

**KEEPING OPTIONS OPEN: COSTS AND BENEFITS OF AND  
SERVICES AVAILABLE OR NEEDED TO ENHANCE  
CHOICE OF SENIORS TO REMAIN AT HOME OR  
TO ENTER A FACILITY**

**FINAL REPORT**

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## EXECUTIVE SUMMARY

The study sought to identify what spouses and children of dependent seniors, providers of home care to seniors, and institutional discharge planners believe to be the benefits and costs of a senior remaining at home or entering a facility; what the individual and/or family can do to influence the exercise of those options, and what services or facilities are needed to support the exercise of those options. To learn this, four ninety-minute focus groups were convened during mid to late November of 2002 with: 1) spouses who were caregivers, 2) children who were caregivers, 3) aides who provided care either at home and/or in a facility, and 4) institutional discharge planners.

Among the *benefits of remaining at home*, participants identified: lower financial cost, emotional rewards to the senior and caregiver, knowledge of the quality of care accorded the senior, and continued independence for the senior. Among the *benefits of entering an institution*, participants identified: enhanced opportunities for sociability; scheduled recreation, medication, and meals; and personal security. Among the *costs of remaining at home*, participants cited recurring concern for security and safety of the senior, the physical and emotional toll on the caregiver, and uncertainty about medication compliance. Among the *costs of entering a facility*, participants identified real financial costs, absence of the physical and symbolic milieu of the real home, loss of freedom for the loved one, and the toll that the “out of sight, out of mind” syndrome can levy on all parties.

To enhance the viability of the at-home or enter-facility option, participants said that individuals and/or family can promote a healthy lifestyle, enter into early-on financial and legal planning, adapt the physical structure of the home to be senior-friendly, become aware of the services and of the agencies that provide services to seniors, nurture meaningful social relationships, and although infrequently noted, attend to one’s own mental health and that of the senior as well.

Participants identified the following services as available in Broome County in support the at-home option: 1) food and shopping, 2) transportation, 3) drop-off day care including senior centers, 4) recreational and educational services, 5) information and referral services, and 6) emergency on-call services. Participants noted that the demand often exceeds supply for on-demand, reasonably priced transportation; day and respite care, senior centers; and senior subsidized housing. Although many participants knew of the Broome County Office for Aging, far fewer recognized or could define the functions of some of the other major senior advocacy or assistance agencies in Broome County. Some participants were confused with the multiplicity of services and agencies serving seniors. Many thought that a single, well publicized Broome County “Senior Hot Line” telephone number would be useful for both potential and active care givers and seniors alike. Participants cited as services needed in Broome County, either *de novo* or in expanded form: consumer, legal, and financial counseling; better day and respite care, improved on demand public transportation to all regions, a register of names, addresses, and telephone numbers of the out of town children of Broome County resident seniors; and, most critically, more aides to care for seniors both in the home and in a facility.

The information provided by these focus groups suggest that among the issues Broome County must address if its growing population of seniors is to live its golden years in dignity include:

- 1. Developing institutions and procedures that will motivate and facilitate earlier planning for aging.**
- 2. Recognizing and rewarding the contributions of those who provide care for seniors either in the home or in an institution.**
- 3. Expanding drop-in day care services and facilities that make life more tolerable for the home care giver and occupy, challenge, and entertain the senior as well.**
- 4. Evaluate the knowledge about and prevalence of mental illness among those age 60 and above and act accordingly.**
- 5. Recognize the benefits that social capital (i.e., networks of relatives, friends, and neighbors) can contribute to the physical and mental well-being of both care givers and those for whom they care.**
- 6. Provide for an enhanced public and professional awareness, early-on, of the organizations and agencies that serve the senior community in Broome County.**
- 7. Facilitate quick, “one-stop” public access to information about and services for seniors.**
- 8. Provide frequent, easily scheduled, and reasonably priced public transportation to seniors.**

In the global village that our interdependent world has become, Broome County shares with other developed and developing nations an aging population. Aging populations are service intensive populations. Service intensive populations are resource intensive populations. How the government and the citizens of Broome County respond to the demand for the resources necessary for its aging population to mature with dignity will do much to define the future of aging in this county.

## INTRODUCTION

As individuals approach, enter, and transit their fifth and sixth decades, they often must choose between remaining in a own home or entering a facility with accommodations ranging from independent through assisted living to skilled care to complete and comprehensive care.

Our task was to learn how individuals may better plan and prepare for this decision, how they (and their loved ones) may make this decision more intelligently, and what types of services would support that decision and its implementation.

Our elected mode of learning was the focus group, a series of 90 minute informal discussions among 9 to 14 invited participants, hosted by a facilitator and co-facilitator, and guided by a set of 4 to 6 open-ended questions of increasing specificity.

Between November 18 and November 26 of 2002, we conducted focus groups with four sets of participants:

1. **Spouses who were caregivers for spouses or significant others (14 participants).**
2. **Children who were caregivers for one or both parents (12 participants).**
3. **Home Care Aides who provided services to seniors (10 participants).**
4. **Discharge Planners for area institutions who arrange for the release, care, and service of seniors, sometimes to home, sometimes to a facility (8 participants).**

One protocol, designed with broad input, was used for focus groups with spouses, parents, and home aides. A modified protocol was used with discharge planners. Each session was tape-recorded. Within several days of the completed focus group, the Principal Investigator prepared transcript of the tape. A thematic analysis was executed *within* each transcript and *across* all transcripts. This report represents a synthesis of the data from across four focus groups: 1) spouses as care givers to significant others; 2) children as care givers to parents; 3) home aides--who most often provide direct care to seniors in the homes of the senior, and, to a lesser degree, in the institutional settings of seniors; and 4) institutional discharge planners. Because of the distinct character and function of the institutional discharge planners, we have not included their responses in this integrative report as extensively as we have the responses of the three other sets of participants. However, as a comparative reading the separate and individual focus group reports in Appendix A reveals, thoughts, comments, and criticisms of the discharge planners parallel quite well those all sets of participants.

Using lists of prospective participants constructed and provided by the Broome County Office for Aging, Ms. Giammarino made initial telephone invitation telephone calls to each of our four target groups approximately 30 days in advance of the date scheduled for that particular group. Most, but not all of those prospective participants, had received an earlier telephone call and/or letter from the Office for Aging, alerting them to a possible

telephone call and briefly explaining the purpose of the study. Often between fifty and eighty percent of those called accepted the initial telephone invitation. One to three days following that acceptance, Ms. Giammarino mailed a letter confirming the purpose, date, time, and location of the focus group and reiterating her telephone offer of \$35.00 (payable as cash) for attendance and the opportunity to participate in a \$50.00 (per focus group) “On-Time-Arrival-Bonus” drawing. Some five to seven days prior to the scheduled focus group, Ms. Giammarino mailed a letter to each prospective participant confirming the focus group followed one to two days later by a reminder telephone call. Actual attendance at each of the focus groups ranged from 80 to 100 percent of all who had accepted the telephone invitation ca. one-month prior. At all stages of the process, participants were told that their first names and only their first names would be used. We did not collect demographic data beyond noting gender composition.

Note: Text in *italics* either denotes a direct quote (via the audio tape transcript) or a close paraphrase of the participant’s words. No deliberate effort has been made to edit incorrect grammatical usage or colloquial expressions from the quotations.

## **STRUCTURE OF THIS REPORT**

The structure of this report follows the sequence of the focus group protocol. We were not able always to ask each group each and every question of the protocol. This is because, at times, the facilitator would permit participants to continue with a subject of intense interest or continue to encourage participants to speak to the topic at hand.

Abbreviated versions of the original questions (designated with Arabic numbers) serve as headings for this report. The original text of the question(s) can be seen in the reports of the individual focus groups.

## **A NOTE OF CAUTION**

Any inferences from focus group participants to the larger population must be executed with appropriate caution. Prospective participants for focus groups are not necessarily selected from a valid sampling frame nor does any such sampling frame necessarily purport to consist of sampling elements drawn in accord with a recognized probability sampling technique. Moreover, focus group methodology does not necessitate the completion of 55 to 75 percent of all prospective “interviews” as it were. Thus, the absence of a well defined population, of a well-defined sampling frame, and of an adequate completion rate preclude a defensible statistical basis for inference from the “sample” to the “population”. Even were those sampling conditions to be met, the very small size of most focus groups, i.e., 8 to 15 participants, would itself generate sampling errors of a magnitude (plus or minus 25 percentage points at the 95% level of confidence) intolerable in most scientific probability samples. Finally, participants in focus groups, by virtue of the very fact that they are interacting in and subject to the influence of the very group in which they are, quite literally, sitting, fail to meet the criterion of “statistical independence” required of all individual sampling elements in inferential statistics.

Nevertheless, ongoing experience with focus groups in academic research, marketing research, health care research, and political and policy research has demonstrated that focus groups can and do provide valuable information of significant insight and policy utility.

## THE QUESTIONS

### Question Nr. 1:

**Assume two individuals approaching their senior years. They are very much alike in every way except: one remains at home and one enters a facility such as a nursing home or assisted living. What are the costs and the benefits, the advantages and disadvantages of one of these individuals remaining at home and of the other entering a facility such as an assisted living facility or nursing home?**

### Summary of Responses

The *benefits* of a senior remaining in his or her own home (or in the home of an offspring) are many and, according to our participants, include: lower costs when compared with institutionalization, the emotional benefits of a continued presence of the loved one in the home, personal day-to-day knowledge that the loved-one is safe, secure and well attended to, and support of the senior's continue sense of independence. The *costs* of a senior remaining at home also are also many and include: the necessity of the care giver to monitor personally (or assure that someone else does) the loved one on a 24/7 basis, the emotional burden of caring for an individual who often can be demanding and who often requires 24 hour oversight, the re-learning of behaviors and attitudes (and the emotional baggage associated with that relearning) necessary to accommodate the role reversals where the son or daughter become the father or mother to a parent and where a husband may become a "wife" to his former spouse. Often, these benefits and costs are not entirely independent as when, for example, care givers knowingly pay the costs of becoming 24/7 monitors in return for the emotional rewards of having the loved one present in their home.

The *benefits* of a senior entering a facility include enhanced opportunities for sociability; being with and around people of similar age and common interests; and being able to avail oneself of entertainment and recreational activities. Benefits also include scheduled meals and scheduled medication. The *costs* of entering a facility involve the real dollar expenses of living in a facility; learning how to adapt to a new and more highly structured environment; a certain loss of freedom and independence; a sense of having been abandoned by one's spouse or children; and of leaving behind the familiar space, things, and routines that had come to symbolize life at home.

## The Responses

### a. Remaining At Home--Benefits. Remaining at home:

#### 1) . . . is less expensive than living in a facility.

SPOUSE OF DEPENDENT: *"I like to keep my husband at home; he was diagnosed with Alzheimer's just this spring and I, ah, really don't want to use all our savings for a nursing home."*

HOME AIDE: *Costs—it's definitely less expensive to keep, essentially, and our hope is that, it is cheaper to keep someone in their own home than placed in a nursing home.*

#### 2) . . . enables the care giving spouse or child to be with, to appreciate, his or her dependent loved one(s). For both the care giver and the person cared for, remaining at home may have emotional benefits.

SPOUSE: *But I would prefer to have him at home. I want to know [all that he is] doing.*

CHILD: *Well, [I have a brother and a sister who decided that it would be best for our father who suffers from severe depression to be in nursing home]. At first, I thought he would get use to the place, but he never did. . . . So, I said, 'Dad—would you come and live with me?' Well, what we managed to accomplish for him is that my daughters are both semi-employed elsewhere, my one daughter is self-employed, so he's [got one of them with him while I work during the day]. He has enough income to have [home care worker?] come in during the day and their job is to keep him happy and he likes to go to the social club, play golf. . . .*

CHILD: *My father has been living with me for 25 years. He was 72 when he retired and is now 97. He broke his leg in September and had to have surgery and [since surgery] his whole personality has changed. . . . Well, from Lourdes, he went into [??] and it was like he was a vegetable, they paid no attention to him. . . . and I had to get him home. [And the social worker said 'Well, leave him here, Medicaid will take care of him. . . .'] And, I said, I can't do that, it was really heartbreaking. At first, when he came home, it was like he was a whole new person, and now he seems to be in a depression again. . . .*

CHILD: *. . . But let me tell you that my mother [now] calls me the 'mother' and herself the 'daughter'. 'Cause she's a hundred years old. We live together so I don't have any of those problems. I am retired with her and we live in the same house. And she has no problems—takes one aspirin a day, that all she takes. Nothing wrong except her memory is a little. . . she don't remember people but*



*she is happy with me in the house. If it comes the day that I couldn't take good care of her or if something happens to me than it is going to be a little different ball game. But she tells everyone that I'm the mother now and she's the daughter.*

- 3) **... enables the loved one to continue in a comfortable environment to which he/she had become accustomed.**

CHILD OF DEPENDENT: *I would probably [assume] three quarters or more of people would want to continue [living at home] because it's the environment they're used to and, secondly, change, regardless of how society is today, is met with resistance.*

- 4) **... facilitates the ability of the spouse or child to have the dependent loved one remain at home and, in some cases, for the care giving spouse to remain occupationally active. Thus, day care and respite services enhance choice about whether to institutionalize the dependent loved one.**

SPOUSE who continues his practice of law, still has his mildly cognitively impaired (his description) wife living with him because during the day she can go to YesterYears and have lunch. When she is home, however, Bob notes she has little to keep her occupied and that he must then spend most of the day with his wife. *When she's occupied, she's happy. She use to do everything at home for me, but now the role is completely changed. . . . Our relationship is now like parent and child in many respects.*

- 5) **... supports the sense of independence that (some) seniors cherish.**

CHILD OF DEPENDENT: *Ah, I think one of the benefits—my mother is 90 and she still lives by herself, I mean she lives at home and I think that is difficult for the caretaker to constantly be there for her. My sister and I spend a lot of time with my mother—her meals, the laundry—but she does not want to give up that independence of living at home. . . .*

**b. Remaining At Home--Costs. The costs of remaining at home:**

- 1) **... often necessitate that the loved one monitor the dependent loved one 24/7. While caring for a loved one can bring benefits to the caregiver, it can also impose a physical and emotional burden. And, remaining at home can jeopardize the health and safety of the dependent loved one.**

SPOUSE speaking of husband with Alzheimer's: *I like to keep my husband at home. He was diagnosed with Alzheimer's just this spring and I, ah, really don't want to use all our savings for a nursing home. I will take care of him as long as I can. It's a 24 hour thing. He's up during the night. \* \* \* But, I would prefer to have him at home, I want to know all that he's doing.*

SPOUSE speaking of father: *My father tried to take care of [his wife who had Alzheimer's] at home; . . . many times they are up at night . . . and it turned out she would get up early in the morning [and wander about] before we put her in the nursing home. [Once] she wandered about in Johnson City around 7:00 a.m. in the morning. \* \* \* Under those circumstances, when an individual reaches that point, you're becoming exhausted [and] unless you can get some help you do have to weigh the costs and what the costs are where they are under supervision 24 hours or you will exhaust your own health.*

CHILD speaking about father who had dementia: *Actually, it was a detriment to him [to stay at home] because working with stoves, toasters, other kinds of stuff, he puts himself in danger . . . . "*

SPOUSE (wife) notes that although she cared at home for her husband following his stroke with right side-paralysis and an inability to speak, after a while *my own health started to fail, so because my health was going down hill and I was wondering who was going to take care of him if I die first, . . . I did place in into a nursing home . . . to preserve myself and what years I have left.*

CHILD: *My mother has the ability to, mentally, to have the judgment; where my father is in the final stages of Parkinson's . . . developed hallucinations and schizophrenia. [Participant tells of an incident where her father took the car one night and drove the wrong way on I-88 before being stopped by the police.] But to see this meltdown now with my mother who can't sleep without an eye open [to keep watch on my father] . . . .*

**2) . . . can trigger role reversals with the dependent loved one: Husband to become wife to the wife. Child to becomes parent to the parent.**

SPOUSE in reference to wife whom he describes as having mild cognitive impairment: *Our relationship now is like parent and child, in many respects.*

CHILD in reference to mother: *. . . but let me tell you that my mother calls me the 'mother' now and herself the 'daughter'.*

**c. Entering a Facility or Institution. The benefits of entering a facility may mean that:**

**1) . . . the former home care-giver may view the facility as more supportive than was the home environment of the interests of the dependent loved one.**

As the woman (SPOUSE) who placed her husband in a facility after caring for him following his stroke noted: *And, he has so much more entertainment in the facility [to keep his mind alive] than he had sitting in the chair in my living room just staring out the window."*

CHILD OF DEPENDENT: . . . [B]ut if she were in a facility where there are other people around, I think there's a social benefit. I think the social is a real benefit rather than being by yourself. She has macular degeneration so she can't read a book by herself; needs other people to stimulate her.

HOME AIDE WITH AN UNCLE IN A FACILITY: I have an uncle who is 93 and I have him in a facility, um, I am so relieved that he is there because the man, he still gets up at 2:00 o'clock every morning. He was a farmer, and he gets in the shower and I was scared to death that he was going to fall in the shower and break something and be there for hours and hours before they found him; he has Parkinson's disease. I am so relieved that he is where he is and so they give him his meds and he is going to eat properly . . . .

- 2) . . . entering a facility may relieve a senior couple of the necessity, of the burden, of having to care for the other.

CHILD speaking about parents: Absolutely, she [mother] kept saying she wanted to remain in her home for their independence. Now [that they are both in a facility] look at the situation. When they went into a nursing home, no one could believe [how] they were intertwined—they were both each other's care takers.

- 3) . . . the essentials of life become routine and assured:

HOME AIDE: I think that, ah, they go into the living arrangements and get their medications on time, their meals on time, and they have someone there to . . . [help them out of trouble].

d. Entering a Facility or Institution. The costs of entering a facility:

- 1) . . . often require an initial period of adaptation for the senior:

HOME AIDE: But, initially the emotional cost is horrid. I really visit my [former at home] patients that go into nursing homes but I give them six weeks before I go visit so that they can adjust, get used to being there, get used to me not being there on a daily basis, whatever, but it gives them a chance to adjust so that when you do visit you're not getting just 'Oh—woe is me'.

HOME AIDES: Mosaic of comments on preceding observation: I don't think it's self pity, it's grieving. The loss of their home. It's a part of their life they're never going back to. No matter what happens, you cannot go back. Exactly. It's just another step, another mile, on the road of life.

- 2) . . . require that the senior divest him/her self of the physical space and of the symbols that had made “home” truly “home”.

HOME AIDE: . . . [P]lus, another thing the elderly don't want to give up is that they know they're going from a house to a space and they have to get rid of their belongings and I think that is, ah, the hardest thing for them to do. 'Well, can't I just take that one dresser and take this piece of furniture [to the facility with me]?'

- 3) . . . can mean a loss of freedom to the individual

HOME AIDE: People feel that they are giving up their freedom. Because you . . . have to do abide so much by the rules and maybe parking a car and going up and down an elevator, uh, you know, . . . being a little more restrictive.

- 4) . . . can involve a loss of significant assets to the individual and family

CHILD: Well, I think we were trying to find the best fit situation, look into assisted living; it kept coming back that it was too expensive to do that, [that they] knew he had assets that could be utilized for that function.

- 5) . . . can mean “Out of sight, out of mind”

HOME AIDE: We'll, I've seen a number of cases working in the nursing home—where one's family places the individual [and] the family disappears.

HOME AIDE: The emotional cost . . . maybe they [the family] feel that mom is just not well anymore so they don't go to see he.

HOME AIDE: Sometimes it's such a relief [to the family] when they place them, and the guilt the families feel . . . about placing them in the facility, it's hard to deal with and sometimes they separate themselves rather when they should be closer so you know it's a widening gap rather than a closing one . . .

### Question Nr. 2:

**What can the *individual* do, either prior to or on becoming a senior, to influence whether he/she will remain at home? NOTE: to facilitate better understanding of this question, the facilitator often restated the question: **Suppose you were 45 or 50 or 55 and thinking about becoming a senior. What could you, as an individual, do to better prepare for that time when you might have to decide to remain at home, on the one hand, or enter a facility, on the other?****

## Summary of Responses

For many participants, the possibility that one might have to make a decision about remaining at home or entering a facility or that one might have to implement that decision (either for one's self or spouse or for one's parents), was above and beyond their radar screens at ages 45, 50, 55 or even 60. When asked what one could do to increase the likelihood that they or their parents would remain at home during the senior years, participants said: 1) stay physically and mentally fit; 2) prepare financially and legally (although many regarded long term care insurance as far too expensive); 3) make the home more user friendly for the senior years; 4) learn about the agencies, services, and facilities available for those in their senior years; and 5) develop and maintain vibrant networks of friends and of friendships.

### The Responses: Participants observed that:

- a. . . . at an early age, a decision about retirement, whether to stay at home or enter a facility, is often not on the radar screen.

SPOUSE: *We weren't thinking about things like that [at age 45].*

- b. . . . one can work to improve one's life style both physically and mentally.

SPOUSE: *You can try to improve your health, take care of yourself, eat properly, exercise, see the doctor regularly—then you will ensure that your health will be well enough that you can stay home for a length of time.*

SPOUSE: *Exercise. I exercise and she [dependent wife] hasn't, so I got her started up at the health center at Hill Top, once a week for an hour or so.*

*Another thing we do is over at Binghamton University, the students have recitals in the afternoon and she [the person who cares for my wife] takes her over there. I think activities are important to keep a person from depression. Stimulation!*

- c. . . . one can prepare both financially and legally.

SPOUSE: *Another thing, now this is the reverse side [of living a healthy life style] is to make it more practical that you can go into a nursing home . . . is to take long term insurance. We have done that but the amount of the insurance coverage . . . [is minimal].*

SPOUSE ON THE COST OF LONG TERM CARE INSURANCE: *The insurance . . . long term care would be too expensive [at my mother's age, now], you couldn't afford it.*

SPOUSE [WHO IS A PRACTICING ATTORNEY]: *Transfer assets . . . [but] a lot of people don't want to give up control of their assets.*

- d. . . . one can physically prepare or adapt home or apartment to accommodate an anticipated senior.

SPOUSE: *Well, my son and daughter have built an apartment over the garage [for the time when we may need to leave our home]*

- e. . . . one can become aware of the available services for seniors.

CHILD: *The only thing I was thinking of was be aware of the services that can be available. That was, the case like my mother, I know that there is help out there . . . . Being near some family.*

CHILD: *I feel that if you just `Remember the Office for Aging!*

HOME AIDE: *I think that the biggest thing is to research the options about what's out there. I think that by the time people get to the age of 70 or 80 or whatever,*

*where they really do have to make those choices, they don't know the differences in the levels of care . . . . And also, there's a financial piece to all that too—if by the time you're that age and you are already a Medicaid patient, uh, it is much more difficult to get into one of those facilities.*

HOWEVER, HOME AIDE continues from just above: *But even the community explaining those options [for seniors]. . . , I've worked in other states and even from state to state the health care system is not a widely known. `How to use it' is I guess the best way to explain. It's not consumer friendly'.*

*. . . [M]ost people don't want to talk about it.*

*. . . [T]hey [consumers] don't take the time to make themselves knowledgeable of the health care system because it's one of those things" `If I don't need to use it, I don't want to know about it'. D-Nile—is more than a river in Egypt!*

**BUT—SOME CITIZENS EITHER WON'T OR DON'T TAKE THE TIME TO LEARN ABOUT AVAILABLE SERVICES**

HOME AIDE: *I opened a case on Friday and the woman had no idea what HEAP was, she had that lovely lavender Action for Older Persons folder in her house and had never looked at it. She so had been presented with the information but she didn't ever . . . `Oh, I didn't know that it was there'; like `Scream it from the roof tops'.*

**f. . . one can and should nurture social relationships, build social capital.**

HOME AIDE: *There's two or three things that I have learned from watching My parents age that are common threads for all of us. And that is, staying with people, friends, and community. Because whether you are at home or in a home, that [family, friends] will become your support group. Plus staying active and actively involved in the community you have a better awareness of what the services are, staying involved with people, staying in touch with people and investing yourself in your physical activity to help prolong whatever we are facing.*

**g. . . with respect to mental health:**

Because virtually no one took the initiative to mention mental health as an issue to which one should be attentive, either as the individual him/her self or as a relative or loved, one, Dick asked specifically about mental health. Many respondents, especially spouses and children, demonstrated little more than a cursory understanding of the incidence and prevalence of mental illness among the elderly, and/or the symptoms to watch for (especially those of depression). The most common explanation for their own self-acknowledged collective ignorance was that 'Mental health is [was] something we do [did] not talk about'.

A notable exception was this female participant providing care for her parent: *I monitor my mental health. My mother suffers from clinical depression and I really believe that now she has [suffered] most of her life. I didn't realize that [earlier]. It scared me—when I see those traits [of depression] in myself. She's tried suicide twice and she gets that way every other week and she did today. And when I see myself straightening the towels in the bathroom or picking up the lint—I begin to get worried.*

Other comments on mental health worthy of note include these (all from Home Aides): 1. *[Some seniors take the position that] I have a right to be depressed. I am going through life changes and I have a right to be depressed. If you when through [these last months as have I] . . . , you [too] would be depressed.* 2. *There is the feeling that this [mental illness] is an unacceptable behavior, so the senior feels he should not tell the doctor.*

### Question Nr. 3:

**What can *family and/or relatives* do to influence whether a senior enters a facility or remains at home?**

#### Summary of Responses

Parents and children can anticipate the time when that decision may have to be made by talking with each, by learning, early-on, their respective preferences. They can anticipate that period by, at the appropriate time, having their home or the home of their parents made more senior-friendly. They can begin to prepare financially and legally for when that decision may have to be made and do so in a manner that will lend viability to each option. And, each and all parties can recognize that a decision to enter a facility may be difficult for all who participate in that decision, i.e., the senior who enters the facility and the children who remain in their homes, sometimes in their homes hundreds if not thousands of miles away.

#### **The Responses: To influence whether a senior remains at home or enters a facility:**

- a. . . . parents can talk with children, children can talk with parents—concerning preferences for, conditions under which, one might remain at home or for enter a facility.**

*SPOUSE: Know what the person's desires are. I think that parents can indicate to their children what they . . . want to do if an when t/he decision has to be made to enter a facility or to remain at home.*

*HOME AIDES—BRIEF CONVERSATION AMONG: I want to point out that a lot of people have the perception that nursing homes are deep, dark dank scary places and I think that . . . there are some very nice nursing homes out there that are beautiful, the care is very good but I think that people have to go and see that so that they [seniors] say 'Oh, this is nothing like I thought it was going to look like, its pretty and the rooms are bright and cheerful l. . .' HOME AIDE: I agree with her. HOME AIDE: [Nursing homes need to] get better at marketing themselves in the community; . . . doing something like tour types of things, so that you could actually see some of the facilities.*

- b. . . . a spouse or the children (finances permitting) can have the home remodeled to make it more user-friendly to seniors with limitations.**

*Home Aide: [A]s far as their home goes, make sure they have a bathroom facility on the first floor that they [senior] can get to, um, when they get to the point you could obtain a hospital bed, a wheelchair, um, make their facility workable . . .*



Home Aide: *Right, and get the equipment they need to live in that facility. And give them support that way and home care . . . .*

Discharge Planner: *. . . [A]t a wheel chair level . . . is the house acceptable for the wheel chair? Will it go through the front door? Can they maneuver it through the house? Can they get in the bathroom?*

**c. . . . family can assist the senior in planning financially for the future.**

Home Aide: *Financially too. Some family members may have a lot of assets and they don't want to spend a lot of money to the nursing home so they need to plan for that give your assets to another family member . . . .*

**d. . . . parents and children can become aware of how changing social, cultural, and demographic conditions affect what parent's expect from children and what children are able to provide parents.**

SPOUSE: *You can get help from your family and kids but . . . you don't want to overtax your kids [with your needs].*

SPOUSE: *In today's culture, the children are all over the world. They don't stay in your neighborhood any more, so they can't physically help you. My children are out of town so they can't help you. I don't want to burden them.*

HOME AIDE: *There's that whole generation thing where if my parents get old in their 60s, well, I'm still going to have young children and I will be working full-time and probably not available to them full time. I could not provide large blocks of time.*

SPOUSE: *I have three [children]. My youngest daughter lives just down the street from us, but I can't put all the load on her. Her sister lives out of town. But I don't want to do anything to jeopardize their relationship [with each other]. If one feels they are put upon, it could blow up . . . .*

SPOUSE: *If you put too much of a burden on them [your children], they don't (sic) want to have nothing (sic) to do with you. . . .*

**e. . . . for all parties involved in the decision to remain at home or to enter a facility, both the process and its sequelae can be difficult and painful.**

**HOME CARE PROVIDER (referring to experience with in-laws):** *It's a tough question. I had an experience with my mother-in-law and my father-in-law both. First my mother-in-law was in a nursing home for approximately 5 weeks. She went into the hospital that . . . that sent her to the nursing home. They released her and she came home and in the meantime I had my father-in-law at the emergency room*

*at least once a week for five weeks. He'd go and they'd send him home. Because of insurance purposes, they could not diagnose him with anything in order to admit him into the hospital. The last time I took him they finally did admit him with pneumonia in one lung and he went to the nursing home. I won't say which one because I . . . he didn't get the care he needed, they would unplug his phone, the nurses would not come in when he rang the bell, was not getting the proper care, no exercise, could not eat by himself. He's home now. I brought him home Saturday so his wife is there with him. She is unable to take care of herself, he has an aide that comes in 5 days a week 1 – 2 hours a day and the man can't really do anything for himself. He's not going back to the hospital and he's not going back to the nursing home—it's a matter of time. He has given up. He expects me to be there, he wants me there 24 hours a day; I cannot do this. I work, I have a daughter, it's very hard." Yes—he does not want to go on living. . . . [T]he man's given up, he wants to die.*

#### **Question Nr. 4:**

**What services are available in Broome County to facilitate individuals being able to remain in their homes rather than entering a facility?**

#### **Summary of Responses**

Participants recognize that in Broome County there are many services that support seniors who choose to remain at home: Meals on Wheels; shopping; light housekeeping; public dial-a-ride transportation; private medical transport; day care and respite services both with and without medical personnel; information and referral organizations; emergency on-demand personal communications systems; and, to a limited degree, subsidized housing for seniors. Not all these services are equally well known among seniors (or even among the professionals who work with and for seniors). Some services are seen as far more costly than others. And some services are judged to be in such short supply that they are difficult to secure even if one is able to pay above-market prices.

#### **The Responses**

To organize the identified responses, we developed a simple classification system and then grouped mentioned services within the appropriate category.

- a. Food and Shopping and Other Services
  - 1) Meals on Wheels. Recognized and/or known by virtually everyone.
  - 2) Shopping Services (Noted only by Home Aides and without much knowledge or specificity.
  - 3) Light Housekeeping

b. Transportation Services

- 1) “Disability Bus”. More correctly known as “BC Lift”. Known by about two-thirds of all care giving spouses and care giving children. Some confusion, however, about the cost of this service and whether it is necessary to schedule a ride and if so how far in advance one must schedule. Preference for virtually instant reservation and use.
- 2) Catholic Charities Van. Fewer participants knew of CCV than of BC Lift. Among those who did know, some thought that the charge was \$12.00 a day, including meal(s). One participant observed that the cost had just increased to \$14.00 per day.
- 3) Medi-Van. Discharge Planner notes that if you take it to and from your own home, the cost is \$50.00 if you go by wheelchair and is Medicaid reimbursable. But, she notes, if you take it from a Nursing home, it is 450.00 each way.

c. Day Care and/or Day Service Facilities

- 1) YesterYears: Mentioned by perhaps two thirds of all participants; locations identified as Johnson City and Endicott. Among those commenting on YesterYears, almost all spoke enthusiastically, noting the quality of recreational services available, the pleasure afforded the loved one, and how this service make it possible to the care giver to get some time to one’s self. Several care givers wished that the service were available to them and their loved ones for at least five days each and every week. Several participants said that YesterYears is a social day care, not a medical day care program and that those who attend have to be able to ambulate and toilet themselves.
- 2) Susquehanna Nursing Home: Several participants believed that the Susquehanna Nursing Home takes persons on a daily basis. Fee cited was \$59.00; this includes, said one or two participants, availability of a Registered Nurse to administer medications.
- 3) Golden Days Program

Somewhat limited recognition of Golden Days among participants. Among those who did recognize, some knowledge that this is a medical day care program operated by a Registered Nurse. Some knowledge that, as one Home Aide put it: *[M]om can go to this place which is at a local nursing home and receive her medications there. They have a hairdresser there, a nurse to do simple wound care . . . so all the care they would get at home they are getting there.*

- 4) Licensed Home Health Agencies (cited primarily by Home Health Aides)
  - 5) Interim care: to do a daily bath of dependent, straighten up clothes.
  - 6) Senior Citizens Centers
- e. Recreational, Educational Services

One spouse participant mentioned the Lyceum. Among spouses, less than a quarter knew about the Lyceum.

- f. Information and Referral Services

- 1) Broome County Office of Aging

Many spouse care givers and children of care givers knew of the BCOFA service guide (The Lavender Book). Participants reported that it provides all kinds of information and lists all kinds of available services. Participants had obtained their copies from various sources including the Broome County Arena and Lourdes Hospital. Very high awareness of this booklet and extremely high praise for its ubiquity and utility.

Spouse and child care givers rated BCOFA very highly for availability, information provided, and empathetic staff. As one child care giver commented: *. . . I got more counseling from the woman I deal with there [the BCOFA] than my own husband would give me in a day's time; more caring and compassion.—Office for Aging—a woman who had never met me but who was so worried about my mental and physical challenges, um, I just love 'em [the people at the BCOFA].*

Participants had learned about the BCOFA through their respective hospitals, other health care providers, and from what one said is a daily column in *The Press & Sun-Bulletin*.

However, as the CHILD provider of care illustrates, some persons exhibit an initial reluctance to phone any agency, including BCOFA, because they do not wish to appear ignorant: *Actually, I know about the Office for Aging but I was not sure what kind of things they could provide for me and I thought, well, you know, I am going to sound stupid, I don't know who to talk to and what do I do when I get on the phone. These people [at BCOFA] may think I am wacko!*

2) First Call for Help

A limited number of participants cited First Call for Help as providing assistance to, for, and about issues that affect seniors. Some participants, however, thought First Call for Help was primarily if not exclusively for younger people and not for senior citizens. Others thought it was primarily for psychiatric disorders or crisis intervention.

3) CASA

Knowledge of CASA (Community Alternative Systems Agency) was limited among *all* of our participants, including among Home Aides and Discharge Planners. Knowledge of precisely what it is that CASA does (beyond “It’s a referral service”) was even more limited.

Home Aide: *We are not exactly sure what they [CASA] do.*

4) Action for Older Persons

Voluntarily cited by few participants. Very limited name recognition. Even more limited knowledge of what AOP does.

5) Home Aide: *Lourdes at Home maintains a referral service where people from the community can call and just have questions like ‘Where can I hire a private aide for my mom . . . ?’.* This participant, however, was unsure whether this referral service continues to be operative.

NOTE: A Home Aide observed that because of a lack of public knowledge of whom to contact when and for what, because of the multiplicity of referral services, and because of the absence of a single, well publicized “911” HELP SENIOR hot line: *They [some seniors] wait until a week when they haven’t had anything to eat and then they get into the health care system [and eventually transfer from the health care system to a facility for seniors].*

g. Emergency Services

Perhaps a third of all participants, across all four groups, cited the Link-to-Life, Life-Line, and other emergency “wear on the person” call services. Among those who cited these services, almost all were aware of an initial purchase fee and subsequent monthly fees. Several Home Aides noted that some subscribers to these services are reluctant to actually use them because to do so (from the perspective of the senior) is tacit admission that the senior is no longer able to function completely independently. One or two Discharge Planners noted that the initial marketing

campaigns for these devices nurtured a negative image among seniors, some of whom, to this day, refuse to wear the device to avoid that stigma.

h. Senior (Subsidized) Apartments and Housing

Cited by several participants in almost each focus group. Very high awareness of the limited supply for senior subsidized housing and of the very long waiting lists (some participants referred to waiting lists of two or more years). One Home Aide said: *So, in other words, if you are 50 and want to get it [subsidized senior apartments] sign up now!* Another observed: *I've got clients who have said 'I had to wait for somebody to die to get this apartment.'*

**Question Nr. 5:**

**And, what services need to be initiated or improved to facilitate individuals being able to remain at home?**

**Summary of Responses**

Participants identified a number of services that need to be created or expanded to better support those who may prefer to remain at home as they enter or pass through their senior years: competent and affordable consumer, legal, and financial counseling; sociability services that provide visitors for seniors at home (or in a facility) and thus give the senior a sense of meaning and attachment; a register of the names, addresses, and telephone numbers of the out-of-town, out-of-state, out-of-country children of seniors who remain in Broome County; and, perhaps most important of all, a substantial increase in the number of persons with requisite motivation and skill to serve as aides to seniors whether the senior resides in a facility or (especially) at home. Increasing the number of home aides, participants asserted, would certainly support the wishes of those spouses and/or children who would prefer to have their loved one remain at home but find themselves unable to exercise that preference because they are unable to hire and retain competent home aides.

**The Responses**

a. Consumer Counselor

Someone (or some office) to provide a wide range of intelligent advice to seniors on issues ranging from personal health to financial and legal services to information about the various levels of living available.

b. Legal Services for estate planning and for preparation of the other legal documents pertinent to aging. Home Aide notes that such services are especially needed in rural areas of the county.

- c. Sociability Services: More needed. Including sociability services that visit the senior in a nursing home and in the senior's own home. A Discharge Planner believes that the Broome County Council of Churches used to provide this type of service but may no longer do so.
- d. Significant increase in funding for the BCOFA In Home Services for the Elderly program. A Discharge Planner described this as a valuable, much needed but significantly under funded program for middle-income seniors.
- e. A register of the names, addresses, and telephone numbers of all children of Broome County Seniors for those children who live outside of the County and/or State. As the Discharge Planner who made this suggestion noted, this roster would expedite communications with those children when the need arises.
- f. Day Care, Respite Care, Home Care and Home Health Aides (and Aides for the Various Senior Facilities)
  - 1) SPOUSE: *One of the problems that I see is that we have a lack of people to come into the home to help people, care givers. And if we do have them, the cost is such that people can't afford it.*
  - 2) MONTAGE OF DISCHARGE PLANNERS DISCUSSION OF SHORTAGE OF HOME AIDES WITH FACILITATOR'S QUESTIONS IN NON-ITALICS: *Many times we can find aide service Monday through Friday but we cannot find it on the weekends . . . .*" FACILITATOR: *Because . . . ? There is a major shortage—all areas of aides, not just nursing home, and its country wide, it's not just Broome County.* FACILITATOR: *In Broome County, given then rather rapid rise in unemployment, why does there continue to a shortage of people as home care aides?" They don't get paid well. The turnover rate is tremendous. Pay scale is low and you can get jobs flipping burgers making the same money and not having to work with individuals and do . . . .* FACILITATOR: *The pay scale is about what--\$6.00 - \$7.00 an hour, minimum wage . . . ? Little higher [than minimum wage]. Depends on what level of aides. There's different levels of aides . . . .* FACILITATOR: *So there's a shortage because the pay scale is too low . . . ? No benefits. Many of the home care agencies don't provide benefits . . . health insurance; don't provide child care. The nursing homes provide benefits but you still are talking a very low salary range and most of the population is single mothers with multiple children, high cost to obtain health care for them and their children, high cost of day care for them and their children, and if you start talking 12 hour shifts and all as far the homes trying to be creative and keep themselves staffed with such a shortage . . . .* FACILITATOR: *Let me ask an obvious question: what stands in the way of raising the pay scale? Medicare and Medicaid. Your reimbursement rates are so low you can't afford to be paying workers . . . .* FACILITATOR: *So money is the issue? Um hum (several concur.) And another thing is called*

*'mandating'. If you have a child that get off the [school] bus at 3:30 and your shift ends at 3:00 o'clock and the aide that comes to replace you doesn't show up, you're mandated to stay and there's your child sitting on the front of the steps. I used to work . . . and I know insurance [family health insurance] sometimes used to run \$80.00 a week and your salary Is \$6.00 to \$7.00 an hour and then you have the transportation to get to the facility and on that kind of money you can only afford 'a meter with a heater' and . . . . FACILITATOR: So salary is a problem, the absence of fringe [benefits] is a problem, the working conditions are a problem . . . . By the way, with mandated time, when you have to stay, were you compensated for that? Yes you were but they only have to give you an hour's notice . . . . [Notes how much of a burden this can impose on the aide-mother who may have to try to arrange for child care at the very last moment . . . . Notes also that] some of the areas the aides come from [referring to areas of the city] you don't want your child sitting out on the stoop" waiting for you to come home.*

## **POLICY RECOMMENDATIONS AND CONCLUSION**

Participants in our four focus groups identified at least eight issues that, if addressed creatively, could improve the prospects for the senior citizens of Broome County. Those eight issues include: 1) learning to plan earlier-on for aging; 2) recognizing the significant contributions made to the dependent senior, the care giver, and the larger community by those who provide care to seniors both in homes and in institutions; 3) increasing the "supply" of available space and time at drop-in day care facilities; 4) raising awareness of mental health and aging; 5) nurturing both a dense network of friends and neighbors and appreciating the contribution that this social capital can make to one's physical and mental health; and, 6) developing an awareness, earlier on, of the organizations and agencies that are available to serve the senior population in Broome County; 7) facilitating quick "one-stop" access to information about and services for seniors; 8) providing easily and frequently scheduled and reasonably priced public transportation to the senior population.

### **1. ISSUE: Learn, earlier-on, to plan for aging.**

Comments from our focus group participants suggest that planning for and decision-making about aging is made not at mid-life when options may be many, but as the senior years begin, when options no doubt are fewer. This mirrors a national pattern often detected in public opinion surveys.

For example, a recent telephone survey of 1,800 Americans age 45 and above commissioned by the American Association of Retired Persons found that almost a quarter had little knowledge of the cost of nursing home care or of care in an assisted living facility. Almost half thought themselves poorly prepared to meet the financial challenges of long-term care. And five times as many who actually had long term care insurance thought that their current insurance would cover such care (AARP.



“Americans nearing retirement ignorant about cost of care” [www.cnn.com/2002/US/12/11/retirement.survey.](http://www.cnn.com/2002/US/12/11/retirement.survey.) ). Intuit, producer of personal financial software, commissioned a study by Roper-Starch of 1,000 Americans age 18 and older and found that only about a quarter of workers earning up to \$25,000 have access to 401(k) retirement programs compared with 56 percent of those earning \$50,000 or more and that among those with access to 401(k) retirement programs, almost half do not contribute the maximum permitted [www.intuit.com/company/press\\_releases/1998-01](http://www.intuit.com/company/press_releases/1998-01).

RECOMMENDATION: Creatively engage and employ a wide range of media to cultivate an awareness of the necessity and benefits of early-on planning to prepare financially, physically, and socially for age 60 and beyond. Media (in the generic construction of this concept) that could be employed to raise early-on awareness of the benefits of early planning for aging include: the secondary schools, the community college, places of worship, health care providers, the print and electronic media. Articulate, persuasive seniors could serve as the outreach ambassadors in this effort to heighten awareness of the benefits of early planning for decision making about aging.

**2. ISSUE: Recognize the contributions of those who give care to seniors, either in the home or in an institution.**

Spouses, children, and home aides alike often feel that their efforts go unrecognized and unappreciated. Caregivers often feel as though they are serving alone with little or no opportunity to share their experiences with others like themselves. Moreover, care that is given by members of the family privately in the home represents a substantial, cost-avoided, economic savings to the public.

RECOMMENDATION ONE: Recognize the contributions of care givers: Create one or more “Care Giver of the Month” or “Year” recognition awards. Solicit nominations for the award via the electronic and print media and via senior centers, *inter alia*. Consider also the creation and use of a panel of caregivers either to initiate or to certify nominations for the award. Use appropriate “theater”, settings and symbols to present the recognition award. Signatures from executives of the various senior advocacy organizations and the Broome County Executive might be appropriate.

RECOMMENDATION TWO: Initiate and creatively and aggressively market *care giver support groups*—semi-structured settings where, periodically, care givers can meet and share with one another their ongoing trials and triumphs so that they may appreciate that they are not alone in their efforts to provide dignity to the aging.

**3. Expand drop-in day care services and facilities, e.g., YesterYears, that, at one and the same time, make life more tolerable for those who care for dependent seniors at home and, at the other, occupy and entertain the minds and hands of dependent seniors.**

Care giving spouses and children spoke enthusiastically about the value to them and to their dependent seniors of day care drop-in facilities like YesterYears. Yet, more than one participant regrettably noted how the scarcity of available times and/or days at such facilities made their lives (and the lives of those for whom they care) more difficult, often disrupting work or other important schedules.

RECOMMENDATION: If a systematic assessment reveals that demand for day care drop-in facilities significantly exceeds the “supply”, secure those additional resources necessary to expand the availability of space and time at these vital facilities.

**4. ISSUE: Evaluate the knowledge about and prevalence of mental illness among those age 60 and above.**

Caregivers and professionals alike required prompting before commenting on mental health and aging. It is, as several participants noted, “not a subject we talk about”. However, as national studies reveal, more than 20 percent of those over the age of 65 suffer from some degree of depression. And an additional 10 percent of the elderly diagnosed with dementia may actually be suffering from depression. (University of Texas, Harris County Psychiatric Center) Yet, as some of our own participants themselves acknowledge, mental health and physical health are closely linked. The absence of remarks about mental illness among the aging cannot, of course, be taken as evidence of the absence of mental illness among the aging of Broome County.

RECOMMENDATION: Consideration should be given to a systematic assessment of the mental health of the senior citizens of Broome County. Efforts to de-stigmatize mental illness and conversation and discussion about mental illness among seniors and to raise public awareness of mental health and aging are probably appropriate and overdue.

**5. ISSUE: Recognize the benefits that social capital\*, (networks of relatives, friends and neighbor), can contribute to the physical and mental well-being of both care givers and to those for whom they care.**

Caregivers frequently mention the benefit of family, friends, and neighbors to the well-being of their dependent spouse, parent, or client. They also mentioned the costs of the absence of family, friends, and neighbors to the well being of their dependent spouse, parent or client. Care givers noted that talking with and listening to other care givers in the focus group setting helped them understand that they were not alone in their problems, experiences, and joys of what, for them, could be a lonely life.

RECOMMENDATION ONE: Utilize existing organizations and media (electronic and print) to educate those 45 and above about the benefits to physical and mental well-being of having or nurturing a network of relatives, friend, and neighbors.

RECOMMENDATION TWO: Initiate “visit-a-senior” or “adopt a senior” partner programs to promote more frequent and meaningful social interaction with seniors. Sources of possible institutional and individual partners for this enterprise include: high schools, academic institutions, neighborhood organizations, Boy and Girl Scouts, Boys and Girls Clubs, churches and synagogues. Work with neighborhoods and neighborhood institutions to cultivate social capital supportive of seniors.

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\*For an introduction to the research on health and social capital, see, for example, Robert G. Evans, Morris L. Barer and Theodore Marmor. *Why Are Some People Healthy and Others Not?* New York, Aldine de Gruyter, 1994; Ichiro Kawachi, Bruce P. Kennedy, and Richard G. Wilkinson, *Income Inequality and Health Volume I.* New York. The New Press, 1999; and The Institute of Medicine. *Health and Behavior: The Interplay of Biological, Behavioral, and Societal Influences.* Washington. National Academy Press. Washington, D.C., 2001.

**6. ISSUE: Provide for an enhanced public and professional awareness, early on, of the organizations and agencies that serve the senior community in Broome County.**

Care givers and (some) professionals lack a thorough, comprehensive knowledge of the organizations and services available in the county that advocate for and serve the senior population.

RECOMMENDATION: Prosaic approaches to increasing public awareness of services for aging, especially among professionals, include the obvious: meetings, coordinating committees, program and service guides that rationalize and systematize agencies and functions.

A more innovative approach to promoting greater service awareness would be to adopt a mode used in neighboring Tompkins County. In that county, AM-radio station WHCU runs a 15-minute program, "Senior Time", that each Sunday morning airs issues of concern to senior citizens. Staffed by broadcast-smart seniors, features include interesting and informative interviews with other seniors, government officials, agency personnel, university faculty, health professionals, *inter alia*. It is true that Broome County has no public service counterpart of WHCU (which, although now privately owned by Eagle Broadcasting, was originally owned and operated by Cornell University). Nevertheless, FCC policy continues to require that broadcast media operate in the public interest. A persuasive and credible proposal to a Broome County FM or AM station (e.g., WNBF, WINR) could well provide access to 15 to 30 minutes of broadcast time each week and at a time convenient for seniors, for Broome County's own edition and version of "Senior Time". Wisely and innovatively used, such a forum would provide an effective means to promote knowledge of issues affecting seniors and of the organizations and agencies available to address those issues.

**7. ISSUE: Facilitate quick, "one-stop" public access to information about and services for seniors.**

Broome County has a multiplicity of government and not-for-profit organizations that serve an aging public. Yet, those who want or need access to these agencies often do not know "whom to call".

RECOMMENDATION: Market the single "Senior Resource Line" telephone number. Marketed creatively and aggressively, the public, whether middle age or senior age, will know whom to call for information and services.

**8. ISSUE: Provide frequent, easily scheduled, and reasonably priced public transportation to seniors.**

Few people have ever been more "auto" mobile than have the people of this nation and, by extension, citizens of this county. With housing dispersed and with shopping and health care increasingly concentrated in dispersed clusters of suburban settings, ease of access to convenient transportation is as essential for life and no less so for the self image of those 65 and over as for those 64 and younger. Yet, as the population ages (especially the baby and echo boom populations), travel by auto becomes difficult, poses greater personal and social risk, and is likely to progressively be restricted by self (spouse or children), physician, and state or federal legislation.

RECOMMENDATION: Assess current and future demand for shuttle-like transport and, as demand justifies, secure those resources necessary to expand current dial-a-ride services to all geographic segments of Broome County.

## CONCLUSION

The populations of almost all industrialized nations are aging. By 2030 those over 65 will account for almost half of adults in both Germany and Japan. As *The Economist* notes: “The figures are pretty much the same for most other developed countries—Italy, France, Spain, Portugal, the Netherlands, Sweden—and for a good many emerging ones, especially China (“The New Demographics”, *The Economist* November 1, 2002)”. In the United States, the percentage of the population age 65 and above is projected to rise from 14 percent in 2000 to 23 percent by 2040 (“The Road Ahead”, *The Economist*, March 16, 2000). Comparable or even larger increases are projected for New York State and, within New York State, for Broome County. With almost one in five residents currently 60 and older, Broome ranks 17<sup>th</sup> among the 63 counties of the state. As the County Office for Aging has observed, this “older population will burgeon between the years 2010 and 2030 when the ‘baby boom’ generation reaches age 65” (BC Office for Aging [www.gobroomecounty.com](http://www.gobroomecounty.com)).

Earlier retirement, coupled with the extension of life expectancy, contribute to making aging a complex and service intensive process. It is thus a resource intensive process. A critical challenge to government and civil society in Broome County, a challenge that will intensify as the aging population of Broome County expands, is the extent to which we shall recognize and provide the economic and human resources required for all to age with dignity. How we meet this challenge will do much to define the future of aging within Broome County.

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## **A P P E N D I X   A**

### **Transcripts from Focus Groups** With:

**Focus Group with Spouses as Caregivers**  
**Monday, November 18, 2002**  
**2:00 p.m. – 3:30 p.m.**  
**United Way of Broome County**

### **INTRODUCTION**

Initial invitational telephone calls had been made to each participants during the early to mid part of October with a confirmation letter on Binghamton University stationary mailed within two days of the participant's "definite" acceptance of the telephone invitation. Each such participant received a reminder telephone call just days prior to the actual focus group itself on November 18<sup>th</sup>.

Fourteen individuals arrived for the afternoon group. All arrived prior to the requested arrival time of 1:45 p.m.; several actually arrived between 1:00 and 1:15 p.m., attributing their early arrival to either the necessity of their means of transportation or to a tendency to arrive early for most events. Upon arrival, each participant was asked to use the wide tip felt marker to print their first name on the provided tent cards and place the card in front of them so that the facilitator and others could see their name. Each participant was either a spouse of or a significant other to a loved one to whom they currently were providing direct care or to whom they had just recently provided direct care prior to the loved one entering a nursing home or assisted living facility. About half of the participants were male, half female. Occupational backgrounds ranged from a former structural ironworker to an attorney with about two thirds appearing to be middle or upper middle class. Participants seemed to range in age from the early to mid sixties through the early to mid eighties.

To initiate the discussion (at about 1:45), the facilitator introduced himself (Dick Rehberg) and his co-facilitator (Lorelle Vanno), noted their respective affiliations with Binghamton University, and informed the participants that the discussion group was

sponsored by the Broome County Office of Aging and funded by a grant from the “L” Wood Johnson Foundation. Dick briefly explained the purpose of the discussion as seeking to learn what services are or would be needed or useful in Broome County to ensure the widest range of options for individuals as they become senior citizens, options that include entering a nursing home or assisted living facility, on the one hand, or remaining in one’s apartment or home, on the other.

Mr. Rehberg noted that only first names would be used and encouraged each member of the group to participate in the discussion. He noted that twenty minutes into the discussion, he would gently ask any non-participant to share his or her thoughts with the group. Conversely, he noted that were anyone to seem to speak without pause, he would reserve the right to signal that individual to give others a chance to participate as well.

## QUESTIONS AND RESPONSES

- 1. (Paraphrase): Assuming two individuals are quite similar, what are the advantages and disadvantages, the costs and the benefits, of one individual entering a nursing home or assisted living facility, on the one hand, and of the other individual continuing to live in his or her own apartment or home, on the other?**

Although posed as a hypothetical question, and subsequently explained and reinforced as such, most participants addressed this question in a highly concrete, non-abstract mode. One might infer that living day to day as a spouse caregiver, their respective real-life situations were so dramatically apparent that they were unable to entertain this question as a hypothetical query.

Because of the “concrete” interpretation accorded this question, we shall provide a condensation of participant responses and then note the themes that describe those responses.

“A”, the first participant to speak, noted that “I stay at home; my wife’s in a nursing home’ cost—cost doesn’t enter into it [“A” probably means that cost did not enter into the decision whether to place his wife in the nursing home; it was a necessity with no choice]; she gets much better care [in the nursing home]”. “A” continues by noting that when his wife was at home, he was on duty 24 hours a day, 7 days a week caring for his wife and house. Now that his wife is in the nursing home, he is no longer required to give care 24/7.

After “A”’s very concrete reply, Dick asks the group to think about the question “hypothetically”.

“B” now observes that “I like to keep my husband at home; he was diagnosed with Alzheimer’s just this spring and I, ah, really don’t want to use all our savings for a nursing home. I will take care of him as long as I can; it’s a 24 hour thing’ he’s up during

the night”. When Dick asks about the costs/benefits of having her husband at home vs in a nursing home, “B” replies again in the concrete: “But I would prefer to have him at home; I want to know [all that he’s ??] doing”. Dick asks if the cost of her husband going into a nursing home might “eat up your savings” to which “B” replies “I would think so, yes”.

“C”—how about you, Dick asks; a hypothetical situation. “C” says “Well, I can look back now to my parent’s situation. My father tried to take care of her [his wife, her mother] at home; but again, as both “A” and “B” both said, it was a matter of they [her parents as they developed Alzheimer’s] has no real sense of time, and, ah, a good many times they are up at night . . . and it turned out that she would get up early in the morning [and wander about] before we put her in the nursing home; [once] she wandered about in Johnson City . . . around 7ish [in the morning] . . . and finally a policeman or a trooper, I can’t remember which it was, brought her back” “C” continues talking about the deterioration of her mother and parents. “But, under those circumstances, when an individual reaches a point, you’re becoming more exhausted that unless you can get some help you do have to weight what the costs are and what the costs are where they are under supervision 24 hours, or you will exhaust your [own] health”.

Dick attempts a summary to this point in the focus group: “From what I sense to this point is that in many cases there really isn’t an option, really isn’t a choice between whether a person goes into a facility or an institution, or remains at home; it almost comes to a point where staying at home become such a burden on the caregivers that it’s really not an option”. Dick asks the group if this is a correct interpretation of what has been said so far.

One or two participants reply that this is a correct interpretation.

“D” then tells his story. In essence, he has become the primary care giver to a woman who for some 22 years was his business partner until she began to develop Alzheimer’s three years ago. “D” says she is now on medication that appears to have stabilized her. “D” notes that she has sufficient insurance that he could have her in a nursing home at any time but “as long as she is able to function I am going to stay with her”. He does have the assistance of [his/her??] five children. “D” notes that she loves to play bridge and plays beautifully but cannot remember who dealt the hands. Again, “D” has addressed the question concretely, not hypothetically.

“E” says he has sort of a unique experience and proceeds to speak of the “Yesteryear Program that the Office of Aging has”. He notes that because she goes during the day, have her lunch there, goes every day but one, he is still able to practice law. “E” has a woman come to the home on that fifth day when his wife is at home and spend the day with his wife. “E” notes that if his wife is alone, she has nothing to do, so it is a matter of keeping her occupied. “While she’s occupied, she’s happy. She used to do everything at home for me, but now the role is completely changed. . . . Our relationship now is like parent and child, in many respects.” “E” describes his wife as having mild cognitive impairment and says that when she goes to Yesteryear, at the Northminster Presbyterian

Church, “she says that I feel like I am wasting my time [at the Church] but, yet, when she’s there, she enjoys that, and I think that the socialization is the thing that is very important. . .” Dick notes to “E” that because of the Yesteryear program, he does have a choice [to institutionalize or not] and “E” agrees that he does have that choice because with the Yesteryear program, “she is not home alone and she is happy with life”. And, “E” says he too is happier with life because of that program.

“F” notes, as we are closing out this question, that “timing” is sometimes the issue. She recounts that she has cared for her husband for over years after he had a stroke with right-side paralysis and an inability to speak. But then, “F” continues, “my health started to fail, so because my health was going down hill and I was wondering who was going to take care of him if I die first, last March I did place him into a nursing home . . . to preserve myself and what years I have left and he has so much more entertainment in the facility [to keep his mind alive] than he had sitting in the chair in my living room just staring out the window”. “And I feel he has a better quality now than he would have with me. . .”

### **Interpretation**

The discussion of this question continues in this manner with participant after participant describing his/her own life situation as a caregiver. Virtually every story glistens with love, devotion, caring, compassion, and sacrifice. But each participant apparently is living so intently in his or her own concrete world of the present that he or she is unable to address the question at a conceptual, at an hypothetical or an abstract level.

Many participants do not seem to view the institution vs at home alternative as being one of “choice” for them. For many, it was (or is or will be) a reluctant decision borne of absolute necessity. Devotion, sense of spousal obligation, and ultimately the necessity of the care giver to preserve one’s own physical (and, secondarily, mental) health seem to be the determining influences on when to take the ultimate step of institutionalizing one’s spouse. Finances do not appear to play a critical role in this decision. Only when the burden of caring for the spouse becomes absolutely overwhelming and/or places the caregiver or spouse at significant physical and/or psychological/mental risk do the “duty” and “moral benefits” of caring become so great that a decision, however reluctant, is made to place the spouse in a facility.

**N.B.: At the end of the discussion of Q. 1, there was a spontaneous “discussion” about whether a three day stay in hospital is necessary for the individual to qualify for Medicare/Medicaid (participants were not sure). Suggests that there is a need for information about eligibility criteria.**

- 2. What can the *individual* do, either *prior to or on becoming* a senior, to influence whether they will be able to remain at home?**



As with responses to the first question, responses to the second question were more concrete than abstract, drawn more from personal life experience than spoken from a conceptual perspective.

“G”: (Dick asked her to begin the discussion to this question.) She replied “I don’t know. I mean, I have him at home. Five years [ago] he was diagnosed with ???, Parkinson’s disease, last three years [indecipherable] there have been three doctors who have wanted to put him in a nursing home. . . .”

Convinced that either participants had misunderstood the question or that as asked they would continue with their concrete, “personal stories”, Dick re-asks the question.

Dick: “Suppose you were 45, 50, 55 or possibly 60 and looking at the years after that . . . ah, as you’re looking at becoming a senior, what could the individual do to increase their chances of really having an option to remain at home or entering a facility. Or, let me rephrase the question: what can the individual do at home to *avoid* having to enter a facility? How could one prepare for being a senior citizen so that one could have *all* the options available to you?”

“H”: “You can try to improve your health, take care of yourself, eat properly, exercise, see the doctor regularly—then you will ensure that your health will be well enough that you can stay home for a length of time”. “Another thing, now this is the reverse side, to make it more practical that you can go into a nursing home . . . is to take long term insurance. We have done that but the amount of the insurance coverage . . . [is minimal].

Participant [Male?] “I would look for options that would ah, as far as long term insurance, would provide greater benefits for home care.

Dick now calls on “I”—who has not participated. “She mentioned healthier life styles and long term care insurance and all that is important”. “I” is a retired iron worker says it took him 3 to 4 months to file for Medicaid. Says his wife never wanted to end up in a nursing home. “I” cares for her [paralyzed on one side]. “Highly conscious about everything around her”.

Dick rephrases the question again: “If you had your life to do over again, what around age 45 or 50 would you do differently so that you would have the option of entering a facility or staying at home”?

Participant [Female] says that at age 45-50 “We weren’t thinking about things like that [at age 45]”.

Another female participant says that at 45, one does not think about such things [retirement, having the option to remain at home, going into a nursing home].

Participant [female]. “Keep your health in check. The insurance . . . long term care would be too expensive [at her age now], you couldn’t afford to do it”. Uh, I think this

generation coming up is much more aware . . . [of the necessity to plan for and prepare for becoming seniors]. “So my husband, he had a stroke at 59 and he was forced into retirement, our income basically zapped—kind of the job he had, you know, had no retirement. So I think that this generation is going to be different”.

“J” (Dick calls on her). “Well . . . my son and daughter have built an apartment over the garage [for the time when we may need to leave our home].”

Dick: “It is interesting. I have been listening to each and every one of you and no one has said anything about depression, and yet isn’t depression a problem among people 60, 65 and over?”

Participant [female]. “We don’t like to admit it”.

Dick: “What might we do in the area of mental health . . . ?”

“K”: “I think every day I ask what am I preparing to do for the worse . . . “ We [she and her husband] swim half a mile three times a week, take the bus, I know many a day my husband could care less about going but he does it for me; he has his music and his games. But I am wondering what I should do [for myself] to get ready [for both mental and physical health]. I have read some of the books, but I don’t finish them, I don’t want to know about what’s coming, I know all the details in the books [but] what can I do about them?”

“E”: “Exercise, I exercise; she hasn’t, so I got her started up at the health center at Hilltop, once a week for an hour or so. Another thing you can do is over at Binghamton University, the students have recitals in the afternoon and she [the person who cares for “E”’s wife] takes her over there. I think activities are important to keep a person from depression”. “Stimulation”.

Dick: Summarizes responses to Q. 2. and supports more discussion.

“E” [the attorney] says “transfer assets” referring to the 3 year prior spend down period for Medicaid eligibility. Notes that “a lot of people don’t want to give up control of their assets”.

Participant [Male] We are giving each of our children \$10,000 a year. In good humor, “E” notes you can now give \$11,000 a year.

“H”: Observes from personal experience that sometimes depression cannot be avoided, it just comes on.

“E” suggests that “H” get Garrison Keeler tapes for her husband, saying that his wife [with dementia] so enjoys them.

“K”: “I think we should talk about what it is that we should ask our children to do”. “K” says she would [have] advised them . . . I have two who are unemployed, are fiftyish, I keep telling them that when I entered my fifties, I had a retirement fund, health insurance. . . ”

“L”—tells part of his fascinating life story [but not all that relevant here, but interesting if you want to listen to the tape]. He says, in essence, that his philosophy of life is to live today for today and to die broke, “don’t take away from yourself to save for your kids”. “I have had the happiest damn life . . . I have never been sick”.

Participants (some) now begin to talk (reminisce) among themselves. Dick allows this to go on for a few minutes.

### **3. Based on your own experience . . . , what can *family and relatives* do to influence whether one enters a facility or remains at home?**

Participant [female]. (Paraphrase) I think that the parents can indicate to their children what they, the parents, want to do if and when the decision has to be made to enter a facility or to remain at home. “Know what the person’s desires are”.

“I”: “You get help from your family and your kids, but . . . you don’t want to overtax your kids [with your needs].” “I” comments that from what he knows and has seen over the country (he is an ironworker who has traveled the US extensively), “only about a third of them [nursing homes] are any good”. “At home, that’s the best place, if you got no choice (sic), then it’s the nursing home”.

“K”: “In today’s culture, too, the children are all over the world; they don’t stay in your neighborhood any more, so they can’t physically help you”. “My children are out of town, so they can’t help you, I don’t want to burden them”.

Participant [male]. “. . . I have three [children]. My youngest daughter lives just down the street from us, but I can’t put all the load on her, her sister lives out of town, I don’t want to do anything to jeopardize their relationship [with each other] if one feels they are put upon, it could blow up. . . ”

“I”[?] “If you put too much of a burden on them [your children] they don’t want to have nothing to do with you then”. “. . . have less and less to do with you [if you put too much of a burden on them [your children]].

“E”: “One of the problems that I see is that we have a lack of people to come into the home to help people, care givers and if we do have them, the cost is such that people can’t afford it. It seems to me that our government . . . [should make some provision for this situation to allow home care providers, on an individual basis, to work and earn money but not be overly taxed for that money]. “E” notes too that some home care workers [freelancers] want cash [so that the money cannot be traced]. “Government

should make it especially, to encourage, women whose husbands have died and want to keep active and want to do this kind of work . . . government should encourage them and maybe exempt them up to certain amount from [earnings][taxes] so that they could supplement their social security.”

A discussion about the quality and/or reliability (or lack of same) of home care assistance and help ensues. One woman begins to weeps as she recounts her situation. A number of participants recount their personal stories/experiences within this context. Dick allows this to continue for several minutes. Some of the participants constitute a real challenge within the context of focus group procedure, seemingly determined to use this forum, this convivial session and setting, to speak, to share with others, the trials and tribulations of their respective lives. Several participants in this [spouses] and in the child care giver group comment to me, privately, after the session is over, how much they appreciated the opportunity to tell their stories, to hear the stories of others, and to know, from this experience, that there is not a life lived alone.

**4. What are the major obstacles . . . that keep people from being able to stay in their homes?**

Because of the pressure of time, Dick decided to skip this question.

**5. What kinds of services are available *here* in Broome County that enables people being able to remain in their home rather than having to enter an assisted living facility or nursing home?**

Various participants begin to enumerate, and, at the mention of each service, Dick asks for a show of hands vis a vis how many of the participants are aware of that particular service.

“Meals on Wheels” (Almost everyone know of Meals on Wheels)

“The Disability Bus”, actually, as one participant points out. “BC Lift” Several participants remark that the cost for BC Lift is \$2.00 each way. About two thirds are aware. Some confusion about whether there is a user fee and/or whether the caretaker rides free. Question is asked about how far in advance one must call to make a reservation for BC Life. Notes that it would be better if one could make an almost instant reservation because at times one does not know all that much in advance if one has to use BC Life.

“Catholic Charities Van” “\$12.00 a day—that’s for the van and your meal(s) all day.” “Just got notice today that it went up to \$14.00 a day.” Again—confusion among participants regarding cost or costs. Difficult to know how many are aware of the Catholic Charities Van.

“Senior Day Care Center” “Yesteryear”. “E” says that there is such a need for these senior centers, they need to be expanded “because they can only take my wife two days a week to begin with and then as somebody drops out you can increase your number of days.” One female participant observes that “there’s two of them, one in Binghamton [Isabell Street], one in Johnson City, and one at Northminister Church.

Another participant mentions that Susquehanna Nursing Home will take persons on a daily basis—at \$59.00 a day. Says one participant: “The girls at the Day Care Centers cannot dispense medication, Susquehanna is, Registered Nurse, so they can administer shots—diabetics or whatever and so it costs more . . . “

Participant [female]. “I want to say something. Office for Aging, Broome County, has a booklet—all kinds of information in it and they give it to you for nothing. . . .” Dick asks how she learned about it and she replies “I go to a caregiver support group . . . at Lourdes Hospital once a month and they . . . facilitated by one of the Office of Aging—she’s the facilitator, one of their employees—and they bring in the booklet and give them to us”.

Participant [male]: “First copy I ever got—they had at the Arena year’s ago.

Asked how many are aware of the BCOOA service guide, virtually everyone indicates that they are.

Dick: “How many know about the BC Office of Aging?” Laughter. Everyone knows!

“CASA” [Participant—male]. “They’re good for referral”. About two thirds knew of CASA before the session.

“K”: “They have a tremendous number of pamphlets at the Office of Aging and they have all the time in the world for you.”

Dick: “What is your experience with the Office of Aging?” “K” says she saw it develop, she speaks exceedingly well of the BCOFA.

“K” mentions the Lyceum. “E” says that the Lyceum is another thing that should be mentioned. Dick asks how many know about the Lyceum. About a third know about the Lyceum. “K” says she started the Lyceum—14 years ago. An brief explanatory Q&A proceeds about the Lyceum. Dick volunteers to take names and addresses of people who are interested in more information about the Lyceum and give it to a representative.

“C”: Notes that services for stroke victims are not well publicized but need to be. She wonders whether physicians do as much as they could/should to provide information to caregiver spouses about stroke, Alzheimer’s, and other disabilities. “It is difficult when you first get into some of this to know where to go . . . ?

**Focus Group with Children as Caregivers**  
**Monday, November 18, 2002**  
**7:00 – 8:30 p.m.**  
**United Way of Broome County**

**INTRODUCTION**

Initial invitational telephone calls had been made to each participants during the early to mid part of October with a confirmation letter on Binghamton University stationary mailed within two days of the participant's "definite" acceptance of the telephone invitation. Each such participant received a reminder telephone call just days prior to the actual focus group itself on November 18<sup>th</sup>.

Twelve individuals arrived for the evening group. All but one was female. All arrived prior to the requested arrival time of 6:45 p.m. Upon arrival, we asked each participant to print his or her first name and first name only with the wide tip felt marker on a 4 x 5 inch tent card and place the card so that their name was visible to the facilitator and other group members. Each participant was caring for a parent (or parents).

To initiate the discussion (at about 7:00 p.m.), the facilitator introduced himself (Dick Rehberg) and his co-facilitator (Lorelle Vanno), noted their respective affiliations with Binghamton University, and informed the participants that the discussion group was sponsored by the Broome County Office of Aging and funded by a grant from the Robert Wood Johnson Foundation. Dick briefly explained the purpose of the discussion as seeking to learn what services are or would be needed or useful in Broome County to ensure the widest range of options for individuals as they become senior citizens, options that include entering a nursing home or assisted living facility, on the one hand, or remaining in one's apartment or home, on the other.

Mr. Rehberg noted that only first names would be used and encouraged each member of the group to participate in the discussion. He noted that twenty minutes into the discussion, he would gently ask any non-participant to share his or her thoughts with the group. Conversely, he noted that were anyone to seem to speak without pause, he would reserve the right to signal that individual to give others a chance to participate as well.

1. I want to talk about two persons, usually senior citizens, who are approaching the time when a choice is made about: 1) going to an assisted living facility or nursing home, or 2) continuing to live at home. Assume that there are two individuals. Both very much the same. However, there is one exception: one goes to an assisted living or nursing home; the other continues to live in his or her own home. In your opinion, what are the costs and the benefits, the

advantages and disadvantages of: 1) the assisted living or nursing home facility option, on the one hand; and 2) continuing to live in one's own home?

“A”: “Um, I think that the cost benefit would have to be predicated upon the health of the individuals. They would first have to have the physical capacity to function in the home environment and also the mental capability . . . . If they did [living at home] is a very viable form of living. I would probably [assume] three quarters or more of the people would want to continue doing that simply because it's the environment they're used to and secondly change, regardless of how society is today, is met with resistance. I think particularly as you get older, you have certain paradigms, live with certain paradigms, and it's harder to make a change.”

Dick: “So, there are benefits, I think you are saying, to the individual. Are there benefits to others, if the person remains at home . . . ?”

“A”: “When you say to other persons, do you mean particularly the immediate family or do you mean to the society at large?”

Dick: “Um—To whomever. You may specify whomever . . . .”

“A”: My only source . . . my father's wife passed away and my father suffers from dementia, so it was really a matter where he didn't have the mental capacity; became a situation there where there was no benefit. Actually it was a detriment to him [to stay at home] because working with stoves, toasters, other kinds of stuff, he put himself in danger . . . .”

Dick: “And the costs . . . ?”

“A”: “Well, I think we were trying to find the best fit situation, look into assisted living, it kept coming back that it was too expensive to do that, [they] knew he had assets that could be utilized for that function. \* \* \* They [“A”'s parents] lived out of state, they lived in Arizona, they would come back here once a year; they would tell us they would go back and look into it [nursing home/assisted living in AZ].”

Dick now asks “B” to speak: “B”—the costs and the benefits of entering a nursing home on the one hand or staying home, on the other?”

“B”: “Ah—I think one of the benefits—my mother is 90 and she still lives by herself, I mean she lives at home and I think that is difficult for the caretaker to constantly be there for her; my sister and I spend a lot of time with my mother, her meals, the laundry, but she does not want to give up that independence of living at home; but if she were in a facility where there are other people around, I think that's a social benefit. I think the social is a real benefit rather than being by yourself. She has macular degeneration so she can't read a book by herself; needs other people to stimulate her.” She lives in an

apartment with other people around her [in other apartments] but mostly she is by herself. We have a housekeeper who comes in twice a week, but she really wants someone there all the time.”

Dick calls on “C” “C”--costs and benefits of . . . to the individual, to relatives, to the relatives, to society?”

“C”: “Well I have ah, a brother and a sister who [unclear] 84 years old and suffers from severe depression . . . decided best thing would be in a nursing home. And, at first I thought he would get used to the place but he never did, strong will and physically a strong man and it never worked out for him. I couldn’t let him live in his own house [apparently at some distance from “C”] but I did not want to move to where he was and give up my children and grandchildren, so I said `Dad—would you come and live with me? [Difficult to make out but “C” refers to the necessity of him having his comfort zone and that it has been devastating to her.] And the man is 84 years old and . . . [becomes unclear at this point; another participant begins to speak . . . ] Well, what we managed to accomplish for him is that my daughters are both semi-employed elsewhere, my one daughter is self employed, so he’s [got one of them with him while I work during the day]. He has enough income to have [home care worker?] come in during the day and their job is to keep him happy and he likes to go to the social club, play golf.

Dick to “C”: “So the benefits then of living at home, not his own original home but his home with you, at least in this case, is that it provides him with some personal space and the opportunity to continue a life somewhat similar to what he was living in his own original home . . . “

“C”: “And loving family, daughters, great grand daughters . . . .”

Dick: As he bring responses to this question to a close, asks for any additional comments.

“D”: “My father has been living with my for 25 years. He was 72 when he retired and is now 97. He broke his leg in September and he had to have surgery and month and a half already [since surgery] and his whole personality has changed . . . well, from Lourdes he went into ??? and it was like he was a vegetable, they paid no attention to him; he is not a very sociable person, he is very quiet and I [kept saying] I had to get him home. [And the social worker said “Well, leave him here, Medicaid will take care of him . . . .” “And I said, I can’t do that, it was really heartbreaking.” “At first when he came home, it was like he was a whole new person, and now he seems to be in a depression again. . . .”

Dick attempts to summarize: “So would it be fair to say then that one of the benefits to the person remaining in their own home or the home of a loved one is that maybe it keeps their sense of who they are in tact more so than if they go into a facility?”

Participant [female]: “To a degree” Dick asks her to clarify. She recounts the case of the one for whom she cared, noting that “I think that staying home maybe longer than



[he/she/they] should have they are both now in a nursing home, and it was not by anyone's other than necessity as a result of just crisis [that they went into a nursing home]. \*\*\* "However [the necessity to go to a nursing home] cost both of them as well because I was the only child here that was given . . . and I worked . . . and I [ended up] going over each day to take care of them. My mother, in a lot of cases couldn't get out of bed and ah she was the supervisor when my father was the boss; he could do the laundry, fold up the clothes but my mother was the one who had to say [to my father] 'here's your medicine, take it now'. It had to be handed to him; when she became too ill he lapsed from taking his medicine; Parkinson's medicine—you cannot miss a dose without severe problems. So, in the end by trying to do that; everyone in the family said 'Mom and dad, consider this. . . ' We had Lourdes at Home and we could never count on those aides. If there is anything about this community—you asked about community—the aides do not have enough dignity, they do not have enough pay and we do not give them enough credit for what they do. And we had a hard time keeping aides coming in so we got so far out of hand that my mother was flat on her back, my father was on the floor for 4 hours and they both went to the hospital at the same time. . . ."

Dick summarizes: "So one of the advantages of remaining at home is that you honoring the person's sense of autonomy, but I think there comes a point where preserving that autonomy, that independence, comes at increasing cost to the senior himself/herself; so there's kind of a judicious point at which one has to make a decision that we no longer honor one's autonomy for the benefit of that individual."

Participant: "It had almost come to the point where we knew the other shoe was going to drop and we honored their wishes as long as we could and we said let's hope the crisis is not severe enough . . . but as "A" said, the change is so hard, my parent's couldn't even fathom . . . and especially when you have a debilitating disease like Parkinson's you need to know where your units are [reference to medications?] when you walk through the kitchen, you need to know where everything is, anything out of whack and he is a different man . . . ."

Dick: Question to preceding participant: "Did you feel a role reversal, a child becoming parent? . . . and that was awkward for you?" "And, it was obviously awkward for your parents?" "So, there's a cost that both the provider and the provided pay as you reverse the role of parent and child?"

Dick: Any other comments about the costs and benefits . . . ?

Participant [female]: "I am not going to talk about that but let me tell you that my mother calls me the "mother" now and herself the "daughter". 'Cause she's a hundred years old. We live together so I don't have any of those problems. I am retired with her and we live in the same house. And she has no problems—takes one aspirin a day, that's all she takes. Nothing wrong except her memory is a little, she don't (sic) remember people but she is happy with me in the house. If it comes the day that I couldn't take good care of her or if something happens to me then it is going to be a little different ball game. But she tells everyone that I'm the mother now and she's the daughter."

Participant [female]: “Even the . . . between spouses . . . . My mother had the ability to, mentally, to have the judgment [?] where my father in the final stages of Parkinson’s developed hallucinations and schizophrenia . . . [recounts an incident where her father took the car at night and drove wrong way on I-88 . . . before cops caught up with him] But to see this meltdown now with my mother who can’t sleep without an eye open [to keep watch on her father] . . . .

Dick—“So increased dependency of one partner reduces the autonomy of the other partner?”

Participant: “Absolutely, she [mother] kept saying she wanted to remain in her home for their independence. Now look at the situation. When they went into a nursing home, no one could believe [how] that they were intertwined—they were both each other’s care takers. . . .”

Dick: Asks for how many is [or has been] driving by parent’s a problem, an is”C”? Four of ten say it is or has been. Discussion proceeds to note that surrendering one’s license is tantamount to surrendering one’s independence. “A” comments that society should reinforce the fact that driving is a *privilege* not a *right*.

**2. Based on your own experience . . . what can the *individual* do before becoming a senior or on becoming a senior to influence whether they will enter an assisted living facility or remain at home?**

Dick states and re-states this question several ways in an effort to ensure that it is understood.

“E”: “The only thing I was thinking of was be aware of the services that can be available. That was, the case like my mother, I know that there is help out there, being aware that there are services you can get, what’s available in the community to help you make the adjustment. Being near some family?”

Dick: “How does one do that in Broome County, becoming aware of the services that are available?”

“F”: “Well, um, actually my mother was living in Syracuse when I first became aware of this, so I called the Office of Aging [in Syracuse] and . . . (indecipherable). So, I took that same idea here in Broome County and I found that it, that they hit the thread [?] travels much more quickly, much more efficiently, here [in Broome County] and I was in touch with individuals giving me support and have continued to. I just feel that if you just “Remember the Office for the Aging” [referring specifically to the Broome County Office for the Aging]. “F” tells story of how her mother goes to Yesteryear’s at the Northminister Church and becomes so socially stimulated that when she returns home she says [good humor] that her daughter is “boring”. [“F” talks more about her mother’s behavior while at home.] When she started at Northminister, everything changed, on

those days that she's there, she's so happy. [?!] In response to question from Dick "F" says her mother happily anticipates going to Yesteryear although her mother is not able to know the day of the week she will go [because of memory loss]. "She gets excited and happy because she gets individual attention; there's she's talking with people her age. . . ."

Dick restates the question: "What can we as individuals do, what can we advise a person age 45 to do to preserve one's options as one becomes a senior?"

Participant [female]: "There's two or three things that I have learned from watching my parents age that are common threads for all of us. And that is, staying with people, friends, with community? Because whether you are at home or in a home, that [family, friends] will become your support group. Plus staying active and actively involved in the community because you have a better awareness of what the services are, staying involved with people, staying in touch with people and investing yourself in your physical activity to help prolong whatever we are facing."

Dick: "Developing and maintaining a healthy lifestyle?"

Participant [female] I have a friend. He's in his 70s. He's invested in long-term care, at home, for themselves, so that they will not be a burden on their children and he has his whole policy set up."

Dick: "So—where possible purchase a long-term care policy that covers at least part of the cost of institutionalization but also provides enough money for you to remain at home to have services provided at home? Is that a fair summary? Participants seem to agree.

Participant [female] Can't quite understand what she is saying.

"A": "I think what is wrong with American society is that we don't have a love or respect for the aging. Look at some of the Asian cultures where ah the elders are respected and valued for their experiences. I don't see that in America. [Says how caring for his father has positively transformed him.]

Dick (asks "G" to share her thoughts): "My mother died when I was 25 [?]; my dad was (I am 38 now) 80 something, he does not speak English, he has no male friends, um, my mother was really his best friend, so when she died he totally depended upon her, [and after she died] I really thought that he was going to drive me crazy and I thought he wanted to drive me crazy . . . but, I guess, you know, that's not the case. It was his dementia that was starting. . . ." "G" seems to be saying that it would have been better were her father to have developed a network of friends rather than, as he did, relying almost exclusively on his wife and then on his daughter. But now he lives with me, he is 91, and my husband helps . . . . You really need a third person [referring to her husband].

Dick: Asks "How many of you here have dependents who participate(d) in Yesteryears? Dick counts about two thirds who raise their hand indicating "Yes".

Participant [female]: Asks whole group how many want *their* children to *plan* for them [the participants]? Mixed response.

Dick now asks about whether one should be sensitive to one's mental health (or that of the senior loved one). "How many of you find that depression in seniors is a problem? About 8 of 10 raise their hands to indicate a "Yes".

Dick asks "Are there things one can do to be sensitive to whether one is becoming depressed and if so what does one then do?"

Participant [female]. "I monitor my mental health. My mother suffers from clinical depression and I really believe that now she has [suffered] most of her life. I didn't realize that [earlier]. It scared me—when I see those traits [of depression] in myself. She's tried suicide twice and she get's that way every other week and she did today. And when I see myself straightening the towels in the bathroom or picking up lint—I begin to get worried."

Dick: "So how many of you are sensitive to yourselves or others of indicators of possible problems with one's mental health?" About half raise their hands to indicate yes.

Participant ["H"?--female]: "I don't know exactly where to begin. I related to [emphasized with] everyone here. In caring for my 88 year old mother, initially started out with more dementia type problems and then progressed to [more physical?] problems and to forgetfulness . . . and then I started intervening and it came to the point that, where, she would put herself in jeopardy . . . but it all happened very quickly, a matter of 5 – 8 years and; my mother is not my natural mother she is my stepmother but she is the only mother I have ever known and, um, regression, probably some of it was depression over the loss of her daughter and after that she could not maintain her home and I have a 28 year old retarded daughter and I was wrapped up in her and then I saw my mother . . . and, um, she was a very independent woman . . . but I know that all these changes in her life [help precipitate her current mental and physical problems]. She's retired, when she was working, that was her life; now she is lost, she feels now even at 88 still in her own apartment that she's not doing enough because she's not productive enough—she feels that I'm [referring to "H", the participant] the lazy one. "H" continues . . . .

"H" [continuing]. All the years she was in her apartment I encouraged her to go to the senior center but she wouldn't go because she said 'I don't have all that much in common with those people [at the senior center]' but I would say 'But, mom, you do. . . .'"

Dick remarks to the group: "I see some of you shaking your heads, yes, you have the same experience" 'I don't have much in common with those people'? [sentiment that has been expressed by the dependents for whom these participants give care].

At this juncture, Dick attempts to encourage "H" to end her remarks; however, "H" continues to speak and relate the later life story of her mother.

“H” relates how difficult she believes it is for seniors to accept aging and the limitations with aging. “But it has been difficult—the role reversal—but mom, things have changed . . .”

“H” continues with her story about her mother and is quite determined that she will tell her story. Many, many, “and then, and then, and then”. “H” is obviously a caring, compassionate, concerned, loving person with much to have others hear. She is engaged in a catharsis.

### **3. What can the *family and relatives* do to influence whether an individual senior enters a facility or remains at home?**

To expedite the discussion given the already elapsed time (about 20 minutes remaining), Dick offers a summary of “H”’s lengthy observations within the context *not* of what the individual but of what *family and relatives* might do to influence the decision of whether to enter a facility or to remain at home.

Dick’s summary: “The one who provides the care needs to be relatively knowledgeable about is”C’s of aging and about the services available; need at times to be directive in a firm sense with the senior; they need to be compassionate with the senior; they need to recognize that as the care provider they have their own limitations, their own vulnerabilities, and to know that when they react emotionally that some of that reaction is within the normal range of emotions [recognize that the caretaker him/herself is also human].” “What did I leave out?”, Dick asks participants.

Participant [female]: “I think that you have to recognize that you have to make time for yourself, that it’s OK to say I need time [for myself]. It is very important too for you to take advantage of what’s out there for you as a caregiver.

Dick [continues with attempt at summarizing]: “So you need to respect both the dignity of the senior, to communicate to the senior that they should respect your dignity and you, as a care provider that you as a care provider, have a right to your dignity.” Is that a fair summary? Participant adds: “And put aside your own guilt.”

“H” notes the need to recognize that caregivers need to recognize that, in most cases, the time will come when “they [the senior loved ones] are going to have to be in someone else’s care”.

Participant [female] recounts a story of her experience with her father in a nursing home the objective of which is to caution that a loved one in a nursing home needs an a loved one as an advocate, a protector, someone to protect the loved one from the unwise or improvident actions of the nursing home and members of its staff.

#### **Q. 4: Skipped because of time.**

#### **Q. 5. What services are available here in Broome County either for seniors or for people who provide care for seniors?**

Dick asks “C” (who has not had much to say) to respond to this question.

“C”: “Interim care, a woman three times a week, she would come in to do a daily bath, straighten up clothes.” Dick per “C”s the question of who provided this service and “C”, after some hesitation, says “CASA”. “Twin Tiers Interim” for physical therapy. “C” recounts her problems with attempting to secure and retain care to come to the home.

Dick asks “C” how she learned of these services. “C” says: “I talked with some of my neighbors, and they had experience, or I knew one that was in the health field and I said where do I go and [he] said ‘The Office for the Aging’ and so I called the Office for the Aging and I got more counseling from the woman I deal with there than my own husband would give me in a day’s time; more caring and compassion—Office for Aging—a woman who had never met me but who was so worried about my mental and physical challenges, um, I just love ‘em [Office of Aging].”

Dick asks “C” “Why do you think that you did not know of the Broome County Office for Aging but had to learn about through friends or neighbors?” “What could the Office for Aging do to become better known?” “C” comments that she thinks the Office now has a [daily?] column in the Press & Sun-Bulletin. “Actually, I knew about the Office for Aging but I was not sure what kind of things they could provide for me and I thought, well, you know, I am going to sound stupid, I don’t know who to talk to and what do I do when I get on the phone, these people may think I am whacko!”

Dick asks how many other participants may have had similar fears and concerns about calling the Office for Aging.

“I”: “Yeah, yeah, I was learning by the seat of my pants, I did not know who to contact.” “I” said she learned about Office for Aging “through the hospital”.

“A”: “I think, in all fairness to the Office for Aging, I think you have to ask at what time frame are we talking about that this agency is available. I think that they have done quantum leaps during the last couple of years as opposed to [before that].”

Dick asks “Is it that the Office for Aging has become more visible or is it that you have become more sensitive to the need for an agency like the Office [as they became caregivers]?” Participants, by rising voices, indicate that it is their increased sensitivity to is”C”s of seniors that has made the Office for Aging more visible.”

Participant: “I don’t think that it is that they are more visible, I think it is that period during my life that I have to do this”.

“H”: “Until we are faced with the situation, we know things are out there but . . . we have no reason to look”.

Dick asks: “Is there a single telephone number in Broome County that you can call as a general reference for any kind of help you may need?”

Participant(s): “First Call for Help”. About a fifth of audience is aware of First Call.

Dick asks: “How many of you know that the Office of Aging has a booklet that lists all of the agencies in the County that provide help for seniors?” About half so know.

Dick asks: “What other kinds of services are available for seniors and/or caregivers?”

Participant: “Golden Days Program” About a third know of Golden Days.

Dick asks: “What about transportation? What if you are a senior and need transportation?”

Participants: “Pick them up for the senior centers.” “RSVP” BC Life (about half know of BC Lift, some discussion follows about the cost and about whether and how much in advance you have to call BC Lift and about the conditions on the lift, etc.

Dick: Asks again for services.

Participant: “Action for Older Persons”

Dick observes: “Interesting, no one has mentioned Action for Older Persons.”

Dick asks “How many know of Action for Older Persons?” Less than half.

**6. What kind of services that you may need as caregivers do you  
*not* have available or that need to be improved  
here in Broome County?**

“A”: Day Care!

Dick asks for clarification—day care where one would take a senior or day care that would come to one’s home for the senior.

“A” replies that he was thinking of a facility where one would take the senior for sociability, for stimulation.

Participant: “Also the senior housing.” Participant talks about both shortage of actual physical housing space for seniors in Broome County and of waiting lists (up to 24 months) for what space is available.

Participant: Respite care.

Participant: “There aren’t enough people to provide respite care for people who need respite care.” Several other participants agree and tell stories of their own problems finding reliable help for respite care. Several speak of the low pay and low prestige of jobs that involving caring for seniors. One participant does speak highly of the compassion, concern, and care shown by some aides to her mother. “So, here’s an aide, the least paid on the staff, who is treating a “H”ient [mother] with compassion, love, and respect.”

Dick: Notes that it is now 8:32 and that although he would stay here another hour he promised to end on time. Proceeds with \$50.00 on-time arrival bonus drawing and payment of \$35.00 to each participant.

Session concludes.



## **Focus Group with Home Aide Caregivers**

**Monday, November 25, 2002  
2:00 p.m. – 3:30 p.m.  
Action for Older Persons**

**Richard A. Rehberg, Ph.D.  
Bartle Professor  
And  
Lorelle Vanno  
Research Assistant**

**Master of Public Administration Program  
Binghamton University**

Transcript of Audio Tape  
(with paraphrases)

### **INTRODUCTION**

Initial invitational telephone calls were made to prospective participants from mid October to mid November. Within two days of the initial call, confirmation letters were mailed to those who had accepted our invitation. Each such participant then received a reminder telephone call several days preceding the date of the actual focus group.

Ten individuals arrived for the Monday afternoon group. All were female. Seven arrived prior to the scheduled start time of 1:45 p.m., three arrived 10 minutes later, attributing their late arrivals to having just finished work. Upon arrival, we asked each participant to print his or her first name and first name only with the wide tip felt marker on a 4 x 5 inch tent card and place the card so that their name was visible to the facilitator and other group members. Five participants represented Lourdes at Home, 4 represented The Family and Children's Society of Broome County, and 1 represented Staffkings (sp?).

Just prior to the start of the focus group, Dee Dee Brooks took several digital photographs of participants, facilitator and co-facilitator. To initiate the discussion (at about 1:45

p.m.), the facilitator introduced himself (Dick Rehberg) and his co-facilitator (Lorrelle Vanno), noted their respective affiliations with Binghamton University, and informed the participants that the discussion group was sponsored by the Broome County Office of Aging and funded by a grant from the Robert Wood Johnson Foundation. Dick briefly explained that the purpose of the discussion was to learn what services are or would be needed or useful in Broome County to ensure the widest range of options for individuals as they become senior citizens, options that include entering a nursing home or assisted living facility, on the one hand, or remaining in one's apartment or home, on the other.

Dick noted that only first names would be used and encouraged each member of the group to participate in the discussion. He noted that twenty minutes into the discussion, he would gently ask any non-participant to share his or her thoughts with the group. Conversely, he noted that were anyone to seem to speak without pause, he would reserve the right to signal that individual to give others a chance to participate as well.

**1. Assume two very similar individuals: what are the advantages and disadvantages, the costs and the benefits, of one individual entering a nursing home or assisted living facility, on the one hand, and of the other individual continuing to live in his or her own apartment or home, on the other?**

“A”: “I think that, ah, they go into the living arrangements they get their medications on time, they get their meals on time, they have someone there to . . . [help them out of trouble] if they fall, whatever; but on that same stock, I have one that um . . . they like being home, you know, they feel safe there [at home] yes, you know lots of times the aide is the only one they see once a week and um she is really [referring to one of her cases now living at home] having a hard time deciding what she wants to do and she wants input from anybody she can get it from, and you have to do what's right for you; if you feel you are going to be better off getting the necessary vital things you need in life, like meals and that, not having to worry about things, getting your pills on time, because she forgets to take them, drops them, now—whatever is going to benefit you during the long run you're going to be healthy in the long run, you know, but [they have lived in their own home for the last 50 years] they're scared about changes. [Dick asks and “A” says that this person] has checked a few of them [assisted living facilities] out, yes, as a visitor.

**Dick:** “So the advantage then is that she would have her daily needs met on a regular predictable basis. The question is . . . “

At this point, “B”, a participant, enters the Conference room some 15 minutes late because of work so Dick takes a minute or two and repeats the question under discussion.

**Dick** asks [cannot decipher name] to pick up at this point.

**Participant**, commenting on the case presented by “A”: “I do, it’s not going to be something she really wants to do—the nursing home—so that’s why we’re there as long as it takes to help her out [in her home] but she’s lonely, you know, and the elderly need that association with other people [Dick says that she would have in a nursing home] right, it’s going to be an assisted living, I ah really think that she should do it but I am not going to force my opinion on her because that’s not what we do . . . “

“C”: “So you [Dick] are essentially lumping assisted living in with skilled nursing facilities. To me that’s two separate . . .”

**Dick**: “You may make that distinction if you wish. One of the problems we had is finding the right word. We could use the term ‘institution’ and the folks with whom we have been speaking so far really have not made the distinctions you are making, but you have more knowledge and expertise than many “civilians” do. So, if you wish to make that distinction, just make it so that the tape recorder can catch it.”

**Participant**: “Well, if you’re in assisted living, very often you will have someone, I am thinking in terms of like Ideal or Elizabeth Church . . . where they have the different standards of care, where you can progress depending upon your needs. So you get to go into an assisted living but you have your own space, you have your own apartment, cook your own meals, but have people around you; yes, that’s three different level of care actually, but as your condition changes you get to choose within that institution, you get to change your level of care.”

**Dick**: “OK—you can go from assisted living perhaps to skilled to something that amounts to total care and then you can have, I guess, ah, remain in your independent apartment but have assisted living in your independent apartment. So is that four levels?”

**Participant**: “No, that’s three: you have your independent apartment where they provide meals and you do everything else and the next level would be adult care where you get your meds and your meals and help with your personal care and then assisted living where they get even more with their personal care and then skilled care where they’re getting total care. So it is more levels.”

**Dick**: “And is adult care in your own apartment or is it in a more congregate kind of facility?”

**Participant**: “Both.”

**Participant**: “Plus, another thing the elderly don’t want to give up is that they know they’re going from a house to a space and they have to get rid of their belongings and I think that that is ah, the hardest thing for them to do; ‘Well, can I just take that one dresser and take this piece of furniture. . . .”

**Dick**: “So the cost to the senior may well be giving up the physical possessions each of which have an important symbolic value; a change to the ecology of their environment.”

Dick: “Any benefits to going to a facility?” “What are the advantages of going to a facility?”

**Participants** (various): “Companionship”, “Socialization” [means sociability], “Having people to help you with your medications, if you can’t see well, regulated care.” “Management of care.”

**Dick:** “And the benefits of living at home?”

**Participant:** “Costs—it’s definitely less expensive to keep, essentially, and our hope is that, it is cheaper to keep someone in their own home than to have them placed in a nursing home.”

“A”: “That is very true. I have a disabled daughter and cost is a big [factor].”

**Dick:** “Cost to whom?”

**Participant:** “Medicare and Medicaid, private insurance and sometimes family.”

**Participant:** “Sometimes to the private individual himself too.”

**Dick:** ““D”: you sit there with your head resting on your hand thinking.” “Ah, costs and benefits, advantages and disadvantages of staying at home vs. going into a facility?”

“D”: “People feel that they are giving up their freedom. Because you aren’t . . . and you do have to abide so much by the rules and maybe parking a car and going up and down an elevator, um, you know, . . . being a little more restrictive . . . .”

**Dick:** “Any other costs?” “Or benefits that we haven’t discussed?”

**Participant:** “I’ve seen a number of cases working in the nursing home--where one’s family places the individual—the family disappears . . . .”

**Participant:** “The emotional cost . . . maybe they [the family] feel that mom is just not well anymore so they don’t go to see her.”

**Participant:** “Sometimes it’s such a relief [to the family] when they place them, and the guilt the families feel . . . about placing them in the facility, it’s hard to deal with and sometimes they separate themselves rather when they should be closer so you know it’s a widening gap rather than a closing one; emotional cost is sometimes higher when they go in sometimes it does not outweigh the financial cost . . . .”

**Dick:** “What about the emotional cost to the senior . . . .”

**Participants:** “That’s always a guarantee.” “Some people fail to thrive once they [are in a facility]. [But some realize that] “I don’t have to cook any more, I don’t have to grocery shop any more, it’s great.” “Yeah”. “But, initially, the emotional cost is horrid; I really visit my patients that go into nursing homes but I give them six weeks before I go visit so that they can adjust, get used to being there, get used to me not being there [in their former own homes] on a daily basis, whatever, but it gives them a chance to adjust so that when you do visit you’re not getting just ‘Oh—woe is me’; you try for an opportunity to . . . about the positive side of that ‘Now, tell me something good about this joint. . . .’”

**Dick:** “So—there’s a period of adaptation that many seniors go through, self pity . . . .”

**Participants:** “I don’t think its self pity, it’s grieving.” “The loss of their home.” “It’s a part of their life they’re never going to go back to. No matter what happens, you cannot go back. Exactly. It’s just another step, another mile, on the road in life.”

**Participant:** “I sometimes tell them when they go that: “Oh look, you are 93 years old and you have faced a lot of changes in your life and you have adapted to every single one of them so far, this is just another change in your life and you need to . . . adjust to.”

**Participant:** “Change is never easy; there’s always a cost”

**“A”:** “I don’t like change. I don’t like change”

**Participant:** “There are not too many people that do [like change].”

**Participant:** “My mother-in-law had a home for the elderly and they were, like, pretty high functioning so she had a rule that when people came to live with her the people [relatives] did not come to visit for a week because of the adjustment period because . . . when you get into these places it’s the basic fear of the unknown; they don’t know what’s going to happen where they know at home what’s going to happen day after day; they may be bored to tears and they may be terribly lonely and that’s what they know so that’s why they want to stay there. But some of them get into a facility and they have people their own age, their own life experiences they can share with so much that they do beautifully.”

**Participant:** “I figure if nothing else, they could argue with each other; they’re communicating; reminiscing.”

**Dick:** “Ah—so you kind of make a point of not visiting them for the first month or so because if you do . . . .”

**Participant:** “You’re going to bring them home . . .

**Participant:** “I initially wait 4-6 weeks before I go to visit [one of my former clients] because by that time they get a chance to adapt to somebody else and find a new best friend.”

**“E”:** I think that something . . . that has to be recognized is with that whole thing with whether a home or a facility is appropriate for a person is what their life style was like at home. If they were somewhat isolated person, then nursing home or facility where they’re going to have a lot more interaction and socialization is not going to be the most appropriate setting for them. They would be far better staying at home and having some people come in and—intermittent care givers in their home vs. a constant 24 hour type care that is provided at a facility—not being able to have their space with people away from them when they want to be left alone in a facility is a lot more difficult than what they can do at home. So knowing their past socialization is an important piece of . . . .”

**“E”:** “. . . so knowing some of that past history, sometimes at home, those same needs can be met as long as a nurse or an aid or caregiver whatever is aware of their likes and dislikes their needs can be met at home without having to go into a facility.”

**Dick:** “Any other comments on costs and benefits of staying at home or going into a facility?”

**“F”:** “I have an uncle who is 93 and I have him in a facility, um, I am so relieved that he is there because the man, he still gets up at 2:00 o’clock every morning; he was a farmer; and he gets in the shower and I was scared to death that he was going to fall in the shower and break something and be there for hours and hours before anybody found him; he has Parkinson’s disease; . . . I am so relieved that he is where he is and so they give him his meds he is going to eat properly; I have not abandoned him but I was so afraid I was going to get that call at 3:00 o’clock in the morning ‘help me’ drowned in the shower because I couldn’t get out . . . But a lot of families are very relieved [when their loved senior goes into a facility].”

**Dick:** “So that the benefit to the family is knowing that the loved one is physically secure, cared for and then if something does happen probably that will be discovered soon enough that they will take appropriate action. Any other comments?”

**Dick** asks how many participants know each other. Raised hands suggest 6-7 of the 10 know each other.

**2. Based on your own experience and observations, what can the individual, him or her self do either before becoming a senior or at the time of becoming a senior to influence whether they will enter a facility, on the one hand, or stay at home, on be able to remain at home, on the other?**

**Or—suppose you were giving advice to a person 45-55 years old about how best to preserve his or her options**

**When they become a senior. What advice  
would you give?**

**“G”:** [Dick says ““G”, I don’t think I heard much from you yet.”] “G” responds: “Knew you were going to ask me this question. Probably—taking care of yourself, your health, um, take care of yourself physically, prepare financially maybe, insure, nursing home insurance—long term care insurance. . . .”

**Participant** comments and others agree about long term care insurance: “Very expensive”

**Participant:** “I think that the biggest thing is to research the options about what’s out there. I think that by the time people get to the age of 70 or 80 or whatever, where they really do have to make those choices, they don’t know the differences in the levels of care; they often start at home care because they have an acute hospitalization and the hospitals often try to get people cared for at home if that’s an option instead of being placed in a facility but by then they are thrown all these words like *ALF* which is assisted living facility and *boarding home* and whatever and these options that by that time is too overwhelming for them to know so at 40 or 50 that’s when the people should be presented with ‘This is what a boarding home can do, this is what an assisted living can do and where people fall to be placed in those groups.’ And also, there’s a financial piece to all that too—if by the time you’re that age and need to go into those and you are already a Medicaid patient, uh, it is much more difficult to get into one of those facilities. There’s also certain scoring mechanisms that have to be applied to a person as to where they fall and, what type of skill level of care, um, and people have, I know, no idea of what all that means, um, obviously the professionals that do that scoring and placement do know but certainly the people do not at the time they actually need the care.”

**Dick:** “So—research at an earlier age . . . “

**Participant:** “But even the community explaining those options, I’ve worked in other states and even from state to state to state the health care system is not a widely known ‘How to use it’ is I guess the best way to explain. It’s not consumer friendly.”

**Dick:** “Why do you suspect that it’s not consumer friendly?”

**Participant:** “Because most people don’t want to talk about it.”

**Dick:** “But that’s from the perspective of the customer, as it were, if we talk about the health care system being not consumer friendly we are talking from the perspective of the provider or the seller.”

**Participant:** “Talking about the consumer—they don’t take the time to make themselves knowledgeable of the health care system because it’s one of those things ‘If I don’t need to use it, I don’t want to know about it’.”

**Dick:** “Or maybe its one of those things where since I don’t want to know about, maybe I won’t have to use it.”

**Participant:** “D Nile—More than a river in Egypt”

**Participant:** “One side of that is I see a big difference in communities too because I have worked in a younger community where the doctors were younger and they wanted to teach their clients. We have a very old base here in this area right here where the doctors are still viewed as God by some of these people and [a home care provider will ask the person] ‘Why are you on this medicine’ [and the person will reply] ‘Oh I don’t know, my doctor gave it to me’. A lot of people are afraid, they don’t know what to ask. They don’t know who to ask and we’re doing a lot more teaching now than we did when I became a nurse 25 years ago. I remember being called on the carpet for teaching a man how to slide on a board to put his butt in a wheel chair because he was going home the next day. . . and we weren’t supposed to teach him anything and now that’s our focus.”

**Participant:** “I opened a case on Friday and the woman had no idea what HEAP was, she had that lovely lavender Action for Older Persons folder in her house and had never looked at it. So she had been presented with the information but she didn’t ever . . . . Oh, I didn’t know that was there; it’s like, ‘Scream it from the roof tops’ We have all these different options but people . . . .”

**Dick:** “So I guess there are several issues: One is the motivation of the potential customer to actually seek information. Two is after they have the information to actually read it or to use it. And three may be that the information may not be that readily available or that easy to secure. Are there any other problems?”

**Participant:** “I’ve been on all sides of the coin . . . so I been on all the sides of the coin and I’ll be honest with you. Up until 5 years ago I knew the options were out there, but the family always decided, my kids are always going to be around and here for my needs . . . but then when they got to the point where one of my parents said, I am sorry but we’re going to a skilled level of nursing facility because we can’t handle it anymore at home even though “B” is there all the time. We need it. Sometimes they [parents] don’t ever get to that point of saying ‘Leave me alone, come in and check on me once in a while, I can still wash in the bathroom, I don’t need any help, I am a very proud person, and that has a lot to do with what we are talking about: They are very proud people, they’ve been handed the folder by an accidental input of . . . and now a crisis has hit and they’re looking at all these piles of paper work. And they [the senior] says, oh—yeah, I’m fine, once I get over this I can stay at home. And in the meantime their family members are saying to them ‘Things are really bad, why don’t we go check out these places’ [And the parent says] You don’t love me anymore, you want to place me in a nursing home.”

**Same participant:** “One more aspect is a lot of people in that age group, and I don’t care if you are 40 and have a disability and you need to go into a different level of care or whether you are 70 or 80 or 90, they get to that point where they think that an institution



is the final place [“Mortuary Manor” says another participant] because, you know what, I’ll tell you why: `From being on the other side as a family, you walk into a nursing home and you are given a stack of papers, which they have to do because it’s the state guidelines . . . and they ask you, the first question is `What funeral home would you like to go to if you should die?’—it is, it is one of the first things they ask you, so they’ve [seniors] have heard this from their friends who have gone into a nursing home and they’ve automatically assumed they have signed their death warrant . . . . Nobody wants to sign a death warrant.”

**Participant:** “Next time out it’s six feet under!”

**Participant:** “But I will say that’s not 100% the case. I’m lucky enough to work in home health, it is not always possible but if there is a strong enough care giver base, not paid individuals, but actual family members, that’s sometimes an option [to return to one’s own home]. There are some people who return home from those facilities, it’s a much smaller number . . . .”

**Participant:** “It’s the perception of the community [that going to a nursing home is a one way trip]. . . .”

### **3. Based on your own experience and observations, what can *family and or relatives* do to influence whether a senior enters a facility or remains at home?**

**“H”:** It’s a tough question. I had an experience with my mother-in-law and my father-in-law both; first my mother in law was in a nursing home for approximately 5 weeks, she went into the hospital that’s the one that sent her to the nursing home; they released her she came home and in the meantime I had my father-in-law at the emergency room at least once a week for five weeks; he’d go and they’d send him home. Because of insurance purposes, they could not diagnose him with anything in order to admit him into the hospital. The last time I took him they finally did admit him with pneumonia in one lung and he went to the nursing home and I won’t say which one because I . . . he didn’t get the care he needed, they would unplug his phone, the nurses would not come in when he rang the bell, was not getting the proper care, no exercise, could not eat by himself, he’s home now, I brought him home Saturday so his wife is there with him; she is unable to take care of herself, he has an aid that comes in 5 days a week 1 – 2 hours a day and the man can’t really do anything for himself. He’s not going back to the hospital and he’s not going back to the nursing home—it’s a matter of time. He has given up. He expects me to be there, he wants me there 24 hours a day; I cannot do this. I work, I have a daughter, it’s very hard.”

**Dick:** “Do you think he views himself as caught between a rock and a hard place?”

**“H”:** “Yes—he does not want to go on living. He has said to me: `Deb, would you go out there and dig me up a pail of dirt?’ Now that tells me one thing—the man’s given up,

he wants to die.” He cannot do what he used to do . . . [“H” talks further about his abilities but his lack of motivation to do much at all.]”

**Participant:** Talks of people who have gone to and returned from a nursing home; “Been there, done that, and am not going to do it again.”

**Dick:** “So in some cases, depending upon the individual, senior, neither the family nor relatives can do much.”

**Participant:** “There is a lot they can do in her [“H”]’s case, I don’t know what more she can do but as far as their home goes: make sure they have a bathroom facility on the first floor that they can get to, um when they get to the point you could obtain a hospital bed, a wheelchair, um make their facility workable so they can . . . you may have to [modify the home a bit].”

**Dick:** “Make the home or apartment physically accommodating to seniors?”

**Participant:** “Right. And get the equipment they need to live in that facility. And give them support that way and home care . . . .”

**Dick:** “And are you saying the relatives or family could act as an advocate, an information seeker to ensure that the senior has the information necessary to make a decision, . . . ?”

**Participant:** “Financially too. Some family members may have a lot of assets and they don’t want to spend a lot of money to the nursing home so they need to plan for that, give your assets to another family member . . . . [Or another (younger) member of the family] could do a room in the basement or an add on so that somebody’s nearby; its not their home [the senior’s] but at least someone is nearby.”

**Participant:** Advocates having children talk, early on, with parents about contingency planning for older age of parents. “What do you really want to do and how can we help accommodate that?” \* \* \* “There’s that whole generation thing where if my parents get old in their 60s, well I’m still going to have young children and I will be working full time and probably not available to them full time, I could not provide large blocks of time. I could not provide enough time of my day [to my parents were they to live at home with serious problems] . . . .”

**Dick:** “So are you saying that one of the things relatives may be able to do is to have conferences with parents before the time to make a decision, run out various . . . what we call scenarios and develop a set of plans among the family that if this happens we do this and if that happens we do that . . . ?”

**Participant:** “Right. I mean hopefully most of those things happen progressively, you know what I mean, it doesn’t just automatically hit [pop] time and tomorrow we have to

do something tomorrow. . . . Most of the times when decisions have to be made fast, you don't get all of the options you want . . . .”

**Participant:** “Living will . . . .”

**Dick:** “So—prepare all of the necessary and appropriate legal documents to anticipate the future?”

**Participant:** “I want to point out that a lot of people have the perception that nursing homes are deep, dark dank scary places and I think that . . . there are some very nice nursing homes at there that are beautiful, the care is very good but I think that people have to go and see that so that they [seniors] say `Oh, this is nothing like I thought it was going to look like, its pretty and the rooms are bright and cheerful. . . .”

**Participant:** “I agree with her”

**Participant:** “[Nursing homes need to] get better at marketing themselves in the community; . . . doing something like tour types of things, so that you could actually see some of the facilities.”

**Dick:** “So one thing [the children] could do is to take their parents on a tour of nursing homes like you took your kids on a tour of colleges.”

**Participant:** Notes that there are some seniors like her mother who don't even want to think about nursing homes.

**Participant:** Tells story about her younger disabled daughter whom she took on a tour of nursing homes.

**4. From your experience and knowledge, what services are available here in Broome County that facilitate people being able to stay in their homes so that, if they wish, they may avoid entering a facility?**

**Participants:** Home health aides.

**Participant:** Licensed home health agencies.

**Participant:** Meals on Wheels

**Dick:** Asks for definition of “Certified Home Health Agency” and a “Licensed Home Health Agency”. Participants proceed to explain the difference.

**Participant:** “The only difference is that a licensed agency cannot fill Medicare prescriptions and a Certified home health agency can. Licensed agency has to bill the

client directly, [certified can bill through Medicare]. Discussion of differences proceeds another several minutes.”

**Dick:** “What other services are available in Broome County that permit people . . . ?”

**Participants:** “Social and medical day care. Day care, Meals on Wheels, Office for Aging, Personal shopping services, Link-to-Life emergency call buttons? Some clarifying discussion follows.”

**Dick to “I”:** “What kinds of services are available in Broome County . . . ?

“I”: . . .

**Participant:** “Transportation. B.C. Lift.” Some clarifying discussion proceeds about cost and need for appointment for BC Lift.

**Participant:** “There’s also BC Country for persons living in outlying areas . . . .”

**Participants:** “HEAP, Electric, HUD, Subsidized apartments.”

**Dick** asks about waiting lists for subsidized senior apartments.

**Participants:** “Oh Boy!!!” “Major waits—months, years. Years.”

**Participant:** “So in other words, if you are 50 and want to get it [subsidized apartments] sign up now!”

Participant: “I’ve got clients who have said ‘I had to wait for somebody to die to get this apartment’ . . . .”

**Dick:** “What other kinds of services are available?”

**Participant:** “Golden Days—a medical day care program run by a registered nurse; one of the programs that is offered through a long term home health program. For Medicaid eligible people but other people can get it . . . . [Provides] socialization, mom can go to this place which is at a local nursing home and receive her medications there, they have a hairdresser there, a nurse to do simple wound care . . . so all the care they would get at home they are getting there.”

**Dick:** “Any other services?”

**Participant:** “YesterYears.”

**Dick:** “Operated by?”

**Participant:** “Office for Aging. That is a social day care program, not a medical. Have to be able to toilet themselves, ambulate, . . . .”

**Dick:** “Is there a charge for Yesteryears? A charge for the food separate from the day service, as it were . . . .?”

**Participant:** “Through social care at Yesteryear’s its [food] provided by Meals on Wheels. It’s at two sites—JC and ??? At Susquehanna Nursing Home, that’s were Golden Days is, they are provided a meal through the home facility . . . .”

**Dick:** “Any other kinds of services . . . .?”

**Participants:** “Senior citizens centers . . . Broome County, like Vestal, each city may have their own . . . . Again a place for a person to leave their home and go to for a few hours . . . .”

**Dick:** “How about CASA? No body mentioned CASA.”

**Participant:** “She [referring to another participant] said CASA.”

**Dick** [in feigned whisper]: “Why has nobody mentioned Action for Older Persons?”

**Participants:** “You know, we were waiting for you. We do not know a lot about it.”

**Dick:** Says to participants how few people in all the focus groups knew of AOP.

**Participants:** “We are not exactly sure what they do. . . . But what does it do? A referral service?” Discussion proceeds for several minutes with Lorrelle Vanno providing some clarification of Office for Aging and Action for Older Persons.

**Dick:** “What about Catholic Charities? Do they have a van?”

**Dick:** “What does a senior do, what does the son or the daughter of a senior do if they know nothing and suddenly they find themselves in the position of having to find what’s available in the community?”

**Participant:** “Talk with the Discharge Planner. Usually happens after a crisis.”

**Participant:** “They [Office for Aging] have a service book with all the services.”

Dick asks how many know about the Lavender book.

**Participant:** About 4 of 10 participants raise their hands to indicate that they know of the Lavender service book.

**Dick:** What about First Call for Help?

**Participants:** “That’s more like a psychiatric type of thing.” “If you are in a crisis and just don’t know where to go.” “For younger people. Seems like from their publicity they are for people under 50 or for those even having trouble with their teenage children.”

**Participant:** Talks of a referral service that was once available to individuals as they moved into or away from area based corporations that would find services for aged parents. Not sure if such referral service remains available.

**Participant:** “Lourdes at Home maintains a referral service where people from the community can call and just have questions like where can I hire a private aid for my mom . . . . People learn that when they go to the hospital. It’s in the Lavender Book.”

**Dick:** “Seems to me what you are saying is that many seniors enter the system through the health care system. When they are in crisis. But if they don’t enter it through the health care system when they are in crisis then they face this myriad of services about which they may then know nothing . . . .”

**Participant:** “They wait until a week when they haven’t had anything to eat and then they get into the health care system . . . .”

**Dick:** “So—then chronic situation become acute.”

**5. What services are not now available in Broome County that should  
or ought to be available to help people make the decision  
about whether to remain at home or enter  
a facility?**

**Participant:** “A consumer counselor who can take that call from anybody, like the referral service, so that they can start making intelligent choices. You know, it can come from the doctor too—you may want to think about these choices. I ran up against . . . I can’t get my mother to think about it, the doctor has to start teaching more, in the office, about what you need to think about, the choices that are available, you ought to think about before the crisis.”

**Dick:** “So what we are saying is that the physician needs to do a better job than you perceive they are doing in preparing people for becoming senior citizens. About not only options with respect to their physical health but to everything . . . .”

**Participant:** “But, the doctors themselves don’t know the difference between independent living and assisted living programs, adult care facility and skilled nursing facility—they don’t know that themselves.”

**Dick:** “Now, what do you think the response of the physicians would be to . . . .”

**Participants:** “It’s not our [physician’s] job!” “We have to put so many products through our office per day . . . .”

**Participant:** “So if we can’t rely on the doctors, maybe they should hire somebody in the office to do that . . . . Cause they [the senior] are going to listen more to what the doctor has to say than to any other family member . . . .”

**Participant:** “A doctor should have somebody in their office, a case manager or whatever, to delve into those services . . . . Maybe the doctor doesn’t have the time but somebody else needs to and then maybe coordinate that with the family . . . . I think it would be a lot better accepted before it’s a crisis.”

**Dick:** “Any other kinds of services that should be available . . . .”

**“B”:** “Yes—there are certain attorneys that will do classes and workshops [on estate planning, etc.] for children and their parents—for free--. And it is really kind of helpful, plus you don’t have to get attached to the attorneys; at least they can give you something to think about. You really should have a good estate attorney ahead of time. And we found that out with our parents. Shop around. They need them in the outreach [rural] areas.”

**Dick:** Asks how one learns of these conferences.

**Participants** respond that some law firms do advertise but the TV spots may run at 12:30 a.m. when seniors are in bed. Also note that some ads are in the newspaper, in the Shopper Service . . . .

**Dick:** “How well do you think the television and radio media in this area cover issues of senior citizens?”

**Participant:** “Response is, generally, that they do a good job; some note Karen Iby’s MedBreak, etc. ‘BNG seems to do a good job.’”

**Dick:** “Nobody so far has spoken about mental health.”

**Participant:** “That’s like clergy—it’s right up there with them.” [Dick does not know and does not clarify whether her reference is to “up there, as in Heaven, or “up there” as in the sense of pastoral counseling.

**Participant:** “Are you talking about mental health services that are available?”

**Dick:** “Well, it is just interesting that, it is my understanding that depression is a condition that affects a good percentage of seniors . . . .”

**Participant:** “I think why you do see it more from this group [discussion of mental health] is because we are the one’s who get it more for them than anyone else.” When

asked by Dick “get what”, participant replies “Medical social worker” [to attend to issues of mental health]. And I would say that the percentage of people [seniors] who get medical social workers is high . . . .”

**Participant:** “When they [seniors] go to the doctors, the minute they go to the doctors, he gives them Zoloft. No matter what’s (sic) the problem is . . . .”

**Dick:** “Do you think we pay enough attention to preventive mental health—for seniors?”

**Participants:** “No, No, No. No. It is something they don’t want to talk about.” Brief discussion proceeds about difference between boredom and depression. Participants note that many of the older generation view mental illness as a personal, as a moral weakness, as a failure to handle one’s daily problems of living and not as an illness qua illness to be treated as one would treat a physical ailment or disease.

**“B”:** Notes that some seniors take the posture: “I have a right to be depressed. I am going through my life changes and I have a right to be depressed. If you went through the last months, “B”, you would be depressed.”

**Dick:** “How would you summarize about mental health?”

**Participants:** “If you don’t have good mental health, you create physical problems. They decline, they go down hill. Stop eating, stop drinking.”

**Participant:** “There is the feeling that this is unacceptable behavior [manifestations of mental illness] so the senior feels he/she should not tell the doctor. Notes that some seniors don’t like the word “depressed.”

**Participant:** “We have to add about the lack of home health aides in the area.” Availability, ability to afford home health aides.”

**Participant:** “We need more home health aids, we need to pay them more.”

**Participant:** Agrees on need for higher pay for home health aides especially for some of the kinds of work they have to do.

**Participant:** “I would kind of like to get holiday pay, sick days, mileage for driving all over the county, personal days.”

**Dick:** “We have just identified all of these needs. Who is going to pay for that?”

**Participant:** “We are—out of our middling income”.

**Dick** asks how many of us would be willing to pay higher taxes if we could see some of these services provided?



**Participants:** Many say they would be willing to pay more taxes provided they would be sure the funds would be well spent and not wasted by officials who, as one participant said, “Pays somebody to come shine his shoes”.

After several minutes of discussion on this issue, Dick tells all participants that they have been really great and a source of many good comments, ideas, and suggestions.

**Participant:** Asks if we would ever have the opportunity to read the report. Dick says perhaps the Executive Summary and suggests that they call the Office for Aging sometime after mid January.

The End

## **Focus Group with Institutional Discharge Planners**

**Tuesday, November 26, 2002  
1:30 p.m. – 3:00 p.m.  
Fairview Good Shepard Home**

**Richard A. Rehberg, Ph.D.  
Bartle Professor  
And  
Lorelle Vanno  
Research Assistant**

**Master of Public Administration Program  
Binghamton University**

Transcript of Audio Tape  
(with paraphrases)

### **INTRODUCTION**

Initial invitational telephone calls had been made to each participant during the early to latter part of October through early November with a confirmation letter on Binghamton University stationery mailed within two days of the participant's "definite" acceptance of the telephone invitation. Each such participant received a reminder telephone call several days prior to the actual focus group itself on November 26<sup>th</sup>.

Seven individuals arrived for the Tuesday afternoon group. Six were female, one was male. All arrived prior to the scheduled start time of 1:15 p.m. and were thus eligible for the \$50.00 on time arrival bonus drawing. Because these individuals were compensated by their respective institutions for the time at the focus group, we did not provide the \$35.00 compensation customary when the participant is donating his or her time. Upon arrival, we asked each participant to print his or her first name and first name only with the wide tip felt marker on a 4 x 5 inch tent card and place the card so that their name was visible to the facilitator and other group members.

To initiate the discussion (at about 1:15 p.m.), the facilitator introduced himself (Dick Rehberg) and his co-facilitator (Lorrelle Vanno), noted their respective affiliations with Binghamton University, and informed the participants that the discussion group was sponsored by the Broome County Office for Aging and funded by a grant from the Robert Wood Johnson Foundation. Dick briefly explained that the purpose of the discussion was to learn what services are or would be needed or useful in Broome County to ensure the widest range of options for individuals as they become senior citizens, options that include entering a nursing home or assisted living facility, on the one hand, or remaining in one's apartment or home, on the other.

Dick noted that only first names would be used and encouraged each member of the group to participate in the discussion. He noted that after some twenty minutes into the discussion, he would gently ask any non-participant to share his or her thoughts with the group. Conversely, he noted that were anyone to seem to speak without pause, he would reserve the right to signal that individual to give others a chance to participate as well.

A protocol designed with the assistance of Neil Hall, M.D. has been previously and specifically for the discharge planners.

## INTRODUCTION

### **1. Currently, from the perspective of your institution, what are the major considerations, the major problems, major issues, that influence whether an acute care elderly patient, senior, is discharged to his or her own home, on the one hand, or to an institution, such as an assisted living facility of nursing home?**

**“A”:** “Well, for me, I evaluate at different levels but for me the very lowest that I can evaluate for someone to go home is the ability to transfer to toilet. These guys can all do a wonderful job of making someone independent in a wheel chair level and if their home is big enough, or can be adapted, they can manage at a wheel chair level; but if they can't transfer to toilet or have someone there that can help then do that, then that person can't go home.”

**Dick:** “So the ability of the person to transfer to toilet . . . .” [Dick asks for and receives clarification of phrase “transfer to toilet”].

**Dick:** “Any other considerations?”

**“B”:** “Along with what “A” said, the ability to transfer, . . . is how safe they are, and whether they have any judgment skills. You know, if they can't remember to reset the wheelchair when they are transferring, if they're forgetting to use their walker when they get up to transfer, those are major issues because you . . . just can't say they are safe to go home because they aren't going to remember to use their proper equipment and/or do their particular activities, how they were taught.”

**Dick:** “So they have to have adequate cognitive skills . . . ? Is that the same as saying they have to have adequate cognitive skills?”

**“C”:** “Part—well some people can have cognitive involvement in some areas; cognitive is areas of thinking and not necessarily . . . safety being impaired.”

**Participant:** “I guess I can sort of see that what we are doing is breaking it down into [pause] . . . there’s levels. If someone is “independent”, they’re showing good safety and the ability to perform the vital functions to go home, to be able to wash, you know we call them Activities of Daily Living—your survival skills. OK and that’s like your ability to wash, dress, bathe, feed yourself, safety, the transfer to toileting, and you can strip it right down to the most basic of them and add services within so they can go home but it depends on how much of those services in terms of hours and times of day that you can fit those services in, like if you put those other services in. Even if you strip away the services, safety and the transfers and the toileting needs—that’s the most basic needs that they have to meet themselves.”

**Dick:** “When you say themselves, do you mean in a situation where they may have home as an option but they may live by themselves?”

**Participant:** “Right—no care givers.”

**Dick:** “Are there other considerations that are involved with whether a person is discharged to the home or discharged to a facility?”

**“D”:** “Medication management.”

**Dick:** “Would you say a little more about that?” Dick explains why he asks for clarification of a concept or process that may appear to be well known and obvious.

**“D”:** “Ah—if the person can be managed with a pill sorter so that their pills are set up for a certain time of the day every day of the week. Nr. 1: who’s going to fill that—the pill sorter for them, and do they have enough cognitive ability to be able to figure out how to use it—take those medications.”

**Dick:** Clarifies that if the person is discharged to the home and are medication dependent, then either the person him/her self need to be able to manage their own medications or have a relative who can do so. “D” then adds “or a service [from the outside] that can do that, [i.e., manage the medications].” The discussion then proceeds to how such a service may be paid for. “D” replies that if the person is eligible then this service would be Medicaid reimbursable. Dick then asks for clarification about the home aides here in Broome County who might provide this service.

**“D”:** “Many times we can find aide service Monday through Friday but we cannot find it on the weekends . . . .”

**Dick:** “Because . . . ?”

**Participants:** “There is a major shortage—all areas of aides, not just nursing home, and its country wide, it’s not just Broome County.”

**Dick:** “I think that virtually every focus group we have spoken with has said that to us. I was curious, in Broome County, given then rather rapid rise in unemployment, why does there continue to a shortage of people as home care aides?”

**Participants:** “They don’t get paid well. The turnover rate is tremendous. Pay scale is low and you can get jobs flipping burgers making the same money and not having to work with individuals and do . . . .”

**Dick:** “Pay scale is about what--\$6.00 - \$7.00 an hour, minimum wage?”

**Participants:** “Little higher [than minimum wage]. Depends on what level of aides. There’s different levels of aides . . . .”

**Dick:** “How do they go from one level of certification to another? Do they have to take a test?”

**Participants:** Discuss and define the various categories, levels, of aides.

**Dick:** “So there’s a shortage because the pay scale is too low . . . ?”

**Participants:** “No benefits.” “Many of the home care agencies don’t provide benefits . . . health insurance; don’t provide child care.”

**Participant:** “The nursing homes provide benefits but you still are talking a very low salary range and most of the population is single mothers with multiple children, high cost to obtain health care for them and their children, high cost of day care for them and their children, and if you start talking 12 hour shifts and all as far the homes trying to be creative and keep themselves staffed with such a shortage . . . .”

**Dick:** “Let me ask an obvious question: what stands in the way of raising the pay scale?”

**Participants:** “Medicare and Medicaid. Your reimbursement rates are so low you can’t afford to be paying workers . . . .”

**Dick:** “So money is the issue.”

**Participants:** “Um hum” (several concur.) “And another thing is called ‘mandating’. If you have a child that get off the [school] bus at 3:30 and your shift ends at 3:00 o’clock and the aide that comes to replace you doesn’t show up, you’re mandated to stay and

there's your child sitting on the front of the steps. I used to work . . . and I know insurance [family health insurance] sometimes used to run \$80.00 a week and your salary is \$6.00 to \$7.00 an hour and then you have the transportation to get to the facility and on that kind of money you can only afford 'a meter with a heater' and . . ."

**Dick:** "So salary is a problem, the absence of fringe [benefits] is a problem, the working conditions are a problem . . . . By the way, with mandated time, when you have to stay, were you compensated for that?"

**Participant:** "Yes you were but they only have to give you an hour's notice . . . . [Notes how much of a burden this can impose on the aide-mother who may have to try to arrange for child care at the very last moment . . . . Notes also that "some of the areas the aides come from [referring to areas of the city] you don't want your child sitting out on the stoop" waiting for you to come home."

**Dick:** "Any other considerations about discharging to the home?"

**E:** "I think that what "A" is saying . . . at a wheel chair level . . . is the house acceptable for the wheel chair. Will it go through the front door? Can they maneuver it through the house? Can they get in the bathroom? Cause some of the houses, especially the older houses, they're just not built . . . ."

**Dick:** "So another consideration is . . . is the home, say, physically user-friendly, particularly is a person in a wheel chair! Uh, if it is not, are there ways to make it physically friendly? And if so, who pays for it?"

**E:** "Comes out of your pocket. Do they need a ramp to get in? We sent a lady home that was basically independent and her husband wanted to take her home and he had a . . . that accepted the wheel chair and he got a . . . and a hospital bed but he had the finances to do that. Not everyone can do that."

**Participant:** "One of the problems I see is that people who are Medicaid vs. Medicare because the Medicaid people, because they qualify usually for a long-term care program they can get a lot of services then (sic) whereas if you have someone who is still Medicare eligible who doesn't quite fit the guidelines to go on to Medicaid who needs just as much service they can't get them because they would have to pay privately . . . or receive a skilled service in the home which isn't always the case [not quite intelligible here]. So if you have someone who is just borderline and are ready to go to Medicaid and they can't afford private pay, they can't afford a private hire . . . ."

**Participant:** "We have a lady tied up in a private nursing home who came in May and is waiting [in her room?] to get Medicaid, she's still . . . and we finished therapy in July and . . . I don't know . . . ."

**Dick:** “What is it that stands between her and her Medicaid eligibility?”

**Participants:** “It’s like bank statements, if they don’t have somebody to go do them for them . . . ?”

**Dick:** “Financial qualification in other words . . . ?”

**Participants:** “A lot of paperwork, a lot of paperwork. It’s tough to apply for Medicaid, but once you get it you can get lots of services but if you don’t have it then . . . .”

**Dick:** “And, I guess it’s easier if you have a mentally and physically capable partner or spouse who could do a lot of that work for you but if you don’t, then you’re at a double disadvantage: not only do you have the same amount of work facing you but you have an impaired ability to do that work.”

**Participant:** “We also have this stigma of the elderly population want to apply for Medicaid . . . . Many people still view it as welfare and they’ve never taken welfare and they won’t accept [Medicaid]. So many times it’s difficult to convince them to apply for it. Or to convince the children of the elder person to allow that person to apply for it.”

**Dick:** “They view it very differently from Social Security?”

**Participant:** “They do. They do. “

**Dick:** “Any other considerations about remaining at home vs. entering a facility?”

**Participant:** “Incontinence. A big issue. A major issue. Because even if they’ve got good safety or even if they can transfer, if we have to look at a lower level of care . . . meaning anything under, lesser than an assistance . . . so whether it be a boarding home or assisted living, or whether it be going home, if incontinence is a big issue a lot of time that issue itself will just disqualify them for any of the other levels of care. If they’re incontinent and it can’t be managed is what I should say. Because if they can wear a brief and change their brief then that’s managing their own incontinence. But a big disqualifier as “A” can tell you is that a lot of the boarding homes and assisted living is that if they’re incontinent, even if they’re pretty mobile, they don’t qualify for that level of care.”

**Dick:** “Why are they [those who are incontinent] then disqualified?”

**Participants:** “State regulations.” “When you get into lower levels of care . . . there are regulations as to what areas in which they can provide a person’s care, how much they can provide, . . . . There’s just different boundaries there for each of those levels. And there’s certain of those levels that are very much lacking in the county . . . . What used to be the old health related . . . . yeah, health related or assisted living . . . .”

**Participant:** “I probably have waiting list of about a hundred or more people that would like to like go into an assisted facility . . . [lack of availability].”

**Participant:** “Or they can’t afford it.”

**Participant:** “Or they’re Medicaid and they [the facilities] don’t want them; the private places don’t want them. Just Renaissance Plaza, that’s the only facility [that accepts Medicaid [patients?]].”

**Dick:** “Because it [Medicaid] is viewed as providing insufficient reimbursement?”

**Participant:** “The privately owned, you know, Hilltop, or um Castle Gardens, it’s costly. And they want to see like a year and a half, two years, of private funds. \$3,500 to \$4,000 a month.”

**Dick:** “So they would want to see perhaps \$100,000 up front?”

**Participants:** “Um huh! Some discussion follows of details of these financial issues.”

**Participant:** “So unfortunately, the HRF, what we call the Health Related or these people that just need a little bit of help, whether it be for safety or they just need a pair of eyes on them, whether it be just a little bit of help because of the incontinence, they’re very few if any options for them so they fall through the cracks. They get to stay in a skilled nursing facility . . . .”

**Participant:** Discussion follows about facility scoring procedures, case severity, case mix, and how scoring can change case mix and bring down overall reimbursement to the facility.

**Participant:** [Because of the scoring procedure] no nursing home want a lot of high scoring individuals.

**Participant:** Notes how case mix determines staffing levels, how many LPNs, RNs, . . . you need on that unit so it really affects a lot of areas . . . .

**Dick:** Any other comments?

**“E”:** What do they [the residents] want! They may want one thing and as therapists we may want something else. We may see something that they may not want to accept. I mean. They want to go home . . . regardless.

**Participant:** And they think that once they are home they will be just like they were before [they entered a facility]. I don’t have a problem.

**Dick:** So what do you do?



**Participant:** You call in the Adult Protective Services. “AMA” [Against Medical Advice]. Technical and legal discussion of definition, procedure, and implications follows.

**NOTE:** Because the discussion that followed question Nr. 1 was productive and insightful, the facilitator permitted that discussion to continue longer than would have otherwise been warranted.

**Dick:** I want to go on to the second question.

**2. What should institutions, such as the ones you represent, do to make it more likely that acute elderly patients are discharged to their own homes rather than to a facility?**

**“F”:** Well, we want to get them rehabbed. We need to know exactly what the situation is at home. Do they have steps to do, how much assistance they need—to try to get them all the services that they need, to get them rehabbed as much as we can, to not discharge them . . . you need to get them to their highest level of functioning and then we have our care conferences where we have family and we have the residents and we have CASA come in, you know, you try to cover all the bases to know exactly what the home situation will be like. We often have trouble that we send people home with services and once they are home they dismiss them all. They don’t want strangers in their home. So they agree to all these things until they hit their door step and once they’re home they are not going to let strangers in their home and they can . . . .

**Dick:** So one of the things you can do is to provide as wide a range of services as possible?

**“F”:** And we really need to know exactly what the home situation is. Physically, as far as health . . . family members, friends, when we have our care conference, you know we have social services, the family and . . . PT is there, and the social workers are there and at that time is when you try to bring all the information together so that you have . . . data from which you can really decide whether this is a good situation or not going to be a good situation and then we always bring CASA in, you know, for their input.

**Participant:** Well, the other thing you have to really look at is you have to be realistic. You have to look at their prior level of functioning; if they were wheelchair bound . . . the chances are you are not going to make them independent, . . . we have to base our goal on what they were doing prior so, that sometimes gets in the way. So, you really have to talk to the patient and the family to say, you know, what do you want to do, what do you think your capabilities, you know, what are your goals because they may not be realistic . . . .

**Participant:** Sometimes the family is relieved. Because they’ve really wanted this for the resident, they know the person . . . and the person has resisted and they [family] will say to us, you know I am so glad they are doing so much better here. I mean that happens

. . . . Yeah—the family hasn't had to make it [the decision to retain the person in the facility].”

**Participant:** “I think that one point that we can all emphasize is that we, since the day of admission, are already starting the discharge planning. OK---the first time we lay eyes on that resident, part of our evaluation process, if you are an OT or a PT, is finding a way out of the home, how many steps are there, who do you live with, who are your caregivers, are your caregivers healthy—I mean it doesn't do you any good to have a husband if you were the caregiver of him. You have to know their caregivers. You have to know their prior level of functioning, because obviously you are only going to get them back to that prior level, perhaps a little bit above it; you need to take all those into consideration and then our goals and our treatment approach are all based on what our projections are of where we are going. Lot's of times we need families to tell us, as to how much help they are going to be able to provide, it won't do them [patient] any good to live with the child if the child works full time, if they are out of the house more than they are in it; and yet they need help throughout the day. So we form that picture in our minds right from the very first interaction we have with them; it's all part of our initial process.”

**Dick:** “So . . . a lot of what you folks do involves very serious judgments?! “

**Participants:** “Um huh.” “Very!”

**Dick:** “You really have, in a significant sense, very serious control over the lives not only of the patient but, indirectly, over the lives of the relatives and loved ones of the patient.”

**Participant:** “Yep! And all we can do is to give advice. I mean, you know, sometimes we are not always right either and sometimes maybe we are a little too mother-hennish, so to speak. But, I think that with years of experience you'll learn where that medium is.”

**Dick:** At this point (with the mention of 'mother hennish') observes that the gender representation around the table (other than for facilitator) is all female with one male participant. He asks if that is true of the profession and the consensus is that it is.

**“E”:** “One of the other things . . . how do we determine . . . we do a home evaluation; go into the home, if the family want it because some say no way, because if you get her [patient] there [back to her home] you will never get [her back in the facility].”

**Participant:** “One of the things we say, because we have run into that situation, where we recommend home assessment and . . . a lot of times when we find people declining that, it's not the resident that's, but it the family doing that, which I find very interesting because if I'm a family member, I would want my reside . . . , my family member to come home with the best benefits and equipment and you know; but I can think of one resident in particular who left us and her daughter, flat out refused for us to come [to her home]. So we recommend that a home assessment be completed by a home agency and

if the family continue to refuse them that is up to them but it is part of our discharge process to do the right thing.”

**Dick:** “Third Question:”

**3. What services, to post discharge seniors or to their caregivers, would make it more likely that they would or could be discharged to their homes rather than to institutions?**

**Participant:** “Meals on Wheels is one.”

**“A”:** “Like a spousal case where you have a 90 lb wife and a 200 lb man and I am thinking of an aide coming into the house to help guide him [patient] into the bathroom during the day.”

**“C”:** “But even that spousal intermittent aide service can make all the difference. Being there for a couple of hours in the morning to help the person get up, get dressed, at different time intervals during the day . . . .”

**Dick:** ““A”: the person you are talking about is where the person has a spouse at home. And the person you are talking about, “C”, is where the person who has been discharged has no one at home, no spouse, no one else.” “A” replies: “Right.”

**Dick:** “So you [both “A” and “C”] are talking about personnel to provide personal services.” Both agree. “And—at the times needed—weekends.”

**Dick:** “What do you do in the case where, say, a male has to get up at 3:00 o’clock in the morning to go to the bathroom and has a 90 lb spouse and she can’t . . . .”

**“A” and “C”:** “A urinal!!!!”

Humorous discussion ensues, were the patient to be a female!

**Participant:** “A Life-Line can be important. Call button. And that is readily available. Two things are cost and pride.”

**Dick:** “Cost is about \$30.00 a month?”

**Participant:** “That is correct with about a \$50.00 - \$75.00 installation. And the other part is pride. Will they wear it or will they hang it on the bedpost?” “[Content of older commercials still make some] embarrassed to be seen wearing either the necklace or the bracelet.”

**Participant:** [Refers to the fear that may inhibit use of Life-Line or the Call button because patient believes he/she may] “. . . be removed from 110 Chenango or their home wherever should it be necessary that outside agencies have to come to the home

and get them off the floor; so they agency [authorities] will know that he/she is falling and maybe not able to manage their care, so fear of losing their ability to remain at home because other people are finding out that they cannot manage their own care . . . . So it's better to fall and not let anybody know about it . . . .”

**Dick:** “What other kinds of services are . . . ?”

**Participant:** “Medication; managed medication.”

**Dick:** “What about something [some service] like paying bills, for example [someone to identify the bills and write checks to pay those bills]?”

**Participant:** “Yes—yeah.”

**Participant:** “Shopping?”

**Participant:** Light housekeeping.

**Dick:** Asks about what shopping services may be available.

**Participant:** “American Red Cross [provides a shopping service]. I believe it is free.”

**Dick:** “Personal financial management?”

**Participant:** “Um hum! “

**Participant:** “A”: “What about transportation? Affordable transportation?”

**Participant:** “A MediVan is \$50.00—if you have to go by wheelchair. It Medicaid reimbursable. But from a nursing home, each time you go out it is \$50.00 one way. And if you are in the outlying area, it's more. Charge so much per mile.”

**Dick:** “What other kinds of services?”

**Participant:** “One of the things I think gets overlooked a lot is socialization [participant means sociability], some type of, some people don't want to go out, some people will go to a nursing home and they will just thrive. Makes you feel alive. A reason for living.”

**Dick:** “Does any kind of service like that exist in Broome County [referring to sociability service]?”

**Participant:** “Through Family and Childrens. Friendly visitor. For free. But they just can't seem to find enough volunteers.”

**Participant:** “Medical Day Care Program.”

**Dick:** “But you go *to* that. It doesn’t come to you?”

**Participant:** “Right. But you get your loved one to it.”

**Dick:** “Asks about Long Term Care Insurance”

**Participants:** Note that relatively few of the cases they work with have LTC insurance because of its expense; they say very small percentage of the population have LTC because of its expense and because it is very selective as to what it covers. Technical discussion ensues of nature of coverage of some LTC policies.

**Dick:** “Any other kinds of services that you could think . . . ?”

**Participant:** “Really the supervision one where people just literally need the safety—glorified baby sitting. [Patient] may be able to do much for him/herself but if they are missing just this [wee bit] of the puzzle [relating to personal safety] then you can’t get them out [of the nursing home back into their own home]. Babysitting service.”

**Dick:** “So as the case manager you need a wide variety of services available so that you, as the case manager, can pick and choose and assemble a mosaic [of services] tailored to that person’s needs? Is that a fair summary? And I think that you are saying that it difficult, if not impossible, to do?”

**Participants:** “Yes. Yeah. Yup. Either financially or staffing wise.”

**Participant:** “Usually there’s three months out of the year when you can’t get services: usually in December and July and August when services dry up. Because holidays (Target, Wal-Mart hire for holidays] summer school is out with single mom’s [then having to full time day provide care for their children].”

*Discussion is now winding down as the 90 minutes draw close.*

**Dick:** Asks “Have any of you been in Europe? Do they deal with these things better?”

**“E”:** “I lived in Germany and it’s socialized medicine and you paid 14% tax but you wanted to go to a doctor and you could go?”

**Dick:** Makes an aside comment that he has seen some estimates published from Harvard that the total administrative cumulative costs of health care in the United States can approach 50 cents on the health care premium dollar. Some discussion ensues.

#### **4. How existent or non-existent, adequate or inadequate, are these services [that we have just been discussing] here in Broome County?**

**Participant:** “I would think that just about all of them are inadequate. Inadequate—but better than a lot of other communities.”

**Dick:** Asks: “Why do you think that?”

**Participant:** “Because of CASA. Other areas don’t necessarily have CASA.”

**Dick:** “Just what is it that CASA does?”

**Participants:** “I don’t know.” “I can’t answer that.” [This query elicits many self-admissions of lack of knowledge vis a vis CASA.]

**Participant Who Represents CASA [“A”]:** “We do assessments and we hook up with agencies and were scavengers and we go around to find out who has what services . . . .” Continues with a fairly complete description of CASA processes and services

**Dick:** “In software terms, the services you perform could be described as “data mining” [defines data mining software and what it does]. So you seek, you synthesize, integrate, process, and help?”

**Dick:** “Who funds CASA?”

**CASA Rep:** “State, county, and federal tax dollars. Appropriations rather than grants. Majority of services that CASA oversees are state mandated services.”

**Dick:** Notes that although CASA has been mentioned in previous focus groups, not too many people had a good ideas of what it is or what it does.

**CASA Rep:** “That’s true. We are the best kept secret.”

**Dick:** “There’s one better: Action for Older Persons. It’s amazing how few people in our focus groups know little about Action for Older Persons.”

**Participant:** “Even we as health professionals—how much do we really know about agencies like CASA and AOP?”

**Dick:** “So you are saying that with respect to providing a wide range of services to the aged in a county like Broome County, there’s a lot that each of you, engaged in your specialized function, may not know about other agencies and organizations that are engaged in trying to provide the same services. Am I correct in that?”

**Participants:** “Yes”—many respond in the affirmative.

More discussion of CASA follows. Several positive mentions of Michelle Berry.

**Dick:** Asks if there is anything else, in addition to what we have already discussed, that you think it would be useful for the Office for Aging or the Robert Wood Johnson

Foundation to know with respect to services for seniors that would facilitate their ability to choose between remaining at home or entering a facility?

**Participant:** “The Office for Aging has a program for what we call middle income clients. It is called the EISEP Program (In Home Services for the Elderly). But it’s a grants program. They have such a small amount of money that they can’t see very many, give services to very many new clients; they have their set number of clients. If one goes to a nursing home or dies, then that opens up a slot for someone else. I personally feel that that program needs more funding. These are people who are not eligible for Medicaid financially, but they need services as those who can’t afford them.”

**Dick:** “So middle income seniors are in need of a wide range, a variety, of services more than are currently available and the programs that fund those services are in need of more funding.”

**Dick:** “What else do you think it would be useful for us to know?”

**Participant:** “How to get in touch with out-of-town children [of parents who still reside in Broome County and whose children have moved to the far corners of the US]. Participant makes a plea to create a data base, a registry, of names, addresses, and phone numbers of out-of-county children of seniors residing in Broome County.”

**Dick:** “What else might be useful?”

**Participant:** “Volunteers to help with socialization [sociability], visits to seniors, shop for groceries.” Another participant notes that the Broome County Council of Churches used to have a volunteer program of this type but that it no longer functions.

**Dick:** “Anything else?”

**Participant:** “I would like to see a ‘shared nurse’ [program] for some of our elderly high rise buildings. We have what we call shared aide sites; they go from one apartment to another, help with the washing. I think it would be good to have a shared nurse program to help with the blood pressure, new medications, etc. We could empty out the facilities a lot better if we had those services.”

**Participant:** “Better aide service available at more times of the week.”

**Dick:** Concludes with the observation that the needs of the growing senior population exceed the resources available. Asks if that inference is true. A number of participants agree; no disagree.

A brief discussion of the role of government in addressing these issues follows after which the focus group concludes with the \$50.00 on time arrival drawing bonus.

The End