

Aging Futures

. . . older adults living well
as they define it.

Community Data Forum Report 2003

A Community Partnership for Older Adults Project

A National Program of The Robert Wood Johnson Foundation

Aging Futures Partnership
Broome County, New York

Our Mission

*Creating and strengthening community systems,
thus enabling persons age 60 and over to maintain
the highest quality of life.*

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About the Partnership

“The beauty of collaboration is the acknowledgement that each organization has a special function, a power that it brings to the joint effort. At the same time, each organization provides valuable services or products critical to the health of its community.” (Winer Collaboration Handbook: Creating, Sustaining, and Enjoying the Journey, 1994)

Since 1989 Broome County has benefited from a dedicated Partnership of consumers, educational institutions, public and private and not-for-profit agencies and faith communities dedicated to enhancing the quality of life for seniors in Broome County. Aging Futures demonstrates their commitment to strengthening Broome County’s long term care system by:

- Engaging seniors, listening to their needs and including them in planning processes
- Promoting the independence of seniors
- Building and supporting a responsive long term care system

Broome County was one of 13 communities nationwide to receive a planning grant from The Robert Wood Johnson Foundation, as part of their Community Partnership for Older Adults initiative. The grant, awarded in August 2002, supported our local Partnership in coordinating a planning process to meet the needs of vulnerable elders and their caregivers in Broome County.

Aging Futures Partnership goals:

- Strengthen a long standing and diverse Partnership focused on long term care services and supports
- Understand local needs, prioritize action steps and act collectively to address them
- Develop strategies that will bring about change in both practice and policy
- Secure funding and evaluate our efforts
- Support and coordinate community education about senior issues

INTRODUCTION

The following report summarizes the Aging Futures Community Data Forum held at the Binghamton Regency on March 18, 2003 in Binghamton, New York. The objectives of the Community *Data Forum* were to:

- Share data collected from and about Broome County seniors.
- Promote awareness of Broome County senior demographics, trends and needs.
- Elevate the level of community discussion on issues of concern to seniors.
- Challenge the community to focus on the frail and vulnerable elderly population and establish committees for the three top issues.
- Establish community priorities and create enthusiasm for workgroup process.

The forum was part of an extensive community planning process coordinated by the Aging Futures Partnership. Planning was supported primarily by resources from The Robert Wood Johnson Foundation's Community Partnership for Older Adults (CPOA) initiative. Grant resources allowed Aging Futures (AF) to repeat a community data collection process similar to one they conducted in the early 1990's.

One hundred and ten people attended the six-hour forum. Aging Futures thanks all those who presented at the forum and those that attended. We especially thank IBM Endicott for allowing Performance Consultant, Dick Orth, to facilitate forum activities.

FORUM PROCESS

After a welcome and brief introductions, opening remarks were offered by Dr. John Capitman, Director of Long-Term Care studies at the Schneider Institute for Health Policy at Brandeis University. Capitman's remarks encouraged those in attendance to listen to the presentations and to place the information in a more global context and to consider issues affecting seniors across the nation.

The forum featured several presentations. Each organization or researcher who coordinated data collection related to the AF Community Partnerships for Older Adults (CPOA) process presented on his/her findings. Presenters included: Lucius Willis, Binghamton University Geography Department; Richard Reberg, Ph.D., Bartle Professor; and Sociologist Louise K. Stein, Ph.D. All of the Partnership's information gathering activities sought input from underserved populations.

DeeDee Camp, Aging Futures Project Manager, presented a Power Point presentation highlighting the results and findings of the Mathematica telephone survey coordinated by The Robert Wood Johnson CPOA initiative on behalf of the 13 communities funded to

engage in community planning. She also presented a report on behalf of the AF Data Committee.

In the afternoon, small groups were asked to meet to share their thoughts on the following questions:

What did you hear?

What do you think is most important?

What else should we considered as we plan for Broome County Seniors?

This process was used to allow participants an opportunity to react to the information presented. Participants identified issues that Aging Futures should address in the CPOA planning phase and in the *Aging Futures Strategic Plan for Long Term Services*.

A spokesperson from each small group identified an issue of concern discussed at their table. Groups gave reports and ideas were projected onto a screen for attendees to see. The process resulted in 32 issues that community members felt warranted consideration (see Critical Issues Identified by Small Groups, pages 10-11). Later, a small group worked with Dick Orth, using GroupSystems software, to collapse the issue statements down to nine critical issue areas (see Critical Issues of Concern to Broome County Seniors, page 12). This process allowed the group to efficiently process the data and community input and then to move confidently into a community prioritization process. The *Data Forum* concluded the Partnership's phase-one development grant activities.

The Partnership used the priority issues identified at the forum to develop a community prioritization survey. A two-part ranking survey was distributed to forum participants and many other vulnerable older adults (i.e. home care clients, those receiving home delivered meals and caregivers). Respondents were instructed to indicate, from the nine issues identified in the survey, which three issues affect them the most. They were then asked to indicate which three issues they would like "our community" to work on, on behalf of our senior population. Over 1,400 surveys were mailed or delivered to seniors. The Partnership analyzed the results of 290 returned surveys. Workgroups were formed to address the three priority issues identified primarily through the prioritization process. Each workgroup identified and planned strategies to improve services.

The Partnership will continue to convene community forums to further community understanding of senior issues, to stimulate discussion about senior issues and how best to promote systemic change that improves services and effectively utilizes community resources.

FORUM HIGHLIGHTS

Keynote Remarks

Keynote remarks were offered by John Capitman, Ph.D., Director of Long-Term Care Studies at the Schneider Institute for Health Policy, Heller School of Social Policy and Management, Brandeis University. Capitman summarized an article he recently had published in the *Journal of Aging and Health*, Volume 15, Number 1, February 2003. From this article, he reviewed what he refers to as the five dimensions of consumer experience:

1. **Life Chances Trump Formal Systems:** Elders and their caregivers often frame their experiences with health and disability in the context of a whole life and the joys and disappointments it has yielded.
2. **Don't Ask, Don't Tell:** Elders sometimes fear telling practitioners about the risks and challenges they are assuming for fear of loss of autonomy.
3. **Nobody Can Help With This:** Low-life expectations due to disability sometimes leave elders and informal supporters satisfied with care arrangements that seem needlessly risky to practitioners or accepting of a far lower level of functioning than might be attained.
4. **Keep Those Knickknacks Dusted:** What care receivers find important to the details of their daily lives might not be viewed as important by health care providers.
5. **Too Much Data, But Too Little Information:** This fifth dimension is one that our proposal directly addresses. It is best illustrated from an antidote Dr. Capitman includes in his article regarding a slightly confused care recipient in New York. This individual acknowledges that she really does not know who to call in an emergency. Yet her refrigerator is plastered with copies of assessment forms and letters of explanation from the different health and long term care providers that are serving her. It is obvious to the outside observer that this consumer has been provided with a wealth of information and is receiving home care services. Nevertheless, she is not able to process the information provided. Perhaps she is overwhelmed by it, or afraid that if she asks she will be seen as less than capable. This inability to process information could very easily lead to breakdowns in the other dimensions listed, thus negatively impacting her quality of life.

The attendees were challenged to consider the consumer experience when planning for the future.

Census and Demographic Highlights

Lucius Willis, MA, Geographic Information Systems Analyst at Binghamton University Geography Department, analyzed Census information and used mapping techniques to highlight Census and demographic trends. His presentation highlighted the following information:

- In Broome County one in five residents is over age 60.
- Although seniors currently comprise 16.2% of the national population and 16.8% of the New York State residents, they represent 20.7% of the Broome County population.
- Broome's most significant growth since 1990 is in the 75 plus population and the 85 plus population.
- Gender is equal among most age groups; however, females generally live longer, and outnumber males in the 75 plus age cohorts.
- The majority of Broome County's elderly population is white. Census data indicates that 1,023 seniors, or 2.5% of the elderly population, are members of minority races. While the minority population is still relatively small it did, in fact, double between 1990 and 2000.
- The educational attainment of seniors did not increase from the last Census. Agencies providing information to seniors need to make sure that all materials and educational programs are in formats appropriate to seniors' needs.
 - 12.6% of Broome County's seniors have less than a 9th grade education
 - 19.2% do not have a diploma but have completed some course work between the 9th and 12th grade level
 - 38.5% have completed high school and/or equivalent
 - 13% have some college but no degree
 - 16.7% have an Associates Degree or higher
- The 2000 Census indicates that 36.2% of those aged 65 and above in Broome County have a disability that limits their activities or impairs their functioning. Eleven percent of the population is considered functionally limited. More often than not, income or economic status is a major issue determining the health (mental and physical) and mobility of seniors.
- Thirty percent of Broome seniors live alone.
- There has not been a significant change in the income status of seniors.

Willis concluded his presentation by demonstrating a mapping technique that demonstrates how service utilization information can be better analyzed by overlaying Census information with agency data.

One-on-One Interviews

Throughout January and February 2003, Louise K. Stein, Ph.D., conducted over 100 hours of face-to-face interviews with 41 seniors (18 caregivers and 23 care receives) residing in Broome County. Dr. Stein sought to answer the question, “*What makes it possible for a frail older person to continue to reside at their home or to return home after a nursing home stay?*”

Semi-structured interviews were conducted in both urban and rural homes, and nursing homes as well. The average age of the care receiver was 82. Special effort was made to travel to the residence of vulnerable seniors to ensure that their stories were included in the data collection process.

Interviews revealed that the following are essential factors to seniors staying in their homes:

- Personal desire or will on the part of the care receiver to stay at home.
- Committed informal caregiver.
- Adaptability. Capable of having some insight into his/her reduced functional capacity and making adjustments in lifestyle to address those changes.
- Some personal feeling of connectedness with others in the community.
- Enough self-confidence to feel safe at home and able to cope with an emergency.
- A home environment which is welcoming; this environment often includes a pet(s) needing care.
- Accessibility. An accessible home or apartment that an individual can get around in with a wheelchair or walker.

Other observations reported by Dr. Stein:

Individuals who are living at home and receiving home care are often very personable. Many care receivers have optimistic, outgoing and engaging personalities. Surprisingly few of the care receivers mentioned financial matters as a major factor in their ability to return home or stay at home. Rural care receivers rarely mentioned transportation issues as a challenge to living in the county.

Focus Groups

In the fall of 2002, four ninety-minute Focus Groups were conducted by Richard Rehberg, Ph.D. The group study sought to identify:

- 1. Perceived benefits and costs of a senior remaining at home or entering a facility.*
- 2. What the senior and family could do, early on, to increase the chances of the senior having the option to remain at home.*
- 3. The services available, or needed, in the county to support the at-home option.*

Benefits of remaining at home identified by focus group participants included:

- Continued independence for the senior
- Lower financial costs
- Emotional rewards for the senior and caregiver
- Knowledge of the quality of care for the senior

Benefits of entering an institution identified by participants included:

- Enhanced opportunities for social activity
- Scheduled recreation, medication and meals
- Personal security

Costs of remaining at home mentioned by participants:

- Recurring concern for security and safety of the senior
- The physical and emotional toll on the caregiver
- Uncertainty about medication compliance

Cost of entering a facility identified by participants:

- Real financial costs
- Absence of the physical and symbolic meaning for “living in one’s home”
- Loss of freedom for the loved one
- The toll that “out of sight, out of mind” syndrome has on all parties.

To enhance the viability of the at-home or enter-facility option, participants said that the following could make a difference:

- Individuals and/or family promoting a healthy lifestyle
- Entering into early-on financial and legal planning
- Adapting the physical structure of the home to be senior-friendly
- Becoming aware of services and agencies that serve seniors
- Nurturing meaningful social relationships

Participants were able to identify a number of services that supported the “stay at home option,” including: food delivery and shopping services, transportation, day care, senior centers, recreational and educational services, information and referral services and emergency on-call services. Participants did mention that demand can exceed supply for transportation, respite and day care and subsidized housing.

Participants suggested a need for expanded services including:

- Consumer, legal and financial counseling
- Better day and respite care
- Improved on-demand public transportation

Providing a quality life for seniors is resource intensive. The community response to those demands will influence seniors’ ability to remain independent and will also influence costs of care.

Mathematica Policy Research, Inc. Phone Survey

The Mathematica phone survey, conducted for the Community Partnerships for Older Adults, was highlighted at the forum. The phone survey was intended to offer communities baseline data, and to compliment local data collection activity. It is assumed that data collection and analysis will promote improvements in the organization and delivery of long term care and supportive services. The phone survey was conducted between June and November of 2002 and includes information from 424 interviews that were conducted by random digit dialing. Of the persons interviewed, 210 were considered vulnerable. Vulnerable persons were either age 75 plus or 60 or older needing help with bathing, using a cane, walker or wheelchair. Vulnerable persons rated their health as fair or poor, afraid to be alone for more than two hours, or have a chronic illness.

Highlights from the survey:

- Most older adults have been in Broome County for over 20 years, and plan to stay.
- Two-thirds of vulnerable adults live with their child or live closer than 20 minutes.
- Eighty-one percent (81%) of those surveyed believe the community should do “a lot more” to address frail elders.
- Eighty-seven (87%) percent of older adults watch television daily and another 78% read a newspaper daily.
- Thirty percent (30%) of older adults report not being as socially active as they would like to be.
- While a correlation did exist between medical status and transportation access, few older adults indicated a problem finding transportation.

- Eight out of 10 consider it “very important” to continue living in their own home.
- Twelve percent (12%) of the total respondents indicated that their home needs some kind of repair that would improve their ability to live there for the next five years.
- Hypertension and arthritis are the most commonly reported health conditions among older adults.
- Gaps in information or awareness of long term care do exist. Thirty-seven percent (37%) of those interviewed were not aware of the Senior Resource Line.
- When older adults need information about personal care at home they tend to seek that information from family or friends (27%), doctors (24%), hospitals (24%) or Office for Aging (24%).
- Forty-three percent (43%) of older adults don’t know whether Medicare covers personal assistance services.
- Ninety-three percent (93%) of care receivers reported they have informal (unpaid) caregivers. Without support from caregivers, a significant number of older adults reported they would need to move to an assisted living or nursing home.

The survey confirms that there is community support for more education and outreach. The survey also assisted the community in better understanding the specific needs of the vulnerable population.

Data Committee Report

The forum featured a Power Point presentation that served as a report from the Aging Futures Data Committee, a standing subcommittee of the Aging Futures Partnership. The Committee spent several months analyzing data from a variety of sources including: Broome County Office for Aging’s *Plan for Services 2000-2004*, Broome County Public Health Department’s *Community Health Assessment 1999 – 2004*, New York State hospital data, and numerous other community documents.

The presentation featured data on senior health status, including mental health, transportation capacity and utilization, and home repair service utilization and compared Broome data to national data. The Partnership strives to have reliable data to support senior planning that is available to agencies and the community at large. The Partnership provides both quantitative and qualitative information to ensure a comprehensive assessment of the issues.

CRITICAL ISSUES IDENTIFIED BY SMALL GROUPS AT THE FORUM

1. People (especially younger people) are not becoming informed and planning for the future.
2. People are starting too late to learn about aging issues.
3. There is insufficient and ineffective support for caregivers.
4. There is a lack of availability of services in outlying areas - transportation, home health services - in certain pockets of rural areas.
5. Isolation in the home – lack of social contact.
6. Unknown strategies for building social capital.
7. There is a lack of knowledge of existing services in the community - pockets of people who don't receive the information because of the way it is communicated (e.g., lack of High School diploma).
8. People are not aware that the *Elder Services Guide* (ESG) exists.
9. There is a lack of educational materials in accessible format for seniors (e.g. large print, tapes, etc.).
10. Transportation – There is a lack of convenient hours, routes, logistics of getting from house to curb, pick-up, delivery.
11. Inability to bring affordable services in to allow the elderly to age in their home or independent housing.
12. There is a lack of qualified home health aides in both rural and urban areas.
13. Inability to meet affordable demand for private, personal care aides – strengthening of the private market.
14. Elders make many transitions in their care arrangements and many lack enough information and help to manage the stressful transition.
15. There is insufficient case management for seniors to organize the support they need (e.g., organize the services, pay bills, interview the caregiver).
16. People have negative perceptions of accepting any type of care (e.g., nursing homes, community care).

17. People needing care are not always identified before the crisis.
18. Elderly are not conveying their health and support needs to physicians or staff and doctors/staff not asking their elder patients.
19. There is a lack of support for chronic disease self-management.
20. There is a lack of education and information on holistic services as an alternative to drugs/surgery.
21. Some people are unwilling to accept care due to the stigma of receiving care before the crisis stage.
22. People lack a sense of control, autonomy, empowerment and hopefulness to master their own care.
23. There is a lack of medication management; seniors taking multiple medications prescribed by multiple physicians.
24. Insufficient senior housing – elder accessible, affordable, on-demand.
25. Insufficient home modifications to improve accessibility of elders' existing homes (opposed to more housing).
26. Ineffective planning services and implementation of elder services – on a continuous basis.
27. There is a lack of opportunities for seniors and providers to “come together” to plan for long-term care and other elder services.
28. Increased cost of prescription drugs and lack of coverage.
29. Elected officials do not make it a priority to establish a national health care policy from birth to death.
30. Sufficient legislation does not exist to fund/assist in providing finances for necessary services.

CRITICAL ISSUE AREAS OF CONCERN TO BROOME COUNTY SENIORS

1. **Advanced planning for aging:** People are not getting educated early enough to plan for aging and long-term care.
2. **Support for caregivers:** Families and neighbors caring for elders do not have enough information, emotional support, and assistance in planning and decision-making.
3. **Rural issues:** People in rural parts of the county are not getting the help they need with transportation, home health, friendly visitors, meals and other services.
4. **Social support:** Some older adults don't have people to count on when they are in need.
5. **Access services / education / information / materials:** People don't know enough about community and long term care services that are available and how to get them.
6. **Middle class people don't get the services they need** (e.g., transportation, help at home, adult day care).
7. **Elders go through many changes in where and how they get help** (e.g., going from the hospital to home, needing more help at home). Elders do not have enough help arranging for care as things change.
8. **Chronic disease / self-management:** Many older people have chronic diseases, such as diabetes, heart trouble, arthritis, and depression. Often they do not receive information and help on how to stay healthy.
9. **Housing:** Elders do not get enough help in making changes to their homes so they can continue to live there, such as bathroom bars, ramp and wide doors.

Additional data and information presented at the Forum is available. Contact Aging Futures at (607) 778-2411.

**Registrants to the
March 18, 2003 Forum**

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Dorothy Babcock
Barbara Badger
Sue Barg
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Laura Henry
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Karen Iovino
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March 18, 2003 Forum**

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