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Demographics, Trends, and a *Call to Action*

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Every discussion of aging in America seems to begin with demographic statistics showing that our population is increasingly old and getting older. But the figures are truly stunning: In 2006 (the latest year for which data are available), 37.3 million persons were 65 years old or older in America; this represents 12.6 percent of the U.S. population—more than one in every eight Americans.¹ By 2030 the number of older people is expected to increase to 71.5 million older persons, over 20 percent of the total population.

The number of old people who are extremely old is also increasing markedly. The number of senior households headed by those 85 or older will grow by an estimated 88 percent from 2.9 million households in 2005 to 5.4 million households by 2030. Although most of the over-65 U.S. population are white, more than 16.1 percent belong to minority groups, whose numbers are also expected to increase dramatically. Between 1999 and 2030, the minority population 65 years old and older is projected to increase by 217 percent, compared to 81 percent for the older white population. The number of African American elders will increase by 128 percent. The population of Asian American elders will increase by 301 percent, and the number of Hispanic American elders will grow by 322 percent. If current demographic trends continue, the number of American Indian and Alaska Native elders will increase by approximately 193 percent by 2030. That's a lot of people, and, although the elderly are unevenly distributed throughout the country, no region is likely to be unaffected.²

¹The statistics regarding the elderly population are from the Administration on Aging website, which has a collection of statistical data about the aging population (Administration on Aging, Statistics on the Aging Population, www.aoa.gov/prof/Statistics/statistics.aspx (last modified July 7, 2008)).

²In 2006 about one-half (51.4 percent) of persons 65 and older lived in nine states: California, Florida, New York, Texas, Pennsylvania, Illinois, Ohio, Michigan, and New Jersey.

The numbers tell only part of the story because the population they reflect is extraordinarily diverse. They include those who are able-bodied, active, and participating fully in life, those incapacitated by disease, and everything in between—and probably most are or will be in between at some point, still wanting to participate in meaningful activities but needing more support to do so. The level of education of senior citizens has also markedly increased.³ Individuals who remain active and independent in old age are likely to demand more choices in living arrangements and activities than ever before. The promise of the historic U.S. Supreme Court decision in *Olmstead v. L.C.* (holding that segregation of individuals with disabilities in institutions may constitute disability discrimination violative of the Americans with Disabilities Act) has not yet been fulfilled, but the case still provides hope for the future.⁴

Old people certainly have a lot of legal problems. First, they have virtually all of the legal problems that younger people may have. Even matters that have not traditionally been considered “elder law” issues, such as benefit programs for children, are not off the table, now that an increased number of old people (4.5 million, according to the 2000 census) are taking care of grandchildren and face many of the same problems that younger families do.

Second, old people have many special problems. They often need legal help to navigate the complex, restrictive, and often inconsistent requirements of the benefit programs and protective laws targeted at old people. They have needs that are frequently not identified initially as legal needs (e.g., the need for help at

home to avoid institutionalization) but where legal intervention may be the only way to attain the goal. And many issues are intertwined: an individual seeking legal assistance to help with an eviction, for example, may have a host of other interrelated problems involving income, benefits, debt, health, and family issues that require legal, social, and medical intervention to solve. Moreover, age and disability may decrease the stamina necessary to pursue legal remedies. Problems with hearing or speech, not uncommon among the elderly, may result in other difficulties in dealing with the legal system, where these infirmities are met with the assumption, born of stereotypes, that the individual is no longer competent.

Income

The social security retirement programs and Supplemental Security Income have improved the economic well-being of people over 65, markedly reducing the number of seniors who would otherwise be below the poverty line.⁵ About 3.4 million elderly persons (10.1 percent) were below the federal poverty level in 2001. Another 2.2 million, or 6.5 percent of the elderly, were classified as “near-poor” (income between the federal poverty level and 125 percent of this level).

One of every twelve (8.9 percent) elderly whites was poor in 2001, compared to 21.9 percent of elderly African Americans and 21.8 percent of elderly Hispanics. Higher than average poverty rates for older persons were found among those who lived in central cities (12.8 percent), rural areas (12.2 percent), and the South (12.4 percent). Older women had a higher poverty rate (12.4 percent) than older men (7 percent) in 2000. Older persons

³Between 1970 and 2006, the percentage of those 65 and older who had completed high school increased from 28 percent to 77.5 percent. About 19.5 percent in 2006 had a bachelor's degree or more. The percentage that had completed high school varied considerably with race and ethnic origin in 2006: 80.4 percent of whites, 70.1 percent of Asians and Pacific Islanders, 55.1 percent of African Americans, and 39.7 percent of Hispanics. The increase in educational levels is also evident within these groups. In 1970 only 30 percent of older whites and 9 percent of older African Americans were high school graduates.

⁴*Olmstead v. L.C.*, 527 U.S. 581 (1999) (Clearinghouse No. 52,203); see Jennifer Mathis, *Where Are We Five Years After Olmstead?* 38 CLEARINGHOUSE REVIEW 561 (Jan.-Feb. 2005); Jennifer Mathis, *Community Integration of Individuals with Disabilities: An Update on Olmstead Implementation*, 35 *id.* 395 (Nov.-Dec. 2001); Ira Burnim & Jennifer Mathis, *After Olmstead v. L.C.: Enforcing the Integration Mandate of the Americans with Disabilities Act*, 33 *id.* 633 (March-April 2000).

⁵See Arloc Sherman & Isaac Shapiro, Center on Budget and Policy Priorities, *Social Security Lifts 13 Million Seniors Above the Poverty Line: A State-by-State Analysis* (Feb. 24, 2005), www.cbpp.org/2-24-05socsec.htm.

living alone or with nonrelatives were much more likely to be poor (19.7 percent) than older persons living with families (5.5 percent). The highest poverty rates (50.5 percent) were experienced by older Hispanic women who lived alone or with nonrelatives.

However, because the federal poverty line—\$10,000 for one person and \$14,000 for a couple in the contiguous forty-eight states and District of Columbia—sets the bar so low, many well above the poverty line do not have nearly enough money to live on.⁶ Even the various “senior citizen” discounts are typically more than offset by much higher expenses for out-of-pocket medical costs.

Accordingly achieving adequate income for clients will remain a critical goal for older people’s advocates. This goal will require continued focus on issues concerning benefit eligibility. Particular attention should be paid to older persons who are not yet 65 but are potentially eligible for the social security and Supplemental Security Income disability programs, which may provide a higher level of benefits than social security early retirement benefits or public assistance benefits.⁷ Careful advocates also will explore possibly overlooked pension eligibility issues, underutilized federal and state benefits, and the like.⁸ The development of one-stop-shopping sites for

benefits—sites such as the Aging and Disability Resource Centers described in this issue—is a promising trend, but the varying eligibility rules for so many benefit programs will continue to be problematic and difficult.⁹

Older persons who want to or must continue to work are virtually certain to face age discrimination, notwithstanding the significant societal advantage of keeping older persons in the workforce.¹⁰ Enforcement of legal protections against age discrimination will continue to require sustained attention.

Housing and Long-Term Care

Housing will continue to be a big issue. Old people, like their younger counterparts, generally want to stay in their homes and communities but may need additional assistance to do so. Living with other family members—an attractive option for some—is often difficult or impossible in our increasingly mobile society. Family members might live far away, and women, the traditional caregivers for aging relatives, are more likely to be employed. As a result, individuals needing more assistance must turn to assisted housing options, nursing facilities, or independent living with home care assistance.¹¹ Certainly, more options are needed, particularly for racial and ethnic minorities tending to be ill-served by many of the existing facili-

⁶See 73 Fed. Reg. 3971–72 (Jan. 23, 2008).

⁷Proof of age is only occasionally a problem in the social security benefit programs, but proof of “disability” meeting the standards of the Social Security Act is much more difficult. Many individuals could qualify if provided with legal assistance to navigate the law’s complex eligibility rules and administrative and judicial review procedures.

⁸In addition to the possibility of a pension being denied based on erroneous application of eligibility rules (e.g., denial of a disability pension when the claimant in fact meets the plan’s disability standard or misapplication of “break in service” pension plan rules), legal claims may arise from pension fraud, breaches of fiduciary duty, mass layoffs or plant closings or both resulting in termination of pension and other benefit plans, age discrimination in benefits, plan-asset transactions prohibited by the Employee Retirement Income Security Act (ERISA), failure to comply with ERISA-mandated administrative procedures (e.g., filing annual reports, making other disclosures, or providing employees with summary plan descriptions), conversions to cash balance plans, and the like. For more information on ERISA and private pension plans, see Mary Ellen Signorille, *A Primer on Private Pension Plans*, 34 CLEARINGHOUSE REVIEW 327 (Sept.–Oct. 2000).

⁹Gene Coffey, *Shaping the Future of Long-Term Care: Aging and Disability Resource Centers and the Role of Title III.B Attorneys*, in this issue.

¹⁰A *New York Times* article describes the potential positive impact on the economy of deferred retirements and the difficulty of getting employers to hire older workers because of concerns about productivity and health care costs (Steve Lohr, *For a Good Retirement, Find Work. Good Luck*, *NEW YORK TIMES*, June 22, 2008, Week in Review at 3, www.nytimes.com/2008/06/22/weekinreview/22lohr.html).

¹¹See Holly Robinson, *Glossary of Common Senior Housing Terms*, in this issue.

ties, which often fail to respect cultural, dietary, and language differences.

One article in this issue discusses how the federal Fair Housing Act may help older persons who have disabilities and are denied admission to or face eviction from assisted-living and nursing homes, and another promotes the addition of Fair Housing Act language to state laws regulating these facilities.¹² These approaches to securing and keeping appropriate housing reflect creative application of the laws protecting individuals with disabilities from discrimination.

The strong public policy in favor of keeping people at home has not always translated into sufficient support for programs that may be essential to avoid institutionalization. The most important need is for care at home, yet Medicare provides virtually no help in this area and generally requires advocates to fight vigorously even for the limited benefits provided under this program. Medicaid potentially covers home care but imposes restrictive, arguably irrational, barriers to eligibility, such as the New York rule excluding “safety monitoring” as a task for which Medicaid-reimbursed home care may be provided.¹³ These limitations may be particularly hard on groups for which cultural norms strongly favor care of relatives by their children but for which virtually no assistance is provided, especially for nonmedical needs.¹⁴ Respite care for family members is seldom available in practice.¹⁵ And although physical abuse of the elderly can never be excused, it can

sometimes be explained by the enormous stress placed on caregivers.¹⁶

Medical Benefit Programs

Medical benefit programs are paramount and sometimes literally life-or-death to older persons dealing with illness and disability. Medicare, with its multiple options as well as its bewildering array of prescription drug programs, has become an enormously complex program. For the more than seven million so-called dual eligibles—those entitled to both Medicare and Medicaid—the situation is even more confusing, and, as an article in this issue points out, they risk incurring increased out-of-pocket costs and decreased access to care if, as a result of misinformation, they enroll in certain Medicare plans.¹⁷

The Medicaid program, providing relatively generous benefits to individuals who meet its restrictive eligibility requirements, has had the consequence of creating a growing army of lawyers in private practice specializing in helping families get their elderly relatives onto the program, generally to save the enormous nursing home and other long-term care costs. A much smaller but dedicated army of public interest lawyers will continue to fight to ensure that individuals who are eligible for benefits receive them and that the more expensive benefits available under the program are not denied under various pretexts. Still unsettled issues of access to the courts will continue to require vigorous advocacy. An article in this issue describes

¹²Aisha Anderson Bierma et al., “We Can’t Meet Your Needs”: Fair Housing Opens Doors to Housing with Services, and Holly Robinson, *Education Through Legislation: Incorporating Fair Housing Act Rights into State Assisted Living Facility Laws*, in this issue.

¹³The Second Circuit, reversing the court below, upheld the exclusion of services deemed “safety monitoring” from New York’s Medicaid program (*Rodriguez v. City of New York*, 197 F.3d 611 (2d Cir. 2000) (Clearinghouse No. 52,696)).

¹⁴Among blacks and Hispanics, 75 percent of caregivers for the elderly are adult children (Administration on Aging, *supra* note 1).

¹⁵The Medicaid program permits states to offer respite to caregivers through the Home and Community-Based Waiver Program (Section 1915(c) of the Social Security Act) (42 U.S.C. § 1396n(c) (2008); 42 C.F.R. §§ 441.300 *et seq.* (2007)).

¹⁶See LISA NERENBERG, NATIONAL CENTER ON ELDER ABUSE, CAREGIVER STRESS AND ELDER ABUSE 8–11 (2002), http://ncea.aoa.gov/NCEAroot/Main_Site/pdf/family/caregiver.pdf. Nerenberg cites studies suggesting that the relationship between caretaker stress and abuse is complex and that factors such as the quality of the past relationship, the caregiver’s pattern of coping, and the caregiver’s perception of burden are also relevant (*id.*).

¹⁷Mary A. Ashkar et al., *Medicare Advantage: What’s the Advantage If You’ve Got Medicaid, Too?*, in this issue.

using the federal preemption doctrine to enforce rights under the Medicaid and Medicare laws, in response to the U.S. Supreme Court's restrictive interpretation of 42 U.S.C. § 1983.¹⁸

Some people buy "long-term care insurance" to avoid the Medicaid morass, and new problems are now emerging as beneficiaries begin to seek the benefits that they thought they were purchasing. Recent news accounts in the *New York Times* and elsewhere describe long-term care policyholders being denied benefits and facing bureaucratic delays in getting paid.¹⁹

Diminished Capacity

The incidence of dementia increases with age. About 3.4 million people, or 13.9 percent of the population 71 and older, have some form of dementia; the prevalence of dementia increases dramatically with age, from 5 percent of those 71 to 79 to 37.4 percent of those 90 and older.²⁰ Individuals with diminished capacity generally require assistance managing their affairs.²¹ Durable powers of attorney (so called because they continue in effect even if the individual executing the power is incapacitated), if properly used, can facilitate the management of the individual's affairs without the expense and delay of a guardianship proceeding. A simple notarized form, easily available for purchase online or in many stationery stores, is sufficient to give someone else broad powers to manage one's affairs. But, in the hands of the wrong person, powers of attorney have aptly been called a "license to steal." Determining the mo-

tives of the fiduciary is sometimes difficult because sometimes funds are gifted or transferred by using a power of attorney in a legitimate attempt to protect assets from Medicaid recovery or to secure eligibility for benefits. An article in this issue describes some of the remedies available against dishonest fiduciaries and how to counsel clients wisely about securing a trustworthy fiduciary.²²

In the absence of a power of attorney, state guardianship proceedings can be a mechanism for protecting the person and property of an incapacitated person. Like a power of attorney, a guardianship can be a double-edged sword. Theoretically, risk of the fiduciary stealing is less because guardianship proceedings are supervised by the courts and subject to reporting requirements, but lax court supervision has permitted many abuses. Guardianships take away autonomy, but sometimes having a guardian is the only way an individual can continue to live in the community. The law will continue to wrestle with how to determine incapacity.

For poor people, the guardianship system presents the additional difficulty in finding appropriate guardians. Individuals with resources have funds to pay fees to individuals to act as guardians, but a guardian for an individual without significant funds not only must work for free, or for very little, but also will have to deal with the challenges of getting services in place for someone unable to pay for them. State public guardianship programs are limited, and many are significantly underfunded and cannot provide adequate service to the current eligible

¹⁸Rochelle Bobroff & Jane Perkins, *Recent Developments in Court Access for Medicaid and Medicare Cases*, in this issue.

¹⁹See, e.g., Charles Duhigg, *Aged, Frail and Denied Care by Their Insurers*, *NEW YORK TIMES*, March 26, 2007, at A1, www.nytimes.com/2007/03/26/business/26care.html. In California nearly one out of every four long-term-care claims was denied in 2005 (*id.*).

²⁰Brenda L. Plassman et al., *Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study*, 29 *NEUROEPIDEMIOLOGY* 125 (2007) (original paper available at <http://content.karger.com/ProdukteDB/produkte.asp?Aktion=ShowPDF&ArtikelNr=109998&Ausgabe=233821&ProduktNr=224263&filename=109998.pdf>). About 2.4 million of those with dementia, or 9.7 percent of the population 71 and older, were found to have Alzheimer's disease, the most common cause of dementia (*id.*).

²¹For information on determining how to represent a client who cannot fully engage in a typical client-attorney relationship, see Robert D. Fleischer & Dara L. Schur, *Representing Clients Who Have or May Have "Diminished Capacity": Ethics Issues*, 41 *CLEARINGHOUSE REVIEW* 346 (Sept.-Oct. 2007).

²²Katrina G. Hull, *Broken Trust: Pursuing Remedies for Victims of Elder Financial Abuse by Agents Under Power-of-Attorney Agreements*, in this issue.

population, let alone the large numbers of individuals who may need guardianships in the coming years.²³ Given the explosive growth of the extremely old population, problems with guardianship are likely to reach crisis proportions soon.

Many individuals of diminished capacity will continue to be housed in nursing homes. As an article in this issue explains, these facilities frequently fail to provide the psychosocial and rehabilitative services to which patients are entitled. Moreover, behavioral issues typical of some dementias can lead to inappropriate use of psychotropic medications and physical restraints or involuntary discharge. The article discusses available remedies, especially those under the Nursing Home Reform Act (42 U.S.C. § 1396(r)(c)(2)).²⁴

There is a tendency to see individuals as either “completely with it” or “completely out of it,” and it must be resisted. This tendency persists notwithstanding guardianship and other laws that in theory recognize that “least restrictive alternatives” should be used. Individuals, even those with cognitive impairments, are often able to participate actively and meaningfully in community and family affairs. An article in this issue correctly condemns the inappropriate disenfranchisement of mentally or physically impaired individuals; excluding individuals from participation may be ironically the cause, not the result, of diminishing abilities.²⁵

Technological Advances

Technological advances will continue to have expected and unexpected impact. Assistive technologies—creating wonderful new opportunities for improving mobility, communication, and participation in activities—hold out the promise of improved quality of life for individu-

als with disabilities. Obtaining coverage under the medical benefit programs for these technologies will continue to be a challenge.

Moreover, the same technology can make things better or worse, as the experience with personal alarm devices demonstrates: these portable alarm devices, connected to a central location that can dispatch help in response to a signal, have facilitated living at home for some but, for others, become an inferior and dangerous substitute for personal care services. A videophone makes it easier to be in touch, yet easier not to visit. An increasingly computer-literate older generation will find it easier to get information and access to services, but let us not forget those who because of age, income, or disability will be unable to use such devices.

Striving to keep older persons as involved as they want to be is crucial as well. An article in this issue explores the need for improved transportation options for those living in the many areas of our county inadequately served by public transportation.²⁶ People in these areas need transportation to have access to medical care, shopping, friends, and families.



While the challenges are enormous, so are the opportunities. Older persons, regarded as “deserving poor,” tend to receive sympathetic responses from courts and legislatures. Undoubtedly selfish considerations may account for the sympathy because the elderly are a minority we all get to join if we live long enough, and many of us, not yet elderly, have elderly relatives and friends whom we are called on to assist. Notably, New York City has proposed “right to counsel” legislation to provide seniors with representa-

²³See PAMELA B. TEASTER ET AL., PUBLIC GUARDIANSHIP AFTER 25 YEARS: IN THE BEST INTEREST OF INCAPACITATED PEOPLE? NATIONAL STUDY OF PUBLIC GUARDIANSHIP PHASE II REPORT (2008).

²⁴Barbara Jones, *Nursing Home Residents with Dementia Need Help to Obtain Appropriate Health Care Services*, in this issue.

²⁵Jennifer Mathis, *Voting Rights of Older Adults with Cognitive Impairments*, in this issue.

²⁶Ana I. Torres-Davis, *The Need for Improved Transportation Options for the Elderly and the Elder Advocate's Role*, in this issue.

tion in the city's housing courts.²⁷ Will this be a dead end or the first step in an emerging right-to-counsel movement?²⁸ While political commentators frequently opine that Americans will reject as "socialistic" a "single-payer" system of national health care (in which the health care expenditures of an entire population are paid for by the government using tax revenues), the elderly have had a single-payer system—namely, Medicare—since 1974. Whether services to the elderly will be expanded or reduced and whether any progress made will extend to other groups

as well remains to be seen. Will the public grow to understand that we can have any kind of benefits we want as long as we have to pay for them and that this might be a pretty good use of our tax money? The future holds many uncertainties, but undoubtedly there are now and are going to be a lot of old people who do not fit the stereotype of contented old folks in their rocking chairs on the porch and who will need dedicated lawyers to help secure the comfortable and dignified old age that everyone deserves.

²⁷Proposed amendment to Title 21, Chapter 10, of the New York City Administrative Code, Local Law Introduced 0682-2008, <http://webdocs.nycouncil.info/textfiles/Int%200682-2008.htm?CFID=1973906&CFTOKEN=86031007>.

²⁸For more information on right-to-counsel issues, see 40 *CLEARINGHOUSE REVIEW* (July–Aug. 2006) (special issue entitled "A Right to a Lawyer? Momentum Grows"). Advocates who are pursuing a right to counsel in civil cases and those who want information about the issue can access the website of the National Coalition for a Civil Right to Counsel at www.civilrighttocounsel.org. The site contains news of recent developments; descriptions of advocacy efforts and links to relevant documents; information about the justice gap, the coalition, and how to become involved in its work; the need for a right to counsel in civil cases; links to journal and newspaper articles; and much more. The national coalition, comprising more than 150 advocates from some thirty states, works to secure a right to counsel in civil cases in which basic human needs are at stake. The new website was created for the coalition by the Sargent Shriver National Center on Poverty Law, in partnership with Maryland's Public Justice Center, the Brennan Center for Justice at New York University Law School, the Committee for Indigent Legal Representation and Civil Legal Equality housed at the Northwest Justice Project in Seattle, and the American Bar Association's Standing Committee on Legal Aid and Indigent Defendants.