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Culture Change in Practice

An Older American Activist Reflects on Deep Systems Change in Eldercare

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During my 89 years, I have fought for racial equality, anti-poverty programs and for the equal rights of women. I am now an activist working to reform the long-term care system in America. It is another movement rooted in principles of social justice, and I am determined as ever to challenge the status quo and push for transformational change in this critical but neglected public health issue.

Several weeks ago a headline in my local newspaper read, "Elderly Care Divides State, Advocates." The story described a conflict over the level of emergency money available for home and community-based care. The conflict is part of a larger dynamic involving the competition for resources between home and community-based care providers and nursing homes and it is playing out at all levels of government.

In reality, government officials and advocates must follow *two* paths toward reform. One is to provide high quality home and community-based care and the other is to transform nursing homes as we know them. Each path requires deep systems change, and we must maintain a sense of urgency to address both issues, not play one off the other in a zero sum game.

The concept of "culture change" or "resident-centered care" has taken hold in a small but growing number of traditional nursing homes and the relationship-based principles of the movement must now guide new efforts to ensure high quality home and community-based care. Over a decade ago pioneering caretakers began replacing the medical-institutional model of the nursing home with a social approach that includes high quality medical-nursing care. These new resident-centered organizations strive to create a real "home" for citizens in their later years, regardless of setting. And just as importantly, the optimum well-being of *staff* is a critical element of all new approaches emerging as part of the culture change movement. The Pioneer Network is a national non-profit organization that champions many models of reform, including the Household Model, the Eden Alternative and the Green House.

About one half of the persons now living in nursing homes are "all alone in the world" – by choice or by undesired circumstances. Home and community-based care as it currently exists is not a realistic option for them because the support necessary to thrive in the community is not there. All Older Americans want to "age in place" in their houses or apartments, but aging in place is not possible without "aging in community." Homebound Older Americans need assistance with activities of daily living, housekeeping, home maintenance and importantly, meaningful relationships to combat the loneliness and boredom that plague them. Home and community-based care options must be designed to meet all the needs of this population, not simply task-oriented functional needs.

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Older American Activist, *cont'd*

If we do agree that the home and community-based care as currently organized has some negative aspects, then we can move forward to discuss and reach agreement about the current system – what to change and how to accomplish change. Systems resist change if no one believes the system is dysfunctional.

Systems begin to change when consumers and providers begin to recognize the systems' dysfunctions. From this recognition failures can be identified and remedied. Managers and their staff usually have the primary power to make real systems change, but consumers know what is going badly for them. Consumers can supply the information to identify what must be changed or added to the system of care so their needs can be met. Non-supervisory staff members – nurse aids, housekeepers, activities and family members – who are part of the caretaker system but who have no part in determining policy are an essential source of valuable information and energy.

As we consider the plight of Older Americans who want to live in their own home of choice, some say we should expand home and community-based care because they represent an alternative to the dreaded nursing home, and because home care saves the taxpayers money. To many this reasoning is logical and to some extent true.

Yet, until recently, some associations of Older Americans have been advocating for more money for home and community-based agencies without considering the quality of such expansion and how such efforts will affect the lives of many of my cohorts who reside in the many nursing homes that operate with limited resources. A need for deep systems change is not mentioned, and needs to be

acknowledged and acted upon in the industry.

Now state and federal legislators are asking our communities to "rebalance" the system toward home and community-based care in each state. But, many home care agencies – and to a lesser extent, community-based organizations like adult day health centers – are still using a medical/nursing model and as such are having similar problems to those encountered in the many nursing homes that have yet to embrace "culture change." Most of the for-profit and non-profit eldercare organizations are managed in old-fashioned ways. Kind and usually well-intentioned staff are conscientious caretakers, but the "patient" usually experiences a loss of self and autonomy. Older Americans have fragmented contact with hands-on caretakers who are often poorly trained and woefully underpaid. The consumer has little input in policy-making or management, even in decisions about her daily living. In addition, staff turnover prevents the establishing of meaningful relationships.

If we do agree that the home and community-based care as currently organized has some negative aspects, then we can move forward to discuss and reach agreement about the current system – what to change and how to accomplish change. Systems resist change if no one believes the system is dysfunctional. Beyond this point we must agree on the actions that will

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achieve the goals we have set for the system. There are four questions we will have to answer. They are 1) Who will have the power to make changes? 2) What model will we use or will we create a new model? 3) Since we know that changes will cost the public and private money, how much do we need and what will be the sources? 4) Who will make it work?

The movement toward the establishment of "resident-centered" real homes for frail Older Americans has been led by staff and consumers of non-profit community organizations. It is likely that home and community-based reforms will be led by non-profit agencies. I am greatly concerned that these efforts will be overtaken by the same for-profit forces that chiefly caused the dysfunctional "nursing home industry." I refer to two major forces: 1) individual and corporate greed, and 2) the low expectations of Older Americans and society in general of what quality eldercare is and what it can be.

My generation may be thought of as the "Greatest Generation" because we did win a necessary war. But we have made one huge mistake: We have not created and implemented a high-quality system of eldercare for ourselves and future generations. Many "Boomers" will not have pensions and health plans to supplement Social Security income and Medicare. The future of their late years is uncertain. Our nation is just now beginning to improve eldercare. Members of my generation are dying and those of us who are survivors are becoming frailer and weaker, but we must raise our voices and help those younger to move toward positive

change in the systems of eldercare. All Americans – particularly those in their 50s and 60s – have very high stakes in these issues about which I have written, and they must participate in making state and federal policies which will lead to realistic funding for their futures.

An important force toward system change and social justice for Older Americans is an emotion that most of us are shy to discuss in public. That emotion is LOVE, the kind of love best known as agape. This word of Greek origin means the encompassing love of humanity. Agape has its competitors in eldercare. They are the motives of people who are working primarily for financial gain and personal power. As a small example, when I searched a definition of "agape" on Google, I found on the right of the screen an advertisement for profit making company which "served seniors" for a fee. This seemed ironic to me and yet symbolic in a way to my argument.

Agape love is often spoken in houses of worship but not in the world of work even among the army of dedicated caretakers, but I am convinced that agape is a primary motivating factor of their caretaking actions at work. It is my hope that belief in social justice and love of each other will sustain us as we together create programs supporting positive systems change for all generations as they live out later years.

Author's note: Since this is not an academic paper I have not footnoted my statements nor have I included comprehensive references. However, I am listing some of my information sources. Other Activists may find

them useful.

1)Anecdotal information from my own experiences as a consumer of most of the housing and healthcare services offered to Older Americans as well as related stories from friends, families and caretakers.

2) Countless books (including *In Pursuit of the Sunbeam* by Shields and Norton) and websites as well as publications from organizations to which I belong: The Pioneer Network, American Society on Aging, Physicians for a National Health Program, National Citizens Coalition for Nursing Home Reform, American Association of Retired Persons and Gray Panthers.

3) Helpful papers: "Nursing home Statistics" E. F. Moody; "Long Term care Quality: Historical Overviews and Current Initiative" by scholars at Brandeis University written for the national Commission for Quality Long-term care(NCQLC); "Out of the Shadows" Vince Mor PhD and Edward Miller PhD of Brown University (NCQLC); "Out of Isolation: A Vision for Long-term Care" Michael Milleson and Edward Miller (NCQLC); "About Long Term Care" Thomas Day; "Understanding General Systems Theory" DeAnn Gillies; "The Live Oak Regenerative Community: Reconnecting Culture Within the Long Term Environment" Barry Barkan; "Senior Agenda 2005-2006" Jessica Buhler and Jack Indeck; and "Honoring Eliza" Joseph Angelelli PhD, the story of a home for "needy older women in the mid-nineteenth century Rhode Island."