

A COMPREHENSIVE APPROACH TO LONG-TERM SERVICES AND SUPPORTS

Long-Term Care Commission

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Commissioners

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Summary

Congress established the Long-term Care Commission in recognition of the current and increasing nationwide need for long-term services and supports (LTSS). The statute establishing the Commission sets out our charge:

“The Commission shall develop a plan for the establishment, implementation, and financing of a comprehensive, coordinated, and high-quality system that ensures the availability of long-term services and supports for individuals in need of such services and supports, including elderly individuals, individuals with substantial cognitive or functional limitations, other individuals who require assistance to perform activities of daily living, and individuals desiring to plan for future long-term care needs....”
[Emphasis added.]¹

The authors of this statement acknowledge the efforts of the entire Commission and staff. But, given the unusually compressed timeframe for our work, the final report does not fulfill this charge. We issue this statement to express our shared vision of what is necessary to meet Congress’s mandate to establish and finance a high-quality, comprehensive LTSS system for Americans who need such services. The authors’ vision is to create such an inclusive LTSS system for people of all ages – a system that will meet individual’s functional and cognitive support needs with quality care in the most integrated setting. We are convinced that no real improvements to the current insufficient, disjointed array of LTSS and financing can be expected without committing significant resources, instituting federal requirements, and developing social insurance financing.

Accordingly, our recommendations follow.

1. To spread the risk for the costs of long-term services and supports as broadly as possible, provide benefits to people of all ages who need them, and allow individuals and families to meet their responsibilities, a public social insurance program that is easily understood and navigated must be established. That program could provide comprehensive benefits or a more limited package. But a social insurance program must be at the core of an effective LTSS financing system. A social insurance core would not eliminate the roles of private insurance or of family financing or caregiving. Rather, it would make these roles more manageable.
2. To ensure high-quality services for individuals and their families in all service settings, the law must assure that direct-care workers are paid a living wage, are well trained, and have opportunities for career advancement.

3. To integrate familyⁱ caregivers into a comprehensive LTSS system, public programs providing services to LTSS beneficiaries must appropriately engage family caregivers and address their needs.

While the nation moves to a comprehensive system for LTSS, and to supplement it as necessary, we recognize that improvements are needed in current programs. Among the improvements suggested by individual Commissioners are the following:

4. To meet the needs of those who qualify for Medicare, the current Medicare program must be adapted to reduce counterproductive, outdated and unreasonable barriers to outpatient therapies, home health and skilled nursing facility care.
5. To strengthen Medicaid, existing financial incentives to states for quality home- and community-based services must be extended and streamlined to make it easier to rebalance Medicaid LTSS. In addition, Medicaid's benefits must be improved for people who rely on Medicaid's services.
6. To provide new ways to access LTSS for persons with disabilities, tax-preferred savings accounts must be provided for people and their families who are not currently receiving LTSS through the Medicaid program, the Medicaid buy-in program for workers with modest earnings must be expanded, and a new program for workers with significant disabilities who have higher earnings must be piloted.

In the text below the authors explain and expand on each of these recommendations in turn.

How We're Failing People Who Need Long-Term Services and Supports (LTSS)

Although the risk of needing LTSS rises at older ages, people of all ages are at risk. The LTSS population includes older adults and people with disabilities associated with chronic conditions including Alzheimer's disease, osteoporosis, heart failure, and stroke. The LTSS population also includes children and young and working-age adults with disabilities, including people disabled from birth who have intellectual and developmental disabilities or other cognitive and physical limitations, and people who develop disabling chronic conditions and illnesses (such as Parkinson's disease, multiple sclerosis, and stroke) or who sustain a disabling injury later in life (a spinal cord injury or traumatic brain injury, for example). Among people under the age of 65, less than two percent have LTSS needs, but they represent nearly five million of the 11 million people who need LTSS. Among people now turning age 65, an estimated three in ten will never need any LTSS, while two in ten will need five or more years of LTSS.²

Most people who need LTSS (over 80 percent of people with LTSS needs living at home) rely solely on family and friends to provide them and do not receive paid services.³ Some people also receive supplemental assistance from paid caregivers, usually home care aides, and only a small

ⁱ We use the word "family" broadly, to refer to all friends and community members who assist an individual who needs LTSS.

percentage of people with LTSS needs living at home (less than 10 percent) rely exclusively on paid care.⁴

There are no comprehensive private or public sector mechanisms for pooling the risk of needing LTSS and spreading the cost for those services. Few people with LTSS needs today, or who are at risk of needing LTSS in the future, have purchased private insurance to meet those needs. With respect to people with current needs for LTSS, few, if any private policies are even offered. Medicare and Medicaid provide substantial assistance to many people with LTSS needs, but neither program provides effective insurance that assures access to appropriate services and supports or protection against financial catastrophe for people who need LTSS. Medicare – which provides health benefits for people 65 years old or older and people with disabilities who receive Social Security benefits for 24 months, regardless of income – does not pay for LTSS. Medicaid, in contrast, provides substantial assistance to people with LTSS needs, but the program is means-tested and requires people to be or become impoverished to qualify for assistance. The services covered by Medicaid – especially home and community-based services, vary widely across states. Waiting lists are common, and the lack of services can lead to unmet needs and human suffering and can force people into institutions. Further, for people with disabilities who are willing and able to work, Medicaid’s stringent means-testing can force people with disabilities not to work, or not to work up to their potential, in order to remain eligible for financial assistance with the cost of LTSS.

People with disabilities who need LTSS, as well as caregivers, friends, and others who assist people who need LTSS, know about the challenges and frustrations, the costs, and, for some, the indignities and suffering that arise as a result of the nation’s woefully inadequate approach. Although needs and circumstances vary widely, the personal stories of people who need care invariably reveal a number of truths about LTSS today: the central role of families, both in terms of caregiving and personal financial resources; the challenges in finding out how to navigate disparate and often inadequate programs; the difficulty in piecing together a plan for supportive services and keeping it in place; the high cost of services relative to the financial resources of frail older adults and younger persons with disabilities; the barriers to financial assistance with the cost of care for people with even modest financial resources; the importance of Medicaid to people with limited resources and costly LTSS needs; and the barriers to work and independence for people with disabilities who need supportive services.

Here are just a few profiles of real people that shed light on a number of these truths about LTSS today.

- **Evelyn Greenberg** was a 76-year-old wife, mother and grandmother when, in 2001, she suffered a serious brain-stem stroke that left her almost completely paralyzed. After much physical therapy, she was only able to regain limited use of her left arm. She required constant supervision and relied on substantial assistance from family members and home health aides to meet her daily needs. Evelyn lived at home in Florida and relied on her husband, Arthur, (who was 71 years old at the time of her stroke) as her primary caregiver for over 7 years until his death at the age of 79 from pancreatic cancer. Evelyn’s children also spent considerable time providing caregiving assistance, which provided respite to their

father. They also provided caregiving to both parents during Arthur's 18-month fight with cancer.

Following Arthur's death, the family struggled to maintain Evelyn in her home in Florida. Evelyn's daughters took shifts taking care of her for 2-week periods of time or longer. But, after 6 months, it became apparent that this situation was not a long-term solution since her daughters had full-time jobs and did not live in Florida. Evelyn moved to Seattle to live with one of her daughters. There, she received assistance from family and friends, and relied on the assistance of a paid caregiver during the day while her daughter was at work. She paid for these formal, supportive services out of her accumulated savings and also contributed to household expenses.

After two years, as her care began to place increasing personal and financial strains on her daughter, Evelyn returned to Florida, choosing to live in a nursing home near her son's home. For roughly two years, Evelyn paid for her nursing-home care out of her own savings. When those resources were exhausted, Medicaid financed the final year of her nursing-home care. Sadly, in March of 2013, after living 12 years with a serious disability, Evelyn suffered a fall from her wheelchair and died several days later at the age of 88.

Although decades earlier—when they retired to Florida at ages 62 and 67—Evelyn and her husband had tried to purchase private LTSS insurance, they were rejected by several companies or offered plans at an unaffordable rate because of Evelyn's osteoarthritis and hypertension and her husband's previous heart attack.

- **Sue Kelly** was a 40-year-old wife, mother and schoolteacher when she was diagnosed with multiple sclerosis in 1985. Over the next decade and a half, Sue became increasingly disabled, using a cane, a walker, and then a wheelchair, and, by 2000 was bedridden and needed 24-hour supervision and support. With her husband Jack at work and their daughter in school, the Kellys exhausted both their personal savings and the savings they had set aside for their daughter's college education paying for home health aide services, at a cost of roughly \$40,000 annually. In 2005, Jack applied for assistance from the Connecticut Department of Human Services. The application was approved and Sue began receiving assistance from a home care aide to feed, bathe, and care for her under the guidelines of the state Department of Rehabilitation. A year later, Sue's eligibility was reviewed and she was again approved for assistance. But three months later, following a review of the family's finances, Jack received the news that Sue was no longer financially eligible for assistance. The family's assets exceeded the program's limits. All assistance ended in September 2006. Jack and Sue were advised to cash in on the cash value of their life insurance policy and to reduce the amount in his retirement savings account and pay bills with his "excess" savings. He did not pursue those options. Instead, his daughter arranges her schedule to be home from college a day or two per week, and his adult siblings (2 of 3 of whom are retired) help Jack defray the expenses of the aide Sue needs 3 or 4 days a week. Jack's consolation is that his life insurance and 401(k) are intact and available to help pay for his wife's care if he dies.
- **John Robertson** was born with spinal muscular dystrophy, which causes significant loss of muscle tone. John relies on complex rehabilitation technology (CRT) to use his wheelchair in order to live independently. He just graduated law school and is contemplating whether to

take a job at a law firm in a major metropolitan area in another state. The job has a good salary at \$120,000 but his personal care costs are approximately \$90,000 which are not covered by his employer-sponsored insurance. Since he would have to pay for all of this out-of-pocket, his salary would essentially be \$30,000, which is not enough to cover his rent and living expenses. He relied on Medicaid as a law student to cover his personal care needs, but Medicaid is not portable to the state in which he would work. He now has to face the tough decision of foregoing this job offer at a prestigious law firm just to maintain access to LTSS. This denies him the ability to live as independently as possible and become a taxpayer instead of someone who is forced to rely on a safety net program just to get these essential services.

- **Joyce McWain-Gray** is a 56-year old widow who resides in Washington, DC. Partially paralyzed by a spinal condition in 2007, she gets by on a modest Social Security benefit (\$710 per month). After a spinal condition paralyzed her legs six years ago, Joyce McWain-Gray crawled to her second-floor bedroom in a rowhouse and remained there for nearly a year. For her weekly medical appointments, the 56-year-old relied on District firefighters to carry her down the 12 steps from her room. McWain-Gray grew hopeless, she said, until a social worker told her about the District's Elderly and Persons with Physical Disabilities Waiver Program. Joyce was enrolled in the District's Medicaid program—specifically its Elderly and Persons with Physical Disabilities Waiver Program. The Medicaid program sent an aide to her house for 16 hours a day to help her bathe, dress, cook and clean. She got a motorized wheelchair and learned to ride the bus. Then one day her freedom ended. The District would no longer pay for her care during evening hours, she learned in a letter from her home health agency. Three days later, the aide left a stack of adult diapers and a cooler of food next to McWain-Gray's bed and left. Like dozens of other beneficiaries whose benefits were wrongfully terminated, Joyce's benefits were subsequently restored. She continues to live independently in her home.⁵
- **Sara Davis**, 46, has been a wheelchair user her whole life. She has lived on her own since college with the help of home care workers. These workers come in every day to help her get out of bed, dress, shower, do dishes, prepare food, and clean her house. Without them, she could not work full-time or participate in her community. However, she's been unable to keep the same aides for any length of time and consequently has not been able to form lasting relationships with the people who come in to perform these essential, and intimate, tasks. It takes time for workers to get to know how she likes things done and even longer for them to develop the kind of trust that makes everything go more smoothly. Her aides have been kind and helpful, but they often leave these jobs to work in fast food or retail where they can earn more, which means that she's constantly starting over. Some days, the agency is so short-staffed that they have no one to send to help her prepare for the day. Without family in the area, she fears that one day she will go without any help and end up in a nursing home.

Recommendations for Reform

We recognize that enhancing and building a new LTSS system needed to satisfy the Commission's statutory charge will take time. But the people who currently need LTSS cannot wait. To transform today's inadequate LTSS system into one that works, we therefore recommend the creation of a new system and, until it is established, improvements to existing public programs to better meet the needs of older adults and younger people with disabilities. Our recommendations follow.

1. Create a Broader Financing Solution

Most people who need LTSS rely solely on family and friends to provide it and do not receive paid services. But families deliver that care at enormous cost and cannot always provide the full amount, intensity, or type of care that is needed. When paid care is necessary, its costs often exceed most families' resources. The resulting need for expensive, extensive LTSS is an unpredictable, catastrophic risk for people at any age.⁶ People under the age of 65 have less than a two percent chance of having LTSS needs. And even among people now turning age 65, three in ten are likely never to need LTSS, while two in ten will likely need care for five or more years. Half of all people turning age 65 will have no private out-of-pocket spending for LTSS, while only about 5 percent are projected to spend more than \$100,000 out-of-pocket.⁷

Although, in theory, savings could help fill the gap between income and service costs, in practice, savings are inadequate to the task. For younger people who need LTSS, their disability often comes well before they have a chance to accumulate savings that might help pay for LTSS costs. Most older people also lack assets sufficient to finance extensive care needs. Given the unpredictable, catastrophic nature of extensive LTSS costs, insurance, not savings, is the most efficient and effective means of preparing for their possible occurrence.

The nation's public health care financing programs, Medicare and Medicaid, provide substantial assistance to many people with LTSS needs, but neither program provides insurance protection for catastrophic LTSS costs. Neither does the private insurance market. The high costs, limited value and uncertainty of private LTSS insurance limit its scope.⁸ Analysts estimate that improvements in the marketplace would, at best, leave eight in 10 Americans without insurance protection.⁹ Tax policies that some advocate to subsidize these policies would disproportionately benefit the better off. And, without substantial regulation, policies would likely fail to provide adequate protection when purchasers need care.

Recommendation #1

To spread the risk for the costs of long-term services and supports as broadly as possible, provide benefits to people of all ages who need them, and allow individuals and families to meet their responsibilities, a public social insurance program that is easily understood and navigated must be established. That program could provide comprehensive benefits or a more limited package. But a social insurance program must be at the core of an effective LTSS financing system. A social insurance core would not eliminate the roles of private

insurance or of family financing or caregiving. Rather it would make these roles more manageable.¹⁰

Today's public-private financing arrangement that concentrates burdens on the individuals and families of those who use services, backed only by a public program when they become impoverished, must be replaced with a public-private financing arrangement that truly spreads risk. That arrangement has room for, but cannot rely upon, private insurance as its core. To spread risk across the broadest population, social insurance must be the foundation of future policy.

That insurance could take a variety of forms.

One way to develop social insurance for LTSS would be to include a comprehensive LTSS benefit in Medicare Part A. This approach has the advantage of relying on a system that is already in place and has history of adapting to changes in its benefit and financing structure.

- Like the Medicare hospice benefit, added to Medicare Part A in 1983, a Medicare LTSS benefit would be triggered when an individual is certified to meet certain qualifying criteria. The demise of the CLASS Act teaches that to be viable, an LTSS program cannot be voluntary; hence the benefit should be added to Part A, which is mandatory. Under this model, a physician would be required to certify that the individual requires assistance with at least two activities of daily living, has needed such assistance for 90 days, and is likely to continue to need the services. Individuals could equally qualify based on certified ongoing and continued cognitive or mental health issues such that independence is impossible or contraindicated.
- Financing a Part A LTSS benefit might come from a combination of an increase to the current Medicare payroll tax and/or to Part A premiums. Of course, the cost of a Medicare LTSS benefit must be analyzed; it is possible that a new financing mechanism for LTSS could be designed to enhance the financial stability of the Part A trust fund.
- Qualifying individuals would be eligible for reasonable and necessary LTSS services such as:
 - Skilled nursing facility care without the need for a prior hospital stay or daily skilled care;
 - Home health care, including coverage for home health aide services, without the need for a skilled service;
 - Personal Care Attendant services;
 - Care management and coordination;
 - Adult Day Center services;
 - Respite care options to support family or other volunteer caregiver;
 - Outpatient therapies;
 - Other reasonable and necessary services.

- Any new Medicare LTSS benefit should not add to the complexity of Medicare and should not diminish the stability of the current program.
- Importantly, since not all people with LTSS needs are eligible for Medicare, consideration should be given to including those who meet the agreed upon benefit criteria, but who would otherwise not be part of the Medicare program. In the alternative, other social insurance funding should be developed to meet these individuals' needs.

Another social insurance option is to create a more limited benefit, within Medicare or in a new public program. This approach has the advantages of creating a manageable role for private insurers by limiting their exposure to catastrophic risk and by making clear the “hole” that people able to prepare in advance should plan to fill, through private resources.

- Under this arrangement, people assessed as meeting a specified threshold of functional impairment would qualify for benefits after a waiting period. The length of the waiting period (shorter for people with lower incomes and becoming longer at higher incomes) would be established at or near retirement age and tied to Social Security-reported income, averaged over a number of years. For younger people who become impaired, the formula relating waiting periods to income would be appropriately adjusted to reflect the lesser accumulation of resources at younger ages.
- To make the benefit available to people currently in need of assistance, an alternative to the proposed waiting period would be necessary, since private insurance to fill it may be unavailable or prohibitively expensive and people may lack the means to otherwise protect themselves. A broadly inclusive benefit would therefore replace the waiting period with an income/asset-related deductible for people who, at the time the new benefit is established, have significant disabilities or are age 75 or older.
- Benefits under this arrangement would be specified as a dollar-amount per day, vary with level of impairment and be applicable to the full range of LTSS services. Individuals could opt for a service rather than a cash benefit.
- Benefits could be financed through a combination of Medicaid savings (federal only or federal and state) and a surcharge on the income tax (higher for people currently near or at retirement age).

Neither of these social insurance models eliminates the private part of the public-private LTSS partnership. On the contrary, they mitigate risks and create a clear and manageable role for private insurance. To support supplementation or gap-filling, new regulations are needed for the private long-term care insurance market to, at a minimum:

- Standardize and limit the types of policies insurers can offer, as in the Medigap market, in order to facilitate comparison and competition.
- Create an electronic market and provide information and direct assistance to consumers, in order to facilitate comparison-shopping and educated choices.

- Create effective consumer protections to ensure people receive fair value and promised benefits.

Any social insurance program, and all private insurance offered alongside it, require adequate mechanisms to ensure coverage is provided for those who meet qualifying criteria and consumers receive fair value. Therefore,

- All social insurance and private LTSS plans must provide easily accessible, meaningful appeals to those who are denied coverage or other rights afforded by their social or private insurance.

Social insurance does not eliminate personal or family responsibility (witness Medicare and Social Security); it makes shouldering that responsibility manageable and affordable. No matter how generous, social insurance will not cover all service needs or eliminate the importance of personal financial contributions of family care. And no social insurance mechanism is likely to eliminate the need for an adequate public safety net — whether within it or through a continued (albeit much smaller) Medicaid program.

Until such a program is enacted and as part of or alongside it once enacted, we recognize that improvements are needed in current programs.

2. Adopt a National Strategy to Improve and Strengthen the LTSS Workforce

Direct care workers provide most (70 to 80 percent) paid hands-on LTSS and are the fastest growing job classification in the country. These workers hold a variety of job titles including personal care assistants, home care aides, home health aides and certified nurse aides. The paid LTSS workforce has been largely invisible, undervalued, and underpaid. The paid workforce also faces a demographic challenge, a challenge that is magnified by low pay, few, if any benefits, heavy workloads, lack of control over their work and few opportunities for advancement—factors cause high turnover and reduce the quality of care.¹¹

The demand for direct-care workers is projected to expand by 70 percent by 2020.¹² But as the need for direct-care workers increases, the LTSS labor pool is dwindling. The turnover rate for LTSS workers is high – 13 to 18 percent higher than the overall labor workforce and 20 percent higher than other service workers. And, the traditional caregiving workforce, women aged 25-54 is expected to grow only marginally over this period, leaving a wide gap between the future supply and demand for these workers.¹³ The majority of states and employers consider LTSS workforce shortages to be a major priority and most have tried (unsuccessfully) to bridge this growing “care gap.”¹⁴

To address quality and access challenges in LTSS, more attention needs to be paid to the difficulties of recruiting and retaining a well-trained, direct-care workforce. The direct-care worker jobs available in today’s LTSS system often pay poverty wages and offer limited benefits. The median annual earnings for direct-care workers were \$17,000 in 2010. About half (47 percent) of all direct care workers live in poor or low-income households, with income below 200 percent of the federal poverty level and fewer than half have health insurance coverage.¹⁵

Home care wages have been suppressed by the reimbursement policies in public long-term care programs that pay for personal assistance services. For the most part, these rates are not subject to regular updating and are not usually based on cost reporting or tied to market rates.

Furthermore, the proportion of the rate to be directed to direct-care labor costs is rarely if ever specified. As state Medicaid budgets grow tighter, legislatures have been quick to cut personal care programs, leaving the providers of these services constantly vulnerable.

State and federal standards, mostly lacking, also fail to provide adequate training for home care aides and career pathways that would improve job satisfaction and the quality of care by reducing turnover and attracting workers into the labor pool. This lack of training also contributes to the high on-the-job injury rates. Many direct-care workers receive little or no training before starting their jobs. The federal government requires 75 hours of training for certified nurse aides and home health aides, a standard that has not been updated in over 20 years. There are no federal training requirements for personal care attendants, and while states may choose to establish training standards, many don't. Other states establish standards of dubious quality and even these standards are often not enforced.¹⁶

A related problem is the lack of oversight and regulation of home care agencies. Most states do not require licensing and certification of home care agencies.¹⁷ As a result, families are unable to determine whether agencies are adequately screening job candidates, providing reliable training and supervision, and overseeing their staff. Because there is no uniform or mandatory agency reporting, there is currently no mechanism for ensuring adequate wages for home care workers are paid out of agency reimbursements.

An estimated 200,000 new LTSS workers are required each year to meet the future needs of our aging population.¹⁸ However, as the need increases, the LTSS labor pool is dwindling. The workforce crisis is a direct result of the fragmented and insufficiently funded LTSS system, which contributes to a poorly paid, insufficiently trained, undervalued, and inadequately supported LTSS workforce. Moreover, these workforce challenges (which lead to high turnover and job vacancies) result in delays in access to care services, and higher costs in the long run as individuals are forced into institutional settings.

Recommendation # 2

To ensure the high-quality services for individuals and their families in all service settings, the law must assure that direct-care workers are paid a living wage, are well trained, and have opportunities for career advancement.¹⁹

The efficacy and stability of the LTSS system are predicated on the relationship between the consumer and the caregiver, but workforce issues are rarely addressed in discussions of system reform. Even with financing reform, access and quality problems in LTSS will remain without proper attention to the wages, recruitment, and retention of the workforce that delivers these services. Thus, our recommendations are to:

- Establish federal requirements for competency and training standards for personal and home-care aides, and reimburse training costs for all direct care workers, update payment rates to provide for adequate wages across settings,²⁰ and collect comprehensive

workforce data. These requirements would build on efforts to identify core competencies, skills and knowledge to provide high quality, person-centered care. Under certain circumstances, personal and home care workers would be permitted to opt out of the training requirement.

- Set federal guidelines that require all states to license and certify home care agencies. Licensing and certification requirements will include routine monitoring and requirements for agencies to submit detailed cost reports to maintain that certification (including detailed employee and revenue information).
- Establish minimum percentages of service rates directed to direct-care labor costs (wages).
- Create a national program to attract individuals to direct care jobs.
- Require detailed workforce plans for federally funded LTSS programs.
- Create career ladders by promoting effective training, incorporating direct care workers into care teams, and revising scope of practice standards.

3. Adopt a National Strategy to Recognize and Support Families in their Caregiving Role

Families bear the primary responsibility for LTSS. Most people who need long-term services and supports rely exclusively on their families to get them. The large majority (91 percent) of people who received any LTSS received services from family caregivers. Most (66 percent) received all of their care exclusively from family caregivers. Another quarter received some combination of family care and paid help; only 9 percent received paid help alone.²¹ Most often, but not always, those caregivers are women – wives, mothers, daughters, and daughters-in-law – and although many caregivers are family members who willingly choose their caregiving roles, they are also often emotionally, physically and financially burdened by their caregiving responsibilities.

Caregivers provide assistance with the ordinary activities of life, but they are also increasingly care coordinators. Further, many family caregivers provide increasingly complex medical care, often with little or no training. When they seek assistance for themselves and a family member with a disability, caregivers face the challenges of navigating fragmented programs with differing administration, eligibility rules, and needs assessments. Caregivers also often experience financial burdens associated with caregiving, including lost work hours and reductions in earnings from work, poor health, and social isolation.

In 2009, an estimated 42.1 million caregivers provided more than 43 billion hours of unpaid care to an adult (aged 18 and older). The value of unpaid family caregiving is estimated at \$450 billion in 2009, exceeding the annual expenditures on LTSS of the Medicaid program, the primary source of public financing for LTSS.²²

As the population ages and more people need care in the decades ahead, the potential pool of family caregivers is projected to decline. The ratio of people in the most common caregiving age

group (aged 45 to 64) to those most likely to need LTSS (aged 80 and older) is expected to fall to 4 to 1, compared with more than 7 to 1 in 2010. By 2050, the ratio could drop to less than 3 to 1.²³ A variety of factors will shrink the available supply of family caregivers, including rising divorce rates at older ages and declining family size. The working-age adults—often women—who typically provide family caregiving are working longer to secure their own retirements.

To assure that families are able to care for their loved ones today and in the future, family caregivers must be at the center of a comprehensive approach to LTSS reform. Families need real choices for affordable and coordinated services and supports for themselves and their loved ones, and they must be recognized and supported in their caregiving roles so that they can not only care for others but also maintain their own health and wellbeing.

In its 2008 report *Retooling for an Aging America: Building the Health Care Workforce*, the Institute of Medicine called for a new perspective on family caregivers: “The definition of the health care workforce must be expanded to include everyone involved in a patient’s care: health care professionals, direct-care workers, informal caregivers (usually family and friends), and patients themselves. All of these individuals must have the essential data, knowledge, and tools to provide high-quality care.”²⁴

Recommendation # 3

To integrate family caregivers into a comprehensive LTSS system, public programs providing services to LTSS beneficiaries must appropriately engage family caregivers and address their needs. Thus, public programs providing LTSS or health care services to people needing LTSS should include family caregivers in all needs assessment and care planning processes, consistent with person-centered care and the wishes of the individual at the core of the care plan. Further, where the family provides care, the assessment and care plan should include the needs of the family as well as the individual receiving services.

- The unit of service in all health and LTSS settings should be redefined to include both individuals with disabilities and their family caregivers, with the person and the family caregiver (as appropriate) treated as integral parts of interdisciplinary services teams.²⁵
- The assessment and care planning process (including care transitions and coordination) must be person- and family-centered, not only identifying functional disabilities but also focusing on meeting personal goals for living as independently as possible.
- All family caregivers should have access to relevant information, educational resources, referral services, training opportunities, and professional supports.
- When an individual chooses to have family caregivers provide care and the care plan or discharge plan is dependent on them: their needs should be assessed along with the person receiving services; they should be included in health information systems that list all caregivers, their contact information, and their involvement in implementing care plans; and they should receive training (including on medical/nursing tasks), equipment, and support needed to carry out their roles.²⁶

While the nation moves to a comprehensive system for LTSS, and to supplement it as necessary, we recognize that improvements are needed in current programs. Among the improvements suggested by individual Commissioners are the following:

4. Strengthen, Broaden and Improve Medicare’s Post-Acute Care Benefit

Medicare – which provides health benefits for people 65 years old or older and some people with disabilities – regardless of income – does not pay for LTSS.²⁷ Although Medicare pays for some nursing home care, Medicare’s skilled nursing facility (SNF) benefit is available only for those who require and receive daily nursing and/or therapy and not just custodial care. Further, Medicare’s SNF coverage is limited to 100 days per benefit period for those beneficiaries who had a prior three-day inpatient hospital stay. (Recently, access for some patients with prior hospital stays has been eroded as hospitals have increasingly classified some stays as “outpatient observation status” rather than as inpatient admissions.²⁸)

Similarly, Medicare covers home health care, including nursing services, physical, speech and occupational therapies, and home health aide services to eligible beneficiaries. But, to qualify for coverage, beneficiaries must be confined to home (often referred to as “homebound”) and must need part-time or intermittent skilled nursing care or therapy. Home health aide services are covered only for people who also need and receive skilled nursing or therapy. Many people who require LTSS, however, do not have ongoing skilled care needs and thus cannot receive Medicare coverage at all for important, non-skilled home health aides services.

Incremental but significant improvements could be made to Medicare to improve the program’s protections for all beneficiaries, including people who need LTSS.ⁱⁱ

Recommendation #4

To meet the needs of those who qualify for Medicare, the current Medicare program must be adapted to reduce counterproductive, outdated and unreasonable barriers to outpatient therapies, home health and skilled nursing facility care.²⁹

- Remove the 3-day hospital stay requirement for SNF coverage so people without the need for an acute inpatient hospital stay can at least get some Medicare nursing facility coverage.
- Revise the homebound requirement for Medicare home health coverage so that people who cannot obtain the services they need outside the home can obtain them at home.

ⁱⁱ One way not to improve Medicare home health coverage is to impose cost sharing for home health care visits or to an annual coverage cap. Proposals being considered to so limit the Medicare home care benefit would further exacerbate the already limited ability of people to obtain home and community-based services.

- Eliminate hospital “observation status,” or, at a minimum, count all days spent in the hospital as “inpatient” for purposes of qualifying for Medicare coverage for subsequent medically necessary SNF stays.
- Eliminate annual caps on physical, speech and occupational therapy services so people with LTSS needs can receive the therapy services they need in the community throughout the year.
- Ensure that the *Jimmo v. Sebelius* settlement is effectively implemented, to eliminate the “improvement standard” requirement for determining Medicare coverage, and ensuring coverage is available for skilled services to maintain an individual’s condition or slow deterioration.

5. Strengthen and Improve Medicaid

Unlike Medicare, Medicaid provides substantial assistance to people with LTSS needs. But Medicaid is means-tested and requires people to be or become impoverished to qualify for assistance, creating untenable choices for people with disabilities and their families. To be eligible for assistance with the cost of LTSS, people must contribute nearly all of their available income to the cost of care. Beneficiaries must demonstrate that they have very modest countable financial assets, generally less than \$2,000. Resource protections for a community spouse are often inadequate.

Medicaid’s protections also vary from state to state and, in most if not all states, fall short of meeting people’s needs. Eligibility for services varies widely across states in Medicaid, and services vary in availability, scope and quality across states.³⁰ Because of variation in financial eligibility rules, the proportion of low-income persons with disabilities who receive LTSS through Medicaid varies widely across the states.³¹ There is even greater variation in benefit spending. Although in many states, community-based supports are available to poor and low-income people who need assistance to live at home, those programs have long been underfunded. Unlike most other Medicaid benefits, home- and community services, without which eligible individuals would need nursing home or other institutional care, are subject to caps on enrollment and waiting lists are common. The lack of services can lead to unmet needs and human suffering and can force people into institutions.

For people with disabilities who are willing and able to work, Medicaid’s stringent means testing can force people with disabilities to accept dependency in order to remain eligible for financial assistance with the cost of LTSS. To help provide access to affordable LTSS to working people with disabilities, Congress gave states an option to let working individuals with disabilities continue to receive LTSS through the Medicaid program when their income or resources exceed Medicaid’s normal limits through an option known as the Medicaid Buy-In (MBI). Although MBI programs offer opportunities for people with disabilities who work to continue to receive LTSS, the variation in state programs and some design flaws limit the effectiveness of these programs to support working individuals with disabilities. These variations and design flaws forcing people to refuse promotions to remain within income or resource limits, make it difficult,

if not impossible, to relocate for a better position, and make people less likely to work because they may not be able to get back onto regular Medicaid if their work attempt fails.

The gaps and inequities that characterize Medicaid today are likely to grow substantially worse in the decades ahead. The population's aging will increase LTSS needs and the demands on Medicaid. It is uncertain whether any state has the capacity to deal with the needs of an aging population, and especially whether states projected to experience the largest increase will be able to sustain, let alone improve, the adequacy of LTSS.

Improvements can be made to Medicaid to expand access to home and community-based services in Medicaid, to reduce inequities across states through increased federal financing, and to reduce work disincentives for people with disabilities who are able to work.

Recommendation #5

To strengthen Medicaid, existing financial incentives to states for quality home- and community-based services must be extended and streamlined to make it easier to rebalance Medicaid LTSS. In addition, Medicaid's benefits must be improved for people who rely on its services.³²

- Require coverage of home- and community-based services in Medicaid and raise asset standards for community residents and spouses, addressing what is commonly referred to in the disability rights advocacy community as the “institutional bias.”
- Rebalance Medicaid financing to support community living.
- Gradually increase the federal share of Medicaid financing for long-term services and supports, thereby reducing burdens on the states.
- Broaden access to LTSS in the community by expanding the existing infrastructure of one-stop shopping and worker registries for people not eligible for Medicaid; fully fund and implement these programs at a national level.

6. Provide New Ways to Access LTSS for People with Disabilities

The United States has made significant strides in changing the expectations of and attitudes toward people with disabilities. The passage of landmark civil rights legislation in the Americans with Disabilities Act (ADA) in 1990 contributed to this evolution of attitudes and creation of opportunities. Court decisions, such as the Supreme Court decision in the historic *Olmstead* case, have also called for the full integration of individuals with disabilities in society. While many doors have been opened, the lack of access to services and supports that allow people with significant disabilities to live and work independently while achieving even a modest level of economic security has hindered the progress that might otherwise have been made.

People with significant disabilities who require supports and services to work often face a catch-22. Currently, Medicaid is the only option available that provides access to the services and supports needed to get and keep a job. Private long-term care insurance is not an option for a variety of reasons, including denial of coverage, cost-prohibitive premiums if coverage is available, services and supports not available in a work setting, and/or short timeframe of authorized benefits. Self-financing the needed services and supports is out of the question for all but the highest earners. And although many working people have access to private health insurance, and more will gain it as a result of the Affordable Care Act, private health insurance does not cover or only inadequately covers many needed services and supports.

Although Medicaid is often the only option, it is an imperfect solution. Medicaid is intended to provide health care and related long-term services and supports to individuals with limited income (both earned and unearned) and resources. Medicaid work incentives allow working people with disabilities to continue their participation in the Medicaid program while allowing them to increase their earnings up to a set limit (usually 250 percent of the federal poverty level (FPL)) and, in some very limited cases, save for emergency expenses or life goals. These work incentives include, but are not limited to, the Medicaid Buy-In programs and the Social Security work incentives program (the 1619(b) program).³³ However, as Medicaid was designed to provide health care to low-income individuals with no other access to insurance coverage, its structure and eligibility rules make it difficult or impossible for working individuals with significant disabilities to achieve a middle-class lifestyle for themselves and their families.

People with significant disabilities often have extraordinary support needs that make it difficult, if not impossible, to get those needs met outside of public programs. People with disabilities often find themselves in the unenviable position of turning down jobs or promotions to maintain access to these vital services and supports. Upper limits on income and resources for program eligibility are often the drivers of career decisions rather than opportunities. The United States must provide people with disabilities a pathway to access service and supports that allow them to earn to their potential, save for their futures, achieve a middle-class lifestyle, and achieve the vision of the ADA.

Recommendation #6

To provide new ways to access LTSS for persons with disabilities, tax-preferred savings accounts must be provided for people and their families who are not currently receiving LTSS through the Medicaid program, the Medicaid buy-in program for workers with modest earnings must be expanded, and a new program for workers with significant disabilities who have higher earnings must be piloted.³⁴

- Amend Section 529 of the IRS code to address the unique needs of families with individuals with disabilities, particularly those waiting for Medicaid home- and community-based services.
- Create a national Medicaid buy-in program (MBI) for workers significant disabilities whose incomes are below 250 percent of the federal poverty level who are likely to

continue their attachment to Medicaid because their earnings remain low or their work is sporadic or inconsistent.

- Pilot a new program for workers with significant disabilities whose earnings exceed 250 percent of the federal poverty level and who need LTSS and other health care-related coverage to remain employed.

Conclusion

The authors of this report, five members of the Long-Term Care Commission, write on behalf of people with disabilities, older people, their families, and direct care workers. Our goal throughout this process was to offer Congress, the President, and the public a vision of what is truly necessary to meet the needs of people who require long-term services and supports today—and of any of us who may need them in the future. We're all at risk, and we're all responsible for building a comprehensive LTSS system. We sincerely hope our recommendations provide a direction for the action our nation so sorely needs.

Notes

¹ American Taxpayer Relief Act of 2012 (ATRA, P.L. 112-240) §643(a)(1)

² Peter Kemper, Harriet Komisar, and Lisa Alecxih, “Long-Term Care Over and Uncertain Future: What Can Future Retirees Expect?” *Inquiry*, 42, No. 2 (Winter 2005/2006): 335-350. add comment re. PDV

³ H. Stephen Kaye, Charlene Harrington, and Mitchell P. LaPlante, “Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?” *Health Affairs* 29(1) (January 2010): 11-2, cited in: Judy Feder and Harriet Komisar, “The Importance of Federal Financing to the Nation’s Long-Term Safety Net,” (Georgetown University, February 2012), funded by the SCAN Foundation. Available at: http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf

⁴ Lee Thomson, “Long-term Care: Support for Family Caregivers,” Georgetown University, March 2004, <http://ltc.georgetown.edu/pdfs/caregivers.pdf>

⁵ Alexia Campbell, “Hundreds in D.C. Lost Medicaid Assistance Without Cause, Attorneys Say,” *Washington Post*, August 1, 2013, http://wpost.com/local/dc-dropped-hundreds-of-people-from-medicaid-rolls-without-cause-attorneys-say/2013/08/11/63d9ec54-002e-11e3-9711-3708310f6f4d_story_1.html

⁶ Much of this discussion draws on Judith Feder, Harriet L. Komisar and Robert Friedland, “Long-Term Care Financing: Policy Options for the Future,” Georgetown University, June 2007. <http://ltc.georgetown.edu/forum/ltcfinalpaper061107.pdf>

⁷ Peter Kemper, Harriet Komisar, and Lisa Alecxih, “Long-Term Care Over and Uncertain Future: What Can Future Retirees Expect?” *Inquiry*, 42, No. 2 (Winter 2005/2006): 335-350. The \$100,000 out-of-pocket spending estimate is a present discounted value.

⁸ Judith Feder and Harriet Komisar, “The Importance of Federal Financing to the Nation’s Long-Term Safety Net,” (Georgetown University, February 2012) Funded by the SCAN Foundation. Available at: http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf

⁹ Richard G. Frank, Mark Cohen, and Neale Mahoney, “Making Progress: Expanding Risk Protection for Long-Term Services and Supports Through Private Long-Term Care Insurance,” (March 2013) Funded by the Scan Foundation. Available at: http://www.thescanfoundation.org/sites/thescanfoundation.org/files/tsf_ltc-financing_private-options_frank_3-20-13.pdf

¹⁰ For additional detail on these recommendations, see the proposals in the Appendix to this report, including “Reconfiguring LTSS Financing to Share Responsibility and Enhance Protection,” and “Adding a New LTSS Benefit to Medicare and Other Comprehensive Reforms.”

¹¹ PHI (2012). Facts 3: America’s Direct Care Workforce. Available at: <http://phinational.org/sites/phinational.org/files/phi-facts-3.pdf>

¹² PHI (2012). Facts 3: America’s Direct Care Workforce. Available at: <http://phinational.org/sites/phinational.org/files/phi-facts-3.pdf>

¹³ Direct Care Alliance. “Direct Care Worker Principles for Health Care Reform.” http://blog.directcarealliance.org/wp-content/uploads/2009/04/dca_health_care_reform_principles1.pdf

¹⁴ Robyn Stone. “Long Term Care Workforce Shortages: Impact on Families. Policy Brief No. 3” Commissioned for “Who Will Provide Care: Emerging Issues for State Policymakers.” October 2001. http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2001_10_policybrief_3.pdf

¹⁵ PHI (2012). Facts 3: America’s Direct Care Workforce. Available at: <http://phinational.org/sites/phinational.org/files/phi-facts-3.pdf>

¹⁶ Dorie Seavy and Abby Marquand, “Caring in America: A Comprehensive Analysis of the Nation’s Fastest Growing Jobs,” Bronx, NY: PHI, 2011. Available at: <http://phinational.org/sites/phinational.org/files/clearinghouse/caringinamerica-20111212.pdf>

¹⁷ Lindquist LA, Cameron KA, Messerges-Bernstein J, Friesema E, Zickuhr L, Baker DW, Wolf M.

“Hiring and screening practices of agencies supplying paid caregivers to older adults.” *J Am Geriatr Soc.* 2012, 60(7): 1253-9. <http://www.ncbi.nlm.nih.gov/pubmed/22724430>

¹⁸ Genworth. “The Cost of Care. 10th Edition 2004-2013.” <https://www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html>

¹⁹ For additional detail on these recommendations see the proposals in the Appendix to this report, including: “Proposals to Address Workforce Needs and Mechanisms to Continue Work Improving Long-Term Services and Supports.”

²⁰ Instruct MACPAC to conduct a thorough analysis of state HCBS reimbursement policies in order to develop guidance that CMS would direct to states regarding effective payment and procurement methods that generate rates adequate to elicit a sufficient supply of competent direct-care workers. Testimony by Carol Regan, before the Commission for Long-Term Care, PHI, July 17, 2013.

²¹ Lynn Feinberg, Testimony to the Long-Term Care Commission, p, 1.

http://www.ltccommission.senate.gov/Feinberg%20Testimony_Commission%20on%20Long-Term%20Care.pdf

²² Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula, “Valuing the Invaluable, 2011 Update,” <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>, and Lynn Feinberg, Testimony to the Long-Term Care Commission, Populations in Need of LTSS and Service Delivery Issues, July 27, 2013. http://www.ltccommission.senate.gov/Feinberg%20Testimony_Commission%20on%20Long-Term%20Care.pdf

²³ Donald Redfoot, Lynn Feinberg, and Ari Houser, “The Aging of the Babyboom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers,” AARP Public Policy Institute, August 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

²⁴ Institute of Medicine. “Retooling for an aging America: building the health care workforce.” Report Brief. Washington (DC): National Academies Press; 2008, p. 257. Cited in “Bridging Troubled Waters: Family Caregivers, Transitions, and Long-term Care,” Carol Levine, Deborah Halper, Ariella Peist, and David A. Gould, *Health Affairs*, January 2010, vol. 29, no. 1, pp. 116-124. <http://content.healthaffairs.org/content/29/1/116.full>

²⁵ See, for example, Lynn Feinberg, Testimony to the Long-Term Care Commission, p, 1.

http://www.ltccommission.senate.gov/Feinberg%20Testimony_Commission%20on%20Long-Term%20Care.pdf and Susan C. Reinhard, Carol Levine and Sarah Samis, “Home Alone: Family Caregivers Providing Complex Chronic Care” AARP, October 2012.

²⁶ Mechanisms to address this may include assessment or care plan requirements, Medicare conditions of participation, accreditation or certification rules, and a caregiver bill of rights. It is important to identify the best points for intervention and follow-up, and to have a menu of options to provide the necessary training and support, such as in-person training or support groups, online resources, or a help line.

²⁷ Harriet Komisar, “Medicare Does Not Pay for Long-Term Care,” AARP, <http://blog.aarp.org/2013/08/22/medicare-does-not-pay-for-long-term-care/>

²⁸ Zanlian Feng, Brad Wright, and Vince Mor, “Sharp Rise in Medicare Enrollees Being Held In Hospitals for Observation Raises Concerns about Causes and Consequences,” *Health Affairs*, <http://content.healthaffairs.org/content/31/6/1251.abstract>

²⁹ For additional detail on these recommendations, see the proposals in the Appendix to this report, especially: “Adding a New LTSS Benefit to Medicare and Other Comprehensive Reforms.”

³⁰ Susan C. Reinhard, Enid Kassner, Ari Houser, and Robert Mollica, “Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers.” AARP Public Policy Institute (Washington, DC: AARP, September 2011).

³¹ Judy Feder and Harriet Komisar, “The Importance of Federal Financing to the Nation’s Long-Term Care Safety Net,” (Georgetown University, February 2012) Funded by the SCAN Foundation. Available at:

http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf

³² For additional detail on these recommendations, see the proposals in the Appendix to this report, including “Reconfiguring LTSS Financing to Share Responsibility and Enhance Protection,” and “Proposals to Bolster Access to LTSS for Working Americans with Disabilities, Families of People with Disabilities, and Current Beneficiaries.”

³³ Medicaid Buy In (MBI) programs allow people to work and save and maintain access to Medicaid while paying co-pays based on income. Most states have MBI programs but income and resource limits vary significantly. 1619(b) programs allow people with disabilities to maintain Medicaid coverage while working, but do not raise resource limits. Every state participates in the 1619(b) program, but income limits vary significantly across states.

³⁴ For additional detail on these recommendations, see the proposals in the Appendix to this report: “Proposals to Bolster Access to LTSS for Working Americans with Disabilities, Families of People with Disabilities, and Current Beneficiaries.”

REPORT APPENDIX

A COMPREHENSIVE APPROACH TO LONG-TERM SERVICES AND SUPPORTS

Long-Term Care Commission

September 23, 2013

Commissioners

Laphonza Butler, Vice President of SEIU, and President of SEIU-United Long Term Care Workers
Henry Claypool, Executive Vice President, American Association for People with Disabilities
Judith Feder, Urban Institute Fellow and Professor, Georgetown Public Policy Institute
Lynnae Ruttledge, Co-Vice Chair, National Council on Disability
Judith Stein, Executive Director, Center for Medicare Advocacy, Inc.

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Reconfiguring LTSS Financing to Share Responsibility and Enhance Protection

Long-Term Care Commission Recommendations of Commissioner Judy Feder

Goal: To build a financing framework that a) provides meaningful protection against the risk of costly long-term care; b) is, to the extent possible, pre-funded by future users; and c) includes significant personal responsibility, an effective insurance market, and a strong safety net.

Premises:

- The need for expensive, extensive long-term services and supports (LTSS) is an unpredictable, catastrophic risk that, like similar risks, can be most efficiently, effectively met through insurance.
- Private insurers faces enormous difficulties in addressing this risk and, even with supportive public policy interventions and possible expansions (short of required purchase), can reach only a modest share of the population.
- A limited public insurance program can establish a financing framework that encourages the purchase of private insurance.
- Given responsible limits to public as well as private insurance, a public safety net will always be essential to assure access to adequate care for people with inadequate resources.

Proposal:

- A. Establish a basic public LTSS benefit available to people assessed as meeting a specified threshold of functional impairment after a waiting period of up to x years.** The length of the waiting period (shorter for people with lower incomes and becoming longer at higher incomes) would be established based on income at or near retirement age (based on data regularly reported for Social Security), averaged over a number of years. For younger people who become impaired, the formula relating waiting periods to income would be appropriately adjusted (shortened) to reflect the lesser accumulation of resources at younger ages. Benefits would be specified as a dollar-amount per day, vary with level of impairment and be applicable to the full range of LTSS services. Individuals could opt for a service rather than a cash benefit. With this type of benefit, people would know throughout their working years the risk or “hole” they should plan to fill (or the protection they might want to supplement) from personal resources or private insurance, should they become impaired.

The benefit could be financed through a combination of Medicaid savings (federal only or federal and state) and a surcharge on the income tax (higher for people currently near or at retirement age).

Costs and associated financing requirements would depend on whether the new benefit is made available only to people who turn age 65 or become disabled in the future or is made current elderly and disabled people. If the benefit is to be made available to everyone, it is necessary to find an alternative to the proposed waiting period, since private insurance to fill it may be unavailable or prohibitively expensive and people may lack the means to otherwise

protect themselves. A broadly inclusive benefit would therefore replace the waiting period with an income/asset-related deductible for younger people with disabilities and people aged 75 and older.

B. To supplement public coverage, create an effective private insurance market (for background and rationale see Richard Frank, Mark Cohen and Neale Mahoney http://www.thescanfoundation.org/sites/thescanfoundation.org/files/tsf_ltc-financing_private-options_frank_3-20-13.pdf)

- 1) Standardize and limit the types of policies insurers can offer, as in the Medigap market, in order to facilitate comparison and competition.
- 2) Create an electronic market and provide information and direct assistance to consumers, in order to facilitate comparison shopping and educated choices.
- 3) Require that alongside current level premium products, insurers offer people under age 65 products that index premiums and benefits in time blocks and apply “term pricing” (i.e., charge an annual premium covering the expected claim costs for a specified “term,” say of 1-5 years, rather than for a lifetime—in order to engage younger people in the purchase of long-term care insurance, provide them lower premiums reflect their own disability risks.
- 4) Established reinsurance arrangements, financed by private insurers, that establish parameters for risk management and mitigate risks to individual companies

C. To address current LTSS inadequacies and inequities across states as well as the unequal burdens of aging, strengthen the Medicaid safety net with enhanced federal financing (for background and rationale see Judy Feder and Harriet Komisar, http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf)

- 1) Gradually increase federal financing for Medicaid long-term care benefits from existing match percentages to 100 percent.
- 2) Define a nationally-uniform benefit (including a mandatory benefit for home and community based care and an increase in the personal needs allowance), to vary with an individual’s level of impairment, as determined by a standardized assessment process. Provide federal match at current rates to states choosing to supplement the federal benefit.
- 3) Set federal payment rates to providers, adjusted for geographic variation in input costs.
- 4) Finance the new benefit in part with state contributions (as in Medicare Part D)—set initially to reflect their current long-term care spending (up to a maximum) and indexed to reflect inflation and economic growth ; the index would hold states “harmless” for increased demand associated with the aging of the population.

Moving forward:

Although this proposal is presented in the order it is to facilitate understanding of its intent and architecture, the timing its implementation (and likely its legislation), should start with section C.

- The highest priority should go to preservation and enhancement of the safety net for people who are most disadvantaged, which is currently at risk.
- Adoption of a long-term strategy for long-term care financing will be a long-term struggle, to which we should not hold this population hostage.



Add a New LTSS Benefit to Medicare and Other Comprehensive Reforms

Long-Term Care Commission Recommendations of Commissioner Judith Stein

Overriding Goal: To provide necessary, quality long-term services and supports for older people and people with disabilities in the least restrictive setting.

Recommendations:

- 1. Make the most of Medicare – the one national program we have now by removing current barriers to Medicare coverage for people with long-term and chronic conditions:**
 - a. Redefine the homebound requirement for Medicare home health coverage so that people who can not obtain the services they need outside the home can obtain them at home.
 - i. Currently the homebound definition restricts some people from getting care at home although they cannot consistently leave home to obtain the services they need.
 - ii. Do NOT add a cap or co-insurance to the Medicare home health benefit
 1. Proposals are being considered to limit home care, which would further exacerbate the already limited ability of people to obtain home and community-based services.
 2. The savings estimate, at \$730 million / ten years for the co-pay, does not warrant this further limitation on home care.
 - b. Remove the 3-day hospital stay requirement for skilled nursing facility (SNF) coverage so people without the need for an acute inpatient hospital stay can at least get some Medicare nursing facility coverage.
 - i. Absent removing the 3-day requirement, eliminate hospital “observation status,” or count all days spent in the hospital as “inpatient” for purposes of qualifying for subsequent SNF stays.
 - c. Eliminate the 24-month Medicare eligibility waiting period for people who qualify for Social Security Disability Insurance (SSDI).
 - d. Ensure the *Jimmo v. Sebelius* settlement is effectively implemented, to eliminate the “improvement standard” requirement for determining Medicare coverage, and ensuring coverage is also available for skilled services to maintain an individual’s condition or slow deterioration.

2. **Add a new Long Term Services and Support (LTSS) benefit to Medicare.** The LTSS benefit would be triggered when an individual is certified to be dependent in two or more activities of daily living and/or has cognitive or mental health issues such that independence is contraindicated. In such cases the individual would be eligible for:
 - a. Skilled nursing facility coverage for up to 150 days per calendar year;
 - i. Without the need for a 3-day hospital stay;¹
 - ii. Without the need for daily skilled care (custodial care alone would be covered).
 - b. Home health coverage, including coverage for home health aide services, without the need for a skilled service;
 - c. Personal Care Attendant;
 - d. Care management and coordination;
 - e. Adult Day Center;
 - f. Respite care to support family or other volunteer caregiver;
 - g. Outpatient therapy without an annual cap;
 - h. Other reasonable and necessary services.

Note: The CLASS Act experience demonstrates that any such LTSS benefit must be mandatory in order to be financially viable.

- a. Various options are possible, but a new Medicare LTSS benefit should not add to the complexity of Medicare and should not diminish the stability of the current program.
 - b. Consider adding the LTSS benefit to Medicare Part A, with a defined % increase to current Part A payroll tax to pay for it. This additional may even strengthen Medicare Part A, which is mandatory for those with Medicare.
3. **Provide quality long term services and supports for older people and people with disabilities in all settings.**
 - a. Develop publically defined standards of care, throughout all long term care settings, that are enforced through a public regulatory structure. (In addition to market-based quality measures).
 - b. Develop enforceable quality measures through an objective regulatory system.
 - c. Ensure sufficient numbers of properly trained staff are present at all times in institutional settings
 - i. There is a high cost of poor care – improving the quality of care provided will improve health outcomes and overall savings when avoidable conditions and injuries are prevented
4. **Ensure adequate numbers of quality LTSS caregivers are available and retained for community-based and facility care.**
 - a. Pay living wages to caregivers in all settings
 - b. Establish a national Caregivers Work Force Advisory Panel to develop innovative and effective means of recruiting and maintaining a quality direct care workforce

¹ The Medicare Catastrophic Coverage Act (MCCA) provided 150 days of SNF coverage per calendar year with no prior hospital stay from 1989 until 1991, when the law was largely repealed.

- c. Establish minimum federal training standards for personal care aides based on current state efforts
- 5. Rebalance Medicaid so that institutional bias is removed, and people who qualify for Medicaid can obtain necessary LTSS in the least restrictive setting that meets their needs.**
- 6. Protect consumers from inappropriate denials of coverage from any public or private LTSS financing system.**
 - a. Develop enforceable national consumer protections for all private long-term care insurance models.
 - b. Provide consumer-friendly, meaningful appeals in all public and private financing systems.

Proposals to Address LTSS Workforce Needs and Mechanisms to Continue Work Improving Long Term Services and Supports

Long-Term Care Commission Recommendations of Commissioner Laphonza Butler

Proposal #1

Adopt National Strategies to Improve and Strengthen the LTSS Workforce

Few dispute the aging of the population, the so-called “silver tsunami,” will generate increased need for long term care services and supports (LTSS) system capacity. In fact, the U.S. will need to recruit 200,000 new LTSS workers each year to meet future demand among our aging population.² However, as the need increases, the LTSS labor pool is dwindling. The turnover rate for LTSS workers in the U.S. is disproportionately high – 13 to 18 percent higher than the overall labor workforce and 20 percent higher than other service workers. The majority of states and employers consider LTSS workforce shortages to be a major priority and most have tried unsuccessfully to bridge this “care gap.”³

The workforce crisis is a direct result of the fragmented and insufficiently funded LTSS system, which contributes to a poorly paid, insufficiently trained, undervalued, and inadequately supported LTSS workforce. Conversely, the efficacy and stability of the LTSS system is predicated on the relationship between the consumer and the caregiver; the workforce is critical to LTSS but often receives little focus when talking about reforming the system. Indeed, turnover and vacancies result in delays in access to care services, and higher costs in the long run as individuals are forced into institutional settings. LTSS system reform will fail without proper attention to the recruitment and retention of the very workforce that delivers these services. In terms of interventions that address these issues, the Commissioner Butler offers the following recommendations that should be undertaken at the Federal level:

- All federally funded LTSS programs should be required to have a detailed plan for workforce recruitment, retention and development as a requirement to continue to receive public funds. Federal agencies should be directed to fund programs that improve working conditions and build career ladders. This includes directing CMS to fund and collect best practices on expanded home care worker role pilots, and to evaluate and expand Value-Based Purchasing Demonstrations that reward nursing home staffing.
- HHS should undertake a number of initiatives to ensure a more stable direct care workforce.

² Genworth. “The Cost of Care. 10th Edition 2004-2013.” <https://www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html>

³ Robyn Stone. “Long Term Care Workforce Shortages: Impact on Families. Policy Brief No. 3” Commissioned for “Who Will Provide Care: Emerging Issues for State Policymakers.” October 2001. http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2001_10_policybrief_3.pdf

- Institute systematic methods for, setting, rebasing, or updating payment rates for Medicaid home and community-based services create greater parity of wages and benefits across long term care settings.
 - Continue the development of national training standards for home care workers not covered by current federal requirements, and have this serve as the minimum standard for training.⁴
 - Align government payment policies to create parity for reimbursing training costs across all direct-care occupations and provider types.
 - Require states to collect workforce data including data on wages, benefits, hours, job vacancies and turnover rates.
- HHS should create uniform Federal guidelines that require states to license and certify all home care agencies. Licensure and certification should include routine monitoring of agency compliance with all regulations and requirements for agencies to submit detailed cost reports to maintain their certification. Cost reports should include detailed employee, wage and revenue information.
 - Creation of a National Program to Attract Individuals to Direct Care Jobs

The Corporation for National and Community Service should develop a program called Direct Care Corp, modeled on its SeniorCorp Companion program, to provide direct care services to individuals in need of LTSS. SeniorCorp currently runs a companion program that matches senior companions for 15 to 40 hours per week with two to four adult clients that live independently in their own homes.⁵ Under the Direct Care Corp model, individuals of all ages who enroll to become direct care workers would receive pre-service orientation, free training and certification, health insurance, and an hourly wage. As an incentive to participate in the program, if individuals agree to serve for a specified amount of time (2-4 years) in that direct care position they would be eligible for a Health Professions Opportunity Grant (HPOG)⁶ to receive fully subsidized training for the health care profession of their choice. HPOG provides education and training to TANF recipients and other low-income individuals for occupations in the health care field that pay well and are expected to either experience labor shortages or be in high demand. HPOG Funds may be used for participant supportive services, including financial aid, child care, and case management.

⁴ These initiatives include the Personal and Home Care Aide State Training grants, US Department of Labor Registered Apprenticeship models, the Center for Medicare and Medicaid Services' Direct Service Workforce "Core Competency Road Map" and existing state and local training models including Labor Management Training programs.

⁵ <http://www.nationalservice.gov/programs/senior-corps/senior-companions>

⁶ HPOG is authorized by Social Security Act, Title XX , Section 2008, Public Law 111-148, 42 U.S.C 1397 and administered b the Administration for Children and Families..
http://www.acf.hhs.gov/sites/default/files/opre/opre_report.pdf

Proposal #2

Encourage State-Based Innovation in LTSS to Help Build to a Federal Solution

States have an important role to play as laboratories of democracy in creating LTSS solutions and programs that move beyond the public safety net of Medicaid or public subsidies for private insurance products. States already administer much of the LTSS in this country through Medicaid. Those with advanced systems are in a position to innovate and build off of existing strengths, and those innovations can then serve as models for future federal solutions.

To this end, HHS should encourage state and local experimentation in LTSS, and set aside grant funding for state and local agencies to develop and implement LTSS innovations, perhaps through the CMS Innovation Center,⁷ that will ultimately remove some of the financial strain off of the Medicaid system. States could open up registries and infrastructure on a FFS basis to connect workers and those in need, advise on the array community based options through case management and the AAA's and ADRC's to expanded populations, and develop state-based funding and delivery models outside of Medicaid in order to provide an affordable and accountable means of access to services especially for the middle and lower income populations, similar to what has been proposed and is currently being explored in Hawaii.⁸

Proposal #3

Continue the Conversation around Building a Better LTSS System at the Federal Level

This Commission was severely limited by the timeframe and resources allotted to it by Congress. While there is broad consensus among the Commissioners that LTSS in this country as it currently operates is not sufficient for current or future needs in this country, it was beyond the realistic scope of that body to propose a meaningful and comprehensive solution within the Commission's existing framework. Perhaps one of the most meaningful recommendations we can make is to propose a means for this work to continue in a meaningful and ongoing manner now that the Commission has concluded. Congress should create a bi-partisan LTSS reform task force, with appointed members from the Senate, House of Representatives, and the Secretary of Health and Human Services. The task force's charge should be similar to that of this Commission, and should use the Commission's work as a jumping off point for its own.

⁷ The Innovation Center was established by section 1115A of the Social Security Act (as added by section 3021 of the Affordable Care Act). Congress created the Innovation Center for the purpose of testing "innovative payment and service delivery models to reduce program expenditures ... while preserving or enhancing the quality of care" for those individuals who receive Medicare, Medicaid, or Children's Health Insurance Program (CHIP) benefits.

⁸ See Hawaii LTC Commission Final Report. Available at:
<http://www.publicpolicycenter.hawaii.edu/documents/HawaiiLTCCFinalReport.pdf>

Ultimately the Task Force will draft a full report, make recommendations, and propose legislation to be voted on by Congress. Additionally, the Office of Disability, Aging and Long-Term Care at the Office of the Assistant Secretary for Planning and Evaluation (ASPE),⁹ should be charged with researching best practices and innovations at the state and local levels in LTSS around workforce, housing, access to services, LTSS education and public awareness, family caregiver support, and service delivery models to both inform the work of the Task force, and develop policy recommendations that can be pursued within HHS.

Additionally, legislation should be passed authorizing the White House Conference on Aging in 2015. The conference should have a focus on long-term services and supports. Decennial White House Conferences on Aging are now embedded in our national history. Past White House Conferences on Aging, first held in 1961 and again in 1971, 1981, 1995, and 2005 have been catalysts for aging policies and significant national programs such as Medicare, Medicaid and the Older Americans Act. The conference has traditionally been a source of innovative solutions, and an opportunity delegates across the country, political backgrounds and professional experiences, and would be extremely valuable in the further development of policy work on long-term services and supports. The scope of the conference should also be expanded to include people with disabilities, and the National Disability Council should be directly involved in the development and coordination of the Conference.

⁹ <http://aspe.hhs.gov/> “The Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the U.S. Department of Health and Human Services on policy development, and is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis.”

Proposals to Bolster Access to LTSS for Working Americans with Disabilities, Families of People with Disabilities and Current Beneficiaries

Long-Term Care Commission Recommendations of Commissioner Henry Claypool

Proposal One

Pilot a program for workers with significant disabilities whose earnings exceed 250% FPL and need LTSS to remain employed without support from the Social Security income assistance programs

U.S. Disability Support Systems Fail People with Disabilities

The United States has made significant strides in changing the expectations of and attitudes toward people with disabilities. The passage of landmark civil rights legislation in the Americans with Disabilities Act (ADA) in 1990 contributed to this evolution of attitudes and creation of opportunities. Court decisions, such as the Supreme Court decision in the historic Olmstead case, have also called for the full integration of individuals with disabilities in society. And while many doors have been opened, the lack of pathways to access needed services and supports that allow people with significant disabilities to live and work independently while achieving even a modest level of economic security has hindered the progress that might otherwise have been made.

Individuals with Disabilities Face Unique Challenges

People with significant disabilities who require supports and services to work often face a catch-22. Currently, Medicaid is the only option available that provides access to the services and supports needed to get and keep a job. Private long-term care insurance is not an option for a variety of reasons, including; denial of coverage outright, cost-prohibitive premiums if able to get coverage, services and supports not available in a work setting, and/or short timeframe of authorized benefits. Self-financing the services and supports is out of the question for all but the highest earners and makes people with disabilities less economically competitive than their non-disabled peers. And although many working people have access to private health insurance, and more will gain it through the Affordable Care Act, private health insurance does not cover at all or inadequately covers many needed services and supports.

Medicaid, While Vital, Doesn't Work for Many Working People with Disabilities

Although Medicaid is the only game in town, it is also an imperfect solution. Medicaid is intended to provide health care and related long-term services and supports to individuals with limited income (both earned and unearned) and resources. Medicaid work incentives allow working people with disabilities to continue their participation in the Medicaid program while allowing them to increase their earnings up to a set limit (usually 250% of FPL) and, in some very limited cases, save for emergency expenses or life goals. These work incentives include,

but not limited to, the Medicaid Buy-In programs and the 1619(b) program¹⁰. However, as Medicaid was designed to provide health care to low income individuals with no other access to insurance coverage, its structure and eligibility rules make it difficult to impossible for working individuals with significant disabilities to achieve the things associated with a middle class lifestyle for a number of reasons.

- Upper limits on income and resources for program eligibility are often the drivers of career decisions rather than opportunities.
- Variations in state Medicaid programs (e.g. income and resource limits for MBI participation, income limits for eligibility, types of waivers and whether slots are available, and the package of services and supports available) make relocating for a better opportunity difficult, if not impossible.
- SSI/Medicaid's resource limits (e.g. a person can have no more than \$2000 in assets for an individual or \$3000 for a couple to be Medicaid eligible) are often problematic making it impossible for people with disabilities who work to save for emergencies and retirement, let alone save to purchase a home or start a business.
- People with significant disabilities often have extraordinary support needs that make it difficult, if not impossible, to get those needs met outside of public programs.

People with disabilities often find themselves in the unenviable position of turning down jobs or promotions to maintain access to these vital services and supports. The US must provide people with disabilities a pathway to access service and supports that allows them to earn to their potential, save for their futures, achieve a middleclass life style, and achieve the vision of the ADA.

Proposed Solution

A pilot program that provides access to the services and supports needed by employed individuals with significant disabilities (meet SSA definition of disability absent the inability to work assessment) combined with a waiver of rules that prevent people with disabilities to earn income and accumulate assets without jeopardizing access to services and supports. This program is designed to wrap-around health insurance products (offered by employer or through the state Marketplaces) and modeled on the 1619(b) program, specific program design elements include:

- Eligibility: To be eligible to receive wrap-around services and supports through this program, a person would have to be a working individual with a disability defined as:
 - Meeting or equaling the Social Security disability listings or qualify for quick disability determination/compassionate allowances for eligibility for the Social Security disability programs
 - Be working, defined as earnings at or above 250% FPL

¹⁰ MBI programs allow people to work and save and maintain access to Medicaid while paying co-pays based on income. Most states have MBI programs but income and resource limits vary significantly. 1619(b) programs allow people to maintain Medicaid access while working but do not change resource limits. Every state participates in 1619(b) but income limits vary significantly.

- Pay applicable cost sharing based on income, employment –related disability expenses, as well as level of services needed.
- Wrap around Package: The program would offer access to services and supports that people with disabilities need to become and stay employed, fill coverage gaps that between what is offered by health care insurance products and the unique health care needs of individuals with significant disabilities. Services and support package available through the program would include: personal attendant care, assistive technology, durable medical equipment and other services and supports.

Proposal Two

Options for Helping Americans Meet Their LTSS Needs

Provide enhanced options counseling to help individuals better navigate LTSS in a “One-Stop-Shop/No Wrong Door (NWD)” way to avoid unnecessary institutionalization, promoting access to home and community-based services (HCBS) and prevent Medicaid spend-down. This should be modeled after the “Enhanced Aging and Disability Resource Centers (ADRCs) Options Counseling Program” initiative released by HHS in 2012. States should be able to access enhanced administrative Medicaid match to build this necessary infrastructure.

Nearly 10 million Americans of all ages need some form of long-term services and supports (LTSS), and about 70% of the people now turning 65 will need LTSS at some point during their life. Yet, when consumers experience a need for LTSS – or want to plan ahead for their LTSS - they are often confronted with a complex and bewildering maze of public and private programs administered by a wide variety of agencies and organizations operating under different, sometimes conflicting, sometimes duplicative, rules, regulations and administrative procedures. Compounding this situation, people often confront the need for long-term support amidst a crisis, such as an unexpected injury, a hospital admission, or the collapse of a fragile unpaid caregiver support network. Under these circumstances, individuals and their families have little time to explore the many options that might be available, which may result in the unnecessary use of nursing facility and other expensive forms of LTSS. The fragmentation in our LTSS makes it difficult not only for our citizens to make informed decisions, but it also makes it challenging to ensure that our public expenditures on LTSS are deployed in the most cost-effective manner possible.

States develop Aging and Disability Resource Centers (ADRCs) programs – also known as One-Stop-Shop/No Wrong Door programs – to make it easier for consumers to learn about and access their LTSS options. The ADRCs program was based on best practices some states had developed to create “visible and trusted” sources of information, one-on-one counseling, and streamlined access to available LTSS options.

The importance of having an access program serve people of all income levels, not just those who qualify for Medicaid, since the vast majority of people who need LTSS are not Medicaid eligible but can be at high-risk of “spending down” to Medicaid.

Proposal Three

Create a national Medicaid buy-in (MBI) program for workers with significant disabilities up to 250% of FPL.

Medicaid is the only affordable option to access long-term services and supports for millions of people with significant disabilities. Standard health insurance policies do not offer coverage for the long-term services and supports (LTSS) required for individuals with disabilities to live in the community. And, although private long-term care insurance coverage does exist, it is not a realistic option for working age individuals with disabilities. To help provide access to affordable LTSS to working people with disabilities, Congress gave states an option to let working individuals with disabilities continue to receive LTSS through the Medicaid program when their income or resources exceed Medicaid’s normal limits through an option known as the Medicaid Buy In, or MBI, programs. States can implement MBI programs under two different authorities: the Balanced Budget Act of 1997 or the Ticket to Work & Work Incentives Improvement Act of 1999. Forty-six states currently have MBI programs and more than 200,000 workers with disabilities are currently working and receiving needed LTSS as result of this option. The different authorities impose different requirements states must follow in creating MBI programs:

	<i>Balanced Budget Act</i>	<i>Ticket to Work</i>
Age limits	None	16-64
Income Limits	Up to 250% of FPL	None
Resource Limits	Up to state	Up to state
Premiums	Based on sliding scale – no upper limit	Premiums and cost sharing based on income
Definition of work	States cannot define work	States cannot define work
Grace period for unemployment	Limited	Not allowed

Although MBI programs offer opportunities for people with disabilities who work to continue to receive LTSS, the variation in state programs and some design flaws limit the effectiveness of these programs to support working individuals with disabilities – forcing people to not take promotions to remain within income or resource limits, making it difficult, if not impossible to relocate for a better position, and making people less likely to work because of not being able to get back onto regular Medicaid if their work attempt fails.

The program would have no upper age limit, with a standard definition of work, grace periods for unemployment that recognizes the episodic nature of many disabilities, allows people to save for current and future needs and retirement, and disregards resources accumulated during MBI participation for access to Medicaid if a person can no longer work. Here are some specifics:

- Income limits vary from a low of 80% of FPL to unlimited income
- Resource limits vary from a low of regular Medicaid limits (\$2000 for an individual) up to unlimited resources
- No grace period for participation
- No pathway back to regular Medicaid if a person accumulated resources while participating in MBI
- Uncertainty regarding eligibility for Medicaid at age 65

Proposal Four

Amend Section 529 of the IRS code to allow for a tax-advantaged savings account to address the unique needs of families with individuals with disabilities, particularly those waiting for Medicaid home- and community-based services.

Across the country, an estimated 400,000 individuals are on waiting lists to receive long-term services and supports (LTSS); many of whom are children who will require these supports over their lifetime.¹¹ A tax-advantaged savings account will allow families of these children an opportunity to save for their needs. Currently, families are providing the bulk of their LTSS needs that in many cases comes at a significant cost to their ability to maintain and improve their economic circumstances, especially for the middle class.¹² AARP estimates that the economic impact of family caregiving for members with significant disabilities at \$350 to \$450 million per year. An account would encourage work, savings, and asset development for families and individuals with disabilities that reduces dependence on scarce public benefits.

A tax-advantaged savings account would allow funds to be withdrawn to cover qualified disability expenses such as healthcare, employment support, housing, transportation, assistive technology and education. These accounts would amend and follow the existing Section 529 of the Internal Revenue Code for Qualified Tuition Programs so that they would be consistent with all the requirements and regulations of a traditional 529 qualified tuition program: they are easy to open and available in any state, and families can make the same annual contributions and

¹¹ Of 3.5 million families with a member with a severe and chronic disability expected to last a lifetime, only 13% are supported by the states' public agency services (Braddock, Presentation to AIDD, February, 2013)

¹² In a national survey conducted by the Arc of the United States, 82% of families reported that their overall economic security is challenged. 73% reported not having adequate savings for retirement, which puts aging parents in particularly vulnerable situations. (*Still in the Shadows with Their Futures Uncertain*, Arc of the US, June 2011). According to Braddock (2013, above) there are 853,000 persons with developmental disabilities/intellectual disabilities (DD/ID) living at home with caregivers over the age of 65 years.

enjoy the same tax-free treatment as under 529 accounts.¹³ In this respect, Section 529 accounts mirror a familiar and popular financial mechanism for many families.

Proposal Five

To strengthen Medicaid, existing financial incentives to states for quality home- and community-based services must be extended and streamlined to make it easier to rebalance Medicaid LTSS. In addition, Medicaid's benefits must be improved for people who rely on its services.

The goal of this proposal is to structure a new long term services and support authority that brings together the best features of some of the 1915 series of waiver and state plan options into a single state plan authority that incentivizes HCBS services; sets a high priority for person-centered and participant-directed services; allows HCBS eligibility to be uncoupled from the institutional level of care; and streamlines the application, administration and reporting requirements for the states. Additionally we propose to include some of the ACA options and incentives that have been made available to encourage states to expand home and community based services, and reduce reliance on institutional settings.

The vast majority of Medicaid beneficiaries of any age that require LTSS prefer to receive those services in their own home or in a community based setting instead of living in an institution. And serving Medicaid beneficiaries that meet a state's level of care for institutional services in community based settings has been proven to be a cost-effective way providing LTSS.

As we approach 2014, many states are fully engaged in studying, designing and implementing strategies to provide health care coverage to low income populations through a Medicaid expansion or other means. Additionally, many state Medicaid agencies are actively developing new aspects of their programs that will better integrate health care services for various populations that rely on both Medicare and Medicaid for basic health care coverage.

Although primarily focused on health reform and expansion, the ACA also enhanced and created new opportunities for states to provide home and community based services (HCBS) to beneficiaries that need these services through several new or modified Medicaid waiver and state plan options.

As a whole, the United States still over-relies on the institutional side of LTSS. Although there has been a growth from 2.1 to 3.2 million HCBS users since 2000, states still spend only 36.8% of their LTSS budgets for aging and physical disability populations on HCBS. The range varies widely with the highest performing state spending 62% on HCBS and the lowest 10%. Only 7 states spend more than 50% on HCBS (AARP 2011 Scorecard). Nursing home utilization also varies widely across the states, with only 84 persons per 100,000 of state population occupying NF beds in the lowest state to 838 in the highest.

¹³ Income earned grows tax- free, withdrawals for qualified disability expenses are tax-free; there are rollover provisions to traditional 529 accounts, and the same reporting requirements apply as to a traditional 529.

On the Developmental Disability side only Mississippi spends less than 50% on HCBS. But of 4.9 million persons with developmental disabilities nationwide, 4.1 million live with their families, of which it is estimated that 25% of the caregivers or parents are over age 60. And many persons with developmental disabilities languish on long waiting lists (Two-thirds of 511,174 individuals that 38 states report on HCBS waiting lists (from the Kaiser 2012 data update).

Currently many state Medicaid programs are consumed exploring ways to expand health care to low income populations or to more efficiently served already covered populations. The capacity of these agencies to simultaneously overhaul and maximize the efficiency of their LTSS systems is under considerable strain. Partly for this reason many states are looking to managed care organizations to administer their Medicaid LTSS systems.

This paper outlines a few of the steps that would reduce the fragmentation and administrative burden across Medicaid, making it easier for states to provide community based services.

Background

Title XIX of the Social Security Act has many provisions aimed at reducing the institutional bias of the Medicaid program by allowing states to provide services to individuals in their homes and communities. Though Section 1915(c), enacted through the Omnibus Budget and Reconciliation Act of 1981, remains the most widely used tool to deliver home and community based services (HCBS), there have been a myriad of other provisions added to the statute since that time, some temporary, some defunct, and some in use today that have sought to level the playing field so that individuals may access HCBS as readily as they can access institutional services. In more recent history, with the Deficit Reduction Act of 2005 and with the 2010 passage of the Affordable Care Act, additional options for HCBS were added and expanded, providing additional opportunities for states to design HCBS systems of care. In addition to the provisions specific to HCBS, there have been a number of tools enacted to enable better integration of physical, behavioral and long term services and supports.

Sections 1915(d), 1915(e), 1915(i), 1915(j), 1915(k), 1915(k), 1929, 1930 have all been attempts to further equalize the playing field or tip the balance of Medicaid to enable more streamlined and widespread use of HCBS. In addition to these provisions of law, there have been many grant programs similarly aimed at bolstering HCBS availability.

Importantly, the recently enacted options have emphasized the ability of consumers to exert maximum choice and control over the HCBS services they receive. Below is a brief discussion of provisions and incentives that have been added in recent years from which a consolidated benefit should emerge, aligning person-centered principles, incentives, quality and administrative functions in order to promote broader HCBS accessibility and consistency.

Money Follows the Person (MFP), enacted through the DRA of 2005 and expanded and amended through the ACA, allows states to draw down enhanced FFP for HCBS services for a full 365 days after a person is relocated from an institutional setting where the person has resided

for more than 90 days. MFP funds can also be used for start-up costs like utilities, first and last month rent, furnishings, and minor housing modifications. In the Affordable Care Act (ACA), Congress shortened the time period the MFP eligible person had to reside in the institution from 180 to 90 days. However only 30,000 persons have moved to community settings in the 6 years since the program's inception, and the shortened time period has had no noticeable effect since most individuals are at risk of losing many of their housing and natural supports prior to the 90 day minimum. Developing new and affordable housing options has proven to be the single biggest barrier to expanding the numbers of people served. Furthermore, this Medicaid option sunsets in 2016, although unspent funds can be carried over until 2020.

The ACA created the Balancing Incentive Program (BIP). Participating states with HCBS expenditures under 25% of total LTSS spending are eligible for 5% enhanced federal match over 4 years and states between 25 and 50% are eligible for a 2% enhanced match. Participating states must make systemic changes including designing a No Wrong Door for entry into LTSS, designing a core standardized assessment tool (or a core data set), and assuring conflict-free case management. States are expected to meet the 25% or 50% HCBS spending targets by the end of the fourth year. Unfortunately with the inclusion of Developmental Disability Services in the calculation of all LTSS expenditures (many states had exceeded the 50% HCBS spending mark in their DD programs already in the 90s) that left only Mississippi eligible for the 5% enhanced match. Without DD expenditures included, about 15 states could have benefited by the elevated 5% match. Currently 13 states are participating in the BIP. The BIP sunsets in 2015. And perhaps its biggest drawback was stopping at 50%. As demonstrated by nearly all the states in Developmental Disability Services, and to a much lesser extent in Aging and Physical Disability Services, the 50% target should just be a measurement in time against a much broader goal of pointing most LTSS expenditures toward home and community based services. States above 50% should equally be incentivized and rewarded for continuing to build out their HCBS systems.

In addition to these demonstrations, the DRA provided authorization for a demonstration to determine the efficacy of adding Psychiatric Residential Treatment Facilities (PRTF) to the allowable alternative level of care/institutional settings for comparison purposes for HCBS waivers. This demonstration enabled a number of selected states to operate 1915(c)-like waivers for children who would otherwise receive services in a PRTF.

The ACA also added a 1915(k) state plan option and modified the 1915(i). The "K" gives states an additional 6% increase in federal match for personal attendant and support services where individuals have a person centered plan and can direct their own care, including the ability to hire and fire their attendants or caregivers. However, the statutory eligibility for 1915(k) invokes the institutional level of care requirement for receipt of the benefit and includes a 150% FPL limit for certain individuals, but not uniformly. (LOC in most states is coupled with income eligibility of 300% of SSI or about 220% of FPL) CFC does not permit states to target the benefit based on diagnosis or other targeting criteria and states offering "k" services must provide them to all eligible beneficiaries .

Conversely, Section 1915(i), which offers states the option to provide HCBS previously only available through Section 1915(c) waivers, allows states to target the benefit to certain

populations and allows states to design a needs based eligibility criteria lower than the institutional level of care, unlinking eligibility from LOC requirements. For the first time, this allows states to significantly narrow their LOC requirements while simultaneously serving a broader “at-risk” population which they were unable to do under the traditional 1915 (c) waivers. This benefit is also limited to individuals under 150% FPL unless the state elects to cover a newly available eligibility group added to the 1915(i) benefit through the ACA which can reach 300% SSI FBR for individuals who would be eligible under a 1915(c) or similar waiver. States have been reluctant to elect this group given the open aspect of the benefit. Unlike CFC, 1915(i) brings no enhancement to the FMAP rate for the state.

Neither 1915(k) nor (i) allow the states to set limits on the numbers of individuals served or to limit the benefit geographically. While both of these options are attractive, many states still facing fiscal challenges are wary of adding state plan options where they cannot set enrollment caps. And states undergoing significant rebalancing efforts may not see it feasible to create expanded HCBS capacity to divert or re-locate individuals from institutions while simultaneously expanding and entitling access to HCBS for new or previously unserved populations.

Importantly, 1915(c) remains the standard bearer for HCBS, with more than 300 separate waivers operated nationally, not including 1915(c) replications covered through 1115 demonstration programs. An attractive feature for state fiscal concerns remains the ability to cap or limit HCBS enrollment growth which the (c) allows.

All of the options above have attractive features but each require completely different applications, protocols, regulations, timeframes, administrative and reporting requirements. It is challenging for a state to bundle and blend these options into a cohesive long-term strategy to completely reform and rebalance its LTSS system, especially since several of these options sunset within the next four years. Furthermore, despite the intentions to provide equal footing, these benefits remain options for the state while they are mandated to provide institutional services, and are largely unable to reduce their institutional licensed capacity and footprint in a manner that would facilitate a more meaningful tipping of the LTSS infrastructure. Finally, the different requirements and structures also serve to impede state efforts to design meaningful person-centered systems of care that integrate services.

Proposal Features:

This proposal would create a single HCBS state plan authority which unifies and bundles the best features of the options described above, and would make permanent the enhanced match incentives in the MFP and BIP programs. The key features would include:

- States can set needs-based functional eligibility less stringent than the institutional level of care
- Allows states to include any or all Medicaid eligibility groups with income standards up to 300% of SSI, with strategies incorporated to ensure the lowest income individuals receive coverage first

- Allows states to craft multiple programs or consolidate multiple programs across disability or other target groups, in a manner that adheres to applicable laws (ADA, etc.)
- Payments for HCBS services are 6% higher than the regular match rate subject to Secretarial approval. The Secretary will determine the specific HCBS services, settings and attributes that will be eligible for the enhanced FFP, including time periods for review of enhanced FMAP eligibility.
- Institutional services are held at the regular match rate
- Makes permanent the MFP feature of full FFP for HCBS costs for one year after relocation from a nursing home, hospital, ICF/DD or PRTF where a person has resided for more than 90 days and includes features of both MFP and the “K” to pay for certain start-up costs
- Adds PRTF as an allowable alternative for LOC determinations
- As a state plan option, states must serve all eligible individuals, however a state may negotiate enrollment growth targets tied to specific rebalancing benchmarks that permanently decrease the state’s institutional footprint. Allows a time-limited differential match for buy down of vacant institutional beds taken off line
- Allows a modest capped HCBS benefit on a cost-sharing basis for individuals who meet functional eligibility and are at high risk of Medicaid spend-down with income and assets no greater than 136 180 days of the average nursing home rate in that state
- Allows a state under this authority to create health homes to coordinate care for a sub-set of eligible individuals who are receiving HCBS services and have two or more chronic conditions, and the state can receive 90% FMAP for up to eight quarters as defined in the affordable care act
- Includes opportunities for easy linkage to tools for integration, such as health homes and managed care authorities, setting forth uniform expectations yet streamlined authority linkage quality and reporting structures
- Will create the possibility for a medically needy income level for community based services

The single state HCBS authority would also have uniform requirements including:

- Meets HCBS settings requirements
- Needs assessments include core elements for all populations but also address specific populations using valid and reliable population-specific assessments
- Person-centered planning requirements for all participants
- No Wrong Door for all intake and eligibility
- Requires a mitigation plan for potential conflicts of interests in the delivery of case management
- Participant direction, including hiring and firing authority over personal care staff and access to an individual budget must be an available option Specified quality measures
- Some level of cost neutrality

The provision will also “clean up” the statute to remove the various provisions (driftwood) to definitively provide a sleek option. However states may still elect to utilize the 1915(c) authority to fund HCBS services tied to an institutional level of care, subject to the periodic review by the Secretary to ensure that the services offered therein comport with established standards for HCBS.