

Fostering Resident Independence, Choice, and Decision-Making in Assisted Living:

Strategies for Owners & Managers



The Long Term Care Community Coalition

www.nursinghome411.org

Coalition of Institutionalized Aged and Disabled (CIAD)

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This guide was originally published in 2005 with the support of the Robert Wood Johnson Foundation. It was revised and updated in 2020. Please see the dedicated page of our website, <https://nursinghome411.org/assisted-living-guidebooks/>, for electronic versions of the four guides in this series.

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INTRODUCTION

This is one of a series of four guides to help assisted living providers and residents improve the quality of life and living environments in their communities. **This guide is for assisted living managers and administrators.** The other guides are for assisted living staff, current residents, and individuals who are considering assisted living for themselves or a loved one.

The guides were developed following a research project that assessed the extent to which the “promise” of assisted living – individualized care and monitoring in a residential setting that provides a more home-like, less institutional setting than the typical nursing home – is actually being realized in the lives of residents. These guidebooks were developed with the help of an advisory committee that reflected a range of stakeholders (including industry and consumer representatives) and pilot tested in four states.¹

Studies indicate that a residents’ sense of belonging in their new community was correlated with retaining a sense of control, preserving personal habits and routines, and engaging with staff, other residents, and family.

All of the guides are available on the Assisted Living page of our website, www.nursinghome411.org. As with all our website’s resources, these guides are free to use, copy, and share. We welcome you to use any of the guides for training and educating your staff and residents.

You are in an exciting profession. Assisted living is an increasingly sought-after option for seniors and families. It attempts to give seniors what they want:

- To continue to be as independent as they can be;
- To have control over their everyday lives and choices;
- To influence and participate in decision-making in the community of which they belong; and
- The ability to remain, for many, in the same residence if they become more dependent.

It attempts to do this not only because seniors want these things, but also because of the strong relationship between control, decision-making, self-esteem, and well-being. When people lose control, they experience low self-esteem, diminished self-concept, and feelings of hopelessness, depression, and helplessness. In addition, research indicates that when the elderly move from place to place, especially when their health is deteriorating, they may become disoriented and sick.

¹ For more information, including the names of committee members, please see the Original Vision and Acknowledgments document on our website at <https://nursinghome411.org/assisted-living-guidebooks-fostering-independence-choice-and-decision-making/>.

Although most staff in assisted living residences want to accomplish these goals and in fact, believe they already do, we have found that achieving these goals can be very difficult. Following are some comments made by assisted living managers who reviewed this guide pre-publication:

“Resident rights are very important and we don’t ever want to discount them. But, is it OK for the resident to take a walk alone even if macular degeneration means they won’t see the curb?”

“Residents come here because they need somebody to make those decisions for them... We have professional staff here trained to make these decisions. Where do you stop independence when it becomes a danger?”

“We do all we can now.”

You are in a perfect position to make changes that will improve your residents’ experiences and the attractiveness of your community to prospective residents. This guide has been written to help you by discussing potential challenges and ways to overcome them. It will help you evaluate your residence to see how well it fulfills the promise of assisted living for residents. And, if you find that your residence does not fully do this, this guide will help you analyze why and identify ways to do so. **This guide has worked for others.**

Following are comments from managers who used this booklet in their residences:

“A valuable guidebook, which challenges management to be open to change, thus maximizing resident satisfaction.”

“The booklets are a great tool to use for talking to our Board of Directors, president, and other non-health workers.”

“This guidebook empowers caregivers to move from task-oriented caregiving to relationship building with those for whom they care. I would definitely use this material for in-service education.”

It makes good business sense to maintain a community where residents’ needs and desires are met. More people will come to live in a residence where basic rights are encouraged.

This guide can be used as a resource for you as you manage your residence and encounter challenges in the future. It contains several exercises that can be used, now and in the future, to put some of the strategies into a context.

We are aware that there are complex issues in assisted living communities and that residents may never be able to have the same freedoms you have. Managers (such as those above) have raised many valid concerns while navigating these difficult challenges. This guide endeavors to help you identify these concerns and respond to them in a way that can help your residence fully embody the philosophy of assisted living.

Before beginning, there are a few points we would like you to know:

- Not every suggestion will work for every residence or every resident.
- Some of you may have already developed ways to encourage choice, control, and independence in the resident's everyday life, but may not have found ways to encourage resident participation in the actual policy, rule-making and decision-making of the residence or participation in the outside community. This guide will help you.
- If a strategy seems impractical, don't dismiss it; discuss it with others. If you disagree with the described solution, try to find a way to solve the problem raised.
- Some of the suggestions we describe have already been used successfully in actual residences. These are called "cases."
- Some of the suggestions are described to elicit discussion and action. These are "scenarios." We encourage you to discuss these and use them in staff training.
- Many of the suggested strategies will be appropriate for residents in the beginning stage of dementia. However, there is also a section for those in the more advanced stages.
- This guide was pilot-tested in four residences in Iowa and Massachusetts, and includes examples of residences using this guide and other guides. Some examples may work in your home as well.

HOW TO USE THIS GUIDE

You, as a manager, can make the ideas in this guide a reality. We suggest following the steps below as you work through the ideas presented to you.

1. Whenever possible, use this guide in conjunction with the guides for direct care workers and residents. The Direct Care Guide and Resident Guide are made to coordinate with this guide. The entire community can work together to make the ideas a reality.
2. Make sure the entire community – especially staff and residents – buys in to the idea of working together to make change. Otherwise you may find some members resistant or frightened of change. Encourage discussion and comments about the major ideas and involve everyone in decisions. This will give you an opportunity to understand the possible resistance and to help your community move forward. It will also provide opportunities to gain valuable insights from residents and workers and, at the same time, strengthen your community.
3. Make sure that everyone understands that this is not a criticism of the work of the residence. In fact, many of the ideas in the guide may already be in place. You can use the guide to become even more of a residence where individuals can be more independent and have greater choices and control over their everyday lives.
4. Come together as a community to continually evaluate the process as things go forward. It is crucial to monitor any changes.

The entire community can work together to make the community a better place to live and work.

CHOICE AND CONTROL

What Do Control and Choice Mean to You?

Please list those things that you are able to decide to do each day. For example, do you decide when to go to sleep? You might consider the following things for your list: bedtime, what to eat, when to eat, who to eat with, when to bathe, whether to take a shower or a bath, activities you want to do such as go to a movie or read a book, whether to take your car out for a ride, what to wear, whether to stay in bed all day on a day off, where to live, and many, many more. Look at the items on your list. If you could not make these decisions – if other people made them for you – how would you feel?

A large rectangular box with a blue border, containing 15 horizontal blue lines for writing. The lines are evenly spaced and extend across most of the width of the box, leaving a small margin on the right side.

HOW MUCH CHOICE AND CONTROL DO THE RESIDENTS HAVE IN YOUR ASSISTED LIVING COMMUNITY?

Look at the list of everyday decisions you make again. How many of those decisions can or do *the residents* make? ***Do the residents:***

- Decide when to wake up and when to go to bed?
- Go for a walk when they want to?
- Take a bath rather than a shower if they want? Take it when they want?
- Regulate the temperature in their room or apartment?
- Use their own furniture and arrange it in a way they like?
- Have a pet if they want to?
- Choose what to eat at each meal, when to eat, and with whom to eat?
- Cook or prepare food if they want to?
- Entertain family and friends in a private place?
- Go out when they want to go?

Ask yourself the following questions:

- What opportunities do I give the residents to have more control of their everyday life?
- How do I train or direct my staff to encourage resident choice and control in everyday life?
- How do I help my staff deal with problems that may arise in this area?
- Do my evaluations of staff include issues related to how well they encourage resident choice and control?
- Do my direct care staff have permission to decide some things directly with the resident, such as skipping a bath if the resident wants to?
- Does my staff know how to discriminate between those things they can decide with residents and those they should discuss with a professional (i.e., resident wants to skip a bath because she feels sick)?

What Might Stand in the Way of Resident Choice and Control in Your Assisted Living Community?

- Some routines and rules, such as specific times for meals or visiting hours, may limit the ability of residents to make their own decisions. Are there any rules or routines in your residence that you feel unnecessarily limit choice that you may be able to change?
- Corporate rules that apply to all residences owned by a company may unnecessarily limit autonomy. For example, a company may require uniform weekly menus, decorations, or furnishings.
- Making things easier for staff may play a part in limiting freedom unnecessarily. For example, staff often work specific shifts, thus mandating certain times for meal and bedtimes. Some residents may need assistance with eating, and it may be more

convenient to group residents together for meals, rather than helping each resident choose where to sit.

- Staff shortages can leave less time for helping residents make choices and decisions.
- You may believe that the resident's family does not want the resident to make their own decisions and you might feel obligated to follow the family's wishes over the resident's.
- Some state regulations do not seem to allow residents to have choices and control.
- Some residents may not speak English, so communication with them may be challenging.
- Your staff may not know how to encourage resident control or believe that residents should not or cannot make decisions on their own.

Strategies to Encourage Resident Choice and Control

Analyze Community Rules and Make Changes if Appropriate to Encourage Choice and Control

Ask yourself the following questions:

- *Do any of the rules unnecessarily limit resident choice?*
- *Do any of these rules exist only to make things easier for staff? For example, it may be easier if visiting hours are limited to times when direct care is not being given so care will not be interfered with. However, residents and their families want the freedom to visit when convenient for them.*
- *Can any rules be removed or modified to permit more resident choice and control?*

As a manager, you know that every residence needs rules. However, some may be inessential and some may unnecessarily limit resident choice. You might consider how you can modify or remove rules that unnecessarily limit choice.

Rules that have potential for removal or modification include:

- Rules limiting visiting hours
- Rules limiting access to outdoor areas
- Rules limiting access to the outside community
- Rules limiting resident choice in room decoration or furnishings
- Rules limiting alcohol and smoking
- Rules limiting pets
- Rules limiting mealtimes

Scenario: A Pet Poll

A residence reviewed some of its rules and identified one rule prohibiting residents from having pets. When several potential and current residents asked to bring their pets, management began to question why such a rule was in place.

Some staff thought the rule stemmed from issues relating to pet care. Others said that if the resident could care for the pet, “why can’t they have one?” Staff were concerned that other residents might be allergic or unhappy with pets walking around, so they decided to conduct a poll.

Poll results indicated that most residents wanted to see pets in the residence. Management found a way to protect the rights of the few who were allergic or did not want to see animals by keeping the animals away from them. The residence removed the rule prohibiting pets and now residents have cats, fish, and birds.

Consider:

Analyzing rules. Don’t do this alone. Form a group or committee of residents and staff (both managers and direct care staff), to analyze the rules. Look at each rule:

- Why do you have the rule?
- Does it limit resident choice?
- Do you need the rule at all?
- Do you need the rule in its present form?

If the decision is that a rule which limits resident choice is needed in certain situations, ask residents and staff to help amend the rule to reduce its negative impact. For example, let residents themselves discuss issues of living together and being considerate of others. Let them decide what is important to them and what kinds of rules are needed to govern this.

Empowering residents in this way can improve both the quality of their individual lives and the quality of life in your residence.

Scenario: Resident Choice

A residence examines its mealtimes. Although some residents want to eat at times the dining room is closed, the staff-resident committee decides that the dining room cannot be open all day and that specific times must be set.

However, they still consider how to meet the needs of those residents who want to eat at different times. They try several ideas: (1) Offering lighter food at different times (continental breakfasts early and late morning, and light lunch and supper both early and late); (2) Extending mealtimes one hour; (3) Setting up a café serving light food between mealtimes or instead of a regular meal. In addition, the residence offer a series of buffet meals to encourage resident choice.

Focus on Staff Training that Will Help Meet the Residents' Needs for Choice and Control

Ask yourself the following questions:

- Do residents come to me with problems related to their choice and control?
- Does staff training respond to these concerns?
- Do staff come to me to discuss challenges they are encountering with encouraging resident choice and control?
- Does staff training respond to these concerns?
- Do direct care staff have access to the information they need to understand resident preferences?

Case: Video Review

With help from management, residents in an assisted living community decided to show how they were routinely ignored by direct care staff. Residents filmed several role-plays, playing the parts of both resident and staff. One video, later used in staff training, showed a care assistant helping a resident put on a shirt as the resident says, "I don't want that shirt. I want the blue one." The care assistant continues to dress him, acting as if she did not hear. The video was a revelation. After viewing the video, staff indicated they were unaware they were not listening.

Consider the following topics for staff training:

- Time management – how can staff best use the time they have?
- Stress management – how can staff cope with the stress that such work brings?
- Ways to work with residents to develop individual routines and schedules by getting to know individual preferences.
- How to work with residents to develop schedules that meet the resident needs.
- Understanding that family may not take away the right of the competent resident to make decisions for himself.
- Ways to work with families who may be limiting resident choice and control.
- When to report an incident to a supervisor and when to deal with an issue themselves.
- How to put needs of residents before convenience of staff.
- How to say “yes” more often than “no” to residents.
- Perspectives from residents and families reported by residents and families.
- Working and caring for residents who are independent and in control.

Case: Act It Out

The residences who used this guide decided to use the different scenarios and cases in their staff training. They asked the direct care staff to act out various situations from the scenarios and from their own experiences. They found role-playing very effective.

Scenario: Dear Diary

A residence conducts an experiment with its staff. Each staff member is asked to keep a diary of resident requests for one week, noting whether they responded positively or negatively to each request. Staff is then broken up into groups to go over the diaries. Staff is asked to give reasons for each “no.” It becomes clear as each group reviews the diaries that many of the “no” responses could have easily been “yeses.”

For example, when residents who needed help dressing asked to be woken at a later time, many of the care assistants said they had a schedule to maintain. Others said, “I can say yes, because I can leave the resident to the end of my schedule; I can help other residents who want to get up early first.”

Analyze Your Staffing Levels and Schedules

Ask yourself the following questions:

- Do I have enough staff to permit resident-directed care?
- Are residents who need help with their activities of daily living such as bathing, dressing, etc., able to be cared for when and how they choose (within reasonable limits)?
- If not, is there any way I can add direct care staff?
- Is there a way to change staff schedules to permit more resident-directed care?

Educate Families

Ask yourself the following questions:

- How do I ensure that residents' choice and control are respected when dealing with families?
- Is the fact that many families chose the residence and pay the bills the reason I may be allowing them to make decisions for competent residents?
- Is the fact that residents are frail the reason I may be allowing families to make decisions that competent residents may disagree with?

Case: Disapproving Daughter

One resident had a boyfriend. Her daughter did not like it and asked the residence to separate the couple. The administrator explained to the daughter that the residents are competent adults and have the right to do what they want.

Consider:

Develop a process for educating all families rather than trying to solve problems on a case-by-case basis. This will help your direct care staff by reducing the number of times they will have to deal with individual family members or come to you for help. Many families feel that they should make decisions for their relatives. It is crucial to help families understand that competent residents have the right to make their own choices.

Include the following topics:

- Sexual issues
- Choice, control, and decision-making with the demented resident
- Rights of competent residents
- Relationship between a resident's health and the ability to maintain choice and control

Scenario: Choice and Control

A residence sets up a series of meetings for families and friends to discuss the importance of resident choice and control. The staff invites speakers, social workers, and psychologists to talk about the connection between residents being in control of their lives and psychological and physical health. The resident council is asked to develop a presentation discussing how residents feel when their family makes decisions for them.

Examine Regulations

Ask yourself the following questions:

- Do my state's regulations seem to hinder resident choice and control?
- Is there anything I can do to change the practice of my state regulators?
- Do any other states have different policies that I can use to convince my state to change?
- Are there things in my state's law or regulation that support or require more resident choice and control?

Document Your Actions

Ask yourself the following questions:

- Am I sure that my state regulations prohibit me from promoting resident choice and control?
- How can I respect resident choice and control and still comply with regulations?
- How can I fulfill state mandates to maximize resident choice and control?

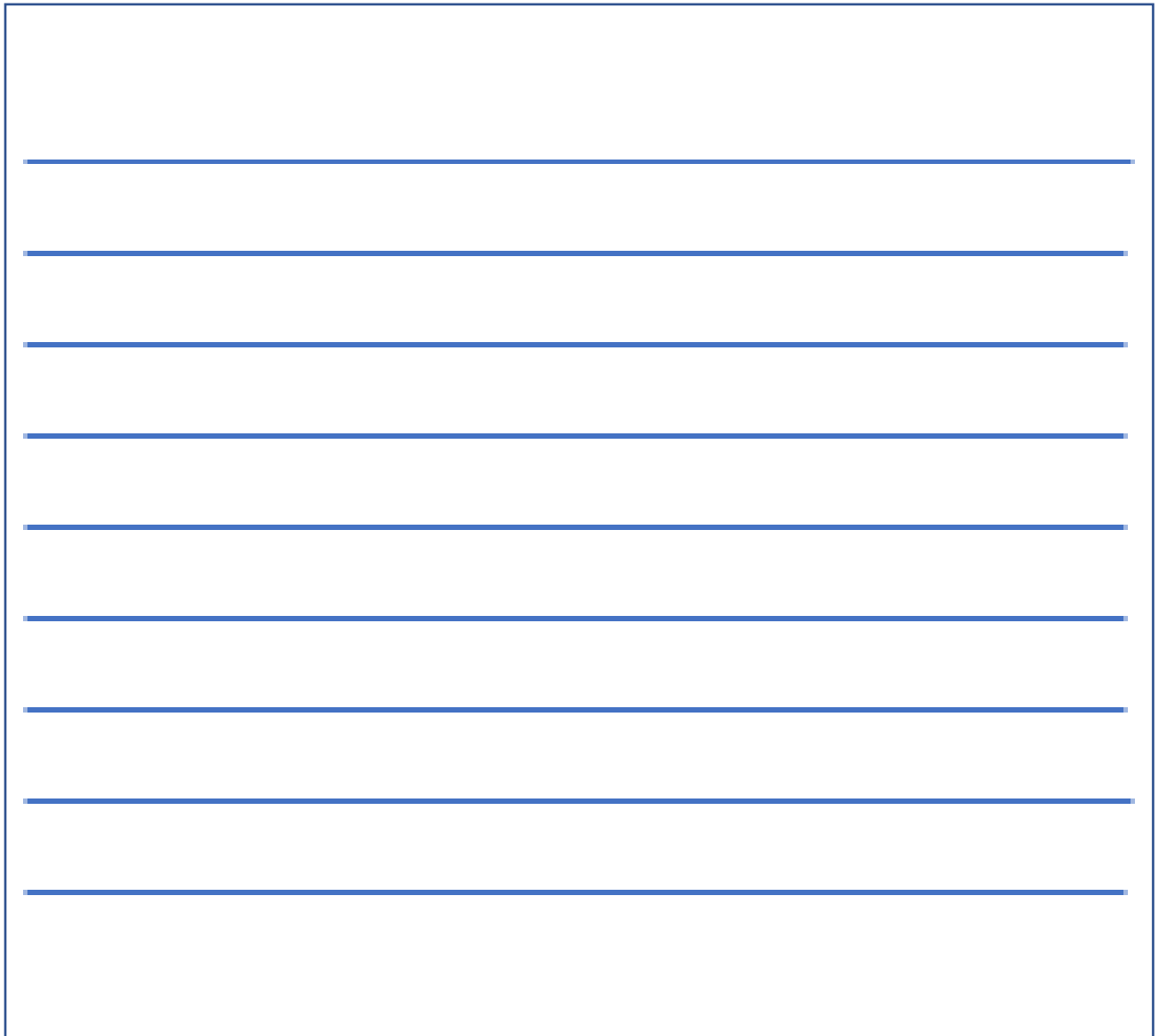
Consider:

If your state regulations appear to restrict your ability to provide resident choice and control, document your approach (indicating how you attempted to keep the resident safe and the family and resident response to the situation). This can help you demonstrate compliance with regulations.

INDEPENDENCE

What Does Independence Mean to You?

Please pick up your pencil and paper again. Write down things you can do for yourself. Think about the days you work and your days off. Think about what you do in the morning, daytime, and at night. Do you shower or use the bathroom by yourself? Cook? Dress yourself? Drive yourself to work? Write down all the activities you can do without help from others. If you needed help to do some of the things on your list, how would you feel?

A large rectangular box with a thin blue border, containing ten horizontal blue lines for writing. The lines are evenly spaced and extend across most of the width of the box, leaving a small margin on the left and right sides.

How Independent Are the Residents in Your Assisted Living Community?

Look at your list of activities you can do by yourself. Which of them do you or your staff help residents with? Do they need help walking? Going to the bathroom? Bathing? Dressing? Because of their frailty, some residents may be dependent on you and your staff for many things. As you know, one of the advantages of assisted living is that some individuals can be even more independent than they would be at home because your staff is there to help them. Is it possible to help the residents be more independent than they are? What could you safely do to encourage resident independence?

What Might Stand in the Way of Resident Independence?

- The physical layout of some assisted living residences may not facilitate independence. For example, in a residence where the dining room is far from the resident rooms, it may be difficult for slow moving residents to get there by themselves. Bathtubs without grab bars makes it difficult for residents to bathe themselves.
- Encouragement of resident independence may be impeded by a desire to make things easier on staff and by fear that more staff would have to be hired. For example, it may be easier for staff to brush a resident's teeth rather than take the time to help the resident do it by themselves. It might be easier for staff to give someone a bath or shower than to arrange things so the resident can wash him or herself with assistance.
- Family members may not want their relative to be as independent as you believe they could be, and they may pressure you.
- Some regulations may not seem to allow residents to be as independent as you feel they should.
- Residents who do not speak English may face challenges communication their wishes.

STRATEGIES TO ENCOURAGE RESIDENT INDEPENDENCE

We know that many residents of assisted living residences are physically or mentally disabled. Many of them are more dependent due to their disability. However, helping residents to live as independently as possible is a major principle of assisted living. Following are some strategies that may help if you feel that any of the problems above are issues in your residence:

EXAMINE YOUR RESIDENCE'S PHYSICAL LAYOUT

Ask yourself the following questions:

- Is there anything in the physical layout of the residence (both inside and outdoors) that limits resident independence?
- Is there anything I can do to change things?

Consider:

- If your dining room is too far away for the residents to walk to on their own, consider small eating areas near resident rooms or developing activities, such as walking clubs, designed to help residents begin walking to the dining area at mealtime.
- If your floors are not non-glare and non-slip, consider replacing or changing their maintenance.
- If you don't have handrails outside the residence to encourage residents to go outside, consider installing them.
- If your residence is not well-lit, make changes.

Scenario: A Grand Tour

The director of a residence takes a small committee made up of management, direct care staff, and residents on a tour of the residence, focusing on whether the physical environment or layout is limiting resident independence. As they walk around, the residents say, "I wish there were places for us to rest when we get tired." The director decided to set up chairs every 10 feet in the halls and lobby areas. This permits more residents to continue to walk with a cane or a walker, rather than a wheelchair. Other findings from the resident tour: floors seemed too glossy in some places (residents were afraid they would fall) and the sidewalks outside the residence were in disrepair and dangerous for residents to walk on.

Focus on Staff Training That Helps Meet Residents' Needs for Independence

Ask yourself the following questions:

- Does my staff know why it is important for residents to be as independent as possible?
- Does my staff know how to evaluate how much residents can do safely?
- Does my staff know when they should go to a professional for help?
- Does my staff know how to encourage independence?
- Does my staff know where they can get help if they are too busy to wait for residents who take time being independent?

Consider:

Involving residents and families directly in staff training. Ask them to talk to staff about their experiences and perspectives.

Make Sure that Non-English Speaking Residents Have Staff Who Speak Their Language

Ask yourself the following questions:

- Are there many non-English speaking residents who have a caregiver who does not speak their language?
- How do these residents make their care needs known?

Cases: Found in Translation

- In one residence, if a resident spoke a foreign language, staff that spoke the resident's language were assigned to care for him. If there were only a few residents who spoke the foreign language and no staff who spoke that language, family members were asked to come in to teach staff basic phrases so they can communicate. Sometimes family members wrote the language phonetically on cards and this is given to caregivers.

Note: Facility staff could also use language translation apps on tablets or mobile phones to overcome language barriers.

- One residence that had several Chinese residents hired both direct caregivers and social workers who spoke various dialects of Chinese. They also hired a Chinese chef. More and more Chinese residents began to apply for admission.

RISK-TAKING

As you know, having independence and control means exercising the right to take risks. A risk in this context may mean that the resident wants to do something that the residence believes is not appropriate because of the resident's physical or mental condition or other factors.

Assisted living philosophy, while considering resident safety crucial, also recognizes the need to balance safety precautions with important quality of life values such as resident choice and control.

Do You Ever Take Risks?

Let's go back to thinking about you. Do you ever do things someone else might consider unsafe or dangerous? Do you smoke? Sit in the sun too long at the beach? Eat more than you should? Do you go on adventurous trips? Have you ever gone scuba diving or mountain climbing?

In thinking about your answers to these questions, consider:

- What happens when you do these things? Do you know what could happen?
- Do you do them anyway? Why?
- How would you feel if you were told not to do the activity, or if someone stopped you from doing it?

Do the Residents Ever Take Risks?

What kinds of things do the residents do or want to do that you consider unsafe? Make a list.

- Do they want to go outside whenever they want to even when you think it is too cold or too hot?
- Do they want to smoke?
- Do they want to go shopping on their own even though you feel they need help?
- Do they sometimes want to eat fattening, salty, or sugary foods when they are obese, have heart problems, or are diabetic?
- Do they want to go for a walk outside, even though you feel they are too frail?

If the residents are not permitted to do things they want to because you consider them unsafe, how do you think they feel?

- Do the residents agree that the action is unsafe?
- If it is truly dangerous, why do you think the residents might want to do it anyway?

What Might Prevent Residents from Exercising Their Right to Take Risks?

- You may be afraid that the resident will get hurt if they do something you think is unsafe.
- You may be unsure that the resident understands the possible consequences of the behavior that you consider unsafe. The resident may be confused or might not understand.
- You may be afraid of being sued if a resident does something unsafe and gets hurt.
- You may be afraid that insurance costs will rise if anything happens to the resident.
- You may not believe that elderly residents can or should make such decisions for themselves. You may believe they are too old and that you know what is best.

- Some regulations may prohibit residents from doing things considered unsafe, even if the residents understand the consequences.
- You may feel you have to listen to the resident's family and heed their wishes if they do not want the resident to do something.

Fostering Positive Outcomes in Risk-Taking Situations

Having the right to take risks is a difficult issue. You are in this profession to help people, to keep them safe. You are not here to permit them to harm themselves. How do you balance what seem to be conflicting needs? If you have found that your residence is prohibiting competent residents from exercise their rights to take risks, consider these ideas below.

Analyzing the Potential Risks

Ask yourself the following questions:

- Is the action the resident wants to take actually risky?

It is important to first find out if what the resident wants to do is risky or dangerous. It may not be. In order to do this, develop a process (that you document) for evaluating the risk that residents might want to take. The process might involve the following questions:

Consider:

- Is the danger real?

Analyze the probability of the resident getting hurt if they take the action. Is it likely or unlikely to cause pain or injury? For example, how likely is it that a resident who wants to take a walk outside will get lost or fall? Some things that we assume to be unsafe may, in fact, carry little risk of harm. If it is not dangerous, encourage the resident to take action with some oversight.

- Is it dangerous or is it something else?

Analyze whether the action is dangerous for the resident or if it would be easier for staff if the action isn't taken. For example, it may be more convenient if all residents remained inside on a rainy day. It may be difficult if a frail resident wants to go to the library in town and requires transportation. Do any of these things influence the belief that the actions are unsafe? If so, plan a way to encourage the action.

- Is it dangerous or are you worried that the residents' families might feel it is dangerous?

Do you believe that families should make decisions for the residents because they are paying, or you feel the resident is too old to make such decisions? Is it dangerous or does the family

think it is dangerous? If so, see ideas for family discussions around this issue in the Choice and Control and Independence section (Page 30) of this guide.

- Is it dangerous or does it make you feel better if residents don't take chances because you're afraid of what might happen?

Develop a Process for Dealing with Real Risk

Ask yourself the following questions:

- Do we always try to find ways to maintain resident choice and control when a resident wants to take a risk?

Case: A Right to Make "Bad Choices"

A resident who was somewhat disoriented wanted to go to a conference. Staff were concerned that she would forget to take her medications. The staff packed the medications and arranged for someone to remind her to take them at the meeting. The staff felt strongly that she had the right to go. "People have a right to make bad choices."

Consider:

After you determine that a risk is real, develop a process for ensuring that the competent resident and their family understand potential risks of the unsafe action.

- As each resident's service plan is developed with the resident (and family, if resident agrees), discuss any actions the resident would like to take that you consider unsafe.
- Make sure that you have carefully determined the real risks associated with these actions by using the developed process and the questions listed above.
- If you still believe the action could harm the resident, think about ways to lessen the risk while still meeting the resident's goals. For example, ask if a staff member can go along when they go out; ask the resident to smoke only in designated places.
- Go over the potential consequences of the action with the resident/family. Make sure that the resident understands what you have said about the risks and possible consequences. Ask the resident to tell you what they think the potential risks are. If they can't, it may mean they do not understand.

- If the resident understands the possible consequences and still wants to take the action, make a note in the individual service plan about the discussion you had and how the individual service plan will help the resident take the action as safely as possible.

Case: Risky Business

In one residence, if a behavior is determined to be risky and the resident continues to want to do it even after the staff attempts to meet his needs in other ways, the residence deals with the issue at a weekly interdisciplinary care conference with department heads. The case is documented, with the potential consequences of the behavior explained to the resident. This residence believes that their state regulations require it to permit residents to take risks if it has followed this procedure.

Training Staff to Deal with Risk-Taking Effectively & Positively

Ask yourself the following questions:

- Does staff training respond to resident, family, and staff concerns about risk-taking?
- Is it up to date in respect to current understanding of the needs and abilities of older adults, including those with dementia?

Consider:

- Help staff understand the importance of the residents' self-determination by involving residents in the training. Ask residents to talk about why having the right to take risks is important to them.
- Help staff understand that the need to feel in control does not diminish with age.
- Let them know that families cannot make decisions for residents who are competent and understand the consequences of their actions, unless the resident wants them to.
- Help them learn how to explain these issues and deal with families who may feel that they should be making the decisions.
- Let them know that resident choice, control, and independence means accepting resident risk-taking and the possibility of harm.
- Explain how to discuss this sensitive issue at individual service plan meetings and how to document all actions taken.

Educating Families About Risk-Taking

It is crucial that families and friends understand the value of residents being permitted to take risks if they want to as well as the possible consequences of taking or not taking the risk. Hold

discussion groups and meetings similar to those discussed earlier in the Choice and Control section (see Page 6). For topics involving risk:

- Explain the process you developed for evaluating risk and your ideas for lessening the potential for negative consequences of risk-taking while meeting the resident's goals.
- If your state regulations mandate that you follow the decision of the competent resident, let the family know this.

Working with Insurers

Some assisted living residences accept anything their insurer tells them to do to eliminate risk, even if management does not believe there is a risk or believes that the action would violate the resident's rights. Some work with insurers to make them understand the rights of residents. If your insurers suggest a way of protecting residents that you believe interferes with their rights, discuss the issue with them and try to come up with ways to keep them safe without interfering with resident rights.

Case: Unintended Consequences

In one assisted living community, the insurer asked the residence to lock its back doors because it believed residents were unsafe. Knowing that the residents liked having the back doors unlocked during the day, management told the insurer that the residents had the right to use the back door. He suggested that if the residence locked the back doors, residents who were taking a walk and had to go to the front to enter might get tired and that this might actually cause more harm. After a dialogue, the insurer and the management agreed that it was safer to leave the back doors unlocked.

Communicating with Your State's Regulators

You may believe that state regulations do not permit you to allow residents to take risks. However, a review of the regulations or a call to your state regulators may prove otherwise. Most regulations give residents many rights to self-determination and your developed processes and documentation may demonstrate that you are in accordance with regulations.

PARTICIPATION IN DECISION-MAKING IN THE ASSISTED LIVING COMMUNITY

How Much Do You Participate in Your Community?

What decisions do you make about issues outside of your everyday tasks? Do you vote? Are you on a tenant board? Are you a member of the PTA? What kinds of decisions do you make? Perhaps as a member of the PTA you help develop activities for your child's school. You might fight for more traffic lights or less noise in your community as a member of a community group. These decisions, although not about your everyday routines, may also have a significant effect on your life. Lessening noise may help you sleep. More traffic lights may keep you and your family safe.

- How would you feel if you had no say in these things – if others decided them for you?

How Much Do Residents Participate in Decision-Making in Their Community?

The residents are a part of their community in the same way that you are a part of yours. What decisions do they make about the assisted living community in which they live? Do they bring any suggestions and concerns about policies to you for consideration?

- If you have a Resident Council, does it participate in decisions made by the residence or does it merely raise problems?
- Does it participate in choosing decorations for the residence?
- Does it participate in deciding mealtimes or the selection of food served?
- Does it participate in staff training?
- Does it or individual residents help interview and choose staff?

What Might Prevent Resident Participation in Decision-Making?

- It may be difficult to help residents become decision makers and/or advisors – either individually or through a Resident Council or other vehicle. For example, some individuals may lack experience with decision-making in their lives.
- It may be difficult to juggle a policy of majority rule with individual rights. If a Resident Council makes a decision, how will this affect other individuals? Should the Council be empowered to change policies that may affect everyone?
- Some residents may not seem interested in participating.
- You may be concerned about losing control over decision-making. Perhaps you feel that managers, not residents, should make decisions.

Strategies to Encourage Resident Participation

If you have found that the limitations listed above are in fact issues in your residence, here are possible solutions:

Develop an Effective Resident Council²

Ask yourself the following questions:

- Do we have a resident council?
- What does it do?
- Does it do more than make complaints?
- Does it function in a way that encourages resident participation in policymaking?
- Is it run by the residents?
- Do the residents choose officers and agenda items?
- Do staff help only when asked?

Resident Councils can help encourage resident choice and control by helping to make known the residents' wishes.

Consider:

- Urge residents to discuss the development of a council if you do not already have one or if residents have not already discussed it.

Use Your Resident Council

Ask yourself the following questions:

- Does the Resident Council help form the community's policies and mission?
- What input does it have?
- Do the residents want to be involved?
- Do many residents come to the meetings?

² For an excellent resource, see the Coalition of Institutionalized Aged and Disabled's *Adult Home Resident Council Toolkit*. Available at <https://ciadny.org/documents/AdultHomeResidentCouncilToolkit%20-%202nd%20Edition%202019.pdf>.

Case: Curtain Calls

A Resident Council has its own officers and keeps its own minutes, focusing on maintenance, food, and minor decoration. The administrator said that, “They had input into the curtains when we redecorated. They were also involved in having the cigarette container outside replaced.”

Consider:

- Residents can and should have a say in the decisions that affect their lives within the residence. Resident Councils can do many things to help the assisted living community.
- Similar to a tenants' association, councils can represent the interests of those living together and can provide a way for residents to have a say in how their residence is run.
- Resident Councils can enrich the lives of all residents and help to recognize their talents and skills. For example, committees can be set up to help non-English speaking residents, visit sick residents, help other residents who need help with such things as voting, address civic issues, and develop resident activities and entertainment.
- Resident Councils can participate in: staff interviewing, hiring and training, decorating the residence, menu planning, scheduling mealtimes, and identifying and resolving complaints, etc. Residents who are involved feel that they are a part of the community and tend to be more satisfied.

Cases: Compromise and Communication

A resident council complained about not having lettuce for their salads and members met with dietary staff to discuss the issue. The dietitian explained that lettuce was extremely expensive (\$4 a head) and that the residence would order lettuce once the price went down. After hearing the cost of lettuce, the residents all agreed that, if they were living in their own home, they would not buy lettuce at that price. They agreed to wait until lettuce prices dropped.

Compromise and Communication

- A residence had ongoing problems keeping a beautician in their beauty parlor for longer than a few months. Management decided to ask residents to help find a new beautician. A committee of residents, including one who had dementia, interviewed several candidates and chose two or three finalists. The inclusion of the individual with dementia proved to be helpful. She asked the same question repeatedly, and that gave the residents a chance to see how the beautician would react. The individual that was hired (the administrator made the final choice) came from this group of three finalists. She has remained longer than any other beautician.
- A residence seeking a new activities director asked candidates to prepare a sample session for residents. The residents were told that management wanted their impressions of the candidates' abilities to lead and be part of the community. After the sessions, management met with the residents to get their feedback. If the feedback was positive, management asked the candidate to come in and chat with them and the residents. Residents asked questions; management observed the interaction and then met with the residents again to get feedback.

Develop Ways for Individual Residents to Participate

Ask yourself the following questions:

- Do I offer individual residents the opportunity to participate?

Residents bring with them the talents, skills, and knowledge developed over a lifetime. Each resident, regardless of age or disability, has a unique contribution to make to the residence and to management. Residents are in a special position to recommend changes that might help the residence better meet their needs and interests. Only they know how it feels to live there. Only they know if services are right for them. Residents' ideas can help improve the services for the entire residence and will add to their feeling of empowerment. This will also help to retain current residents and be more attractive to new residents.

Cases: Tap into Their Talents

- A residence asked a resident, who was an artist, if she would be willing to conduct a few art classes. She was thrilled!
- One residence had a resident who used to run a restaurant. She often complained about the dining room staff's inefficiency and the unappetizing food. Rather than labeling the resident a "troublemaker," the residence asked her to work with the food service director to help make the dining program more efficient and more satisfying to the residents. It worked!
- Another residence, after using this guide, decided to invite residents to go shopping with the head chef for food for meals and urged residents to supply recipes of meals they have enjoyed.

Consider:

- Encourage individual residents to come to you with issues related to the running of the community by responding to their suggestions and ideas.
- Give opportunities for residents to talk among themselves about what is going on in the residence. Perhaps one activity could be current events at the residence. Thus, residents will know what is going on at all levels so they can make suggestions.

PARTICIPATION IN THE OUTSIDE COMMUNITY

Think about ways in which you are part of your neighborhood or community. Do you enjoy dining out or going out socially? Do you go to temple, church, or mosque? Do you go to a beauty salon or barbershop? Do you go to the movies?

- How would you feel if you were never allowed to leave your house?

How often do the residents leave the assisted living community? How easy is it for them to go out into the larger community? What can residents do in the outside community?

- Do they go to temple, church, or mosque for services or other activities?
- Do they go to the movies or theater?
- Do they go shopping?

- Do they go to the library?

What community relationships or activities would you want to continue if you lived here?

What Stands in the Way of Resident Participation in the Outside Community?

- You may be afraid that frail residents will get hurt if they leave the residence.
- It may seem too difficult to arrange access to the outside community.
- It may seem expensive. You may need staff to go along or may need to supply transportation.
- Residents don't seem to be interested or seem afraid to go out.

Strategies to Encourage Resident Participation in the Outside Community

Just as doing things outside of the house is important to you, so is it important for many older adults. Facilitating resident involvement in the outside community can make your assisted living community a better place to live. If you feel that some of the things listed above are issues in your residence, here are suggestions that may help:

Fostering the Ability of Residents to Access the Outside Community

Ask yourself the following questions:

- How often do the residents go out into the outside community?
- Do most of the residents continue their community activities once they come here?
- Do the residents want to continue this involvement?
- Are they afraid?

Case: Bathroom Breaks

In one residence, the activity director was concerned that no matter what outside trip she recommended, few residents signed up. After investigating, she realized why so few residents were signing up for trips outside the residence such as going to the beach: they were concerned about bathroom access and availability. She designed the trip to include several bathroom stops and had no problem finding residents to sign up after that.

Consider:

- Make transportation to outside activities routinely available for groups or individuals. The activities could be a large group outing or could be an individual trip to the library.
- Repave sidewalks if needed and/or create safe walkways.
- Evaluate the success of your activity program by seeing how often individuals or groups get involved with the outside community.
- Eliminate or reduce resident fear. If residents are afraid to go out, try to learn what they are afraid of and find ways to deal with that fear.
- Find ways to bring the outside community into the residence. Have community groups meet in the residence and invite residents to participate or sit in on meetings. This may help get them involved with the outside community.

Cases: Community Field Trips

- In one urban residence, residents go on many trips and have access to transportation for errands, shopping, and events. The residence has its own bus that is used for daily outings to stores, banks, casinos, churches, park concerts, and other places.
- One residence, after reading this guide, decided to add to their available transportation. The van, in the past, was used only for doctor's appointments. Now it is also used to take residents shopping.
- Staff in one residence brought together local school children. Children often came to visit and the residents went out into the community to see the children perform in school plays and were invited to graduation exercises.
- One community called the local houses of worship and helped arrange for parishioners to pick up residents who wanted to attend services.

Community Field Trips

- One residence had a relationship with the Kiwanis Club (a service club) that had monthly meeting luncheons. Each month, a different resident joined the club for lunch and spoke about their life and experiences. The resident always came back feeling uplifted and involved in the outside community. Club members also came to the residence once a month, sponsoring birthday cakes and giving out cards and presents.
- One activity director says she has walked many residents down the road to the snack shop to help them access the outside community in a positive way.
- A residence, after using this guide, called a local store to find out if it was willing to open the store at special times or “if it was willing to make special accommodations” for its residents. The store agreed.

DO YOU HAVE AN ENVIRONMENT THAT FOSTERS CHOICE, CONTROL AND INDEPENDENCE?

Ask yourself the following questions:

- Do the residents know that it is my goal to support their ability to exercise their independence, choice, and control over their everyday lives? How do they know? What have I done to let them know?
- Do my admission and evaluation processes gather information about resident preferences and does the residence take steps to satisfy these preferences?
- Do direct care staff have access to this information and are they involved in giving the residents what they prefer?
- Do residents feel free to express preferences and talk to staff about what they want to do? Do they make their preferences known to you or to their resident care assistants?
- When they do, how often does staff accommodate these preferences?
- Do the residents feel free? How do I know?

THE COGNITIVELY IMPAIRED RESIDENT

For many residents at the beginning stage of dementia, the ideas listed above will be appropriate. For others, adjustments may be needed. Staff training should include the following ideas.

- Many cognitively impaired residents wander, explore, and like to poke through different items. Rather than try to stop this behavior, staff should encourage their ability to make choices, and should be trained to find ways for residents to do the things they want. **For example**, urge your staff to let residents wander if they want and not to tell them to sit down. You might consider developing places where residents can wander safely. Train your staff to set up situations where residents can look through things without disturbing others if they like to rummage. A common complaint from demented residents is: “They boss me around.”
- Make sure that your staff encourage residents to make decisions about their everyday lives by having staff learn as much as they can about resident preferences for getting up, going to sleep, etc., by speaking to families and friends and by observing the resident. This means that your staff must be able to see the information gathered by admission staff related to residents’ past experiences and likes and dislikes.
- Train your staff to try to set resident schedules according to their past routines. Tell staff that if they set a time for personal care and find that the resident is not ready, they should back off and come back later.
- Encourage your staff to help residents maintain their identity.
- Train staff to limit any choices to two, particularly for residents with cognitive impairment. **For example**, rather than ask the resident what they want to eat, as staff might with the less cognitively impaired, ask the resident if they want chicken or fish (choosing two types of food they like). Have healthful snacks available so these residents can help themselves.

Case: Let Them Be

Some female residents with dementia carry handbags even if they’re not going anywhere. In one residence, residents were carrying heavy pocketbooks and a resident care assistant urged them to put them down. Another resident care assistant told the first resident care assistant to let them be. “It is important to them to feel that they are doing things they have always done.”

- Many cognitively impaired residents can be independent if staff help them. However, staff must facilitate independence by setting things up, giving reassurance, and coaching.
For example, to encourage independent eating, staff may need to get the eating motion started by initiating the feeding. They may need to put the toothpaste on the brush and start the brushing motion before the resident will take over.
- The cognitively impaired resident can also participate in the assisted living community. The best approach is to ask “yes or no” questions.
For example, if you are choosing fabric for drapes, ask the resident if they like the fabric. Ask if they like the food.

Case: Fresh Air

It was snowing very hard and a resident with Alzheimer’s wanted to go outside. Staff asked her to wait until it stopped snowing. She refused, saying she wanted fresh air. Staff figured out a way to help the resident do what she wanted safely. The staff person asked her to get her jacket, gloves, and boots and then took her out to a wrap-around porch. The resident stood there, saw the snow, and got her fresh air. Staff said, “I was able to let her do what she wanted to do in a safe way. It makes you feel good.”