



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**

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# TABLE OF CONTENTS

|   |      |
|---|------|
| <b>ACKNOWLEDGMENTS</b> .....  | ii   |
| <b>EXECUTIVE SUMMARY</b> .....  | iii  |
| <b>I. INTRODUCTION</b> .....  | 1    |
| Purpose of the Study .....  | 2    |
| Methods .....   | 2    |
| Organization of the Report.....   | 2    |
| <b>II. NEGOTIATED RISK AGREEMENTS: DEFINITION, CONCEPTS, AND USE</b> .....                | 4    |
| State Regulations Regarding NRAs.....   | 5    |
| Use of NRAs .....   | 6    |
| <b>III. THE DEBATE ABOUT NEGOTIATED RISK AGREEMENTS</b> .....                             | 8    |
| Purpose of NRAs .....   | 8    |
| Ability of NRAs to Limit Liability.....   | 14   |
| NRAs and State Admission and Discharge Requirements .....                                 | 15   |
| Service Plans as an Alternative to NRAs .....   | 17   |
| Types of Risk Considered Appropriate for NRAs .....                                       | 18   |
| Determining and Reassessing Cognitive Function and Capacity.....                          | 20   |
| <b>IV. SITE VISIT FINDINGS</b> .....  | 25   |
| Introduction .....  | 25   |
| Factors Affecting the Decision to Initiate an NRA .....                                   | 25   |
| NRA Processes and Formats .....   | 28   |
| Family and Other Third Party Involvement.....   | 29   |
| Use of NRAs with Cognitively Impaired Residents.....                                      | 30   |
| NRA Topics.....   | 31   |
| Resident, Family, and Staff Views about NRAs .....  | 33   |
| Summary of Key Site Visit Findings .....  | 38   |
| <b>V. CONCLUSIONS</b> .....   | 41   |
| <b>ENDNOTES</b> .....   | 44   |
| <b>APPENDICES</b>   |      |
| <b>APPENDIX A:</b> Methodology .....  | A-1  |
| <b>APPENDIX B:</b> State Policy Regarding Negotiated Risk Agreements.....                 | A-5  |
| <b>APPENDIX C:</b> Experts Consulted and Stakeholders Interviewed .....                   | A-27 |
| <b>APPENDIX D:</b> Characteristics of Assisted Living Residents and Staff .....           | A-31 |
| <b>APPENDIX E:</b> Organizations' Policy Positions on Negotiated Risk<br>Agreements ..... | A-34 |
| <b>APPENDIX F:</b> Sample Negotiated Risk Agreement Form.....                             | A-41 |

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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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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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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.*