Recommendations for the Long-Term Care Commission

The National Council on Aging (NCOA) is a nonprofit service and advocacy organization that works to improve the lives of millions of older adults, especially those who are vulnerable and disadvantaged. For decades, NCOA has been a national leader on long-term services and supports (LTSS) policy issues, and strongly values collaborative leadership that brings together nonprofit organizations, businesses, and government to develop creative solutions.

Our recommendations have been informed by our collaborative work within the Leadership Council of Aging Organizations (LCAO) and the Consortium for Citizens with Disabilities (CCD). These two coalitions, collectively representing hundreds of national aging and disability organizations, came together and agreed on a set of Principles for Long-Term Services and Supports, which NCOA endorses. In addition, our recommendations were informed through the Friday Morning Collaborative, a coalition we lead of 35 national aging and disability organizations working together to advance LTSS policy.

In developing our recommendations, we have taken a pragmatic approach. We have strived to propose common sense ideas that we believe can garner broad-based, bipartisan support from private and public sectors and the aging and disability communities. Our recommendations adhere to the following tenets:

- Promote affordability and personal responsibility;
- Make markets work better for consumers;
- Support individuals at home and family caregivers; and
- Promote greater consumer choice and control.

Finally, we believe they are not only the right thing to do but the smart thing. Many of the recommendations we have selected will achieve scorable savings in Medicaid. Some require investments. However, as a whole, they will produce cost-efficiencies and bend the Medicare and Medicaid cost curves over time as our population ages and more individuals need LTSS.

**Long-Term Services and Supports Financing**

- Establish a voluntary, national long-term care insurance program that: (1) is actuarially sound, (2) is largely self-funded, (3) increases affordable options for working Americans, (4) does not exclude purchasers based on pre-existing health conditions; (5) improves market opportunities for private insurance options; and (6) produces significant savings to Medicaid.

Creation of a national long-term care insurance program based on principles of social insurance would pool risk, make premiums more affordable, increase business
productivity, and promote growth in the private market. Approximately 87% of Americans who decide not to purchase private long-term care insurance cite costs as the leading factor. Over the past decade, private insurance options have become increasingly unaffordable for most lower and middle-class families. Today, the vast majority of purchasers have incomes over $50,000 and assets over $100,000.

Providing more affordable options, particularly to lower and middle-class families, can produce significant Medicaid savings over time. The extent of Medicaid savings would depend a great deal on how the program is designed. A mandatory program offering a 5-year, $50 per-day benefits could reduce federal and state Medicaid spending by $49 billion over the first 15 years. A comparable voluntary program with a modest up take rate would result in at least $5.6 billion in Medicaid savings. Additional savings could be achieved if steps were taken to enhance enrollment, particularly of low and middle-class individuals who are most likely to rely on Medicaid in the future. A report from the Moran Company estimated the potential annual reduction in Medicaid spending due to the availability of a national LTSS program to be up to $47.7 billion, varying based on the benefit package.

A national program would also help raise awareness of the need for American families to plan, which would stimulate opportunities in the private market. Offering a foundation of protection, in conjunction with a strong education and marketing campaign, would promote new market opportunities in the private sector to supplement the base plan, similar to the way the passage of Medicare gave rise to the private Medigap policy market.

In order for a voluntary program to be sustainable and actuarially sound, enrollment must to be maximized. Subsequent recommendations address these issues in further detail. Many ideas have come forth demonstrating the possibility of establishing viable options that can be “actuarially sound and attractive” to consumers within a voluntary model that addresses adverse selection and provides affordable premiums. Some ideas include: strong work requirements, phasing in enrollment (starting with the large group employer market), and flexibility on benefit options, including less than lifetime benefits, longer vesting periods and varying benefit amounts.

Flexibility is needed to finding the right balance. Therefore, Congress should outline the broad parameters of such a program, invest in the necessary actuarial work, and appoint a workgroup including consumer representatives and other experts to decide among actuarially sound plans that build reserves over time sufficient to pay for future needs in an affordable manner. If the right balance is struck, it will be a win-win for consumers, the private sector, and state and federal governments.

- **Establish on-line national and state-based exchanges, as well as potential private exchanges, to simplify the market and assist individuals and employers with purchasing qualified private and public long-term care insurance.**

  Roughly half of non-buyers of private long-term care insurance cite market complexity and confusion about policy choices as reasons for not buying. In addition, about two-
thirds of non-buyers are concerned about sudden rate increases after buying policies. Simplification and standardization of the marketplace could enhance meaningful consumer choice and improve take-up rates.

National and state-based electronic exchanges/marketplaces, as well as potential private exchanges, should be established that provide consumers with limited choices by standardizing sets of offerings and presenting simple and clear descriptions of the key elements of the products. Experiences from the Minnesota Long-Term Care plan and the Federal Long-Term Care Insurance Programs demonstrate that such an approach can significantly increase enrollment rates.

Plans allowed on the exchange would have to meet minimum criteria and standards, including consumer protections such as those addressing unreasonable rate increases, standardized underwriting practices, pricing discrimination based on gender, and minimum loss ratios. This is a complex task, probably best left to the National Association of Insurance Commissioners (NAIC), which provides for a broad range of stakeholder input. Meeting standards and inclusion in the exchanges could also enable qualified private plans to receive budget-neutral reinsurance protections.

- **Require mid-size and large employers (with more than about 150-200 employees) to offer their employees qualified private and public long-term care insurance options that meet key standards.**

The U.S. working population is highly concentrated within large companies. Approximately 80% of all U.S. employees work within 9% of U.S. companies. However, only about 20% of companies with 100 or more employees currently offer long-term care insurance to their employees. There is a large untapped group market of employees who currently do not have access through their employer.

Larger employers typically have benefit infrastructures that could easily be adapted to provide options for qualified private and public long-term care insurance options. The requirement to offer long-term care insurance should also be coupled with the establishment of on-line exchanges and marketplaces to ease the burden on employers and ensure plans being offered meet minimum criteria and standards for consumers.

- **Remove barriers for individuals to acquire and access personal assets to pay for long-term services and supports needs.**

The majority of wealth of older individuals is tied to home equity and savings in qualified retirement plans—including individual retirement accounts (IRAs), 401(k), and 403(b) accounts. When needs for long-term services and supports arise, the ability to tap into these personal assets can allow individuals to remain at home and live with dignity and independence in the community.
Reverse mortgages, which are designed for homeowners age 62 and older, can be an effective way for seniors to remain in their homes and pay for long-term services and supports. However, access to unbiased third party reverse mortgage counseling is imperative. Adequate federal funding for reverse mortgage counseling is critical for low income seniors to obtain the required counseling. Similarly, removing barriers to withdrawing from individual retirement plans without penalty could also be explored as ways to assist individuals with paying for long-term services and supports needs. Finally, the Achieving a Better Life Experience (ABLE) Act of 2013, which has strong bipartisan support in the House and Senate, could assist individuals currently living with disabilities to acquire assets and help pay for long-term services and supports and other disability-related expenses.

**Medicaid Improvements**

- **Remove the “institutional bias” within Medicaid and enhance choices for individuals to receive more cost-effective services and supports in their homes and communities.**

  Currently within the Medicaid program, states are required to provide nursing facility coverage while most home and community-based services (HCBS) are optional. This not only denies individuals choices to remain at home, but contributes to unnecessary costs by forcing individuals into more costly institutional settings.13 14

  While steps have been taken to reduce this “institutional bias,” more can be done. The Community First Choice option provides states with a financial incentive (6% enhanced federal match) to provide all Medicaid-eligible individuals who would qualify for nursing facility services the option of receiving community-based personal attendant services and supports. Some states have expressed interest in adopting this state plan option; and two states have done so to date (California and Oregon).

  Within five years, Community-First Choice should be required in all states as part of their state Medicaid plan. To assist states, the 6% additional federal match could be increased and targeted to states needing more assistance in meeting this requirement (i.e. states spending less on home and community-based services and states with high unmet needs and waiting lists).

- **Require states to provide individuals receiving Medicaid HCBS opportunities to self-direct their services and supports.**

  States currently have several mechanisms to provide individuals with options to self-direct their services and supports through Medicaid state plan options and 1915(c) HCBS waivers. Extensive research, including research from the Cash and Counseling demonstrations, highlights the benefits of providing individuals and families with greater control over their services and supports.15 However, real options for individuals to hire, direct, and supervise their direct care workers remain very limited. In a handful of
states, the majority of individuals are provided such options. However, in most states options remain limited to certain programs and populations.

Opportunities to self-direct should be viewed as a right for consumers, not an option for states. Evidence from states such as Washington and Oregon suggests that allowing more individuals to self-direct with adequate supports such as fiscal intermediaries can result in significant Medicaid savings. A modest increase in self-direction could result in billions of dollars in savings to the federal government and states. Therefore, within five years, states should be required to provide all individuals receiving Medicaid HCBS, options for self-direction. As an incentive to encourage states to implement self-directed options earlier, a shared savings approach could be adopted, allowing states to share a percentage of federal savings within the five-year period leading up to the requirement.

- **Invest in development of outcome-oriented, person-centered home and community-based quality measures for duals integration and Medicaid managed long-term services and supports programs.**

Rapid transformations are occurring within states towards duals integration and Medicaid Managed Long-Term Services and Supports (MLTSS). Twenty states are actively pursuing proposals for duals integration demonstrations, six of which now have approved Memoranda of Understanding with CMS. In addition, many states are designing new, and expanding existing, MLTSS programs. As many as 26 states could have MLTSS programs by 2014.16

Quality measurement is particularly important in a managed care environment. Quality and performance measures are often tied to payments. They are critical tools for consumers and states to use to achieve desired outcomes. Quality measures also allow for continuous monitoring and improvements in programs as well as consumer choice among plans.

Valid and reliable measures have been developed for clinical outcomes and are in use by Medicare and Medicaid health plans. However, the extension of managed care to include long-term services and supports is relatively recent. Currently, there are no HCBS quality measures that have been endorsed by the National Quality Forum (NQF), the nationally recognized entity that endorses quality measures. NQF has highlighted HCBS quality measurement as a significant gap.17 They have identified some promising measures, but significant investment is needed.

As states move forward with duals integration and MLTSS programs there is very little guidance on HCBS quality measurement and no core set of measures. In order for duals integration and managed care to effectively work as a tool to improve outcomes and achieve cost efficiencies, a significant investment is needed to develop HCBS quality measures. Moreover, the development of quality measures should adhere to a person-centered paradigm of HCBS and actively involve aging and disability consumer perspectives.
• Establish a maintenance allowance for individuals receiving Medicaid HCBS, allowing individuals to retain assets for expenses associated with housing, food, clothing, utilities, transportation and medicines.

Under current law, federal Supplemental Security Income (SSI) rules are used to determine asset and income eligibility for Medicaid benefits. In general, in determining eligibility under SSI and Medicaid, federal countable resources must be worth $2,000 or less for an individual, or $3,000 or less for a couple. These amounts are not adjusted for inflation and have not been updated since 1989. Under Medicaid, federal asset limit requirements are identical for nursing homes and HCBS. This makes no sense because persons in the community must pay for housing, food, clothing, utilities, transportation and medicines, whereas those in nursing homes do not incur these costs.

Asset limitations are a major barrier to receiving Medicaid HCBS. For example, a study by the Urban Institute found that 39% of Medicare beneficiaries with incomes below 135% of the Federal poverty line failed to meet the SSI/Medicaid asset test. Incentives could be created by giving states a higher Medicaid match if they provide for some form of maintenance allowance in meeting the asset test for HCBS eligibility. The allowance could be the equivalent of 6-12 months of community living expenses.

• Make spousal protections for Medicaid home and community-based services permanent

Under current federal law, spousal impoverishment protections are mandatory for spouses of institutionalized enrollees, but not for spouses of HCBS enrollees. The Affordable Care Act repairs this discrepancy, but not until 2014, and the legislation is scheduled to sunset in 2019. The need for equivalent protections exists now, so the extension of the protections should not be delayed and should be made permanent.

Family Caregiving and Workforce

• Establish a refundable caregiver tax credit to assist informal caregivers and maximize their efforts to support their loved ones at home.

Research has highlighted the economic impacts of informal caregiving on caregivers, families, and business. Studies have found high out-of-pocket costs by informal caregivers for caregiving related expenses. One study found that caregivers of individuals 50 and older spent an average of 10 percent of their annual income ($5,531) on such costs. Family caregivers cut back on savings and retirement. They make other sacrifices such as foregoing preventative medical care. Due to caregiving demands, many caregivers also are forced to cut back on employment or turn down promotions. Lost income and benefits for family caregivers age 50 and older who leave the workforce due to caregiving average $303,880 over their lifetime. Moreover, U.S.
businesses lose up to $33.6 billion per year in lost productivity due to informal caregiving demands.\textsuperscript{21}

Over the past decade, legislative proposals for a refundable tax credit in the range of approximately $3,000 to assist informal family caregivers have been introduced in Congress. Bills have historically gained strong bi-partisan support. Moreover, in the most recent National Alliance for Caregiving national survey of family caregivers in the United States, families rated a refundable tax credit as their most favored policy option.\textsuperscript{22} Over a third (37\%) rated it as their top choice and more than half (56\%) rated it in the top two policy options. This policy option is an efficient way to assist families with the costs of care and maximize their ability to support their loved ones at home.

- **Increase funding for family support programs, including the National Family Caregiver Support Program and Lifespan Respite Care Program.**

  The National Family Caregiver Support Program provides grants to States and Territories to fund a range of supports that assist family and informal caregivers. Supports include information and assistance with accessing available services, counseling, training, support groups, respite, and other supplemental services. The Lifespan Respite Care Program provides grants to states to develop coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs.

  Both programs have had wide bipartisan support. However, current funding for these programs is well below authorized levels and has not kept pace with the increased prevalence of family caregiving. There are over 42.1 million family caregivers in the U.S. The care they provide has an estimated annual economic value of $450 billion.\textsuperscript{23} Yet, current funding levels for the programs only allow them to support a very small fraction of caregivers that could benefit. In FY 2010, the most recent year for which service data is available, the National Family Caregiver Support Program assisted approximately 700,000 caregivers. Respite and other family supports benefit the well-being of caregivers and can delay and prevent placement of individuals needing LTSS in more costly nursing homes and institutional settings.

- **Improve data collection on Medicaid home and community-based services, including data on the direct care workforce, self-direction, and waiting lists/unmet needs for services**

  Improvements in data collection and reporting are needed to better inform policy and practice across states. Current data reporting is minimal and typically provides limited information about participants, expenditures, and services. Serious consideration should be given to expanding the collection of collecting state Medicaid data.

  No systematic information is reported on the workforce, such as turnover rates, job vacancies, staffing levels, training, wages and benefits. No reporting is required on the number of individuals that have options to self-direct their services. Data on waiting lists
and unmet needs for home and community-based services is also unclear since no uniform standards exist for states to maintain lists and therefore, many do not report any data. Finally, additional data is needed on eligibility, reimbursement rates, and caps on service hours and dollars. CMS, in conjunction with the Administration for Community Living, should be directed to convene expert stakeholders, including researchers and consumer advocates, and develop improved standards and mechanisms for data collection.

- **Provide financial incentives to states to establish matching services registries to assist individuals with finding and hiring qualified direct care workers.**

  One the greatest barriers for individuals and their families is often assistance in finding and hiring qualified direct care workers. This is a barrier for individuals trying to self-direct their Medicaid home and community-based services as well as for individuals paying out-of-pocket or through private long-term care insurance options that allow for self-direction. Such registries could also be used to allow consumers to weed out workers who are not qualified.

  Some states have initiated matching service registries to assist individuals with finding and hiring qualified direct care workers. Financial incentives should be provided to states to develop registries. This could occur through demonstration grants through the CMS and the Administration for Community Living. Alternatively, incentives could be tied to an enhanced federal Medicaid match for home and community-based services tied with requirements for structural changes to address the workforce, including the development of registries.

- **Enact comprehensive immigration reform that provides a pathway to citizenship for direct care workers and helps fill projected shortages in the direct care workforce.**

  A severe shortage of direct care workers is projected as the U.S. population ages and the number of individuals needing long-term services and supports doubles in coming decades, from 12 million to 27 million by 2050.\(^{24}\) Conservatively, an additional 1.6 million direct care workers are needed by 2020; and an additional 3 million by 2030.\(^{25}\) Individuals with disabilities, seniors, and their families currently struggle to find workers. The projected shortage of future workers will create even more difficulties individuals and their families, particularly in home and community-based settings.

  Immigration reform can be part of the solution to addressing this projected shortfall. About 20-23% of the current direct care workforce is foreign born. While approximately half of this population is naturalized, and others have permanent legal status, some workers are unauthorized.\(^{26}\) Providing a pathway to citizenship for direct care workers will help stabilize the workforce, ensure protections for workers, and improve the quality of services and supports. Moreover, an enhanced visa program for low-skilled workers (such as the W-Visa Program in the Senate-passed immigration reform bill) could help fill projected shortages.
Recommendations for Continuing Post-Commission Engagement

- **Establish Senate Finance and House Energy and Commerce Subcommittees on Long-Term Services and Supports.**

  Particularly given the short timeframe provided, we are very hopeful that the Commission’s work will launch a set of policy recommendations for further consideration, debate, and congressional action. However, structural reforms may be necessary to continue the discussion, particularly within Congress. Therefore, we recommend the establishment of subcommittees of the relevant Senate and House committees with jurisdiction to more fully engage in addressing this critical issue.

- **Establish a formal Commission on Long-Term Services and Supports similar to MedPAC and MACPAC.**

  Similarly, we recommend the formation of a more formal Long-Term Services and Supports Advisory Commission similar to MedPAC and MACPAC. A formal, ongoing Commission with adequate resources could more fully investigate, convene stakeholders, and report to Congress on trends and policy recommendations in such areas as the growing needs for long-term services and supports, trends in the private market and government programs, and the direct care workforce.

Thank you for the opportunity to comment. We applaud the commitment of the commissioners and the hard work of the Long-Term Care Commission to advance long-term services and supports policy. If you have any questions about the comments or would like further information, please contact Joe Caldwell, Director of Long-Term Services and Supports Policy, at joe.caldwell@ncoa.org or 202-600-3153.

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