THE CHALLENGE OF ASSISTED LIVING TO FOSTER INDEPENDENCE
CHOICE, CONTROL AND DECISION-MAKING

STRATEGIES *for* MANAGEMENT *in an* EVOLVING INDUSTRY

FOSTERING AUTONOMY & INDEPENDENCE

The Long Term Care Community Coalition (LTCCC - formerly the Nursing Home Community Coalition)
Coalition of Institutionalized Aged and Disabled (CIAD)

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A VISION

We are excited by the mission and promise of assisted living to allow people to have maximum independence and control over their lives and the ability to remain in place, even when they need more care.

However, this can be challenging and hard to accomplish. A three-year study of assisted living in New York State we conducted (supported by the Fan Fox and Leslie R. Samuels Foundation, Inc.), identified the difficulties of fulfilling this promise. As a result, we began a project to work with the assisted living industry to move closer to making these ideals a reality. In order to advance this vision, we have written educational materials for both consumers and assisted living providers. There are four different guides:

1. A guide for potential residents, to help them choose an assisted living community where the goal of resident choice and decision-making power is a reality;
2. A guide for people now in assisted living, to help them evaluate their residence in terms of this goal and suggests ways to work with staff and other residents to make it a reality;
3. A guide for assisted living staff who work directly with residents, to help them make this goal a reality in the residents' everyday lives; ***and***
4. **This guide**, for assisted living managers, which looks at the obstacles that might prevent this goal and suggests ways to overcome them.

The purpose of these guides is to generate both discussion and action among consumers and providers about how to deal with any concerns raised and how to maximize choice, independence and the ability to remain in a residence as one becomes more dependent. We do not expect to see the promise of assisted living achieved overnight. This is a vision for the future. It is a work in progress.

Cynthia Rudder, Ph.D., ***Executive Director***
Long Term Care Community Coalition

Geoff Lieberman, ***Executive Director***
Coalition of Institutionalized Aged and Disabled

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Participants in Pilot Testing the Use of the Guides

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Suleika Cabrera Drinane, ***Executive Director***
Institute for the Puerto Rican/Hispanic Elderly, Inc.

Olivia Filerman, ***Chair***, Assisted Living Subcommittee
Women's City Club of NY

Beth Finkel, ***NYS Manager of State Operations***
AARP

Thomas H. Grape, ***Chairman and CEO***
of Benchmark Assisted Living and
Chairman of ALFA

Rosalie A. Kane, ***Professor***,
School of Public Health, University of Minnesota

Karen Love, ***Founder and Chair***
Consumer Consortium on Assisted Living

Sandra Moya, ***Director*** Leonard Covello Senior Center, Institute for the Puerto Rican/Hispanic Elderly, Inc.

Lisa Newcomb, ***Executive Director***, Empire State Association of Adult Homes and Assisted Living Facilities

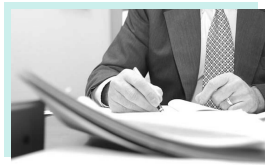
David Nolan, ***Managing Director***
NCB Development Corporation

Benay Phillips, ***CEO***, The York Group Assisted Living

Sharon Ricardi, ***Regional Director of Operations***
for Benchmark Assisted Living

Lani Sanjek, ***Acting Executive Director***, New York StateWide Senior Action Council

David B. Smith, ***Professor***, Healthcare Management Program, Temple University, Fox School of Business and Management



INTRODUCTION

You are in an exciting profession. Assisted living is an idea whose time has come. 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 choice, influence and decision-making in the community of which they are a part
- 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 research shows that these are necessary for the elderly – the relationship between control, decision-making, self-esteem, well-being and health is very strong.

As you know, when people lose control over their lives they experience low self-esteem, a 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 sicker.

Although most staff in assisted living residences want to accomplish these values and in fact, believe they already do, we have found that these are very difficult goals to accomplish. Listen to some comments made by managers after reading the booklet but before putting it into use:

> ***"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, as managers, are in a perfect position to make things change. This guide has been written to help you by discussing possible difficulties and ways to overcome them. It will help you evaluate your residence to see how well it does in fulfilling the promise of assisted living. 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 with others. Listen to comments from managers who actually 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 such a residence if it can create a community where these basic rights are encouraged. We have also written educational materials to help consumers choose residences that meet these needs and expectations. Hopefully, consumers will learn to seek out such residences.

This guide is meant to be read by you and to become a resource for you as you manage your residence. The guide contains a number of pencil and paper exercises. Some may seem simplistic, but we think it is important for you to go through them. It will put some of the strategies into a context.

We are aware that the residents in an assisted living community may never be able to have exactly the same freedoms you have and that there are issues that are clearly beyond your control. These issues are complex and there are many valid concerns that have been raised by managers (such as those above) as they have attempted to deal with these difficult issues. This material attempts to look at your concerns and respond to them in a way that we hope will help your residence fully embody the philosophy of assisted living.

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

- Not every suggestion will work for every residence.
- Not every suggestion will be new; some of you may already do many of the suggestions in this guide.
- Some of you may have already developed ways to encourage choice, control and independence in the resident's everyday life, but may not have been able to find 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 some of the strategies seem impractical to you, please don't dismiss them out of hand; discuss them with others. If you don't agree 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 called, "scenarios." We hope you will discuss these with others and use them in staff training.
- Many of the suggested strategies will be appropriate for residents who are at the beginning stage of dementia. However, there is also a special section for those in the more advanced stages.
- Drafts of this booklet have been used by four residences in Iowa and Massachusetts. You will find examples of how they used this guide and the other guides in their residences. Some of these examples may work in your home as well.

HOW TO USE THIS GUIDE

The entire community can work together to make the ideas in this guide a reality. Make sure the entire community "buys in."

You, as a manager, can make the ideas in this guide a reality. However, we suggest a few steps to follow as you work through the ideas we present to you.

First, whenever you can, try to use this guide in conjunction with the guides for direct care workers' and residents. The Direct Care Guide and the Resident Guide are made to coordinate with this guide. The entire community can work together to make the ideas in this guide a reality.

Second, make sure the entire community "buys in." If you are interested in implementing changes based upon ideas raised in this guide, it is important to make sure that the entire assisted living community understands the issues and is involved. Otherwise you may find some members resistant or frightened of change. The entire community – direct care workers, residents and family members – needs to come together, read the guides and discuss ways for using the guides. Encourage discussion and comments about the major ideas and involve everyone in deciding on what and how things might be changed. This will give you an opportunity to understand the possible resistance and to help your community move forward. It will also build a stronger sense of community. 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.

Third, come together as a community to continually evaluate the process as things go forward. It is crucial to monitor any changes.

CHOICE AND CONTROL

What Do Control and Choice Mean To You?

You will need a pencil and paper for this section. On paper, 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?

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 any way they like?
- Have a pet if they want to?
- Choose what to eat at each meal, when to eat and who to eat with?
- Cook if they want to?
- Entertain family and friends in a private place?
- Go somewhere whenever they want to go?

We know that there may be many reasons why the residents in your residence do not have the freedom to make the same decisions you do. A resident with a mental disability may not be able to go out whenever she wants to; a resident in an assisted living residence with rooms that do not have separate temperature controls may not be able to control the temperature in her room.

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 things they should speak to a professional about (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 the company may unnecessarily limit autonomy. For example, the residence may be required to have 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, which seems to mandate 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 where she chooses to sit.
- Staff shortages can mean there is less time to help residents make choices and decisions.
- You may believe that the resident's family may not want the resident to make his own decisions and you might feel you have 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 and the staff may not understand them.
- Your staff may not know how to encourage resident control or believe residents should not or cannot make decisions on their own.

Strategies to Encourage Resident Choice and Control Over Their Everyday Lives

✓ 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?
- Are any of these rules in existence only because it makes 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 and privacy can be more easily maintained. However, residents and their families want the freedom to visit when convenient for them.
- Should any rules be removed? Should any be changed to permit more resident choice and control?

Scenario

A residence looks at rules that had been in place for many years. One prohibits residents from having pets. Management begins to ask why they have such a rule. Many potential and current residents are asking to bring their pets. Some staff thought it had to do with the problem of taking care of the pets. Others said that if the resident could care for the pet, why shouldn't she be able to have one? Some felt that there was a concern that other residents might be allergic or unhappy with pets walking around. Others said: why don't we find out? They took a poll of the residents and found that most wanted to see pets in the residence. Management figured out a way to make sure that the rights of the few who were allergic or did not want to see animals were protected by making sure that the animals were never near them. The residence removes this rule and now residents have cats, fish and birds.

As a manager, you know that every residence needs rules, however, some may not be necessary and some may unnecessarily limit resident choice. You might consider how few rules your residence can live with or how you can change some that unnecessarily limit choice. ***Some rules to think about:***

- Rules limiting visiting hours
- Rules limiting resident choice in room decoration or furnishings
- Rules limiting alcohol and smoking
- Rules limiting pets
- Rules limiting meal times
- Rules limiting free access to the outside community

Consider:

Analyze 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?

Scenario

A residence examines its meal times. Although some residents want to eat at times the dining room is not open, the staff-resident committee decides that the dining room cannot be open all day and 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 decide to try a number of things: (1) lighter food can be offered at different times: continental breakfasts available both early and late morning; and light lunch and supper both early and late; (2) mealtimes can be extended an extra hour; (3) a café can be set up where residents can get light food in between mealtimes or instead of a regular meal. In addition, the residence, in order to encourage resident choice, could offer a series of buffet meals.

Case

With help from management, residents in one residence decided to show direct care staff how often they tended not to listen to the residents. They taped a number of role-plays where they played the parts of both resident and staff. In one, they role-played a resident being dressed. The tape, which was later used in staff training, shows 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 discussion held after staff viewed the tape indicated that staff were unaware of not listening and that the tape was an awakening.

- 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. This not only helps empower residents but it also will help empower direct care staff and really make a community out of a residence. They will be doing this together.

✓ Focus on Staff Training That Will Help Meet the Resident's 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?
- Does staff come to me with problems they are encountering with encouraging resident choice and control?
- Does staff training respond to these concerns?
- Does direct care staff have access to the information they need to understand resident likes and dislikes?

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 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.

Scenario

A residence conducts an experiment with their staff. They ask each staff member to keep a diary of resident requests, and whether they responded positively to these or not, for a week. Staff then is broken up into groups to go over the diaries. Staff is asked to give reasons for each "no" they gave. It becomes clear as each group goes over the diaries that many of the "nos" could have easily been "yeses." For example, when residents who needed help dressing asked to be woken up later than they were being woken up, many of the resident 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 wanted to get up early first."

Case

The residences that 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.

✓ 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 no, 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:

- Is the fact that many families of residents 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?

- Do I deal with conflicts on a case-by-case basis or do I develop policies that give clarity while respecting individual needs?
- How do I make sure that residents' choice and control is respected when dealing with families?

Consider:

Develop a process for educating all families rather than to try to solve problems on a case-by-case basis. This will help your direct care staff by limiting the number of times they will have to either deal with individual family members or have to 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 must be able to make their own choices. In fact, some state regulations demand this. Include the following topics:

- Sexual issues
- Choice, control and decision-making with the demented resident
- Rights of competent residents
- Relationship between resident choice and control and health

Case

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

Scenario

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. (See "For Further Reading" at the end for help with sources of information).

✓ 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 laws or regulations that support or require more resident choice and control?

Texas is one state that requires assisted living residences to promote policies that maximize resident dignity, autonomy, privacy and independence (see: Mollica, R.L. (National Academy for State Health Policy) and Robert Jenkins, (NCB Development Corporation), State Assisted Living Practices and Options: A Guide for State Policy Makers, September 2001, p. 22 for other states).

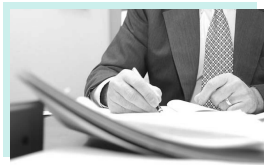
✓ Document Your Actions

Ask yourself the following questions:

- Am I sure that my state regulations will not allow me to encourage 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 (due to their frailty), document your approach (indicating how you attempted to keep the resident safe and the family and resident response to your actions) so that you can better make a case for your activities that support resident choice and control and to demonstrate that you are in 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? Drive yourself to work? Put down all of the things that you can do without help from others. If you needed help to do some of the things on your list, how would you feel?

How Independent Are The Residents in Your Assisted Living Community?

Look at your list of things you can do by yourself. What things 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 a slow moving resident to get there by herself. A bathtub without grab bars makes it unlikely that a resident will bathe himself.
- Encouraging residents to be as independent as possible may be limited by a desire not to make things too difficult for staff or 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 himself. It might be easier for staff to give someone a bath or shower than to arrange things so the resident can wash 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 find it hard to communicate.

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 there on their own, consider small eating areas near resident rooms or having 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 putting them up.
- If your residence is not well lighted inside and out, make changes.

Scenario

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 there is anything in the physical environment or layout that limits resident independence. As they walk around, the residents begin to say, "I wish there were places for us to rest when we get tired." The director decides to set up chairs every ten feet in the halls and lobby areas for sitting. This permits more residents to continue to walk with a cane or a walker, rather than have to consider a wheel- chair. Other things discovered: 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 Will Help Meet the Resident's 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 the 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? Walking, dressing, bathing?

Consider:

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

✓ Make Sure That Residents Who Do Not Speak English Have Staff That Speaks Their Language

Ask yourself the following questions:

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

✓ Educate Families

Here, too, families may stand in the way of resident independence. Hold discussion groups and meetings, similar to those discussed earlier, under Choice and Control.

✓ Examine Regulations and Document Your Actions

Take similar action as discussed under Choice and Control above.

Case

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

Case

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

RISK-TAKING

As you know, having independence and control means exercising the right to take risks. A "risk" means that the resident wants to do something that the residence does not believe is 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. In fact, the Assisted Living Federation of America (ALFA)[1] discusses the difference (see Further Reading at the end of this guide) between nursing homes and assisted living residences as the attempt of assisted living to shift away from the medicalization of long-term care. ALFA states that nursing homes try to make the environment as safe as possible and services are planned and provided in ways that will reduce the possibility of an adverse outcome. This often results in a lower quality of life.

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 skydiving? Do you go on adventurous trips?

Look at the answers to the questions above. For each, answer the following questions:

- What happens when you do these things? Do you know what could happen?
- Do you do them anyway? Why?
- If they are dangerous, how do you feel when someone tells you you shouldn't be doing some of these things or refuses to let you do them?

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?

[1] See: Burgess, 2000, pgs. 13, 14 in Further Reading at end.

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

- Do the residents agree that the action is unsafe? If it really is 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 not be sure that the resident really 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 go up 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 not permit residents to do things considered unsafe, even if the residents understand the consequences.
- You may feel you have to listen to the resident's family and if they do not want the resident to do something, you have to heed their wishes.

Strategies To Set An Environment Where Residents Can Do Things You May Consider Unsafe If They Want To And Understand the Possible Consequences

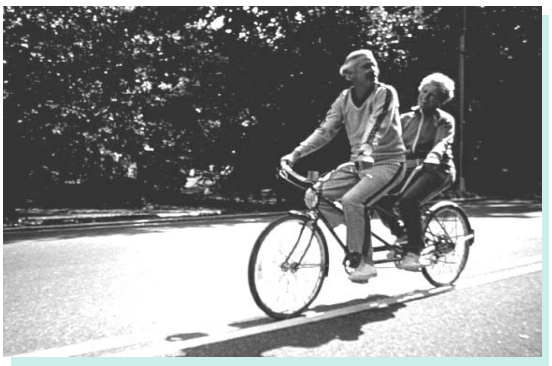
Having the right to take risks is a difficult issue. You are in this profession to help people, to keep them safe. You are not here to permit them to harm themselves. How do you balance what seem to be conflicting needs? If you have found that your residence is not permitting competent residents to exercise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

✓ Analyze the Potential Risk

Ask yourself the following question:

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

It is important to first find out if what the resident wants to do is really 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 what the chance is that the resident will really get hurt if she takes 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 actually 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 the action with some oversight.

- Is it dangerous or is it something else?

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

- Is it really dangerous or are you worried that the residents' families might feel that it's 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 a decision? Is it really dangerous or does the family think it is dangerous and you feel that you are in the middle? If so, see ideas for family discussions around this issue in the Choice and Control and Independence section of this guide.

- Is it really 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?

Consider:

After you determine that a risk is real develop a process for making sure that both the competent resident and her family understand the potential risks of taking what you consider an unsafe action.

- As the service plan for each resident is being 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.

Case

A resident who was somewhat disoriented wanted to go to a conference. Staff was concerned that she would forget to take her medications. The staff packed the medications and worked out arrangements to make sure someone reminded 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."

- 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 he goes 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 he thinks the potential risks are. If he can't, it may mean he does not understand.

Case

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.

- 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.

✓ Focus on Staff Training That Will Deal With Risk-Taking

Ask yourself the following question:

- Does staff training respond to both resident, family and staff concerns about risk-taking?

Consider:

- Help staff understand that self-determination for residents is crucial 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.

✓ Educate Families

Once again, 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. For topics involving risk:

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

✓ Reduce the Risk of Lawsuits

The Assisted Living Federation of America (ALFA)[2] discusses this issue. It states that there are legal principles long upheld by the courts that may help alleviate concerns of lawsuits. Two of these are: (1) the concept of informed consent and (2) the assumption of risk.

Informed consent. A competent individual has the right to self-determination. This principle has been used most often in medical situations. Individuals have the right to make choices and do things that professionals do not recommend, even if their choices are dangerous. For instance, a patient can refuse operations and treatment against their doctor's advice.

Assumption of risk: A competent individual has the right to participate in most activities, even those that have known potential risks. If an individual participates in an activity knowing that there could be certain inherent risks, the individual is deemed to have accepted those risks.

Both of these principles assume that the resident is able to understand and express his preferences, and has been fully informed (by the residence) of the possible risks and understands them. In addition, ALFA indicates its belief that it does not think that courts will ignore the basic precepts of assisted living (autonomy, choice and independence) and equate it with nursing facilities, "ignoring the large body of research, professional literature and state regulations which acknowledge the differing philosophies of the two."

✓ Work 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 be against the resident's rights. Some work with insurers to make them understand the rights of residents. If your insurers suggest a way of protecting the 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.

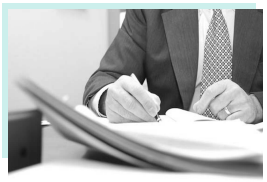
[2] See: Burgess.

✓ Communicate With Your State's Regulators

It is a good idea to communicate with your state regulators and find out how they view the value of risk-taking. If your regulations prevent your residents from taking risks, you might try to encourage changes in state policy. In addition, you may think 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.

Case

In one assisted living community, the insurer asked the residence to lock its back doors because it believed the 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. The director 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 management agreed that it was safer to leave the back doors unlocked.



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 could not have a say in any of these things – if others decided these things for you?

How Much Do the 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 help 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 meal times 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 in an Assisted Living Community?

- 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 not have had a lot of 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 that you will lose control over decision-making. Perhaps you feel that managers, not residents, should make decisions.

Strategies to Encourage Resident Participation in Their Assisted Living Community

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

✓ Develop an Effective Resident Council[3]

Ask yourself the following questions:

- Do we have a residents' council?
- What does it do?
- Does it do more than make complaints?
- Does it function in a way that encourages residents' influence and 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 the wishes of the residents known.

[3] See: Coalition of Institutionalized Aged and Disabled, "Organizing a Resident Council in Your Home," 1997.

Consider:

- Urge residents to discuss the development of a council if you do not already have one or if residents have not already gotten together to discuss 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?

Consider:

- Residents can and should have a say in the decisions that affect their lives within the residence. Resident Councils can do many things that will help the entire 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 the way their residence is run.
- Resident Councils can enrich the lives of all the residents and help to recognize the talents and skills that many residents have. For example, various 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

Case

The Resident Council in one residence is resident run and half of the residents participate. It has its own officers and they keep the minutes. They focus 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."

Case

Residents in one residence complained that they did not get any smoked salmon ("lox") that they were used to eating. Staff met with a small group of residents about this issue and explained that lox was very expensive. The residents discussed why it was important to them to have lox: it reminded them of Sunday mornings when they lived at home with their families. Both management and residents compromised and lox is now being offered once or twice a month.

Case

A residence had problems over the years keeping a beautician in their beauty parlor for longer than a few months. Management decided to ask residents to help find a new beautician for the home. A committee of six or seven residents, including one who had beginning dementia, interviewed a number of candidates and chose two or three finalists. The inclusion of the confused individual was a stroke of genius: she kept asking the same question repeatedly and it 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.

meal times, 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.

✓ Develop Ways for Individual Residents to Participate

Ask yourself the following question:

- Do I offer individual residents the opportunity to participate?

Residents bring with them the talents, skills and knowledge that they have developed over a lifetime. Each resident, regardless of age or disability, has a unique contribution to make to the residence and to the management. Residents are in a special position to recommend changes, which 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.

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.

Case

A resident council complained about not having lettuce for their salads during a time when lettuce was very expensive. Members of the council met with dietary staff and discussed 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. On 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 the price came down.

Case

A residence, looking for a new activities leader, asks the candidate to prepare a sample session for residents. The residents, a cross section of the community, are told that he is a candidate for the activities position and that management wants their impression of this person and his ability to lead and be part of the community. After the session, management meets with the residents to get their feedback. If the residents are positive, management asks the candidate to come in, chat with them and the residents. Residents ask questions; management observes the interaction and then meets with the residents again to get feedback. If the residents do not care for the candidate, management will not offer the individual the position.

Case

Another residence asked a resident, who was an artist, if she would be willing to conduct a few art classes. She was thrilled!

Case

One residence had a resident who used to run a restaurant. She often complained about the inefficiency of the dining room staff and the unappetizing food. After using this guide, rather than label her a "troublemaker," she was asked to work with the food service director to help make the dining program more efficient and more satisfying to the residents. It worked!

Case

One residence holds meetings several times a year and asks residents to vote on items that will become part of the on-going menus.

Case

Another residence, after using this guide decided to invite residents to go shopping with the head chef for food for meals and urge residents to supply recipes of meals they have enjoyed.

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, mosque or synagogue? Do you go to the store or 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 kinds of things do the 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 Might Stand 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 too 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 are important to you, so is it important for many older people. 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, following are some suggestions that may help...

✓ Make the Ability of Your Residents to Access the Outside Community a Priority

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?

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.

Case

In one residence, the activity director was concerned that no matter what outside trip she recom-mended, few residents signed up. After investigating, she figured out why so few residents were signing up for trips outside the residence such as going to the beach: they were afraid that they would have to go to the bathroom and there would be no bathrooms. She designed the trip to include a number of bathroom stops. She had few problems finding residents happy to sign up after that.

Case

One activity director says she has walked many residents down the road to the snack shop in order to help residents do what they want.

Case

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 outings everyday to churches, stores, banks, racetracks, casinos and concerts in the park.

Case

Another residence, after reading this guide, decided to significantly add to their available transportation. The van, in the past, was used only for doctor's appointments. Now the van is also used to take residents shopping.

- 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 find out what they are afraid of and find ways to deal with the 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.

Case

Staff in one residence brought together local school children and residents. Children often came to visit and the residents often went out into the community to see the children perform in school plays and were invited to graduation exercises.

Case

One residence has a relationship with the Kiwanis Club. The Club has monthly meeting luncheons. The residence sends a different resident each month who joins them for lunch and speaks a little about his lifestyle, place and thoughts. The resident always comes back feeling uplifted and involved in the outside community. Members of the Club also come in once a month and sponsor a birthday cake and help to give out cards and presents.

Case

Another community has called the houses of worship in their area and helped arrange for parishioners to come and pick up those residents who want to attend services. If this is not possible, a staff member walks the residents to services.

Case

A residence, after using this guide, decided to call local stores, such as K Mart, 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?

ALFA[4] believes that it is important to make sure that your residence is one 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 remain in the assisted living community and help them 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 attempt to give the resident what he prefers?
- Do direct care staff have access to this information and are they involved in giving the resident what he prefers?
- 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[5]

For many of the residents who are at the beginning stage of dementia, the ideas listed above will be appropriate. For others, some adjustment will need to be made. 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, their ability to make choices should be encouraged by urging and training your staff to find ways that they can do the things they want.

  For example, urge your staff to let residents wander if they want to and not to tell them to sit down. You might consider developing places where they 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 life by learning as much as they can about resident preferences for getting up, going to sleep, etc., by

[4] See: Burgess.
[5] Based on an interview with Della Frazier-Rios, Director, Education and Training, NYC Chapter Alzheimer's Assoc.

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 the resident's schedule according to his past routines. Tell them that if they set a time for personal care and find that the resident is not ready, they should leave and come back later.
- Encourage your staff to help residents maintain their identity.
- Train staff to limit any choices to two.

  For example, rather than ask the resident what she wants to eat, as staff might with the less cognitively impaired, the resident should be asked if she wants chicken or fish (choosing two types of food that she likes). Have healthful snacks available so these residents can help themselves.

- Many cognitively impaired residents can be independent if staff helps them. However, staff will need to facilitate independence by setting things up, giving reassurance and coaching.

  For example, to encourage independent eating, staff may need to actually 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 he likes the fabric. Ask if she likes the food.

Case

Some of the female Alzheimer residents still carry handbags even if they are not going anywhere. In one residence, a resident care assistant, seeing some of the women carrying heavy pocketbooks, 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."

Case

It was snowing very hard. A resident with Alzheimer's wanted to go outside. Staff asked her to wait until it stopped snowing. She refused. She said she wanted to get 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."

REMAINING IN PLACE IF ONE GROWS MORE DEPENDENT

As mentioned previously, most seniors want to remain in your community even if their health deteriorates. As you know, research indicates that when the elderly move from place to place, especially when their health is deteriorating, they may become disoriented and sicker. In addition to these concerns, there has been some discussion of how the Americans with Disabilities Act (ADA) will affect assisted living in terms of decisions to admit or retain certain individuals. In a recent article in ***Assisted Living Today*** (see related reading), a case is made that if your state has admission and retention laws or guidelines allowing you to admit and retain individuals with certain medical conditions, you may be vulnerable to a case brought by a disabled person that you are discriminating if you do not want to admit and/or retain her. Federal anti-discrimination laws may not allow a residence to self-define its fundamental character even if admitting certain individuals would create a burden – if the individual offers to pay a supplement. Below are some thoughts about trying to keep individuals with failing health safely in the community.

How Do You Feel When You Have to Move?

If you became more dependent or your health deteriorated would you want to be forced to move out of your home? And, if you moved into a residence such as the one where you work, would you want to move again if you became even more dependent?

Think about when, in your life, you had to move.

- Was moving to a new place an easy thing to do?
- What were some of the problems you encountered? Making new friends? Adjusting to a new place and new routines? Going to a new school? Finding new places to shop?

How Do You Think the Residents Feel About The Possibility of Moving?

- Think about new residents who come to the residence. What kinds of problems have they had adapting to their new home?
- If they are required to move, how do you think they feel about having to move?
- Why would they want to stay?

What Might Stand in the Way of Residents Remaining in the Same Residence If They Become More Dependent?

Most individuals would prefer to remain in the same residence even if their health deteriorates. If they have to move, they lose important social support networks like the friends they have made and staff like you, who they know and who know them. This is a real risk that residents should not have to take

if there is any way they can stay. Following are some possible obstacles to staying in the residence if residents become more dependent:

- The more independent residents (and/or their families) may object to being in an environment with residents who are becoming more dependent physically or cognitively.
- You may not want the residence to "look like a nursing home."
- You may not feel the staff can care for residents that are more dependent.
- You may feel that state regulations will not permit dependent residents to stay.

Strategies to Develop a Community Where Residents Can Remain If They Grow More Dependent

If you have found that the issues listed above are concerns in your residence, and you want to become a place where residents can remain no matter how dependent they may get, here are some possible solutions:

✓ Think About Ways to Permit a Deteriorating Resident (Who Wants to Stay) to Remain Even When You Believe He Needs Another Level of Care

Although you may find yourself with residents who present care issues that you have never dealt with before, these cases may present an opportunity to think about handling matters in a way that will meet the needs of the residents and might help you develop a capacity for dealing with higher levels of need. Of course, the freedom to care for such residents may be limited by state regulations and, possibly, additional costs.

Ask yourself the following questions:

- Do we have an inflexible rule about retention?
- Is it possible to make these rules less rigid?
- Is transferring to another level of care the only way to safely care for a resident who seems to be deteriorating?

Case

A blind resident in one residence developed diabetes and needed to check her blood sugar and give herself insulin. Because she was unable to use the standard device for checking her blood sugar or give herself insulin and the state the residence was located in would rule her ineligible for assisted living if a nurse came in, the residence felt it had to discharge her to a nursing home. It was suggested to the staff that the residence contact the Commission for the Blind. The Commission recommended the resident buy and use a device that verbally states the blood sugar count, determines the need for insulin and then beeps as the insulin is given. She did and she remained in the residence.

Consider:

- Ask yourself the following questions so you can assess whether you really must transfer the resident if you are faced with residents who seem to be deteriorating.
  - Is it a temporary situation? Would a physician be able to attend to it?
  - Is there a way to modify the service plan by bringing in other help? Can community resources be brought in to help? Can hospice services be brought in if necessary? Is there any public funding to cover this? If not, is it possible for the assisted living residence to cover it? If private pay, can the resident or family pay?
  - Can any special equipment be brought in? Is there any public funding that would cover equipment such as a hoyer lift (if state regulations allow)?

- Anticipate changes in the residents so that the assisted living residence does not "look like a nursing home."
  - Figure out ways to store equipment that may be needed, such as walkers or wheelchairs, so that they will not be in the way of residents that are more independent; make sure there is ample room in halls and elevators for maneuvering.
  - Decorate and design with resident dependency needs in mind. For example, provide a place where residents who wander can wander safely, use fabrics that are easily cleaned and have places for people to sit throughout the residence.

Case

In one residence a resident needed to be lifted by a hoyer lift. After thinking of all the possible solutions discussed above, the residence said that it would be willing to train its staff if the family was willing to rent the lift. The family agreed and the resident remained.

Scenario

One residence institutes two major initiatives: (1) programs evaluating causes of problems that usually lead to someone having to go to a nursing home; and (2) educational sessions with residents and families about the value to them of keeping residents who become more dependent. Staff is trained to keep data on the number of residents who have bowel and bladder accidents and the possible reasons for these accidents: are they caused by medications? Are they caused by anything temporary such as an infection? Can anything be done to lessen the number of falls? If a resident does become permanently incontinent, staff is trained to teach residents how to manage their incontinence. Staff meets with residents that are more independent and their families to discuss the fact that the residence is committed to keeping residents as long as possible. Advantages for them are discussed: if they become dependent, they will not have to leave. In addition, these discussions are a chance to air problems the residence must deal with as residents become more dependent.

- Develop ways to lessen any negative impact that the more dependent residents might have on the quality of life of the more independent residents.
  - Help integrate dependent residents into the residence. Be proactive. If they are perceived as an important part of the community, they gain wider acceptance. Make sure your staff knows that a cognitively impaired resident should join other residents only for appropriate activities at appropriate times of the day, so that they will not disturb others.
  - Work with both independent and dependent residents and staff to develop ways to remove the nursing home "feel" as residents grow more dependent. Use the Resident Council as a vehicle for thinking about these issues.
  - Make sure that your residence has places where residents can be quiet and alone if they want to. For example, an independent resident that does not want to eat with residents that are more dependent might like an alternative place to eat in the residence such as a small café, cafeteria or tables for two.
  - Give thought to types of activities and entertainment and where they will be located. Give thought to how roommates (if applicable) are assigned.
  - Make sure direct care staff is prepared to help deal with conflicts between independent residents and residents with cognitive or physical impairment by being ready to intervene if necessary. It may mean helping to quiet down a cognitively impaired resident; it may mean being prepared to clean up a urinary accident quickly.

- Educate more independent residents about the advantages of being able to stay if their health deteriorates.
- Identify other states that encourage remaining in place if your state's rules do not. Try to urge your state to adopt such rules.

Case

One administrator said that the way he approached the Resident Council when the residence began to consider admitting and retaining people with walkers was to say, "Thank God, I don't need a walker. If I needed a walker, would you be willing to let me stay?" He explained the planned changes in policies and asked for their feedback. He said that if he had just sent out a memo he would have had a lot of complaints. He had few complaints with the method he used.

In Maine, residents with nursing needs may remain in assisted living if certain provisions are met. Draft rules in Vermont allow exceptions that allow people with certain conditions to be served, if certain provisions are met that add a measure of safety (See: Mollica). In New York, a new law (2004) permits residents to "age in place" if the residents' needs can be safely and appropriately met at the residence.

We hope that some of these ideas will be useful and help you do what you want to do to meet the future needs of our seniors. The authors welcome any comments.

FOR FURTHER READING

"Aging and Health: Effects of the Sense of Control", Rodin. (1986). 233 Science 1271, 1272.

"A National Study of Assisted Living for the Frail Elderly: Results of a National Survey of Facilities." Catherine Hawes, M. Rose and Charles Phillips look at independence and choice. Office of Disability, Aging and Long Term Care Policy. Assistant Secretary of Planning and Evaluation, Department of Health and Human Services and the Public Policy Institute Research Group, AARP, December, 1999.

"Assisted Living and Negotiated Risk: Reconciling Protection and Autonomy." Marshall Kapp and Keren Brown Wilson explore the concept of negotiated risk by presenting hypothetical scenarios that illustrate various practical applications of this idea. This paper delves into the issue of promoting optimum health standards, while preserving personal dignity. The article can be found in the ***Journal of Ethics, Law, and Aging,*** Vol. 1, No. 1: 5-13; 1995 (Springer Publishing Company, New York).

"Assisted Living: Recent Developments and Issues for Older Consumers." Stephanie Edelstein, associate staff director of the American Bar Association's Commission on Legal Problems for the Elderly, takes a critical look at the concept of "aging in place." Published in the ***Stanford Law and Policy Review,*** Vol 9:2, Spring 1998. Copies can be obtained through Stanford University.

"Consumer Perspectives on Private Versus Shared Accommodations in Assisted Living Settings." This study (1996) strongly reaffirms the preference of consumers and their families for private apartments in assisted living. Copies can be obtained through the AARP Public Policy Institute Research Group at www.research.aarp.org.

"The Effects of Control and Predictability on the Physical and Psychological Well-Being of the Institutionalized Aged." R. Schultz. (1976). ***Journal of Personality and Social Psychology*** 33: 563-573.

"The Effects of Relocation on the Elderly": A Reply to Borup, J.H., Gallego, D.T., and Hefferman, P.G. 21. N. Bourestom and L. Pastalan (1981). ***The Gerontologist 4, 5.***

"Gray Charade." This ***Smart Money*** article encourages providers and prospective residents to take a closer look at the philosophy of "aging in place," what is promised and what is being delivered. The article can be obtained by contacting SmartMoney magazine at www.smartmoney.com. (Stires D: ***The Gray Charade.*** Smart Money: 138-145; November 1999. P.139).

"Involuntary Residents in a Nursing Home." ***Journal of Long Term Care Administration*** 19: 9-18.

"Measuring Perception of Choices in the Nursing Home." R.M. Brooke and R.A. Short (1996). ***Journal of Nursing Measurement*** 4 (2): 103.

"High Service or High Privacy Assisted Living Facilities, Their Residents and Staff: Results from a National Survey." For information about the study, you may visit the DALTCP home page at http://aspe.os.dhhs.gov or contact the ASPE Project Officer, Pamela Doty, at HHS/ASPE/DALTCP, H.H. Humphrey Building, Room 424E, 200 Independence Avenue, SW, Washington, DC 20201.

"Negotiated Risk Agreements in Assisted Living Communities: A Publication of The Assisted Living Federation of America (ALFA)." Kenneth L. Burgess, Esq. 2000.

"Opportunity or Obligation? Flexibility in States' Admission and Retention Laws May Give Consumers the Right to Demand Facility Accommodation of Medical Conditions." Eric Carlson and Karen Dyke discuss the affect of the ADA on assisted living. Originally in Assisted Living Today, June 2002, p. 37. Also available at website of National Senior Citizens Law Center, www.nsclc.org/issues_health_asstliv.htm.

"Resident-Centered Care in Assisted Living." In this study, residents reported relatively independent and autonomous lives, yet many experienced unmet health and long-term care needs and limited participation in meaningful activities or community life. Strong support was found for the hypothesis that assisted living program and site features influence resident experiences, particularly in regard to supporting independent lifestyles, minimizing avoidable care problems, and increasing community involvement. Copies available for a fee from the Haworth Document Delivery Service: 1-800-342-9678.

"Residents Leaving Assisted Living: Descriptive and Analytic Results From a National Survey." June, 2000. Charles Phillips and Catherine Hawes of Texas A&M University provide information on departures from assisted living, the reasons for departure, and those resident and facility characteristics that affected the likelihood of various resident outcomes associated with departure. This report was prepared under contracts #HHS-100-94-0024 and HHS-100-98-0013 between the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy (ASPE) and Research Triangle Institute. For additional information about the study, you may visit the DALTCP home page at http://aspe.hhs.gov/daltcp/home.shtml or contact the ASPE Project Officer, Pamela Doty, at DHHS/ASPE/DALTCP, H.H. Humphrey Building, Room 424E, 200 Independence Avenue, SW, Washington, DC 20201. Her e-mail address is: Pamela.Doty@hhs.gov.

"State Assisted Living Practices and Options: A Guide for State Policy Makers," a joint publication of NCB Development Corporation's Coming Home Program and the National Academy for State Health Policy, designed as a resource for policy makers considering new assisted living regulations or regulatory revisions. See, www.ncbdc.org.

"Therapeutic Recreation Intervention, An Ecological Perspective." R. Howe-Murphy and G. Charboneau (1987). Englewood Cliffs, Prentice-Hall.

White Paper on Assisted Living. This White Paper discusses major legal issues including contracts and risk management. Published by the National Academy of Elder Law Attorneys See, www.njelderlaw.com/library_listall_authorup.asp.

LTCCC LONG TERM CARE COMMUNITY COALITION

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THE LONG TERM CARE COMMUNITY COALITION (LTCCC) is a New York statewide coalition of consumer, professional and civic groups that work to improve the quality of care and life for residents of nursing homes and assisted living residences. LTCCC has produced a number of studies on nursing homes and assisted living and has written and distributed educational materials, including a video, for consumers and providers.

Cynthia Rudder, Ph.D., ***Executive Director***
Richard J. Mollot, Esq., ***Associate Director***
242 West 30th Street, Suite 306
212-385-0355 (T)
212-239-2801 (F)
www.ltccc.org
www.assisted-living411.org
www.nursinghome411.org

THE COALITION OF INSTITUTIONALIZED AGED AND DISABLED (CIAD) is a non-profit, consumer led organization of adult home and nursing home residents and residents' councils. CIAD provides residents with the information and skills they need to advocate for themselves, and works to improve the quality of their lives and their care. CIAD organizes residents into resident councils, educates residents about their rights, and promotes their participation in the affairs of their own residences as well as broader policy issues.

Geoff Lieberman, ***Executive Director***
425 East 25th Street
New York, NY 10010
212-481-7572 (T)
212-481-5149 (F)
www.ciadny.org

Layout and design by Pattie Stone, www.pattiedesign.com