

ONE HUNDRED FOURTEENTH CONGRESS  
**Congress of the United States**  
**House of Representatives**  
COMMITTEE ON ENERGY AND COMMERCE  
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**MEMORANDUM**

**February 28, 2016**

**To: Subcommittee on Health Democratic Members and Staff**

**Fr: Committee on Energy and Commerce Democratic Staff**

**Re: Subcommittee Hearing on “Examining the Financing and Delivery of Long-Term Care in the U.S.”**

On **Tuesday, March 1st, at 10:15 a.m., in Room 2322 of the Rayburn House Office Building**, the Subcommittee on Health will hold a hearing titled “Examining the Financing and Delivery of Long-Term Care in the U.S.”

**I. BACKGROUND**

Long-term services and supports (LTSS) are medical and personal care assistance for individuals who have difficulty completing daily living activities that will probably persist over a prolonged period of time (months to years).<sup>1</sup> The services can range from basic assistance such as feeding or bathing to more complex assistance such as meal preparation or management of medication regimens. The provision of services exists across a wide spectrum, ranging from unpaid assistance by loved ones to adult daycare to full-time nursing home care.<sup>2</sup>

**A. Demographics of Long-Term Care Population**

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<sup>1</sup> Erica L. Reaves and MaryBeth Musumeci, *Medicaid and Long-Term Services and Supports: A Primer* (Dec 15, 2015) (online at <http://kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/>).

<sup>2</sup> *Id.*

Approximately 12 million Americans require LTSS.<sup>3</sup> These patients are a varied population and include those with intellectual and developmental disabilities, behavioral health diagnoses, spinal cord or traumatic brain injuries, or other disabling chronic conditions. Overall, 50 percent are under the age of 65.<sup>4</sup> Importantly, however, elderly individuals are at increased risk of requiring LTSS. Of those 65 years of age or older, 70 percent will require LTSS at some point in their lives.<sup>5</sup> Of those requiring LTSS, 14 percent will need a high level of LTSS over a prolonged duration (greater than five years).<sup>6</sup> Additionally, those who are 85 years and older, which is the fastest growing segment of the U.S. population, are four times more likely to need LTSS than those between 65 and 84.<sup>7</sup>

Patients requiring LTSS can vary tremendously in the amount of care needed. While some may have few needs beyond simple assistance and can still remain in the workforce, others may be chronically disabled or bed bound. For 10 percent of older adults, total costs of paid care will be less than \$25,000.<sup>8</sup> On the other end of the spectrum, 15 percent of older patients will require total care at costs exceeding \$250,000.<sup>9</sup>

## **B. Providers of Long-Term Services and Supports**

The term “long-term care” encompasses the entire spectrum of providers ranging from unpaid friends and family members to institutional care. Unpaid caregiving often serves as the front line of LTSS. In 2013, approximately 40 million of these caregivers provided 37 billion

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<sup>3</sup> HHS, Office of the Assistant Secretary for Planning and Evaluation (ASPE), *Long-term services and supports for older Americans: Risks and Financing* (July 2015) (online at [https://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb\\_0.pdf](https://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb_0.pdf)).

<sup>4</sup> H. Stephen Kaye, et al., *Long term care: who gets it, who provides it, who pays, and how much* (2010) *Health Affairs* 29(1):11-21.

<sup>5</sup> ASPE, *Long-term services and supports for older Americans: Risks and Financing* (July 2015) (online at [https://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb\\_0.pdf](https://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb_0.pdf)).

<sup>6</sup> *Id.*

<sup>7</sup> Ari Houser, Wendy Fox-Grage, Kathleen Ujvari, *Across the states: Profiles of long-term services and supports*, AARP (2012) (online at [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf)).

<sup>8</sup> ASPE, *Long-term services and supports for older Americans: Risks and financing research brief* (July 2015) (online at [https://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb\\_0.pdf](https://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb_0.pdf)).

<sup>9</sup> *Id.*

hours in unpaid services.<sup>10</sup> In addition to home caregivers, LTSS can be delivered by either home and community-based services (HCBS) or institutional settings.

Traditionally, the general public has viewed long-term care to be one in the same as nursing home care; increasingly, though this is not always the case. Over the last several decades, care has steadily shifted from institutional services to HCBS.<sup>11</sup> In fact, 2013 was the first year on record in which the majority of Medicaid LTSS spending was for HCBS rather than on institutional care.<sup>12</sup> One reason for this shift was the Supreme Court’s *Olmstead* decision, which held that unjustified segregation of persons, including institutionalization of some patients, constitutes discrimination in violation of Title II of the Americans with Disabilities Act.<sup>13</sup> Another reason for the shift is the significant annual cost differential between institutionalization and HCBS. The annual cost of nursing home care is approximately \$91,250, compared to \$45,800 for a home health aide or \$18,000 for adult day care.<sup>14</sup>

## II. PAYMENTS FOR LONG-TERM SERVICES AND SUPPORTS

### A. Overall Long-Term Care Costs/Medicare and Medicaid Coverages

In 2014, the U.S. spent approximately \$340 billion on LTSS.<sup>15</sup> Public payers covered nearly three-quarters of this expense (71.4 percent).<sup>16</sup>

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<sup>10</sup> Susan C. Reinhard, Lynn Friss Feinberg, Rita Choula, and Ari Houser, *Valuing the Invaluable: 2015 Update, Undeniable Progress, but Big Gaps Remain*, AARP Public Policy Institute (July 2015) (online at <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>).

<sup>11</sup> Jennifer Ryan, Barbara Edwards, Henry Claypool, et al., *Rebalancing Medicaid long-term services and supports* (Sept 17, 2015) (online at [http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief\\_id=144](http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=144)).

<sup>12</sup> *Id.*

<sup>13</sup> *See Olmstead v L.C.*, 527 U.S. 581 (1999) (institutional placement of the disabled can perpetuate unwarranted assumptions that they are incapable or unworthy of participating in community life and confinement in an institution can severely diminish the everyday life activities of individuals)

<sup>14</sup> Genworth, *Genworth 2015 Cost of Care Survey: Home Care Providers, Adult Day Health Care Facilities, Assisted Living Facilities and Nursing Homes* (April 2015) (online at [https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/130568\\_040115\\_gnw.pdf](https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/130568_040115_gnw.pdf)).

<sup>15</sup> Kirsten J. Colello, *Who pays for long-term services and supports?*, Congressional Research Service (CRS) (Jan 5, 2016) (online at <http://www.crs.gov/reports/pdf/IF10343>).

<sup>16</sup> *Id.*

Although it is a common misconception that Medicare covers the lion’s share of LTSS, it in fact pays for only limited amounts of those associated costs. The Medicare portion of LTSS is generally limited to reimbursement for post-acute care services at skilled nursing facilities for up to 100 days after a qualified hospital stay.

Medicaid, on the other hand, is the single largest payer of LTSS in the U.S., spending over \$142 billion in 2014.<sup>17</sup> This is shown by and reflected in the statistic that LTSS represents roughly one-third overall of all Medicaid spending.<sup>18</sup>

**B. Flexibility for States Through Medicaid in Covering LTSS**

States hold a great deal of flexibility in covering LTSS under Medicaid. While institutional services are required to be covered in every state, wide variations in HCBS benefits exist across states.<sup>19</sup> Much of this flexibility to provide an institutional level of care in the community is granted to the states in the form of optional HCBS State Plan Options and a variety of *1915 waivers*, the most common of which is a *1915(c) waiver*. These waivers are utilized in nearly every state.

In 2012, there were 290 active 1915(c) waivers.<sup>20</sup> These waivers allow a state to provide a defined set of HCBS to target populations who require an institutional level of care. States are provided additional incentives to utilize HCBS through the Money Follows the Person and the Balancing Incentive Payment Program. However, these programs are on course to expire, or have already expired.

Beyond government public spending, private individuals and families contribute significant amounts of personal funds toward LTSS costs. In 2014, out of pocket expenses accounted for over \$53 billion, which was nearly 16 percent of national LTSS spending.<sup>21</sup> While direct out of pocket spending is a significant dollar amount, the \$53 billion only represents a fraction of the real-costs that are seen and incurred by families. Across the country, 17 percent of working adults provide unpaid care for family members or friends, which amounts to an

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<sup>17</sup> *Id.*

<sup>18</sup> *Id.*

<sup>19</sup> Kirsten J. Colello, *Medicaid Coverage of Long-term services and supports*, CRS (Jan 14, 2016) (online at <http://www.crs.gov/reports/pdf/R43328>).

<sup>20</sup> *Id.*

<sup>21</sup> Kirsten J. Colello, *Who pays for long-term services and supports?*, CRS (Jan 5, 2016) (online at <http://www.crs.gov/reports/pdf/IF10343>).

estimated \$470 billion annually in labor costs.<sup>22</sup> Lost productivity is estimated to cost the economy an additional \$34 billion annually.<sup>23</sup>

### C. Private Long-Term Care Insurance

Although private long-term care insurance (LTCI) does exist in the LTSS space, it has not gained significant traction to date and remains a small portion of the market. In 2012, there were only approximately 7-8 million Americans with private LTCI policies.<sup>24</sup> Additionally, the LTCI marketplace has been stagnant, with only 20 companies still engaged in the LTCI industry compared to over 100 in 2002.<sup>25</sup> Overall, the private LTCI industry has struggled for a variety of reasons including high-premiums, adverse selection of enrollees, misconceptions among the general public about LTSS coverage, personal finances and low prioritization of potential plan purchasers.<sup>26</sup>

## III. CHALLENGES FACING LONG-TERM SERVICES AND SUPPORT

Although it already remains a significant portion of national health spending, long-term care services are expected to place increasing strain on the budget in the future. As a result of the ageing *Baby Boomer* generation, the number of Americans requiring LTSS is expected to rise significantly. Of note, by the year 2050, the population of Americans over age 65 is expected to double and the population above 85 will triple.<sup>27</sup> This will result in approximately 90 million

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<sup>22</sup> Susan C. Reinhard, Lynn Friss Feinberg, Rita Choula, and Ari Houser, *Valuing the Invaluable: 2015 Update, Undeniable Progress, but Big Gaps Remain*, AARP Public Policy Institute (July 2015) (online at <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>).

<sup>23</sup> MetLife Mature Market Institute, *Market Survey of Long-term Care Costs* (Nov 2012) (online at <https://www.metlife.com/assets/cao/mmi/publications/studies/2012/studies/mmi-2012-market-survey-long-term-care-costs.pdf>).

<sup>24</sup> Marc A. Cohen, *The current state of the long-term care insurance market*, (March 2014) (online at [http://iltciconf.org/2014/index\\_htm\\_files/44-Cohen.pdf](http://iltciconf.org/2014/index_htm_files/44-Cohen.pdf)).

<sup>25</sup> *Id.*

<sup>26</sup> Bipartisan Policy Center, *America's Long-Term Care Crisis: Challenges in Financing and Delivery*, (April 2014) (online at <http://bipartisanpolicy.org/wp-content/uploads/sites/default/files/BPC%20Long-Term%20Care%20Initiative.pdf>).

<sup>27</sup> Ari Houser, Wendy Fox-Grage, Kathleen Ujvari, *Across the states: Profiles of long-term services and supports*, AARP (2012) (online at [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf)).

Americans over age 65 by 2055, with half of these individuals over 75.<sup>28</sup> At this trajectory, LTSS expenses are predicted to double as a share of the economy over the next 30 years.<sup>29</sup>

The *Baby Boom* phenomenon also poses a different difficulty; decreased availability of family caregivers. The diminishing size of the American family is expected to decrease the supply of available caregivers for the upcoming generation. In 2010, there were an estimated 7.2 caregivers available to assist with the LTC needs of every individual.<sup>30</sup> However, by 2050, this number is expected to shrink to 2.9.

#### **IV. RECENT PROPOSALS**

Given the significant costs and challenges to the long-term care system, numerous organizations have expressed interest in improving the long-term care system across the country. In the last month, three organizations—the Bipartisan Policy Center, the Convergence Center for Policy Resolution and LeadingAge— have put forth recommendations to improve LTSS in the United States. Their findings are briefly summarized below.

##### **A. The Bipartisan Policy Center**

In 2013, the Bipartisan Policy Center (BPC) launched a long-term care initiative with the goal to raise awareness about the importance of finding a sustainable means for financing and delivering LTSS and to improve the quality and efficiency of both public and private long-term care.<sup>31</sup> In April of 2014 they released an initial report characterizing the challenges of the current

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<sup>28</sup> Favreault M, Johnson R, *Projections of lifetime risk of long-term services and supports at ages 65 and older under current law from DYNASIM*, Urban Institute (2015).

<sup>29</sup> Congressional Budget Office, *Rising Demand for long-term services and supports for elderly people* (June 2013) (online at <https://www.cbo.gov/sites/default/files/113th-congress-2013-2014/reports/44363-LTC.pdf>).

<sup>30</sup> Redfoot D, Feinberg L, Houser A, *The aging of the baby boom and the growing care gap: a look at future declines in the availability of family caregivers*, AARP Public Policy Institute (August 2013) (online at [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](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)).

<sup>31</sup> Bipartisan Policy Center, *America’s long-term care crisis: Challenges in financing and delivery*,” (April 2014) (online at <http://bipartisanpolicy.org/wp-content/uploads/2014/03/BPC-Long-Term-Care-Initiative.pdf>).

LTSS system. Later, in February 2016, the group released its initial recommendations to improve the financing of long-term care.<sup>32</sup>

Overall the group does not believe that a single, comprehensive solution to address LTSS would be financially or politically viable. Thus, they opted to issue a set of targeted recommendations to varying public and private sector providers as well as differing patient groups under four broad recommendations:

- *Increase the availability and affordability of private long-term care insurance to extend existing resources.* BPC recommends making private long-term care insurance (LTCI) more accessible through a number of mechanisms. These mechanisms include establishing a lower-cost, limited benefit private LTCI product that may be easier for LTCI carriers to manage, and making such a product available through state and federal insurance marketplaces.
- *Expand options at home and in the community for older Americans and individuals with disabilities under Medicaid.* BPC dedicates a portion of their recommendations to Medicaid reforms. Much of these focus on streamlining the 1915 waiver programs to create a more attractive and uniform option for states. The goal is to further incentivize Medicaid financing for HCBS and to continue the move away from institutional care.
- *Create a new option for working individuals with disabilities.* The group also notes that for certain Americans working with disabilities, successful employment can lead to the loss of Medicaid coverage and thus create a disincentive to participate in the workforce. To rectify this, they recommend the creation of a new system that allows recipients to receive LTSS while still remaining in the workforce.
- *Address the needs of Americans with significant LTSS needs through exploration of a public catastrophic option.* BPC acknowledges that the reforms recommended above still leave a gap in coverage for individuals who may experience catastrophic LTSS expenses (over \$250,000). They note that these individuals generally are uninsurable, result in costs that are insurmountable for the individual, and are unsustainable for the states. With that in mind, they recommend a public insurance approach targeted at this particular population that works in tandem with Medicaid and the private market for a holistic LTC financing system.

## **B. Convergence Center for Policy Resolution**

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<sup>32</sup> Bipartisan Policy Center, *Initial recommendations to improve the financing of long-term care* (Feb 2016) (online at <http://bipartisanpolicy.org/wp-content/uploads/2014/03/BPC-Long-Term-Care-Initiative>).

In 2012, the Convergence Center for Policy Resolution began working to develop solutions to the long-term care crisis. A diverse group of experts in the field from across the political spectrum met and formed the Long-term Financing Collaborative.

In February 2016, the collaborative released its “Consensus Framework for Long-Term Care Financing Reform.”<sup>33</sup> The report builds off of the four principles developed by the group a year earlier with five agreed-upon recommendations, which include:

1. A universal catastrophic insurance program to provide financial support to those with high levels of LTSS care needs over a long period of time;
2. A number of private market initiatives and public policies to bolster the long term care insurance marketplace to address non-catastrophic LTSS risk;
3. Measures to increase retirement savings and flexible use of home equity to allow individuals to cover out of pocket costs associated with LTSS;
4. Enhanced Medicaid LTSS safety net for low-income individuals; and
5. Stronger support for family and community caretakers.

Recommendations given by the Collaborative are a policy framework rather than a specific proposal. The group acknowledges that within this framework, several policy decisions would be required. An example of this would be the type of benefit offered under the universal catastrophic insurance program. The Collaborative offers different options including offering beneficiaries a choice between discounted cash benefits or direct services. Additionally, they offer an array of financing options for the plan, ranging from a payroll tax, an income tax or premiums. Each recommendation offers several specific policy options within the framework and notes several areas where future research would be beneficial.

### C. LeadingAge

In 2012, LeadingAge convened a task force to examine the issue of the LTSS financing. Subsequently, in February 2016, the group issued its “Pathways Report” detailing a variety of policy options for addressing LTC financing.<sup>34</sup> This report built on their 2013 study that outlined

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<sup>33</sup> Long Term Care Financing Collaborative, *A consensus framework for long-term care financing reform* (Feb 2016) (online at <http://www.convergencepolicy.org/wp-content/uploads/2016/02/LTCFC-FINAL-REPORT-Feb-2016.pdf>).

<sup>34</sup> LeadingAge, *LeadingAge Pathways Report Perspectives on the challenges of financing long-term services and supports*, (Feb 2016) (online at [https://www.leadingage.org/uploadedFiles/Content/Members/Member\\_Services/Pathways/Pathways\\_Report\\_February\\_2016.pdf](https://www.leadingage.org/uploadedFiles/Content/Members/Member_Services/Pathways/Pathways_Report_February_2016.pdf)).



seven distinct policy pathways which could theoretically be taken to address the issue.<sup>35</sup> These pathways included a variety of options that approached the issue based on: keeping the status quo, elevating personal responsibility, encouraging private markets, promoting private catastrophic coverage, promoting public catastrophic coverage, a common good approach, or a comprehensive approach.

Overall, LeadingAge concluded that no single solution would be sufficient, but certain options would be more promising than others. First, they note that the status quo is untenable. Second, they note that because higher levels of participation results in optimal coverage and costs in any particular insurance model, a mandatory universal insurance approach that covers catastrophic events would be the most effective pathway to pursue.

Beyond a mandatory, universal insurance approach, LeadingAge notes that additional pathways could be beneficial as well. Specifically, they conclude that a separate pathway may better address younger people with disabilities and that innovations in LTCI are worth additional research.

## **V. WITNESSES**

### **William J. Scanlon, PhD**

Consultant

West Health Institute and National Health Policy Forum

### **Anne Tumlinson**

CEO, Anne Tumlinson Innovations, LLC

Founder, Daughterhood.org

### **Alice Rivlin, PhD**

Co-Chair, Long Term Care Initiative

Bipartisan Policy Center, Senior Fellow, Economic Studies Program, The Brookings Institution

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<sup>35</sup> Leading Age, *LeadingAge Pathways: A framework for addressing Americans' financial risk for long-term services and support* (Oct 2013) (online at [http://www.leadingage.org/LeadingAge\\_Pathways\\_Framework\\_Addressing\\_Americans\\_Financial\\_Risk\\_for\\_LTSS.aspx](http://www.leadingage.org/LeadingAge_Pathways_Framework_Addressing_Americans_Financial_Risk_for_LTSS.aspx)).