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# Facilitating individual long-term care planning : the role of Care Choice Ohio

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# Facilitating Individual

# Long-Term Care Planning:

# The Role of Care Choice Ohio


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# Facilitating Individual Long-Term Care Planning: The Role of Care Choice Ohio

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## ACKNOWLEDGMENTS

This research was made possible through funding from the Ohio Department of Aging to the Scripps Gerontology Center, Miami University, Oxford, Ohio. Many people assisted with this project in a variety of capacities. Judith Brachman, Roland Hornbostel, Doug Beach and Sara Abbott of the Ohio Department of Aging created the opportunity for this project. A focus group held at the Ohio Department of Aging provided valuable input that shaped and refined our thinking. Thanks to participants Sara Abbott, Doug Beach, Kevin Flannigan, Roland Hornbostel, Sande Johnson, HeeSoo Kim, Beverly Laubert, Randy Leffler, Matt Ottiger, Judy Patterson, and Robert Applebaum. A number of other people around the state assisted with the planning for the focus groups and recruiting of participants. These included Shane Herlet, Janet Russ, and Linda Gillespie.

At Miami University, our appreciation goes to Dr. Robert Applebaum for his input into study methodology and his comments on earlier versions of this report. Research assistant Barbara Lingvai assisted in developing the literature review. The office staff at the Scripps Gerontology Center, Cheryl Johnson, Betty Williamson, and Thelma Carmack, provided invaluable support with focus group organization and the preparation of this report.

Staff from the PASSPORT Administrative Agencies who took time to share their experiences with the Care Choice Ohio program provided valuable insights regarding the operation of this important program. Finally, focus group participants who shared their experiences and thoughts about long-term care provided the information from which this report was developed. Without the cooperation of all of these individuals our work would not have been possible.

## EXECUTIVE SUMMARY

### Facilitating Individual Long-Term Care Planning: The Role of Care Choice Ohio

### Scripps Gerontology Center, Miami University

### BACKGROUND

The growth in our nation's older population provides a major challenge for our society. Because advanced age increases the likelihood that one will require assistance with daily tasks such as bathing or preparing a meal, those sectors involved in financing and delivering health and long-term care services are dramatically affected by this demographic change. Families and friends provide much of the long-term care needed by those experiencing a disability but a significant level of support is provided through formal services such as nursing homes and home care agencies. Medicaid expenditures on long-term care in Ohio grew to over $2.5 billion in 1995, with about three-quarters of these funds allocated to institutional care (Burwell, 1996).

Educating Ohio's citizens about how to plan for potential long-term care before a crisis occurs is one step toward reducing the growth in demand for state funded long-term care. Long-term care applicants and their caregivers need information about alternatives to nursing homes while they can still take advantage of them, that is, while community housing and informal caregivers are still in place. Once an informal caregiver has become exhausted or one's independent home has been relinquished the likelihood that one could take full advantage of home and community-based options for long-term care is reduced.

In 1995 the Ohio Department of Aging introduced a long-term care consultation service called Care Choice Ohio to assist people with long-term care planning before nursing facility

admission is needed. The Care Choice program uses nurse and social work staff at the Area Agencies on Aging to provide information about long-term care planning options to Ohio's citizens. This paper links research on long-term care planning and decision-making with the experience of Ohio's new Care Choice program. The goal of the report is to explore how Care Choice Ohio can facilitate individual long-term care planning for older Ohioans.

Researchers at the Scripps Gerontology Center, Miami University, completed a study with potential and actual long-term care consumers and Care Choice Ohio staff to answer two key questions: 1) What is the most effective way to reach potential long-term care consumers to encourage and facilitate long-term care planning? and 2) What do prospective consumers need to make a comprehensive long-term care plan?

### Study Findings

Findings from the study suggest that a variety of methods for reaching potential long-term care consumers are necessary. The focus group study with current and potential long-term care recipients identified critical questions concerning why, how, and what consumers need in order to develop a viable long-term care plan.

Study results indicated that prior to engaging in long-term care planning the consumer goes through a series of steps. A model was developed outlining seven conditions that lead to long-term care planning. These are:

- Perceived vulnerability, a sense of personal risk for long-term care dependency;
- Perceived timeliness, a sense that the risk of long-term care dependency merits attention now;
- Perception of responsibility, the sense that responsibility for one's care is, at least in part, one's own;

- Perceived control, the sense of having a choice or say about one's circumstances;

- Adequate information, sufficient knowledge about policies, program and service options, costs and eligibility requirements;

- Adequate resources, sufficient financial and/or social/environmental assets to invest in a long-term care plan; and

- Rational decision to commit resources now toward an unpredictable future.

Planning requires ongoing review and revision as policies and programs, personal values, circumstances, and resources change.

Based on the study, we identified four types of long-term care planners.

- Non-Planners, who had not moved beyond the first four conditions to engage in any related information-gathering or decision-making activity;

- Pre-Planners, who had engaged in information gathering and may also have taken an inventory of their financial and social resources to inform a decision;

- Planners, who had gathered information, taken a personal inventory of resources, and made a decision to plan; and

- Risk Choosers, who had gathered information, taken an inventory and made a rational decision not to commit resources toward a plan.

Findings from our review of the Care Choice program indicate that the strength of the Care Choice initiative involves the independent structure of the information process. Consumers reported the benefits of having an independent forum to receive critical information about long-term care options. Despite this important strength the program faces major challenges. The majority of consumers are waiting until a crisis before exploring long-term care options, thus reducing the number of Ohioans using the Care Choice option.

Educating people about their likelihood of dependency, the advantages of timely planning, the importance and advantages of personal responsibility, and the advantages of

personal control is a relatively new task for the Ohio Department of Aging. As our model shows, these conditions must be established before an individual commits to long-term care planning activity. Although past Care Choice efforts have focused on facilitating planning for those who were ready to do so, additional efforts must be devoted to encouraging others to begin thinking about the possibility of long-term care. Given the reluctance to think about long-term care reported by Care Choice staff and focus group participants, this task will be a considerable challenge for the initiative.

## BACKGROUND

The growth in our nation's older population provides a major challenge for our society. Because advanced age increases the likelihood that one will require assistance with daily tasks such as bathing or preparing a meal, those sectors involved in financing and delivering health and long-term care services are dramatically affected by this demographic change. In Ohio, the number of severely disabled persons over the age of 85, those most likely to be in need, is expected to increase by 29% to 112,000 between now and 2010 (Mehdizadeh *et al.*, 1996). Families and friends provide much of the long-term care needed by those experiencing a disability, but a great deal of support is provided through formal services such as nursing homes and home care agencies. Medicaid expenditures on long-term care in Ohio grew to over $2.5 billion in 1995, with about three-quarters of these funds allocated to institutional care (Burwell, 1996). Medicaid long-term care expenditures have increased at over 10% per year over the past 15 years and the strain of paying for long-term care now and in the future is stretching Ohio's budget. Educating Ohio's citizens about how to plan for potential long-term care is one step toward reducing the growth in demand for state funded long-term care. To address this growing concern, this paper links research on long-term care decision-making with the experience of Ohio's new Care Choice program. The goal of the report is to better understand how Care Choice can assist and support older Ohioans in long-term care planning.

In response to increasing fiscal pressures, as well as a concern for appropriate long-term care service usage, in 1993 the Ohio Legislature passed a requirement for a pre-admission review process for long-term care applicants. The legislation was based on two principles: 1) Before making a long-term care decision, consumers and their families need

information about a variety of potentially appropriate long-term care services, and 2) Before receiving Medicaid funding for long-term care, applicants must meet a certain level of disability.

In its first year of implementation, pre-admission review (PAR) was limited to Medicaid applicants. In January, 1995 implementation was expanded to include all applicants (with certain exemptions), making it a universal pre-admission review (UPAR). An evaluation of PAR, conducted by the Scripps Gerontology Center, provided some important findings about the long-term care decision making process for Medicaid applicants. "Hospital, nursing facility, and PASSPORT assessment staff members consistently agreed...that the early discussion of long-term care alternatives was most effective at influencing a family or applicant's decision-making" (Applebaum et al. 1995, 61). Long-term care applicants and their caregivers need information about alternatives to nursing homes while they can still take advantage of them, that is, while community housing and informal caregivers are still in place. Once an informal caregiver has become exhausted or one's independent home has been relinquished the likelihood that one could take full advantage of home and community-based options for long-term care services is limited.

These findings raised important questions for the success of Universal Pre-Admission Review. When is the appropriate time for discussion of long-term care alternatives? What kind of intervention helps with the long-term care decision-making process? In 1995 the Ohio Department of Aging introduced a long-term care consultation service called Care Choice Ohio to supplement the required Universal Pre-Admission Review. Its purpose was to provide an

earlier intervention to assist people with long-term care planning before a nursing facility admission was requested.

## REPORT OVERVIEW

This report examines consumer understanding and decision-making in long-term care from several perspectives. First, a review of the literature on long-term care decision-making provides information about how decisions are made in this complex process. Second, a qualitative focus group study provides information about those who protect themselves against long-term care needs by exploring options and planning for them, as well as those who are unprotected against such needs. We present a model of long-term care planning, explore the planning behaviors people engage in, and provide some reasons for people's failure to plan while others achieve a comprehensive plan for their future long-term care needs.

In the second section of this report we discuss the Ohio Department of Aging's programmatic response to advance long-term care planning: Care Choice Ohio (CCO). Written materials about the program from the Ohio Department of Aging and qualitative telephone interviews with Care Choice staff around the state inform this discussion. We look at the administration of Care Choice Ohio, the types of clients served, the program successes and barriers to effective implementation. Information from focus groups regarding the desirability and usefulness of Care Choice Ohio is also presented. The report concludes with an analysis for long-term care policy based on our review of the literature, the focus group study, and the interviews with Care Choice Ohio staff.

## LITERATURE REVIEW

In preparation for our work, we examined the existing research on long-term care decision-making. A wide array of literature contributes to our understanding of the long-term-care decision process. Most of this literature, however, focuses on crisis decision making, for example, nursing home placement decisions upon hospital discharge. Less has been written about pre-crisis planning. Related articles in financial planning and popular senior publications are directed toward the protection of individual financial assets in the face of increasing costs of long-term care (Bergstrom & McLaughlin, 1991; Budish, 1994; Merline, 1996; Novack, 1995; Smith, 1992).

The National Health Expenditures Survey indicates that about 2% of nursing home costs nationwide are covered by private health insurance. According to Pauly (1990), that number is not likely to increase significantly. Pauly concludes that the failure of older people to buy coverage "against high-loss, low probability events" such as long-term-care dependency is a common but paradoxical pattern in the insurance market. Pauly argues that *rational* insurance purchasing is characterized by coverage for high-probability, low-loss care such as that covered by MediGap insurance.

Why is it that older adults fail to plan for high-loss events? In the area of long-term care insurance, recent research has focused on affordability and demand. Affordability is a function of price and the financial capacity (income/assets) of consumers to purchase long-term care insurance. Willingness of consumers to invest is not determined by affordability alone. Demand is somewhat more complex and may be negatively influenced by attitudes toward insurance, ambiguous messages about the availability and reliability of public support, and

lack of familiarity with the relatively new concept and product of long-term care insurance (Cohen, M.A., Kumar, N. & Wallack, S., 1993; Rivlin, A. & Weiner, J., 1988). Studies designed to identify the potential size of the long-term care insurance market used varying criteria or thresholds for "affordability" and the resulting range of estimates is wide: Rivlin & Weiner (1988) estimate that 10-21% of individuals 67+ could afford to purchase insurance; Cohen *et al.* (1991) estimate that 50% of the 65-74 age group but only 10% of those 85+ could afford policies; all other findings range somewhere between the more conservative Rivlin and Weiner estimates and the more optimistic Cohen *et al.* (1991) estimates (Ball, R. & Bethell, T., 1989; Friedland, R., 1990; Meiners, M., 1983; Zedlewski, S. & McBride, 1992).

In an article exploring women's perceptions about long-term-care planning, Rosenthal and Morith suggest that women "resist thinking about their own long-term-care needs" (1993, p. 67) because 1) there is a reluctance to confront the physical realities of aging; 2) "fears of dependence" impede further thought; and, 3) especially for the cohort over age 55, women are less comfortable or experienced with financial matters. Although limited to women, this article represents a first step in examining the "psychology" of thinking about the possibility of late-life dependency.

Considerable work has been done to explore social norms and values about responsibility for long-term care: public vs. private responsibility and intra-family responsibility. Mixed messages about responsibility for long-term care abound. Although government has assumed responsibility for the major burden of health care for the older population through Medicare, the program's role in providing for long-term care is significantly limited. Medicaid, the other major public provider for health care, assumes an

enormous long-term care burden, but its role was designed for those with low income, requiring one to "spend down" assets before becoming eligible. The American Association of Retired Persons (1988) reported that nearly four-fifths of its members believe that Medicare covers long-term nursing home stays. Finally, unclear social norms about filial (child-to-parent) obligation to provide or finance care add to the ambiguous context of planning considerations (Brody, 1990).

Clark (1987) argues that personal planning can be encouraged, and that issues of personal autonomy and empowerment are at the heart of the challenge. Clark suggests that long-term-care planning is a "natural extension" of the national shift in health care policy toward more individual responsibility for health and health care decisions.

The need for public education and increased access to information has been proposed as essential to stepping up individual planning activity. A recent awareness survey, conducted by the Harvard School of Public Health, found that respondents knew of few options for long-term care other than nursing homes and home health care. Furthermore, those aware of the nursing home option were not up-to-date about recent trends in nursing home care toward rehabilitation and shorter stays. Misconceptions about continuing care retirement communities, assisted living, and congregate housing were also common (Fisher, 1995).

Recent literature about long-term-care planning suggests a broad range of obstacles and issues, from the reluctance of people to consider their own risk of dependency to the ambiguous messages about family, self, and governmental responsibility, to the lack of information required for informed planning. These areas of interest are among those included in the focus group study of long-term-care planning.

# FOCUS GROUP STUDY ON LONG-TERM CARE PLANNING

To gain a better understanding of how older Ohioans plan for their long-term care needs, a focus group study was conducted. The emphasis of the study was on the long-term care planning process and factors that contribute to planning and non-planning. Focus group interviews were designed to explore values, knowledge and circumstances that drive planning or non-planning, as well as to identify key actors in the planning process. Findings led to the development of a model that attempts to identify conditions essential to the pursuit of long-term care planning. The focus group study was designed to address the following specific questions: 1) What is the most effective way to reach prospective consumers to encourage and facilitate long-term care planning? and 2) What do prospective consumers need to make a comprehensive long-term care plan?

## STUDY APPROACH

The focus group is a tool designed to elicit group interaction around a set of questions or areas of interest. Participants are encouraged to share their individual stories, experiences, and ideas, and to respond to those of others. Although the groups examine specific areas of interest, other relevant issues may also emerge.

Participants were recruited for five focus groups across the state (Columbus, Mansfield, Cleveland, Central Ohio, and Maumee), with a total of forty-three participants.

*The Insured* (10 participants) were older adults who had engaged in financial planning such as purchasing long-term care insurance, reserving sufficient financial assets for potential long-term care expenses (self-insurance), or moving into a continuing care retirement community (CCRC) which provides a range of living options from independent living through skilled nursing care.

*CCO Clients* (8 participants) had each received a Care Choice Ohio consultation.

*Nursing Home Residents* (6 participants) had moved into a nursing home without having engaged in any significant pre-admission planning behaviors.

*Mixed group* (9 participants) were older adults recruited with a criterion of exclusion: none had purchased long-term care insurance, were self-insured, or had moved into a CCRC. These participants represented a range of planning behaviors, from none to limited long-term care planning, such as housing changes.

*Adult Children* (10 participants) were adult children of older adults receiving some form of long-term care services or at risk of needing long-term care services due to extreme age. In the exploration of planning attitudes and behaviors, these adult children were treated in this study as older adults themselves (average age 59), as well as proxies for their parents.

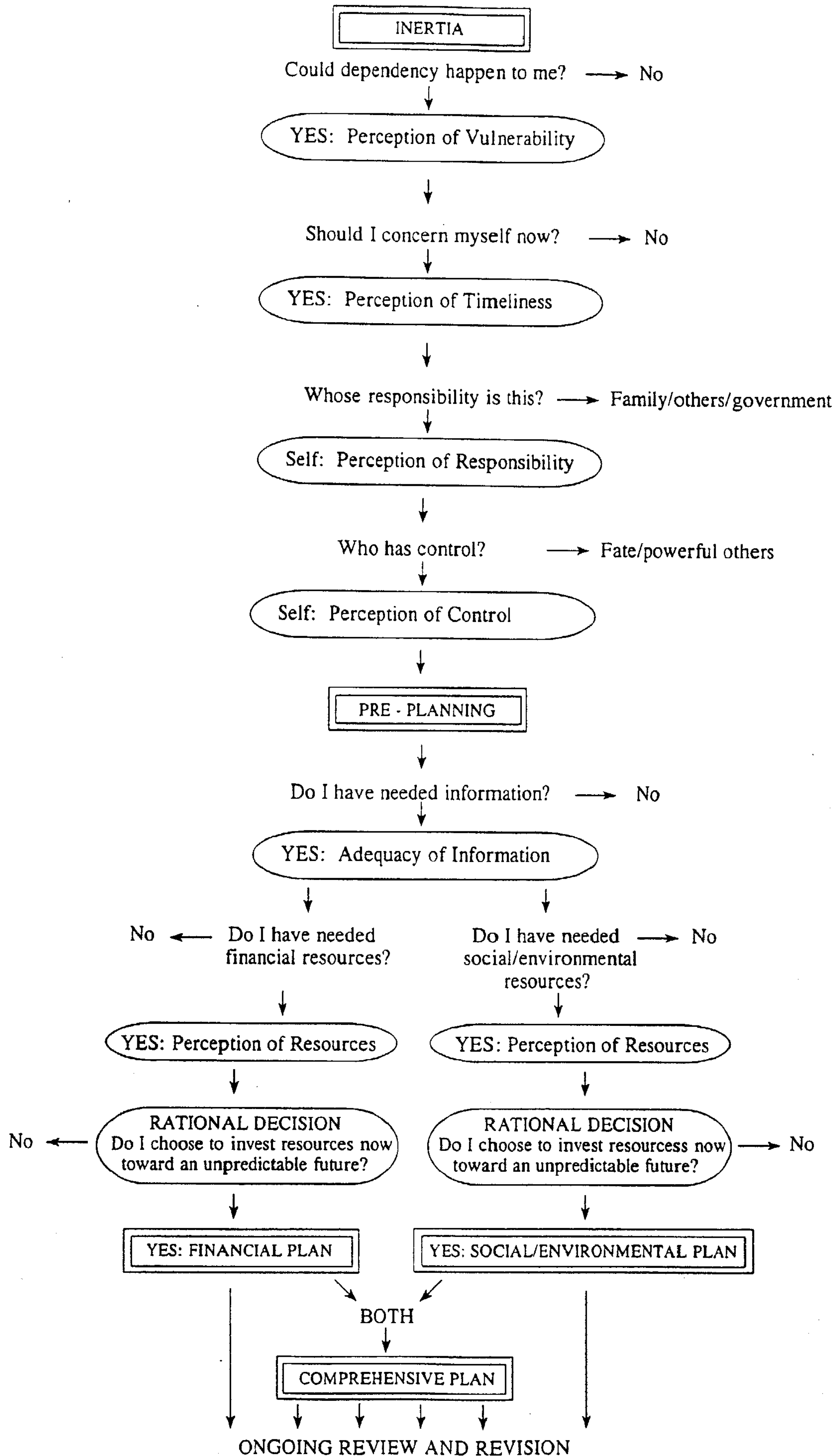
(See the Appendix for a description of the characteristics of group participants.)

## FOCUS GROUP RESULTS

What do people think about long-term care planning? From our focus groups, it became clear that pre-crisis planning for long-term care will occur only when a set of conditions is fully met. The conditions are necessary to move people from a state of inertia regarding long-term care, to the activities of pre-planning, to a planning decision or strategy. The conditions are: Perception of Vulnerability, Perception of Timeliness, Perception of Responsibility, Perception of Control, Adequacy of Information, Perception of Resources, and Rational Decision. A model identifying the conditions and their relationship is found in Figure 1. The order of the conditions can be regarded as a path to long-term care planning; if any one of the conditions is not met along this path, the individual is unlikely to engage in long-term care planning.

The first condition is the Perception of Vulnerability or a sense that the issue of long-term care needs is potentially, personally relevant. *Could this happen to me?* The second condition is Perception of Timeliness, or the conclusion that personal vulnerability to

FIGURE 1 PATH TO LONG-TERM CARE PLANNING



future long-term care needs is an issue now. *Should I concern myself yet?* Third, Perception of Responsibility is the value that the burden of responsibility for future care is, at least in part, one's own. *Is this up to me?* Fourth, Perception of Control is the belief that assuming responsibility for long-term care is within one's own control, not within the control of fate or powerful others. *Do I have a choice about this?*

A positive response to the first four questions leads to the Pre-Planning phase, characterized by information gathering, inventory taking, and ultimately, decision making. The fifth condition, Adequacy of Information, is characterized by having enough accurate information about options, policies, programs, costs and eligibility requirements to make informed decisions. *Do I know what I need to know?* Sixth, Perception of Resources, is the sense that, given one's understanding of the options, programs and eligibility requirements, one has sufficient material or social resources to commit to a long-term care plan. *Do I have what I need to have?*

The seventh and final condition, Rational Decision, is the calculated choice one makes to invest time and resources now toward an unpredictable future. The significance of the seventh condition is that even when all preceding conditions are met, individuals may make the decision not to commit to a plan and therefore to risk facing the need for long-term care without a plan in place. *Do I choose to plan or do I choose to risk?* An individual who chooses to plan may commit to a financial plan, a social/environmental plan, or, optimally, a comprehensive plan combining financial and other planning.

The "end" of the path to long-term care planning is not a fixed place: the plan (or the risk) requires ongoing review and may require revision. Policies, programs and eligibility

requirements change, as do informal support systems. Individual health status and personal resources change as well. These changes necessitate a continual process of information gathering and inventory taking and may result in altered perspectives about planning and risk-taking, and thus a modified plan.

**Planner Types**

Related to the seven conditions for planning, four broad types of planners emerged from this study: Non-Planners, Pre-Planners, Planners, and Risk Choosers. Non-Planners are still in a state of inertia or have not moved beyond the first four conditions. All Nursing Home Residents were Non-Planners and Non-Planners were found in the Mixed group and the Adult Children group as well. Participants who *have* met the first four criteria and are in the phase of information gathering and inventory taking are called Pre-Planners. All Care Choice Ohio clients are Pre-Planners as well as some members of the Mixed group and the Adult Children's group. Participants whose pre-planning activities have led to a rational decision to plan are called Planners. All of the Insured group were Planners as well as a few members of the Mixed group and some of the parents of Adult Children. Participants whose pre-planning activities have resulted in a decision not to take action are called Risk Choosers. Risk Choosers were found in the Mixed group.

**Areas of Planning**

**Financial Planning** Financial planners have engaged in long-term care planning by committing financial resources toward potential long-term care dependency. This includes the purchase of long-term care insurance, reserving sufficient assets for potential long-term care expenses (self-insurance), or moving into a continuing care retirement community (CCRC). Such planning requires financial resources beyond the capacity of many individuals.

Social/Environmental Planning A social/environmental plan includes changing or adapting housing; changing living arrangements; shoring up informal support systems; preparing for crises with good information about options and services; and clear communication, including legal agreements, about health care preferences and wishes. This type of plan does not provide complete protection against the need for nursing home care or intensive home care and is regarded as a limited plan.

Comprehensive Planning A combination of financial and social/environmental planning contributes to a comprehensive plan that provides maximum protection against the consequences of long-term care dependency. An effective comprehensive plan must be supported by sufficient material and social resources for its implementation. While the perception of sufficient resources is necessary to *initiate* planning, sufficient *actual* resources are required to operationalize and sustain the plan.

Decisions about long-term care are seldom made in isolation. Discussions and/or negotiations between husband and wife or with adult children are evident in every stage along the planning path. The role of adult children in the planning and provision of long-term care is significant. This role was further explored in the focus group of Adult Children, and the influence of adult children was apparent in each of the conditions necessary for long-term care planning.

In order to promote and facilitate planning through policies and programs such as Care Choice Ohio, we must understand the perceptions, needs, and experiences that encourage or discourage planning. What makes a Planner? A Non-Planner? A Risk Chooser? As will be demonstrated in the following discussion, there was much variability among focus group participants in perceptions and behaviors regarding planning for long-term care. Non-Planners, Pre-Planners, Planners, and Risk Choosers reflected both shared and different values and experiences in confronting the conditions along the planning path.

## Moving away from Inertia

**<u>Perception of vulnerability</u>** *Could dependency happen to me?*

Perceiving that one might need long-term care is necessary to begin planning. Without a perception of personal relevance, ideas and information about long-term care---even scare tactics---are regarded, if attended to at all, as stories about *others*. Although not all focus group participants demonstrated a sense of vulnerability to long-term care *dependency*, nearly all acknowledged their own *mortality*. Indeed, when it came to planning behaviors, the majority of participants in all groups, with the exception of nursing home residents, described detailed plans for burials and cremations. Many had purchased cemetery lots, caskets, and headstones already engraved with their names. A few had written their own obituaries. Several participants joked that they had planned everything for their deaths but the dates.

In contrast to this acknowledgement of mortality, several Non-Planners expressed "never thinking" about the possibility that they might be vulnerable to dependency in late life. This is particularly true for the nursing home residents whose need for long-term care took them by surprise.

> *"When I retired, I didn't think I'd end up in a place like this, because I had money, I had everything I needed. Everything just dropped out of the bottom and I had no choice".... "I never thought of different places or ideas to go to. I never thought of it before I came here".... "I never gave it a thought. I didn't think of getting this old".... "I didn't think anything. I didn't anticipate".... "I never thought that I'd see the day that I'd live in a place like this".... "I never thought I'd be in a nursing home. Never. Then all of a sudden, the tables turned upside down."*

The good health, active lifestyles, and histories of family longevity of some of the Non-Planners appear to contribute to a sense of invulnerability to dependency, or a rationale for postponing thinking about it.

*I think when you are in good health and can do like you have done for years, I don't think you think about long-term care. You mow the lawn, you do a garden, and do lots of canning and freezing and all these things....you don't think about that! You don't have time!*

For others, surviving a health crisis appeared to contribute to a special sense of strength. And, for some, good health behaviors are perceived as a way of staving off a crisis. *I try to stay busy. I think that's good health insurance.*

Many Non-Planners told stories of the experiences of vulnerable others without translating these stories into warnings of personal vulnerability. One nursing home resident whose own husband had been cared for in the very nursing home in which she now resided, did not consider the same possibility for herself, saying, *I never thought about it. It never occurred to me.*

It is clear that there are many factors that contribute to a failure to see oneself as vulnerable; without such a sense an individual will remain a Non-Planner. Planners and Pre-Planners, in contrast, demonstrated a variety of factors that contributed to their sense of personal vulnerability. A clear sense of vulnerability may require an age consciousness developed from body cues, changes in health, or the experiences of others.

*As you know, I'm old. I do live alone. I own my own home, but I realize that'll come to a screaming cease one of these days. So far I've been able to handle it, but I'm interested in what's going to happen in the future, and what's going to happen to my little addled brain, you never know what's going to happen up there, whether or not you're going to be capable of making decisions for yourself.*

*Very early in our married life, we took care of [my wife's] parents...they lived with us until they passed away, so that was an impetus for us to plan, and then I saw my mother who was very well off, and everything that she had disappeared through nursing home costs.*

While family longevity, for Non-Planners, may serve as a reason to anticipate or hope for a healthy future, for Planners such a history triggers a recognition that long life may bring problems.

*My mother died when she was 46, my father at 70. So, all through my forties and fifties I figured I wouldn't live to be very old....but then my older brother had his eightieth birthday and I thought I might make it to 90! I might just get to be 90 and I'd better start doing something about it.*

Those who do not consider the possibility of dependency or who feel invulnerable to it remain in their state of inertia regarding long-term care planning. Those who ask the question, Am I vulnerable to dependency? may also ask, What are the potential consequences to me of long-term care dependency? What are the costs to my family, my assets, and my future autonomy? It is these costs that will be weighed and calculated in the seventh and final step (Rational Decision) on the path toward long-term care planning. Pondering potential costs at the first and second stages, Perception of Vulnerability and of Timeliness, is more a matter of imagination than calculation. Even so, imagining the impact of dependency may have an effect on the outcome of the second stage, Perception of Timeliness.

**Perception of timeliness** *Should I concern myself yet?*

Even when people have a sense of personal vulnerability to long-term- care dependency, it does not follow that they will engage in pre-planning behaviors. This requires a perception that active thinking about the future is appropriate and called for, *now*. It is clear that there is no age determinant of timeliness. The oldest participant in the study, nearly 85 years old, had recently decided it was time to "plan ahead". In contrast, one of the younger participants, age 66, had already purchased long-term care insurance. Many had a sense that a

time for serious thinking would come, but were vague about when that might happen. *"It's too far down the road for me. I don't even think about it."; "[It seems] all in the distance....and I'm very much a NOW person, not a future person."*

One Non-Planner argued that the possibility of a change in perspective by the time he needed care would render any decisions made today unreliable. Unable to anticipate his future circumstances, he felt unready to commit to pre-planning today:

*Well, I'm 68 and, uh, today I can hook up my 6,000 pound travel trailer and haul it across the country, I feel real proud of the fact....We travel, I bowl, I use all kinds of power tools....Uh, maybe ten years from now I won't be able to do that. My thinking then will be entirely different from what it is now, I know. I could talk about [long-term care], but my feelings now would not necessarily be the same as they would be when I needed it. My attitude would be entirely different when I'm no longer able to do all this.*

Adult children can reinforce a state of inertia by their reluctance or refusal to engage in discussions about their parents' vulnerability or mortality. Some participants were given messages by children that such concerns were premature.

*[My children] will say, "Oh, let's don't talk about that, we'll talk about it another time." Well, we'll talk about it later, but never actually saying what they're gonna do if we're incapacitated.*

Parents can be equally reluctant, however, as described by one adult daughter:

*My mother refuses to talk about these things. She assumes I know what she wants.....It's just like, she doesn't want to see the end result. I'd like to discuss what she would like, but she will not discuss it.....She puts an end to the subject.*

Some Non-Planners were able to identify circumstances that would cue them to begin thinking about a long-term care plan.

*I think you probably start thinking about it when your health is changing, not even necessarily a crisis, just the realization that you are getting pretty old....that time is fleeting. I don't feel we're there yet.*

*If you're in fairly good health you don't think about it. You adjust your life...as things come up. When the time comes that one is incapacitated, then you'll do something. I guess I don't look too far ahead.*

What triggers a sense in Pre-Planners or Planners, even Risk Choosers, that the risk of dependency merits attention now? In contrast to those who were discouraged from thinking about planning, others were provoked or pressured by family or friends to regard thinking about long-term care as timely. As one Planner's friend said, *"Do it now!"*

*Our family doctor made a suggestion years ago when we were younger and active, and he said, "Sometime when you get the family together for a joyful occasion, why don't you say, 'What do you think would be a good idea for our future?" And I think it was a good suggestion. We did it.*

Several Planners or Pre-Planners mentioned the value of planning now, while they "still had [their] sanity". Some are motivated to think about planning now by current conditions they understand may become worse, requiring long-term care. For these people, fears of financial devastation and dependency on Medicaid are compelling. This may create a sense of timeliness, if not urgency.

*I have a spouse who has been ill for twenty-one years. How much am I going to lose? Am I going to lose my house....? It's a very terrifying emotional thing to live with every minute of every hour of every day.*

Some Planners had witnessed examples of the value of planning now and/or of the consequences of waiting until it was "too late".

*We have seen what other couples have together, moving in [to a CCRC] before that point when they are on their last legs, and that is really very inspirational.....We've talked about it, and we'll [make the move] sooner than we really would like to, to avoid leaving when it's necessary, or not our choice.*

For one participant, a Planner who had self-insured for a long-term care contingency, planning "started fifty years ago."

*My earliest understanding about money came during the worst of the Depression. Every time I had a dime in my pocket, my first thought was, put it away, you may need it, and I've lived that premise. So, I've always tried to provide ahead for what I would need at a later date. So I've covered my tracks before I ever get to the point where I seriously need it.....I don't think you can start too young.*

**Perception of responsibility** *Whose responsibility is this?*

Having met the conditions of perceived vulnerability and timeliness, an individual will continue to move toward the Pre-Planning phase only if he or she feels that the responsibility for care and related planning is, at least in part, one's own. The two major providers of long-term care for disabled older adults are family and government, with family providing the overwhelming proportion of care.

***Family responsibility***

When individuals believe that the responsibility for their care rests with family, they are unlikely to take personal responsibility for developing an alternate plan. One Non-Planner delegated responsibility to his family, acquiescing to the major decision of nursing home placement: *I didn't request [being here]. I turned everything over to my kid and it's in his hands. They are in charge of everything for the simple reason I thought they were the proper ones to do it.*

Another Non-Planner expressed strong sentiments that long-term care is a family responsibility and that she believed she could rely on it.

*My great-grandmothers, both of them lived with us and it was wonderful. And I think children should take care of their parents and that the parents should feel welcome. I just think it's something that should be done if at all possible. I think I would be welcome [in my son's home]. I don't think it'd be a problem.*

With few exceptions, however, Non-Planners, Pre-Planners, Planners, and Risk Choosers alike fervently expressed a wish not to burden their children with responsibility for their care.

*The lifestyles of adult children now are so busy that they can't do it anymore, they are scattered all over and a lot of them are working, and they have their own problems, and I would never want to do that to them.*

*It's cutting a lot out of their lives, you know...that's a lot of hardship, when you depend on your kids, I mean it's not fair to them, it really is not.*

One participant described a "real covenant" in her family that parents not burden their children.

*In our family...it's very historical, every generation...we do not say that we will ever live with our children. There's probably been a history in our family of bad experiences where my mother and other people in the family have experienced and saw how bad it was for the family.*

While most participants in this study vehemently expressed a belief that long-term care should not be the burden of adult children, many of the adult child participants argued that there was an expectation of care from children. The adult children shared a perception of filial responsibility for assuming at least some of the burden for long-term care. The range of this perceived burden is variable, however. One adult daughter described her role as a listener. *My role with my mother was to listen to her decide [about moving to a CCRC], and it took her five years to decide.* This mother asked little more of her daughter. *It wasn't as though I could be helpful with the decision. She really didn't want me to help her to decide...she just wanted me to listen.* At the other end of the responsibility continuum, one daughter described her assumption of full responsibility for her mother's welfare. *Finally I said, You're coming home with me. She didn't put up a fight.*

At least one participant expressed that children could not be relied upon to be responsible for long-term care. *Your kids may be tremendous today, but you don't know what they're going to be like two days from now.*

Some participants had no family and others had no reliable family. This reduced the possibilities for assumption of burden to self and government. It was evident that these people felt personally responsible at least by default. *I have no one to look after me. I have no people. My people are all gone. I don't depend on nobody but myself.*

***Government responsibility***

Few participants alluded to the responsibility of government to provide care through Medicaid or other public support. Those who did regarded such support as earned through a personal history of hard work and tax paying. One nursing home resident remarked: *I am on Medicare or Medicaid or something. I worked all the time to get it. I've worked ever since I was big enough to work.*

Another Non-Planner expressed a belief that Medicaid would provide for her and her husband's care. Her attitude toward Medicaid, and toward nursing homes, was clearly less negative than that of most participants. In response to a question about how she anticipated long-term care would be paid for, she responded:

> *Medicaid. I mean, when your money's gone it's gone and you're on Medicaid. My husband and I do think about it and talk about it, and ... I hope by the time we need it, it won't matter whether our money's all gone and we're on Medicaid or what. I wouldn't have to be mentally gone. I think you can get fairly good care in the right nursing home on Medicaid, the same custodial care that you would if you were paying for it.*

In contrast, a Planner lamented the effect of recent social policies on the erosion of personal and family responsibility for long-term care:

*Over the period of the last twenty years, something happened in the family that now there is something in the state law that the state is supposed to handle this problem and this responsibility for our families. I just kind of feel at a loss. When did this take place? You could squander, you could overbuy, you could do a lot of things that you didn't do just to protect yourself from a situation that would be demanding on somebody else. But, in the age past, you kept those resources within the family so that you could cover for yourself.*

For the most part, participants expressed a perception of shared responsibility. While they assumed responsibility for their own care, they anticipated some support from family and their fair share of earned support from government.

**Perception of control** *Who has control?*

Even when individuals have a value of personal responsibility for their own welfare, they may feel powerless to influence their own circumstances and make their own choices. According to locus of control theory, individuals with an internal locus of control perceive events to be controllable by themselves; those with an external locus of control perceive events to be in the hands of fate or in the control of powerful others, such as family members, doctors, etc. (Levenson, 1974). The latter are unlikely to plan for an event that they see as being in someone else's hands. Those with an internal locus of control feel empowered to gather information and participate in other pre-planning activities that will facilitate their personal objectives. They have a sense of power to shape the plan.

The nursing home residents demonstrated the most striking examples of external locus of control. This clearly contributed to their status as Non-Planners. Most of these participants clearly indicated the powerful force of family or professionals in their long-term care decisions, particularly at a time of crisis. It is perhaps the crises themselves that rendered these individuals "powerless", at least in their perceptions of themselves in their situations.

*"My son...had me to come here. There wasn't much talk".*

*"They put me in this nursing home. [Who?] My doctor. I don't want to be pushed".*

*"I don't know how I got here. My son is the one who takes care of the business".*

For some Non-Planners loss of control is expected along with dependency. *Any choices or decisions I have to make for myself. That's the way I want it. Of course, if I get so that I can't make decisions, then they'll have to do the best they can.*

Adult children participants provided helpful insights into their role in these issues. Their involvement in their parents' long-term-care decisions illustrates the potential for ambiguity and confusion: Whose decision is this? Whose objectives are these? Three participants had parents living in CCRCs, and had been relatively passive in any discussions while the CCRC decision was made. These children appeared especially deferential to their parents' wishes and decisions and expressed full support of them. In other cases, however, the reluctance to discuss issues and/or the confusion of responsibility with control appeared to impede progress toward long-term-care planning. Clearly linked to issues of filial responsibility are issues of control. Adult children who take some of the responsibility for their parents' care may become "powerful others" in their parents' perception of control. And, adult children with the best of intentions may reluctantly assume or readily embrace control. In most cases, the children assume control when the parents are perceived as dependent on others for care or decisions about care. A shift in control is most likely to occur in the midst or aftermath of a crisis.

*It was our decision because of her despondency. She was losing weight and talking about wanting to die. [If I had not intervened] she would not have received any of the services.*

*I brought my dad home from the nursing home after he broke his hip. I made him come home.*

The adult children's assumption of control is reflected in the language "let her" go home, "made him" come home, "took her" to day care, "got him" to go, "I started" the services, "I got" some services, etc. It is defended in many cases by the belief that the parent's decision-making capacity is somehow impaired.

*When it comes to judgement.... she wouldn't have the slightest idea what she was even looking at! I mean, I think I always feel like as our parents get older, we become the parents and they become the children. I mean, when they really get up in years, they really become dependent on our input.*

One daughter described the manner in which she and her sister guide their mother's decisions. She said, "*We sort of lead her in a certain direction but we let her think she is still in the lead.*" While allowing her mother the illusion of control, this daughter was still able to achieve a particular outcome along her mother's planning path.

In contrast, many Pre-Planners and Planners were working to preserve future autonomy by struggling for control now. Many participants articulated a need for control and their efforts to maintain it. *I don't want someone else to have to do this for me if I can do it for myself.*

One participant asserted that, while loss of control may occur someday, it is important to delegate future, substituted control for that eventuality. This she described as a planning behavior. *I think you need to talk with one of your children, or with your child, so that they know what's going on, and maybe have a power of attorney so that when the time comes they can carry right on....*

One Planner suggested that control of one's own circumstances is a luxury enjoyed by a privileged few. Speaking for herself and her fellow Planners, she said:

> *I think we probably have all grown up in circumstances where...there are resources for us that keep our minds going in some sort of direction instead of just saying, "Well, somebody's going to take care of me, I don't know who." Others are too busy on their day-to-day sustenance to be able to plan for the future. I think we're privileged to be in that part of society that can take time to protect our assets, our future....I don't think we're typical.*

**Pre-Planning Phase**

Years of thinking, in the form of wondering, imagining, and musing about issues of vulnerability, responsibility, and control, may pass before a person enters the pre-planning phase of information gathering about options and takes an inventory of personal resources. Information gathered in this phase is added to, or used to modify, knowledge already accumulated through everyday sources and experiences. Obviously, not all participants had reached the Pre-Planning phase; however, all participants possessed some level of information about long-term care, whether or not they had engaged in the active pursuit of it. Therefore, even those who had not met the first condition of perception of vulnerability, or those for whom thinking about long-term care was not timely, or those for whom decisions were perceived to be out of their control, had *some* information, however adequate or accurate, about long-term care. Therefore, even Non-Planners contributed to our understanding of the quality and level of information among the forty-three participants.

**Adequacy of information** *Do I have the needed information?*

For informed planning decisions, individuals need adequate accurate knowledge of policies, programs, options (including local services), costs, and eligibility requirements. In addition, being armed with information about the course and prognoses of their already

existing illnesses or conditions enables individuals to better anticipate future needs. Participants in this study who were in the Pre-Planning phase or beyond shared numerous accounts of information-seeking activity.

*Accuracy of information*

Although many participants were armed with accurate information about such things as nursing home costs and the limits of Medicaid, some participants appeared to fill information gaps with assumptions that were sometimes accurate, sometimes erroneous. *I think Social Security pays the whole thing (nursing home care).*

*We have always said that if we are ever sick, we'll take care of the sick person at home and have a nurse come in. We've known of that in two cases, where the Hospice nurse comes in, and I haven't checked, but I think it would be a lot cheaper than going to a nursing home.* [Another group member: *"It has to be terminal."] Oh, it has to be terminal? Oh. Well, anyway, that's what we've said.*

Some information was infused with rumor. In the following case, the rumored shortcomings of in-home care led to the conclusion that it was an undesirable option.

*You could live in your place and have help come in and help you. But they don't always show up. They don't wanna come at night. They don't want to work holidays or Saturdays or Sundays.*

Long-term care insurance has only recently achieved a relatively high profile and there was wide variability among participants in their related knowledge. Many participants demonstrated limited information about long-term care insurance and readily admitted the insufficiency of their knowledge in this area. Some were overwhelmed by the "fine print" and uncertain about costs and criteria for participation.

*Well, the qualifying conditions of some of these policies that I read, you had to have certain things in order to qualify. If you didn't have all or most of them, you would be ineligible. I haven't clarified that lately. I think they are obstacles.*

*Sources of information*

Several participants, both Planners and Non-Planners, revealed missing information through their questions or through statements to others in the group. Some participants acknowledged this absence of information; others, however, were unaware of the existence of the information at all. In one Non-Planner's words, information was received *"Catch as catch can"...We're not aware of what's available. No one explained it to us. No one offered information pertaining to it.*

Several Pre-Planners described the sometimes frustrating experience of information seeking, portraying themselves as floundering, without direction or guidance. Until they made their Care Choice Ohio contact, there was no clear sense among these participants that a source of information was available to them. *I did not know these [long-term care] organizations. I had never heard of them. Because I had been fishing, fishing, fishing....nobody knew anything...you know, about these things.*

Adult children, assuming responsibility and control for their parents' welfare, were frequently engaged in information seeking and gathering, mostly in response to an immediate need. Their long-term-care-related activities suggested a system of crisis management, with only minimal crisis anticipation and prevention. Therefore, the adult children were seldom instruments of the development of a long-term care plan but were important sources of information and linkages to services.

The Planners appeared to have had particular success or fortune in information gathering. For some, this was serendipitous, for others, deliberate.

*There was quite a layout in the newspaper, where they listed all the different insurance companies and all the goods and bads. It was quite a super list of options.*

One Pre-Planner credited her living in the capital city with enhancing her access to information, and another aggressively pursued information through the mail:

*I live in Columbus and I consider myself very fortunate...that they put out a lot of literature quickly on what's new. And I read as much as possible to keep current.*

*I sent to AARP. They have very good information and ...the Department of Aging puts out a book they call the Senior Handbook, but they list all kinds of resources. That would be another area I would turn to if I were looking for resources.*

***Trustworthiness of information***

Even when information is understood, it may not be trusted. Several participants expressed concern about being able to trust the sources of information available to them. For many, conflicting messages rendered all information untrustworthy and an impediment to planning, as suggested by this Pre-Planner:

*Another thing is all this information you get through the mail from insurances and you wonder, can you trust the company? And you see the advertisements on TV, these older actors saying well they rely on it...but how can you be sure? They're paying them [to say that]. Sure he endorses it because he gets money for it, but how about us that have to be relying on the money coming back to us?*

Finally, one participant, a Non-Planner, suggested that information is adequate only as long as it is current, and that what we understand about policies and programs today may be irrelevant tomorrow, given the changing tide of sentiment toward public entitlements and private responsibility. She summed it up simply: "*How sure* are *we of Medicaid?*" Another group member replied, "*We can't be confident of anything.*"

*Costs and eligibility*

Very much on the minds of most participants was the financial cost of long-term care. For some participants, it appeared that a perception of the high costs of care inhibited their sense of control, thereby discouraging further thinking toward planning. With descriptors such as "prohibitive" or "ridiculous", they abandoned any notion that meeting these costs was within the realm of possibility. Those who maintained a sense of control and sought further information used information about costs to assess the adequacy of their personal resources and the viability of a plan.

As stated earlier, many participants were informed about the costs of nursing home care. Few related information, accurate or otherwise, about the costs of in-home care. General observations about long-term care costs were the rule:

*Now, you either have to have nothing or have a potful, a bottomless pit. The middle class, where we are, falls through the cracks and has to pay. If you don't have anything, you go on Medicaid and of course if you are a Rockefeller...you can have nurses around the clock to take care of you.*

Another member: *You don't need to be a Rockefeller.*

*Well, they say that only the people who have money can afford long-term care insurance.*

While general observations contribute to information, only individuals who are adequately and accurately informed about policies, programs, costs and requirements can move successfully to, and engage effectively in, the next requirement on the planning path: Perception of Resources.

**<u>Perception of resources</u>** *Do I have the needed resources?*

*Financial Resources*

With the exception of the Planners, the vast majority of participants perceived themselves to have insufficient resources to afford long-term-care planning. Claiming fixed or limited incomes, limited savings, or the financial devastation of medical expenses already incurred, these individuals described the costs of long-term-care planning, particularly of long-term-care insurance, as "too expensive", "prohibitive", "ridiculous", "too high", "an arm and a leg", and "out of reach" .

> *We pay 20% of physician's visits, prescriptions and hospitalizations which has amounted to up past $60,000. $7,000 for prescriptions....and doctor visits...I don't have to tell you how much that is.....Someone has to pay for it, and your income does not go up.*

It is clear that many participants were caught off guard by the perceived mismatch between projected long-term-care costs and their capacities to afford them. They expressed a combination of dismay and hopelessness. *Everybody here put money aside for their own upkeep later on. We thought we were doing it. I've lost a lot of hope.*

It is evident that many individuals, relying on a superficial assessment of their financial status, do not take a thorough personal inventory of financial capacity to plan for long-term care costs. For those who do, some find that it comes too late, that indeed, while they might have once had sufficient resources to accumulate toward this need over time, the cost is now prohibitive. Finally, some individuals have never had discretionary resources to commit to a long-term care plan. A perception of limited financial resources can lead to a sense of futility and a failure to take stock of personal, non-financial assets and supports. As one Non-Planner

said: *I don't know what you can plan! What can you plan if you don't have long-term care insurance?*

***Social/Environmental Resources***

What happens to individuals armed with adequate accurate information but without sufficient resources to make a rational decision to commit to a long-term-care financial plan? Though their planning options are limited, these individuals may develop other strategies for preparing for the possibility of long-term-care dependency.

A social/environmental plan may be characterized by a number of decisions, all of which were represented among the study participants. Individuals who change or adapt housing to prepare for potential limitations in mobility enhance the likelihood of living independently for a longer period of time. Those who move to be nearer to informal social supports, particularly family, expand their base of potential caregiver support. One Pre-Planner without family sought to share her home with someone, having decided that it *"isn't really safe for someone [my] age to be living alone."* This woman regarded her home as an asset she could exchange for care. *"Well, there are lots of people who need a place to live and I have that."*

A social/environmental plan may also include informing oneself about the range of long-term-care service options, and making preferences about options clear, so that in the event of a crisis, decisions about services may be made more expeditiously and appropriately. *I don't know what I'm gonna need in the future, but I want to know what's available to me to make good decisions.*

Finally, a social/environmental long-term-care plan may include legal arrangements and agreements with family or other designated individuals who can make health care decisions consistent with the wishes of an impaired older adult. Several participants in this study had designated a durable power of attorney for health care, and several had signed living wills.

The reality of a social/environmental plan is that, without a way to afford a full range of care options over an extended period of time, there cannot exist full protection against the consequences of long-term-care dependency. Housing changes, living arrangements and legal agreements can only go so far to enhance options and reduce the Medicaid burden.

### *Combined Resources for Comprehensive Planning*

Optimal preparation for long-term-care contingencies includes a combination of financial planning, necessary changes or adaptations in housing or living arrangements, the development and maintenance of a social support system, education about services, and legal agreements for health care and other decisions. The members of the Insured group had not only committed financial resources toward long-term care, but had engaged in most other forms of planning as well.

## Rational Decision

Even when an individual determines that he or she has sufficient financial, social, or environmental resources to invest in a long-term-care plan, a rational decision must be made to invest time, energy, and resources now toward an unpredictable future. Although long-term-care planning requires a perception of vulnerability, long-term-care dependency is perceived as a possibility---at most, a probability--, but is rarely perceived as a certainty. Except in the cases of pre-existing degenerative conditions such as Alzheimer's Disease, the

likelihood of long-term-care dependency is essentially unknowable and needs are unpredictable. Healthy, independent individuals considering an investment toward an uncertain future must weigh their perceived risk against the costs of the investment.

**Deciding to commit to a plan** *Do I choose to invest time, energy, and/or resources now toward an unpredictable future?*

Many Planners regarded their decisions to commit to a financial plan as a means of protecting both their children (from the burden of care) and their assets (from depletion).

*I had annuities put away back a long time ago to pay all expenses so that I didn't need to worry about it. For the good of the family, which little family I have...I have a couple of daughters who are good at looking after me, but for the good of them, and who knows what their futures hold.......*

**Choosing risk**

Like the Planners, Risk Choosers had moved through the six earlier stages of the planning path and had achieved a point of rational decision. Unlike the Planners, however, Risk Choosers decided not to commit resources toward the risk of long-term-care dependency, but to forego planning and take their chances.

*I've read the literature and I decided I didn't want to get involved with that: spending all the money to do that. It would be easier...I mean I could end up...it's a gamble. I could end up where I really need it, or I could spend thousands and die of a heart attack or something.*

*We do talk about it...the fact that we hope it doesn't happen that we have to have the care, but who knows? Life is a gamble, like we've said.*

The decision to "gamble" rather than plan may be the result of an informed, deliberate process. Without a change in their weighing of the costs and benefits of making a plan, Risk

Choosers are unlikely to commit time and resources toward a comprehensive long-term care plan.

### Review and Revision

As stated earlier, effective planning requires continual review and revision according to changes in perceptions, needs, options, and resources. One Planner described switching from one insurance company to another, while another described in detail the eye he keeps on his finances and related communications (updates) with his daughter. Another Planner had bought long-term care insurance and was looking toward a move to a CCRC in another five years.

## SUMMARY

Each of the seven conditions necessary to arrive at a plan for long-term-care represents significant challenges to the average individual. Acknowledging and accepting one's own vulnerability to a period of dependency in late life is a difficult achievement. Without a recognition of personal vulnerability, however, the inertia of "doing nothing" cannot be overcome. It is clear that there is no magic trigger to provoke people into a perception of vulnerability. The triggers varied in intensity and type among the participants in this study.

A perception of timeliness appears almost as challenging. What drives a 66-year-old to purchase long-term-care insurance while a 68-year-old argues that it is "not time" to think about such matters. What brings an 84-year-old to decide it is now time to "plan ahead"? There does not appear to be a magic moment or age at which individuals arrive at a sense of timeliness. Again, triggers varied in intensity and type.

There is considerable variation in ideas about personal, family and government responsibility for long-term-care. The mixed messages sent by both family members and

government serve to confuse, if not erode, perceptions of personal responsibility for care. For at least one participant, reliance on Medicaid support for nursing home care was regarded, if not as a plan, at least as a safety net.

Personal control in long-term-care decision making appears to be at risk in the more vulnerable individuals, characteristic of the nursing home residents and the adult children's parents, many of whom were receiving some type of long-term-care services. Few of these individuals appeared to be at the center of control of their futures, and it was not surprising that they had become passive about long-term-care decisions and plans. Also threatened were individuals who believed that their precarious financial circumstances put plans about their care at the mercy of others.

Participants in this study shared a wide array of experiences and attitudes about information sources and information gathering. They expressed concerns about identifying appropriate sources for information and were especially concerned about the accuracy and trustworthiness of information they had received. Several participants acknowledged ignorance about policies, programs, costs and eligibility, while others expressed confidence that they were sufficiently informed. Nearly all expressed an understanding that policies and programs change and that this requires vigilance on the part of the consumer.

A wide range of socioeconomic backgrounds was reflected in wide variation in the perception of resources for long-term care. Even so, even the more "privileged" of the participants appeared quick to decide that they had inadequate resources. With the exception of the planners, few seemed to have taken the thorough personal inventory necessary for a

rational decision. Regarding informal social supports as a resource, few participants had discussions with their children to clarify expectations about caregiving.

The knowledge gained from the focus group study about the path to long-term care planning provides a foundation for understanding how to encourage and facilitate planning, and provide appropriate information to individuals at all stages of the long-term care planning process. This information has particular relevance for Ohio's long-term care planning service, Care Choice Ohio. A description of Care Choice Ohio follows in the next section along with implications for practice and policy.

## CARE CHOICE OHIO

Ohio's program to assist older adults and their families in long-term care decision-making is called Care Choice Ohio (CCO). To gain an understanding of Care Choice Ohio, Scripps completed interviews with staff members involved in Care Choice at 10 of the PASSPORT Administrative Agencies (PAAs) across Ohio. In addition, a focus group was conducted with consumers who had participated in the Care Choice process in order to understand more about their experiences with the program. Questions about the Care Choice program elements were also addressed by the four focus groups described in the previous section. The following section summarizes the information gathered from the PAA staff interviews, written materials about Care Choice Ohio from the Ohio Department on Aging, and the focus group.

## Program Description

### What is Care Choice Ohio?

Care Choice Ohio staff provide free consultation to anyone requesting assistance with planning for their long-term care needs. Care Choice Ohio was developed by the Ohio Department of Aging, and is administered by Ohio's thirteen PASSPORT Administrative Agencies.

### How Did Care Choice Begin?

Care Choice Ohio was piloted in two regions during the Fall of 1995, and was expanded statewide early in 1996. Brochures for seniors and their families, professionals, and staff involved in providing Care Choice Ohio consultations were developed and tested. In addition, focus groups and interviews with consumers provided data about the types of information needed by people exploring long-term care options and the places they turned to for that information. A comprehensive plan for marketing the Care Choice Ohio program was developed and implemented statewide. Statewide training sessions were held for staff at the PASSPORT Administrative Agencies who would be responsible for administering the program. These training sessions provided information about long-term care service alternatives to PASSPORT and nursing homes, long-term care planning, financial information related to long-term care needs, and advance directives such as power of attorney.

### How does Care Choice Ohio work?

Most requests for Care Choice consultations come in via the telephone, and screening personnel determine the kind of assistance needed by the caller. In some cases a need for service is immediate; these clients are referred for a PASSPORT assessment. For others, a

Care Choice consultation meets the client's needs. Most callers ask general questions about long-term care services. Consultants are typically social workers and nurses who meet with individuals to discuss service options, financial resources, financial eligibility for programs, and other areas of concern. PASSPORT assessors, who have experience helping those with long-term care needs, provide the majority of consultations statewide. Two sites have also trained some non-licensed personnel to do Care Choice Ohio consultations.

Administratively, all PAAs had placed responsibility for provision of Care Choice consulting activities either in a PASSPORT assessment unit, or as a shared responsibility between a screening unit and an assessment unit. Most of the sites also placed some responsibility for Care Choice Ohio marketing activities with the Area Agency "public relations" staff. Coordination between consultation and marketing activities was very close at some PAAs, while almost entirely separated at others. Most of the PAAs that had not closely aligned their marketing and consultation functions planned to more closely integrate the two components of Care Choice Ohio in the future.

## CARE CHOICE ACTIVITIES

### How is the word getting out about Care Choice Ohio?

Typical marketing activities involved heavy distribution of Care Choice Ohio brochures to professionals such as lawyers, physicians, physician's office managers, and financial planners. Brochures and posters intended to increase consumer knowledge about the availability of Care Choice Ohio consultations have been placed in senior centers, grocery stores, pharmacies, libraries, municipal buildings, and courthouses. Some sites have relied more heavily than others on the promotional brochures and posters provided by the Ohio

Department of Aging. Most sites have mailed these brochures to appropriate agencies, but some have used them in inventive ways. For example, Care Choice Consultants at one PAA distributed brochures to nursing facilities, hospital discharge planners, and physicians offices in person. They felt that distribution of brochures provided an opportunity for personal contacts with other professionals and would result in increased referrals for consultations. Every site reported speaking engagements to promote Care Choice Ohio consultations and to provide general long-term care planning information. All sites had also distributed literature at health fairs, county fairs, or other places where the Area Agency on Aging had a booth or display. Media exposure was more limited--one site reported that the local television station would not produce a free public service announcement; another site had mailed radio announcements to several radio stations, but none of the staff had ever heard the announcements on the air. Other sites used letters to the editor and press releases for articles to generate newspaper coverage. Several PAAs suggested that they felt word-of-mouth was the most effective advertising in their area. They concentrated heavily on speeches to service and senior organizations to generate Care Choice Ohio referrals. One PAA enlisted their screeners to make personal telephone calls to local ministers to inform them about the availability of Care Choice Ohio consultations.

Most PAAs reported that they felt the marketing materials provided by ODA had been helpful, and they had relied heavily on those materials. However, half of the sites also reported problems with the professionally produced materials. Two sites mentioned that the words "long-term care" are still associated with nursing homes. "*I'm never going, so I don't need that plan*" one older woman observed at a health fair. Another site produced their own

"sack stuffers" which were placed in bags at several supermarkets. The words "long-term care" were not included on this flyer which promoted consultations about service information. They received more information requests from this avenue of promotion than from distribution of the professionally produced brochures. Another PAA thought that the brochures were "slick", but were very vague and misleading. Two sites provided an example of how the brochures could be misinterpreted--in two cases financial planners expressed concern that Care Choice Ohio consultants were acting without financial planning licenses. At another site, several nursing facilities had called to express their concerns about a service which they perceived as designed to keep private pay people out of nursing homes. A spokesperson at one site mentioned that the words "care plan" included in the brochures present the service as something for someone who needs care immediately, rather than a method of planning for the future. Another spokesperson from a site where Medicare HMOs have been heavily marketed said they had received many questions as to whether Care Choice Ohio was an HMO. As reported in our focus group study, long-term care may have negative connotations that discourage people from using the Care Choice service. It appears that additional materials to appeal to different age groups and clients with different types of needs might be helpful. Overall, the sites we contacted had all made a serious effort at promoting Care Choice Ohio. Several viewed the Care Choice promotion as an opportunity to promote PASSPORT and the Area Agency as well.

## Who does Care Choice Ohio Serve?

As of October 1996, a total of 750 Care Choice Ohio clients had been identified to participate in a client follow-up survey conducted by the Ohio Department of Aging (ODA) (Johnson & Kim, 1996).

Perceptions of the "typical" Care Choice client by each PAA do not provide consensus about the type of people most likely to be served by Care Choice Ohio. Two sites indicated that the typical client was someone in their late 50s through their mid 60s, recently retired, or thinking about retirement. Other sites indicated that they had hoped to attract this type of person, but were attracting people with more immediate long-term care needs. People with mild dementia, people within 6 months of needing long-term care, and people with mild functional disabilities who currently wanted limited assistance were described as typical clients. Most PAAs noted that their clients were of higher socioeconomic status and were much less impaired than the typical PASSPORT client, but many of these clients still did not have the financial resources to plan for anything other than an eventual dependence on Medicaid long-term care services. One site mentioned that their PASSPORT assessors (who also provide Care Choice consultations) had developed a more accurate picture of the aging population from their exposure to older people from all socioeconomic strata with wide variability in their functional limitations.

Most sites indicated that about half of the time families of older persons had called for a consultation, and were more actively involved in the consultation and planning process than older persons themselves. Often a precipitating event such as a fall, a hospitalization, or a serious illness had occurred shortly before the consultation. The event served as a "wake-up

call" that caused the family or the older person to realize "*this could've been more serious*". This finding confirms our earlier findings from the focus groups that emphasized the importance of one's need to see long-term care information and planning as personally relevant. It also reinforces the important role that adult children play in the long-term care planning and decision-making process.

**What is a Care Choice consultation?**

Most consultations are performed in individuals' homes, although all sites indicated that some clients only wanted answers to questions that could be provided on the phone or with some written information. Several also mentioned that some clients had specifically requested meetings elsewhere because of a reluctance to have someone visit their home. Two sites indicated that most of their clients' concerns were about financial matters and program eligibility, while two others sites specifically mentioned that most clients were more concerned about service availability rather than financial resource questions. Clearly, client expectations about the type of information Care Choice Ohio provides are very different.

All sites rely heavily on written materials, such as generalized planning guides and lists of county resources for services. One site mails appropriate materials to individuals before the consultation while most others provided staff with materials to distribute at the consultation. All sites mailed additional materials, or provided answers to specific questions after the consultation visits if necessary. Respondents from those sites providing written materials at the consultation visit indicated that after clients had read materials they often called back with additional questions. Advance distribution of written materials to the client before the

consultation may provide an opportunity for a more focused consultation once the client has already gained some knowledge.

Respondents showed wide variation in the kind of activities that they defined as Care Choice consultations. This variability in definitions makes it difficult to determine the actual number of CCO consultations that have actually been performed. Estimates ranged from a total of 4 at one site, to 5 per month at another. Consistency in defining and differentiating the different types of consultation activities for clients will be necessary for the Ohio Department of Aging to accurately chart the program's growth over time.

The community assessment service that PAAs have always provided established an important link to the Care Choice Ohio program for many sites. Three PAAs reported that their staff felt very comfortable with Care Choice Ohio initially because they were accustomed to the community assessment process, and viewed the Care Choice Ohio program as a familiar activity. The extensive training provided by ODA was reported as being helpful and increasing staff confidence about their ability to expertly provide long-term care consultation services.

### Achievement Of Care Choice Ohio Goals

All sites felt that it was important to attract consultation clients before long-term care services were needed, and most saw this as the main goal of Care Choice Ohio. For those older adults who recover from an illness or a spell of dependency and are able to plan, Care Choice provides an excellent opportunity. Many others, however, were still facing long-term care needs with little preparation or planning. Respondents at one site said they were "trying not to get discouraged" about their low number of consultations, but all felt that Care Choice Ohio had been a positive addition to their PAA. The increased knowledge required for CCO

consultants, particularly in financial matters and program eligibility, had proved to be a challenging growth experience for their employees. PASSPORT staff were reported to be, "*enthusiastic about presenting options to nursing homes*", and "*very positive*". Two sites reported frustration because few alternatives to PASSPORT or nursing homes were available in their areas, and thus they felt that an exploration of care alternatives wasn't truly possible.

Many sites mentioned that the success of Care Choice could best be measured over the long-term. As more and more people become exposed to the idea of planning for long-term care needs, "*it will eventually become part of planning for retirement*". Education was seen as a primary goal of the program, along with an opportunity to reduce the Medicaid bill to taxpayers. As people become aware that there are cost-effective alternatives to nursing homes, they will learn to rely on those services first, before choosing a nursing home. Word-of-mouth was mentioned as an important way that long-term care information is transmitted; the information provided in one Care Choice Ohio consultation may actually reach many potential long-term care consumers. In addition, the extensive efforts to provide information about Care Choice Ohio to professionals may also be reaping benefits. One PAA mentioned that their referrals to PASSPORT from physicians seemed to be increasing, "*because we worked hard to let them know that we had alternatives to nursing homes that we could talk to people about, and the more experience their patients have with PASSPORT, [the] more doctors are starting to trust home care*".

Others mentioned that as younger adults participate in Care Choice Ohio consultations with older family members, "*they get the information that they can use for their own lives too. After all, the adult children are usually people in their 50s and 60s themselves--the people*

*we're trying to attract.*" Some pointed out that even when consumers had a consultation and did not follow up by purchasing long-term care insurance, visiting nursing homes or talking to home care service agencies in their area, or implementing other planning behaviors, the program was still helpful. "*Even if they don't do anything with the information, and they still make a decision in a crisis, at least they know what their choices are*". Staff who took the long view were generally more positive about the program in their sites.

**Feedback from Care Choice Ohio consumers and Older Adults**

As previously discussed, a focus group was held with clients who had participated in a Care Choice consultation. In the CCO Client Group, members evaluated the impact the consultation had on their thinking and/or planning behaviors. In the other four groups, the Care Choice Ohio concept and program was introduced for discussion and feedback.

**The experience of Care Choice Ohio clients**

The CCO Clients regarded their consultations as beneficial. While none of these clients reported radical changes in their knowledge, thinking or behavior, all agreed that they were better informed about planning for long-term care. One client gave a rich account of her experience:

> *I believe we read about it in "50 Plus". So [my husband] called and a very wonderful girl came...just beautiful...and I think we kept her over, and we just talked and she just added so much to what we thought, gave us a lot of ideas, and she...sent us more information...later on.....She relieved a lot of my husband's worries. Finding out that there are a lot of people in this situation, and that they are trying to do something, and that they are checking into new alternatives, and that as information is available they are always willing to share it. And she suggested that we do this living trust...and we figure that might be a much better method. [We learned] we don't have to rely on the kids.*

Others discussed their disappointment with traditional planning sources as evidenced by the following exchange in the CCO Client Group:

*We had contacted three different attorneys and none of the three of them were able to come up with a solution for us.*

Another member: *Attorneys don't know much about our problems.*

A third member: *They don't know any more about it than a man on the moon.*

Others described feeling supported and reassured by their CCO consultation.

*I [valued] the fact that they listened to us. Up until then, nobody seemed to know anything.*

*A lady came out and talked to me and then I got these books which are very informative about places that...they're not nursing homes...they're assisted living...and that's good, that's good.*

Clients were connected to Care Choice Ohio through a wide range of mechanisms. One was referred by the Governor's office, and one by a friend who works for the Area Agency. Some were not clear about their source of information about the service: *"I don't remember what brought that about. I must have seen an ad. Have there been ads in the paper?"... "I saw it in Ohio Heritage"..... "I'm not sure where I read about it or heard about it".*

For the most part, CCO Clients appeared to regard their consultants as interested and trustworthy sources; all indicated that they would be likely to call again as their circumstances change.

**Response to the Care Choice Ohio concept**

None of the members in the other four focus groups had heard of Care Choice Ohio until introduced to it through the groups. The response to the concept (providing free, in-home consultation about long-term-care planning) was overwhelmingly positive, although

Nursing Home Residents considered it of little personal value to them now. "*Years ago, CCO might have helped.... You might have had choices that you're not aware of.*" Most participants expressed an interest in *"hearing their pitch"*.

CCO's greatest appeal was in the objectivity participants felt a public agency would bring to information about options and policies. Two participants, one of the Adult Children and one Planner, summed this up:

> *I'd be interested in knowing right now what the services are that are available...what are the quality providers of long-term care...information about insurance. And I'd love it if it were not from an insurance person, just somebody to give guidance and information.*

> *[T]he state is going to give us an overall view, not a warped view.*

One participant reminded her fellow group members that the service is really not "free": *We'd be paying for it though, don't forget that, as taxpayers*! Another cautioned that she was only interested in certain kinds of information: *It would depend on how well informed they would be on your local facilities, whether it would be worth listening to or not. I don't want the general picture of what goes on in the United States.*

**SUMMARY**

The PASSPORT Administrative Agencies charged with implementing the Care Choice Ohio program have begun to educate Ohioans about the importance of planning for long-term care needs through the Care Choice Ohio program. Implementing the program has provided increased visibility for the Area Agencies, the PASSPORT program, and the Ohio Department of Aging. It has improved staff knowledge about all long-term care services, not just those provided by Medicaid. It has provided an opportunity to educate other professionals about long-term care services, and it has assisted many older Ohioans and their families in getting

information about long-term care options. The program's slow growth can most likely be attributed to public attitudes and feelings about long-term care in general.

Our findings from the focus groups and the interviews with the PAA's suggest the importance of a marketing strategy with multiple approaches. PAAs that used marketing techniques and materials to attract a variety of older adults were among those who felt the program had been most successful. Care Choice Ohio provides a vehicle for shaping and changing people's perceptions of long-term care. Educating the public is a process that is often difficult. Appealing to older adults at all steps of the path to long-term care planning is the challenge faced by the Care Choice Ohio program.

Although none of the Care Choice clients in the focus group had yet developed a comprehensive plan as a result of their consultation, many felt better armed to face a crisis and had a greater understanding of their options. If their perceptions about timeliness of planning, or about resources change, they will have the information necessary to develop such a plan. The objectivity of the state-sponsored consultation is one of the program's greatest strengths.

Today's cohort of older long-term care consumers did not have many alternatives to nursing homes as recently as 10 years ago. Exploring their options or planning to use alternative sources of care was not an activity that would have been valuable. Today's cohort of older adults, through programs like Care Choice Ohio, are gradually becoming educated that options to nursing homes are available, and learning how to cost-effectively manage their resources to take advantage of those options. Tomorrow's cohort of long-term care consumers will have experience with alternative sources of care. Knowing that alternatives exist, they

may be more likely to prepare their resources to take advantage of options. The success of Care Choice Ohio is best measured in years, not in months.

## IMPLICATIONS FOR POLICY AND PRACTICE

### POLICY IMPLICATIONS

The principles which guided the development of Universal Pre-Admission Review have also guided the development of Ohio's Care Choice program. Ensuring that long-term care consumers have the opportunity to explore their options before a crisis occurs can assist consumers in identifying the range of service options and settings available, while also informing them about the likely costs and eligibility requirements if and when those services were needed. However, from our focus group study and our interviews with PAA staff it is clear that there are several policy areas that could benefit from additional attention.

First, we noted in our path to long-term care planning the importance of perceptions of responsibility regarding long-term care. Although a variety of opinions were noted, most participants talked about several responsible parties--family, self and government. Policies that support individual responsibility and family responsibility can relieve some of the burden on government. Tax incentives or state subsidies for the purchase of long-term care insurance, and payments or tax incentives to families who provide care for older adults are being tried in other states. Careful monitoring of the success of these programs can provide important insights for Ohio policy.

In order for an exploration of alternatives to be valuable, actual alternatives must exist. One PAA site reported that there were limited alternatives to nursing home care available in their community and thus had little to offer people in a Care Choice Ohio consultation. Other

participants in the focus groups were pleased to learn about long-term care that didn't occur in nursing homes. Assisted living, home-sharing programs, and increased community and home-based options provide proven alternatives.

The Ohio Department of Aging faces a challenge in encouraging older Ohioans to plan for their long-term care needs. Interviews with the PAAs elicited concerns from several that the value of the program might be underestimated because of limited participation, but all felt that for those who took advantage of it, it provided a valuable service. Preliminary results from the ODA study support this, with about 90 percent of the clients surveyed reporting they had learned new information, and nearly three-quarters (74%) reporting that the information was useful to them (Johnson & Kim, 1996). Maintaining the program's image as an unbiased source of information will continue to be an important factor for success. Those who viewed the program with an eye to the future could see that education was slowly making a difference in their communities, and expected that continued long-term efforts would result in a better informed long-term care consumer population.

### Practice Implications

How can Care Choice Ohio most effectively achieve its objectives? This report suggests several implications for program design and practice approaches. First, it appears that CCO has five potential target populations: Non-Planners, Pre-Planners, Planners, Risk Choosers, and Adult Children. Each of these populations represent strikingly different needs for intervention and education. Effective approaches, therefore, will necessarily be different for each group. Second, the seven conditions outlined on the planning path represent seven significant challenges for Care Choice Ohio.

Non-Planners have not moved toward pre-planning because they have not achieved one or more of the first four planning conditions: perceptions of vulnerability, timeliness, responsibility, or control. Can Care Choice Ohio have a role in moving people from a state of inertia to a perception of vulnerability? Because there is no one identified formula for provoking a sense of vulnerability, multiple messages may be required in order for one message to "do the trick". Clearly, a program of education that informs about odds, risks and probabilities is likely to contribute to more informed perceptions of vulnerability.

Creating a perception of timeliness in the population of Non-Planners is a related challenge. Outreach to Non-Planners should carry visual and verbal messages that long-term-care planning is appropriate and desirable at younger ages. Making Care Choice Ohio's presence felt in places of employment or other venues populated by younger ages would normalize the time-appropriateness of early long-term-care planning. On the other hand, Care Choice Ohio messages should also communicate that it is never "too late" to plan. Again, the juxtaposition of these two recommendations for outreach strategy suggests the need for a multi-message approach.

Care Choice Ohio can have a role in clarifying messages about responsibility by educating about the purpose and limits of Medicare and Medicaid and by encouraging family communication about caregiving expectations.

Long-term-care planning consultations and communications that promote and affirm a sense of control in the older adult are likely to lead to more active involvement in planning. PAA staff discussed the high numbers of long-term care applicants who have lost the opportunity for choice in a crisis. Planners in this study were well aware of maintaining

decisional control over their later needs. Strategies that emphasize planning as a way of maintaining autonomy and choice may prove appealing to many older people.

Pre-Planners, engaged in information seeking and resource inventory taking, are a good match for Care Choice Ohio consultation. The linkage between Care Choice Ohio and the population of Pre-Planners is a logical one. Pre-Planners expressed a need for objective, trustworthy information. They indicated a need for the dispelling of myths, rumors and inaccurate information. They also indicated a need to be kept informed on an ongoing basis. Interest in local services and programs was especially strong. Because Pre-Planners are such strong candidates for planning, the Care Choice Ohio relationship with these clients should be reinforced with follow-up and with regular communications providing information updates and helpful suggestions for planning. Care Choice Ohio can establish itself as *the* information source for its clients and can strengthen the identities of these information-gatherers as Care Choice Ohio clients.

Pre-Planners are also engaged in inventory taking and, for those who determine that they have material or social resources to invest, rational decision making. Care Choice Ohio can contribute to the rationality of these processes by offering risk assessment information and guidance and by making appropriate referrals for legal and/or financial planning.

Planners also have their place as Care Choice Ohio clients. Because no plan is 100% comprehensive and because review and revision necessitate an ongoing process of information gathering and inventory taking, Care Choice Ohio can serve much the same role as it does for pre-planners.

Risk Choosers represent a unique challenge to the Care Choice Ohio program. Can the right, and the choice, to forego planning be reconciled with the objectives of Care Choice Ohio? Care Choice Ohio can continue to offer its services through outreach and education. It is possible that information disseminated by the program can function to tip the costs-benefits scales of the rational decision maker; therefore, the Risk Chooser should not be abandoned as a potential CCO client.

Adult Children represent an unusual opportunity for Care Choice Ohio. While recognizing the important role adult children play in their parents' planning decisions, and while working with adult children to facilitate desired outcomes for all involved, Care Choice Ohio can exploit the opportunity to educate these adult children toward their own long-term-care planning. It should be noted that work with adult children requires a sensitivity to the parents' perceptions of responsibility and control. CCO consultants should not lose sight of the question: "Whose plan is this?"

In summary, the outreach, education, and consultation strategies of Care Choice Ohio require an understanding of the very real differences within and among these groups; this understanding should be reflected in multiple adaptable messages and approaches. Flexibility in the conceptualization of "consultation" is important. Given the importance of word-of-mouth information gathering, presentations and Q&A sessions to community groups would be valuable. Collaboration with Employee Assistance Programs and retirement planning programs in the public and private sector could have a significant impact.

Care Choice Ohio provides an important supplement to the required pre-admission review. As shown by the previous Scripps evaluation, and by the focus group findings

reported here, most people still make decisions at the point of crisis. Turning one's attention to long-term-care service alternatives on the day of hospital discharge is too late. Over one-third of Ohio's population will spend at least some time in a nursing home. Programs that encourage and facilitate individual long-term care planning will be critical as the state approaches the 21st century.

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# APPENDIX

The Insured (6 females, 4 males) ranged in age from 66 to 83; all were white. Eight were married and 2 were single; all but two had at least one living child. Three lived in a CCRC and seven lived in their own homes. All but three were retired; those working were semi-retired. Members had retired from middle to upper income work.

Seven had purchased long-term-care insurance and one had reserved financial assets for long-term-care contingencies. None had relocated to live near children. All had signed a living will and all had assigned a family member with durable power-of-attorney for health care. Three had consulted with a financial planning or long-term-care planning professional.

Care Choice Ohio Clients (7 females, 1 male) ranged in age from 44 to 84; all were white. Four were married, two were widowed, one was divorced, and one was single; six had at least one living child. The 44-year-old had no children, and had called Care Choice Ohio because of concerns about her aging mother. Participants represented a wide range of occupational backgrounds and socioeconomic status; all but the 44-year-old were retired. Three lived alone in their own homes, four lived in their own homes with a spouse, and one lived alone in her own home with occasional spells of an adult son living at home.

None had purchased long-term care insurance; none reported significant savings or self-insurance. Two had relocated to live near children. Two had signed living wills and two had assigned a family member with durable power-of-attorney for health care.

Nursing Home Residents (4 females, 2 males) ranged in age from 76 to 85; one was African-American, and the remaining white. All were widowed; all had at least one living

child. Their mean length of stay in the nursing home was 2.28 years. All were retired from blue-collar occupational backgrounds with one exception. None had purchased long-term-care insurance. and three reported significant savings. Two had signed a living will and two had assigned a family member with durable power-of-attorney for health care. None had consulted with a financial planning or long-term-care planning professional.

The older adults represented by this group had not engaged in any of the behaviors identified in the Planners group. This interview examined the influence of adult children on their parents' planning behaviors; because the mean age of the adult children themselves was 59, the interview also included questions about their own planning or non-planning values, knowledge and behaviors.

Mixed Group (5 females, 4 males) ranged in age from 71 to 82; all were white. Seven were married and two were widowed; all had at least one living child. Seven lived in their own homes with spouses; two lived in their own homes alone. All were retired from middle to upper income work.

None had purchased long-term-care insurance and three reported significant savings. One had relocated to live near children. Four had signed a living will and six had assigned a family member with durable power-of-attorney for health care. None had consulted with a financial planning or long-term-care planning professional.

Adult Children (8 females, 2 males) ranged in age from 51 to 67; their parents ranged in age from 79-89. All were white. Nine were married and one was widowed; seven had living mothers and three had living fathers. Three had parents who lived in a CCRC; two in a nursing home, one in congregate housing, two in their own home alone, and two in their own

home with another family member (son and niece). Two had parents who had purchased long-term-care insurance and three had reserved financial assets for long-term-care contingencies. Four had relocated to live near children. Six had signed a living will and four had assigned a family member with durable power-of-attorney for health care. Three had consulted with a financial planning or long-term-care planning professional.