

# Restructuring Public Policy for Large Numbers of Elders Living with Disabilities

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## ABSTRACT

With nearly twice as many elderly Americans living with disabilities expected within a dozen years, public policy must update and revise the social arrangements that support caregiving, disability, and old age. Needs that already often go unmet will mount, growing from quietly suffered indignities to broadly felt breakdowns. Inequities faced by young and old will compound this shared strain.

Creating long-term care financing arrangements, accessible housing stock, and resilient macroeconomics for an aging population will require long lead times and therefore prompt convergence and enactment of policies and programs to address these needs. For example, while academic and independent policy institutions have recommended public catastrophic long-term care social insurance and private insurance market reforms, delay in enacting these modest policies keep the US on a default course to underfunded but crippling expensive safety net obligations, any gaps in which will impoverish elders and their families. The US has not even developed a serious dialogue on disability adapted and affordable housing or on the macroeconomics facts that demand investment in highly productive young adults.

Equity, efficiency, and capacity of social services, caregiving, and medical care also require redesign over the next few years. Community arrangements shape much of the experience of declining health in old age. The US urgently needs to enable a number of communities (counties, cities, and rural regions) to move ahead aggressively to redefine excellence and affordability in eldercare, making exemplars that the rest of the nation could emulate.

Some critical issues do not yet have the language for public discourse, being treated as taboo subjects. We outline four of these and call for data and reflection.

We all deserve to come to old age confident that we have the needed supports, so that we can enjoy the last of life with comfort and meaningfulness, without impoverishing the next generations.

**Keywords:** homecare, health care delivery policy, aging network, Older Americans Act, social insurance, long term care insurance

## **Reestructuración de la política pública para un gran número de ancianos que viven con discapacidades**

### RESUMEN

Con casi el doble de estadounidenses de edad avanzada que viven con discapacidades dentro de una docena de años, las políticas públicas deben actualizar y revisar los arreglos sociales que apoyan el cuidado, la discapacidad y la vejez. Las necesidades que ya a menudo quedan insatisfechas aumentarán, pasando de indignidades sufridas en silencio a crisis generalizadas. Las desigualdades que enfrentan los jóvenes y los mayores agravarán esta tensión compartida.

La creación de acuerdos de financiación de la atención a largo plazo, el inventario de viviendas accesibles y la macroeconomía resistente para una población que envejece requerirá largos plazos de entrega y, por lo tanto, una pronta convergencia y promulgación de políticas y programas para abordar estas necesidades. Por ejemplo, si bien las instituciones de política académicas e independientes han recomendado reformas catastróficas públicas del seguro social y del mercado de seguros privados a largo plazo, la demora en la promulgación de estas políticas modestas mantiene a los EE. UU. En un curso predeterminado con obligaciones de red de seguridad insuficientemente costosas pero agobiantes, cualquier brecha en lo que empobrecerá a los ancianos y sus familias. Estados Unidos ni siquiera ha desarrollado un diálogo serio sobre viviendas adaptadas para discapacitados y asequibles o sobre los hechos macroeconómicos que exigen inversiones en adultos jóvenes altamente productivos.

La equidad, la eficiencia y la capacidad de los servicios sociales, el cuidado y la atención médica también requieren un nuevo diseño en los próximos años. Los acuerdos comunitarios configuran gran parte de la experiencia de deterioro de la salud en la vejez. Estados Unidos necesita con urgencia permitir que varias comunida-

des (condados, ciudades y regiones rurales) avancen agresivamente para redefinir la excelencia y la asequibilidad en el cuidado de los ancianos, convirtiéndose en ejemplos que el resto de la nación podría emular.

Algunos temas críticos aún no tienen el lenguaje para el discurso público, siendo tratados como temas tabú. Esbozamos cuatro de estos y solicitamos datos y reflexión.

Todos merecemos llegar a la vejez confiando en contar con los apoyos necesarios, para que podamos disfrutar lo último de la vida con comodidad y sentido, sin empobrecer a las próximas generaciones.

**Palabras clave:** atención domiciliaria, póliza de atención médica, red de envejecimiento, Ley de estadounidenses de edad avanzada, seguro social, seguro de atención a largo plazo

## 为大量残疾中老年人重组公共政策

### 摘要

鉴于未来十二年里年老的残疾美国人数量将是现在的两倍，公共政策必须更新且修订那些支持看护、残疾、和老龄的社会安排。那些经常未被满足的需求将会上涨，从不出声地忍受侮辱发展为大规模的崩溃。年青人与老年人面对的不平等将加重这样的压力。

为老龄化人口打造长期护理资助安排、可获取的住房存量、以及有韧性的宏观经济将需要长时间的准备阶段并因此推动政策及相关项目的融合与采纳，以应对这些需求。例如，尽管学术机构与独立政策机构已经建议对糟糕的公共长期护理社会保险和私人保险市场进行改革，但在通过这些适当政策时的拖延一直让美国处于一种默认资金不足但极为昂贵的安全网义务的过程，这种义务出现任何形式的不履行都将让中老年人及其家庭一贫如洗。就针对残疾人士的可负担住房或针对要求对高生产力的年青成人进行投资的宏观经济事实，美国甚至还未提出相关严肃对话。

公平、效率、以及社会服务、看护及医疗方面的能力也需要在未来几年里进行重新设计。社区安排对老龄人口健康情况下降的经历具有相当的影响力。美国急需让一些社区（县、城市和农村地区）快速取得进步性发展，以重新定义老年护理方面的卓越性和可负担性，为全国其他地区创造能够效仿的模范。

一些关键问题目前还不能在公共话语中出现，被视为禁忌主题。我们列出了四个禁忌主题并呼吁取得相关数据及反思。

我们都值得在老年时对我们所需的支持感到自信，进而能以舒适和有意义的方式享受生命的最后时光，同时不让后代贫穷。

关键词：家庭护理，医疗交付政策，老龄化网络，《美国老年人法案》，社会保险，长期护理保险

## Introduction

Most Americans will grow old; for that, we are thankful. Most of us will have a substantial period of illness and disability in the last years of life; for that, we are unprepared. Indeed, left to drift without deliberate change, current societal arrangements will leave many elderly people without housing and food during their last years, many families bankrupted, and ensuing generations in despair. Known and proven strategies to avert these outcomes abound; what is missing is the will to undertake substantial changes.

At the start of the 1900s, the average age at death was just forty-six years old. The dominant causes of death in adulthood included childbirth for women and occupational hazards for men; most Americans still lived on farms (Noymer & Garenne, 2000). The few people who lived into advanced old age usually had many descendants available to take them in, if needed. While old age has grown more common, fewer elderly have adult children capable of providing support and residing nearby

(Ryan, Smith, Antonucci, & Jackson, 2012). We forget that supporting large numbers of disabled elderly people is new and that our society's practices were established in a very different era. Updating poses a set of public policy challenges.

Most of us will live past the traditional retirement age of sixty-five; and, while we will likely have some chronic conditions, we will mostly be quite functional at that age. But death is rarely entirely sudden. Modern living conditions and medical care have made it commonplace to live for many months with advancing illness and disabilities. Sudden death, or even dying over a few days, has become rare. Instead, elders now mostly gradually lose resilience due to illness (including frailty), so that staying alive becomes more and more precarious, and some unpredictable small disruption can create a cascade of inadequate responses that end in death (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). The average duration of disability in old age, sufficient to require daily help from another person, is now around two years, with an average price

of \$266,000, and fully 14 percent of us will need this level of help for more than five years (Favreault & Dey, 2016).

We are woefully unprepared. The median household at retirement (ages sixty-five through seventy-four) has no savings at all, and the households with some savings average only \$148,000 saved (U.S. Government Accountability Office, 2015, pp. 14-15), requiring elders to hope that other sources will meet their needs. Fewer own their homes than in the past, and banks hold more of the value of homes owned by retirees than ever before (U.S. Census Bureau, 2019; Rosnick & Baker, 2016, p. 23). About 10 percent have any insurance to help cover supportive care. Families are small, dispersed, and older. Nearly all housing stock has barriers to living with disabilities: entry steps, narrow bathroom doors, a flight of stairs to bathrooms and bedrooms, inaccessible tubs and showers, and so on. Personal care aides are scarce, poorly trained, paid below a living wage without benefits, and culturally distant from the elders they help. Many elderly people are isolated and lonely with no human contact for weeks at a time. Discriminatory practices in housing, jobs, and access to capital and savings make the situation even worse for African-Americans, Latinos, and women.

## **The Situation**

**T**his is not the future we desire, and it is not the future we are doomed to endure. We can do so much better, but creating a worthy last phase of life will require mobilizing

attention and practical improvements, some of which require a lead-time of a decade or more. The large rise in disabled elders will come in the 2030s, as the population over age eighty-five is set to double between 2015 and 2032 and to triple by 2050. In America in 2015, one person in fifty was older than eighty-five; by 2050, one in every twenty people will be (Houser, Fox-Grage, & Ujvari, 2018). The US has put off serious consideration of how to support elders who are living with serious disabilities, but we have run out of time. We must act soon or we will have to learn to abandon a very large number of elders who have no means of support.

As one would expect, social change as dramatic as the new prevalence of disabled elderly people will have ramifications throughout the broad society. The major issues that this essay will develop are in these domains: financing, housing, the macroeconomy, the direct-care workforce, medical care, food provision, transportation, and inclusion in human relationships. The urgency of reforms is driven by the quite predictable rise in the number of disabled elders, with issues like financing, housing, and the economy having priority because they require long lead-times.

## **Reforms that Require a Decade or More**

**M**any Americans remember a time when people in their last years of regular work often threw a party to tear up the paid-off mortgage. A few years later, they re-

tired, with a pension, Social Security, and a secure home. And then they died, mostly within a decade, living frugally but having enough, especially when Medicare started picking up the medical bills. Most elements of this picture have become rare. Few have pensions, many lost their home equity in the recession in 2008, many cannot fully retire because they need additional earnings from the gig economy, and more and more are losing their housing.

How dire is the financing of retirement and the period of ill health and disability? Within a decade, most Americans who lived in the middle class during their working years will be unable to afford housing and supportive services (Pearson et al., 2019). More than two-thirds of Americans in the decade leading up to age sixty-five have less saved for retirement than a year of current income—a sum sure to be inadequate for the typical twenty years of retirement (Brown, Saad-Lessler, & Oakley, 2018, p. 11). One-half of those in the first decade after age sixty-five have no savings at all (U.S. Government Accountability Office, 2015, p. 14). Likewise, long-term care insurance provides a variable level of protection for only one-tenth of the retiree population, and premiums increase and coverage declines for most policies every year (Johnson, 2016).

In short, we face a future in which most elderly persons will not have financial resources to cover their needs in retirement and eventual disability. Some will qualify for Medicaid, but Medicaid's threshold for long-term

care support will have to become ever more draconian since states must balance their budgets. Elders with income or assets above Medicaid limits will have to rely upon family and community supports. When those are not enough, disabled elders will have to go without food, heat in winter, cooling in summer, medical care, personal care, and housing. Relying upon family to support a destitute elder generates financial depletion for successor generations, an approach that epitomizes imprudent social arrangements when done on the broad scale that is anticipated.

The costs of living in retirement and eventually with disabilities pose a classic situation ripe for an insurance solution. No one can know what he or she will need—whether no long-term supports at all or two decades of around-the-clock personal care. Every American family with members in or approaching old age will be forced into a pernicious gamble, held accountable for the unpredictable amounts of care for disabilities that elders will experience in old age. A thoughtful middle-aged person could scrimp and save to cover as much as two years of nursing home care, around \$250,000, and still have the misfortune of needing four years, or twenty years. That thoughtful person cannot buy long-term care insurance to cover these extreme risks since no company now offers this sort of policy. Much like fire insurance or liability insurance, it makes sense to pool funds to cover the most threatening of the risks when the costs are unpredictable. No insurance company can enroll enough people to take on the extreme

risks – the persons who live in nursing homes for twenty years or more. These risks are very expensive and require a very large enrolled population to build a useful insurance product (Convergence Center for Policy Resolution, 2016, pp. 8–10). This is the sort of situation that should lead to government involvement, where funds can be automatically collected from large numbers of people to provide a pooled resource.

However, elderly people living with disabilities have an astonishing variety of personal preferences and family resources, including financial assets and personal relationships. Getting governments involved in making an unending array of fine distinctions as to family obligations and fair allocation of government support would be detrimental to good order, trust in government, and the value of family. Having individuals make decisions that reflect their situation, preferences, and acceptance of risks is much better public policy, which is what this proposal encourages. Furthermore, this proposal adds only a modest part of the overall costs of long-term care to government control, making it more acceptable. Thus, an optimal policy is to have the government pick up the exceedingly long needs for long-term care and leave the typical shorter-term needs to individuals and their communities and organizations (Cohen, Feder, & Favreault, 2018; Convergence Center for Policy Resolution, 2016, p. 12).

The fact that elderly persons needing supportive services will mostly have had the opportunity to work, usu-

ally for many years, makes it appealing to derive the funding for governmental long-term care coverage from collections from income during those working years, thus paying for catastrophic protections in a palatable manner over many years. Automatic participation lowers administrative costs and mitigates the effects of outliers because of the broad risk pool. For the same reason, working persons with existing health risks for disability would not be excluded from the insurance pool, unlike their frequent exclusion from private markets (Johnson, 2016, p. 5). A high-wage earner would be expected to self-fund more long-term care, based on their ability to have saved or bought insurance for a longer initial period of long-term care needs. Lower wage earners would have a shorter delay for which they must plan for their own long-term supports and services, since they would have had less opportunity to save for disability in retirement.

This approach has been modeled with a ten-year minimum contribution period before allowing pay-outs from the insurance, with individuals covering their needs for one to four years depending upon their earnings (Cohen, Feder, & Favreault, 2018). An elder's self-coverage period would begin once documented to be dependent in two activities of daily living (ADLs), such as moving about, getting dressed, and feeding oneself. After the first one to four years, the public insurance would provide \$110 per day (in 2010 dollars) for as long as needed. This particular structuring would cost about 0.85 percentage points added to the earnings

tax for Medicare after workers reach age forty. The surcharge would sustain this long-term-care backstop for at least the next seventy-five years (p. 22). For workers, the catastrophic insurance mechanism costs them less than half of what they have been found to be willing to pay out of each paycheck for long-term care premiums (p. 9). Note, however, that this approach would require a ten-year introductory phase before any benefits were paid, so it would be helpful for financing of long-term care by the early 2030s if implemented now. This approach would greatly reduce the number of elderly who spend-down to Medicaid, thus reducing the pressure on Medicaid. Liberal and conservative think tanks alike have suggested frameworks similar to the proposed structure (Calmus, 2013; Veghte, Bradley, Cohen, & Hartmann, 2019).

How would elders pay for the first years of needing supportive care? We could save through our working years, we could have large and well-financed families willing and able to be of help, our communities and organizations could pitch in (as Washington state has done with \$36,500 of first-dollar coverage for workers in that state (Veghte, Bradley, Cohen, & Hartmann, 2019, p. 190), and we could buy long-term care insurance privately that reflects our situation and willingness to take risks. Insurance companies, freed of the risks of very long durations of long-term care, would offer a variety of coverage packages to individuals, companies, and organizations to precede and wrap around the government's catastrophic coverage. The insurers might

offer a mix of long-term care coverage with annuities, for example. Minnesota is investigating adding first-year coverage of long-term care costs to Medigap policies. Very likely, a wide variety of vehicles for covering the first year(s) will arise.

A second element that requires substantial lead-time is housing, because only a small proportion of a community's housing is built in any one year. Most existing housing poses challenges for disabled elderly people on three counts: inaccessibility, risk of harm, and unaffordability (Smith, Rayer, & Smith, 2008). Some existing housing can be modified to accommodate a disabled person at a reasonable cost: for example, with entry ramps, hand bars in the shower, and handrails on the steps. Under federal law, 7 percent of new housing built with public funds must be disability-accessible, but that housing need not be sold or rented to a person who needs it. In 1985, Singapore started requiring all new housing and major renovations to include elements enabling disabled persons to function well, making most housing accessible now to a person using a walker or wheelchair (Graham & Bilger, 2017). Communities in the US could follow that example. The federal government could require more disability-adapted housing when rebuilding after disasters or providing insured loans, and local zoning laws could facilitate the housing additions seniors need to age in place (Scharlach, 2012; Smith, Rayer, & Smith, 2008). When planning and subsidizing housing for seniors who downsize in late middle-life, communities can low-

er barriers to mobility, thus reducing the costs of frailty (Prosper, 2004). This country would still have challenges in the supply and costs of housing, but at least the challenges would not disproportionately afflict persons living with disabilities.

A third element that requires substantial lead-time is deliberately investing in a stronger economy (National Research Council, 2012). Some developed countries, such as Japan, have realized that having a large population that is no longer conventionally productive in old age will require having a robust economy that can bear some added taxation. They invest in ensuring that children arrive at young adulthood with marketable skills and jobs. The US is still willing to have most children be born in poverty and to sustain high rates of incarceration and low-wage jobs, which suppress the economy. Being concerned about low wages for service jobs and marginalization of children, immigrants, and people of color may seem far afield of eldercare policy, but the connections are quite strong and obvious. The wellbeing of elders depends on keeping the US economy growing.

### **Reforms to Services in Local Communities**

**M**uch of the experience of living with disabilities in old age depends upon the arrangements that have developed, usually without much planning, in the local community. How difficult is it to get food delivered to a homebound elder?

Is the food appealing and appropriate to the person's medical conditions and culture? Are homecare aides available and are they skilled in handling behavioral problems arising from dementia or the personality of the elder being served? Is there transportation from door to door or only curb to curb, or does public transportation leave the frail to navigate the first and last miles? Are services affordable? Does the elder have a medical team that participates in developing comprehensive care plans that reflect the priorities and preferences of the elderly person and their family? Do local employers support family caregiving?

Communities vary greatly in their readiness to support disabled elderly people. Many cities now have more than six-month waiting lists to get home-delivered food, and most do not offer door-to-door transportation. Some have active "Villages" that help with neighborly services, like getting groceries, making minor repairs and upkeep, and providing companionship, while other communities have no such services.

The federal support for these services comes through the Area Agencies on Aging (AAAs), which are established under the Older Americans Act (OAA). Every part of the country has an AAA, which is required to develop a directory of services, provide nutrition services, assess community needs, and advocate for eldercare in their locality. The OAA has had nearly flat funding for the past twenty years, while the population needing services keeps growing. Some agencies and

communities supplement the resources available; however, this strategy is less effective for areas with few resources. OAA funding needs substantial escalation. Once it approaches an adequate funding level, automatic adjustments to funding to match inflation and the number of elderly people in need will be essential. Medicare spending more than doubled between 2004 and 2015, while OAA funding grew by less than 5 percent, and the population older than age sixty-five rose by more than a third (Parikh, Montgomery, & Lynn, 2015, p. 401). For example, a diabetic senior, waiting with an empty pantry and empty stomach, dials up Meals on Wheels and is placed on a many-months-long waitlist. However, calling for an ambulance gets that diabetic senior treated by high-paid specialists, “rescuing” that elder from harms that could have been avoided by having food at home.

The workforce for personal eldercare includes family (and sometimes other volunteers) and paid direct-care workers. Severe shortages of these workers limit supports for disabled elders. Both kinds of caregivers suffer from limited training and support. Family caregivers often must provide services that would require professional licenses if performed in hospitals or nursing homes, and they often must be on standby twenty-four hours per day. A family member caregiving full-time loses an average of \$303,880 of income and retirement security, often guaranteeing inadequate funding for the caregiver’s retirement and long-term care (Met Life Mature Market Institute, 2011). The psychological burden, lost career

advancement, and lost leisure time cost the caregiver much more (Coe, Skira, & Larson, 2018; Mudrazija, 2019).

Paid caregivers still work, on average, for less than \$12 per hour, mostly without benefits, making this one of the most difficult and injury-prone occupations at one of the lowest wage scales in the nation (Scales, 2019, p. 43). Workers have no career ladders to justify long-term commitment. One-third of these workers are immigrants (p. 27). These paid workers usually have incomes at or below the federal poverty line, never have the opportunity to save for retirement, endure cultural and personality differences with the person served, and experience a high rate of job-related injuries. The fact that caregiving to elders has a severe supply shortage is hardly surprising, and the corrective policies are evident (pp. 67–101).

Paying adequately for caregiving would challenge private resources and Medicaid, but doing so seems to be required, both to encourage economic growth and to appropriately value this difficult work. The US should professionalize paid caregiving, with adequate compensation and benefits, ongoing education, and career ladders. For family caregivers, the US should provide targeted financial support, training, respite, back-up, employer flexibility, credit for caregiving work in Social Security and long-term care catastrophic insurance, and neighborly support for a range of tasks appropriately done by a volunteer.

Indeed, the advent of substantial numbers of elders needing help to live

in the community calls for a revival of neighborliness. Neither Medicaid nor elderly people should generally pay for the kinds of help that nearby residents could readily offer: minor repairs, minor upkeep of the outdoor area, changing light bulbs, delivering groceries, taking out the trash, and just being a friendly companion. Widespread and coordinated volunteers would reduce the per capita costs of disabilities and add meaningfulness and socialization to our later years. The Villages movement has started reforms in this arena, but coverage needs to grow rapidly and probably needs a variety of arrangements. Widespread volunteer services pose a public-management opportunity requiring new policy guidance, free-of-charge management software, and other inducements. Governments at all levels could provide these encouragements.

Communities also need to attend to their transportation arrangements. Some disabled elders can readily use public transportation, where available. But many can only get to the curb and some need help getting that far. Internet-enabled transportation services (like Uber and Lyft) might inspire a new generation of targeted mass transit that address not only the “last mile” but also the last few feet. Self-driving cars, some with attendants, might open substantial possibilities. All too often, an elderly person with mobility challenges is effectively imprisoned due to a lack of adequate help in getting around.

The most far-reaching reforms involve moving services to the disabled elder’s home efficiently. The US has an

unexamined belief in competition as the heart of reducing costs and securing quality, one that ignores key complexities in eldercare. Many areas have competing homecare services that incur the costs of servicing a small percentage of the elders in need in a large area, and then impose minimum visit durations to reduce travel time. Between travel time and minimum stays, homecare services can waste half of the payment dollar. Most countries arrange homecare dominantly by geographic area, so a nurse, an aide, or any other service provider can move from one home to the next efficiently and thereby get to know the resources and challenges of that neighborhood. In France, for example, mail carriers—who already visit every home—check in with local elders on behalf of family, who subscribe to the service for a nominal fee (Poll, 2019).

The US would be in a much better position to undertake serious transformation to improve eldercare if we enabled a small number of quite diverse communities (counties, cities, and regions) to put all the community-anchored reforms in place, monitored by population-based metrics (Lynn, 2016). We do not now have any exemplar communities, and we do not trust that we could follow good practices demonstrated by communities in other countries.

## **Reforms in Medical Care**

**I**f we had convened a dozen ninety-year-olds and their caregivers to design Medicare, they almost certainly would have included dental care,

hearing aids, vision care, podiatry, and rehabilitation. But we did not do that. Medicare was designed to cover the expensive medical procedures needed by persons near retirement age—mostly surgical operations. Revisions since have covered dialysis and drugs but not the elements needed to live with declining hearing, vision, and mobility. Indeed, medical care for elderly persons living with progressive illnesses and disabilities is all too often marked by overuse of medical interventions, as well as some discriminatory underuse. Very few physicians are trained in geriatric syndromes, and even fewer engage in comprehensive care planning that reflects what matters most to elderly persons and their families. Home visits are rare, concern for the caregiver(s) is uncommon and not generally documented in the patient or caregiver record, and continuity across settings and time is nearly nonexistent. Efficient care for patients in their later years requires a high-functioning continuity team with substantial engagement with their community and skills in behavioral management, spiritual support, rehabilitation, prevention, treatment, and care planning—all in an environment where critical supportive services are readily available. This is out of reach for nearly all Americans.

Medicare could start covering more of the elements that are important—either for everyone or by beneficiary choice. Continuity and care planning should be key to the “care redesigns” encouraged by the Center for Medicare and Medicaid Innovation. Medicare pays for most graduate medi-

cal education—physician trainees could be required to learn how to serve ill or disabled elders. Medicare could generate community-level data as to how well eldercare arrangements are working. This relatively small change could generate a culture of learning among the many systems serving elders. For personal planning and in the community interest, the public should know elements that are not now available: e.g., the risks and causes of impoverishment in old age, the likelihood of care at home rather than in the Emergency Room, and the risks of and protections against neglect or abuse. The public should demand honest prognoses, comprehensive care planning, and reasonable availability of supportive services, and local governments should help manage eldercare arrangements in their area.

#### **Four Challenging Considerations for Reformers**

**E**ldercare in the US is boxed in by a lack of direction with regard to four issues that have rarely been discussed as matters affecting public policy:

1. How shall we serve those among us who lose memory and cognition?
2. What shall we do about the remarkable disparities in resources and lifespan that afflict persons arriving at old age with the life-long effects of discrimination?
3. How shall we begin to work with the obvious interaction of the timing of death and the resources used?

4. What burdens will we expect family members to bear?

These difficult challenges have mostly gone unexamined. When people lose their sense of self and recognition of others, some courts have found them to be disabled within the meaning of the protections for disabled persons and have ordered life-extending treatments (even those that incur substantial pain and distress), while many people see this situation as one of living with a fatal illness that calls for palliative care and little life-extension. Bearing the effects of life-long discrimination and limited opportunities, African-Americans at retirement average only one-seventh of the savings that white households have (Bricker, 2017; Carr, 2019). Our evaluations of treatment strategies often evaluate mortality or cost, but seldom explicitly consider that most costs of living with disability arise from living with disability, and an earlier or later death often has more impact on costs than any treatment effect or effort to achieve savings. Finally, our habits in planning for and delivering eldercare assume that families will take care of their own, but family members now often do not exist, or they cannot or will not take on the burdens of caregiving for indefinite time periods with limited support; these situations are not explicitly incorporated in decisions about public support.

The lack of public discussion of these issues arises from the lack of established language to address the issues, the newness of the situations, and a lack of leadership. However, these are im-

portant issues, and we will eventually have to find ways to acknowledge them and find morally acceptable responses.

## Conclusion

Whenever public figures talk about eldercare and caregiving, they most often tell their own family story, usually about how an older parent is faring or fared before death. Remarkably, just like most other Americans, these policymakers relate positive or negative aspects of their experience with the family member's situation and the elder; they do not usually take note of how policies shaped what happened and what can happen now. Yet, how this society has structured itself profoundly shapes the possibilities for how one can live with disabilities in old age. Our structures are overly generous about medical care, making all of it an entitlement. The situation warrants substantial reinvestment in supportive services. We could bring dental care, hearing and vision supports, and home delivery of medical care and food into the scope of medical insurance coverage. We could support family caregiving and pay direct care workers a fair wage. Because of the long timeline, we must quickly work on the financing issues, aiming to make self-funded long-term care the norm by supplementing the Medicaid-based public safety net with a combination of public catastrophic insurance and private savings. For the same reason, we need to invest now in disability-adapted housing and in facilitating young adults' contributions to a highly productive economy. Along the

way to these good ends, many additional reforms should be enacted. We all deserve to age with confidence that we will have the support we need and that we will be able to enjoy the last phase of life with comfort and meaningfulness, without impoverishing the next generations.

## References

- Bricker, J., Detting, L. J., Henriques, A., Hsu, J. W., Jacobs, L., Pack, S., Sabelhaus, J., Thompson, J. (2017). *Changes in U.S. Family Finances from 2013 to 2016: Evidence from the Survey of Consumer Finances* (No. Vol 1., No 3). Retrieved from Federal Reserve Board of Governors website: <https://www.federalreserve.gov/publications/files/scf17.pdf>
- Brown, J.E., Saad-Lessler, J., & Oakley, D. (2018). *Retirement in America: Out of Reach for Working Americans?* Retrieved from National Institute on Retirement Security website: <https://www.nirsonline.org/wp-content/uploads/2018/09/FINAL-Report-.pdf>
- Calmus, D. R. (2013). *The Long-Term Care Financing Crisis* (No. 7). Retrieved from Heritage Foundation website: [https://s3.amazonaws.com/thf\\_media/2013/pdf/CPI\\_DP\\_07.pdf](https://s3.amazonaws.com/thf_media/2013/pdf/CPI_DP_07.pdf)
- Carr, D. (2019). *Golden years?: Social inequality in later life*. New York: Russell Sage Foundation. Retrieved from [www.jstor.org/stable/10.7758/9781610448772](http://www.jstor.org/stable/10.7758/9781610448772)
- Coe, N. B., Skira, M. M., & Larson, E. B. (2018). A comprehensive measure of the costs of caring for a parent: Differences according to functional status. *Journal of the American Geriatrics Society*, 66(10), 2003–2008. <https://doi.org/10.1111/jgs.15552>
- Convergence Center for Policy Resolution. (2016). *A Consensus Framework for Long-Term Care Financing Reform*. Retrieved from <https://www.convergencepolicy.org/wp-content/uploads/2016/02/LTCFC-FINAL-REPORT-Feb-2016.pdf>
- Favreault, M., & Dey, J. (2016). *Long-Term Services and Supports for Older Americans: Risks and Financing* [Research Brief]. Retrieved from U.S. DHHS ASPE ODALTC website: <https://aspe.hhs.gov/system/files/pdf/106211/ElderLTCrb-rev.pdf>
- Graham, W. C. K., & Bilger, M. (2017). Financing long-term services and supports: Ideas from Singapore. *The Milbank Quarterly*, 95(2), 358–407. <https://doi.org/10.1111/1468-0009.12264>

- Houser, A., Fox-Grage, W., & Ujvari, K. (2018). *Across the States 2018: Profiles of Long-Term Services and Supports*. Retrieved from <https://www.aarp.org/content/dam/aarp/ppi/2018/08/across-the-states-profiles-of-long-term-services-and-supports-full-report.pdf>
- Johnson, R. W. (2016, August 2). *Who Is Covered by Private Long-Term Care Insurance?* Retrieved from <https://www.urban.org/research/publication/who-covered-private-long-term-care-insurance>
- Lunney, J. R., Lynn, J., Foley, D. J., Lipson, S., & Guralnik, J. M. (2003). Patterns of functional decline at the end of life. *JAMA*, 289(18), 2387–2392. <https://doi.org/10.1001/jama.289.18.2387>
- Lynn, J. (2016) *MediCaring Communities: Getting What We Want and Need in Frail Old Age at an Affordable Cost*. <https://medicaring.org/book/>
- Met Life Mature Market Institute, National Alliance for Caregiving, Center for Long Term Care Research and Policy, New York Medical College. (2011). *The MetLife Study of Caregiving Costs to Working Caregivers Double Jeopardy for Baby Boomers Caring for Their Parents*. Retrieved from <https://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf>
- Mudrazija, S. (2019). Work-related opportunity costs of providing unpaid family care in 2013 and 2050. *Health Affairs*, 38(6), 1003–1010. <https://doi.org/10.1377/hlthaff.2019.00008>
- National Research Council. (2012). *Aging and the Macroeconomy: Long-Term Implications of an Older Population*. <https://doi.org/10.17226/13465>
- Noymer, A., & Garenne, M. (2000). The 1918 influenza epidemic's effects on sex differentials in mortality in the United States. *Population and Development Review*, 26(3), 565–581. <https://doi.org/10.1111/j.1728-4457.2000.00565.x>
- Parikh, R. B., Montgomery, A., & Lynn, J. (2015). The Older Americans Act at 50—Community-based care in a value-driven era. *New England Journal of Medicine*, 373(5), 399–401. <https://doi.org/10.1056/NEJMp1503493>
- Pearson, C. F., Quinn, C. C., Loganathan, S., Datta, A. R., Mace, B. B., & Grabowski, D. C. (2019). The forgotten middle: Many middle-income seniors will have insufficient resources for housing and health care. *Health Affairs*, 38(5), 851–859. <https://doi.org/10.1377/hlthaff.2018.05233>

- Poll, Z. (2019, October 9). In France, Elder Care Comes with the Mail. *The New Yorker*. Retrieved from <https://www.newyorker.com/culture/annals-of-inquiry/in-france-elder-care-comes-with-the-mail>
- Prosper, V. (2004). Aging in place in multifamily housing. *Cityscape: A Journal of Policy Development and Research*, 7(1), 81-106.
- Rosnick, D., & Baker, D. (2016). *The Wealth of Households: An Analysis of the 2016 Survey of Consumer Finance*. Retrieved from <http://cepr.net/images/stories/reports/wealth-of-households-2017-11.pdf>
- Ryan, L. H., Smith, J., Antonucci, T. C., & Jackson, J. S. (2012). Cohort differences in the availability of informal caregivers: Are the boomers at risk? *The Gerontologist*, 52(2), 177–188. <https://doi.org/10.1093/geront/gnr142>
- Scales, K. (2019). *Envisioning the future of home care: Trends and opportunities in workforce policy and practice*. New York: PHI.
- Scharlach, A. (2012). Creating aging-friendly communities in the United States. *Ageing International*, 37(1), 25–38. <https://doi.org/10.1007/s12126-011-9140-1>
- Smith, S. K., Rayer, S., & Smith, E. A. (2008). Aging and disability: Implications for the housing industry and housing policy in the United States. *Journal of the American Planning Association*, 74(3), 289–306. <https://doi.org/10.1080/01944360802197132>
- U.S. Census Bureau. (2019). *Housing Vacancies and Homeownership Annual Statistics: 2018; Table 17. Homeownership Rates by Age of Householder and Family Status for the United States*. Retrieved from <https://www.census.gov/housing/hvs/data/ann18ind.html>
- U.S. Government Accountability Office. (2015). *Most Households Approaching Retirement Have Low Savings* (No. GAO-15-419). Retrieved from <https://www.gao.gov/assets/680/670153.pdf>
- Veghte, B., Bradley, A. L., Cohen, M., & Hartmann, H. (Eds.). (2019). *Designing Universal Family Care: State-Based Social Insurance Programs for Early Child Care and Education, Paid Family and Medical Leave, and Long-Term Services and Supports*. Retrieved from [https://universalfamilycare.org/wp-content/uploads/2019/06/Designing-Universal-Family-Care\\_Digital-Version\\_FINAL.pdf](https://universalfamilycare.org/wp-content/uploads/2019/06/Designing-Universal-Family-Care_Digital-Version_FINAL.pdf)