POLICY ESSAY

THE WIDE RANGE OF CHALLENGES FACING SENIORS

REPRESENTATIVE DINGELL*

I. INTRODUCTION

Residents of the United States face numerous challenges as a growing number of citizens begin to age. The segment of the U.S. population aged sixty-five or older is expected to comprise nineteen percent of the population by 2030, twice the size of the older population in 2000.[1] The difficulties accompanying this rapid increase include a greater number of elderly entering the confusing bureaucratic system through which healthcare is delivered; a growing need for family members to move or quit a job to care for aging parents or spouses; the constant struggle in finding the proper support systems in the community; and many others. As more Americans will soon have a loved one entering this later stage of life, they will encounter a fragmented system with multiple programs intended to support their needs and the needs of their loved ones, each of which has its own complicated rules and regulations.

The lack of comprehensive and integrated long-term care programs results in poor health outcomes, which decreases quality of life and increases anxiety among family members. The current fragmented system is a pressing problem that requires immediate attention from Congress. The average American might think that Medicare provides for long-term care, but then would be shocked to learn of the complicated eligibility criteria for that program.[2] Many would be surprised to discover that Medicaid is also a payer of some of these services.[3]

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* Member, United States House of Representatives (D-Michigan, 12th Congressional District). B.A. Georgetown University, 1975. Representative Debbie Dingell was elected in 2014 and currently serves on the House Budget Committee and the House Natural Resources Committee.

[1] U.S. Dep't of Health and Human Servs., *Aging Statistics*, ADMIN. FOR COMMUNITY LIVING, http://www.aoa.acl.gov/Aging_Statistics/index.aspx (last visited Mar. 22, 2015), *archived at* http://perma.cc/Q525-ACMV.

[2] *See Medicare Eligibility: Who is Eligible for Medicare*, KAISER PERMANENTE, https://medicare.kaiserpermanente.org/wps/portal/medicare/plans/learn/eligibility, (last visited Mar. 5, 2015), *archived at* https://perma.cc/6HDU-7W9X (discussing different eligibility requirements for Medicare Part A, B, C, and D, as well as the Medicare Cost plan).

[3] *See Medicaid's Role in Meeting the Long-Term Care Needs of America's Seniors*, HENRY J. KAISER FAM. FOUND 2 (Jan. 14, 2013), https://kaiserfamilyfoundation.files.wordpress.com/2013/02/8403.pdf, *archived at* https://perma.cc/Z3EZ-PKYF; *see also Seniors & Medicare and Medicaid Enrollees*, CTRS. FOR MEDICARE & MEDICAID SERVS., http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Population/Medicare-Medicaid-Enrollees-Dual-Eligibles/Seniors-and-Medicare-and-Medicaid-Enrollees.html (last visited Mar. 3, 2015),

The bottom line is that there is not a single place where people can find answers to their questions regarding long-term care and other services. More importantly, it is unclear where they can receive the care they need at an affordable cost. The lack of clarity and resources makes coordination of care difficult, discourages efficiency in the healthcare system, promotes uncertainty among individuals seeking care, and makes it more difficult to craft a long-term solution to this problem. There are over fifty individual Medicaid systems: one for each state, territory, and the District of Columbia.[4] The result is over fifty distinct long-term care regimes; yet, what America needs is a uniform national system to address long-term care for the elderly population. A streamlined, simplified system that provides long-term care for those who need it should be a shared priority among national policy-makers.

This Article will first look at the current fragmentation of long-term care in the United States, defining long-term care, receipts, and funding sources. Next, the Article will turn to another important part of long-term care: family caregivers and the substantial amount of long-term care they provide, often accompanied by a significant amount of monetary and emotional stress. The third part will detail the "Long-term Care Black Hole," which is the large gap in care resulting from the ineffective utilization of home-based and community-based services both in the Medicaid and Medicare programs. The final section of the Article is dedicated to a further discussion of the impacts of diseases affecting seniors on long-term care. Finally, the Article will provide several solutions for the fragmented long-term care system going forward, including changes to family caregiver support and the Medicaid program, as well as engaging a larger national conversation.

II. The Fragmentation of Long-term Care in the United States

Since the Great Depression and its aftermath, the United States has developed a complex network of programs to work as a social safety net, designed to assist individuals with specific needs such as low-income levels and disabilities.[5] Neither Medicare nor Medicaid was specifically designed

archived at http://perma.cc/N5C5-54GJ (explaining that Medicaid provides health coverage for over 4.6 million low-income senior citizens and that 8.3 million Americans are "dually eligible" for both Medicare and Medicaid).

[4] U.S. Dep't. of Health and Human Servs., A Profile of Medicaid: 2000 Chartbook 6 (2000), *available at* http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/TheChartSeries/downloads/2tchartbk.pdf, *archived at* https://perma.cc/42E5-9UKL?type=pdf (explaining that as "each state establishes its own eligibility standards, benefits package, payment rates and program administration under broad federal guidelines . . . there are essentially 56 different Medicaid programs—one for each state, territory and the District of Columbia.").

[5] *See* Robert A. Moffitt, Stanford Ctr. on Poverty and Inequality, Social Safety Net and the Great Recession, A Great Recession Brief 1 (Oct. 2012), *available at* https://web.stanford.edu/group/recessiontrends/cgi-bin/web/sites/all/themes/barron/pdf/SocialSafety_fact_sheet.pdf, *archived at* https://perma.cc/CUE8-2ACW (noting that "the U.S.

to provide long-term care to elderly Americans, leaving a critical gap in our system.[6] The missing pillar of the social safety net is long-term care insurance, and this hole needs to be addressed in the coming years.

A. What is Long-term Care?

Long-term care encompasses many different health-related services linked to helping people engage in daily living activities over an extended period of time. Examples include providing assistance with eating, bathing, dressing, reading, or hearing.[7] Long-term care is not a medical service and is not designed to treat a specific disease or ailment. The goal of these services is to improve the quality of life for beneficiaries by helping them with activities of daily living that they are no longer able to perform on their own so they can live as normal of a life as possible.[8]

B. Who is Receiving Long-term Care?

The fragmented nature of the long-term care system in the United States is best illustrated by examining who is receiving the care services and who pays for them. Currently, 10.9 million individuals receive long-term care in a community or home setting and 1.8 million people receive such care in an institution.[9] While this Article will primarily focus on elder care, it is important to note that the need for long-term care services is not limited to those sixty-five and older. In fact, nearly half of the 10.9 million people who

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safety net is of course a complicated assemblage of programs"); *see also* DUSTIN A. CABLE & REBECCA M. TIPPETT, WELDON COOPER CTR. FOR PUB. SERV., UNIV. OF VIRGINIA, POVERTY AND THE SOCIAL SAFETY NET PART II: THE ROLE OF THE SAFETY NET IN VIRGINIA 2 (Feb. 2012), *available at* http://www.coopercenter.org/sites/default/files/publications/NumbersCount_Poverty%20and%20the%20Social%20Safety%20Net%20Part%20II_02_28_12.pdf, *archived at* http://perma.cc/E82U-KXRK (describing the expansion of safety net programs after the New Deal).

[6] Medicare was originally designed to provide hospital insurance for seniors, with an option for outpatient coverage. Medicaid was designed to provide health insurance to low-income people. Neither program provides comprehensive long-term care or offers long-term care insurance. *See* U.S. Dep't of Health and Human Servs., *Medicare*, LONGTERMCARE.GOV http://longtermcare.gov/medicare-medicaid-more/medicare/ (last visited Mar. 6, 2015), *archived at* http://perma.cc/4WB6-TM8P (noting that Medicare primarily focuses on providing "medically necessary care" and "short-term services"); U.S. DEP'T OF HEALTH AND HUMAN SERVS., *supra* note 4, at 6–7 (noting that though one goal of Medicaid is to provide long-term care to the elderly, it is a "means-tested" program and thereby not universally available to all elderly patients).

[7] *See* U.S. Dep't of Health and Human Servs., *What is Long-term Care?*, LONGTERMCARE.GOV, http://longtermcare.gov/the-basics/what-is-long-term-care/ (last visited Mar. 6, 2015), *archived at* http://perma.cc/Q557-AQJV.

[8] *Id.*

[9] H. Stephen Kaye et al., *Long-Term Care: Who Gets It, Who Provides It, Who Pays, And How Much*?, 29 HEALTH AFFAIRS 11, 11 (2010), *available at* http://content.healthaffairs.org/content/29/1/11.full.html, *archived at* http://perma.cc/6ZTA-KBTC.

receive care in a community setting are younger than sixty-five.[10] As the nation continues to age, the demand for these services will continue to increase. In 2012, there were forty-three million Americans older than sixty-five; this number is projected to increase to ninety-two million in 2060.[11] Consequently, there will be a doubling in the need for long-term care in the next forty years.[12]

C. Who Pays for Long-term Care?

Healthcare spending in the U.S. comprises a massive amount of total expenditures, and the funding for these services comes from several different sources. In 2012, the U.S. spent a total of $2.4 trillion on personal health expenditures. Specifically, $324.2 billion (13.7%) was spent on long-term care services.[13]

Medicaid is the largest payer of long-term care costs, accounting for $136.3 billion in spending, or 42% of all long-term care expenditures.[14] The funding stream from Medicaid, however, is surprisingly disproportionate when compared to the population enrolled in the program. This $136.3 billion in spending on long-term care represents thirty-five percent of all Medicaid spending in 2012, and yet these funds only went to 6.7% of Medicaid recipients.[15] Additionally, while Medicare is not intended to be a primary funding source for long-term care, the program still spent a significant amount ($72 billion) on skilled nursing facility and home health services combined, representing 22.4% of all spending on long-term care.[16]

Both Medicare and Medicaid are critical elements of our social safety net, but neither system was specifically designed to provide long-term care to Americans who need it.[17] As Congress continues to consider solutions for how to improve the solvency of these programs without reducing benefits, the possibility of generating significant savings through long-term care reform must not be ignored. Any money saved from improvements or increased efficiencies in long-term care would go a long way towards putting

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[10] *See id.* at 11 (noting that "although about half of long-term care recipients are under age sixty-five, four-fifths of long-term care spending is for elderly recipients.").

[11] U.S. Census Bureau, CB14-FF.07, Profile America Facts for Features Older Americans Month May 2014 (2014), *available at* http://www.census.gov/content/dam/Census/newsroom/facts-for-features/2014/cb14-ff07_older_americans.pdf, *archived at* http://perma.cc/3NQ4-UVAQ.

[12] Dep't of Health and Human Servs., The Future Supply of Long-Term Care Workers in Relation to the Aging Baby Boom Generation: Report to Congress 3 (2003), *available at* http://aspe.hhs.gov/daltcp/reports/ltcwork.pdf, *archived at* http://perma.cc/L4A7-549C.

[13] Kristen J. Colello & Scott R. Talaga, Cong. Research Serv., R43483, Who Pays for Long-Term Services and Supports? A Fact Sheet 1 (2014).

[14] *Id.* at 3.

[15] *Id.*

[16] *Id.*

[17] *See* U.S. Dep't of Health and Human Servs., *supra* note 6 and accompanying text.

Medicare and Medicaid on sounder fiscal footing while providing America's seniors with the care they deserve.

D. Who Should Pay for Long-term Care?

The current funding sources for long-term care are not the most sustainable or efficient ways to provide these services, mainly because the programs that currently provide funding are not intended to support this need. While Medicaid may be the largest provider of long-term care in the United States, the program's main purpose is not to provide such services. Medicaid is instead designed to provide basic health services to low-income individuals.[18] This mismatch with the largest funding source presents a crucial problem for long-term care going forward. It makes little sense to have Medicaid provide long-term care, especially as the population of elderly citizens continues to rise and the demand for long-term care experiences a parallel increase.[19]

Even though many may think Medicare should be a bigger part of the solution, this program similarly does not offer a sustainable answer to the problem. Medicare has potentially confusing eligibility requirements and a complicated reimbursement formula.[20] As such, seniors may be left confused and unable to access much needed care.[21] Their only options are the few and expensive supplemental policies on the private market.[22] Unless the system for providing care is reformed, a major gap in coverage will continue to grow. The poorest citizens will receive access to an increasingly strained

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[18] *See* U.S. Ctrs. for Medicare & Medicaid Servs., *Medicaid & CHIP Coverage*, HEALTHCARE.GOV, https://www.healthcare.gov/medicaid-chip/getting-medicaid-chip/ (last visited Mar. 7, 2015), *archived at* https://perma.cc/SJY8-EK2B; Julia Paradise*Medicaid Moving Forward*, HENRY J. KAISER FAM. FOUND (Mar. 9, 2015), http://kff.org/medicaid/fact-sheet/the-medicaid-program-at-a-glance-update/, *archived at* http://perma.cc/94MB-RH4F.

[19] *See* discussion *infra* Part II.B.

[20] *See* UNITED HEALTHCARE, MEDICARE MADE CLEAR 6–8 (2014), http://www.medicaremadeclear.com/~/media/MMC/Files/Guides/Guide_Show_Me_2015.pdf, *archived at* http://perma.cc/H6F9-XDG2 (noting the various eligibility criteria and dispelling criteria assumptions such as having a Medicare-eligible spouse); *see also* U.S. Ctrs. for Medicare & Medicaid Servs., *Determine Your Eligibility and Calculate Your Premium*, MEDICARE.GOV, http://www.medicare.gov/eligibilitypremiumcalc/ (last visited Mar. 7, 2015), *archived at* http://perma.cc/SJ5C-GFL4 (providing a tool to determine eligibility and premiums, thus demonstrating that Medicare eligibility and coverage is not intuitive).

[21] *See* UNITED HEALTHCARE & NAT'L COUNCIL ON AGING, SURVEY OF BOOMERS AND SENIORS 8 (Aug. 2011), *available at* http://www.ncoa.org/assets/files/pdf/9-16-11-UHC-NCOA-Survey-Results-Report-FINAL.pdf, *archived at* http://perma.cc/3L3A-32Z5.

[22] *See* U.S. Ctrs. for Medicare & Medicaid Servs., *What's Medicare Supplement Insurance (Medigap)?*, MEDICARE.GOV, http://www.medicare.gov/supplement-other-insurance/medigap/whats-medigap.html (last visited Mar. 7, 2015), *archived at* http://perma.cc/3JDP-WP4S; *see also* Jennifer T. Huang et al., *Medigap: Spotlight on Enrollment, Premiums, and Recent Trends*, HENRY J. KAISER FAM. FOUND. 281 (Apr. 2013), https://kaiserfamilyfoundation.files.wordpress.com/2013/04/8412-2.pdf, *archived at* http://perma.cc/ZT4V-AABM (noting that the average Medigap monthly premium was $183 in 2010; however, that premium varied widely by insured's age and state of residence.).

Medicaid system,[23] while the very wealthy can purchase expensive private insurance or incur high amounts of out-of-pocket expenses. Not only does this likely scenario further burden the Medicaid system, but it also means that there will be many individuals who are not eligible for Medicaid and cannot afford private insurance. Consequently, a large portion of the ever-increasing elderly population will be without any options for long-term care, and national policy reform is needed to fix this pressing issue.

III. The Critical Role of Family Caregivers

Family caregivers serve a crucial role in the provision of long-term care services, both in terms of time and money spent to address the needs of elderly individuals. The money spent in the family caregiver context is most likely not an accurate reflection of the true reliance placed on this sector of care services. Although out-of-pocket spending was only 16.8% of total long-term care spending in 2012 (a total of $54.4 billion), family caregivers are often the first line of support during a time of need.[24] This pattern is two-fold: first, people will oftentimes prefer to receive care from a loved one and someone they are familiar with; and second, there may not be a better alternative available, such as paid support. This reliance on family and close personal relationships for care provision has major implications not only for the health and well-being of the elderly receiving the care, but also for the financial stability of caregivers.

A. Family Caregivers Provide a Significant Amount of Care Services

Family caregivers can take many different forms, all putting a significant amount of responsibility on the individual providing the care—for example, the wife who works the night shift to care for her husband during the day; the child who quit her job and moved across the country to take care of her parents; and countless others who make innumerable sacrifices to care for those they love.

The typical family caregiver spends about twenty hours per week providing unpaid care to a family member for nearly five years, totaling a massive amount of unreimbursed time and energy.[25] Furthermore, caregiving

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[23] *See* The Kaiser Comm'n on Medicaid and the Uninsured, *How Much Will Medicaid Cost in the Future and Why: A Look at Federal Projection*, Henry J. Kaiser Fam. Found. 1–2 (Aug. 2013), https://kaiserfamilyfoundation.files.wordpress.com/2013/08/8430-how-much-will-medicaid-cost-in-the-future.pdf, *archived at* http://perma.cc/5H6N-HEY9 (noting that "federal Medicaid expenditures are expected to grow by an average annual rate of about 8%" and "Medicaid enrollment is expected to grow from 71 million in 2012 to 91 million by 2023, an average annual rate of about 2% per year.").

[24] Colello & Talaga, *supra* note 13 at 2, 4.

[25] Lynn Feinberg et al., *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving,* AARP Pol'y Inst. 27 (2011), http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf, *archived at* http://perma.cc/XE2X-QHHH.

within the family is not equal across genders. The resource drain has a disproportionate impact on women: although forty-two percent of U.S. workers have provided some sort of care to a friend or family over the last five years, sixty-five percent of the caregiver population are women.[26]

B. Family Caregiving Creates Significant Emotional and Financial Stress for Caregivers

The contributions and sacrifices family caregivers make are endless and have real impacts on their health and economic well-being. Seventeen to thirty-five percent of family caregivers report that their own health is "fair to poor,"[27] and forty-seven percent of family caregivers are more likely to feel high emotional stress.[28] Additionally, family caregiving affects more than just the caregivers' emotional and psychological well-being. Family caregivers age fifty and older who leave the workforce to care for a loved one will lose an average of $304,000 in wages and benefits over their lifetime.[29] Once again, women suffer greater economic losses—on average, men will lose $283,716 in benefits and wages while women will lose an average of $324,044.[30]

While family caregiving currently accounts for a substantial amount of unreimbursed care, this source of care cannot be relied upon to support the increasing need of long-term care services in future years, and family caregivers should not be expected to fill the gap. Some may be financially stable enough to sustain a major loss in income so they can care for a loved one, but many simply do not have the resources to do so.

Furthermore, as our population continues to age, the availability of family caregivers will become increasingly scarce. In 2010, the United States had more than seven caregivers for each person age eighty or older.[31] Projections indicate this ratio could decline to four caregivers per every one elderly individual by 2030, and three to one in 2050.[32] The current system of care is unsustainable as the number of available caregivers declines rapidly.

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[26] *Id.*

[27] *Id.* at 8.

[28] NAT'L ALLIANCE FOR CAREGIVING, CAREGIVING IN THE U.S. 16 (2009), *available at* http://www.caregiving.org/data/CaregivingUSAllAgesExecSum.pdf, *archived at* http://perma.cc/B69N-AMGZ.

[29] Lynn Feinberg & Rita Choula, *Understanding the Impact of Family Caregiving on Work,* AARP POL'Y INST. 2 (2012), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf, *archived at* http://perma.cc/8RMB-F9ZA.

[30] *Id.*

[31] Donald Redfoot et al., *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers*, AARP POL'Y INST. 1 (2013), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf, *archived at* http://perma.cc/K7UG-342W.

[32] *Id.*

From both a personal well-being and an economic standpoint family caregiving cannot be relied upon as a primary solution moving forward.

IV. The Long-term Care Black Hole—How People Get Lost in the System

Although family caregiving accounts for a significant amount of long-term care services,[33] there are still many people who are not fortunate enough to have family caregivers. Even if family caregivers do make sacrifices for an extended period of time, they can only do so for so long before their resources are exhausted. In both of these situations, people are then forced turn to the very limited safety net programs that exist in the United States today.

A. An Overview of Medicaid Home and Community-Based Services

A closer examination of the eligibility requirements and regulations for both Medicare and Medicaid will illustrate the problems resulting from our fragmented healthcare system. As part of a federal-state partnership, the federal government lays out broad guidelines that states must follow when creating and implementing their Medicaid programs.[34] States are also required to offer certain services to eligible beneficiaries, while other services are completely optional, and it is up to the discretion of the state whether to provide the services or not.[35] To give a particularly relevant example, long-term care provided in an institution, such as a skilled nursing facility, is a mandatory service under Medicaid, while home and community-based services ("HCBS") are optional.[36]

States that choose to offer long-term care services in a home-based setting have two main options to pursue. First, they can include HCBS in their state Medicaid plan. Alternatively, states may pursue the second option which includes seeking a waiver from the Center for Medicare and Medicaid Services ("CMS") that would permit them to provide HCBS outside the scope of their state Medicaid plan.[37] The waiver from CMS essentially "au-

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[33] *See* discussion *supra* Part III.A; *see also* Lynn Feinberg et al., *supra* notes 25–27.

[34] *See* U.S. Ctrs. for Medicare & Medicaid Servs., *Federal Policy Guidance*, Medicaid.gov, http://medicaid.gov/federal-policy-guidance/federal-policy-guidance.html (last visited Mar. 7, 2015), *archived at* http://perma.cc/BK7E-Y9X6; U.S. Ctrs. for Medicare & Medicaid Servs., *Medicaid*, Healthcare.gov, https://www.healthcare.gov/glossary/medicaid/ (last visited Mar. 7, 2015), *archived at* http://perma.cc/QH27-FWYF.

[35] *Federal Core Requirements and State Options in Medicaid: Current Policies and Key Issues*, Henry J. Kaiser Fam. Found. 6 (Apr. 1, 2011), https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8174.pdf, *archived at* https://perma.cc/AQB9-3EQU.

[36] *Id.* at 10.

[37] *Id*; *see also* Waivers of State Plan Requirements, 42 C.F.R. § 430.25 (2014) (newly-adopted regulation pertaining to purpose and effect of state waivers); U.S. Ctrs. for Medicare & Medicaid Servs., *Home & Community Based Services*, Medicaid.gov, http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/

thorizes the Secretary of Health and Human Services to waive certain Medicaid statutory requirements so that a state may offer HCBSs to state-specified group(s) of Medicaid beneficiaries who otherwise would require services at an institutional level of care."[38]

If long-term care is a formal part of a state Medicaid plan, the program must comply with three main requirements: 1) comparability, 2) statewideness, and 3) freedom of choice.[39] First, the "comparability" requirement mandates that services be available to enrollees in an equal amount, duration, and scope.[40] Second, the "statewideness" requirement ensures that the benefit is available across the entire state.[41] Finally, the "freedom of choice" requirement ensures that enrollees have a choice amongst health care providers or managed care entities when choosing this service.[42] Pursuing a waiver-based approach allows a state to disregard some or all of these requirements.[43] The state could instead test an innovative model as a pilot project, or perhaps the program could not be extended statewide.

Many states have decided to pursue waivers under Section 1915(c) of the Social Security Act to provide HCBS in their state.[44] Services permitted under Section 1915(c) include reimbursement for case management services, a home health aide, and respite care, among others.[45] In addition, these waivers must be targeted at a specific population (e.g. the elderly or the disabled), so states oftentimes have several waiver programs in place.[46] The Secretary of Health and Human Services approves these waivers on a case-by-case basis,[47] and while the waivers allow states to experiment with different policies by offering certain services to a limited population, this flexibility

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Home-and-Community-Based-Services/Home-and-Community-Based-Services.html (last visited Mar. 7, 2015), *archived at* http://perma.cc/L7XD-BRPJ (listing regulations and program overviews for home and community-based services); *see generally* Henry J. Kaiser Fam. Found., *Medicaid Home and Community Based Services Programs: 2011 Data Update*, HENRY J. KAISER FAM. FOUND.(Dec. 22, 2014), http://kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2011-data-update/, *archived at* http://perma.cc/KN3L-AH8D.

[38] State Plan Home and Community-Based Services, 79 Fed. Reg. 2947, 2950, 3003 (Jan. 16, 2014).

[39] *See* 42 C.F.R. § 440.240 (2014) (comparability); 42 C.F.R. § 431.50 (2014) (statewideness); 42 C.F.R. § 431.51 (2014) (freedom of choice).

[40] Comparability of Services for Groups, 42 C.F.R. § 440.240 (2014).

[41] Statewide Operation, 42 C.F.R. § 431.50 (2014).

[42] Free Choice of Providers, 42 C.F.R. § 431.51 (2014).

[43] *See* State Plan Home and Community-Based Services, 79 Fed. Reg. 2947, 2950, 3003 (Jan. 16, 2014); Waivers of State Plan Requirements, 42 C.F.R. § 430.25 (2014); U.S. Ctrs. for Medicare & Medicaid Servs., *supra* note 37; Henry J. Kaiser Fam. Found., *supra* note 37.

[44] U.S. Ctrs. for Medicare & Medicaid Servs., *National Overview of 1915(c) HCBS Waivers*, CMS.GOV, https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-Roadmap/Resources/State-Federal-Relationships/National-Overview-of-1915c-HCBS-Waivers.html (last visited Mar. 7, 2015), *archived at* http://perma.cc/555T-TYNR (showing that thirty-three states have elected to take advantage of 1915(c) waivers).

[45] Social Security Act, 42 U.S.C. § 1396(n) (2012).

[46] *Id.*

[47] *Id.*

comes at the price of reducing uniformity. As a result, wide disparities exist across our nation in terms of access to HCBS under Medicaid.[48]

Furthermore, because 1915(c) waivers must be targeted to a specific population, their effectiveness in providing care to a broad population is limited. As a result, long waiting lists exist for many of these programs.[49] In 2010, there were over 523,000 people on waiting lists to receive care under these programs, including over 35,000 elderly people.[50]

While access to long-term care services has increased in the home-based and community-based context,[51] many individuals still do not have access to this care. The single largest flaw in the design of this care system is that long-term care services in the home setting are optional for states, which leads to incredible disparities throughout the nation. This disparity is often referred to as the "institutional bias" in Medicaid.[52] The fundamental problem created from the institutional bias must be addressed to ensure American citizens have access to the care they deserve.

Given state discretion over long-term care in the home setting, Medicaid's institutional bias makes it harder for people to receive care in their own homes, which is the preferred setting, according to polls.[53] Moreover, home-based care is more expensive for those who seek it.[54] Legally, institutional bias is problematic because it seems inconsistent with the 1999 Supreme Court decision in *Olmstead v. L.C.*[55] In this landmark ruling, the Court held that it was a violation of Title II of the Americans with Disabilities Act to care for a person in an institution when "the State's treatment professionals determine that such placement [in community-based treatment] is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."[56] While this decision was primarily focused on people with disabilities

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[48] *See* Henry J. Kaiser Fam. Found., *Waiting Lists for Medicaid Section 1915(c) Home and Community Based Services Waivers*, Henry J. Kaiser Fam. Found., http://kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers-2010/ (last visited Mar. 7, 2015), *archived at* http://perma.cc/M9CS-7Y9F.

[49] *See id.*

[50] *See id.*

[51] *See* Henry J. Kaiser Fam. Found., *supra* note 37.

[52] *See* Susan C. Reinhard, *Diversion, Transition Programs Target Nursing Homes' Status Quo*, 29 Health Affairs 44, 45 (2010), *available at* http://content.healthaffairs.org/content/29/1/44.full, *archived at* http://perma.cc/C8K9-9X5D.

[53] *See* Inst. of Medicine Comm. on Care at the End of Life, Approaching Death: Improving at the End of Life 45 (M.J. Field & C.K. Cassel eds., National Academy Press 1997) ("Two Gallup Polls, one in 1992 and another in 1996, found 9 out of 10 respondents reporting that they would prefer to be cared for at home if they were terminally ill with six months or less to live").

[54] See Wendy Fox-Grage & Jenna Walls, *State Studies Find Home and Community Based Services to Be Cost Effective,* AARP Pub. Pol'y Inst. 1–3 (Mar. 2013), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/state-studies-find-hcbs-cost-effective-spotlight-AARP-ppi-ltc.pdf, *archived at* http://perma.cc/DEX3-4Z8V.

[55] 527 U.S. 581 (1999).

[56] *Id.* at 607.

and not senior citizens, it has generally been applied to all state-funded institutions, including nursing facilities.[57] Since then, states have increased access to HCBS under Medicaid in response to *Olmstead*,[58] but significant variations remain. Decisive changes will need to be made to the current system to meet the ideals articulated in the decision.

B. The Medicare Home Health Benefit and Skilled Nursing Facility Benefit—No Real Solution for Seniors

The flaws in Medicaid coverage of long-term care are evident from the analysis of the optional state programs described previously. When searching for other solutions, many would turn to Medicare as a possible avenue, but this program is not the answer. While Medicare does offer a home health benefit and a skilled nursing facility ("SNF") benefit,[59] both programs are very limited in their duration and scope.[60] As a result, neither can be considered a reliable or primary funding source for seniors looking to pay for services associated with long-term care.

In order to receive Medicare coverage at a SNF, beneficiaries must comply with several requirements. First, they must satisfy the "72 hour rule," which means they must be an inpatient at a hospital for at least three consecutive calendar days.[61] Then, patients must be admitted to the SNF within thirty days of discharge from the hospital.[62] In addition, the treatment

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[57] *See* GARY SMITH ET AL., OFFICE OF THE ASSISTANT SEC'Y FOR PLANNING AND EVAL., U.S. DEP'T OF HEALTH AND HUMAN SERVS., UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER 1–4 (Oct. 2000), *available at* http://aspe.hhs.gov/daltcp/reports/primer.pdf, *archived at* http://perma.cc/E5CK-FGJ7; OLMSTEAD RIGHTS, *The Olmstead Supreme Court Decision in a Nutshell*, http://www.olmsteadrights.org/about-olmstead/ (last visited Mar. 7, 2015), *archived at* http://perma.cc/3CJB-YGM8 ("Courts quickly made clear that Olmstead applied to all state and Medicaid funded institutions, including nursing facilities.").

[58] *See* U.S. Dep't of Justice, *Olmstead Community Integration for Everyone*, ADA.GOV, http://www.ada.gov/olmstead/index.htm (last visited Mar. 7, 2015), *archived at* http://perma.cc/R8ZL-PM5R; *see also Questions and Answers about the Legal Interpretations of the Olmstead v. L.C. Decision*, NAT'L DISABILITY RIGHTS NETWORK, http://www.ndrn.org/issues/community-integration/311—olmstead-v-lc-decision-qa.html (last visited Mar. 7, 2015) *archived at* http://perma.cc/JE6H-B9MH (noting that Olmstead rights have been asserted and recognized in cases concerning nursing facilities and also have been considered in cases involving assisted living centers and board and care facilities).

[59] *See* CTRS. FOR MEDICARE & MEDICAID SERVS., CMS PRODUCT NO. 10969, MEDICARE AND HOME HEALTH CARE 8–10 (2010), *available at* http://www.medicare.gov/Pubs/pdf/10969.pdf, *archived at* http://perma.cc/E556-22N8; Ctrs. for Medicare & Medicaid Servs., *Home Health Services*, MEDICARE.GOV, http://www.medicare.gov/coverage/home-health-services.html (last visited Mar. 9, 2015), *archived at* http://perma.cc/GD5U-NKGL.

[60] *See* CTRS. FOR MEDICARE & MEDICAID SERVS., CMS PRODUCT NO. 10969, MEDICARE AND HOME HEALTH CARE 10 (2010), *available at* http://www.medicare.gov/Pubs/pdf/10969.pdf, *archived at* http://perma.cc/E556-22N8 (noting a wide-range of home health services not covered by Medicare including meal delivery and homemaker services).

[61] *See Frequently Asked Questions CR 7502*, CTRS. FOR MEDICARE & MEDICAID SERVS. 2 (Jun. 14, 2012), http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/AcuteInpatientPPS/Downloads/CR7502-FAQ.pdf, *archived at* http://perma.cc/222J-FUU3.

[62] *See* CTRS. OF MEDICARE AND MEDICAID SERVS, *Chapter 8–Coverage of Extended Care (SNF) Services Under Hospital Insurance*, *in* MEDICARE BENEFIT POLICY MANUAL (2014),

they receive at a SNF must be the same treatment they received during their time at the hospital.[63] Once these criteria are satisfied, Medicare will only pay for 100 days of the stay at a SNF.[64] In short, the Medicare SNF benefit has extremely tight eligibility criteria and a very limited benefit.

The Medicare home health benefit is equally confusing. There are several criteria that must be met in order to receive coverage for home visits by skilled healthcare professionals. First, the patient must be receiving regular care from a doctor, and the doctor must certify that the patient needs skilled nursing care, physical therapy, or speech-language pathology services.[65] Second, Medicare will only cover up to sixty days of care,[66] meaning that the doctor must come up with a plan of care which addresses these conditions in that time frame. Finally, the patient must be homebound, which is defined as having a condition that prevents her from leaving home without help, or that leaving the home is not recommended by a doctor.[67]

Seniors are often confused and challenged when confronted with this patchwork of regulations while trying to understand what type of care they are eligible to receive.[68] Especially in cases concerning the home health benefit, seniors may become frustrated when they learn that those who may not meet the exact definition of "homebound," but would still benefit from having home health services, are not eligible. For example, someone with multiple chronic conditions and some functional limitations may benefit from hands-on home health care, but may not be eligible for this benefit because she could technically leave her house on her own. Further, the provision of such services at the outset of a problem may prevent her from being admitted to a hospital and receiving much more expensive care at a later date.

Medicare also has significant gaps when it comes to providing care for chronic conditions often faced by seniors. In addition to not covering most long-term care, Medicare does not cover hearing aids, dental care, eye examinations, or foot care.[69] An increased focus on quality-of-life issues for seniors with chronic health conditions, such as hearing loss, would help improve the beneficiary's experience with the program and would have health benefits as well.

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available at http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/bp102c08.pdf, *archived at* http://perma.cc/9WBS-SR5E ("The beneficiary must also have been transferred to a participating SNF within 30 days after discharge from the hospital.").

[63] *See id.*

[64] *See id.*

[65] *See* MEDICARE AND HOME HEALTH CARE, *supra* note 59, at 5.

[66] *Id.*

[67] *Id.*

[68] *See* UNITED HEALTHCARE & NAT'L COUNCIL ON AGING, *supra* note 21.

[69] See Ctrs. for Medicare & Medicaid Servs., *What's Not Covered by Part A & Part B*, MEDICARE.GOV, http://www.medicare.gov/what-medicare-covers/not-covered/item-and-services-not-covered-by-part-a-and-b.html (last visited Mar. 7, 2015), *archived at* http://perma.cc/2H96-QXBP.

Hearing loss is a great example. One-third of all Americans above age sixty-five experience some form of hearing loss.[70] However, three out of five elderly Americans with hearing loss do not use a hearing aid because of the prohibitive cost and the fact that Medicare will not pay for the device.[71] This unfortunate result has negative health impacts on seniors—thirty percent of non-hearing aid users with hearing loss reported increased social isolation and sad feelings,[72] and studies have found a positive correlation between hearing loss and dementia.[73]

Therefore, seniors who need long-term care in the United States cannot turn to existing safety net programs for the provision of long-term care. Medicaid, the largest provider of these services, is limited to low-income Americans, does not provide uniform coverage for home care services, and has extensive waiting lists. Similarly, even though Medicare is a program targeted at seniors, it does not include a comprehensive long-term care benefit, and significant gaps remain in terms of programs the help improve quality of life for seniors. It is clear that comprehensive policy change is needed.

V. The Solution: Putting Seniors and Caregivers First

As the population of senior citizens continues to grow, the problems discussed previously in this Article will only continue to worsen. Reforming long-term care remains the most urgent priority in that regard. As demonstrated, the current U.S. system of paying for and providing long-term care is in need of serious reform. A new approach could help American seniors receive the benefits they deserve while generating real savings for the nation overall. However, there are also several immediate steps that can be taken in the short-term that would go a long way towards solving the problem of long-term care provision and would have a direct, positive impact on people's lives.

A. Supporting Family Caregivers

Family caregivers who remain on the front lines of providing care for those in need must be supported. One form of support could be provided by formally integrating family caregivers into plans of care for a patient, either

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[70] *See* Letter from The Hearing Loss Association, to Congressman Matt Cartwright (Oct. 18, 2013), *available at* http://www.hearingloss.org/sites/default/files/docs/HLAA_ltr_of_support_HEAR_Act.pdf, *archived at* http://perma.cc/8HLY-7T4Y.

[71] *See Untreated Hearing Loss Linked to Depression, Social Isolation in Seniors,* Am. Acad. of Audiology, http://www.audiology.org/publications-resources/document-library/untreated-hearing-loss-linked-depression-social-isolation (last visited Mar. 7, 2015), *archived at* http://perma.cc/3UQ2-37V8.

[72] *See id.*

[73] *See Untreated Hearing Loss in Adults: A Growing National Epidemic*, Am. Speech-Language Hearing Ass'n., http://www.asha.org/Aud/Articles/Untreated-Hearing-Loss-in-Adults/ (last visited Mar. 7, 2015), *archived at* http://perma.cc/39LT-BVZY.

once the patient is discharged from an institution or when the patient is transferred from one institution to another. However, family caregivers often do not have any medical training and are asked to administer complicated medical regimens or procedures without any supervision.[74] Unsupervised medical care could lead to adverse events for the patient and hospital readmissions, which could drive up costs.

Another step in supporting caregivers is to have a dedicated caseworker assigned to each patient as she is discharged. Even if caregivers do have a more formal role in the system, they are still left with a host of problems and do not have a designated place to turn for questions. An assigned caseworker will complement the formal incorporation of the caregiver into the plan of care by giving them a designated point-of-contact to call with questions or concerns.

At the national policy level, the U.S. Department of Health and Human Services ("HHS") should take immediate steps to improve options for family caregivers as much as possible. While there are some successful initiatives already occurring at the state and local level,[75] a national policy is needed to promote uniformity and reduce geographic disparities in the provision of care. HHS should immediately study all of the existing programs that hospitals, payers, and other stakeholders have developed in the private sector to incorporate family caregivers into plans of care, with the goal of issuing a report summarizing best practices in this area. The agency should also focus on ensuring that family caregivers have an accurate and reliable source of information available to them. Following the issuance of this best-practices report, Congress should study the results and implement a coherent, national policy for formally integrating family caregivers into plans of care.

B. Ending the Institutional Bias in Medicaid

Medicaid is currently the largest payer for long-term care in the United States, so every effort should be made to ensure the program is operating as efficiently and effectively as possible. The best way to improve the program is to immediately end the "institutional bias" by making HCBS services mandatory for states. Congress would have to amend the law to do so, but this change would go a long way towards ensuring that the elderly receive the care they need in the setting they deserve. Covering care in an institution, but not in a home, not only provides the wrong incentives for care but is also expensive. A 2008 study of patients in California found that the average

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[74] *See* Susan Perry, *Family Caregivers Often Asked to Perform Tasks with Little or No Training*, MINN POST (Dec. 23, 2014), http://www.minnpost.com/second-opinion/2014/12/family-caregivers-often-asked-perform-medical-tasks-little-or-no-training, *archived at* http://perma.cc/KDW5-624M.

[75] *See* Press Release, United Hosp. Fund, Family Caregivers' Role Integrated into National Reducing Preventable Hospital Readmissions (Jun. 3, 2014), http://www.uhfnyc.org/news/880986, *archived at* http://perma.cc/V4JS-TPV7.

spending on care in nursing homes was $32,406, while only $9,129 was spent on average for home and community-based services.[76] Simply mandating that every state provide these services under Medicaid would save the program money by encouraging people to receive care at home rather than in an institution while also reducing the extreme geographic disparities of care across the country.

C. Reforming Medicare for Seniors: Eliminating the "72 Hour Rule" and Improving Quality of Life

Although Medicaid is the largest payer of long-term care, Medicare is still the primary federal program targeted at seniors, and there are several steps we can take in the short-term to improve the program. First, the "72 hour rule" must be reversed by Congress. It creates perverse incentives that encourage overutilization of medical services and shifts the emphasis from medical need to finding loopholes. If a doctor is providing care to Medicare beneficiaries and has completed their treatment in a hospital in eighteen hours but may need some follow-up care in an SNF, the doctor may keep them in the hospital for longer than needed so they are eligible for the SNF benefit. Alternatively, a doctor could discharge a patient after her course of treatment is completed in under a three-day stay, and then when follow-up care at an SNF is needed, the beneficiary is shocked to learn that Medicare will not cover her stay. The volatile nature of the "72 hour rule" must be reversed so that referral to an SNF is based on medical need and not on an arbitrary time limit. Congress should pass legislation that achieves this goal.

Furthermore, since Medicare does not adequately provide long-term care services for seniors, there must be a greater focus on quality-of-life issues for seniors. One easy fix would be to mandate Medicare coverage of hearing aids. These devices range in price from $1,500–$3,000,[77] which can be prohibitively expensive for some seniors. Two-thirds of Americans aged seventy and over suffer from some form of hearing loss, but only fifteen percent of this segment receive the treatment they need.[78] This gap is especially troubling as untreated hearing loss is linked to a decline in cognitive function and emotional health, but these trends are reversed when a hearing aid is used.[79] Passing legislation that mandates Medicare coverage of hearing

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[76] *See* Fox-Grage & Walls, *supra* note 54, at 7.

[77] *See* Cathie Gandel, *Paying for Your Hearing Aid*, AARP BULLETIN (Oct. 3, 2014), http://www.aarp.org/health/conditions-treatments/info-05-2011/paying-for-hearing-aids.html, *archived at* http://perma.cc/9BLW-L4N9.

[78] *See* Press Release, Johns Hopkins Med., Hearing Loss Accelerates Brain Function Decline in Older Adults (Jan. 23, 2013), http://www.hopkinsmedicine.org/news/media/releases/hearing_loss_accelerates_brain_function_decline_in_older_adults, *archived at* http://perma.cc/8AZN-CV46.

[79] See Cynthia D. Mulrow, et al., *Quality of Life Changes and Hearing Impairment,* 113 ANNALS OF INTERNAL MED. 188, 191 (1990).

aids would make a real improvement in the lives of seniors. This should be a top priority for Congress.

D. Initiating a Large National Conversation

Finally, there needs to be a national conversation about the best way to finance long-term care in the United States. The institutional bias in Medicaid and the lack of support for family caregivers are just symptoms of the larger problem: the lack of a social safety net that is specifically designed for long-term care for the elderly.

The ultimate goal of these suggested reforms is to provide people with financial assistance so that they can access care from a trained professional in a setting of their choice. There are many different ways to achieve this goal and it will require a significant amount of hard work to achieve consensus among the varied stakeholders. The federal government must play a strong role in providing these services. Caring for America's seniors is a shared responsibility, and it is clear from the problems described in this Article that the current programs are not adequately providing the care needed by seniors in the United States today.

Congress should enact long-term care legislation that adheres to the following principles. First, the needs of seniors should be put first when designing a new, comprehensive program. Second, this new program must provide financial assistance for both institutional and home care. Patient choice is critical to ensuring this system is both fair and effective. Finally, this legislation must be actuarially sound and sustainable. Long-term care is the missing pillar of our social safety net, and steps must be taken to ensure this program will function properly for years to come. Paying for this new program will not be easy. However, progress can be made only by initiating a national conversation on paying for long-term care. This conversation is a sorely needed first step on the path to providing seniors with the care they need and deserve.

VI. Conclusion

As our nation ages, long-term care will continue to be a pressing issue for the American people. It is clear that serious policy reform is needed. This reform is crucial both for current beneficiaries who are not receiving all of the services that they need, as well as for future generations who will expect to have these services provided to them in a cost-effective manner when they get older.

Our current system badly needs reform and difficult choices will need to be made. Medicare does not pay for long-term care services, and Medicaid is only available to those with low-income levels. Family caregivers provide support for many families, but those contributions cannot be ex-

pected to continue forever, nor should they be expected to comprise a national solution.

This pressing problem requires action in both the short-term and the long-term. Congress could take immediate action today through direct incremental changes to care delivery, such as incorporating family caregivers into plans of care and having a dedicated caseworker assigned to each patient that is discharged from an institution. In the long-term, Medicaid should pay for home care in every state in the country. Similarly, Medicare should end the "72 hour rule" and cover hearing aids and other services that could have a real impact on quality of life for seniors.

To put the nation on a sustainable path, a national conversation needs to be initiated about long-term care in the United States and how to pay for it. This conversation will not be an easy discussion to have, and tradeoffs will have to be made. However, each day that passes will be another day whereby progress is not made and senior citizens have to live in an imperfect system. We can and must do better—the American people demand it.