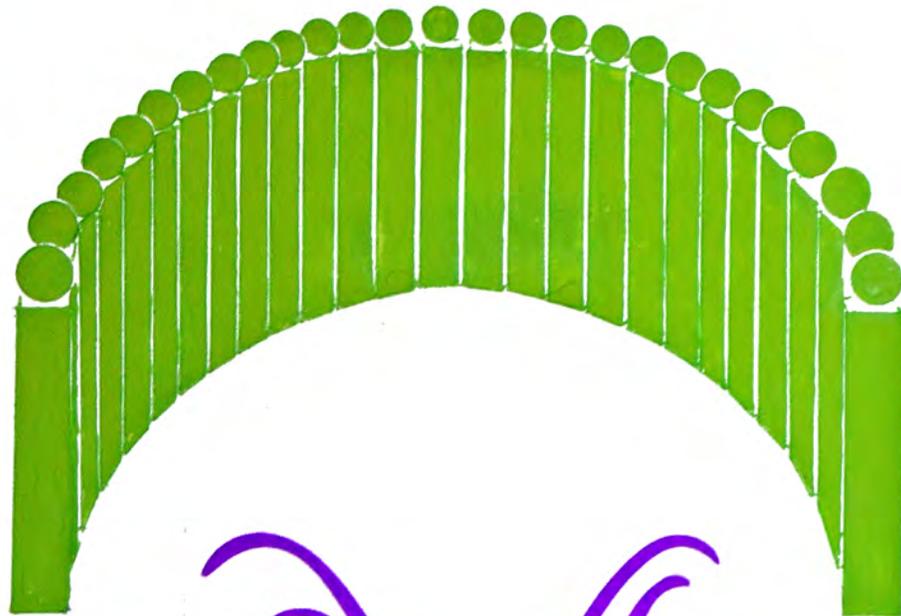


2016

MOTHER'S DAY
REPORT

AGING IN
COMMUNITY



OWL

*On Mother's Day, we honor the past
and shape the future.*



THE VOICE OF WOMEN 40+

*OWL's mission is vital. For over 30 years, we have
been the only national membership organization
focused solely on issues affecting women over 40—
economic security, cost effective and comprehensive
healthcare, and an enhanced quality of life.*

*OWL is committed to the belief that ALL women
deserve quality lives.*

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A MESSAGE FROM OWL'S PRESIDENT

“Aging in Community” has long been an OWL goal, this has become a much more important issue as the world ages. In this report we explore some of the major models for

become a generally more aging-friendly community – how they are organized, governed, managed, and funded. Many services are funded by taxes, others by philanthropic endeavors, and some by consumers. Each of the models has benefits, and challenges. The emerging goal must be to work on collaborating across groups and organizations who are trying to contribute something toward aging well. Collaboration is much more difficult than working within one silo of service, but because we need to be more efficient in using scarce resources we need to

work together. A wide variety of public-private partnership have been developed. We have many model-projects, but relatively few have been sustained.

I have drawn heavily on excellent research being done by colleagues focused on the Village movement. Because I have been developing a Village for over six years, this is a particularly intriguing movement because it makes such good use of talented older adults. Villages are organized and run by their members, a quite distinctive model. Now it up to the readers of this report to think how to integrate all the models. We are grateful for all those who support this cause.

Happy Mother's Day!

—Margaret Hellie Huyck

EXECUTIVE SUMMARY

This OWL report recognizes the significant successes of the past decades: more individuals are surviving to be old, and very old. We have, in all developed nations, an aging population. This fact presents multiple challenges at a personal, societal, and global level. Both challenges and opportunities arise from changes in demographics, family constellation and functioning, economic structures, and technologies.

Aging often involves increasing impairments, which can turn into disabilities when the larger environment is not able to compensate. *It is clear that disability is partially a reflection of the social and the built environment.* Even morbidity and mortality reflect more than physical and genetic vulnerabilities.

The aging population has resulted in a widespread need to create Aging-Friendly Communities. The World Health Organization has established a checklist for determining success.

There are multiple models for bringing about Aging-Friendly Communities. *The most ambitious goal is to create and sustain communities that support the effective functioning of all individuals at all ages.* In this

review, we focus on strategies for promoting healthy aging in community.

A major source of support for seniors are programs funded by federal taxes, often passed on to states for local distribution, and by state and local taxes. In addition to Social Security and Medicare, the Older Americans Act has mandated funding for many programs that address the needs of all older Americans, as well as funding for seniors most in need. The advantage of this system is that with political support, funding is stable. The disadvantage is that priorities established at the taxing level may not match those at the local level. The Aging Network emerging from OAA funding since 1965 is now challenged to establish partnerships with private service providers and to move toward evidence-based programming.

Many programs to enhance the lives of seniors are designed and funded by philanthropic groups. These groups often provide great latitude in programming, targeting particular challenges (such as nutrition, social isolation, affordable housing, arts education, or homelessness). If they have sufficient funds, they may be a more reliable source of support for organizations. On the other hand, the foundations or individuals providing the support may change their priorities. They

create their own mission; they have no mandate such as those imposed on the AOA programs.

Consumer-driven models of aging in community have emerged in several forms. Nationally Occurring Retirement Communities (NORC) consist of clusters of seniors who have ended up in a building or a set of close-by residences, where a significant portion of the residents are older and need special support services. Tax-based and philanthropic services often reach out to such clients; the clients tend to be older and less economically secure than average.

Another consumer-driven model are the Villages, organized by peers, funded by membership dues and donations, and managed by members. Members determine what services and programs they desire, and members provide many of the services as volunteers. There are four major Village models; the factors related to sustainability are very similar. Villages are effective in increasing social integration, by having members create and participate in social activities. Villages so far serve moderate-income members who can preserve their resources longer. It is unclear how sustainable they will be as members become more frail and need more help than can be provided by their neighbor-members.

Future needs focus on community planning, to create not only aging-friendly communities, but dementia-friendly communities. Generally, the call is for cross-sector collaboration, so that services are no longer planned and carried out within silos.

One of the major challenges for aging in community is to create a sustainable program of long-term care in the community. Currently there is no coherent plan for providing or funding the levels of care needed in our increasing life course. Many plans have been offered, but none have received strong enough support.

The political challenge revolves around what we owe each other: can we work collectively to provide quality of life for all, or is this an individual responsibility? With increasing income-inequality and strong disagreement about the role of government in providing benefits and services, this is a crucial question.

THE CHALLENGES OF SUCCESS: MANY OF US GROWING OLDER

OVERVIEW

This OWL report recognizes the significant successes of the past decades: more individuals are surviving to be old, and very old. Many are living with illnesses that might have been fatal in past eras, but have become manageable chronic illnesses. In addition, infant and youth mortality had already been reduced, and a variety of social changes have led to changes in fertility patterns which result in fewer births. We have, in all developed nations, an aging population. This fact presents multiple challenges at a societal and at a global level; some respond with alarm, and some with pleasure.

At a more personal level, this means more of us are confronting the realities that we may outlive our parents and our grandparents. We must plan ahead for a long life. We already know that most of us would prefer to remain in our home, or at least in our community. We often will realize that neither our homes nor our communities are well suited to our

needs and preferences as we grow older, particularly as we become more limited in capabilities.

Personally and collectively, we probably recognize that family and social realities have changed in recent decades. While the model of aging in past centuries was probably best described as “aging within the family” or perhaps “aging within the culture,” the reality for many persons now is they will either age “in community” which implies a degree of connectedness and support similar to that in families in the past, or in a disconnected or institutionalized setting.

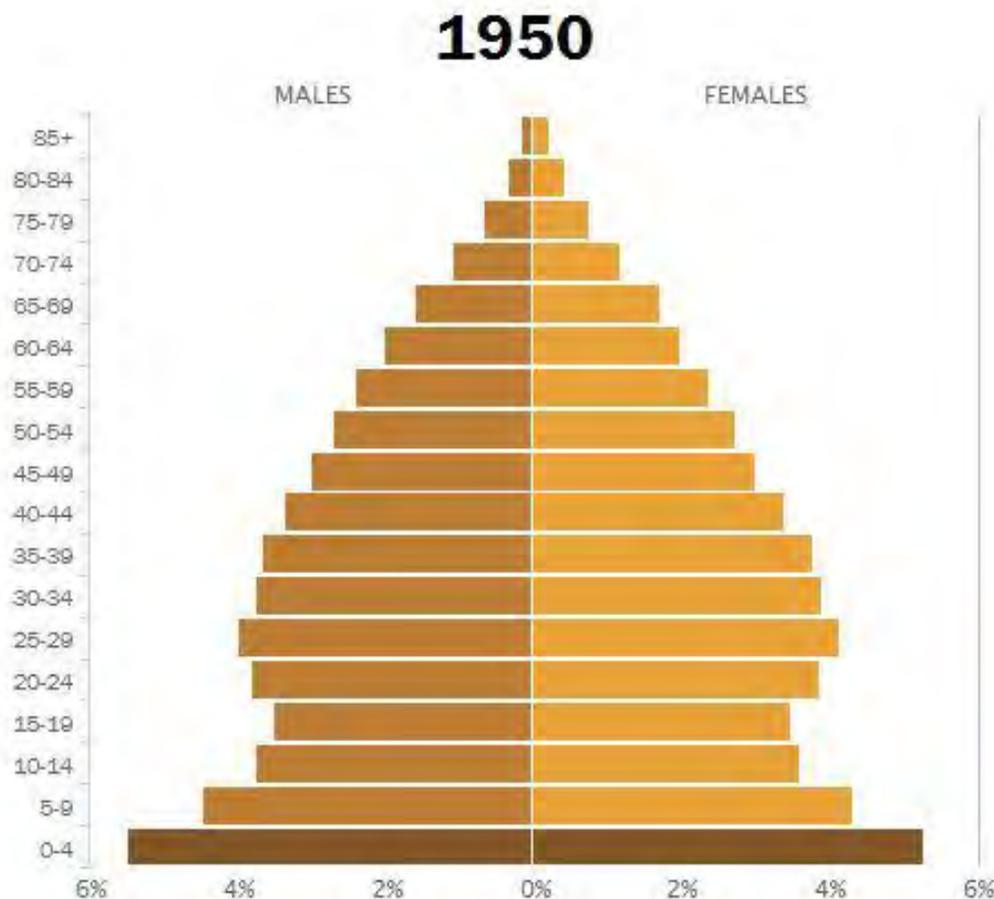
Over the past few decades many individuals and organizations have struggled with these realities. This report will summarize some of the evidence about the challenges identified, models for thinking about these challenges, and various proposals for dealing with the challenges.

The goal is to create and sustain communities that support the effective functioning of all individuals at all ages.

As with all OWL Reports, we will draw from these analyses recommendations for policy and practice changes.

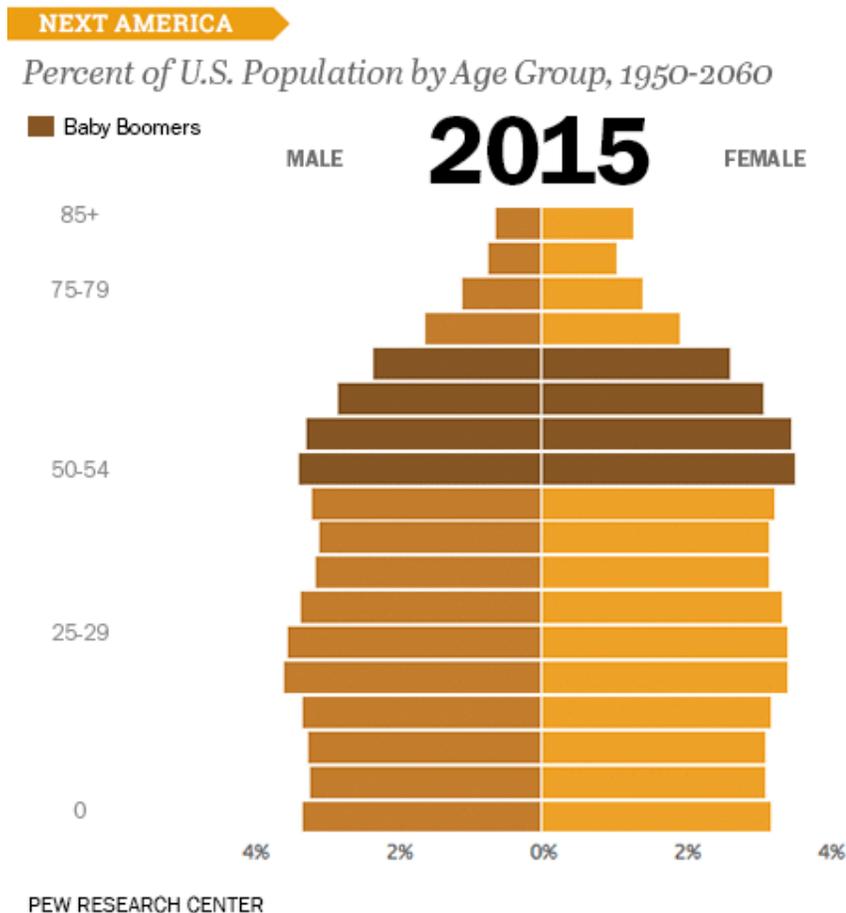
The Demographics: Age Pyramids

One useful way to capture a particular population is to describe or picture it in terms of particular characteristics. The traditional Population Pyramid can be constructed for any group. Minimally, they inform us about age and sex, because these two characteristics have been demonstrated to have such profound impacts on shaping the life course. The population pyramid for the U.S. in 1950 shows a steady pattern of attrition at each age group, ending with a small portion of elders.



We can see the small birth cohort during WWII, and the beginning of the “Baby Boom” generation born after the War ended.¹ If a community has such a profile, one immediately understands that one needs to plan for multiple services targeted at children and youth, and that there will be many in younger age groups to care for the few surviving elders.

However, the current picture in the U.S. is far different. This has been termed the “rectangularization of the life chart.”

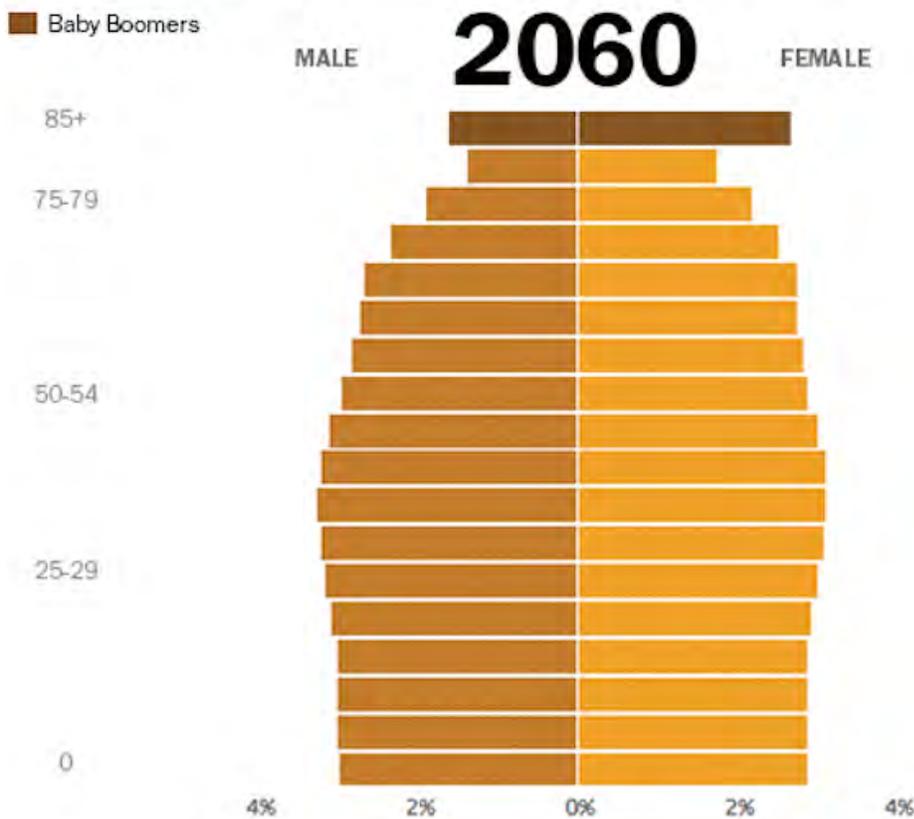


While not all survive to very old age, it is clear that many more survive to become old, and there are fewer in younger generations to tend to the special needs of elders. In addition, the contemporary pictures make clear the advantaged survival rates for women.

Projections are that by 2060 these trends will be even more pronounced.

NEXT AMERICA

Percent of U.S. Population by Age Group, 1950-2060



Life charts like these have evoked many responses. As Ted Fishman described his thesis in *The Shock of*

Gray: “The aging of the world’s population pits young against old, child against parent, worker against boss, company against rival, and nation against nation.”² It has been called an “aging tsunami”³ or the “silver tsunami”⁴ and all manner of perils are predicted. Most of these dire warnings rely on some assumptions about the aging process and the elders themselves: that the process of growing older inevitably means significant decline in physical, mental, and emotional functioning; that elders and youngers necessarily and inevitably have different priorities; that elders will necessarily become dependent on the more “able” members of the society; and that no society can support or sustain this much of a departure from the traditional age structure.

While there is some merit in all these observations, they are catastrophic rather than informed and realistic. As noted by Matilda White Riley over two decades ago, the extent and timing of decline in all aspects of physical and psychological functioning is highly variable, and not tightly tied with chronological age. In fact, the functioning of elders is strongly linked to the social structure.⁵ Since current elders are usually members of families, they turn out to share many values and

interests. Elders typically want their descendants to thrive, and are often willing to sacrifice their own comfort and remain as independent as possible, far longer than most professionals consider wise, in order to protect and provide for their children and grandchildren. Their children and grandchildren cherish the elders, appreciate the support and guidance provided over the years, and are clearly willing to provide extraordinary care for their elders when needed. The fact is, we do not know how all generations can be productive and creative in designing individual, familial, social and governmental structures that will support the current possibilities of aging.

The age/sex images do not reveal other major changes within age/sex groups. Most of the “traditional” population structure images assumed a fair amount of homogeneity overall. The reality now is that all the groups are more heterogeneous in terms of cultural ancestry and heritage (and thus beliefs and practices about how to grow up and grow older), accumulated advantages and disadvantages of formal education, wealth accumulation, and social status. Because we are a nation of immigrants, our age/sex groups are more varied than in many cultures. This may mean, for example, that it is

difficult to find home or health care for elders with caregivers who are “like them” in language and culture. It may also mean that the younger members of an immigrant cultural group no longer support the same norms for family care of elders (or children) when they become more assimilated to the American culture of individualism.

It has been clear for many years that wealth matters. In the early 21st century, men in the top 1% of income among American men live 15 years longer than the poorest 1%; for women the gap is 10 years. The inequality of life spans between rich and poor have widened from 2001 to 2014.⁶ What is most striking about recent findings is that the poor in some cities—big ones like New York and Los Angeles, and quite a few smaller ones like Birmingham, Alabama—live nearly as long as their middle-class neighbors or have seen rising life expectancy in the 21st century. In some other parts of the country, adults with the lowest incomes have a life expectancy comparable to people in much poorer nations like Rwanda, and their life spans are getting shorter. These findings lead to optimism that the right mix of steps to improve habits and public health could help people live longer, regardless of how much money they make or where they live.⁷

Changes in Family Constellation and Functioning

We can take a century ago as a reference point—since many of the surviving elders in our society grew up with the norms, expectations, and realities of that century. We learn what it means to grow up, to be adult, and to grow older in a social context: from family examples, but also from media, gossip, and fiction. In 1915 the norm for Euro-Americans was certainly to recognize clear distinctions based on biological sex, to establish a heterosexual union based on mutual attraction and support, to produce and socialize the next generation, to support one's extended family members, and to participate in the “civil” society as much as one could (remembering that women were not yet allowed to vote, nor own property, nor obtain credit on their own). Marriage was very important, for both men and women but for somewhat different reasons. As Simone de Beauvoir observed about women, “we are married, or have been, or plan to be, or suffer from not being.”⁸

Then, as now, there were important social class distinctions. Middle class women married in their late teens or early 20s, and they were often allowed to have at least some higher education (the first woman's college, Mt. Holyoke, was founded in 1837).

Men were expected to have some professional education or training and married somewhat older because they were expected to be financially established before marriage. Women were expected to be homemakers and care-givers, hiring help as needed to run households. Working and lower class women married younger, and often continued working out of economic necessity; they cleaned their own houses as well as those of the more advantaged. They provided direct care for ailing relatives, and paid care for families affluent enough to hire them as nannies and nurses for the elders.

These general expectations and behaviors persisted in the U.S. until the Great Depression and WWII. During the depression, couples postponed childbearing, leading to a smaller birth cohort. During WWII, many middle-class women were recruited into the paid work force, and men were drafted into military services. After the war, men returned, and the society was devoted to rebuilding. Marriages, many children, and sexual division of labor bloomed. We also experienced GI-funded education for many who would not otherwise have had higher education, suburban housing designed to support growing single-family needs (which is now one of the problems with aging-in-place designs),

and the withdrawal of many women from the paid labor force. Women were expected to provide professional-level care for all family members, young and old; there were many young and few old needing care. *Occupation: Housewife* became a middle-class norm, and many appreciated the autonomy and control over their own realm, and recognized the competitiveness instilled for meeting standards of care for the home, children, and (much less) elders.⁹

In the 1960s the second wave of feminism (the first being the drive to obtain the right to vote for women) emerged with the publication of Betty Friedan's book *The Feminine Mystique* in 1963.¹⁰ She challenged the cult of homemaker and mother that flourished in the earlier decades, pointing to the wasted talents and energies of educated, middle class (white) women who were not allowed to participate fully in the paid economy and enjoy the independence and recognition they desired.

The dramatic changes in family structure and function that followed were not attributable only to her, or to the feminist movement, but they did occur. Divorce rates rose; women returned to school and to the paid labor force; child-bearing rates decreased; remarriages resulted in complex family relationships. Concomitant were challenges to

expectations regarding sexual behavior, at least partly because of the discovery of easy birth control; sex became separated from marriage, and, eventually, parenthood has become separated from marriage. Individuals now cohabit, procreate, and may share responsibilities for care of children, parents, extended kin—or not. There are few norms, social or legal, to guide the complex relationships between individuals who are related to each other by past or current relationships, “blood ties,” or affectional bonds.

Matilda White Riley in 1993 suggested that the notion of the “family tree” should be re-conceptualized as a “family bush” with various ties created legally or by mutual choice.¹¹ The “bush” model is not bound by widely accepted obligations and privileges, nor necessarily by law; the bonds may be evoked by mutual consent at any point along the life line. In this model we may not be able to count on a son to care financially or emotionally for his aging mother, but she may receive bountiful, loving care from the woman her son divorced 20 years ago.

Recently, more challenges to family structure and function have come with the challenges regarding sex/gender/sexuality identification. Individuals who

are attracted to someone of their own sex, and want to live in a recognized and supported unit as a family, have won rights for legal and social recognition. These rights, however, are still unevenly provided. When we consider the importance of a spouse in supporting an aging, ailing partner—or an aging parent of either of the partners—some homosexual partners are still denied recognition as the most significant social support partner.

There have always been exceptions to the average, normative expectations and behaviors. As documented in a recent book about unmarried women by Traister: ¹² “there have always been women who rejected marriage, or were deemed unmarriageable, for many reasons, and with varied consequences. Many unmarried women were “appointed” to care for aging/ailing family members; some appointed themselves to be the adventurer in

Median Income by Sex Non-Hispanic Whites Over 18		
Marital Status	Male	Female
Single, never married	\$26,056	\$24,690
Married, spouse present	\$51,835	\$26,321
Married, spouse absent	\$36,485	\$22,321
Widowed	\$30,630	\$20,948
Divorced	\$36,196	\$28,492

the family.” While a few unmarried women have become wealthy, as a group they have been economically disadvantaged. The table below shows the impact of marital status, sex, and marital status in 2014 among non-hispanic whites (the most privileged group generally).¹³

The economic “price” of gender is clear: regardless of marital status, women have lower median incomes. The sex differences are least evident among the single, never married groups (presumably also younger). What is perhaps surprising, and provides some support for Traister’s thesis that women have learned to succeed on their own, is that median income is highest among divorced women—still substantially below men, but better than other groups of women.¹⁴ It is also clear that household income is highest among married, spouse-present families.

By later life, women are clearly worse off economically. The table above shows the percent of

Poverty Status by Sex and Age		
% Below Poverty Level	Men	Women
60-64 years	10.3%	11.3%
65-69	5.9	9.0
70-74	5.7	8.7
75-79	6.7	12.3
80-84	6.3	13.8

seniors at the poverty level or below, according to the 2011 census.¹⁵

We must take these income levels and gender inequalities into account as we consider programs for Aging In Community. In addition, we must be sensitive to variations among different ethnic groups; generally, the profiles for minorities show lower median incomes and higher rates of poverty among both genders.

At the middle of the last century, at least 90% of American women were married at some point in their lives. At that time, motherhood without marriage was socially disgraceful. At this time, thanks to the availability of contraceptives to individuals (rather than only to married couples), legal changes recognizing women as individuals capable of making contracts and being held responsible, and expanded opportunities for women socially and economically, about half of first-time births are to unmarried women; for women under thirty, it is almost 60%.

Traister (2016) argues that being an unmarried woman now, and/or a mother, is a mass behavior rather than an exception; it is just a viable option. Such a woman may marry for awhile, or be in partnership for periods of time, but she remains

basically independent economically, socially, and politically. It is not clear how these women will fare as they grow older, and what kinds of communities will support them in the absence of semi-traditional supports of family.

Changes in Economic Structures

As America moves from a production to a service economy and from a local to a global economy, these shifts affect the options as one grows up and grows older. The production economy experience of many adults who are now old relied on physical strength and endurance; many of the men and women who did such work now find themselves physically damaged and unable to function effectively even before they retirement age. Some have resorted to disability support to sustain themselves until they qualify for Medicare and Social Security.

Shifting toward a service economy may mean that some older workers retain skills and competencies that enhance their ability to remain competitive in the paid work place, as long as they can learn the new computer literacy skills. Many of the interpersonal skills prized for service jobs are more evident among women, including older women.¹⁶ However, service jobs have traditionally been less

valued in the American economy. There is ample evidence that service workers earn less than those who are regarded as producing a “product” or wealth; lower level service workers are disproportionately women.¹⁷ The global economy also means that many service jobs have been shifted elsewhere in the world, where workers are paid less and have fewer job protections.

The global economy and our past and current patterns of immigration mean that individuals who can function in multiple cultures may thrive, in adulthood and in later life. Immigrants who only retain the languages and customs of their native culture may have great difficulty in “Aging in Community” unless their new community adapts to them. Many American communities are doing this, by publishing materials about supportive services available in multiple languages; providing interpreters for the situations requiring legal adjustments (passports, citizenship, benefits); and providing opportunities for elders to maintain their cultural traditions while learning about American ones.

Changing Technology

Technological changes have been breathtaking in the past century. Modes of communication, transportation, and housekeeping have all changed. The rapid growth of personal communications via telephone, email, Twitter, Facebook, and Messaging means that persons in every generation who can afford and learn to use some kind of cell phone or smart phone can remain in contact with friends, family, and service providers more rapidly than possible even two or three decades ago. Even when physically impaired, individuals can “experience” the wide world via telecommunications. The concept of “social isolation” must be re-conceptualized: this now means those who either lack the means or the desire to be in touch. However, even the technologies of “being in touch” do not replace the desires and needs to be in touch personally.

Also very important for an aging community are the changes in medicine. Medical systems can now diagnose, treat, cure or defer the consequences of many diseases. Data systems can track health indices over time and across patients, and information can be shared among health care providers, and often with relatives monitoring health and professional care from a distance. Wellness

checkups, directions for care, visual conversations with professionals and patients, and even some diagnostic tests can be carried out long-distance, extending the reach of medical services far beyond those who can travel to an excellent medical center.

In a world of health-care devices that are wirelessly connected to the cloud, an “Internet of Caring Things,”¹⁸ a “smart pad” could answer a doorbell or unlock a door, so the client would not have to get out of bed or negotiate a walk to the door. Monitoring in-home behavior has become quite sophisticated: mugs can measure how much liquid has been consumed, sensors placed under a mattress detect restlessness and monitor abnormal breathing and pulse rates when sleeping; monitors can measure a patient’s gait to help predict falls. A smart carpet that can detect falls is under development. Current professional caregivers report that bed sensors can predict illness 10 days to a month out, and falls can be predicted two weeks to one month ahead of the event.¹⁹

But with all this technology come ethical questions. Who decides how such monitoring and controlling will be done? Elderly often want to retain their privacy and independence, feel that introducing such devices will signal that they are frail and need

constant monitoring, and may fear that they will operate the technology incorrectly. Caregivers want to have more information, without having to be with the client all the time. They want safety and efficiency.

Enhancements in technology enable individuals with diabetes to be fitted with workable prosthetic limbs, individuals with faulty kidneys to receive dialysis or a transplant, and some individuals with hearing loss to decode speech and communicate even in a group. These advances are among the reasons for increased survival to be very old. But though technology can preserve life, it cannot always improve the quality of life. This has increasingly led to debates about end of life care.²⁰ We have the expertise to prolong life, preserving basic life functions such as breathing and nutrition, but not the expertise to ensure brain functioning, communication capabilities or any sense of the meaning of life.

A PARADIGM FOR ADAPTIVE FUNCTIONING

Any program of changes for aging in community must be based on a sound model of how individuals adapt to change. Change is the only constant in life

span development; our goal is to maximize the functioning of every individual at every stage of life.

One of the most useful models is one proposed by Lawton and Nahemow in 1973, the Ecological Theory of Adaptation and Aging.²¹ M. Powell Lawton was a gerontologist deeply interested in the impact of environmental factors on human functioning, and Lucille Nahemow was a clinical psychologist immersed in individual functioning. Together they constructed a model which recognized the importance of both in assessing and altering functioning. (While their model was presented in the context of aging studies, it is clearly applicable for any age.)

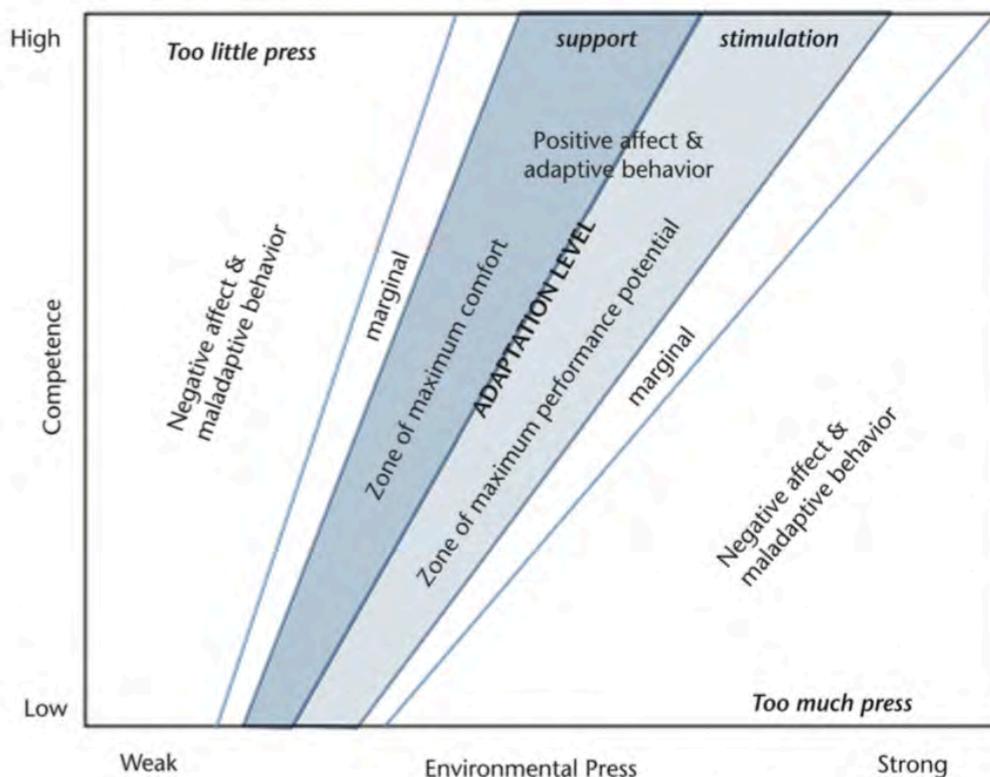
At any age, one's behavior is partly determined by competence. This includes such factors as genetic potential, intellectual intelligence, emotional intelligence, physical fitness, health/disease, and personality—the usual modes of responding to various kinds of situations. In many models it also includes level of formal education, social supports like family and close friends. These are the basic personal resources with which any individual confronts environmental demands.

The second dimension of the model is all the ways in which the natural, built, and social environments

place demands (or “press) on the individual. This dimension includes the climate, physical location, architectural features of buildings used, laws governing behavior, technologies (transportation, communication media, machinery), prevailing social norms and means of enforcement, rules governing possible supports, etc.

When we picture competence as a vertical scale and environmental demands as the horizontal, we can chart likely outcomes. Positive affect and adaptive behavior is most likely when there is a match between the two dimensions; persons with high competence (like the 80 year old who still enjoys climbing mountains, doing crossword puzzles, teaching children to play chess, and learning new cuisines) is likely to be happy in a setting that enables those activities, encourages acquiring new skills, and respects the accomplishments, but bored, anxious, even depressed, and resentful in a setting where adherence to a routine is expected, novel experiences are not available, and age is regarded as an automatic stigma. They proposed that the zone of optimal adaptation is one where environmental demands slightly exceed current competence. This model has been amply affirmed.

This model provides a guide for intervention: we can modify adaptation by changing either dimension—but we need to recognize that any time we modify only one dimension it may have unintended consequences if we do not modify the other. The best models of Aging in Community try to deal with both dimensions.



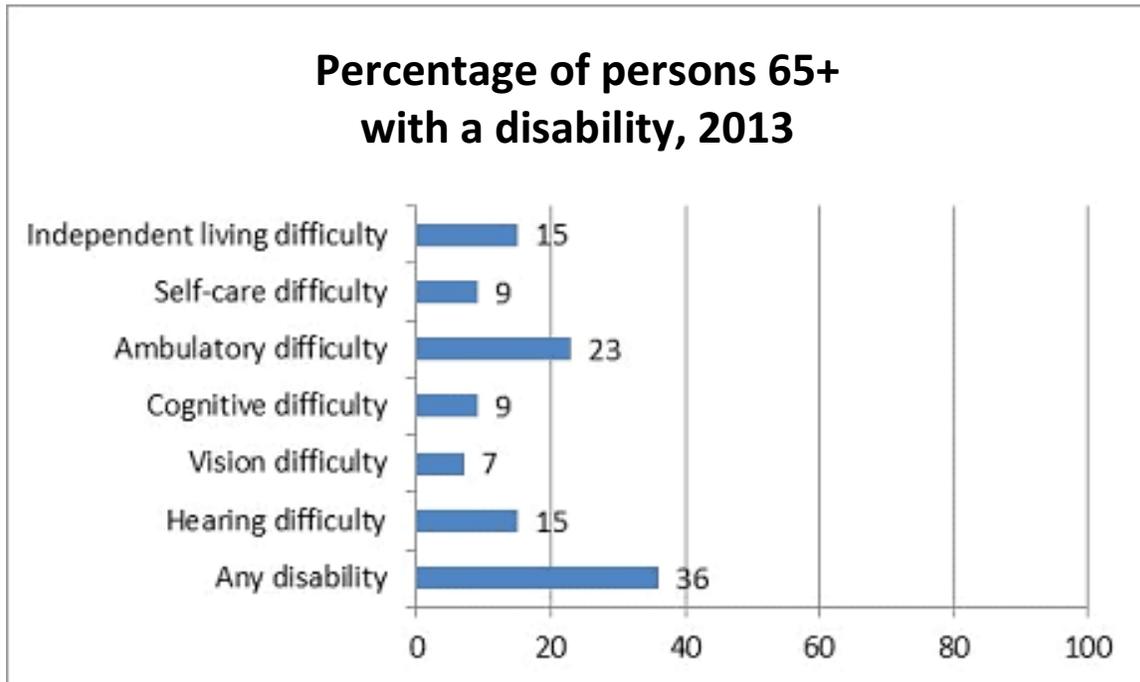
Lawton & Nahemow's model measures an individual's adaptability as an intersection of differing levels of individual resources vs. levels of environmental "press," or demands. Individuals are happier with slightly more resources than demands, but perform better with slightly more demands than resources.

Creating—or Avoiding—Disability

The Lawton model is also very useful in understanding the process of becoming disabled, or the options for avoiding disability in spite of impairment. Disability is the consequence of an impairment that may be physical, cognitive, mental, sensory, emotional, developmental, or some combination of these that results in restrictions on an individual's ability to participate in what is considered "normal" in their everyday society.²²

Many individuals have some impairments throughout life. Disability usually arises because of environmental circumstances. What “demands” are placed on the individual, and what resources are available to deal with the impairment? The more we learn about brain structure and function, the more evident it is that all of us have some ways of perceiving, thinking, reasoning, or responding that may make it difficult to participate in what is considered “normal.” Children who have novel ways of perceiving events may be considered “creative” or “strange,” depending on the culture. Being labeled “strange” (hardly a technical term, but one used by teachers, peers, and families) can become a disability.

We know that with advancing age, we have more impairments. In 2013, 36% of persons 65+ living outside of institutions had a disability, according to the U.S. Census definition.²³



Vision (7%) and hearing (15%) impairments are particularly common. Yet many adults with visual impairments are not disabled because they can obtain and afford glasses that correct their vision. Impairments in balance, muscular-skeletal and motor functions (23%) may or may not become disabling. The availability of physical therapy, canes, walkers, scooters, etc. can compensate for such impairments, but only if the physical and built environments are suited to their use. A building which is only accessible by stairs, especially if there

are no hand-railings, can turn an individual using a cane or walker into a disabled person; buildings with ramps and/or elevators allow such a person to be “normal” in that context.

Disability Case Study: Hearing Loss

Hearing loss is one of the most common, and potentially devastating, impairments in later life. Beginning in midlife, many individuals begin to lose the ability to perceive high-range tones and to distinguish words that include high-pitch nouns or vowels. For many, losses are progressive. When impairments become severe, the result is often social isolation, which is related to depression, impaired immune functioning, and premature death.

A recent study²⁴ examined health care use by nearly 562,000 adults between the ages of 55 and 64 who had private insurance. The rate of hearing loss triples between the ages of 50 and 60, until 60% of U.S. adults over the age of 70 have age-related hearing loss. They found that over 18 months, those with hearing loss had 33% higher health care costs (\$14,165), on average, than those without hearing loss (\$10,629). Further research is needed into the causes of these relationships between age and hearing loss, and hearing loss and health care use

and costs. At the least, anyone planning for successful aging in community, these challenges must be taken into account.

Interventions are available—the variety and usefulness of hearing aids has improved substantially over the past decade. However, most are still very expensive, and there appear to be substantial markups over actual device costs.

My Hearing Loss

Dolores Rosenblum, Ph.D., MSW

I began to lose hearing ability at mid-life. The onset of this disability was disappointing, but not surprising, as my mother and several of her cousins manifested signs of hearing loss at this point in their lives. I have been diagnosed with hereditary nerve cell loss in both ears, for which there is no cure, and my loss has progressed through the past 35 years to a level called "severe to profound." I have also progressed through three sets of technologically increasingly advanced hearing aids, at a total cost of about \$15,000: my latest set cost \$6000 for the two, and the expense is out-of-pocket.

I consider myself as having an "invisible disability." Hearing loss has no visible marker or prosthesis. In fact, hearing-aid manufacturers and consumers prize "invisibility" as a feature of their devices. So there is considerable stigma attached to the disability, and most hearing impaired persons will go to some lengths to disguise their loss. In most social situations I am obliged to tell other people that I am hearing impaired, and advise them what kind of accommodation I need. This requires a certain assertiveness that some people may not feel comfortable with. Women of my cohort, for instance, were often acculturated to avoid "loudness" in speaking.

Like other disabilities, hearing loss brings with it not only experiential difficulties, but a certain embarrassment and loss of status. Does that person think I'm stupid or dull because I do not respond or respond inappropriately? A similarly disabled friend recounts an experience we frequently share. He asks me: "Do you ever find yourself in a group where the speaker makes a joke and everyone laughs, and you laugh too, BUT YOU HAVEN'T HEARD THE JOKE?" Unfortunately, we hearing impaired don't get the lowered tones of a joke or an aside.

As I age, however, I find myself less concerned with appearances than with getting accurate information and participating fully in a group. My tools for coping include

my hearing aids, of course, which are always "on" in my waking hours (except for the times my head is under water), and my own voice in choosing to announce my disability to individuals or a group. Often I have to take the social risk of interrupting, as politely as I can, a conversation that has already begun. I also have a large button, which I don't always remember to wear, that reads: PLEASE FACE ME WHEN SPEAKING—PLEASE. SLOWLY. That's about all I can supply.

The rest depends on those willing and able to adapt the environment. Closed captioning, in whatever format or venue, is my chief prosthetic device. My church has a wireless system which works very well when I apply a device to my ear and everyone speaks at a microphone. Social hour in a lovely, resonant room is a cacophony of meaningless sound, and I resort to smiling amiably. There are other installed wireless systems that work well with certain hearing aids, but they are expensive, and not consistently available in public spaces. What works best for me is a group of six people, in a normal-sized room, seated at a round or oval table, and willing to project their voices slightly, choosing to speak distinctly. And. Slowly. In that situation I am less obviously "disabled." Communication for me requires that I adapt—and you, my community, adapt as well.

WHAT IS AN AGE-FRIENDLY WORLD?

According to the WHO (World Health Organization), “An age-friendly community is a place that enables people of all ages to participate in community activities. It is a place that treats everyone with respect, regardless of their age. It is a place that makes it easy to stay connected to those around you and those you love. It is a place that helps people stay healthy and active even at the oldest ages. And it is a place that helps those who can no longer look after themselves to live with dignity and enjoyment. Many cities and communities are already taking active steps toward becoming more age-friendly, but many barriers still persist. Some of these are physical, such as poorly designed buildings or lack of transportation to take older people to places they want to visit. Many barriers, however, result simply from the way we think about ageing and the way we view and treat older people.”²⁵

WHO has conducted a great deal of research to determine what specific features are needed to make a city age-friendly. They have met with groups of citizens in 33 cities in 22 countries. Their focus is on the Environmental aspects in the ecological model of adaptation. They have a suggested “Checklist of

Essential Features of Age-friendly Cities” that includes specific items in the following categories:

- Outdoor spaces and buildings
- Transportation
- Community and health services
- Respect and social inclusion
- Civic participation and employment
- Communication and information

Many of their suggestions for the built environment draw on principles of Universal Design: from the beginning of the building process, plan everything so that persons with any physical or cognitive impairments can use the space effectively. One of these features that is now common is the use of curb cuts on streets, ramps for access into and out of buildings, and wider doorways. While initially planned to accommodate wheelchair users, it turns out that the new designs are also very helpful for baby buggies, delivery persons, and anyone who needs a safe way to navigate the environment.²⁶

Along the Personal Competence dimension of the Ecological Model, there is a great deal of research about what contributes to well-being and high functioning in later life. The best evidence comes from longitudinal studies that have begun to

articulate what kinds of competencies are associated with good outcomes.

Not surprisingly, good health is important in confronting the many challenges encountered along the life span. However, probably just as important is a quality known as resilience – the ability to maintain a positive attitude and a sense of hope in the face of adversity, and a determination to accept personal responsibility for making what changes in oneself might improve the situation. For many people it is important to feel there is meaning in their lives, both in what they have done and what they are now doing. What the individual defines as “meaningful” may change: As Atul Gawande reported, toward the end of his life one of his colleagues’ father could barely move; he was no longer the vigorous, socially involved man he had been for so long. Dr. Gawande feared that this man would become depressed. However, this man explained that it would be good enough “if he could still watch football on television and eat chocolate ice cream.”²⁷

It is also important to have desired social involvements. Being objectively alone is not the same as feeling lonely or socially isolated, at any age.²⁸ Low levels of social contact may be chosen as

“solitude”; it may also be felt subjectively as being isolated. The key seems to be the sense of control over the intensity and quality of social relationships.

MODELS FOR PROMOTING HEALTHY AGING IN COMMUNITY

The research²⁹ showing that poor individuals do as well as the middle classes in life expectancy in some geographic areas but not in others provides important new clues about what may make a difference in health status. Interestingly, the findings did not provide strong support for four common explanations for socioeconomic differences in longevity: (1) differences in access to medical care (as measured by health insurance coverage and proxies for the quality and quantity of primary care), (2) environmental differences (as measured by residential segregation), and (3) adverse effects of inequality and (4) labor market conditions (as measured by unemployment rates).

Rather, most of the variation in life expectancy across areas was related to differences in health behaviors, including smoking, obesity, and exercise. Individuals in the lowest income quartile who live longer have more healthful behaviors and reside in

areas with more immigrants, higher home prices, and more college graduates.

A vast number of strategies have been used to deal with the challenges identified thus far in enabling individuals to remain healthy, engaged, and active in their communities as long as possible. They can be differentiated many ways, including the source of inspiration, funding, and enactment. Major sources of funding are taxes, collected at all levels of government; foundations and philanthropies; individual donations of time and money; and fees paid to private for-profit businesses.

Government Programs

The most important programs supporting aging well are undoubtedly the Social Security, Medicare, Medicaid, and Disability programs. While they are not targeted specifically toward aging in the community, they provide the basic financial resources and health care coverage to allow some choices in how and where to live. Recent revisions have been directed more toward recognizing that much support must occur in the community. The Social Security program was enacted in 1935 to provide retirement benefits only to workers; spouses and minor children of retired workers were added in

1939, and a Disability program was added in 1954. In 1965 the Health Insurance for Aged and Disabled (Medicare) and Grants to States for Medical Assistance Programs for low-income citizens (Medicaid) were added. Supplemental Security Income (SSI) was added in 1972, the State Children's Health Insurance Program for low income citizens (SCHIP) was added in 1997, and in 2003 a Voluntary drug benefits with supplemental Medicare insurance payments from recipients was added.

These federal programs have many advantages. They are funded through taxes, and over the years there have been many adjustments in how the sources of revenue are collected. Social Security is funded through payroll taxes on current employers and workers. Over the years, the rates of taxes collected has varied: in 1937 the OASDI tax rate was 2% on maximum earnings of \$3,000; as the projected pool of retirees grew the tax rate has increased to 12.4% on maximum earnings of \$118,500 in 2015. Thus, when critics warn that there will be no Social Security safety net for those who are now young adults or in mid-life, they ignore the long history of planning ahead to collect the funds.

It is clear that the resources needed to fund Social Security benefits in the decades ahead can be collected by many strategies. Among those recently recommended are a) raising the cap on income taxed (to at least \$200,000), b) raising the minimal retirement age, c) adjusting the COLA (Cost of Living Adjustments), d) expanding the pool of workers by including state and federal employees, etc. This broad coverage and flexibility in collecting operating funds is a major advantage of working with federal models.

A major challenge in working with federally funded programs is that policies regarding who and what is covered are typically directed by professionals far removed from local realities and preferences. In addition, many politicians want to limit the role of government in planning or funding programs.

In partial response to this challenge, federal agencies typically have provisions for sharing part of the revenues collected with state and local units. In some respects, the challenges are just shifted downward to a somewhat smaller scale—policies and practices may still be subject to the preferences of a ruling group of political leaders who will follow party preferences in what to fund. A current example is

the fight among states as to whether to opt into the expansion of Medicaid programs made available under the Affordable Care Act (ACA).

Generally, medical and social care for the poor has been relegated to the states. The ACA recognized the extreme discrepancies in providing support for the poor among states, and tried to work toward more equitable provision by offering a federally funded expansion of Medicaid health care support for states who would accept the oversights required in any federally funded program. About half the states accepted that offer, and have been able to cover many more adults at all ages with whatever supports the federal program decides to offer; such provisions are being continually revised. For example, some states have created an “advanced practice pharmacy” designation to expand pharmacists’ scope of practice so they can provide direct patient care, including medication therapy management, which can include medication therapy reviews, pharmacotherapy consults, anticoagulation management, immunizations, health and wellness programs, as well as other clinical services.³⁰

Medicaid is also trying to integrate social services into care for beneficiaries, recognizing that social factors such as housing, employment and access to

nutritious food can strongly influence an individual's health status. For example, Medicaid funded Hennepin Health, an Accountable Care Organization (ACO) that operates in partnership with the state of Minnesota. Hennepin Health targets "high need, high cost" Medicaid-eligible adults. They use up-front Medicaid funding to support access to county-based social services funds to help high-risk patients find housing and jobs. They report that the program has helped shift care from hospitals to outpatient settings. Emergency department visits decreased by 9.1% between 2012 and 2013, while less-costly outpatient visits increased by 3.3%. The percentage of patients that received care for diabetes, vascular conditions, and asthma at optimal levels increased. People who were newly housed made up for housing costs by reduced ER and hospitalizations.³¹ Other states have opted not to accept any federally funded Medicaid expansions; seniors and the poor in their localities will have to accept the consequences.

The Older Americans Act (OAA), originally enacted in 1965 under Health and Human Services, supports a range of home and community-based services. As President Lyndon Johnson stated in 1965:

The [law} clearly affirms our nation's sense of responsibility toward the well-being of all of our older citizens... Every State and every community can now move toward a coordinated program of services and opportunities for our older citizens. We revere them; we extend them our affection; we respect them.

Although older individuals may receive services under many other Federal programs, today the OAA is considered to be the major vehicle for the organization and delivery of social and nutrition services to this group and their caregivers. It authorizes a wide array of service programs through a national network of 56 State agencies on aging, 629 area agencies on aging, nearly 20,000 service providers, 244 tribal organizations, and 2 Native Hawaiian organizations representing 400 tribes. The OAA also includes community service employment for low-income older Americans; training, research, and demonstration activities in the field of aging; and vulnerable elder rights protection activities. Amendments were made in 2006, which focused on explicitly including Assistive Technology (rather than the more limited Assistive Devices), Elder Justice, Principles of Choices for Independence, and Civic Engagement.³²

The Administration on Aging (AOA), was also created in 1965 to administer the varied programs authorized by the OAA and to serve as the Federal focal point on matters concerning older persons.

From the beginning, ACL was based on a commitment to one fundamental principle—that people with disabilities and older adults should be able to live where they choose, with the people they choose, and to fully participate in their communities. Inherent in this principle is the core belief that everyone can contribute, throughout their lives.

The next major development under Health and Human Services was to establish the Administration for Community Living (ACL) in 2012. Initially, ACL brought together the Administration on Aging, the Office on Disability and the Administration on Developmental Disabilities. Since then, ACL has grown significantly. Through budget legislation in subsequent years, Congress moved several programs that serve older adults and people with disabilities from other agencies to ACL, including the State Health Insurance Assistance Program, the Paralysis Resource Center, and the Limb Loss Resource Center. The 2014 Workforce Innovation and Opportunities Act moved the National Institute on Disability, Independent Living, and Rehabilitation

Research and the independent living and assistive technology programs from the Department of Education to ACL.

ACL is structured to provide general policy coordination while retaining unique programmatic operations specific to the needs of each population served.

ACL is composed of the following units:

- Office of the Administrator*
- Administration on Aging (AoA)
- Administration on Disabilities (AoD)
- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
- Center for Integrated Programs (CIP)
- Center for Management and Budget (CMB)
- Center for Policy and Evaluation (CPE)

It is clear, then, that these federally-funded and staffed units can potentially have enormous impact on Aging in Community, and the ability for any community to meet the criteria for an Aging Friendly Community. Within the units listed above, AoA programs remain central to our interests.

The Aging Network: Contributions and Challenges

The OAA legislation established a large network of locally-based organizations dedicated to carry out the mission of the Act; those who staff such units came to be known as the Aging Network (AN). AN members include many different disciplines; one commonality is that they direct their professional expertise toward older clients. Members of the AN have organized into national (e.g. National Association of Area Agencies on Aging) and local versions to share education and problem-solving. Each state developed Senior Centers to provide nutrition services, social programs, wellness education programs; each led by professional leaders who were mandated to provide services to all seniors, and who were expected to learn about their communities and provide whatever services were requested. In addition, each state and major city developed a unit to provide specified services to particular groups (e.g., the Chicago Department on Aging), often dealing with income-based services. Within AoA, “the Aging Network (AN) is gradually becoming recognized as an essential component of healthcare service delivery for a burgeoning number of community-dwelling adults 65 and over”³³

The AN is also recognized as challenged—or threatened.³⁴ The ACL Administrator and Assistant Secretary for Aging, Kathy Greenlee, has noted the importance of maintaining the AN’s “mission-driven work to assist all older adults in need” while also urging those concerned to recognize that rising needs and flat funding during the last decade have significantly reduced the purchasing power of OAA federal dollars. Greenlee pointed to the need to transition into an evidence-driven, cohesive system, responding to a modified values system stressing lowering cost, improving care, and providing better health.

Better health outcomes and stabilized costs? This is a major challenge, particularly in the context of Aging in Community, where our plan is to stay out of hospitals and nursing homes as much and as long as possible (while taking full advantage of medical and technological advances to enhance the quality of our added years of life).

Philanthropic Models of Care

Americans have a long history of providing care for the “needy” or the “disadvantaged” through funds provided not by taxes collected from the populace at large, but from donors who decide to share a portion

of their wealth with those who have less. In our system, donations to groups/ charities who provide services but do not profit from the services provided can be recognized as special entities legally; individual (or corporate) contributions to legally-designated non-profit organizations can deduct their donations from the amount of “income” on which they pay taxes. This is a powerful incentive for corporate and individual donors. Thus, many programs that fund Aging in Community programs are inspired by the tax system as much as by missionary zeal.

There are thousands of nonprofit foundations that provide resources for support services for Aging in Community, and not-for-profit organizations that organize to receive the funding needed to provide services. Foundations range from family-funded organizations that fund a very narrow range of causes and do not allow open applications, to large foundations with billions of dollars in assets, highly specialized methods of processing applications, sophisticated methods for tracking performance and outcomes, and creative modes of engaging other possible funding sources for projects.

For example, the Mather Lifeways Foundation³⁵ began with investments in real estate, including

specialized housing for older adults. They have expanded to include a substantial unit that performs research on effective aging, including developing an 8-session course on Cognitive Aging designed to improve cognitive functioning in later life. In the Chicago area, Mather is best known for creating the “Mather—More Than a Café” concept for facilitating aging in the community. Each café is centered on a restaurant that serves freshly-prepared breakfasts and lunches, modestly priced. While many come to dine, they also become involved in a wide variety of fitness activities, learning experiences (computer classes, languages), support groups, and social activities. Individuals join for a modest yearly rate and receive discounts on classes and activities. Most of the cafés are located in communities that serve lower-income elders with few other aging resources.

This model is attractive in so far as the professional staff are kind, caring, and creative. They can respond to desires for particular kinds of programming (like line dancing on Friday evening) and to local tastes in food. Since they do not receive city or state funding, they are free to carry out any programs that they can afford, and they are not placed in jeopardy when tax funds do not come in a timely fashion.

However, it requires substantial funding to maintain such programs. Few foundations are willing to be the largest or sole provider for such organizations. Unlike the organizations authorized by government and funded by tax money, philanthropies and foundations have a mission, but not a mandate, to provide particular services. Foundations can change direction, sometimes fairly rapidly, leaving the organizations without resources they have depended upon.

An additional concern about relying on philanthropy to fund aging-in-community programs is the lack of diversity among the staff and governing boards.³⁶ While 36% of the overall population is racial and ethnic minorities, the latest data from the Council on Foundation Grantmakers research show that just 16% of foundation board members and 24% of full-time grantmaker employees are considered racial and ethnic minorities.³⁷ Other kinds of diversity are also under-represented, such as persons with various disabilities, sexual orientations, or gender identities.

Tax-funded services and philanthropic support are often targeted toward less affluent older adults, particularly when demands are high and funds seem low. There is no basic assumption in this country

that health care is a right, or that every person should live in a safe neighborhood with access to appropriate housing and nutritious food. Although some of the rhetoric in the legislative acts creating the AoA sounds very inclusive, the reality is that funds do not stretch to provide the services needed to all who need them.

Consumer-Driven Models: “Neighbors Helping Neighbors” in Villages

The Village model has developed in the past two decades to help create aging-friendly communities by relying largely on volunteers—neighbors helping neighbors. The initial village was developed in Beacon Hill in 2002 by individuals who wished to remain in their own homes, rather than feel pressed to relocate to a retirement community. They formed an organization designed to pool their abilities and resources. Other communities followed the Beacon Hill model, adapting their practices to fit their own communities. There were 190 villages open in 2015, with another 150 in formation.³⁸ In 2015, 34% were in urban areas, 38% suburban, 22% rural, and 6% were not clear. The structures vary; some have a central office and local activities, some are “hub-and-spoke” models serving multiple communities

with a central office. Most villages charge a membership fee, for which members receive a variety of supportive services (typically transportation, grocery shopping, household help), and informal supports (such as calls or visits), and access to social activities. Some villages have two levels of membership, one for those who just want social activities, and another for those who want to be able to request volunteer services. In addition, many villages provide member-recommended service providers, and/or discounts for members, and they try to link their members to services that are beyond the capacity of the volunteers.

Decisions about what services volunteers will provide, what kind of screening and training they should receive, and who should receive services are all decided by the board members who run the village. Villages have banded together in the Village-to-Village Network, and have yearly conventions and ongoing discussion boards where these issues are discussed. For example, many villages are uncertain about when to determine that a volunteer can no longer be a driver, or when a member is too cognitively disoriented to be cared for by a volunteer.

Villages are run by their members, and the programs and services offered are determined by the

members. Most Villages employ some staff, averaging about 1.5, largely to coordinate service requests and support members in running programs. Some of the larger Villages have more employees, such as a nurse and/or a social worker, and provide transition support from hospital to home. Villages raise their own funds; membership fees cover approximately 50% of the budget for most villages. They rely on fund-raising for the remainder. A few villages have partnered with city tax-funded agencies to provide some of the services that would otherwise be done by the agency, and some have contracted with hospitals to provide discharge planning and follow-up, linking patients to existing Village programs and services. Some villages have received substantial support from Foundations (such as the Mather Foundation).

Common services available to Village members include:



Transportation



Social events



Peer learning



Intergenerational learning



Field trips

Villages and Naturally Occurring Retirement Communities (NORC)

A study comparing Villages with NORC programs highlights the similarities and distinctions between these two models.³⁹ Naturally Occurring Retirement Communities arise in geographic locations with dense concentrations of older persons that were not designed originally as senior housing. They are intended to receive funding through private-public partnerships, with support from government, foundations, housing providers and individuals contributions. In 2013, there were approximately 100 NORC programs nationally, with roughly half in New York City. The comparison included information from 62 NORC respondents and 69 Village respondents. Both kinds of programs placed the most emphasis on promoting access to services, and secondarily on strengthening adults' social relationships and reducing social isolation.

Villages were more likely to provide assistance with transportation, technology assistance, and home maintenance or repair; NORC programs focused more on home-delivered meals and congregate meals, and on health care and health promotion activities. NORC programs are typically

located in large apartments or clusters of smaller units close together; 39% of Villages are in towns or cities. NORC programs were more likely to be in communities where the dominant socioeconomic status was low, low to middle, or middle; Villages were more likely to be in middle or middle to high SES. NORC programs were designed to benefit adults over 60; most of the beneficiaries were 85 and over. Villages are more likely to serve adults 65-74, though many programs were designed for a wide range of adults. Consistent with the different profiles of consumers, NORC programs are more likely to be delivered by paid staff members, often those with special training to work with populations of high need. Villages rely a great deal on unpaid staff (e.g. those with job titles and significant responsibilities), but still only half of the services are provided by volunteers. The authors of the study raise some doubts about the viability of the Village model to deliver peer-to-peer supports as envisioned in the model.

The potential advantages of the Village model are clear. This model serves a gap in federally funded and philanthropic programs for aging in place: individuals who cannot afford to purchase all the supportive services they need as they grow older, but

who do not qualify for the programs designed for the “poor.” The ideal for services is that they be directed by those receiving the services themselves—such as from a loving daughter who really wants to make her parent as comfortable and as engaged as possible, and who gets support in providing this care while also caring for younger family members.

All the models described are based on the expectation that such superb, individualized care is not available to all elders, and that compromises must be made. We have developed a language and an expectation (and even legal mandates) that services provided by strangers should also be “person-centered” and “consumer-driven” rather than driven by the needs of the agency providing the service. Villages, insofar as the activities offered are controlled by the members themselves, may be more likely to provide such personalized services.

Liability is another important concern for the Village model.⁴⁰ When a Village sends out a volunteer to escort a member to a medical appointment, what happens if the member falls while getting into the volunteer’s car? If the Village recommends a vet for caring for an ill cat, what if the cat dies? If the Village accepts a college student as a volunteer to provide gardening services, or computer

consulting services, what if that student is not actually qualified?

Do Villages Work?

The answer is not yet clear because this is a new model of aging in community. One line of research has asked whether the Village model helps to foster age-friendly communities.⁴¹ Andrew Schalarch and his research team identified 69 (of 80) Villages listed in the Village to Village Network in 2012 that were providing services to older adults and were at least partially consumer-driven. In 2012 a representative from each of the Villages was contacted and asked about organizational development, governance, structures, financing, programs and services, membership characteristics, member involvement, and sustainability. Following the survey, respondents were interviewed. Measures were selected to operationalize the eight types of age-friendly community supports identified by the WHO Global Network of Age-Friendly Cities and Communities program: social participation; civic participation and employment; respect and social inclusion; community support and health services; communication and information; transportation; housing; and outdoor spaces and buildings.

Analysis revealed that 85.5% of the Villages provided assistance with at least six of the WHO domains, but only 10.1% implemented features of all eight. More than one-third were engaged in direct or indirect efforts to improve community physical or social infrastructures or improve community attitudes toward older persons. While 97% of the Villages offered home repair and maintenance services, only 10% of the Villages advocated for specific improvements in the physical environment such as installing sidewalk benches, making crosswalks more pedestrian friendly, developing alternative options within the community, and advocating for a community senior center.

Overall, the researchers concluded that *Villages have substantial potential to help create and sustain aging-friendly communities*. By working with both paid and volunteer workers, and by establishing partnerships with existing community entities, they can maximize the use of limited resources. In addition, about a quarter of the Villages were working to improve attitudes toward older persons. The members served were younger, more economically secure, and less likely to reside in communities with low or middle socioeconomic status than the general U.S. population aged 65 and

older,⁴² but 87% of the Villages had provided services to non-members in the past year.

Another, more crucial line of research is to examine the impact of participation in Villages on health, well-being, and social engagement. For this analysis, researchers obtained data from 282 active members from five Villages in California; all were located in predominantly urban areas, with members predominantly female (two-thirds), White and English-speaking.⁴³ Most respondents were in their 70s and 80s; approximately 80% had completed a bachelor's degree or graduate school, and 41% lived alone. Less than 10% of the participants reported they were financially insecure. Three of the Villages were independent and free-standing; two were a program within a larger social service agency. The outcome measures were constructed to assess the perceived impacts of Village participation on members' social functioning, health and well-being, access to services, and self-efficacy for maintaining independence.

The results were promising in some areas. Nearly 79% of the respondents agreed that they knew more people as a result of the Village membership, and 59% felt more socially connected. The Villages were effective in helping members to access services and

health care, through directing members to recommended providers and transportation. However, only one-third of the members reported feeling healthier because of Village membership; as the researchers pointed out “this may be because Villages do not currently offer many specific disease management or personal care-related services.”⁴⁴ Assistance with technology, used by a minority of members, was associated with increased confidence in aging in place. As the researchers noted, “this is particularly promising, as the use of the Internet and communication technology can increase social engagement and facilitate access to health-care information.”⁴⁵

An additional important finding is that “the members reporting the greatest impacts are those who participate in Village-sponsored social and education events, use companionship services, volunteer, or receive technology assistance. Unfortunately, Villages appear to have less impact for those members in worse health.”⁴⁶

Sustainability & Business Models

Based upon the rapid growth of Villages in the U.S., the obvious need to develop new, more effective models for aging in community, and the promising

results of some of the early Villages, the Capital Impact Partners undertook a systematic analysis of four different business models currently used by operating Villages.⁴⁷ These models include:

- **Grassroots:** The most common structure for a Village where the organization is a stand-alone nonprofit administered through a combination of paid staff and volunteers. Members are encouraged to participate in the governance by serving on the board or committees.
- **Parent Sponsored Village:** The parent organization serves as a fiscal agent and supports the Village organization by providing the back office, legal, financial management, and office space.
- **Hub and Spoke:** Brings together multiple communities or neighborhood enclaves to share costs and back office support in order to serve a wider area. This model allows multiple smaller Villages (“spokes”) to be created in an area with a central Village (“hub”) that handles the ITR, database management, accounting, and other support roles.
- **Village with TimeBanks™:** Combines the TimeBanks™ model with the Village. TimeBanks™ allows members to “exchange time” and earn time

dollars for volunteering. Time dollars are exchanged for services, or donated to a community pool to benefit those unable to provide a service. This model is attractive as a way to create a lower fee structure for Village membership where time “banked” is provided as a part of the membership fee.

The authors of this report (Candace Baldwin, Janis Brewer and Judy Willett) have drawn upon the substantial research evidence with nonprofit organizations to identify factors which enable organizations to survive. As the authors noted: “Sustainability is about acquiring and maintaining control over the organization’s financial health and stability.... sustainability relies on leadership, adaptability, and program capacity, as well as understanding where a Village is in terms of the organizational lifecycle.”⁴⁸ Capital Impact Partners did research on 15 Villages in order to identify the characteristics of Villages that are likely to be sustainable, in terms of criteria ascertained from other non-profit organizations.

- *Founding & Governance: On average, Villages ensure that 51% or more of the Board of Directors is represented by Village members. They use the*

organization committees to continually “feed” board membership. Villages transition from founding to operating Board of Directors on average two-three years after full launch of Village operations.

- *Staff & Volunteers:* 66% of Villages participating in this research have paid staff, with one paid staff member for every 78 members, or a 1.15 FTE ratio. Sustainable Villages maintain healthy volunteer pools. Villages have one volunteer for every 4.2 members to ensure strong program capacity.
- *Member Services and Village Programs:* Village-sponsored social events are the most prevalent (70%) membership benefit offered. Surveys and asset mapping activities during concept and startup stages help the Village to understand the service and program needs of prospective members. Villages do not replicate services already in the community, but strive to address unique challenges and opportunities older adults face living at home. As Villages mature, so do their members; they will begin to request more assistance and support for higher-level medical and health concerns.

- *Partnerships:* Villages are part of a larger local aging services community, which provides many opportunities to build partnerships. Leveraging partnerships that extend the Village’s ability to serve its members can reduce costs and increase member benefits. Understanding the local aging landscape helps Villages to identify potential partners and ensures non-duplication and unnecessary competition with local service providers.
- *Marketing and Communications:* Marketing includes messaging, outreach, and visibility, as well as getting new members. Villages dedicate at least 5% of volunteer and staff time on community outreach and general marketing activities. Member testimonials and house parties (a.k.a. coffee chats) hosted in member homes have the greatest impact. The most effective messaging promotes hope, fun, social care, positive interdependence, and it positions the Village as the “go-to” place for aging gracefully, with dignity and connecting their community. The authors provide a guide to language use for Villages: Distancing language includes “aging, independence, resources, assist, access, program, enroll, caregivers, and model”; Connecting

language includes “Friends, freedom, happiness, neighbors, community, safe, confidence, enrich, and engage.”

- *Financial Viability and Longevity*: Diversity in funding ensures longevity. Extensive use of volunteers and in-kind services can significantly reduce overhead costs. Membership fees cover, on average, 45% of expenses, though they recommend that Villages should strive for membership fees to cover at least 70% of operating expenses. Within this group surveyed, 20% of revenue came from individual donations, 11.5% from private foundations or corporations, 5% from government funds, and 18% from other sources.

Capital Impact Partners determined *that “the key factors for sustainability are similar for all Villages regardless of the business model chosen.”* (p. 27) However, they also identify unique challenges in each of the four business models. The all-volunteer programs can only work where there are residents with natural tendencies of obligation and reciprocity, and who have a substantial amount of free time to ensure an uninterrupted pool of engaged volunteers. The Parent Sponsored models often have shorter start-up times, more diverse streams of revenue, and

unique abilities to build upon partner programs to offer extended services to members. One challenge in marketing is to differentiate the Village from the Parent. The Hub-and-Spoke model allows spokes to plan programs based on their areas' unique needs and assets, supported by the hub. The few Villages included in this study showed sustainable profits, but the authors warn that this may not hold over time and with more diverse Villages. Finally, the TimeBanks™ model requires the most investment in coordination of volunteers; there is a software platform that facilitates this.

Another challenge is inclusivity. The data from several Village surveys are clear that members currently are drawn from Euro-Americans who are younger, more financially secure, and somewhat healthier than the older population at large. If this model is to be truly effective in helping older adults aging in community, there need to be strategies for including the greater diversity of older adults. Some of the barriers to participation now are financial. Some (67%) Villages offer subsidized memberships for individuals with lower incomes,⁴⁹ based on the Elder Economic Security Index, though some simply let the Executive Director make an assessment.

The Chicago Hyde Park Village (CHPV) posed a challenge to a consulting team from the University of Chicago Catalyst student group to develop a plan for a subsidized membership program. It had always been the intention for CHPV to include such a provision, but they had not been able to figure out how to manage it. CHPV did not begin with any philanthropic or agency support, and were entirely funded by membership fees and individual donations. The UC consulting group explored the experiences of other Villages, and recommended a plan to include subsidized memberships while being sustainable.⁵⁰ They recognized that funding subsidized memberships was not a good idea if the funds came only from short-term funds (e.g. grants) that might not be available in subsequent years.

The consultants developed a program for calculating how many subsidized members could be accommodated each year, depending on the number of members in different categories (full, associate) and the amount of subsidy to be provided (from \$25 to full membership). Using their program, a village could enter in various numbers to see what the likely impact would be on the budget. In the case of CHPV, with about 100 members, offering a subsidy of \$50 per year could support 9 members.

Obviously, as more funds are generated by non-membership fees, the number subsidized can increase.

While some Villages reach out actively to communities of color and LGBT populations, there has been limited success. It is not clear whether this reflects the general tendency for people to congregate with “people like them” or whether this is evidence of continued bias.⁵¹

For-Profit Business Models: “Villages” for Affluent Seniors

Businesses have noticed the increasing market of products and services designed to appeal to seniors who can afford to purchase comfort, independence, and care as they wish to have it. Early models, like the Sun City retirement communities, have been around for a long time. One common feature is that residence is limited to those above a specified age; multi-generational family living is not allowed. Activities offered vary among facilities, depending on consumer demand and business considerations about what services can be offered at profitable prices. Many of the first retirement communities were planned for less urban areas, with the assumption that golf would be a major pastime.

The emerging baby boomer markets are likely to come into later life with many more demands for options in aging. Once they become acquainted with recommendations from the WHO, they will want places that offer all those features, including housing that incorporates Universal Design accessibility. They will probably demand their choices of modern technology to bring their health care more under their own control. They will want to control the level and kinds of social interaction. No doubt some will want aging-friendly communities to be enjoyed by all generations; others will prefer to associate mostly with elders. Some will prefer cultural events to golf courses. Some may want the option of a special facility nearby for those with dementia. At a minimum, they may want to ensure that the larger community is “dementia friendly.”⁵² While many older adults would probably appreciate such communities, most will not be able to afford them. But many will come into later life with resources to pay the fees, and they are creating a market for products that are not widely available.

PLANNING AHEAD

The emerging focus is clearly on Integration of Services.^{53 54} For many reasons, the primary concern is the health of our aging population—how to maintain healthy functioning while adding years to life. For many decades the emphasis has been on medical advances, with investments in various screening and treatment options. Concerns have been mounting about the costs of medical treatments, the lack of medical practitioners trained in geriatric care, and the evidence that medical care does not translate to quality of life. There is much more emphasis now on the recognition that health is influenced powerfully by non-medical factors. There is evidence that mortality among the poor is significantly influenced by the community; where the community “ethic” emphasizes healthy behaviors and social investments in the poor are greater, being poor does not have the life-threatening consequences evident in less supportive communities.⁵⁵ Many factors that are associated with health and quality of life (and not just mortality) have been identified in the various efforts to delineate factors that create an aging-friendly community—such as appropriate housing adapted for use by those with various impairments, and the

design of community spaces where one can walk to shops, social gathering places, and medical facilities. The crucial importance of social integration and meaningful engagement in the community has been demonstrated.

There are thousands of nonprofit groups with missions to support various aspects of aging-friendly communities. Every component listed in the checklist for a desirable community may have its own set of organizations competing for resources to address housing, transportation, recreation, employment, social interaction, continued education, and health care. One of the major challenges then becomes to fund and coordinate such services.

Several approaches to integrative services have been developed so far.⁵⁶

Community Planning

AARP reported that in 2015, 44 towns, cities, and counties, representing localities inhabited by 28 million people had enrolled in the age-friendly network designed to respond to the WHO priorities. All of these initiatives involve large-scale, top-down planning by government entities, consulting with many consumers and agencies. As pointed out by

Scharlach and Lehning,⁵⁷ these models recognize the many ways in which built environments can create barriers to health, well-being, and social inclusion. These are very promising movements, though slow. It may take years to do a comprehensive community assessment and make a strategic plan. Often these models place a high priority on documenting their effects on older adults and other community residents. In the long run, these evaluation efforts will be required to identify the most crucial changes to be made.

One shortcoming of the work so far is that the needs of elders living in rural communities are seldom included, and there is currently no way to know whether the prescriptions for creating an aging-friendly community will be useful across the broad range of communities. As with any large-scale planning, another challenge will be to implement and sustain the changes desired in any community.

Cross-Sector Collaboration

As Scharlach and Lehning point out, one of the difficulties now evident is the fragmentation, lack of coordination, and service gaps that are typical of community aging and long-term care systems. "For the most part, those systems exist as separate silos

(e.g., transportation, housing, health care, social services) supported by separate financing sources, federal policies, state and local programs, and authorization and regulation systems. What results is a plethora of narrowly targeted programs that are highly fragmented and poorly coordinated.”⁵⁸ One response is to develop a collaboration across sectors that focuses on collective impact. This involves “the commitment of a group of important actors from different sectors to a common agenda for solving a specific social problem”⁵⁹ As scholars of community systems point out “*Most of the problems we will face in the 21st century will require multi-sectoral, multi-disciplinary, and multi-component efforts.*”⁶⁰ Five key conditions distinguish collective impact from other types of collaboration: a common agenda, mutually reinforcing activities, shared measurement systems, continuous communication, and the presence of a backbone organization.

A number of important cross-sector collaborations have been enacted. “While many of these efforts have had positive impacts for specific groups of community seniors, there is considerably less evidence of larger-scale improvements in community aging friendliness.”⁶¹ Also, as many have noted, these collaborations are very difficult to sustain over

time. Resource shortages, limited staffing, threats to organizational autonomy and creation of structures that are sustainable over time are challenges.

Funding silos can exacerbate turf issues, particularly when newer programs are entering into collaborations with established Aging Network programs. Scharlach and Lehning suggest that “sustainability is likely to be enhanced when the collaborative effort has taken on a life of its own, including developing a separate organizational structure apart from the collaborating organizations, with its own independent funding and its own supportive constituents committed to its survival.”⁶²

Federally funded programs have supported a number of pilot demonstration programs to test how relating social and community support programs with health care programs can benefit both. There are many demonstration programs; for example, the 2006 reauthorization of the Older Americans Act included funding for Community Innovations for Aging in Place demonstration programs, which provided 3 years of support for 14 communities in the United States to implement local initiatives. Unfortunately, many of the pilot programs end after their initial period. Also unfortunately, there are typically inadequate measures of impact,

particularly given the complex phenomena involved in creating an aging-friendly community. In order for any of the programs to be sustainable, it is crucial to conduct methodologically rigorous evaluations of aging-friendly initiatives.

THE HUGE CHALLENGE: LONG-TERM CARE IN THE COMMUNITY

When we discuss aging-friendly communities, growing older in the community, etc., we are concerned with individuals managing their own aging. The reality is that many who survive to be very old will need significant assistance. Currently, four in ten die only after an extended period of worsening debility, dementia, and dependence.⁶³

This slow process involves reliance on family members, professional caregivers, and on caregiving institutions. The challenges of caregiving have been the subject of many OWL Reports since the founders, Tish Summers and Laurie Shields, wrote their pathbreaking book, *Women Take Care*.⁶⁴

The reality is that we have no good systems for providing long-term care. Each of the models described above can contribute somewhat to meeting the challenges of caregiving, but there is no system

in place for the many who are aging. When one thinks of the care for the very frail and those with advanced dementia, we think about institutional care, which is what most people are trying to avoid. Such care is not covered by Medicare, it is expensive, and the quality of care is uneven. One option is to “spend down” to a level near poverty where such care is covered by Medicaid. This is very expensive for states, and they are making concerted efforts to keep elders out of nursing homes and in the community by providing more home-and-community-based care (HCBC).

However, this still leaves the issue of who is and will be providing care in the community.

Traditionally, such care has been provided by unpaid family members. A national survey in 2000 found that more than a quarter of adults reported providing care for disabled family members during the past year.⁶⁵ The average time spent on family caregiving was eight years, with a third providing care for over a decade. Most serve out of love and loyalty, and most find caregiving meaningful and rewarding. However, it seems unlikely that we can count on such caregivers in the future to the same extent. Medical advances have enabled elderly and frail patients to survive much longer with serious

chronic illness and disability than in the past. Families are smaller now, and there are fewer descendants to count on. Women, who have been the primary caregivers, now often are employed outside the home.

Another concern is the financial burden on families or individuals caring for elders. The Alzheimer's Association in 2016 conducted a nationwide poll of nearly 3,500 Americans. Among those who had a relative or friend with dementia, about one in seven respondents said they had provided financial assistance and/or caregiving. On average, they spent \$5,155 per year of their own money to take care of the patient, although the annual expenditures ranged from \$1,000 to more than \$100,000. Spouses spent an average of more than \$12,000 a year, while adult children spent an average of about \$4,800 per year. Most common expenses included food and other groceries, travel, medical supplies (such as adult diapers, medications), non-medical in-home care, and in-home health care. Caregivers often struggled with being able to afford enough food for themselves and their family.⁶⁶

The available pool of paid caregivers is not likely to solve the problem. Home care workers typically

face low wages, no fringe benefits, difficult relationships working with troubled clients, and the lack of a “career ladder,” making elder care an unattractive career choice.

Each of the models discussed above can contribute to this “crisis” of caregiving. Federal-agency models have traditionally dealt with the problem by funding nursing home care through the states, and by providing some caregiver respite programs through home- and community-based service programs. However, many of these support programs are underfunded and thus subject to an economic means test that leaves many in need unserved. Organizations funded largely by philanthropies and private donations, like the Alzheimer’s Association, the Chinese American Service League (in Chicago), the Council for Jewish Elders, and other faith-based organizations have developed programs to provide supportive care, with sliding-scale fees. Independent businesses have arisen to provide a wide array of home care services; using such service may be less costly than nursing home care, but is still likely to be more than many families can afford. Villages may offer limited services to caregivers, such as offering caregiver respite, by providing companionship to the person at

home, taking the person out for a walk, staying with the person while the caregiver takes a bath, goes out to for shopping, or even attends a Village social event.

These are patchwork efforts, and will not suffice. Many policymakers are working to develop systems for long-term care that bring together public-private partnerships and are coordinated across sectors.

PUBLIC POLICY RECOMMENDATIONS

1. Preserve and expand Social Security as a publicly funded social insurance program. This has been an OWL advocacy issue from our inception in 1980, and it remains crucial for the well-being of older women. Social Security contributes more to the income of older women than for men, even though women receive lower average amounts for Social Security than men.
2. Preserve and expand Medicare, particularly to cover assistive technology for sensory losses in hearing and vision, and coverage for dental care. The ultimate goal must remain to provide affordable and appropriate care for all ages; this is the only strategy to maximize successful aging in the community long term.
3. Support programs that include social-environmental factors as part of health care.
4. Support programs for creating dementia-friendly communities.

5. Support programs for integrating programs and services across sectors to address problems of healthy aging.
6. Plan for a coherent system of long-term care that supports individuals in the community and outside of nursing homes as long as possible. This involves developing appropriate supports for unpaid family caregivers and for paid caregivers.

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