In one setting, a representative from the corporate office clearly understood and advocated the use of risk agreements. In another, the manager felt that they were designed by the administrators/ owners simply to document discussions about risky behaviors and the facility’s attempt to address them. One staff person said she did not support their use but used them because they were required by corporate policy.

A direct care employee said that having an NRA was much better than just having a discussion because it made more of an impression on the resident and family and documented the discussion. In Wisconsin, two managers noted that if their own parents were in RCACs they should be able to make their own decisions and choices and that NRAs would make it easier for them to do so. They also felt that they were useful to staff because they provided a mechanism for recognizing potential risks and challenges in providing care for a given resident and for focusing on prevention by educating residents and families about the risks of certain behaviors. They also discussed their importance as a tool to make residents and families deal with important issues.

For example, in one facility, a resident needing transfer assistance often did not call for assistance and had fallen several times. The NRA was used to make the family aware that staff was available to assist their parent, but the parent needed to request assistance. In another case, a son wanted the facility to prevent his diabetic mother from buying and eating candy, and the NRA specified that the facility could not exercise that level of control over his mother.

Managers were divided in their views about whether a formal NRA provided protection against lawsuits or decreased liability in the event of a lawsuit. One manager said that the NRA is not a contract that relieves the provider of responsibility, but it is a document that “lets everyone know about the situation.” However, many assisted living staff spoke about providers’ need and right to be protected from liability if residents choose not to follow staff’s advice and are injured as a result.

Many managers believe that NRAs are needed to allow residents autonomy in a residential care setting that is intentionally different from more heavily regulated nursing

facilities. Specifically, while many recognized that assisted living is a licensed setting that is expected to protect the well being of residents, it is also a consumer-driven model of service delivery that needs to balance this protection with residents' rights to make decisions even when they entail risk. Some staff expressed frustration, saying that regardless of what is documented in the NRA and their best efforts to take care of residents, they will be held responsible for any negative outcomes.

Some felt that NRAs would not hold up in court, but others felt that in the event of a lawsuit, a formal NRA documenting both the resident's choice to incur risk as well as the facility's efforts to educate the resident about the risks and to offer alternatives to the risk behavior could be helpful. None of the staff we spoke with had heard of or experienced a lawsuit involving an NRA.

**Residents.** For residents with NRAs, their views regarding the purpose of NRAs were personalized to their own particular circumstances, although some made contradictory statements and others did not appear to understand their purpose. For example:

- "It says you need to be careful and ask for help when you need it. I think it needs to be written because that's the rule."
- "I don't mind people talking to me about risk. I'd prefer to do things and decide things myself. If someone says something is risky, I'll listen but I prefer to make decisions myself. If they told me to wait for assistance because doing something was risky, I would wait even if they were late to assist me."
- "I don't know if I have an NRA--I'm sure my daughter did it for me. I would always follow advice about what to do and not to do; therefore, there is no need for me to have an NRA. *Are you comfortable with the idea of having to sign an NRA to do what you want?* Yes. I'm responsible for my own actions."
- "Negotiation is the only way--you need to have a solution that everyone is comfortable with. If a facility is clearly uncomfortable--then they need to express this and help you understand it. It's necessary--it levels the playing field--it forces a discussion." [Son of a resident.]

### ***Attitudes about NRAs***

**Staff.** Assisted living staff expressed both positive and negative attitudes about NRAs. Reflecting the use of managed risk agreements as behavior modification agreements by the Oregon facilities, some Oregon staff noted that the risk agreement itself might not lead to a change in residents' behavior. Others worried that residents required to enter into a NRA to exercise their choice felt "picked on" and that initiating them upsets the resident or makes them think they have done something "wrong." Still others felt they helped residents make choices important to them.

Staff in Oregon and Wisconsin said that NRAs made them feel more comfortable when addressing difficult situations because they provide a formal, written process for uncomfortable discussions. Some said that being able to “blame” the requirement for an NRA on state regulations or corporate requirements made it easier to use them to raise and address risky or problem behaviors.

In all three states, at least some staff stated that they or “others” are not certain about how to use NRAs, which makes them feel uncomfortable. A manager in Wisconsin noted that she only used them “because the state makes us” and did not think they really helped because the facility would not admit residents who posed major risks. A nurse in another state noted that her facility screens at admission and does not admit people with problems that might require an NRA, particularly people who are noncompliant.

Several managers and nurses said NRAs make them more comfortable with allowing residents to make choices that pose risks. One nurse said that NRAs “put everything out on the table” for the resident, staff, and family to discuss together; she noted that the nursing home where she used to work made family members sign “waivers of responsibility” if they refused to allow the staff to apply physical restraints.

Some administrators indicated that they would not use NRAs at all if it were up to them but that their corporate offices required them as a risk management tool. They said that they were not comfortable allowing residents to do things that could lead them to “get hurt.” One nurse noted that if she felt a resident was really at risk of harm she would not keep them in the facility because “I feel responsible for anyone who lives here--if they don’t have the judgment and the family doesn’t exercise good judgment, then I can’t keep them here.” Similarly, another nurse said she was satisfied with the NRA process, but if a noncompliant diabetic was experiencing very high blood sugars on a daily basis, “we would tell the family she needs to go to a nursing home.”

An administrator said she was reluctant to use NRAs because the concept of allowing residents to do things that could hurt them conflicted with her sense of professional responsibility and personal ethics, both of which required the protection of residents. In another facility, a manager strongly supported resident autonomy and the use of NRAs to assure it. Reflecting these differing views, one manager said that the degree of risk that the facility was willing to tolerate was based in large part on individual nurses’ views about promoting autonomy and assuring protection.

Several staff said that additional guidance about NRAs would be useful because some people don’t know how to use them; one noted “it would be nice to have information about options that you would not otherwise think about.”

**Residents.** In general, residents spoke clearly about their desire to make choices and indicated that neither families nor facilities should tell them what to do when their choice did not endanger others. The most positive statements included opinions that the approach is fair, that it reminds residents that they have both rights and responsibilities,

and that it demonstrates that employees are looking out for their well being. However, when presented with hypothetical situations, residents who believed that they personally should have full capacity to accept risk were less sure that other residents should be allowed to make risky decisions. Several said that other residents should do what their nurses or doctors tell them to if it is for their own health and safety.

Residents in Oregon had more negative views, with some feeling threatened by the process. A few indicated that if they did not sign the agreement they would lose a privilege or be evicted. Others felt it was unfair and that it would be better to just talk about an issue rather than have to sign an agreement. One noted it was fair but felt the facility's rules were too strict. In the one instance where the NRA dealt with a health risk--when the resident refused to eat a pureed diet--the resident stated that initially she did not understand why she had to sign an NRA and was a little annoyed, but now feels that she did the right thing.

The following comments illustrate the range of residents' attitudes in all three states:

- "I signed the NRA for the sake of the staff. It's OK to sign it, but you shouldn't have to leave if you refuse to sign it."
- "They told me about the dangers involved and I want to take the risk."
- "I can't think of any other way than using an NRA. There's nothing wrong with it. I'm not intimidated by it--but others might be, depending on their personality and age."
- "The purpose is to keep them [the facility] from being liable. I shouldn't have had to sign the NRA to stay here--it should be my decision to eat what I want."
- "I didn't mind signing it. The administrator explained that it was for me to accept responsibility in case of harm, but it doesn't make any difference in making choices."
- "The administrator explained the negative outcomes of a nondiabetic diet, talked to me as an adult, left the decision to me."
- "I'm old enough to know what I should and shouldn't eat. It's reasonable for the facility to have some liability protection; I wouldn't sue anyway."
- "I don't remember signing it but I would because I want to live here. It's my decision, not my family's. If I eat what I want, it's my fault, not the facilities."
- "Once in a while if you want something sweet you should be able to make that choice. In general, though people shouldn't be able to take on too much risk."

- “I want my bedrails because they help me to help myself. I couldn’t see the reason why I shouldn’t have them. My daughter agreed. It’s OK to sign an NRA for this.”

Of the two family members interviewed, one was very positive about using NRAs to allow his mother who had cognitive impairment the freedom to take walks outside the facility because he did not want her to feel confined. At the same time he recognized the facility’s concern about their liability if she were harmed while walking. The other family member expressed concern about whether or not her mother actually understood the risks that were discussed. She questioned the NRA’s effectiveness when her mother didn’t remember the discussion or signing the document. She noted, “Just because she signs doesn’t mean she understands.”

## **Summary of Key Site Visit Findings**

Our NRA study surveyed seven facilities in three states. It is important to remember that this is a very limited and nonrepresentative sample of providers, staff, and residents. Our findings, therefore, are not generalizable. Instead, they suggest areas for further research or confirmation. With this caveat in mind, our major findings are:

- With the exception of Wisconsin, which mandates NRAs for all RCAC residents at the time of admission, NRAs appear to be used infrequently and selectively, generally only when informal discussions have not resolved an issue that has arisen more than once.
- NRAs are generally viewed as a complement to service planning to address specific issues.
- Several residents did not remember signing the agreement or the specific details of their agreements. However, all residents believed strongly that they should be able to make lifestyle and personal decisions that may place them at risk and many indicated that neither families nor facilities should tell them what to do when their choice did not endanger others. Some residents were comfortable with the use of NRAs but others said they should not have to sign them as a condition of exercising a choice.
- Staff view NRAs primarily as a complement to service planning and a useful method for formally discussing issues, resolving disagreements, and addressing residents’ behaviors or choices that providers believe pose risks to their health and safety. All staff agreed that behaviors that place staff or other residents at risk are not appropriate for negotiation.
- A significant benefit of NRAs noted by staff is to require discussion about difficult issues that providers, residents, and families might otherwise avoid. In fact, the

process' utility appears to have led to its use in areas involving difficult discussions that do not involve risk.

- While some staff believe that NRAs could provide some liability protection in the event of a lawsuit over a negative outcome, they do not view this potential protection as the sole or primary purpose of the NRA. All management and professional staff agreed that an explicit discussion with residents and families about risk and of measures that can be taken to reduce risk can reduce providers' liability exposure.
- All staff agreed that behaviors that place staff or other residents at risk are not appropriate for negotiation.
- Staff had mixed feelings about NRAs, sometimes expressing frustration with the desire for residents to be autonomous. This frustration appeared to stem from two concerns: (1) fear that residents might get hurt while they have a moral obligation to protect them, and (2) concern that they are held responsible for all negative outcomes.
- Often, direct care staff did not have much familiarity with the concept of NRAs, know that an individual resident had an NRA, or, if they knew a resident had an NRA, they did not know what impact it had on service delivery or a resident's ability to assume risk. This lack of knowledge, in some cases, negated the effectiveness of an NRA as a tool to empower resident decision-making.
- None of the NRAs we reviewed supported the view that providers are using NRAs exclusively as a liability "dodge" to allow them to admit and keep residents beyond the facility's capacity to care for them--or for poor quality care. However, some standardized NRAs were overly broad and inappropriate for persons with cognitive impairment (e.g., one facility had a standard NRA form that included a statement that a resident accepts responsibility for risk of injury due to wandering).
- In most cases, providers are not using standardized assessment methods to assess decision-making capacity. Most staff appeared unaware of the legal standards for determining capacity to consent--which is analogous to decision-making capacity--and appeared to lack knowledge about the cognitive domains and other factors that affect this capacity. Most staff said they determined decision-making capacity primarily on the basis of informal observation of a resident's memory even though memory is not a cognitive component of the capacity to consent.
- Some facilities are allowing surrogates to sign NRAs without knowledge of their legal standing to accept risk on behalf of the resident.

- Some facilities are using NRAs for issues or purposes that are not within the boundaries of NRAs as originally conceived by early advocates. This includes using NRAs to document one-sided, nonnegotiable discussions involving a behavior that the facility requires the resident to stop, using NRAs to identify a resident's general condition that may increase risks (e.g., blindness), and using NRAs as a general waiver of liability (e.g., loss of personal property) or to control behaviors that may be offensive to staff or other residents.

## V. CONCLUSIONS

Assisted living providers, policy makers, aging advocates, and LTC experts have defined NRAs as a mechanism to enhance resident choice by providing a rigorous process designed to balance autonomy and risk for residents and providers in assisted living.

While our sample is small and not representative, our findings suggest that NRAs can be a useful tool to help residents and providers achieve a balance between desires for autonomy and concerns about safety. At the same time, they suggest that the NRA concept is proving difficult to broadly and consistently operationalize.

- NRA processes and purposes are not well understood and appear to vary widely across states, providers, and even staff in the same facility. While this may not be surprising given that assisted living varies widely within and across states, it does raise significant concerns about standards for the process. As identified in this study, the appropriate use of NRAs requires at a minimum, guidance in their use, as well as education and training.
- NRAs are not being used uniformly to maximize resident autonomy by balancing specific risks and consumer preferences as supporters advocate. Few of the NRAs we reviewed adhered to a form, process, or guidelines appropriate for the practice concept or to the recommendations in the Assisted Living Federation of America's report on NRAs.<sup>45</sup> While some NRAs fit advocates' concepts, others that we reviewed addressed appropriate issues but did not include a discussion of alternatives or a negotiation, presenting topics in an either/or framework. Some NRAs simply identified the risk, stated that the resident should not do what they identified as risky, and then noted that the resident planned to continue and accepted the risk.
- Some NRAs were used for issues other than specific risks. These NRAs were used to control behaviors that were outside of community norms or to note a general risk factor like blindness or obesity, which the provider wanted to highlight. Some were used as behavior modification agreements, stating that unless a resident ceased a particular behavior, like smoking or disturbing the peace, they would be discharged from the facility. However, in no case, with the information available to us, did we determine that NRAs were being used to pressure residents into accepting inadequate care, the primary concern of NRA opponents.

### *Liability Waivers*

The inclusion of liability waivers in NRAs is the most contentious issue in the NRA debate. Some argue they are essential, some that they will be exploited, and others that they are unenforceable. However, it appears that NRAs can be structured to address

provider and consumer concerns without using formal or even implicit liability waivers. Most experts agreed that the availability of a signed document recording formal discussions between the facility and resident regarding risky choices, staff attempts to reduce risk, and the residents' acknowledgment of their choice despite the risks, is comparable in protection to a formal waiver of liability in the event of a law suit.

The enforceability of liability waivers has not been tested in the courts but most experts do not believe that NRAs with such waivers provide any more liability protection than those without them. While one legal expert asserts that an NRA could have an enforceable liability waiver, none of the NRAs we reviewed appeared to follow the process this expert outlined to assure their enforceability.<sup>46</sup> Other legal experts suggested that NRAs may not need a liability waiver to accomplish the protection sought.<sup>47</sup>

NRA proponents who believe liability waivers are essential should be equally concerned about the use of NRAs with residents who lack decision-making capacity, because in the event of a lawsuit, NRAs with or without waivers are likely to be voided by the courts if the facility cannot prove that it accurately determined a resident's decision-making capacity.

### ***Use of NRAs with Cognitively Impaired Residents***

Whether NRAs should be used or continued with residents who have cognitive impairment is unclear. If an individual includes the authority to enter into an NRA in a power of attorney, and if a court has granted a guardian this power, legal concerns about the use of surrogates are lessened. In most states, guidelines regarding NRAs and surrogates are either completely lacking or do not adequately address this issue.

Additional state guidance regarding appropriate and inappropriate use of surrogates would be helpful to providers and would afford protection to persons with cognitive impairment. A long history of what some call protective paternalism towards persons with mental retardation (MR) led to a movement to support self-determination--even if it entails risk. States may find useful information in the MR literature to inform the development of guidance regarding the use of NRAs or similar tools with older persons with impaired decision-making capacity.

### ***Alternatives to NRAs***

It may be possible to address certain risk topics found in our review of NRAs using a process that is more closely tied to service planning, particularly to address areas of risk that are typically dealt with in service plans, such as prescribed diets, medications, and use of bedrails. For example, to obtain the primary advantages of fostering communication and documenting discussions and choices, providers could use forms that address "specialized service planning issues" as well as forms that are treated as addendums to the service plan.

This approach would have the advantage of being part of initial and ongoing service planning while avoiding the legal complexities of an NRA. However, an enhanced serving planning approach would not afford the benefits of negotiation and risk assumption that many proponents believe are their main value--both to enhance resident autonomy and protect providers from liability for the consequences of residents' choices. Some stakeholders believe that many issues related to lifestyle choices, such as having pets and smoking, can be or should be dealt with in residency/tenant agreements.

In sum, stakeholders and experts disagree about the advantages and disadvantages of NRAs. The meaning of "risk" and views regarding the relative importance of protection and autonomy varies among the many disciplines involved in assisted living practice--providers, consumer advocates, regulators, nurses, social workers, attorneys, and insurers. Even among advocates, especially between traditional advocates for the elderly and advocates for persons with disabilities, views on the need for NRAs and implementation standards vary widely.

While many advocates and opponents characterize the debate as absolute for or against NRAs, the debate is better characterized as an attempt to determine acceptable limits to choice and what process best achieves a balance between autonomy and safety. It seems likely that with increasing attention to the rights of persons with disabilities to exercise choice and assume risk in both LTC settings and independent housing, strategies for enhancing older persons' autonomy will become increasingly important.

NRAs or similar processes show some promise in providing a practical approach to enhancing resident autonomy in a living environment where a regulatory emphasis on safety and concerns about liability are salient factors affecting provider behavior. However, if NRAs are the correct tool for striking a reasonable balance between safety and autonomy, states, consumer advocates, provider associations, and the legal community need to give more detailed attention to how their use should be operationalized so they can play a significant role and to prevent potential abuse. Stakeholders also need to examine what role NRAs can or should play in providing a process for "reasonable accommodation" when state or provider proscribed admission and discharge limits conflict with residents' preferences.

## ENDNOTES

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14. To confirm our findings, we reviewed statutory and regulatory reviews conducted by others who have explored this issue, including Ken Burgess, Eric Carlson, Allen Lynch and Sara Teachworth, Keren Brown Wilson, and Robert Mollica. Their prior research and generous assistance was invaluable to this project. Carlson and Mollica include Kansas in their list of states with provisions related to negotiated risk agreements. We did not include Kansas because its regulations pertain only to negotiated *service* agreements and reference only the risk of refusing a recommended service.
15. Residential Care Apartment Complexes (RCACs) are one of two types of residential care facilities in Wisconsin. RCACs are the less regulated of the two; they are not licensed and require certification only if serving Medicaid waiver participants.
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24. Carlson, E. (2003) *op. cit.*

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27. OHIO 3701-17-58 states that "if a resident needs services or accommodations beyond that which a residential care facility is authorized to provide or beyond that which the specific facility provides, refuses needed services, or fails to obtain needed services for which the resident agreed to be responsible under the resident agreement required by rule 3701-17-57 of the Administrative Code, the residential care facility shall take the following action:
  - (1) Except in emergency situations, the residential care facility shall meet with the resident, and, if applicable, the resident's sponsor and discuss the resident's condition, the options available to the resident including whether the needed services may be provided through a Medicaid waiver program, and the consequences of each option;
  - (2) If the lack of needed services has resulted in a significant adverse change in the resident, the residential care facility shall seek appropriate intervention in accordance with paragraph (A) of rule 3701-17-62 of the Administrative Code. If an emergency does not exist the facility shall provide or arrange for the provision of any needed services that the resident has not refused until the resident is discharged or transferred or the resident and the facility have mutually resolved the issue in a manner that does not jeopardize the resident's health or the health, safety or welfare of the other residents. This paragraph does not authorize a facility to provide skilled nursing care beyond the limits established in section 3721.011 of the Revised Code; and
  - (3) The residential care facility shall transfer or discharge the resident in accordance with section 3721.16 of the Revised Code and Chapter 3701-61 of the Administrative Code if the resident needs skilled nursing care or services beyond what the facility provides and the residential care facility, based on the meeting with the resident required by paragraph (G)(1) of this rule, determines that such action is necessary to assure the health, safety and welfare of the resident or the other residents of the facility.

The residential care facility may retain a resident who refuses available services if doing so does not endanger the health, safety, and welfare of other residents and the resident does not require services beyond that which a facility is authorized to provide under Chapter 3721 of the Revised Code and rules 3701-17-50 to 3701-17-68 of the Administrative Code.

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29. Wilson, K.B. (1996). *Assisted Living: Reconceptualizing regulations to meet consumers' needs and preferences*. Washington DC: AARP Public Policy Institute; Burgess, K. (2000) *op. cit.*; Kapp, M.B., Wilson, K.B. (1995) *op. cit.*
30. *Newsweek* recently ran a cover article titled *Lawsuit Hell: How Fear of Litigation is Paralyzing Our Professions* (12/15/03). The article chronicles the extraordinary practices that some medical and other professionals are adopting to lower the risk of liability in the face of a "litigation explosion," perceived or real.

31. "It may be a mistake to assume that the facility can absolve itself of responsibility for the resident by negotiating and having the resident execute a waiver, release of liability, or other form of "negotiated risk agreement." No matter what an assisted living provider recites in the contract, it may be liable if avoidable harm to a resident in its facility is foreseeable and the provider stands by and makes no reasonable effort to intervene. Any written contract that purports to exonerate a facility from such a fundamental civil duty is likely to be deemed by the courts to be unconscionable and against public policy, particularly when a waiver or release pertains to future unknown events. Moreover, an elderly person signing such an agreement probably will be considered disadvantaged and unable to engage in an enforceable, arm's-length transaction." (Gordon (1999) cited in Carlson, E. (2003) *op. cit.*)
32. Burgess, K. (2000) cited in Lynch, A.A., Teachworth, S.A. (2002) *op. cit.* Lynch and Teachworth argue that NRAs can meet the basic premises of contract law, and if these are met in a specific NRA it will increase the likelihood of its enforceability. They construct this argument based on case law they believe to be relevant to determining how courts will view liability waivers in negotiated risk agreements. Carlson, E. (2003), based on the case law he believes is relevant, firmly states that standards of care, unequal bargaining positions between providers and consumers, and regulatory mandates, make risk agreements unenforceable under existing law.

Carlson criticizes Lynch and Teachworth's review of the enforceability of liability waivers in negotiated risk agreements, stating that in an effort to build support, they rely exclusively on sports-related cases. These cases, Carlson argues, are not applicable to the circumstances in a long-term care setting. "Liability waivers are almost always invalid in a consumer context," according to Carlson, except in sports-related cases, "especially extreme sports like skydiving."

However, the case law Carlson cites appears to lack direct applicability to the issues at hand as well, focusing on situations where a liability waiver is found invalid because existing state law already protects a provider:

"However, defendant need not rely on a covenant not to sue to protect itself from liability for inherent risks and unforeseen consequences. Under traditional tort law principles, medical care providers are not liable for such inherent risks and unforeseen consequences (Cudnik v. William Beaumont Hospital, 525 N.W.2d 891, 896 (Mich. Ct. App. 1994) cited in Carlson, E. (2002)) or where obvious negligence is involved--failure to change light bulbs and repair broken stairs--and a waiver is unenforceable as a result."

None of Carlson's examples speak to the specific situation that proponents of NRAs describe--a situation where liability waivers are introduced as a defense when a bad outcome has occurred, without provider negligence, after a competent resident in a regulated setting chose to opt out of established practice or regulatory standards in order to pursue a preferred but riskier course. Experts agree that this "perfect" case does not currently exist and that, until it does, firm conclusions regarding the enforceability of NRAs are more about convictions and individual bias than parallel "fact patterns."

33. One attorney suggested the lack of litigation involving NRAs might indicate that they work (i.e., they prevent lawsuits through better communication with residents and families about difficult issues, which is preferable to depending on an NRA as a defense in a negligence case).

34. Lynch, A.A., Teachworth, S.A. (2002) *op. cit.*
35. Lynch, A.A., Teachworth, S.A. (2002) *op. cit.*
36. Section 21325, Act No. 437, Public Acts of 2000, Enrolled House Bill No. 5689.
37. Some experts noted that NRAs might become an important tool in implementing rights guaranteed through disability rights law. These experts commented that the trend in case law is to use the ADA, the FHA, and the FHAA, to strike down overly broad regulatory limits to occupancy in community care settings, and require reasonable accommodation of residents' preferences when limits are based on state or provider-determined disability categories.  
Courts are beginning to focus on the specific capacity of the resident, his or her stated preference and risk tolerance, and the provider's or a third party's ability to meet the resident's needs.  
  
Some of these experts believe that as case law continues to define consumers' rights to assume risk, risk agreements are a potentially strong tool with which to implement consumer choice in congregate settings accustomed to a prescriptive regulatory and program culture. These experts also expressed the need for a formal process, perhaps an NRA, to document consumer preferences and provider responsibilities as consumer preference begins to take precedence over strict regulatory structures designed to assure safety and adequate care.
38. Carlson, R. (Spring 2003). In the sheep's clothing of residents rights: Behind the rhetoric of negotiated risk in assisted living. *NAELA Quarterly: the Journal of the National Academy of Elder Law Attorneys*. Available at:  
[http://www.naela.com/PDFFiles/Quarterly\\_spring2003.pdf](http://www.naela.com/PDFFiles/Quarterly_spring2003.pdf).
39. Lynch, A.A., Teachworth, S.A. (2002) *op. cit.* One expert noted that while NRA opponents argue that NRAs lack mutual consideration for residents when they are implemented because the resident is not receiving anything that they do not already have, NRAs may also lack mutual consideration for the provider if they do not include a waiver of liability, because they are being used to allow behaviors that could increase a provider's liability without any corresponding benefit.
40. We asked more specific questions of the 27 experts and stakeholders we initially interviewed. We asked more general questions of the experts and stakeholders in Florida, Oregon, and Wisconsin.

41. In a study of licensed facilities in four states, prevalence was estimated at 21-33 percent. Sloane, P.D., Zimmerman, S., Ory, M.G. (2001). Care for Persons with Dementia, pages 242–270 in Zimmerman, S., Sloane, P.D., Eckert, J.K. (Eds.) *Assisted Living: Needs, Practices, and Policies in Residential Care for the Elderly*. Baltimore: Johns Hopkins University Press.

In a national sample of facilities that self-identified as assisted living, prevalence was estimated at 12-20 percent. Hawes, C. Phillips, C.D., Rose, M. (2000). *High Service or High Privacy Assisted Living Facilities, Their Residents and Staff: Results from a National Survey*. Washington, DC: DHHS, ASPE. Available at: <http://aspe.hhs.gov/daltcp/reports/hshp.htm>.

A study of four facilities in Maryland found a prevalence of 66 percent. Rosenblatt, Samus, Steele, Baker, Harper, Brandt, Rabins, Lyketsos (October 2004). Maryland Assisted Living Study. *Journal of the American Geriatric Association*. A summary can be found at [https://hopkinsnet.jhu.edu/servlet/page?\\_pageid=1723&\\_dad=porta130p&schema=PORTAL3OP](https://hopkinsnet.jhu.edu/servlet/page?_pageid=1723&_dad=porta130p&schema=PORTAL3OP).

42. Wisconsin's RCAC rules require that tenants must be competent to understand and express their needs and preferences at admission. Consequently, RCACs may not admit individuals who have an activated power of attorney for health care, who are under a court-determined guardianship, or who have been found by a physician or psychologist to be incapable of recognizing danger, summoning assistance, expressing need or making care decisions. The rules address the issue of cognitive decline once admitted by requiring facilities to ensure that any resident who becomes incompetent or loses the ability to summon help, recognize danger, or make care decisions has a guardian appointed or has an activated power of attorney for health care, or a durable power of attorney, or both.
43. Sugarman, J., McCrory, D.D., Hubal, R. (1998). Getting meaningful informed consent from older adults: A structured literature review of empirical research. *Journal of the American Geriatric Society*, 46:17-24.
44. In Florida, the physician's opinion of a resident's cognitive capacity is a professional judgment but is not required to be based on formal assessment methods.
45. Burgess, K. (2000) *op. cit.*
46. Burgess, K. (2000) *op. cit.*
47. Lynch, A.A., Teachworth, S.A. (2002) *op. cit.*

# **APPENDIX A: METHODOLOGY**

To conduct this study, we used standard qualitative analysis techniques, including a review of the published and unpublished literature; a review of statutes, regulations, and case law; discussions with experts and key stakeholders in long-term care law, policy and practice; and in-depth interviews with the staff and residents of assisted living facilities in three states. We describe each of these methods in detail below.

## **Literature Review**

We searched five primary databases to identify literature addressing NRAs or similar concepts.

- Academic Search Premier: An online searchable database, including the following databases: CINAHL, MEDLINE, and Social Sciences Abstracts.
- AgeLine: A searchable electronic database sponsored by AARP, containing detailed summaries of publications about older adults and aging, including books, journal and magazine articles, research reports, and videos.
- Google: An Internet search engine with access to over three billion web pages.
- ResearchPort: An on-line searchable database, including Academic Search Premier, ArticleFirst, Catalog USMai, MasterFile Premier, and Worldcat.
- LexisNexis Academic: An online research database that accesses over 5,600 news, business, legal, medical, and reference publications.

We used the following search terms: risk agreement, managed risk, negotiated risk, shared responsibility, assisted living, residential care, senior housing, and board and care. We also used a combination of individual terms and Boolean structures (e.g., risk agreement AND assisted living). We conducted the literature review in January and February 2004. Most of the published literature on NRAs is not in peer reviewed journals or law reviews. The majority is in newsletters from legal, provider, and advocacy associations, other trade publications, and papers prepared by legal advocacy groups. We used our contacts with the assisted living trade associations and consumer groups to identify this literature. Several of the experts with whom we consulted also sent us unpublished analyses. No studies have been published to date on the content and outcomes of NRAs.

## **Review of Statutes and Regulations**

We conducted the regulatory review in January and February 2004. We used three primary sources to identify state statutes and regulations governing NRAs.

- Westlaw: An online legal research service that accesses over 17,000 databases. Permits searches of stated administrative codes, case law, and statutes.
- LexisNexis Academic: Codes & Regulations by state: includes statutory laws, court rules from all states and attorneys general opinions from all states.
- National Academy of State Health Policy: Website [<http://www.nashp.org>] was used to access state rules on assisted living. States with digital (i.e., WORD, PDF or HTML) files accessible via a web site were reviewed using the search above terms.

The primary search terms we used include: risk agreement, managed risk, negotiated risk, and shared responsibility. Additionally, we searched each state's full regulation and/or statute database for the phrase "risk AND assisted living" (we substituted appropriate terms for assisted living, such as board and care and residential care facility, in states that used different terms. This broader search yielded many general mentions of risk, such as health or safety risks, but also lead us to the Arkansas codes that use the term "compliance agreement."

Because our search strategy may have overlooked statutes or regulations that use terms other than those we used, we checked the list of states we identified with NRAs (or similar concepts) in regulations or statute against lists developed by other experts, including Robert Mollica, Eric Carlson, Allan Lynch and Sara Teachworth, and Keren Brown Wilson. When our list varied from that of the other experts, we revisited the state regulations and statutes and adjusted our list as necessary.

## **Consultation and Interviews with Experts and Stakeholders**

We identified experts in long-term care policy, practice and law, assisted living, and NRAs in consultation with the project officer based on the authors' knowledge and expertise and the literature review. We added other experts using a "snowball" method based on suggestions made by the first set of experts. We discussed NRAs with a total of 27 people using a structured discussion guide. In most cases the discussions took place via telephone. A few individuals preferred to write their responses to the questions. See Appendix C for a list of the experts and stakeholders with whom we consulted.

## Site Visits

We conducted site visits to assisted living facilities in three states to obtain information about how NRAs are used in practice.

### *State Selection*

Based on expert interviews and a review of state regulations and statutes governing assisted living facilities, we identified 15 states that reference some type of risk agreement process in their statutes and/or regulations. The states vary in the scope, content, and definition of negotiated risk. The budget allowed for three site visits and we used the following primary site selection criteria:

- a state that requires a risk agreement between provider and resident,
- a state that provides a detailed process, and
- a state that defines NRAS generally as a process.

An additional criterion included the maturity of the state's assisted living experience as represented by the year that the governing rules were adopted. Based on the criteria, we selected three states.

- **Florida** uses a general, process-based definition of managed risk and the state's rules have been in effect since 1991. The state has also experienced a high rate of provider liability suits in long-term care, which we thought might make providers more likely to use NRAs.
- **Oregon** first defined assisted living in 1990 and originated the concept of NRAs in assisted living. The rules define the process for risk agreements in detail, but do not require them.
- **Wisconsin** has required one specific type of residential care setting--an unlicensed apartment model--to use NRAs. The state created this setting--called Residential Care Apartment Complexes (RCACs)--in 1997. Wisconsin's rules are among the most detailed in scope and content. The rules restrict the use of risk agreements to waiver other regulations for this setting.

### *Institutional Review Board Approval*

The study team had existing relationships with assisted living providers, stakeholders, and/or regulators in all three of these states and we contacted them for assistance in identifying and recruiting facilities to participate in the study. We selected three facilities in Florida, three in Oregon, and two in Wisconsin. In Wisconsin and Oregon, we visited one for profit and one non-profit facility; in Florida we visited one non-profit and two for profits.

Once we identified facilities that were willing to participate, we prepared informed consent forms, discussion guides, and permission forms to review resident records in accordance with requirements of the Health Insurance Portability and Accountability Act (HIPAA). We customized consent forms for professional and management staff, direct care staff, and residents. We submitted all forms to RTI's Institutional Review Board for review and approval before asking providers to recruit residents to participate in the study.

### ***Discussions with Staff and Residents***

We asked assisted living managers in Florida and Oregon to identify residents with active NRAs who were willing to speak with us. Because everyone in Wisconsin in RCACs has an NRA, we asked the manager to identify residents with a range of risk topics. At each facility we talked to at least two management-level employees who had direct experience with NRAs and at least one direct care employee; we interviewed a total of 22 residents and 24 staff. See Appendix D for a summary description of study participants.

# **APPENDIX B: STATE REGULATIONS REGARDING NEGOTIATED RISK AGREEMENTS**

Our statutory and regulatory search identified 14 states with provisions regarding negotiated risk agreements (NRAs) or similar concepts, and the District of Columbia (*hereafter*, the states). We first present each of the 15 states relevant provisions,<sup>1</sup> followed by an overview of the statutory and regulatory provisions presented in two tables. Table B-1 summarizes the format required by each state, such as whether or not the agreement must be signed, how it relates to the service plan, and whether it must be reviewed. Table B-2 summarizes characteristics and requirements, such as whether or not an NRA is required, how it is defined, and whether topics such as resident capacity, liability, residency criteria, and residents' rights are addressed. It also includes information categories that are included in the state's NRA provisions, such as reference to assisted living values, residents' capacity to understand the agreement, and whether liability waivers are addressed.

## **Alaska [AS §§ 47.33]**

Alaska states that one of the purposes of its regulations is to establish standards that will protect residents of assisted living homes, while at the same time promoting an environment that will encourage resident growth and independence, without discouraging the establishment and continued operation of the homes. Alaska's rules for Assisted Living Homes do not specifically define a negotiated or managed risk agreement, but there are two sections that refer to recognizing risks and responsibilities for decisions, and this meets the intention of NRAs defined in other states.

The rules addressing the content of the assisted living plan states that the plan will "recognize the responsibility and right of the resident or the resident's representative to evaluate and choose, after discussion with all relevant parties, including the home, the risks associated with each option when making decisions pertaining to the resident's abilities, preferences, and service needs, and recognize the right of the home to evaluate and to either consent or refuse to accept the resident's choice of risks."

The rules addressing health-related services allowed in assisted living homes, state that "if a resident has received 24-hour skilled nursing care for the 45-day limit, the resident or the resident's representative may elect to have the resident remain in the home without continuation of 24-hour skilled nursing care if: (1) the home agrees to retain the resident after either the home or the resident or the resident's representative have consulted with the resident's physician; and (2) the home and either the resident

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<sup>1</sup> Provisions regarding NRAs are included in various sections of states' regulations, generally in the sections regarding definitions, residency criteria, and service planning. We have combined all the provisions for each state.

or the resident's representative have discussed the consequences and risks involved in the election to remain in the home; and (3) the portion of the resident's assisted living plan that relates to health-related services has been revised to provide for the resident's health-related needs without the use of 24-hour skilled nursing care, and the revised plan has been reviewed by a registered nurse or by the resident's attending physician."

## **Arkansas** [A.C.A. §§ 20-10-17]

Arkansas states that one of the purposes of its regulations is to encourage the development of facilities that promote the dignity, individuality, privacy, and decision-making ability of individuals who reside there, and that the services available in these facilities, either directly or through contract or agreement, are intended to help residents remain as independent as possible.

The regulations define a compliance agreement as a written formal plan developed in consideration of shared responsibility, choice and assisted living values and negotiated between the resident or his or her responsible party and the assisted living facility to avoid or reduce the risk of adverse outcomes that may occur in an assisted living environment. The state does not mandate the use of a compliance agreement, and notes that it "can be used if needed."

The state has specific requirements for the compliance agreement process:

When the resident evaluation indicates that there is a high probability that a choice or action of the resident has resulted or will result in any of the outcomes of placing the resident or others at risk, leading to adverse outcomes, violating the norms of the facility or program or the majority of the residents, or any combination of the events, the assisted living facility shall:

- Identify the specific concern(s).
- Provide the resident or his or her responsible party (and if the resident agrees, the resident's family) with clear, understandable information about the possible consequences of his or her choice or action.
- Negotiate a compliance agreement with the resident or his or her responsible party that will minimize the possible risk and adverse consequences while still respecting the resident's preferences. Nothing in this provision requires a facility to successfully negotiate a compliance agreement.
- Document the process of negotiation and, if no agreement can be reached, the lack of agreement and the decisions of the parties involved.

Any compliance agreements negotiated, or attempted to be negotiated, with the resident or his or her responsible party shall address the following areas in writing:

- Consequence to resident--any situation or condition that is or should be known to the facility that involves a course of action taken or desired to be taken by the resident contrary to the practice or advice of the facility and could put the resident at risk of harm or injury.
- The probable consequences if the resident continues the choice or action identified as a cause for concern.
- The resident or his or her responsible party's preference concerning how the situation is to be handled and the possible consequences of action on that preference.
- What the facility will and will not do to meet the resident's needs and comply with the resident's preference to the identified course of action.
- Alternatives offered by the assisted living facility or resident or his or her responsible party to reduce the risk or mitigate the consequences relating to the situation or condition.
- The agreed upon course of action, including responsibilities of both the resident or his or her responsible party and the facility.
- The resident or his or her responsible party's understanding and acceptance of responsibility for the outcome from the agreed upon course of action and written proof that the resident or his or her responsible party is making an informed decision, free from coercion, and that the refusal of the resident or his or her responsible party to enter into a compliance agreement with the facility, or to revise the compliance agreement or to comply with the terms of the compliance agreement may result in discharge from the facility.
- The date the agreement is executed and, if needed, the timeframes in which the agreement will be reviewed.

The regulations define "responsible parties" as individuals who "agree to act on behalf of a resident or applicant for the purposes of making decisions regarding the needs and welfare of the resident or applicant."

The occupancy admission agreement can be terminated under any one of several conditions, including: "the resident or his or her responsible party refuses to enter into a negotiated compliance agreement, refuses to revise the compliance agreement when there is a documented medical reason for the need of a negotiated compliance agreement or revision thereto, or refuses to comply with the terms of the compliance agreement."

The regulations state that residents may not remain in an assisted living facility if their condition requires 24-hour nursing care or other services that an assisted living facility is not authorized by law to provide. It specifically states that “this prohibition shall apply even if the resident is willing to enter into an agreement to relieve the facility of responsibility or otherwise manage the risk.”

On the other hand, the regulations state that “an assisted living facility may retain a resident whose condition requires episodic, 24-hour nursing care, or who becomes incompetent or incapable of recognizing danger, summoning assistance, expressing need or making care decisions provided that the facility ensures” that a number of requirements are met, including “that both the service agreement and compliance agreement, if required, is signed by the guardian and the health care agent or the agent with power of attorney, if any...”

Under a provision titled, “Bill Of Rights,” the regulations state that residents “be given the opportunity to refuse medical treatment or services after the resident or his or her responsible party is advised by the person providing services of the possible consequences of refusing treatment or services, and acknowledges that he or she understands the consequences of refusing treatment or services.” A compliance agreement is not listed as a requirement in such a situation.

## **Delaware** [*Del. Regs 16-2 § 63.0 et seq*]

Delaware defines Managed/NRAs as “a signed document between the resident and the facility, and any other involved party, which describes mutually agreeable action balancing resident choice and independence with the health and safety of the resident or others.”

Shared Responsibility is defined as a “concept that residents and assisted living facilities share responsibility for planning and decision-making affecting the resident.”

The state requires that the resident who signs a service agreement “must be able to comprehend and perform their obligations under the agreement.” The regulations state that “the service agreement shall be based on the concepts of shared responsibility and resident choice. To participate fully in shared responsibility, residents shall be provided with clear and understandable information about the possible consequences of their decision-making. If a resident’s preference or decision places the resident or others at risk or is likely to lead to adverse consequences, a managed/negotiated risk agreement section may be included in the service agreement.”

The regulations specify that a managed managed/NRA must meet the following criteria:

- the risks are tolerable to all parties participating in the development of the managed/NRA;
- mutually agreeable action is negotiated to provide the greatest amount of resident autonomy with the least amount of risk; and
- the resident living in the facility is capable of making choices and decisions and understanding consequences.

If a managed/NRA is made a part of the service agreement, it shall:

- clearly describe the problem, issue or service that is the subject of the managed/NRA;
- describe the choices available to the resident as well as the risks and benefits associated with each choice, the assisted living facility's recommendations or desired outcome, and the resident's desired preference;
- indicate the agreed-upon option;
- describe the agreed upon responsibilities of the assisted living facility, the resident, and any third parties;
- become a part of the service agreement, be signed separately by the resident, the assisted living facility, and any third party with obligations under the managed/NRA that the third party is able to fully comprehend and perform; and
- include a time frame for review.

The assisted living facility shall have sufficient staff to meet its responsibilities under the managed/NRA.

- The assisted living facility shall not use managed/NRAs to provide care to residents with needs beyond the capability of the facility. A managed/NRA shall not be used to supersede any requirements of these regulations.
- The assisted living facility shall make no attempt to use the managed/negotiated risk portion of the service agreement to abridge a resident's rights or to avoid liability for harm caused to a resident by the negligence of the assisted living facility and any such abridgement or disclaimer shall be void."

### **District of Columbia** *[DC Code Ann. § 44-101 & 102 & 106]*

The District of Columbia states that its regulations should be interpreted in accordance with the following philosophy of care:

- The design of services and environment should acknowledge that a significant number of residents may have some form of cognitive impairment. Services and

environment should offer a balance between choice and safety in the least restrictive setting.

- Both the program and environment should support resident dignity, privacy, independence, individuality, freedom of choice, decision making, spirituality, and involvement of family and friends.

Shared responsibility is defined as:

- A process to deal with disagreements, wherein “the resident, or the resident’s surrogate, and the ALR arrive at an acceptable balance between resident’s desire for independence and the facility’s legitimate concerns for safety. The purpose of shared responsibility is to provide complete information to the resident and the surrogate so that the parties can arrive at an informed agreement of which services are to be provided and in what manner.”
- “A formal written agreement that outlines the responsibilities and actions of all parties. The agreement is a process for resolving discrepancies between the individual resident’s right to independence and the provider’s concerns for the safety and well being of the individual and others.”

Additional regulations state that residents have the right:

- “to engage in a shared responsibility agreement with the ALR (assisted living residence), which is acceptable to the resident and the ALR and does not violate any applicable law;
- to refuse to participate in any service once the potential consequences of such participation have been explained and a shared responsibility agreement has been reached, if necessary, between the resident, the surrogate, and the ALR.”

The regulations provide additional guidance on the use of shared responsibility agreements, specifying that “whenever disagreements arise as to lifestyle, personal behavior, safety, and service plans the ALR staff, resident or surrogate, and other relevant service providers shall attempt to develop a shared responsibility agreement.” A shared responsibility agreement represents a tool for ALRs to recognize an individual resident’s right to autonomy by respecting his or her right to make individual decisions regarding lifestyle, personal behavior, and individual service plans.

In some cases, a resident’s decision may involve increased risk of personal harm and therefore potentially increase the risk of liability by the ALR absent an agreement between the resident and ALR concerning such decisions or actions. In such instances the ALR shall:

- explain to the resident, or surrogate, why the decision or action may pose risks and suggest alternatives to the resident; and

- discuss with the resident, or surrogate, how the ALR might mitigate potential risks.

If, after consultation with the ALR...a resident decides to pursue a course of action, such as refusal of services, that may involve increased risk of personal harm and conflict with the ALR's usual responsibilities, the ALR shall:

- Describe to the resident the action or range of actions subject to negotiation.
- Negotiate a shared responsibility agreement, with the resident as a full partner, acceptable to the resident and the ALR, that meets all reasonable requirements implicated. The shared responsibility agreement shall be signed by the resident or surrogate and the ALR.

The regulations state that when shared responsibility agreements are necessary, they shall be included in the individualized service plan.

### **Florida** [*Fla Stat. Ann. §§ 400.402*]

Assisted living facilities in Florida that are licensed to provide extended congregate care services shall:

- “Adopt and follow policies and procedures that maximize resident independence, dignity, choice, and decision making to permit residents to age in place to the extent possible, so that moves due to changes in functional status are minimized or avoided.
- Allow residents or, if applicable, a resident's representative, designee, surrogate, guardian, or attorney in fact to make a variety of personal choices, participate in developing service plans, and share responsibility in decision making,” and “implement the concept of managed risk.”

Florida defines managed risk as “the process by which the facility staff discuss the service plan and the needs of the resident with the resident and, if applicable, the resident's representative or designee or the resident's surrogate, guardian, or attorney in fact, in such a way that the consequences of a decision, including any inherent risk, are explained to all parties and reviewed periodically in conjunction with the service plan, taking into account changes in the resident's status and the ability of the facility to respond accordingly.”

The state defines shared responsibility as a method for “exploring the options available to a resident within a facility and the risks involved with each option when making decisions pertaining to the resident's abilities, preferences, and service needs, thereby enabling the resident and, if applicable, the resident's representative or designee, or the resident's surrogate, guardian, or attorney in fact, and the facility to

develop a service plan which best meets the resident's needs and seeks to improve the resident's quality of life.”

## **Hawaii** [*Haw. Admin. R. 11-90*]

Hawaii states that three principles are to be applied in assisted living facilities:

- aging in place,
- negotiated plan of care, and
- managed risk.

The state defines choice as “viable options created for residents to enable them to exercise greater control over their lives.” Managed risk is defines as “a formal process of negotiating and developing a plan to address resident needs, decisions, or preferences to reduce the probability of a poor outcome for the resident or of putting others at risk for adverse consequences.”

The state does not mention risk as part of its definition of a negotiated plan of care or service plan or agreement. However, it states that the service plan must be a formal process that “includes recognition of the resident’s capabilities and choices.”

## **Illinois** [*210 Ill. Comp. Stat. Ann. 9/5 & 9/10 & AC 77.295*]

Illinois states that assisted living establishments and shared housing establishments are based on a social model that promotes dignity, individuality, privacy, independence, autonomy, and decision-making ability, and the right to negotiate risk.

The regulations state that “assisted living, which promotes resident choice, autonomy, and decision making, should be based on a contract model designed to result in a negotiated agreement between the resident or the resident’s representative and the provider, clearly identifying the services to be provided. This model assumes that residents are able to direct services provided for them and will designate a representative to direct these services if they themselves are unable to do so. This model supports the principle that there is an acceptable balance between consumer protection and resident willingness to accept risk and that most consumers are competent to make their own judgments about the services they are obtaining.

Regulation of assisted living establishments and shared housing establishments must be sufficiently flexible to allow residents to age in place within the parameters of this Act. The administration of this Act and services provided must therefore ensure that the residents have the rights and responsibilities to direct the scope of services they receive and to make individual choices based on their needs and preferences. These establishments shall be operated in a manner that provides the least restrictive and

most homelike environment and that promotes independence, autonomy, individuality, privacy, dignity, and the right to negotiated risk in residential surroundings.”

The state defines negotiated risk as “the process by which a resident, or his or her representative, may formally negotiate with providers what risks each are willing and unwilling to assume in service provision and the resident’s living environment. The provider assures that the resident and the resident’s representative, if any, are informed of the risks of these decisions and of the potential consequences of assuming these risks.” It further defines a NRA as “a binding agreement...describing conditions or situations that could put the resident at risk of harm or injury,” and describing the resident’s agreement with the establishment for how those conditions or situations are to be handled.

Illinois distinguished NRA from risk management, which is defined as a “process by which an establishment assesses and addresses potential liability.”

The regulations also specify the required content of NRAs, noting that they shall be signed by the resident or the resident’s representative and the licensee and shall describe the following:

- “the problem, issue or service that is the subject of the agreement;
- the choices available to the resident, as well as the major risks and consequences associated with each choice;
- the resulting agreement;
- the responsibilities of the establishment and the resident and any other involved individual; and
- a time frame for review.”

The regulations further state that a NRA:

- may be negotiated or renegotiated at any time during the resident’s stay in the establishment and may initiate a reevaluation of the service delivery plan;
- shall be limited to a resident’s individual care and personal environment;
- shall not create a risk to the health, safety, or welfare of other residents and shall not infringe upon the rights of other residents; and
- shall not waive other regulatory requirements.

Several additional provisions reference NRAs.

- Those relating to physician’s assessments state that when an assessment is completed for any reason required by regulation (e.g., when a significant change in condition occurs, “all current negotiated risk agreements shall be renegotiated as necessary”).
- Those relating to requirements that are triggered when a significant change in the resident’s condition, which is defined as a change that is “substantial enough to

indicate to a reasonable person that current supports and services are insufficient, taking into account the resident's wishes as addressed in any negotiated risk agreements in effect.”

- Those relating to the service plan state that “the establishment shall respect and accept the resident’s choices regarding the service plan,” and “service plans shall address any risk being negotiated.”
- Those relating to rights state that residents have the right “to direct his or her own care and negotiate the terms of his or her own care,” and “to refuse services unless such services are court ordered or the health, safety, or welfare of other individuals is endangered by the refusal, and to be advised of the consequences of that refusal.”

Additionally, the regulations specify that “nothing in this Part limits a resident’s ability to direct his or her own care and negotiate the terms of his or her own care. Residents have the right to refuse certain services or approaches that would otherwise be recommended based on the physician’s assessment if the resident has received clear information regarding the risks and benefits of such a choice and the choice does not put other residents or staff at risk. Disclosure of the risks of refusing services or approaches must be documented in the service plan.”

## **Iowa** [*Iowa Admin. Code r. 321-27*]

Iowa defines assisted living to include encouragement of family involvement, tenant self-direction, and tenant participation in decisions that emphasize choice, dignity, privacy, individuality, shared risk, and independence.

The regulations require facilities to disclose their managed risk policy prior to occupancy. The state requires assisted living program to have a managed risk statement “which includes the tenant’s or responsible person’s signed acknowledgment of the shared responsibility for identifying and meeting needs and the process for managing risk and upholding tenant autonomy when tenant decision making may result in poor outcomes for the tenant or others.”

## **New Jersey** [NJ Admin. Code. Title §§ 8:36 and NJ Stat. § 30:13-8.1 (2003)]

New Jersey's regulations state that "assisted living promotes resident self direction and participation in decisions that emphasize independence, individuality, privacy, dignity, and homelike surroundings." The state defines managed risk agreements and related concepts as follows:

- "Bounded choice means limits placed on a resident's choice as a result of an assessment...which indicates that such resident's choices or preferences place the resident or others at a risk of harm or lead to consequences which violate the norms of the facility or program or the rights of others."
- "Managed risk means the process of balancing resident choice and independence with the health and safety of the resident and other persons in the facility or program. If a resident's preference or decision places the resident or others at risk or is likely to lead to adverse consequences, such risks or consequences are discussed with the resident, and, if the resident agrees, a resident representative, and a formal plan to avoid or reduce negative or adverse outcomes is negotiated."
- Managed risk agreement means the written formal plan developed in consideration of shared responsibility, bounded choice and assisted living values, and negotiated between the resident and the facility or program to avoid or reduce the risk of adverse outcomes which may occur in an assisted living environment.

Additional provisions regarding managed risk agreements state that:

- "The choice and independence of action of a resident may need to be limited when a resident's individual choice, preference and/or actions are identified as placing the resident or others at risk, lead to adverse outcome and/or violate the norms of the facility or program or the majority of the residents."
- When the resident assessment process...indicates that there is a high probability that a choice or action of the resident has resulted or will result in any of the preceding, the assisted living residence, comprehensive personal care home or assisted living program shall: (1) identify the specific cause(s) for concern; (2) provide the resident (and if the resident agrees, the resident's family or representative) with clear, understandable information about the possible consequences of his or her choice or action; (3) seek to negotiate a managed risk agreement with the resident (or legal guardian) that will minimize the possible risk and adverse consequences while still respecting the resident's preferences; and (4) document the process of negotiation and, if no agreement can be reached, the lack of agreement and the decisions of the parties involved.

The state requires that managed risk agreements include:

- “the specific cause(s) for concern;
- the probable consequences if the resident continues the choice and/or action identified as a cause for concern;
- the resident’s preferences;
- possible alternatives to the resident’s current choice and/or action;
- the final agreement reached by all parties involved; and
- the date the agreement is executed and, if needed, the time frames in which the agreement will be reviewed.”

New Jersey also references NRAs in its training requirements for assisted living administrators, who are required to complete: (1) “at least 40 hours in assisted living administrator training,” which shall cover a range of topics, including “shared responsibility and managed risk,” and (2) “a practicum, consisting of a minimum of 16 hours, at a New Jersey licensed assisted living facility which shall include satisfactory completion of a resident service needs assessment, service plan and risk management agreement.”

New Jersey regulations clearly state that “any provision or clause waiving or limiting the right to sue for negligence or malpractice in any admission agreement or contract between a patient and a nursing home or assisted living facility, whether executed prior to, on or after the effective date of this act, is hereby declared to be void as against public policy and wholly unenforceable, and shall not constitute a defense in any action, suit or proceeding.”

### **Ohio** [*Ohio Rev. Code Ann. § 3721*]

Ohio regulations state that a “residential care facility may enter into a risk agreement with a resident or the resident’s sponsor. Under a risk agreement, the resident or sponsor and the facility agree to share responsibility for making and implementing decisions affecting the scope and quantity of services provided by the facility to the resident. The facility also agrees to identify the risks inherent in a decision made by a resident or sponsor not to receive a service provided by the facility. A risk agreement is valid only if it is made in writing.”

The state requires residential care facilities that use risk agreements to provide prospective residents (or their sponsors) a written explanation of the policy and the provisions that may be contained in a risk agreement. The facility must obtain a signed acknowledgement that the individual has received the information.

Additional regulations link risk agreements with the provision of personal care services, stating that residential care facilities shall “provide personal care services to its residents who require those services, unless the resident and the facility have entered into a risk agreement...or the resident has refused services.” Furthermore, “if a resident

requires certain personal care services that the residential care facility does not offer,” the facility must first meet with the resident and her responsible party (if appropriate). Depending on the results of a resident evaluation, there are three possible outcomes: the facility or the resident shall arrange for the services to be provided, the facility shall transfer the resident to an appropriate setting or discharge the resident, or the facility and the resident may enter into a risk agreement if the facility has a policy of entering into such agreements.

### **Oklahoma** [*Okla. Admin. Code § 310:663*]

The code governing assisted living centers specifies that if residents’ choices or decisions place them or others at risk or are “likely to lead to an adverse consequence” the center is required to: (1) advise the resident and the resident’s representative of such risk or consequences, (2) specify the cause for concern, (3) discuss the concern with the resident and representative, if any, and (4) attempt to negotiate a written agreement that minimizes risk and adverse consequences and offers alternatives while respecting resident preferences. Both agreements and lack of agreements must be documented.

### **Oregon** [*Or. Admin. R. 411-056*]

Oregon defines assisted living to include a program approach that promotes resident self-direction and participation in decisions that emphasize choice, dignity, privacy, individuality, and independence.

The state defines managed risk as a “process by which a resident’s high-risk behavior or choices are reviewed with the resident. Alternatives to and consequences of the behavior or choices are explained to the resident and the resident’s decision to modify behavior or accept the consequences is documented.” The service plan is defined as a separate document, a written plan for services that reflects the resident’s capabilities, choices and if applicable, measurable goals and managed risk issues; and includes agreed upon actions if a managed risk plan is developed.

In the section on residents’ rights, the regulation states that residents are to be given “informed choice and opportunity to select or refuse service and to accept responsibility for the consequences;” Oregon rules regarding residents’ ability to enter into such an agreement state that facilities are required to identify the need for and develop a managed risk plan following the facility’s established guidelines and procedures. They require that managed risk plans include:

- “an explanation of the cause(s) of concern;
- the possible negative consequences to the resident and/or others;
- a description of resident preference(s);

- possible alternatives/interventions to minimize the potential risks associated with the resident’s current preference/action;
- a description of the services the facility will provide to accommodate the resident’s choice or minimize the potential risk; and
- the final agreement, if any, reached by all involved parties.”

The state also requires the facility to “involve the resident, the resident’s designated representative and others as indicated, to develop, implement and review the managed risk plan. The resident’s preferences shall take precedence over those of a family member(s). A managed risk plan shall not be entered into or continued with or on behalf of a resident who is unable to recognize the consequences of his/her behavior or choices. The managed risk plan shall be reviewed at least quarterly.”

The regulations state that a criterion for involuntary move-outs is resident behavior or actions that repeatedly and substantially interfere with the rights or well being of other residents, after the facility has documented prudent and reasonable interventions that it has attempted to address the problem.

**Vermont** *[ALR, § 7102. Statutes, Title 33, Part 5, Chapter 71]*

Vermont defines assisted living to include a program that promotes “resident self-direction and active participation in decision-making while emphasizing individuality, privacy and dignity.”

Negotiated risk is defined as a “formal, mutually-agreed upon, written understanding that results after balancing a resident’s choices and capabilities with the possibility that those choices will place the resident at risk of harm. Negotiated risk does not constitute a waiver of liability. Licensees are required to establish policies and procedures regarding the negotiated risk agreement process, including the identification of the responsible staff person.”

Additional provisions state that negotiated risk discussions must be resident specific, and that:

- “Whenever the licensee determines that a resident’s decision, behavior or action places the resident or others at risk of harm, the licensee shall initiate a service negotiation process to address the identified risk and to reach a mutually agreed-upon plan of action.”
- The licensee shall initiate the negotiated risk process by notifying the resident and, if applicable, the legal representative, verbally and in writing. The licensee shall also give notice to the resident and legal representative that the state Long Term Care Ombudsman is available to assist in the process.

- If the licensee and the resident reach agreement, the mutually agreed upon plan shall be in writing.
- The written plan shall be dated and signed by both parties to the negotiation.

NRAs are clearly linked to the care plan. “The care plan shall describe the assessed needs and choices of the resident and shall support the resident’s dignity, privacy, choice, individuality, and independence. The licensee shall review the plan at least annually, and whenever the resident’s condition or circumstances warrant a review, including whenever a resident’s decision, behavior or action places the resident or others at risk of harm, or the resident is incapable of engaging in a negotiated risk agreement.”

Provisions on involuntary discharge reference NRAs, stating that “the licensee shall not initiate a discharge because a resident’s choice might pose a risk if the resident is competent and the choice is informed and poses a danger or risk only to the resident. Otherwise, an involuntary discharge of a resident may occur only when the resident presents a serious threat to self that cannot be resolved through care planning and the resident is incapable of engaging in a negotiated risk agreement;” or when “the resident presents a serious threat to residents or staff that cannot be managed through interventions, care planning or negotiated risk agreements in the assisted living residence. If the licensee and the resident are not able to reach agreement, the licensee shall notify the state long term care ombudsman if the failure to reach agreement results in a notice of discharge.”

### **Washington** [*Wash. Admin. Code § 388*]

The Washington State code for boarding homes has a number of assisted living service standards stating that the contractor “shall ensure that both the physical environment and the delivery of assisted living services are designed to enhance autonomy in ways which reflect personal and social values of dignity, privacy, independence, individuality, choice and decision-making of residents.” Additionally, contractors are required to: (1) provide resident services in a manner that supports managed risk which includes the resident’s right to take responsibility for the risks associated with decision-making; and (2) develop a formal written, negotiated plan to decrease the probability of a poor outcome when a resident’s decision or preference places the resident or others at risk, leads to adverse consequences, or conflicts with other residents’ rights or preferences.

Washington State also requires that service planning be negotiated. “The boarding home must provide the care and services as agreed upon in the negotiated service agreement to each resident unless a deviation from the negotiated service agreement is mutually agreed upon between the boarding home and the resident or the resident’s representative at the time the care or services are scheduled.” Residents are permitted to refuse any particular service “unless adjudged incompetent or otherwise found to be

legally incapacitated to direct his or her own service plan and changes in the service plan,” and “so long as such refusal is documented in the record of the resident.”

Washington State clearly states that facilities may not waive a resident’s rights: “the boarding home must not require or ask the resident or the resident’s representative to sign any contract or agreement, including a negotiated service or risk agreement, that purports to waive any rights of the resident or that purports to place responsibility or liability for losses of personal property or injury on the resident.” In another section, the rules state that “no long term care facility or nursing facility shall require or request residents to sign waivers of potential liability for losses of personal property or injury, or to sign waivers of residents’ rights set forth in this chapter or in the applicable licensing or certification laws.”

Provisions relating to the coordination of health care services also reference NRAs: “when authorizations to release health care information are not obtained, or when an external health care provider is unresponsive to the boarding home’s efforts to coordinate services, the boarding home must: (1) document the boarding home’s actions to coordinate services; (2) provide notice to the resident of the risks of not allowing the boarding home to coordinate care with the external provider; and (3) address known associated risks in the resident’s negotiated service agreement.”

“When coordinating care or services, the boarding home must (1) integrate relevant information from the external provider into the resident’s assessment, and when appropriate, negotiated service agreement; and (2) respond appropriately when there are observable or reported changes in the resident’s physical, mental, or emotional functioning.”

## **Wisconsin** [*Wis. Stat. Ann. § 89-Chapter 50*]

Wisconsin’s statute on residential care apartment complexes specifies that they should “operate in a manner that protects tenants’ rights, respects tenant privacy, enhances tenant self-reliance and supports tenant autonomy in decision-making including the right to accept risk.”

A risk agreement is defined as a “binding stipulation identifying conditions or situations which could put the tenant at risk of harm or injury and the tenant’s preference for how those conditions or situations are to be handled.” Wisconsin differs from other states by requiring a signed, jointly NRA with each tenant by the date of occupancy “as a protection for both the individual tenant and the residential care apartment complex” that that “identifies situations that could put the resident at risk and for which the resident understands and accepts responsibility.”

Because tenants need to be competent to understand and express their needs and preferences, enter into a service agreement and understand and accept risk, the state specifies restrictions on who can be admitted to a residential care apartment complex.

The following persons may not be admitted unless the person being admitted shares an apartment with a competent spouse or other person who has legal responsibility for the individual:

- a person who has a court determination of incompetence and is subject to guardianship,
- a person who has an activated power of attorney for health care, and
- a person who has been found by a physician or psychologist to be incapable of recognizing danger, summoning assistance, expressing need or making care decisions.

“Incapable of making care decisions means unable to understand one’s own needs for supportive, personal or nursing services; to choose what, if any, services one wants to receive to meet those needs; and to understand the outcome likely to result from that choice. The term refers to the ability to make a decision and not to the content or result of the decision.”

Regulations state that a residential care apartment complex may retain a tenant who becomes incompetent or incapable of recognizing danger, summoning assistance, expressing need or making care decisions, provided that the facility ensures all of the following:

- That adequate oversight, protection and services are provided for the individual.
- That the tenant has a guardian appointed under, or has an activated power of attorney for health care, or a durable power of attorney, or both. The activated power of attorney for health care or durable power of attorney shall, either singly or together, substantially cover the person’s areas of incapacity.
- That both the service agreement and risk agreement are signed by the guardian and by the health care agent or the agent with power of attorney, if any.

The state specifies that the risk agreements must identify and state all of the following:

- Risk to tenants.
- Any situation or condition which is or should be known to the facility which involves a course of action taken or desired to be taken by the tenant contrary to the practice or advice of the facility and which could put the tenant at risk of harm or injury.
- The tenant’s preference concerning how the situation is to be handled and the possible consequences of acting on that preference.
- What the facility will and will not do to meet the tenant’s needs and comply with the tenant’s preference relative to the identified course of action.

- Alternatives offered to reduce the risk or mitigate the consequences relating to the situation or condition.
- The agreed upon course of action, including responsibilities of both the tenant and the facility.
- The tenant's understanding and acceptance of responsibility for the outcome from the agreed upon course of action.
- *Unmet needs.* Any needs identified in the comprehensive assessment which will not be provided for by the facility, either directly or under contract.
- *Notice regarding enforcement in registered facilities.* For registered facilities only, notice that the department does not routinely inspect registered facilities or verify their compliance with this chapter and does not enforce contractual obligations under the service or risk agreements.

Wisconsin states clearly that a risk agreement may not waive any provision of this chapter or any other right of the tenant, but also states an obligation to negotiate in good faith: "neither the tenant nor the facility shall refuse to accept reasonable risk or insist that the other party accept unreasonable risk." The rules state that the risk agreement must be signed and dated by both an authorized representative of the residential care apartment complex and by the tenant or the tenant's guardian and agents designated under an activated power of attorney for health care or a durable power of attorney.

Risk agreements must be updated when the tenant's condition or service needs change in a way that may affect risk, as indicated by a review and update of the comprehensive assessment, by a change in the service agreement or at the request of the tenant.

Several additional provisions reference NRAs.

- "Services shall be appropriate to the needs, abilities and preferences of tenants as identified in the comprehensive assessment, service agreement and risk agreement.
- Services shall be provided in a manner which respects tenant privacy, enhances tenant self-reliance and supports tenant autonomy in decision-making, including the right to accept risk.
- A tenant may contract for additional services not included in the service agreement from providers of the tenant's choice, so long as the tenant informs the facility, complies with applicable facility policies and procedures and agrees to have the arrangements reflected in the risk agreement.

- A comprehensive assessment shall be performed prior to admission for each person seeking admission as a basis for developing the service agreement and the risk agreement.” The comprehensive assessment shall identify and evaluate various factors relating to the person’s need and preference for services, including situations or conditions which could put the tenant at risk of harm or injury.
- “A tenant’s capabilities, needs and preferences identified in the comprehensive assessment shall be reviewed at least annually to determine whether there have been changes that would necessitate a change in the service or risk agreement. The review may be initiated by the facility, the county department, or at the request of or on the behalf of the tenant.”
- Residents may “choose which services are included in the service agreement, including the right to refuse services provided that the refusal would not endanger the health or safety of the other tenants.” They have the right to receive services consistent with the service agreement and risk agreement.
- Except as provided for in the service agreement or risk agreement, the facility may not “interfere with the tenant’s ability to manage his or her own medications or, when the facility is managing the medications, to receive all prescribed medications in the dosage and at the intervals prescribed by the tenant’s physician and to refuse a medication unless there is a court order.”

## **Summary Overview of States’ Statutory and Regulatory Provisions**

The following two tables provide an overview of the statutory and regulatory provisions of the states that reference NRAs. Table B-1 summarizes the NRA processes each states requires, such as whether or not the agreement must be signed, whether it is defined as a negotiation tool, and whether it must be reviewed. Table B-2 summarizes specific other features of states’ NRA regulations, including whether an NRA is required, and whether topics such as resident capacity, provider liability, residency criteria, and resident rights are addressed.

<b>TABLE B-1. Negotiated Risk Agreement Processes</b>					
<b>State</b>	<b>Resident's Signature Required</b>	<b>Provider's Signature Required</b>	<b>Defined as Part of Service Plan</b>	<b>Method of Record-Keeping Specified</b>	<b>Timeframe for Review Specified</b>
Alaska			✓	✓	✓
Arkansas	✓			✓	✓
Delaware	✓	✓*	✓	✓	✓
District of Columbia	✓		✓	✓	
Florida			✓		
Hawaii				✓	
Illinois	✓	✓	✓	✓	✓
Iowa					
New Jersey				✓	✓
Ohio				✓	
Oklahoma				✓	
Oregon			✓	✓	✓
Vermont	✓	✓	✓	✓	
Washington	✓		✓	✓	✓
Wisconsin	✓		✓		✓

\* Provider's signature required only if the agreement is part of the service plan.

**TABLE B-2. Characteristics of States' NRA Provisions**

State	NRA Required	Rules Reference Autonomy & Choice	NRA Process/Format Defined <sup>1</sup>	Capacity to Understand NRA is Addressed <sup>2</sup>	Provider Liability Addressed <sup>3</sup>	Residency Criteria Addressed <sup>4</sup>	Role of NRA in Discharge Defined <sup>5</sup>	Residents' Rights Reference NRAs <sup>6</sup>
Alaska		✓	General	---	---	General	General	General
Arkansas	✓*	✓	Specific	General	---	Specific	Specific	Specific
Delaware		✓	Specific	Specific	Specific	Specific	---	---
District of Columbia		✓	Specific	Specific	General	---	---	Specific
Florida			General	General	---	---	---	---
Hawaii		✓	---	---	---	---	---	---
Illinois		✓	Specific	Specific	General	---	General	Specific
Iowa	✓*	✓	---	---	General	---	---	---
New Jersey		✓	Specific	General	Specific	---	---	---
Ohio			General	---	---	---	General	Specific
Oklahoma	✓*		General	---	---	---	---	---
Oregon		✓	Specific	Specific	---	General	General	Specific
Vermont	✓*		Specific	Specific	Specific	---	Specific	---
Washington	✓*		General	Specific	Specific	---	---	Specific
Wisconsin	✓	✓	Specific	Specific	Specific	Specific	Specific	Specific

\* Arkansas, Iowa, Oklahoma, and Vermont require facilities to initiate a negotiation *process* when they determine that a resident's decision, behaviour or action places the resident or others at risk of harm; under the same circumstances, Washington requires providers to develop a formal, written negotiated plan.

- NRA Process/Format Defined.** This column indicates whether the states' rules describe the process or format for an NRA. "Specific" means that the state mandates the format or process for an NRA (e.g., New Jersey defines six areas that must be addressed in writing). "General" means that the state gives broad guidance for the process or format but does not provide specific guidance (e.g., Ohio indicates that risks associated with resident decisions must be addressed and recorded in writing, but do not specify a process or format). "----" means the state does not address the process or form of an NRA.
- Capacity to Understand NRA is Addressed:** This column indicates whether the rules reference the capacity (or ability) of the resident to understand the NRA. "Specific" means that the rules state parameters (e.g., Oregon rules indicate that a risk agreement should not be entered into or continued on behalf of an individual who is unable to recognize the consequences of his/her behavior or choices; the District of Columbia explains that the design of services should recognize that a significant number of residents might be cognitively impaired and that services should offer a balance between safety and choice). "General" means that a state references capacity but does not provide specific guidance (e.g., Alaska and New Jersey state that NRAs should be explained or written in understandable language). "----" means the state does not address resident capacity regarding NRAs.
- Provider Liability Addressed:** This column indicates whether a state's rules explain that an NRA may **not** represent a waiver of liability. "Specific" means that a state prohibits a waiver of liability (e.g., Delaware mandates that the "facility shall make no attempt to use the managed/negotiated portion of the service agreement to abridge a resident's right or to avoid liability for harm caused to a resident by the negligence of the assisted living facility"). "General" means that a state's rules indicate that NRAs can not waive provider responsibilities under other requirements of the rules (e.g., Illinois states that NRAs "shall not waive the requirements of this Part"). "----" means the state does not address liability waivers.
- Residency Criteria Addressed:** This column indicates whether the state's rules contain guidance on NRAs use when the issue involves residency criteria, i.e., rules about who may be admitted to an assisted living facility. "Specific" means that the rules contain guidance on how NRAs interact with residency criteria (e.g., Arkansas rules prohibit the admission or retention of individuals who require 24-hour nursing care, "even if the resident is willing to enter into an agreement to relieve the facility of responsibility or otherwise manage risk"). "General" means that the rules reference risk and residency (e.g., Risk assessment is part of the process for determining admission and retention). "----" means the state does not address how NRAs interact with residency criteria.

**TABLE B-2 (continued)**

5. **Role of NRA in Discharge Addressed:** This column indicates whether a state's rules contain guidance on NRAs use when the issue involves discharge criteria (i.e., rules that define how and if residents may be given notice to move out). "Specific" means that the rules contain guidance on how NRAs interact with discharge requirements (e.g., Arkansas rules cited in Note 4 are one example; Vermont takes a different approach, indicating that the facility may not discharge a resident because the resident's choice might pose a risk, if the resident is competent, the choice is informed, and the risk is to the resident only). "General" means that rules reference NRAs and discharge (e.g., Alaska rules consider risk assessment to be part of the service plan, and a resident may be discharged if the home can no longer meet the resident's needs as specified in the plan; Oregon allows involuntary move-out only after the assisted living provider has tried prudent and reasonable interventions, which must be documented). "---" means the state does not address how NRAs interact with discharge.
6. **Residents' Rights Reference NRAs:** This column indicates whether state rules regarding residents' rights refer to risks or NRA principles. "Specific" means that the rules reference NRAs (e.g., DC specifies that residents have the right to engage in a shared responsibility agreement and the right to refuse services once the potential consequences have been discussed and the resident has agreed to them). "General" means that the rules residents' rights section references risk taking (e.g., Alaska specifies that the resident has the right to participate in the assisted living plan, and the plan must include a discussion of potential risks related to choices). "---" means the state rules do not mention risk in the residents' rights section.

# **APPENDIX C: EXPERTS CONSULTED AND STAKEHOLDERS INTERVIEWED**

## **Consumer Advocates**

**Michael Allen, JD**  
Senior Staff Attorney  
Bazelon Center for Mental Health Law

**Katie Maslow**  
Associate Director, Quality Care & Advocacy  
Alzheimer's Association

**Eric Carlson, JD**  
Attorney  
National Senior Citizens Law Center

**Don Redfoot**  
Senior Policy Advisor  
AARP Public Policy Institute

**Stephanie Edelstein, JD**  
Associate Staff Director  
American Bar Association Commission on Law  
and Aging

**Dorothy Siemon, JD**  
AARP

**Karen Love**  
Chairman  
Consumer Consortium on Assisted Living

**Bruce Vigerny, JD**  
AARP

## **Providers and Provider Representatives**

**Lynn Bentley**  
Senior Director of Assisted Living & Life Safety

**Ann McDermott**  
State Relations Consultant  
Assisted Living Federation of America

**Maribeth Bersani**  
National Director of Government Affairs  
Sunrise Senior Living

**Doug Pace**  
Director, Assisted Living  
Association of Housing and Services for the Aging

**Janet Forlini**  
Sr. VP/Director of Public Policy  
Assisted Living Federation of America

**David Schless**  
President  
American Seniors Housing Association

**David Kylo**  
VP National Center on Assisted Living  
American Health Care Association

## State Program and Policy Staff

### **Meredith Cote**

State Long Term Care Ombudsman  
Oregon Department of Human Services

### **Wendy Fearnside**

Program and Policy Analyst  
Bureau of Aging and Long Term Care Resources  
Wisconsin Department of Health and Family  
Services

### **Rick Harris**

Director  
Bureau of Health Provider Standards  
Alabama Department of Public Health

### **Kary W. Hyre**

State LTC Ombudsman  
Washington State LTC Ombudsman Program

### **Ruth A. Morgan**

District LTC Ombudsman, Kentucky  
Cumberland Trace Legal Services

### **Dennett Taber**

Assisted Living Program Coordinator  
OR Department of Human Services

## Long-Term Care Policy Experts

### **Elias S. Cohen, JD, MPA**

### **Marshall Kapp, JD, MPH**

Professor & Director of the Office of Geriatric  
Medicine & Gerontology  
Wright State University School of Medicine

### **Deborah Hedgecock**

Doctoral Candidate  
University of South Florida

### **Laurie Powers**

Associate Professor of Public Health  
Oregon Health & Science University

### **Mauro Hernandez**

Research Associate  
University of California, San Francisco

### **Keren Brown Wilson, PhD**

President  
Jessie F. Richardson Foundation

### **Rosalie A. Kane, DSW**

Professor  
Division of Health Services Research & Policy  
School of Public Health  
University of Minnesota

## Florida

### **Ron Daddio**

Agent  
The Plastridge Insurance Company

### **Mary Ellen Early**

Senior Vice President – Public Policy  
Florida Association of Homes for the Aging

### **Alberta Granger**

Manager  
Assisted Living Unit, Bureau of Long-Term Care  
Agency for Health Care Administration

### **Robin Khanal, JD**

Attorney  
Quintairos, Prieto, Wood & Boyer

### **Mary Ann Koopman, PhD**

Vice President & Region 3 Director  
Florida Life Care Resident's Association

### **Steven Schrunk**

President  
Florida Assisted Living Association

### **Vicky Sims**

Medical Health Care Program Analyst  
Florida Medicaid Program, Agency for Health  
Care Administration

### **George Tokesky**

**GOC III**  
Program Manager – Coming Home Program  
Florida Department of Elder Affairs

### **Paul Williams**

Director of State Affiliate Relations  
Assisted Living Federation of America  
(former Executive Director of Florida ALFA)

## Oregon

### **Jerry Cohen, JD, MPA**

Director  
Oregon Office of AARP

### **Jim Davis**

Director  
United Seniors of Oregon

### **Ruth Gulyas**

Executive Director  
Oregon Alliance of Senior & Health Services

### **Cindy Hannum**

Director, Office of Licensing & Quality of Care  
Seniors and People with Disabilities  
Oregon Department of Human Services

### **Megan Hornby**

Community-Based Care and Nursing Manager  
Seniors and People with Disabilities  
Oregon Department of Human Services

### **Julia Huddleston**

Director of Rate Setting  
Finance & Policy Analysis  
Oregon Department of Human Services

### **James D. Toews**

Director  
Seniors and People with Disabilities  
Oregon Department of Human Services

## **Wisconsin**

### **Mark Andrews**

Licensing and Certification Specialist  
Wisconsin Department of Health and Family  
Services

### **Kevin Coughlin**

Section Chief  
Bureau of Quality Assurance  
Wisconsin Department of Health and Family  
Services

### **Helen Marks Dicks, JD**

Director, Elder Law Center  
Coalition of Wisconsin Aging Groups

### **Wendy Fearnside**

Program and Planning Analyst, Bureau of Aging  
and LTC Resources  
Wisconsin Department of Health and Family  
Services

### **Jim Murphy**

Executive Director  
Wisconsin Assisted Living Association

### **Brian Purtell, JD**

Director of Legal Services  
Wisconsin Health Care Association

### **John Sauer**

Director  
Wisconsin Association of Homes and Services for  
the Aging

### **David Slautterback, PhD**

Retired, former member of AARP task force on  
RCAC

### **Claudia Stine**

Director of Ombudsman Services  
Wisconsin Board on Aging and LTC

### **Burt Wagner, JD**

Provider Attorney  
Wisconsin Association for Homes for the Aging

## **APPENDIX D: CHARACTERISTICS OF ASSISTED LIVING RESIDENTS AND STAFF**

<b>TABLE D-1. Characteristics of Residents</b>				
<b>Age, Race, Gender</b>	<b>Diagnosis/Condition</b>	<b>Length of Residence (years)</b>	<b>Prior Residence</b>	<b>NRS Topic(s)</b>
51 WF	Diabetes and schizophrenia	4+	Nursing facility for 2.5 years	<ul style="list-style-type: none"> <li>• Shouting/threatening staff and residents</li> <li>• Refuses vital signs monitoring</li> <li>• Does not care for feet despite fissures</li> <li>• Refuses housekeeping; kitty litter scooping</li> </ul>
60 WM	Diabetes, bi-polar and anxiety disorder, history of stroke, falls; uses wheelchair		Subsidized	<ul style="list-style-type: none"> <li>• Smoking in apt/bed</li> </ul>
60+ WF	Bi-polar affective disorder, schizophrenia, hepatitis C, HIV+, COPD		Not sure	<ul style="list-style-type: none"> <li>• Behavior management plan for wandering/elopement</li> </ul>
66 WM	Alcoholism, possible dementia	5	Rehab for 12 months, before that in an apartment	<ul style="list-style-type: none"> <li>• Smoking in apt</li> <li>• Loud music</li> <li>• Verbal abuse</li> <li>• Alcohol consumption to point of intoxication (4 topics in one form)</li> </ul>
66 BM	Does own laundry, self-medicates, does housekeeping	<1	Own home	<ul style="list-style-type: none"> <li>• Eats sweets despite diabetes</li> </ul>
67 WF	Morbidly obese, mild MR; gets help with IADLs, bathing, dressing, meds	3	With mother, then brother	<ul style="list-style-type: none"> <li>• Morbidly obese, does not follow diet and cannot wear shoes = fall risk, risk for infection, skin tear</li> </ul>
68 WM	Cancer, rheumatoid arthritis, history of hip fracture		Subsidized apartment	<ul style="list-style-type: none"> <li>• Smoking in apt</li> </ul>
74 WF	Emphysema, dialysis, depression, anxiety	1	Own home	<ul style="list-style-type: none"> <li>• None</li> </ul>
74 WF	Diabetes; history of falls	1	Apartment	<ul style="list-style-type: none"> <li>• Diabetic diet compliance</li> </ul>
75 WF	Cerebral palsy	6	Following husband's death, lived with brother who now is in the nursing home	<ul style="list-style-type: none"> <li>• Refuses thickened liquid diet despite choke hazard</li> </ul>
77 WF	Macular degeneration, cataracts; doesn't need much ADL help; self-injects insulin after family fills; one fall since arrival	<1	With daughter and son-in-law 18 months	<ul style="list-style-type: none"> <li>• Eats sweets despite diabetes</li> </ul>

**TABLE D-1 (continued)**

<b>Age, Race, Gender</b>	<b>Diagnosis/Condition</b>	<b>Length of Residence (years)</b>	<b>Prior Residence</b>	<b>NRS Topic(s)</b>
79 WF	Poor memory, diabetes, depression, CHF	<1	In townhouse in another state	<ul style="list-style-type: none"> <li>• None</li> </ul>
81 WF	Needs assistance with meds	<1	Another ALF; didn't like it, had to share a room and wasn't allowed to lock door	<ul style="list-style-type: none"> <li>• Pushes friend in wheelchair and gets sore shoulder</li> </ul>
81 WF	Parkinsons	<1	Moved to AL following hospitalization for hip fracture	<ul style="list-style-type: none"> <li>• Fall risk, needs to use walker</li> </ul>
82 F	History of falls; hip fracture	5	With daughter for 1 year	<ul style="list-style-type: none"> <li>• Self medicate</li> <li>• Fall risk</li> </ul>
83 WF	Blind since 16	2	Alone, at home	<ul style="list-style-type: none"> <li>• Blind, will ask for assistance if she needs it, wants to be independent</li> </ul>
84 WF	Diabetes, poor vision; gets help with laundry, cleaning, meds, reading mail	3	Lived in own home, fell	<ul style="list-style-type: none"> <li>• "No concentrated sweets diet"</li> </ul>
85 WF	Gets help with meds, IADLs, blood sugar check, variable does insulin, MD coordination	2	With daughter for 2 years	<ul style="list-style-type: none"> <li>• "No concentrated sweets diet"</li> </ul>
86 WF	Stroke, history of falls	1	With family	<ul style="list-style-type: none"> <li>• Fall risk</li> </ul>
87 WF	Uses wheelchair	6	Own home	<ul style="list-style-type: none"> <li>• Bedrails</li> <li>• Agrees to use wheelchair for long distance, spouse will push</li> </ul>
87 WF	Uses wheelchair; history of falls	<1	Independent unit on same campus	<ul style="list-style-type: none"> <li>• Fall risk</li> <li>• Bedrails</li> </ul>
89 F	Dementia	4	Condo with paid/volunteer help	<ul style="list-style-type: none"> <li>• Wandering</li> </ul>

<b>TABLE D-2. Characteristics of Employees</b>		
<b>Position</b>	<b>Years Employed at Facility</b>	<b>Prior Work Experience</b>
Director/Administrator	4	2 years in assisted living, dormitory manager before that.
Director/Administrator	4	Has worked in assisted living a total of 8 years, began as PSA.
Director/Administrator	1	5 years in another assisted living facility, 4 years in senior housing before that (total of 10).
Director/Administrator	5	Started here in high school as kitchen staff.
Director/Administrator	6	Began at this facility as director of nursing, then administrator. Long-term care since 1987; worked in 5 facilities.
Director/Administrator	3	Was director of nursing at a drug rehabilitation facility for 6 years.
Director/Administrator	13	30 years in hospitals & NF, mostly long-term care.
Assistant Director	2	Case manager and social services with various populations--prostitutes, troubled kids, developmentally disabled.
Associate Executive Director	4	Long-term care since 1981, RN since 1974.
Risk Officer	12	Another assisted living provider.
Director of Nursing	2	Director of nursing in nursing facility for 25 years.
Director of Nursing	9	Nursing facility for 7 years.
RN	1	11 years in skilled nursing facility, home health, oncology, psychiatric care.
LPN	5	Other assisted living facilities, doctor's office, LPN for 12 years.
Social Worker	6	10 years in long-term care.
CNA Supervisor	2	None, caregiver to mother.
CNA/Med Tech	<1	Resident aide in nursing facility, adult day health, group home for developmentally disabled for 8 years.
CNA/Med Tech	7	25 in nursing facility, home care.
CNA/Med Tech	9	None.
Med Aide	4	Worked in another assisted living for 2 years before coming here.
Med Aide	6	Began as a personal service attendant here during high school.
Resident Aide	9	
Personal Service Attendant	4	Worked in assisted living since 1989, three facilities.
Server	<1	Day care with children.

## **APPENDIX E: ORGANIZATIONS' POLICY POSITIONS ON NEGOTIATED RISK AGREEMENTS**

Only a few national organizations other than providers have official policy positions regarding negotiated risk agreements (NRAs). The 27 experts contacted for this study (see Appendix C), identified only three organizations with written policy positions: the AARP, the Assisted Living Federation of America (ALFA), and the National Senior Citizens Law Center (NSCLC).

The AARP (2003) incorporates negotiated risk into their definition of assisted living, which includes "A process for legitimate negotiated risk agreements between facilities and residents, allowing residents to enhance their autonomy and independence and providers to maintain a safe and appropriate environment."

The ALFA supports the use of NRAs as a tool for operationalizing autonomy and choice in a realistic way, especially given that we have a "litigious society." They published a guidebook, written by attorney Ken Burgess (2000) and have model documents available for purchase. In the forward to the guidebook, then ALFA president Karen Wayne explained that, "negotiated risk agreements are emerging as an important tool in promoting resident choice and autonomy and thus in furthering the mission of the assisted living industry."

The National Senior Citizens' Law Center (NSCLC, 2004) has a new policy strongly opposing NRAs. This group clearly identifies this practice as inappropriate, focusing almost entirely on risk agreements as a tool for waiving facility liability. The statement is presented here in its entirety:

*"The National Senior Citizens Law Center is opposed to any use of negotiated risk agreements. Negotiated risk agreements release long-term care facilities from their legal responsibilities to provide adequate care, without providing any benefit to facility residents. Negotiated risk agreements are illegal and unenforceable under existing law, which prohibits a business from using a consumer contract to release itself from the legal responsibility to provide adequate care and safe accommodations. Admission to a long-term care facility is traumatic and confusing for residents and their families. Particularly given the vulnerability of residents during the time of admission, negotiated risk agreements are one-sided and unfair. Residents should be able to make choices regarding their lives without signing away their rights."*

While only three organizations have formal published policies, the positions of 27 organizations that voted on the Assisted Living Workgroup (ALW) proposed "shared responsibility agreement" definition provides additional information about organizations that are "for" or "against" this practice. We list these groups below.

The ALW proposed a definition for “shared responsibility agreements” that defined such agreements as a “tool for communication” and resident empowerment when there is a “deviance from an accepted standard” and “there is a lack of consensus on a course of action” between the resident and the provider and “the risk of an adverse outcome is high” (ALW, 2003: 152). The goals for shared responsibility agreements included resident empowerment, realistic assessment of potential harm and outcomes, building consensus, and providing appropriate documentation of choices made, options presented, and provider responsibilities. The recommendation explained that as an extension of the service plan, the assisted living facility staff and the resident may choose to enter into a shared responsibility agreement, that the agreement should cover the exception not the rule, that “shared responsibility shall not be a waiver of liability,” and that the shared responsibility agreement should include a written statement to identify resident choice, provider concerns, alternatives, final agreement, follow-up, and signatures.

While some of the following organizations lack a formal policy position on the topic, each made their formal policy position regarding risk agreements clear in their support or opposition of the ALW “shared responsibility agreement” recommendation, which failed by three votes to achieve the two-thirds majority vote required to be formally adopted. Of the 27 organizations that voted on the recommendation (out of 50+ participating organizations), the following 15 organizations supported the ALW’s shared responsibility agreement recommendation:

1. American Association of Retired Persons
2. American Association of Homes and Services for Aging
3. American Seniors Housing Association
4. Assisted Living Federation of America
5. Association of Professional Geriatric Care Managers
6. Catholic Health Association of the United States
7. Consumer Consortium on Assisted Living
8. JHACO
9. National Association for Home Care
10. National Center for Assisted Living
11. National Hospice and Palliative Care Organization
12. National Multiple Sclerosis Society
13. NCB Development Corporation
14. Paralyzed Veterans of America
15. Pioneer Network

The first 12 of these organizations provided a supplemental position to the Shared Responsibility Agreement, including an emphasis on the process as “a tool for communication,” noting that NRAs empower residents “to exercise choices” (ALW, 2003: 153) by providing a mechanism “through which assisted living providers can operationalize and preserve the values of independence, autonomy, and choice” when the “wishes and preferences” of the resident must be balanced against a “normally unacceptable level of risk” (ALW, 2003: 154). These supporters also included a

statement that “nothing in such agreements [should absolve] providers from responsibility for negligent actions” (p.153). These organizations stated that “ultimately, the shared responsibility agreement process is simply a systemized method of accommodating individual resident choices, or finding acceptable alternatives to those choices, and the propriety of its use depends upon the unique facts and circumstances pertaining to each resident” (ALW, 2003: 153).

The last three organizations on the above list of those supporting the ALW shared responsibility agreement recommendation provided a supplemental position emphasizing that risk agreements may be a useful means of weighing resident preferences against their health and safety needs. Further they indicated that “the negotiated risk process responds to the legislative and policy directive to foster and promote these resident values and helps deliver the promise of assisted living” (ALW, 2003: 154).

The 12 organizations opposing NRAs at the ALW include:

1. American Geriatrics Society
2. Association of Health Facility Survey Agencies
3. Center for Medicare Advocacy
4. National Association for Regulatory Administration
5. National Association of Local LTC Ombudsmen
6. National Association of Social Workers
7. National Association of State Ombudsman Programs
8. National Citizens Coalition for Nursing Home Reform
9. National Committee to Preserve Social Security and Medicare
10. National Conference of Gerontological Nurse Practitioners
11. National Network of Career Nursing Assistants
12. National Senior Citizens Law Center

These 12 groups provided a supplemental position that the recommendation and NRAs are “confusing and unnecessary” and that rather than expand resident choice and control, NRAs actually limit resident choices and are designed to protect the interests of the facility. Further, these organizations argued that, “it is unclear what type of real-world fact pattern would require the use of a ‘shared responsibility agreement,’ particularly given the availability and general acceptance of the care planning process” (ALW, 2003: 153). Finally, these groups raised a concern that such agreements existed only to serve the financial interests of assisted living providers, “shared responsibility agreements are designed almost exclusively to protect the facility from regulatory requirements and legal action” (p.153).

## **ALW Negotiated Risk Agreement Recommendation Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging**

### **Recommendation: D.13 Shared Responsibility Agreement**

**Recommendation** (2/3s Majority agreement not reached)

Shared Responsibility Agreements are a tool for communications. They may be exercised when the resident\* is not complying with the goals and outcomes listed in the Service Plan or the Policies and Procedures of the ALR. As an extension of the Service Plan, the ALR and the resident\* may enter into a Shared Responsibility Agreement. The Shared Responsibility Agreements should cover the exception not the rule.

Shared responsibility shall not be a waiver of liability. A shared responsibility agreement is simply a written agreement between both parties--the Assisted Living Residence and the resident\*--which memorializes the parties' discussions and agreements regarding the resident's preferences and how they will be accommodated in the community.

Shared Responsibility Agreements may be used when any or all of the following are true:

- There is a deviance from an accepted standard.
- There is a lack of consensus on a course of action.
- The risk of an adverse outcome is high.

The goals of the Shared Responsibility Agreement are:

- Empower the resident to exercise choice regarding service delivery (within established boundaries).
- Identify resident preferences.
- Perform a realistic assessment of potential harm due to resident preferences.
- Identify potential outcomes.
- Seek consensus around decision.
- Document process of negotiation and decision.
- Provide acknowledgement of the discussion.

A Shared Responsibility Agreement should:

- Identify the cause for concern.
- Identify the probable consequences of the resident's choice.
- Make clear what the resident wants.
- Describe possible alternatives.
- Set forth the final agreement.

- Decide what staff will be notified of the agreement and how often follow-up is necessary.
- Agreement is signed by the ALR and the resident\*.

### *Rationale*

The agreement itself is an extension of the service plan and the end product of a process in which the Assisted Living Residence, or the ALR and the resident together, identify a resident preference (e.g., to engage in or avoid certain activities or behaviors) which the ALR normally would not recommend or allow, or would remove, because they involve unacceptable risk to the health and safety of the resident or others in the ALR.

### *Implementation*

Ultimately, the shared responsibility agreement process is simply a systemized method of accommodating individual resident choices, or finding acceptable alternatives to those choices, and the propriety of its use depends upon the unique facts and circumstances pertaining to each resident.

Recognition of the need for a shared responsibility agreement normally arises in one of three ways. In some cases, a resident will verbally express to ALR staff a desire to engage in certain activities or behaviors that normally would be prohibited. In other cases, ALR staff may raise the issue where a resident repeatedly engages in behaviors which normally would not be allowed for that resident. Occasionally, third parties such as family members, or ombudsman or other resident advocates may suggest a shared responsibility agreement to resolve complaints or concerns raised by a resident or family.

### *Organizations Supporting This Recommendation*

No Vote Recorded

### *Organizations Opposing This Recommendation*

No Vote Recorded

### *Organizations Abstaining From the Vote on This Recommendation*

No Vote Recorded

## **Supplemental Postions for D.13**

### *Supplemental Postion #1*

Many states are requiring shared responsibility or negotiated risk agreements as a part of the management of services in assisted living residences. Recommendation D.13

does an excellent job of describing the legitimate uses of such agreements, they are “a tool for communication” between residents and providers where residents are empowered to exercise choices in activities and expect services according to their preferences.

The recommendation also makes it very clear what are not legitimate uses of such agreements: “Shared responsibility shall not be a waiver of liability.” While providers may reasonably use such agreements as part of their risk management policy, nothing in such agreements absolves providers from responsibility for negligent actions.

Perhaps the most useful part of the recommendation is its detailed outline of a process for negotiating such agreements. Many states require negotiated risk or shared responsibility agreements without providing guidance on how they should and should not be developed. The process recognizes that the provider has a responsibility to identify the consumer’s preferences as well as potential risks that may be associated with certain behaviors. The process also recognizes that not all courses of action are possible or reasonable, but that resident preferences should be honored even when the provider does not believe them to be in the resident’s best interest.

The undersigned organizations believe that this recommendation strikes the right balance between the resident’s preferences and the provider’s responsibility to provide services within a safe environment. It provides much needed guidance to states as they move into this relatively uncharted area of the law.

*AARP, American Association of Homes and Services for the Aging, American Seniors Housing Association, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, NCB Development Corporation, Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network*

#### *Supplemental Postion #2*

We oppose this failed recommendation. This recommendation is confusing and unnecessary, and seems to reduce a resident’s right to make choices.

It is unclear what type of real-world fact pattern would require the use of a “shared responsibility agreement,” particularly given the availability and general acceptance of the care planning process. Although “shared responsibility agreements” purportedly are designed to advance resident choice, they actually diminish resident choice, as shown by the fact that they are to be employed when the resident “is not complying with the goals and outcomes listed in the Service Plan or the Policies and Procedures of the ALR,” or there is “a deviance from an accepted standard” or “a lack of consensus on a course of action.”

The rationale emphasizes that the “shared responsibility” process is to be employed when the assisted living residence disagrees with decisions made by the resident, even if the only person affected is the resident himself or herself. This raises the inference, confirmed by the debate within the Workgroup, that shared responsibility agreements are designed almost exclusively to protect the facility from regulatory requirements and legal action. There is no need for this confusing and self-contradictory recommendation. Resident/facility disputes are currently being addressed through care planning in assisted living residences around the country.

*American Geriatrics Society, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of Social Workers, National Association of State Ombudsman Programs, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Conference of Gerontological Nurse Practitioners, National Network of Career Nursing Assistants, National Senior Citizens Law Center.*

### *Supplemental Postion #3*

We support the recommendation. Negotiated risk agreements are becoming recognized as one of the primary tools through which assisted living providers can operationalize and preserve the values of independence, autonomy, and choice upon which the assisted living model rests so directly. Statutory and/or regulatory mandates in virtually every state direct both regulators and providers to further and nourish resident independence and autonomy in assisted living communities. The negotiated risk process focuses the attentions of resident, community staff, resident families, resident advocates, and regulators via a systematized process on one central issue--what are the wishes and preferences of the resident as balanced against the resident’s health and safety needs. By so doing, the negotiated risk process responds to the legislative and regulatory directive to foster and promote these resident values and helps deliver the promise of assisted living.

The negotiated risk process is an individualized planning process designed to maximize a resident’s ability to make his or her own decisions by facilitating discussions and analysis of a resident’s stated choices where those choices create a normally unacceptable level of risk for the resident. Negotiated risk is not a waiver of liability on the part of the provider of its obligations under governing regulations.

*Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations*

Source: <http://www.aahsa.org/alw/dc.pdf> [accessed April 8, 2004]

# **APPENDIX F: SAMPLE NEGOTIATED RISK AGREEMENT**

**From National Provider**

## **Negotiated Risk Agreement and Release**

**Note: This agreement should be noted on the Service Plan.**

This Negotiated Risk Agreement and Release is entered into \_\_\_\_\_ and \_\_\_\_\_ (the "Resident"). The Resident is a resident of \_\_\_\_\_ and a specific issue regarding the Resident's care has arisen. This issue is described in detail below under "Issue(s)/Concern." The Resident understands that how this issue is addressed may have significant consequences upon the Resident's health and quality of life including but not limited to those listed under "Possible consequences of desire or preference." The Resident further acknowledges that he/she has had these consequences fully explained to him/her and having considered these consequences wishes to have his/her care delivered as outlined in this Negotiated Risk Agreement and Release despite the fact that the Resident may experience a decline in health and/or may experience other significant negative outcomes including injury or death. The Resident and Provider have agreed to address the issue as outlined below under "Agreed Course of Action."

Resident's Name: \_\_\_\_\_

Issue(s)/Concern(s): \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Resident/Family desire or preference: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Possible consequence of desire or preference: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Alternative approaches to minimize risk: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Agreed course of action: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Either party may terminate this Agreement by giving the other party written notice. The release contained in this Negotiated Risk Agreement and Release shall survive any termination.

The Resident, being of lawful age, in consideration of Provider's agreement to allow the Resident to receive care as outlined in the "Agreed Course of Actions," in this Negotiated Risk Agreement and Release, for himself/herself, his/her heirs, executors, administrators, and assigns, hereby release and forever discharge Provider, its directors, owners, management, agents, employees from any and every claim, demand, action or right of action, of whatever kind or nature, either in law or in equity arising from or by reason of any bodily injury or personal injuries known or unknown, death or property damage resulting or to result from the care and/or oversight provided by \_\_\_\_\_, whether by negligence or not.

Resident further states that he/she has carefully read the Negotiated Risk Agreement and Release and knows the contents thereof and signs this Negotiated Risk Agreement and Release as his/her own free act.

In witness whereof, resident has executed this release at \_\_\_\_\_ on \_\_\_\_\_, \_\_\_\_\_.

**SIGNATURES:**

Resident: \_\_\_\_\_ Date: \_\_\_\_\_

Provider: \_\_\_\_\_ Representative: \_\_\_\_\_

Date: \_\_\_\_\_

**Family Member(s):** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Witness:** \_\_\_\_\_ **Date:** \_\_\_\_\_