

Critical Issues Roundtable Aging and Long-Term Care: How Do We Make It Better? Clarion Conference Center February 17, 2005

Executive Summary

On February 17, 2005, the Community Foundation of Tompkins County hosted a Critical Issues Roundtable on *Aging and Long-Term Care: How Do We Make It Better?* Attending the event were 105 community and civic leaders, representing a broad cross-section of caregivers, consumers, volunteers, social service and government agencies, education, health-care providers, arts and cultural organizations, and long-term care residential representatives. Joining the Community Foundation as co-hosts for this roundtable were: Community Health Foundation of Western and Central New York; Ithaca College Gerontology Institute; Lifelong; Tompkins County Office for the Aging; and Tompkins County Long-Term Care Services.

Framing the Issues: Aging in Tompkins County and the Meaning of Long-Term Care

According to the 2000 Census, county residents age 60+ comprised 12.4% of the population of Tompkins County (11,967), a rise of 5.8% since 1990. Those age 85+ (1,252) increased 27.1% in the same time period. According to a recent county-wide survey of seniors by the County Office for the Aging, 16.5% of seniors age 60+ need help with activities of daily living. Our needs increase with age; for those 85+, 48.9% need such services. As a result, our long-term care system is currently experiencing a marked increase in individuals who are most likely to have both physical and cognitive disabilities and who are most likely to be faced with the need for in-home assistance or residential placement. These numbers will continue to grow. According to the New York State Office of the Aging's Project 2015, the number of seniors in Tompkins County is estimated to increase by 27% in both the 60+ and 85+ populations while the general county population will increase less than 3%. By 2015, seniors 65+ will comprise 15% of our total population in Tompkins County.

Long-Term Care (LTC) refers to the medical, social, personal care, and supportive services needed by people who have lost some capacity for self-care because of a chronic illness or condition. For most people nationwide, LTC usually represents a network of care: 66% is informal caregiving (friends, family, voluntary services); 26% is a blend of informal and formal caregiving; and 9% is formal care. Paying for LTC can be challenging. Medicare, supplemental insurance, and standard health insurance do not cover most LTC expenditures. Medicare pays for short-term in-home and nursing home care under certain circumstances. For most people, there are three primary ways to pay for LTC:

- personal income and resources are the largest source, with 62% of costs being out-ofpocket costs and 46% representing nursing home costs;
- Medicaid covers home-care and nursing home care in New York State for individuals who are low-income and who have few resources; most nursing home residents qualify for Medicaid once they have exhausted their own personal resources; and

 Long-term Care Insurance is another source of help; however, policies vary as to whether they will cover nursing home care, assisted living, home care, or a combination of these services. Costs are based upon the age of the buyer and the amount of coverage purchased.

On average, nursing home costs reflect coverage in these proportions: 8% Medicare; 41% Medicaid; 5% private insurance; and 48% out-of-pocket. For home care, costs reflect coverage accordingly: 15% Medicare; 17% Medicaid; 5% private insurance; and 62% out-of-pocket. Clearly, then, financial planning well ahead of our anticipated aging needs should be a high priority for all of us.

Addressing these broad areas, Dr. John Krout, Director of The Ithaca College Gerontology Institute, opened the roundtable by focusing on several key points: our expectations for aging, both as a community and as individuals; and long-term care, its meaning, its scope, and its challenges. Aging and long-term care affect us all: in our own lives, for others we love, and for us as part of a caring community or place of business. A multitude of resources within Tompkins County is available. While many of these resources are frequently underutilized or inappropriately utilized as people face crises, others agencies or services face waiting lists and insufficient funding. Issues, then, that were considered as part of the overall discussion at the Roundtable included:

- identifying the issues of aging and care early enough;
- understanding how available services and resources fit together to produce effective help;
- considering the gaps or barriers in accessing appropriate care; and
- dealing with the costs of care or aging in general.

Dr. Krout stressed the need for people to assess and anticipate their needs, to engage in preplanning for care options as well as financial coverage, and to become aware of our community's resources.

Defining Our Expectations for Aging and How to Mobilize Our Resources

Participants were asked to address two key questions in the first round of discussion:

What are your top priorities for aging well?

• How would you identify decisions and mobilize resources early enough to avoid a crisis? Participants agreed that their top priorities for aging included: continuing good health and well being; independence; financial security; intellectual engagement; and family networks. Additional priorities mentioned were education about/access to available services, preventive medical programs, respect, and transportation options. People also agreed that anticipating their needs and mobilizing resources were not things they had considered fully. An important element in any of these discussions involved the role of family and informal networks of care (friends, congregations, volunteer groups); for many, candid conversations with potential caregivers about one's own wishes and health-care needs became one of the most challenging steps to take. For those who had been caregivers to others, these conversations, had they been held, would have proven valuable and reduced the stress so commonly experienced in the caregiving role.

Identifying the Barriers and Gaps

Participants were asked to consider several other questions:

- What are the gaps and barriers to receiving or giving appropriate care and assistance?
- What are the most important next steps in addressing these particular issues?

The most common barrier expressed by many was engaging in the difficult conversations with loved ones, either about our own care or how we might provide care to loved ones, and the sense of denial most families face as loved ones age. The next most frequently noted barrier was having sufficient financial resources to provide independence or sufficient care, when needed. Many hoped that the red tape or amount of paperwork involved in accessing social services or medical care could be reduced and made less complicated. Isolation and fear were other factors that inhibit seeking the care one might have. Overall, people expressed the need for heightened educational efforts to broaden awareness of available services and to maximize the service networks, the need for alternative or expanded housing options, and even more effective legislation for considering the needs of an aging population. Three distinct workforce issues were discussed:

- 1) too little respect for those who provide care either in a formal or informal basis; and
- 2) too few professional care providers and salaries that do not encourage more to enter the field of professional care services; and
- 3) the toll taken on workers who are also formal or informal caregivers (higher absence rates, increasing health concerns of their own, etc.).

Results of the Overall Discussion

Participant feedback indicated that the most immediate and important reaction lay in the general discussions around each table. People were very enthusiastic that they had had the opportunity to come together and explore issues of aging and LTC. Many were surprised to learn about the broad variety of services available in Tompkins County and they were eager to help expand awareness for others on a community-wide level. Many expressed an interest in having another roundtable to pursue the ideas and next steps identified. 82% of the participants completed individual response forms, through which they shared personal perspectives relative to their own needs and situations. In addition to sharing their own perspectives, they indicated various ways they could volunteer in future activities in a committee role (32%) or as leaders (19.5%), in developing collaborations or partnerships (22.9%), through individual services they could provide (20.6%), or by providing financial support (2%).

In closing remarks, Dr. Krout summarized the table reports in ten points:

- LTC is multifaceted and most frequently is a blend of personal, family, and community factors and seldom a simple matter;
- cultural and personal differences often reflect very diverse ways of addressing aging and long-term care;
- systems do exist for most needs to be met;
- we as a society need to get busy advocating for the needs of the aging;
- knowledge is power and, therefore, we should become aware of the resources available to us and our loved ones;
- family communication is essential;
- respect for older adults and their participation in decision making is critical;
- we must involve the private sector more fully in addressing the needs of the aging;
- there is a role for youth in our community to play with regard to the aging; and
- workforce issues do need attention, particularly as these focus on who informal or formal caregivers might be and how well they are trained.

Dr. Krout reminded us that aging and long-term care are complex issues, requiring each of us to be thoughtful, anticipatory, and courageous in identifying what we need and how we will accept or provide help.

Next Steps

The Planning Committee will analyze the participant responses to guide the next steps in addressing the issues raised in the roundtable. For those who attended and volunteered to help, you may be contacted at a later date.

Summary and Thanks to All

The Critical Issues Roundtables represent a series of community-focused conversations hosted by the Community Foundation in its role as a convener for exploring unmet needs and community-wide opportunities. The roundtables are intended to encourage more effective strategic decisionmaking and planning practices, promote positive results for our communities, and foster enlightened philanthropy. The Foundation invites others to co-host these meetings as a means of encouraging partnerships, fostering collaborative efforts, and identifying the natural leaders who are prepared to pursue the next steps.

Essential to this community discussion on aging and long-term care was the dedicated Planning Team whose work has covered many months and whose wisdom identified the main discussion points for the roundtable. Members of the Planning Team were: Eric Clay, Chair of the Grants Committee, Community Foundation of Tompkins County; Micaela Corazon, Program Director, Community Dispute Resolution Center; Willard Daetsch, Community Volunteer and Long-Term Care Committee; Betty Falcão, Director, Health Planning Council; Bill Hawley, Executive Director, Lifelong; Peg Hendricks, Executive Director, Community Foundation of Tompkins County; Christine Klotz, Program Advisor, Community Health Foundation of Western and Central New York; John Krout, Director, The Ithaca College Gerontology Institute; Joan Murphy, Director of Home Care, Family & Children's Services; Liz Norton, Long-term Care Coordinator, Tompkins County Department of Social Services; Lenore Schwager, Executive Director, Finger Lakes Independence Center; Larry Shinagawa, Director, Center for the Study of Culture, Race, & Ethnicity, Ithaca College; Irene W. Stein, Director, Tompkins County Office for Aging. In addition, we thank all those who served as facilitators and scribes for each table's discussion.

We thank our co-hosts of the roundtable: Community Health Foundation of Western and Central New York; The Ithaca College Gerontology Institute; Lifelong; Tompkins County Office for Aging; and Tompkins County Department of Social Services.

On behalf of the Planning Team and the Co-Hosts, we thank all who participated in the roundtable on *Aging and Long-Term Care: How Do We Make It Better?*