
*A Principled Approach to the Medicaid Long Term Care
Program*

Averting the Looming Fiscal Crisis

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A Blueprint for Reform: Medicaid Long-Term Care

Introduction

All people – including those with disabilities and older Americans -- share common human aspirations for freedom, dignity and equality. People with disabilities and older Americans want and deserve what we all take for granted as American citizens. They want the power and authority to decide where and with whom they live. They want control over the services they receive. They want an opportunity to work and have private income. And they deserve the supports that will break down the barriers that exclude them from participating in community life.

Government has an obligation under the Americans with Disabilities Act (ADA)¹ to protect people with disabilities from discrimination. The Supreme Court's Olmstead decision in 1999 (Olmstead)² affirmed that the isolation and segregation of individuals with disabilities is a serious and pervasive form of discrimination. However, various disability populations, including older Americans, continue to be segregated from mainstream American society by a Medicaid³ system that promotes forced institutionalization for many younger and older Americans and often requires personal impoverishment for people with all types of disabilities before individuals can receive the supports and services they need--especially those who rely on Social Security benefits. Simply, Medicaid services and supports are too often inadequate to satisfy the requirements of Olmstead and the ADA.

Self-Determination,⁴ including various forms of self direction advances, mental health recovery approaches and independent living philosophies have all recently converged to challenge common cultural assumptions in our various systems of long term support for

¹ ADA Regulations and Technical Assistance Materials. ADA Home Page, U.S. Department of Justice, which provides free materials on the Americans with Disabilities Act. Available at <http://www.ada.gov/publicat.htm>.

² OLMSTEAD v. L. C., 527 U.S. 581 (1999). The Olmstead decision interpreted the ADA to prohibit discrimination against individuals with disabilities by providing long-term supports and services reimbursed by Medicaid only in skilled nursing and large congregate settings rather than providing those supports and services in integrated, community-based settings. The Court explained that states should make "reasonable accommodations" in their long-term care systems, including community placements with adequate supports. Available at www.usdoj.gov/osg/briefs/1998/3mer/1ami/98-0536.mer.ami.pdf.

³ Medicaid is a state administered program and each state sets its own guidelines regarding eligibility and services, although certain groups must be covered by federal mandate. Medicaid does not provide medical assistance for all poor persons. Low income is only one test for Medicaid eligibility; assets and resources are also tested against established thresholds. As noted earlier, categorically needy persons who are eligible for Medicaid may or may not also receive cash assistance from the TANF program or from the SSI program. Medically needy persons who would be categorically eligible except for income or assets may become eligible for Medicaid because of excessive medical expenses. See Medicaid, Centers for Medicare & Medicaid Services, U.S. Department of Health and Human Services at <http://www.cms.hhs.gov/home/medicaid.asp>.

⁴ Principles of Self-Determination: <http://www.self-determination.com/principles/index.html>.

individuals with disabilities, those in recovery and aging Americans. This new common foundation recognizes and addresses the struggle to overcome isolation, stigma and segregation that has existed across disability and aging for over a century. Put simply, it is a struggle for equality and full citizenship. We must give this opportunity to all of those who choose it. In order to accomplish this goal the community must become the default system of the future and not the institution.

In contrast the current Medicaid long-term care system too often promotes the forced institutionalization of people with disabilities. The Medicaid program pays for almost half of all health care services for older Americans and people with disabilities and is the single largest payer within a total expenditure that well exceeds 300 billion dollars.⁵

As much as 70 percent of Medicaid long term care spending (Approximately 108 billion dollars this year) goes to institutional care.⁶ In 2005, 1.1 million people were confined to institutions, while only 600,000 people with disabilities were given the opportunity to receive services and supports necessary in the community through state “waiver programs.” Approximately 1.96 million individuals with disabilities received some form of often limited Medicaid funded personal care assistance or home health care.

(Attachment A contains the data utilized for this analysis and the conclusions drawn)

The Medicaid long term care program has two sides: the institutional and the community. On the institutional side there are two major programs—skilled nursing homes (NF) and intermediate care facilities for individuals with developmental disabilities (ICF/DD). On the community side of this equation are two other major programs—state plan services available to all who qualify and Medicaid Home and Community Based Waiver Services which can serve one or more distinct populations of individuals with disabilities and aging Americans who require assistance. State plan services usually allow for some form of home health care or personal assistance services. Waiver programs tend to be richer in services offered but can be capped as to the number and specific disability (s) served.

Because Medicaid is essentially a state program with federal oversight and matched funding there are in fact over 50 Medicaid programs. Each state gets to design especially through the “Waiver” program just who will be served and how many. In practice this frequently means that some remained unserved or underserved. This often includes populations with mental illness, sometimes autism or brain injury and, even when covered, the type of services available can vary widely.

Just as problematic is the fact that there are growing waiting lists for these programs. Thousands with Down syndrome, e.g., remain on waiting lists for services for years.

⁵ Kaiser Family Foundation Report: "Long-Term Service and Supports: The Future Role and Challenges for Medicaid," by Judith Kasper, Barbara Lyons, and Molly O'Malley (September 2007, .PDF format, 30p.). www.kff.org/medicaid/upload/7671.pdf

⁶ CMS 2006 New Freedom Initiative Conference (Baltimore, MD). Administrator Mark McClellan Remarks. 10 April 2006.

Add to that the growing demographics especially of the aging population and we are confronted with an emerging crisis that will eventually overwhelm state budgets. In some states Medicaid spending is now approaching 25% of total state appropriations.

Family caregiving responsibilities are rising and creating greater stress than ever before especially as future potential family caregivers decline in numbers. An estimated 2.9 million people with intellectual or developmental disabilities are living with caregivers – many parents who are approaching 55 years and about one quarter 55 years and older.⁷ One reason for the heavy dependence on family caregivers is that the community system keeps Medicaid beneficiaries personally impoverished and requires the impoverishment of older Americans who must rely on public supports. Older individuals are frequently caught between their fear of nursing homes and becoming a burden to their adult children. Few have long term care insurance and many of modest resources deliberately impoverish themselves five years before they actually require assistance in order to qualify for Medicaid.

The vast majority of the federal state Medicaid long term care budget—over \$108 billion this year-- is spent on supporting older Americans with disabilities and many younger individuals with disabilities in nursing homes and institutions for those with developmental disabilities. (Only small amounts of Medicaid dollars are spent on psychiatric institutions) In spite of their avowed preference to live in the community and stay in their own homes, thousands of individuals each year are forced out of their homes and communities because they do not get the support they need from this vital program. *at less cost on average than the nursing home and institution.*

The institutional program requires personal impoverishment and frequent loss of control over both where a person lives and who provides support. Only on the institutional side of the Medicaid long term care program can room and board be included in Medicaid billing. This plan for reform features ending the institutional bias in the Medicaid program, promoting technology for community living and enabling all individuals with disabilities eligible for the Medicaid benefit to choose the community and live at home with assistance that is under their control with help from close family and allies when necessary—including paying them when appropriate. This strategy will return the initial public investment of dollars many times over simply by diverting 5 to 10 percent of older Americans from nursing homes. Much more is possible.

This 10 point reform plan will:

- Invest \$100 million in up to ten states in the first of several rounds that will completely realign and balance their long-term care systems to make community and home 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 those Medicaid eligible with a disability no matter the label if they require assistance.

⁷ Ansberry, Clare. “When Crisis Hits the Disabled.” Wall Street Journal. April 29, 2008.

- Assist all Medicaid beneficiaries now in an institutional setting who want to move to the community the ability to do so.
- Serve all of Medicaid beneficiaries on waiting lists for supports.
- Provide the Medicaid benefit directly to the beneficiary with appropriate fiscal support for anyone who so desires it.
- Allow Medicaid dollars to supplement beneficiaries' Social Security benefits for room and board costs.
- Coordinate and make available all federal and state sources of funds including Medicaid for creating completely accessible homes and provide needed technology when appropriate to ensure accessibility, communication and mobility.
- Provide a Social Security Waiver for all working age individuals that will remove the disincentives to work embedded in the Social Security benefit that penalize earnings
- Provide the mechanism to save in special savings accounts targeted to improving the quality of life of Medicaid beneficiaries without jeopardizing necessary benefits (Individual Development Accounts)
- Add a new benefit for direct support workers that will enable them to create matched savings accounts (Individual Development Accounts) for housing down payments, post secondary education and training opportunities and creating their own micro enterprises
- Allow families and friends to provide 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 benefits

Principles and Goals for Reform

The long-term care system must be fundamentally reformed so that Medicaid beneficiaries are:

- Given a choice of life in the community rather than being directed to an institution because that is where the resources are located.
- Able to meet their unique needs and preferences for a full array of community-based services.
- Given control over the money with accountable support to pay for their services, if they choose.
- Provided unbiased support to help successfully manage their money and direct their services.
- Assured quality services and supports, so that they can live productively, safely and happily in the community of their choice.
- Provided all federal sources of money including Medicaid to assist individuals to make their homes accessible and barrier free.
- Able to use Medicaid funds for community living in order to supplement Social Security income for room and board.
- Linked to a new commitment to identify, evaluate and remove existing barriers in the Social Security system that militates against employment and income and asset development and preservation.

- Encouraged to bring private resources to be melded with public dollars from work, trusts, long term care insurance and ethically structured reverse mortgages

Implement Demonstrations of Substantial Medicaid Reforms

A comprehensive demonstration program followed by national replications in all states for reforming the system of long term care in this country needs to give each individual effective opportunity to live a meaningful life in the community of his or her choice.

Rules and regulations must be modified so that earned and unearned private income can become part of the support system;

Direct support workers need to be provided wages, benefits and improved training and support to feel engaged and flourish in their profession;

And finally, public resources must move directly under the control of those who desire to craft their own life support plans.

This reform plan addresses the expressed desires of those with disabilities and older Americans who require assistance to live in the community of their choice. Redesigned state plans will be encouraged to address the poverty of those who rely on public assistance, the near poverty of the direct support workforce and encourage the introduction of private dollars into the long term care system. Up to ten complete state reform plans will be financed under new, streamlined rules, fiscal transparency and equity and fairness in the distribution of public funds. These plans will vary with creative approaches to solve the issues presenting today. The original 10 demonstrations will then be offered in all their diversity to the other 40 states for replication and improvements.

These plans will begin the transformation of multiple systems that will make it clear that no one will have to choose a nursing home or not be able to leave because the supports are not available where they now live or want to live; that no adult beneficiary will be wary of attempting employment or self employment because of complex regulations that erect barriers to earnings; that states can feel secure that the federal government will partner with them in designing creative approaches to public funding that will result in more equity for all those with disabilities and begin to address cost efficiencies in ways that do not discriminate against those with more significant disabilities; and, finally, that individuals with disabilities themselves will be an integral partner in the redesign of our long term care system.

These provisions would constitute a concrete expression of a tangible commitment to Olmstead, The Community Choice Act of 2007, the Class Act of 2007⁸ and a commitment to address the massive unemployment and underemployment of citizens with disabilities. The Medicaid reforms can be carried out under Section 1115 of Title XIX which allows for broad experimentation and research.

⁸ As of this writing current presidential candidates have not focused on rescuing or reforming the Medicaid long term care system.

There are two core components that will guide a comprehensive reform movement of the Medicaid long-term care system. The first component will focus on state realignment of resources to advance community participation. The second component will focus on administrative changes at a federal level to provide a single office dedicated to support state comprehensive reforms.

a. Realignment of State Resources

Establish an initial fund of 100 million dollars—just less than one tenth of one percent of current Medicaid long term care spending—to work with up to 10 states to create an historic realignment of resources with individuals who qualify for public support. This realignment will move public dollars to where individuals live in our communities. The original investment of 100 million dollars can be easily recaptured the first years of implementation through modest nursing home transitions alone. Every three years another 10 states will be solicited with a similar fund to participate in this system redesign effort until all states have an opportunity. **A TEN PERCENT DIVERSION RATE FOR CURRENT NURSING HOME ADMISSIONS ALONE WOULD RETURN HUNDREDS OF MILLIONS OF DOLLARS ON AN ANNUAL BASIS TO STATES THAT VOLUNTEER TO REDESIGN THEIR SYSTEMS AND ARE SELECTED FOR THIS FUNDING.** These funds could be used for those unserved and underserved. States who volunteer to redesign their systems and are selected for this funding must agree to the following conditions:

1. Create a state plan with timelines in conjunction with representative disability leaders and Medicaid beneficiaries as partners in all aspects of the plan and its implementation. This will include all disabilities and aging. The plan must address all those who desire to leave a nursing home and/or an institution, all those on waiting lists and all those, no matter the significance of their disability, including those who want to control the funding allocated for their Medicaid services and live self-determined lives.
2. Engage those most affected by job changes in planning for transitions when they are necessary.
3. Engage organizations that may be affected by helping them plan to retool their service delivery.
4. Cover equally all those with disabilities who meet Medicaid eligibility criteria and provide equity for those with mental illness within a new recovery Medicaid program.
5. Put in place central structural elements such as fiscal management agencies, brokering and peer supports and best friend advocates as well as provision for highly creative individual budgets based on individual allocations, person controlled planning and deep quality of life outcome based standards.

b. Dedicated Office to Support Comprehensive Reform

Reorganize the Medicaid (Center for Medicaid and State Operations) long_term_care section within the Centers for Medicare and Medicaid Services to include a single office devoted to providing technical assistance in all aspects of planning and implementation by working in partnership with the participating states:

1. Assisting participating states in writing simplified Medicaid programs that combine the best of current Waiver programs with new ideas and strategies in order to clearly lay out in a transparent way the supports covered, the ability for states to be creative, the new mandate to plan with the entire disability and aging community, reductions in paperwork requirements and the simplifying of complex regulations. Priority for state selection will rest on both comprehensiveness and creativity.
2. Assisting these states to write quality assurance plans that emphasize the living of full lives deeply embedded in our communities.
3. The creation of unitary programs for establishing Medicaid long term care eligibility that identifies eligibility based on support and health needs and not on level of care or “placement” eligibility or traditional “institutional” eligibility. These unitary eligibility assessments will offer the values of self-determination requiring states to move targeted amounts of public funding under the control of individuals, families where appropriate, and their freely chosen allies in ways that promote the values of everyday freedoms as an option anyone can choose. Intensity of need will not preclude someone from choosing the community.
4. Eligibility and preference will also be determined by a doctrine guided by fairness to the total number of individuals that require support and equity in the allocation of resources between institution and community. Plans of support will be based on a person directed planning process that will feature living in natural community homes, establishing personal futures and/or recovery plans, incorporate needed technology and transportation and sustain or promote long term relationships and community membership.
5. Provide technical assistance in the development of Medicaid equity plans with each of the states to realign Medicaid resource allocations consistent with where people with disabilities now live and especially where our older Americans in need of assistance live in intergenerational communities. Plans will include targeted completion dates that will be done within a decade. This would mean that states must, pursuant to the implications of the Supreme Court decision in Olmstead, invest Medicaid dollars in ways that create equity for those now living in the community commensurate with their estimated numbers versus the numbers of those

presently in an institutional setting, reduce waiting lists for community supports and end the fiscal institutional bias in present Medicaid expenditures for all populations served. *This means especially that the largest housing subsidy for Americans with disabilities—the institutional subsidy for room and board—will move to the community in these new plans.*

6. Establish within this department (CMS) as public policy the purpose of public funding as assistance to individuals with disabilities to craft meaningful lives in the community, sustain current and facilitate future relationships, obtain meaningful community membership, produce private income whenever possible and address the forced impoverishment of individuals within this system: younger persons who almost never escape poverty and older Americans who must become impoverished in order to receive support.
7. Redefine the notion of what we mean by quality in human services by moving from simple satisfaction with human services to the attainment of personal outcomes related to the new public policy that promotes the attainment and continuation of meaningful lives deeply imbedded in our communities for all those with disabilities. Health and safety will be closely linked to the presence of long term committed relationships and power and authority (with assistance as necessary) over the resources needed to support those lives.
8. Address the workforce issue by assisting in an historic coalition of individuals with disabilities and those who support them directly. Invite organized labor and disability leaders to work together in mutual concert and create new arrangements that honor the value of both groups. Specifically this endeavor would target for income and asset development both individuals with disabilities and those who support them directly: the first and the second most impoverished groups in human services.

Social Security and Private Income

The introduction of private money at the intersection of Medicaid and Social Security should become a feature of any plan to reform the Medicaid long term care system.

Medicaid beneficiaries of working age typically receive either Supplemental Security Income or Social Security Disability Income. Both programs contribute inadvertently to the continued impoverishment of these recipients. The SSI rules, e.g., deduct 1 dollar for every two dollars earned after an \$85 disregard is taken. This has the effect of creating a 50% tax on earnings until the entire SSI benefit is lost. As the data in the appendix show the unemployment rate for Medicaid/Social Security beneficiaries is an astonishing 91%. Of those 9% who are working the average annual income is only \$6500. Almost all

beneficiaries remain personally impoverished. Their cash Social Security benefit by itself is hardly enough to obtain a safe place to live and to eat since room and board is typically excluded in Medicaid funded community programs. The risk of working, however, under exceedingly complex rules and disincentives, keeps so many who want to work from the labor market.

Until the Congress addresses this problem a modest addendum to this plan might incorporate a waiver from the Social Security Administration of the \$85 trigger for reducing earnings and move that figure to about \$400 a month which is where it would have been if the figure had been simply adjusted for inflation over the last 30 years. Combined with the creation of individual development accounts or savings accounts for specific purposes that do not jeopardize benefits, a major attempt at creating real employment and self employment to address these distressing figures would be possible. Private income generation would begin the process of reducing average per capita costs as well.

Older adults who become disabled frequently plan to divest their assets five years in advance of seeking Medicaid support. Instead, for those who are able to afford private long term care insurance (and subsidies for those who can't) individuals could be rewarded for contributing to the cost of support in older years without having to suffer the indignity of giving up all of their assets as they melded private insurance coverage with Medicaid support in an unbroken line.

Currently, only about ten percent of Americans over the age of 55 have private insurance protection for long-term costs. Medicaid does pay for long-term care; however, it pays only for those who have exhausted nearly all of their own resources first. In order to receive Medicaid coverage, an individual must “spend down” their assets.

The Robert Wood Johnson Foundation funded a demonstration project, the *Program to Promote Long-Term Care Insurance for the Elderly* (originally called the Partnership for Long-Term Care), to provide states with resources to plan and implement private/public partnerships (Partnership programs). The original demonstration model has been underway since 1992 in California, Connecticut, Indiana and New York. The Partnership programs joined private, long-term care insurance with Medicaid to offer high-quality insurance protection against impoverishment from the costs of long-term care — including both nursing home care and/or home care.

Consumers who purchase such policies are insured for long-term care up to a pre-set dollar level through the private insurer. Once the private insurance is exhausted, they can continue their long-term care under Medicaid without spending their assets, which is usually required to meet the criteria for Medicaid eligibility. In this program, Medicaid covers long-term care costs incurred beyond the terms of the private coverage, and assets protected by the private long-term care policies also are exempt from the Medicaid asset test.

In 1993, citing concerns about the appropriateness of using Medicaid funds for this purpose, Congress imposed a moratorium on new states entering the Robert Wood Johnson Foundation demonstration project in the Omnibus Budget Reconciliation Act of 1993. However, with the passage of the *Deficit Reduction Act of 2005* in February 2006, the technical barriers have been lifted now allowing for the expansion of the Partnership to other states. This new legislation authorizes changes in state law to allow individuals to purchase private long-term care insurance that coordinates with Medicaid. For states that adopt this approach, individuals will be able to purchase private long-term care insurance policies with the assurance that Medicaid will cover long-term care costs that may be incurred beyond the terms of the private coverage. Individuals with this private insurance will not be required to “spend down” their remaining assets to qualify for Medicaid. (“From Impoverishment to Income and Assets: A Roadmap Out of Poverty” is a report that details the myriad ways private dollars could be brought to bear on the costs of long term care. It is soon to be released by the Center for Self-Determination)

Many older Americans are house rich and cash poor. In return for contributing to their support and supplementing Medicaid coverage these older Americans could accept ethically structured reverse mortgages that would allow them to stay in their homes and also receive a monthly cash allotment while also preserving assets. Based on the approach pioneered through the melding of long term care insurance with Medicaid this is an additional way to assist older Americans and preserve their right to remain well served in their own homes.

The Gathering Storm

The traditional Medicaid funded long term care system is under enormous pressure and that will only increase in the coming years. States are proposing cuts in the magnitude of billions of dollars without thought as to their consequences. A recently proposed reduction in case management utilization would actually result in increased expenditures for unnecessary institutional care. Some present efforts recognize the need for reform but fail to understand the need for a more comprehensive approach that does not harm individuals and families. A true bi-partisan effort is required, and the political will to get the job done.

The aging of America with fewer family members to provide support for individuals with disabilities represents part of what is now clearly a perfect storm. The pressure to serve disparate populations of those who experience disability is growing. Many states show increasing waiting lists and narrower definitions of eligibility. With total Medicaid spending now reaching and even exceeding expenditures on primary and secondary education in many states, the pressure to control costs will increase exponentially.

The choices currently being considered to severely limit eligibility for Medicaid and deny necessary services represent a serious retreat from a historical commitment to our nation’s most vulnerable citizens. Current budget deficits at a state and federal level have focused the attention of policymakers on finding ways to control costs. At the same time, the expectation level of individuals with disabilities and their families to restore everyday

freedoms and expand the level and scope of community participation continues to grow. A reform proposal for Medicaid and Social Security can support both of these objectives. Policymakers need to study this issue carefully and come up with new and original proposals, not just thoughtless budget cuts

APPENDIX

This Appendix provides detailed background statistics and related information to support the proposal in the reform plan.

Patterns of Change in Medicaid Long-Term Services and Supports

In spite of some gains in community based supports for older adults and people with physical disabilities, the majority of our public resources are still heavily invested in nursing homes. As Chart 1 illustrates the distribution of Medicaid long-term care expenditures (LTC) with major Medicaid programs between 1995 and 2006. It shows that the most rapidly growing Medicaid program during the period was Home and Community Based Services (HCBS) for Elderly and Disabled (E/D) recipients. Still at the end of the period nursing facility expenditures made up 70% of all Medicaid expenditures for E/D recipients. There remains strong institutional focus in the Medicaid program, despite a growing percentage of total dollars going to community-based supports.

Chart 1. Medicaid LTC Expenditures for Older Adults and People with Physical Disabilities, in 1995 and 2006

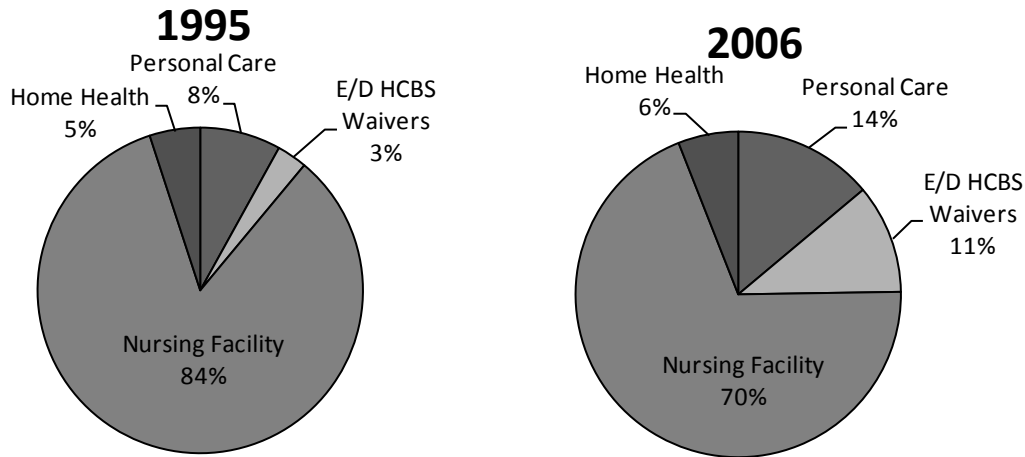
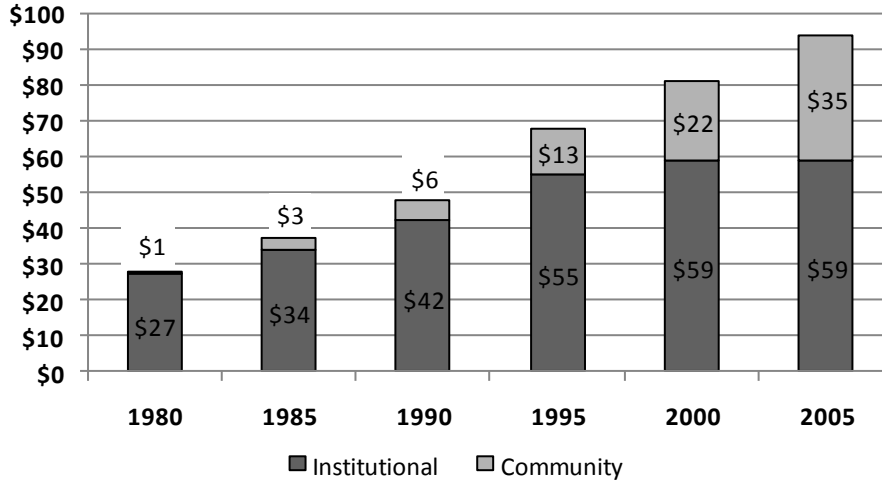


Chart 2 provides a breakdown of expenditures for Medicaid institutional care (nursing facility and intermediate care facility) and community care (HCBS, personal care and home healthcare) between 1980 and 2005 with adjustments for inflation using the Skilled Nursing Facility Input Price Index. This chart includes expenditures for E/D LTC recipients and also for recipients with intellectual and developmental disabilities (ID/DD). It shows first that the community care expenditures increased substantially in real terms between 1995 and 2005. But during the same period institutional expenditures, even expressed in inflation adjusted dollars increased from 55 to 59 billion dollars, and institutional expenditures, similar to what was noted with E/D recipients in

Chart 1, by far the largest expenditures (59 billion dollars as compared to 35 billion dollars for community care services).

Chart 2. Medicaid Institutional and Community-Based Expenditures in 2005 Dollars: FFY 1980-2005



Source: CMS Form 64 Reports, adjusted for price increases based on the Skilled Nursing Facility Input Price Index.

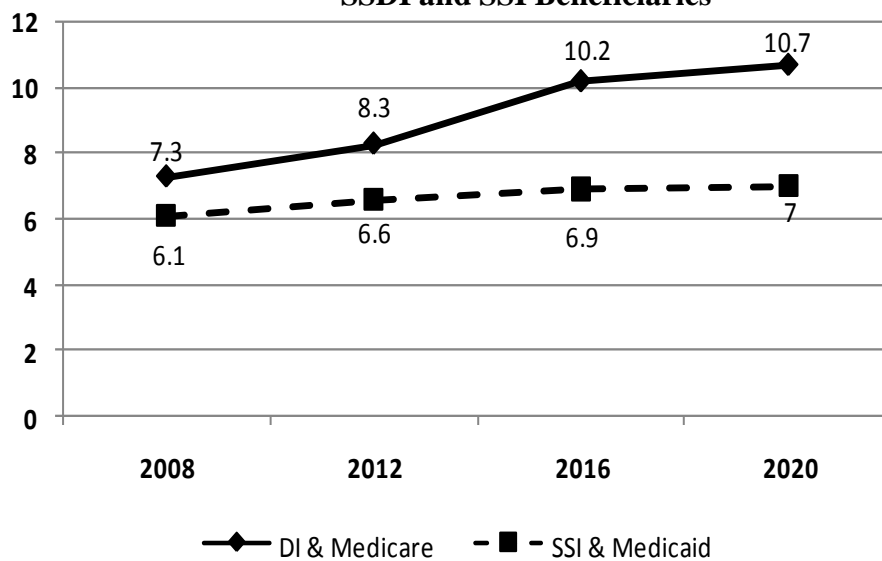
Four major programs provide health, cash assistance and long term care for individuals with disabilities: Medicaid, Medicare, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). These programs intersect in that SSDI recipients are eligible for Medicare and in most states SSI eligibility also establishes eligibility for Medicaid. As shown in Chart 3 these programs are expected to increase in size rapidly in the near future, from serving approximately 13.4 million Americans in 2008 to just under 18 million by 2020, assuming that current standards of eligibility and financing policy are maintained.⁹

These projected increases in total numbers of persons who will be eligible for disability programs will greatly exacerbate already existing problems in meeting demand. In 2005 there were over 260,000 people on waiting lists for services and supports necessary to live in the community.¹⁰

⁹ NISH Institute for Economic Empowerment. (2008). Exploring the Interaction Between the NISH AbilityOne Program and Federal Benefit Programs.

¹⁰ Kaiser Family Foundation Report: "Long-Term Service and Supports: The Future Role and Challenges for Medicaid," by Judith Kasper, Barbara Lyons, and Molly O'Malley (September 2007, .PDF format, 30p.). www.kff.org/medicaid/upload/7671.pdf

**Chart 3. Projected Growth in
SSDI and SSI Beneficiaries**



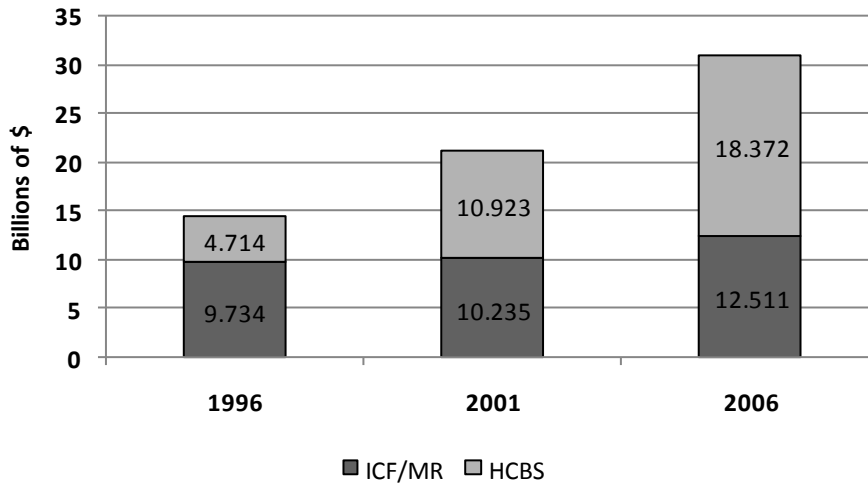
Source: ©2008 NISH Institute for Economic Empowerment

Access to funding for community services for those with intellectual and developmental disabilities is better. As shown in Chart 4 in 2006, 40.5% of the \$30.9 billion dollars was spend on Medicaid institutional services; 59.5% on Medicaid home and community services. The proportion of expenditures for community services continues to grow.

Although there has been a shift in total expenditures for persons with intellectual and developmental disabilities from institutional care the per person expenditures for institutional care are much greater than for community care and the difference continues to grow. In 2006 it cost on average three times as much for institutional care as for home and community services. Chart 4 summarizes the difference in average per person annual expenditures for Medicaid long-term services in institutional and community settings in 1993 and 2006.¹¹

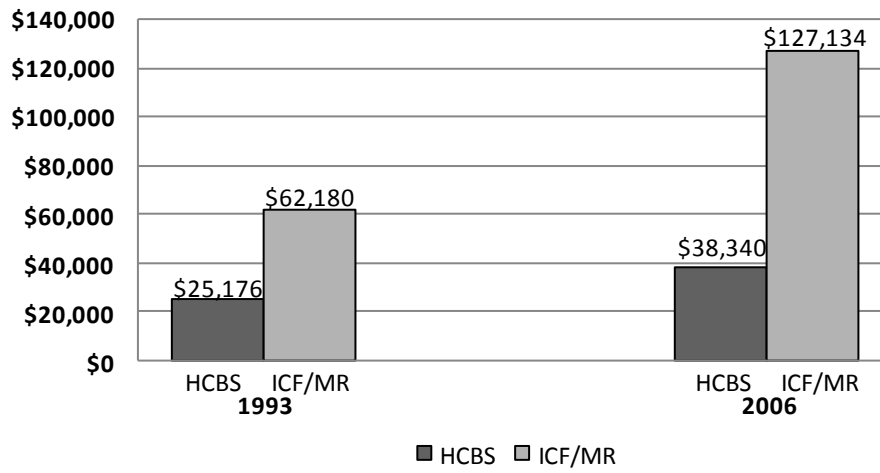
¹¹ K.C. Lakin, K. Alba, and R.W. Prouty. (2007). Chapter 9: Utilization of and Expenditures for Medicaid Institutional and Home and Community Based Services. In R.W. Prouty, Gary Smith & K.C. Lakin (Eds.), Residential services for persons with developmental disabilities: Status and trends through 2006. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Chart 4. Distribution of Medicaid Long-Term Care Expenditures for Medicaid Institution (ICF/MR) and Home and Community-Based Services, 1996, 2001 and 2006



While total expenditures for persons with intellectual and developmental disabilities receiving home and community services now exceed expenditures for persons in Medicaid institutional programs, there remains a substantial imbalance with regard to per person expenditures. Unlike the closing gap between total institution and community expenditures for persons with intellectual and developmental disabilities, the gap in per person expenditures between institutional and community services continues to grow. In 1993 the average per person annual expenditures for Medicaid home and community based services was about \$25,200 as compared with about \$62,200 for institutional care (a difference of \$37,000 per person per year or 147% more for institutional care). In 2006 the average per person annual expenditure for Medicaid home and community based services was \$38,400 and for Medicaid institutional care was about \$127,100 (a difference of \$88,800 per person per year or 231% more for institutional care). The growing imbalance in expenditures for institutional and community services is difficult to ignore in the context of the tens of thousands of people waiting for services and the steadily increasing total Medicaid expenditures.

Chart 5. Average Per Person Annual Expenditures for Medicaid Long-Term Services and Supports, 1993 and 2006



Source: 2008 RISP Report (2007)

In addition to difficult funding issues, the workforce issue is critical to discussions of a community-based support system. Assuring community-based supports will rely heavily on underpaid and undervalued direct support workers and families. Family care giving responsibilities are rising and creating greater stress than ever before especially as future potential family caregivers decline in numbers. An estimated 2.9 million people with intellectual or developmental disabilities are living with caregivers – about a quarter of whom are parents who are 55 years or older.¹² One reason for the heavy dependence on family caregivers is that the community system keeps Medicaid beneficiaries personally impoverished and requires the impoverishment of older Americans who must rely on public supports. A plan for systemic reform must address all of these issues and change the default from institutional care to the community so that no one will have to choose a nursing home or institution simply because institutions also provide housing and food.

The Federal and State funded Medicaid program together with Social Security and Medicare are a lifeline for poor Americans and for those with disabilities. Its long term care provisions for almost 14 million presently consumes almost 40% on average of all state Medicaid resources—more than half in some states and expends over \$100 billion federal and state funds. Total Medicaid expenditures for acute and long term care were \$303,882,398,422 in FY 2006.¹³ On average, for both acute and/or long term care children cost \$1,509, adults \$2,021, elderly \$11,455 and disabled individuals \$13,014. This results in a national average expenditure of \$4,202 per enrollee. However, State expenditures vary widely with average expenditures varying from a low of \$2,722 in Arizona to highs of over \$7,000 per enrollee in states like New York, Connecticut, Maine and Rhode Island. These programs serve almost 50 million individuals in a wide array of different programs governed by regulations of varying complexity. In 2004, about 20% of the population was enrolled in the Medicaid program.—the largest group being children enrolled in acute care coverage.¹⁴

The Medicaid program has been described by the National Governor’s Association as their biggest single budget worry.¹⁵ It has been described by beneficiaries and families as institutionally biased, unnecessarily complex and often unfair.

At the intersection of Medicaid, Medicare and Social Security there are hundreds of thousands of pages of regulations. By way of contrast, the entire Internal Revenue Service Code only takes up 75,000 pages of regulations.

¹² Ansberry, Clare. “When Crisis Hits the Disabled.” Wall Street Journal. April 29, 2008.

¹³ The Kaiser Family Foundation, statehealthfacts.org. Data Source. Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on data from Centers for Medicare and Medicaid Services-64 reports, July 2007. <http://www.statehealthfacts.org/comparetable.jsp?cat=4&ind=177>.

¹⁴ 2007 CMS Statistics. U.S. Department of Health and Human Services. This reference booklet provides significant summary information about health expenditures and Centers for Medicare & Medicaid Services (CMS) programs. Available at www.cms.hhs.gov/CapMarketUpdates/Downloads/2007CMSstat.pdf.

¹⁵ *The Fiscal Survey of States: December 2007*. National Association of State Budget Officers (NASBO) and the National Governors Association (NGA). This edition of The Fiscal Survey of States reflects actual fiscal 2006, preliminary actual fiscal 2007 and appropriated fiscal 2008 figures. The data were collected during fall 2007. Available at www.nasbo.org/Publications/PDFs/Fiscal%20Survey%20of%20the%20States%20December%202007.pdf.

Within the present long term care Medicaid community program, there are eight different configurations for developing state plan and waiver programs including mixed authorities and the ability to provide for a single disability population per Waiver or multiple populations per Waiver. Under the Deficit Reduction Act of 2005,^{16 17} certain Waiver provisions may be moved into State plan provisions that do not require reauthorizations. Each program has its own eligibility criteria and service definitions. Often states have several Waivers (some with 8 or 9 including several for the same populations) with additional state plan provisions.

Three primary institutional arrangements can be funded by Medicaid: skilled nursing homes, institutions for those with developmental disabilities, and hospitals for a smaller mental health population. Together, these arrangements consume approximately 59% of all long term care Medicaid resources. However, states may seek waivers that allow them to provide community-based services and supports rather than funding only these institutional arrangements. There are currently 297 active Waiver programs in the 50 states.¹⁸ The cost of housing and food generally cannot be paid as part of any of these community programs.

The number of people served in institutional arrangements is a fraction of those eligible for supports now and in the future especially compared to those living in the community and receiving support or waiting for support including those will soon reach eligibility.¹⁹ In fact, Medicaid community programs are fast becoming overwhelmed by those seeking admission. Waiting lists for supports are growing and in some states outnumber those served. Institutional placements are guaranteed, but community supports under waiver programs are not. There are over 260,000 people on waiting lists for community based services. The real number is not known but is probably much higher. Some states do not keep waiting lists. In 2006, 280,176 individuals were on waiting lists for 93 waivers in 31 states, up from 260,916 individual in 2005 and 206,427 individuals in 2004.²⁰

Three major populations are illustrative of the enormous fiscal and personal issues confronting this country: older Americans, those with physical disabilities and those with developmental disabilities.

¹⁶ Deficit Reduction Act of 2005: <http://www.whitehouse.gov/news/releases/2006/02/20060208-9.html>.

¹⁷ The Kaiser Family Foundation. The Kaiser Commission on Medicaid and the Uninsured, Deficit Reduction Act of 2005: Implications for Medicaid, Issue Brief, February 23, 2006. Available at . <http://www.kff.org/medicaid/7465.cfm>.

¹⁸ CMS Waiver and Grant Management Database (WGMD); CMS 64 Reports; and Medstat review of state and CMS websites.

¹⁹ Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on data from Centers for Medicare and Medicaid Services-64 reports, July 2007.

²⁰ The Kaiser Family Foundation. The Kaiser Commission on Medicaid and the Uninsured, Medicaid Home and Community-Based Service Programs: Data Update, Issue Paper, December 2007. Available at . <http://www.kff.org/medicaid/7720.cfm>.

Persons Who Are Aged and/or Disabled

Most Medicaid expenditures for persons who are aged and disabled (A/D) go to nursing facility care. In 2006, about \$20.3 billion dollars were spent on Medicaid personal care, home health, and home and community-based services for persons who are A/D as compared with \$47.7 billion dollars for nursing facility care.²¹ But it is important to recognize that nursing facilities are not exclusively places of long-term housing and nursing facility populations are not static. People come in and out for a variety of reasons. The 2004 National Nursing Home Survey (NNHS) did not report information on admissions, but in 1999 the NNHS estimated that two-thirds (68%) of nursing facility stays were 3 months or less.²²

The most manageable way to look at nursing facilities is probably a snapshot of nursing home residents in mid-2006. According to the Kaiser Family Foundation, there were at that time about 1,376,000 nursing facility residents.²³ According to the estimates of the most recent National Nursing Home Survey (2004),²⁴ about 45.2% of nursing facility residents were 85 years and older, about 43.1% were 65-84 years and 11.7% were persons under 65 years old. About 33,200 of the persons in nursing facilities were persons with intellectual and/or developmental disabilities—a placement that is especially onerous and inappropriate.

Of course, not all nursing home residents are Medicaid recipients. Only an estimated 65%, or about 894,500, nursing facility residents in mid-2006 were Medicaid recipients. With fiscal year 2006 Medicaid nursing facility expenditures of \$47.7 billion dollars,²⁵ the annual average per person expenditure was about \$53,300. This compares with a reported \$66,800 average annual cost of nursing home care for private-pay residents in shared rooms, according to the 2006 MetLife Market Survey of Nursing and Home Care Costs.²⁶ More recent reports set the average annual nursing home expenditure at \$70,000.²⁷

²¹ Eiken, S. and Burwell, B. Medicaid HCBS Waiver Expenditures, FY 2001 through FY 2006 Thomson Healthcare: August 2007.

²² Jones A. The National Nursing Home Survey: 1999 summary. National Center for Health Statistics. Vital Health Stat 13 (152). 2002.

²³ C. Harrington, H. Carrillo, C. Crawford, and C. LaCava. Table 4, "Nursing, Facilities, Staffing, Residents, and Facility Deficiencies, 2000 Through 2006," Department of Social and Behavioral Sciences, University of California, San Francisco, accessed January 2008. Available at <http://www.pascenter.org>. Based on the Online Survey, Certification, and Reporting system (OSCAR), Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services.

²⁴ US National Center for Health Statistics: "2004 National Nursing Home Survey," (August 2006, compressed ASCII and SAS format (data), .PDF (documentation), and SAS, SPSS, and Stata input statements). <http://www.cdc.gov/nchs/nnhs.htm>

²⁵ Eiken, S. and Burwell, B. Medicaid HCBS Waiver Expenditures, FY 2001 through FY 2006. Thomson Healthcare: August 2007.

²⁶ MetLife Mature Market Institute, *The MetLife Market Survey of Nursing Home & Home Care Costs*, September 2006 (2007).

²⁷ U.S. General Accounting Office. 2007. Medicaid Long-Term Care: Few Transferred Assets before Applying for Nursing Home Coverage; Impact of Deficit Reduction Act on Eligibility Is Uncertain. GAO-07-280. Washington, DC: March 2007.

Using the estimates of the 2004 NNHS,²⁸ in 2006 there were about 622,000 persons who were 85 years old and older in nursing homes. These persons made up approximately 11.75% of all persons 85 years and older in the U.S. Using the NNHS estimates, there were 593,100 nursing facility residents between 65 and 74 years. These persons made up about 1.9% of the 31,963,000 persons between 65 and 74 years. In contrast only about 0.6% of the 262,138,000 persons younger than 65 years in the U.S. in 2006 were in nursing facilities.

According to the most recent edition of the Older American's Chartbook for 2008,^{29 30} in the United States in 2006, there were an estimated 37 million people age 65 and over. By 2030, this age group is expected to grow to 71.5 million, and increase to over 80 million by 2050. In 2006, there were 5.3 million people aged 85 and over. By the year 2030, people in this age group are expected to grow to a little under 10 million, with a projected rapid growth to about 21 million by 2050. Therefore, at present rates of nursing facility placement the number of nursing facility residents between 65 and 74 years will increase from about 593,000 in 2006 to 879,000 in 2020, 1,174,000 in 2030, 1,227,000 in 2040 --- more than doubling in just more than 30 years. Among persons 85 years and older, the dynamics are even more notable. In 2006 11.75% of persons 85 years and older were nursing home residents. If such "placement rates" were maintained, the numbers would increase from 622,000 in 2006 to 854,100 in 2020, 1,128,350 in 2030, and 1,810,600 in 2040 (three times the number of 2006). Much smaller growth would be evident among persons under 65 years.

The total impact of this aging of the U.S. in terms of nursing facility placements (presuming no changes in nursing facility placement rates) is shown in Chart 6. Chart 6 reveals that between 2006 and 2030 the nation's nursing facility population (in the absence of placement rate changes) will increase by about 1.1 million persons or about 80%. Again, assuming maintenance of current practices and placement rates in 2040 nursing facility residents would be 2.3 times as many as in 2006.

Chart 6. Projected Nursing Home Residents (in Millions) Without Placement Rate Changes, 2006-2040

Year	<i>Projected Nursing Home Residents (in millions)</i>			Total
	<u>Under 65</u>	<u>65-74 yrs.</u>	<u>85+ years</u>	
2006	.16	.60	.62	1.38
2020	.17	.90	.85	1.92
2030	.18	1.17	1.13	2.48
2040	.19	1.23	1.81	3.23

²⁸ US National Center for Health Statistics: "2004 National Nursing Home Survey," (August 2006, compressed ASCII and SAS format (data), .PDF (documentation), and SAS, SPSS, and Stata input statements). <http://www.cdc.gov/nchs/nnhs.htm>

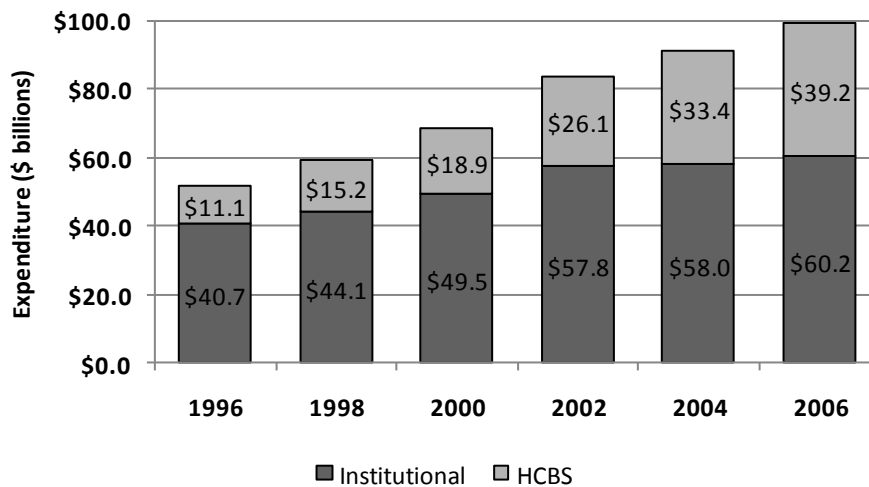
²⁹ Federal Interagency Forum on Aging-Related Statistics. Older Americans 2008: Key Indicators of Well-Being. Federal Interagency Forum on Aging-Related Statistics, Washington, DC: U.S. Government Printing Office. March 2008. Available at http://www.agingstats.gov/agingstatsdotnet/Main_Site/Data/Data_2008.aspx.

³⁰ U.S. Census Bureau projections. Table 2a. Projected Population of the United States by Age and Sex: 2000 to 2050. Available at <http://www.census.gov/ipc/www/usinterimproj/>.

Medicaid nursing facility expenditures continue to increase. They grew from \$39.6 billion in 2000 to \$47.7 billion in 2006 (20%).³¹ Resident populations of nursing facilities have been considerably stable in recent years, increasing from 1,344,000 in 2000 to 1,376,000 in 2006 (5%). (Again only about 65% of nursing facility residents are Medicaid beneficiaries).

In the midst of the demographic pressures noted above, the relatively slow growth in nursing facility residents is attributable to a fundamental shift in the focus and associated costs of Medicaid support. In recent years there has been steady expansion of non-institutional Medicaid financed services. This is most notable in comparing Medicaid institutional service expenditures (nursing facility and ICF/MR) with Medicaid Home and Community Based Services expenditures. Between 2002 and 2006 the former increased by about 4% while the latter increased by 50%. This is shown in Chart 7.

Chart 7. Medicaid Expenditures for Institutional and Home and Community Services, 1996-2006.



Source: Thomson Healthcare annual reports on Medicaid expenditures.

In spite of this alarming data on demographics, the preference for avoiding nursing homes is dramatic. Since 1985 the percentage of older individuals entering nursing homes has declined from 4.2% to 3.6% in 2004 for all those over the age of 65. Even more dramatic is the decline in admissions for those over the age of 85 when chronic disability is more common. That sub group of older persons over 85 went from a 21.1% admission rate in 1985 to 13.9% in 2004--the most dramatic decline of all within the population of older Americans in nursing homes. Nursing home utilization rates declined. While the number of certified nursing home beds increased 15% between 1985 and 2004 the number of residents increased by only 10%.³² Total Medicaid costs, however,

³¹ Eiken, S. and Burwell, B. Medicaid HCBS Waiver Expenditures, FY 2001 through FY 2006 Thomson Healthcare: August 2007.

³² Lewin Group, Nursing Home Use by Oldest Old Sharply Declines (November 21, 2006).

increased proportionately. This means that while older Americans are rejecting the nursing home as a preferred alternative the sheer numbers of the increase in this population will continue to focus public resources on the less preferred alternative. Nursing home services are an entitlement under Medicaid while community services under the Medicaid Waiver law remains an option at the discretion of the individual state. Many Medicaid State Plan supports do not equal in intensity the needs of some elders.

Among persons who are aged and/or disabled (persons other than those with ID/DD) who in the absence of home and community-based services would be at risk of nursing facility placement, it is estimated that approximately 1.96 million receive Medicaid personal care (PC) and home health (HH) services (here we rely on 2003 data) and about 600,400 (2004 data) receive Medicaid Home and Community Based Services (HCBS). In 2006, the combined expenditure for home health, PCA and HCBS for these persons was an estimated \$20.3 billion (including \$13.1 billion for Medicaid personal care and home health services). The average Medicaid HCBS expenditures for aged and/or disabled persons were about \$12,100 per year. The average annual expenditures for Medicaid personal care and home health services for persons who are aged and/or disabled were about \$6,700.

Persons with Intellectual and Developmental Disabilities

Persons with intellectual and developmental disabilities (ID/DD) are considerably more likely to receive Medicaid Home and Community Based Services (HCBS) than institutional (ICF/MR) services. In June 2006, of the 578,000 combined HCBS and ICF/MR recipients, 83.0% were HCBS program participants³³ and approximately 2.8 million of the 4.7 million persons with ID/DD in the United States were receiving residential support from family caregivers.³⁴

About 41% of all HCBS recipients and 72% of all HCBS expenditures in 2006 were for persons with ID/DD. Both institutional (ICF/MR) and HCBS expenditures for persons with ID/DD are considerably higher on average than for persons who are aged and/or disabled. Institutional (ICF/MR) care for persons with ID/DD averaged \$124,969 per person per year in FY 2006 as compared with \$53,300 per person for Medicaid financed care in nursing facilities. (Now estimated as much higher) Home and community based services for persons with ID/DD averaged \$39,819 in 2006 as compared with \$12,100 for persons without ID/DD.

The importance of the shift from Medicaid ICF/MR to HCBS for persons with ID/DD includes both benefits in individual outcomes as well as cost benefits. To exemplify the cost-benefits, in 1993, 63.0% of all 234,333 Medicaid ICF/MR and HCBS recipients with

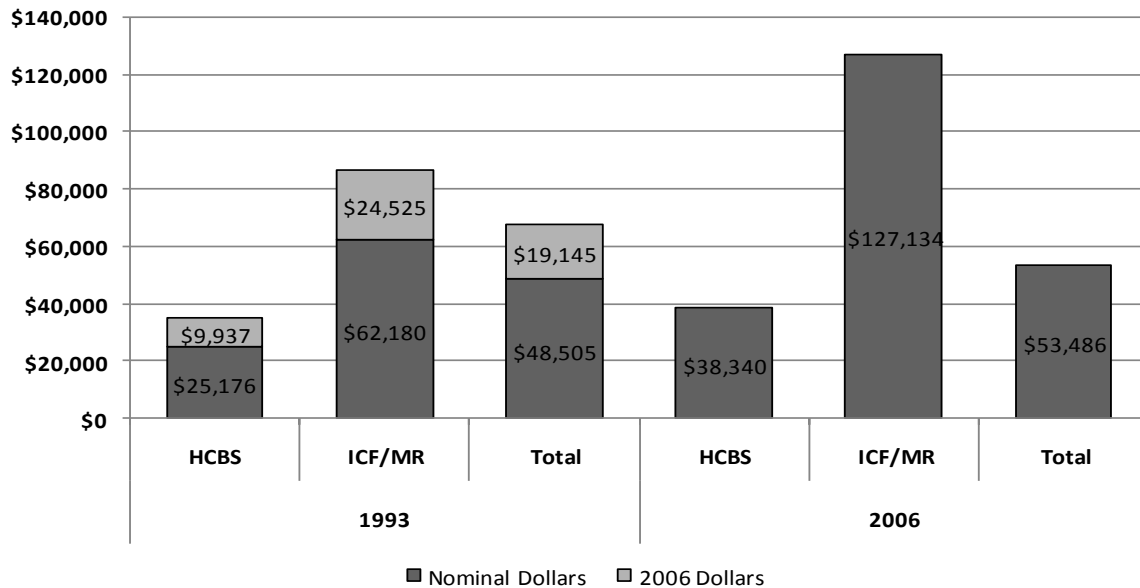
³³ Lakin, K. C, Prouty, R, and Alba, K. Medicaid Institutional and Home and Community-Based Services Expenditures for Persons With ID/DD Within the Overall Medicaid Program. Intellectual and Developmental Disabilities: December 2007; 45 (6):418-421.

³⁴ Braddock, D., Hemp, and R., Rizzolo. (2008). State of the states in developmental disabilities: 2008. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado.

ID/DD were in ICFs/MR.³⁵ The combined average cost of their services in 1993 was \$62,180. In 2006 only 17.0% of all Medicaid ICF/MR and HCBS recipients with ID/DD were in ICFs/MR and their average cost was \$127,134 per year.³⁶ In 1993 the 37.0% of ICF/MR and HCBS recipients with ID/DD receiving HCBS had an average annual cost of services of \$25,176 (dividing average recipients by total costs). In 2006, the 87.0% of all ICF/MR and HCBS recipients receiving HCBS had an average cost of \$38,340.³⁷

Because of the substantial shift from high cost institutional services to lower cost HCBS, even though the average per person expenditures for ICF/MR and HCBS costs increased by 104% and 52%, respectively, the total per person average for the combined total of Medicaid ICF/MR and HCBS recipients increased only from \$48,505 per year in 1993 to \$53,468 per year in 2006 (10%). In inflation-adjusted 2006 dollars the average actually decreased from \$67,650 to \$53,468 (-20%). Chart 8 shows the impact of this shift on average expenditures for Medicaid long-term care services for persons with ID/DD.³⁸

Chart 8. Average Per Person Annual Expenditures for Medicaid Long-Term Services and Supports for Persons with ID/DD in Nominal Dollars and 2006 Dollars, 1993 and 2006



Source: RISP 2007

³⁵ Lakin, C, Prouty, R, and Coucouvanis, K. Average Per Person Medicaid Long-Term Services Costs Increased at One Fourth the Rate of Inflation Between 1993 and 2004 With Shift to Home- and Community-Based Services. *Mental Retardation*: 2005 October; 43 (5):381–384.

³⁶ Lakin, K. C, Prouty, R, and Alba, K. Medicaid Institutional and Home and Community-Based Services Expenditures for Persons With ID/DD Within the Overall Medicaid Program. *Intellectual and Developmental Disabilities*: December 2007; 45 (6):418-421.

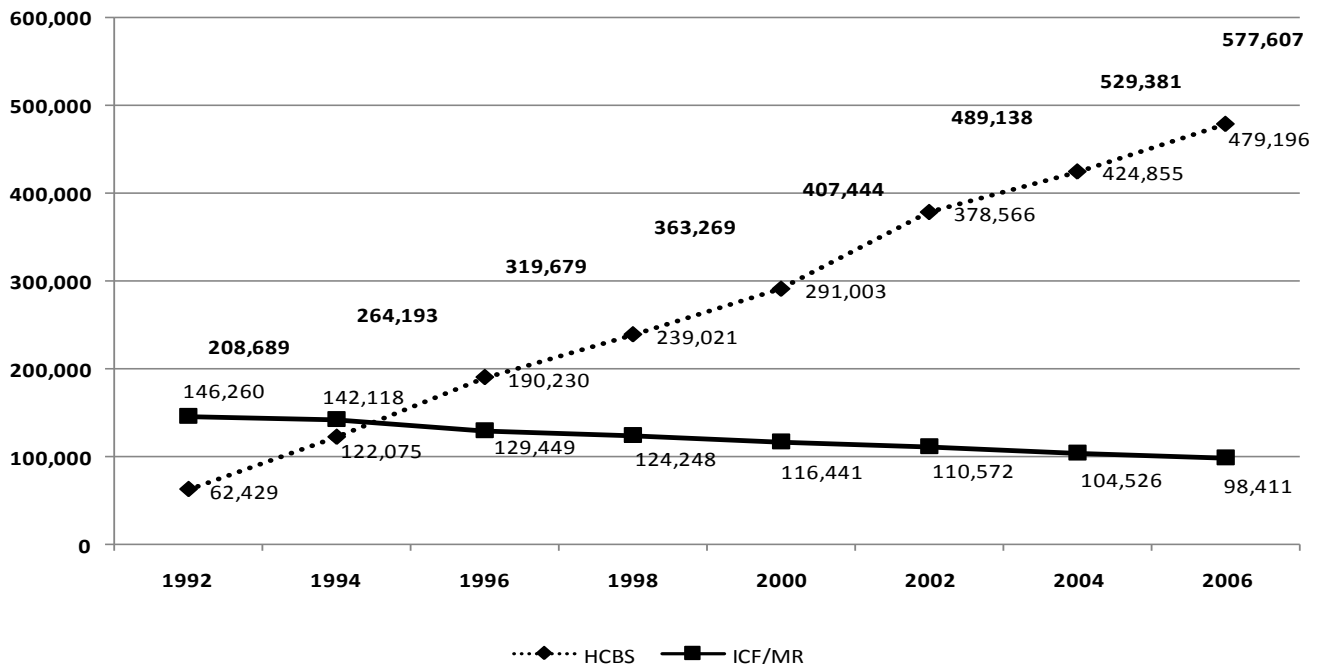
³⁷ K.C. Larkin, K. Alba, and R.W. Prouty. (2007). Chapter 9: Utilization of and Expenditures for Medicaid Institutional and Home and Community Based Services. In R.W. Prouty, Gary Smith & K.C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

³⁸ Ibid.

One of the significant factors in controlling the per person expenditures for HCBS recipients (a real dollar increase of only 10% between 1996 and 2006) has been the steady growth in the number of HCBS recipients living with family members, from 21.1% of the total in June 1992 to 46.8% in June 2006.³⁹ Clearly when individuals live with family members many of the supports that would be provided by paid staff in other settings are provided by family members. Data from a random sample of 1,400 adults with ID/DD in 4 states in 2005 indicated that including both HCBS and other Medicaid services, average annual expenditures for persons living with family members (\$25,072) were 41% of the average annual expenditures for HCBS recipients (\$61,788).

Of course, per person expenditures are just one component of overall costs. There has been a rapidly growing number of HCBS recipients in recent years⁴⁰ (from 62,400 in June 1992 to 291,300 in June 2000 to 479,200 in June 2006). There has been a much more modest decrease in institutional (ICF/MR) recipients (from 146,300 in June 1992 to 116,900 in June 2000 to 98,400 in June 2006). These are shown in Chart 9.

Chart 9. Medicaid ICF/MR and HCBS Recipients, June 1992-June 2006



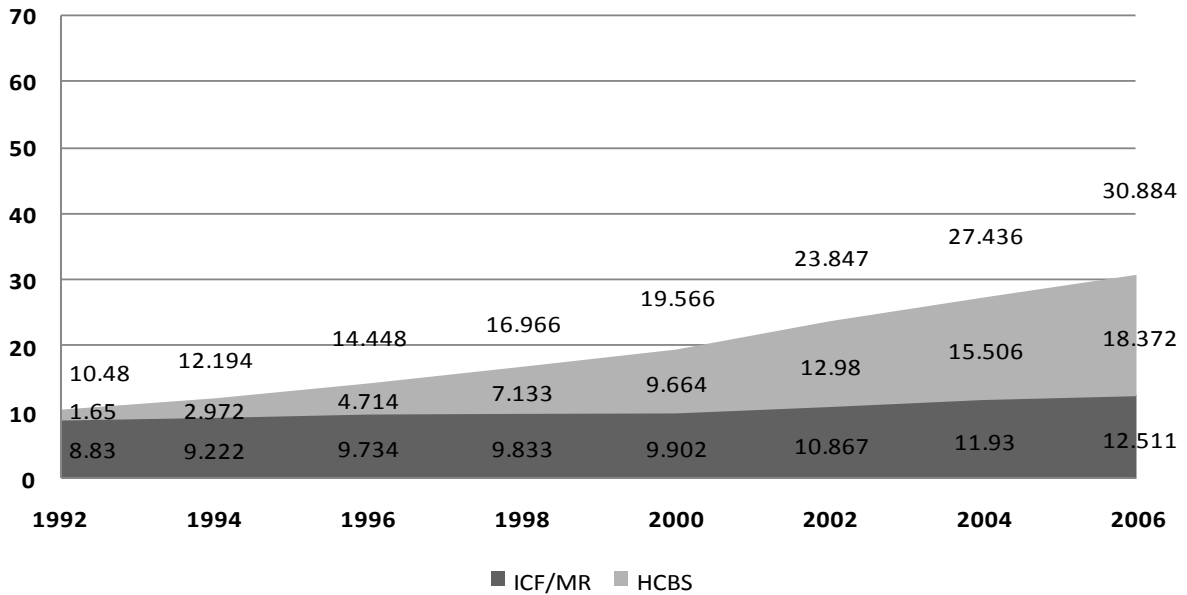
As a result of the major increases in total combined Medicaid HCBS and ICF/MR service recipients (from about 208,700 in 1999 to 577,600 in 2006); Medicaid expenditures for persons with ID/DD have grown rapidly. These combined expenditures increased from

³⁹ Lakin, K. C, Prouty, R, and Coucouvanis, K. HCBS Recipients Are Increasingly Likely to Live With Parents or Other Relatives. *Intellectual and Developmental Disabilities*: October 2007; 45 (5):359-61.

⁴⁰ K.C. Lakin, K. Alba, and R.W. Prouty. (2007). Chapter 9: Utilization of and Expenditures for Medicaid Institutional and Home and Community Based Services. In R.W. Prouty, Gary Smith & K.C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

\$10.48 billion in 1992 to \$19.55 billion in FY 2000 to \$30.88 billion in FY 2006. The increases are shown in Chart 10.

Chart 10: Medicaid ICF/MR and HCBS Expenditures FY 1992-2006



Although there has been rapid growth in Medicaid long-term services and supports for persons with ID/DD in the past 15 years, the demographics of aging parents rather than potential service recipients will play a dramatic role in future expansion of service demand for persons with ID/DD though potentially less than is the case for persons with other disabilities. Support needs for persons with ID/DD are much less associated with reaching advanced age, as intellectual and developmental disabilities by definition are essentially life-long. Growth in need for support for persons with ID/DD is more directly linked to the size of the adult population than the elderly adult population. *There are, however, significant potential pressures on service demand because of the total number of persons with ID/DD living with family members who are 55 years and older.* Here is where demographics once again play a significant role. According to the National Health Interview Survey-Disability Supplement, there were an estimated 583,000 persons with ID/DD living with family members 55 years and older in 1995. Given demographic shifts that number today exceeds 600,000, more than all the people with ID/DD receiving residential supports in non-family living arrangements. In addition to demographics of age, other socio-demographic factors will increase demand for Medicaid services and support. It is clear that there will be significant implications in the long-term.

(People Waiting for Services

The demographic pressures of aging populations, aging caregivers, increased longevity (and hence service years), the changing expectations for and response to support needs of family caregivers and other factors have created demands in services and supports for persons who are A/D and ID/DD that substantially exceed availability. Statistics on persons waiting for services are complicated by many factors including states' rules about waiting lists, and tendencies for people to put themselves on lists well in advance of need. Statistics on persons waiting for services also appear to be more consistently reported for persons with ID/DD than for persons with A/D. The state reports of waiting lists for persons with A/D suggest they are much larger than for persons with ID/DD, in part because of growing demographic pressures but also relatively smaller proportions of service dollars committed to community supports. In a relatively narrow definition of only people waiting for out-of-family residential services who have developmental disabilities desired in the next 12 months, an estimated 84,500 people were waiting in June 2006. To meet that narrow definition of persons waiting for services would require a 20% increase in spending for services for persons with ID/DD or over 6 billion more dollars. But beyond these statistics national estimates of the total numbers of disabled persons waiting for both in-home and residential service reach 300,000 and more.

Implications of Growing Demand on Formal Support Providers

In addition to the major fiscal challenges in financing the growing demand for Medicaid long-term services and supports, even with current service delivery approaches, should resources be available, there will be great difficulty in recruiting and retaining the needed support providers. Chart 11 uses Department of Labor estimates to show the magnitude of that difficulty.

Chart 11. Projected Growth in U.S. Labor Force (in hundred millions) and in the Number of Persons Employed in Long-Term Services and Support (LTSS) (in millions)

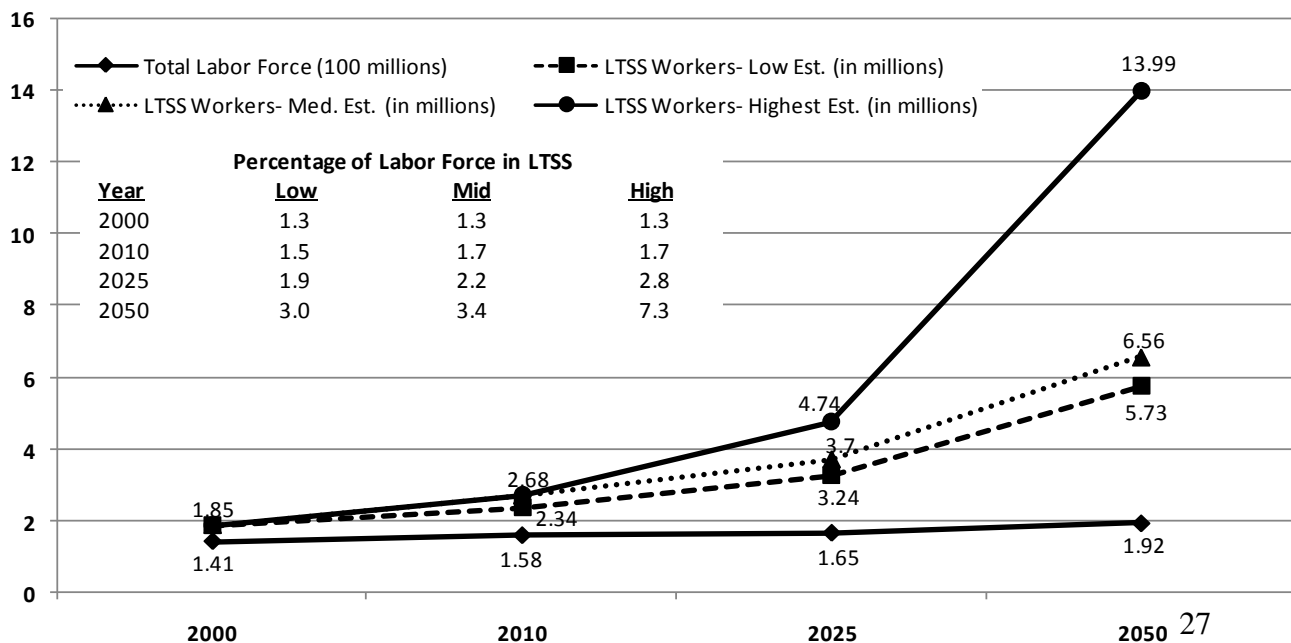


Chart 11 shows low, middle and high estimates by the Department of Labor of the growth in the number of persons who will be needed to be employed in providing long-term services and supports in the U.S. between 2000 and 2050. The solid line on the bottom shows the increase projected for the total U.S. labor force. Focusing on the middle estimate and looking out only until 2025, the percentage of the total U.S. labor market employed in long-term services and supports is projected to increase from 1.3% to 2.2%, or in terms of total persons from 1.85 million to 2.68 million (45%). The projected growth in U.S. labor force is expected to grow from 141 million to 165 million during the same period (17%). This represents enormous challenge in a system that is already plagued by chronic turnover averaging 50% or greater nationwide and widespread vacancies that frequently results in people authorized to receive services not receiving those services or receiving less of them than they were determined to need.

This serious labor force issue can be expressed another way as well. With regard to older Americans for those with resources, assisted living and some home based care has begun the diversion of many away from nursing homes. Medicaid does pay for home health care for those eligible and, while a growing number are taking advantage of it, many do not know about it or assume the nursing home is the only alternative. Nearly 12% of those now in nursing homes received no assistance at home prior to admission⁴¹. (Gold, 2008)

The majority of assistance, however, for those who choose to remain at home is provided by a relative--usually an adult female child. Up to 41% of baby boomers now provide financial or personal care assistance to an aging parent. 61% are female. While the number of aging persons almost doubles by 2030 the number of adult female children declines from 1.74 per older adult to under 1. Put more directly, as the population of older individuals almost doubles the traditional female caregiving population only increases by 7%.⁴² As a result, society depends on the caring work of many paid professionals and our society will increasingly depend on these workers as the number of elderly continues to grow.⁴³ In fact, direct care jobs are projected to be the fastest growing occupations in the nation between 2004 and 2014.⁴⁴ Direct care workers (personal care assistants, home care and home health aides, and certified nursing assistants) generally receive lower wages and lack health insurance and experience high turnover. Variation exists in terms of wages: hospital aides have the highest median hourly wages (\$11.06), followed by nursing home aides (\$9.13) and home health aides (\$8.50). In 2005, (60% of direct care workers had health insurance through the private sector), 38% received health insurance through their employer, 22% relied on public health insurance (primarily through Medicaid or Medicare), and 25% had no health insurance coverage.⁴⁵ When a large but vastly underpaid community workforce is added

⁴¹ Nursing Home Data Compendium - http://www.cms.hhs.gov/CertificationandCompliance/12_HNs.asp

⁴² "Toward a Stable and Experienced Caregiving Workforce," by Mary Ann Wilner. In *Generations*, Vol. XXIV, No. 3, Fall 2000.

⁴³ Smith, Kristin, and Reagan Baughman. 2007. Low wages prevalent in direct care and child care workforce. Carsey Institute. Policy Brief 7:1—12.

⁴⁴ Hecker, D. 2004. "Occupational Employment Projections to 2012." *Monthly Labor Review*. Washington, DC: U.S. Bureau of Labor Statistics.

⁴⁵ Smith, Kristin, and Reagan Baughman. 2007. Low wages prevalent in direct care and child care workforce. Carsey Institute. Policy Brief 7:1—12.

to this equation the preferred community alternative for the majority of aging Americans becomes more problematic.

Almost Universal Impoverishment

As distressing as the 70% unemployment rate for all individuals with disabilities is, the unemployment rate and the underemployment rate for recipients of Social Security benefits and Medicaid and Medicare is far worse. Of all 10,811,00 persons receiving public benefits in 2006 only 55,742 or 0.005% left the benefit program for work. Social security data for 2006 indicate that only 9% of all beneficiaries worked—a startling unemployment rate of 91%. Of those who did work the average wage was just over \$6,500 keeping even this small sub population way below the poverty line.

Of 6,807,000 Disability Insurance recipients only 36,242 left the rolls for work. More than twice as many or 89,335 left the beneficiary program through death. Of 3,812,000 SSI beneficiaries only 19,500 left for work in contrast to 109,372 who died that year. (Source: ©2008. NISH Institute for Economic Empowerment)

The Changing Paradigm

The philosophy of Independent living advanced for decades by individuals with physical disabilities, the new recovery movement in mental health and the self-determination movement to ground supports deeply in our intergenerational communities among all populations including those with the most significant disabilities are all converging and joining their voices in a call for reform of the long term care system in this country. This reform is principle based and includes moving control of public dollars from facilities and programs directly to individuals usually through the mechanism of a fiscal agent employed by the state. It includes the use of brokers or peer mentors to support individuals and the ability to create a personal support budget from a targeted allocation of public dollars.

Self direction and self-determination are now present in some form in all of the states. Michigan state regulation allows any individual with a developmental or psychiatric disability to control an authorized sum of dollars to create a support plan.⁴⁶ Further, Michigan wrote a definition of “medical necessity” that includes community and relationships that are “Designed to assist the beneficiary to attain or maintain a sufficient level of functioning in order to achieve his goals of community inclusion and participation, independence, recovery, or productivity.”⁴⁷ Wisconsin’s new Waiver⁴⁸ for

⁴⁶ Michigan Department of Community Health, Mental Health and Substance Abuse Services, Self-Determination Policy & Practice Guidelines. (July 18, 2003). Available at www.michigan.gov/documents/SelfDeterminationPolicy_70262_7.pdf.

⁴⁷ Michigan Department of Community Health. Medicaid Provider Manual, Mental Health/Substance Abuse, 2.5. Medical Necessity Criteria. Version (April 1, 2008), p. 12. Available at http://www.michigan.gov/mdch/0,1607,7-132-2945_5100-87572--,00.html.

individuals with physical and developmental disabilities, as well as older individuals who qualify for support is based on the philosophy of self-determination.

Indeed, the cultural revolution led by younger adults with disabilities appears to have begun working on older Americans who, like their younger counterparts, universally reject the nursing home and institution as a first choice. Today all states permit older adults to participate in at least one self directed service and recent research on those who experience dementia have shown that with proper assistance they can benefit as well.⁴⁹

But older Americans and those soon to be are not accepting the system as it is presently designed. New cooperatives run by community members especially those who are older and in need of supports are developing across the country. These are cooperatives dedicated to assisting older Americans to continue to live in intergenerational communities.⁵⁰ They are assisting individuals to purchase everything from home repairs and modifications to personal care assistance.

For those with various psychiatric disabilities fundamental reform is already underway. One of the most significant recent projects is the Florida self direction pilot for 400 individuals with psychiatric disabilities.^{51 52} The Florida pilot like so many other projects indicate that a growing body of research and practice that promote recovery are more successful and lead to greater stability and less frequent hospitalizations.

The National Council on Independent Living recently testified before the Congress that they had successfully prevented 28,000 people from entering nursing homes, helped 2,800 leave nursing homes and served another 300,000 individuals with disabilities in their own community.⁵³

This evolving grass roots movement is characterized by a core value system that promotes the ongoing contribution that individuals with disabilities make to their communities, the resulting cost effectiveness of creating alternatives to costly institutions support for a “place of one’s own” and control (with assistance when needed) of the resources necessary to live or continue a meaningful life deeply embedded in the community. With one voice, they are also raising profound objections to a system that keeps them personally impoverished or requires it in return for receiving public support.

⁴⁸ Wisconsin Community Options Program. The Community Options Program (COP) and the Community Options Program Waiver (COP-W) help people get the long-term support they need to remain in their own homes and communities. More information is available at http://dhfs.wisconsin.gov/LTC_COP/cop.htm.

⁴⁹ Tilly, Jane, Consumer-Directed, Home and Community Services for Adults with Dementia, Alzheimer’s Association, Public Policy Issue Brief, July, 2007.

⁵⁰ “A Grass Roots Effort to Grow Old at Home,” *New York Times*, 14 August 14 2007, Section on Health. Available at <http://www.nytimes.com/2007/08/14/health/14aging.html?pagewanted=1&r=1>.

⁵¹ Haines, S. LMHC, Spaulding-Givens, J. MSW (2007) The Philosophy, Principles, and Practice of Florida Self-Directed Care and Recovery Coaches. Florida Department of Children & Families, Substance Abuse & Mental Health Program Office.

⁵² Hall, R. Ph.D. (2007) Report on the Effectiveness of the Self-Directed Care Community Mental Health Treatment Program. Florida Department of Children & Families, Substance Abuse & Mental Health Program Office.

⁵³ National Council on Independent Living's 2nd Annual Congressional Policy Briefing. 26 February 2008.

