

A BI-PARTISAN CALL TO TRANSFORM THE FEDERAL/STATE MEDICAID LONG-TERM CARE SYSTEM

We, the undersigned, call for a fundamental restructuring of the long-term care system in the United States. The current federal/state Medicaid financed long-term care system is institutionally biased, excessively complex, overly expensive, not reflective of best practice, provider-driven, and inherently unfair.

The existing system of long-term care funding reflects the paternalistic, maintenance-oriented biases toward people who have disabilities and older Americans with disabilities that were commonplace in the era during which it was constructed.

This system of long-term care funding perpetuates second-class citizenship for people who have disabilities of all ages, as it perpetuates community exclusion. By so many measures, we know its costs are unsustainable as designed.

We can make this system both more affordable and substantially more rational in how all people who have disabilities are supported, by ending the institutional bias inherent in Medicaid, and by encouraging the supplementation of increasingly scarce public dollars with private resources through a combination of sources, including earnings from work, asset protection and development, trusts, and private insurance.

During the last 40 years we have seen a paradigm shift from condemning persons who have disabilities and older Americans to institutions and nursing “homes” to assisting them to lead inspired lives of full participation in their communities. This shift has not come from the top down.

Rather it has been a volcano of creativity growing, bubbling and gathering power and momentum, one person at a time, in pockets of community all around the country. These new cultures, now known as self-determination, recovery, and independent living, have brought hope and the realization of dreams to millions of Americans. It is imperative that the Medicaid system now be transformed to align with these newer, and now proven, cultures and values.

All people – including those with disabilities of all ages – share common human aspirations for freedom, dignity, and equality. People with disabilities and older Americans want, and deserve, what most American citizens take for granted:

- The power and authority to decide where and with whom we live.
- Control over the freely chosen services and supports we need and receive.
- Supports that help us break down the barriers that continue to exclude us from fully participating in community life.
- The opportunity to work and keep, or generate, private income, and save for (and during) our old age.

Medicaid is the largest public funding mechanism for the vast majority of people with disabilities and older Americans. Some of what is funded may include personal care, psychosocial

rehabilitation, peer support, respite for caregivers, community living supports, job attainment and assistance with money management and independent brokering, transportation, and assistive technology and durable medical equipment.

And yet.....

The vast majority of federal/state Medicaid long-term care spending - the total now over \$108 billion this year (see link to CMS Actuarial Report and detailed data at the end) - is spent on supporting older Americans who have disabilities and many younger individuals who have disabilities in nursing homes and institutions, despite their avowed preference for living in the community and staying in their own homes. The Medicaid program requires personal impoverishment and, typically, the loss of control over both where a person lives and who provides support.

The current Medicaid funded long-term care system is predicted to grow at an unprecedented rate of up to 7.9% a year unless major reform is implemented. States are already proposing cuts of billions of dollars, with predictably dire consequences for millions of people who have disabilities. Since every state has unmet need in terms of Medicaid-funded long-term care services, there will be negative consequences even in those states able to get by with only small cuts.

While we applaud the current efforts to reform the health care system, we urge similar commitment and focus to address the growing challenges in long-term care. We further urge that the long-term care system be transformed in a manner that supports the universal, fundamental human aspiration to live a full quality life in the community that is not “facility” based, nor provider-driven.

We believe these reforms can be accomplished through a combination of administrative policy decisions, regulatory action, and legislative changes. We further believe that these reforms can be accomplished with minimal and temporary increase in short-term funding - an increase that will quickly result in savings of hundreds of millions of dollars compared to the current approach.

Our proposal is outlined as follows:

A NEW APPROACH...“COMMUNITY FIRST”

Self-Determination¹, including various forms of self-direction, mental health recovery approaches, and independent living philosophies, have all grown separately from the grassroots, and have recently converged in an increasingly unified movement to challenge the commonly held assumptions in our traditional systems of long-term support for individuals with disabilities, those in recovery, and those who are aging.

This new common foundation for equality and full citizenship, and the related responsibilities, recognizes and addresses the struggle to overcome isolation, stigma, and segregation that has existed across disability and aging for over a century. We must give the opportunity for meaningful, productive lives in the community to all who choose it. In order to accomplish this, the community, *not the institution*, must become the standard system of care and support of the future. The changes

¹ Principles of Self-Determination: <http://www.centerforself-determination.com>

recommended below are transformational because they are based on a shift in the fundamental assumptions upon which present funding is based.

We call for the nation’s long-term care system to be fundamentally transformed to promote “Community First Whole Health” so that Medicaid beneficiaries are:

- Given the unbiased choice of life in the community rather than being forced into an institution (facility) simply because that is where the resources are currently located.
- Able to meet their unique personal needs and preferences from a full array of community-based services and supports that include non-clinical services and supports, such as job and housing assistance.
- Given control of a specific funding allocation (often at less than the cost of institutional or facility-based services) to pay for their chosen/needed services, with accountable support where necessary, and when people choose that form of assistance.
- Provided with unbiased assistance through non-clinical peer supports, brokering, and self-determination budgeting processes to help them successfully and efficiently manage their money and direct their supports for the best possible outcomes.
- Assured of the quality services and supports necessary to live productively, safely, and happily in the community of their choice.
- Provided all appropriate federal, state, and private sources of money, including Medicaid, to assist them to make their homes accessible, safe, and barrier-free.
- Able to use Medicaid funds to supplement SSI and/or SSDI to pay for affordable, accessible, integrated housing in the community.
- Linked to a new concerted and systematic effort to identify, evaluate, and remove existing barriers in the Social Security system that thwart or discourage employment and income and asset development and preservation.
- Encouraged to bring private resources such as earnings, trusts, investments, long-term care insurance, and ethically structured reverse mortgages to blend with public dollars.

Medicaid reform is both good public policy and fiscally sound.

We propose a 10-point transformation approach (one among many possibilities) that will:

- **Invest \$100 million in up to ten states**, in the first of several rounds, that will allow those states to completely realign and rebalance their long-term care systems and make home and community-based services and supports available to anyone who so chooses, no matter the significance or type of their disability. Each redesigned state plan would have to cover all of those who are Medicaid eligible who have a disability, regardless of diagnosis or the categorical label, if they require assistance. This redesigned state plan must be developed in active partnerships between state officials and disability and aging leaders.
- **Assist all Medicaid beneficiaries now in institutional settings** who want to move to the community to do so, as in the limited “Money Follows the Person” grants currently in practice.
- **Serve all of Medicaid beneficiaries on waiting lists** for services and supports related to their disability or age. This requires a long-term plan and clear implementation policies. The savings will come from the current cost of institutional and facility-based care.

- **Enable beneficiaries to direct their community supports by providing control over how the Medicaid benefit is spent directly for the beneficiary** through self-determination budgets, person-directed planning, consumer-directed peer supports, and appropriate fiscal intermediary supports for anyone who so desires it.
- **Allow Medicaid dollars to be used to supplement beneficiaries' SSI/SSDI benefits** for room and board costs.
- **Coordinate all federal and state sources of funds**, including Medicaid, and make them available to create completely accessible homes and provide needed technology as required to ensure accessibility, communication, and mobility.
- **Provide a Social Security Waiver, and/or changes in policy/regulation** that will remove all disincentives to work that penalize earnings in the SSI/SSDI programs.
- **Establish special savings accounts that enable people to save funds** that are targeted to improving the quality of life of Medicaid beneficiaries without jeopardizing benefits that provide for survival costs (similar to Individual Development Accounts and PASS plans).
- **Allow families and friends to supplement public benefits by providing resources in special trust accounts** that will be tax-deductible and available to provide assistance with housing, work, transportation and other important quality of life expenses.
- **Add a new benefit for direct support workers** that will enable them to create matched savings accounts (similar to Individual Development Accounts) for housing down payments, post-secondary education, other training opportunities, and transportation.

If you agree with the above premises and this proposed solution, we urge you to become a signatory to this plan. Click the following link to [Sign on in Support of the Bi-Partisan Call](#) or go to www.centerforself-determination.com and click on the “*Medicaid Transformation*” button.

Click the following link to read the long version of this plan entitled, [The Perfect Storm: The Impending Collapse of Medicaid and a Plan for Transformation](#)

You can read the Executive Summary by clicking the following link [The Executive Summary of the Medicaid Transformation](#)

To review the CMS actuarial report: <http://www.centerforself-determination.com/docs/MedicaidReport2008.pdf>
or go to <http://www.cms.hhs.gov/ActuarialStudies/downloads/MedicaidReport2008.pdf>

Original Signers:

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