Study of Funding and Support for Home and Community-Based Care

for Older Adults and Persons with Alzheimer's Disease

Special Act 14-6

Submitted to the Connecticut General Assembly
January 1, 2015

Prepared by:

Connecticut's Legislative Commission on Aging

~ a nonpartisan public policy and research office of the Connecticut General Assembly

State Capitol, Room 509
210 Capitol Avenue
Hartford, CT 06106

Website: cga.ct.gov/coa
email: coa@cga.ct.gov
Phone: 860-240-5200

In Special Act 14-6, An Act Concerning a Study of Funding and Support for Home and Community-Based Care for Elderly Persons and Persons with Alzheimer's Disease, the Commission on Aging was charged with studying:

- private sources of funding available to elderly persons and persons with Alzheimer's disease in need of home or community-based care;
- the availability of programs funded by the state that provide home or community-based care to elderly persons and persons with Alzheimer's disease in need of home or community-based care; and
- the cost effectiveness of such programs funded by the state;
- with recommendations on which state programs should be expanded

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Snapshot of Long-Term Services and Supports:

- Connecticut is the 7th oldest state in the nation with the 3rd longest lived constituency.
- Over 70,000 people age 65 and older live with Alzheimer's Disease or another dementia. (Alzheimer's Task Force, 2014)
- Disabilities affect 10.4% of all Connecticut residents or 367,557 individuals in 2010 (LTC Planning Committee, 2013).
- People of all ages may require long-term services and supports (LTSS).
- It is estimated that 69% of people 65 year of age and older will need LTSS at some point: 79% for women and 58% for men. On average, they will need three years of LTSS (Kay, 2010).
- Home and community-based services (HCBS) which honor individual preference and rights and costs less for both the private pay consumer and the state/federal government.
- Medicaid is the primary payer of LTSS. In Connecticut, Medicaid LTSS expenses accounted for 47% of the Medicaid budget and 14% of the State budget, in 2012 (LTC Planning Committee, 2013).
- A major transformation is taking place in Connecticut to "rebalance" the LTSS system to be person-centered and honor individual choice in where and how they receive LTSS (toward HCBS) which costs less.
- This shift toward prioritizing HCBS is reflected in the increased proportion of Medicaid LTSS expenditures for HCBS (in contrast to institutional care) from 23% in 1996 to 43% in 2013 (Department of Social Services, MFP 2013).
- Connecticut has an array of HCBS, funded primarily through federal funding streams with a state match (Medicaid). Few state HCBS programs exist in isolation of another funding source.
- Though the rebalancing movement is specific to Medicaid LTSS, it will have a ripple effect, creating sweeping change across the entire system and on behalf of individuals of all ages and disabilities (and payer sources) who receive LTSS.
- Due to rebalancing, aging demographics and consumer choice, demand for HCBS is expected to increase exponentially in coming decades.
- The majority of HCBS for older adults and persons with disabilities is provided by informal caregivers. The estimated economic value of informal care in Connecticut is $5.8 billion (AARP-CT, 2014).
- Though progress has been made to spur culture change, improve choice, enhance self-direction and access to HCBS, many inequities, barriers and service gaps remain.
- Although less expensive than nursing home care, the cost of HCBS could exhaust roughly 77% of the median income of the typical older middle-income family in Connecticut (AARP, 2014).
- State policies must create new ways to help individuals pay for their LTSS needs (while maintaining economic security), support the informal and formal workforce and continue to improve LTSS systems.
- Connecticut's communities are encouraged to foster "aging in place" and create 'livable communities" that include affordable and accessible housing and transportation options, supportive community features and opportunities for meaningful community engagement.

Overview ~ Long-Term Services and Supports Landscape

Demographics: Connecticut is undergoing a permanent and historic transformation in its demographics. Between 2010 and 2040, Connecticut's population of people age 65 and older is projected to grow by 57%, with less than 2% growth for people age 20 to 64 during the same period (see Figure 1). Moreover, residents born in Connecticut today can expect to live to be 80.8 years old—the third highest life expectancy in the nation. These demographic shifts will affect many facets of society including our families, communities and government on all levels.

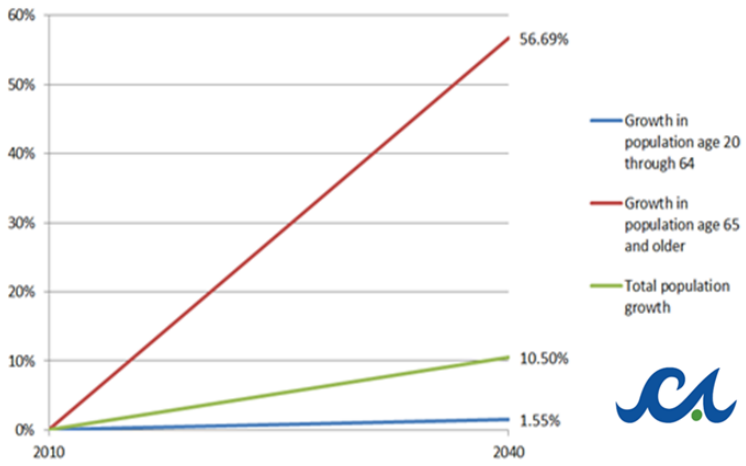


Figure 1: Projected Population Growth in Connecticut from 2010 to 2040. This figure was created and information calculated by Connecticut's Legislative Commission on Aging with population projections provided by the University of Virginia Weldon Cooper Center for Public Service (from 2010 U.S. Census Data).

It necessitates redefining a range of systemic and structural foundations such as: retirement, health care, the formal and informal direct care workforce, long-term services and supports, community livability, and other areas. The goal is to improve the quality of life (e.g. health, economic security and well-being) for present and future populations of older adults, while being responsible regarding the interrelated budgetary and cross-generational issues.

Alzheimer's Disease: This dynamic of changing demographics yields many opportunities and challenges. Specific to people with Alzheimer's disease and other forms of dementia (the population featured in the language that authorized this study) barring effective treatment and prevention – it is estimated that their numbers will nearly triple by 2050 (Herbert, 2013). In Connecticut, there are an estimated 70,000 people 65 years of age and older living with Alzheimer's disease or another dementia (Alzheimer's Task Force, 2014). By 2050 that number is estimated to reach 210,000 people with Alzheimer's or related dementias in Connecticut alone.

Dementia refers to the symptoms caused by disorders that affect the brain impacting memory loss, interfering with normal activity and causing personality changes. Brain damage, strokes or diseases like Alzheimer's cause dementia.

This remarkable increase in the number of those diagnosed with dementia will put a strain on individuals, families, our communities and the health and long-term services and supports systems. For instance, individuals with the disease are hospitalized 2 to 3 times as often as people in the same age group who do not have the disease, and 68% of nursing home residents have a cognitive impairment (Alzheimer's Task Force, 2014). *In addition to the recommendations contained within this report, a comprehensive report was submitted by a legislatively-mandated Task Force on Alzheimer's Disease and Dementia to the Connecticut General Assembly in 2013 (Special Act 13-11).*

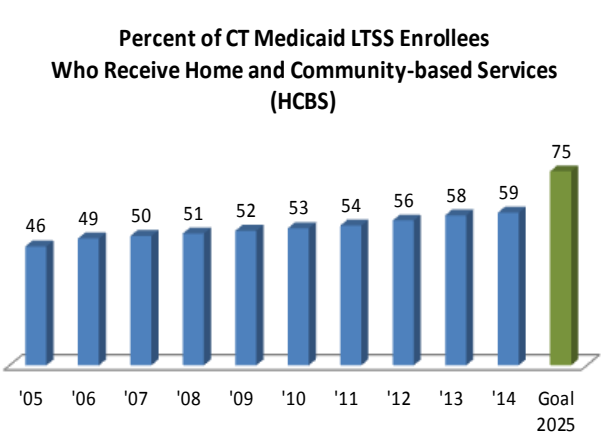
Long-Term Services and Supports (LTSS) Background: LTSS are utilized by individuals of all ages with functional limitations and chronic illnesses who need assistance to perform routine activities of daily living, such as bathing and dressing. The relatively recent focus on LTSS places great emphasis on choice and person-centeredness, the most enhanced and least restrictive setting, with community connection and inclusion. It is provided in a range of settings such as nursing homes, assisted living, congregate housing, personal homes, etc.

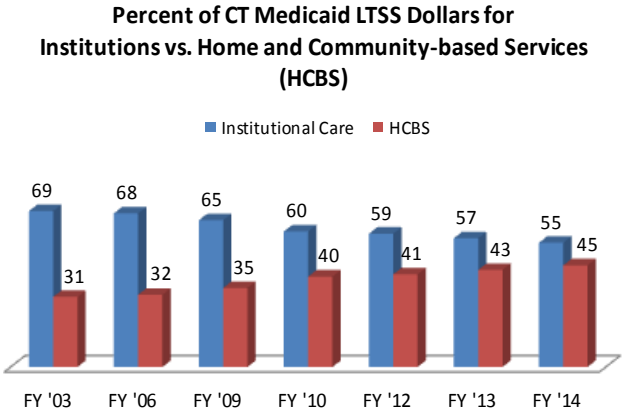
Home and Community Based Services (HCBS): The vast majority of older adults and persons with disabilities want to age in their homes and communities as opposed to receiving care in institutions. Connecticut and states across the nation have a vested interest in providing HCBS as it costs less than institutional care. Medicaid is the primary payer of LTSS. For Connecticut the LTSS paid for by Medicaid represents approximately 14% of the state budget. Historically, Medicaid policy has been institutionally biased in that people who met the functional and financial eligibility requirements were entitled to nursing home care, yet accessing HCBS has been far more subjective. An example of a disparity is if an individual wants nursing home care then they are admitted while Medicaid eligibility is being determined. However, if there is availability in one of the Medicaid HCBS Waivers then the individual must wait, sometimes several months, to receive care while the eligibility determination process is taking place. Though the HCBS system is complicated and difficult to access and navigate, that dynamic is changing in a sweeping fashion spurred by federal funding opportunities and directives and state commitment to planning and policy development.

LTSS Planning and Policy: Personal preference toward HCBS, budgetary motivations and individual rights (please see *the U.S. Supreme Court Olmstead v. L.C.* decision) have led to the federal government, over the past several years, offering states major initiatives designed to incent LTSS "rebalancing". The "rebalancing" movement is the provision of LTSS in the least restrictive setting, compatible with appropriate care and available resources. Under the federal Centers for Medicare and Medicaid Services (CMS) definition, a balanced LTSS system offers individuals a reasonable array of options with adequate choices of community and institutional services, and without a financial and service bias for facility-based services and supports.

Connecticut has been aggressive in utilizing incentives and opportunities provided by the federal government. The federal government through the Deficit Reduction Act and later the Affordable Care Act has been supplying incentive dollars through enhanced Federal Medical Assistance Percentages (FMAP) to help Connecticut and state across the nation rebalance. These initiatives are highlighted on page 7 of this report.

Additionally, Connecticut has dedicated a great deal of planning and conducted several studies and developed comprehensive plans on LTSS. The state of Connecticut, initially through the Long-Term Care Plan, set a goal several years ago that by 2025 the Connecticut Medicaid program should be serving 75% of LTSS clients with HCBS, with only 25% opting for institutional care. Steady progress has been made toward that goal by providing more choice for those with LTSS needs and assuring access. In illustration, the proportion of Medicaid LTSS clients receiving HCBS supports has increased from 46% in state fiscal year 2003 to 59% in state fiscal year 2014. This represents a gradual and steady increase. As far as Medicaid expenditures, 45% was spent on home and community-based services and 55% on institutional care in 2014 (Long-Term Care Planning Committee, 2014).





Though these rebalancing efforts are specific to Medicaid LTSS, they will have a sweeping impact across the entire system and will affect change on behalf of a variety of stakeholders including all individuals regardless of their age, diagnoses, disability or payer source (private, public or some combination) in need of LTSS.

As recommendations for this study are identified, it is important to note that the state LTSS planning approach and programmatic implementation has deliberately been inclusive and has not segmented out certain groups of individuals by age or disabilities. This approach is intended to help minimize gaps that occur when services are designed for a specific age group or diagnoses. Instead, the approach promotes a system that is person-centered and focused on the needs of the individual (LTC Plan, 2012). The majority of the most recent LTSS planning and policies in Connecticut reflect this value.

Additional Policy Consideration: Demand for HCBS will increase due to rebalancing, consumer choice and the aging of our population. Among other HCBS areas, we need continued strategic thinking and action. Below are highlighted areas of consideration:

- **The informal direct care workforce** often referred to as caregivers provide the majority of all care provided. In Connecticut, it is estimated that close to 500,000 people provide assistance to their loved ones with bathing, dressing, finances, transportation and even complex medical tasks like injections and wound care. The total economic value of the care provided by unpaid caregivers is $5.8 billion, double the amount the state invests in LTSS ($2.8 billion) (AARP, 2014).
- **The demand for a formal (paid) direct care workforce** is growing. In illustration, between 2010 and 2040, age 65+ population is expected to increase by 57%, while the "working-age" population is expected to increase by only 2%. By 2022, the Department of Labor (DoL) projects Connecticut will need 68,000 direct care workers (presently 55,000 workers). The largest projected growth is for personal care aids (PCA's), as the demand for PCA's is expected to increase by almost 9,000 workers by 2022 (CT Department of Labor, 2014). With the population shift and rebalancing movement well underway, the need for focused efforts to recruit, train, retain and support paid and unpaid caregivers is essential.
- **Communities clearly have a significant role** in helping people with their HCBS needs and "age in place". Often, communities are the first point of contact for individuals looking for information about LTSS. However, state and federal programs change regularly and local community contacts are not sufficiently engaged with the state to have the necessary resources and information to help their community members navigate the complex system. Further, as our society ages and expects to stay in their homes and communities, the community must be prepared and have the basic "livable community" elements: affordable, accessible and diverse housing and transportation options, supportive community features and services and opportunities for meaningful community engagement.
- **Individuals must plan in advance**. The likelihood that people will need LTSS as they age is significant (an estimated 69% of all people 65 years of age and older will need some kind of LTSS) and LTSS are costly (Kay, 2010). However, planning for future LTSS is minimally done. Individuals and families should plan in advance to create a strategy for LTSS. Doing so enables individuals to utilize their finances most effectively (less likely to deplete savings) and makes it far more likely that care preferences will be realized.

Several HCBS recommendations addressing these and other considerations and obstacles are contained in the "Recommendations" section of this report. These multi-dimensional recommendations suggest that policies must create new ways to help individuals pay for their LTSS needs (and maintain economic security), support the formal and informal direct care workforce, continue to improve LTSS systems and simplify access and engage and encourage Connecticut's communities to reflect new demographic trends and preferences.

Major Reports and Plans: Connecticut has dedicated a great deal of planning to address long-term services and supports (LTSS) in a multi-faceted way with individual choice and budgetary efficiencies as primary drivers. This study highlights much of the in-depth work contained in various comprehensive reports and plans conducted in recent years by subject matter experts, stakeholders and state government innovators. Though not an exhaustive list of all the state LTSS related reports, below are those most prominent and utilized:

- **Connecticut Long-Term Care Planning Committee.** ***Balancing the System: Working Toward Real Choice for Long-Term Services and Supports in Connecticut***, January 2013. The LTSS Plan is developed every three years by the Long-Term Care Planning Committee (comprised of various executive branch state agencies) in consultation with the Long-Term Care Advisory Council (comprised of consumers, advocates and providers) and submitted to the Connecticut General Assembly. It represents the foundation for LTSS planning in our State.

- **State of Connecticut, Department of Social Services (DSS).** ***Strategic Rebalancing Plan: A Plan to Rebalance Long Term Services and Supports, 2013 – 2015***. January 29, 2013. This plan is a result of stakeholder briefings and engagement and data and systems analysis. It also met the requirements of Public Act 11-242, which requires DSS to develop a strategic plan, consistent with the LTSS Plan, to rebalance the Medicaid LTSS system.

- **Alzheimer's and Dementia Task Force Report (Special Act 13-11):** Report of the Task Force was submitted to the Connecticut General Assembly in January 2014.

- **Aging in Place Task Force Report (Special Act 12-6**): The report was submitted to the Connecticut General Assembly in January 2013. It examined 1) infrastructure and transportation, 2) zoning changes to facilitate home care, 3) enhanced nutrition programs and delivery options , 4) improved fraud and abuse protections, 5) expansion of home care options, 6) tax incentives, and 7) incentives for private insurance.

- **Livable Communities Annual Report (Public Act 13-109):** The first of these annual reports was submitted by Connecticut's Legislative Commission on Aging to the Connecticut General Assembly in July 2014.

- **Money Follow the Person (MFP) Quarterly Reports:** These detailed quarterly reports prepared for the Department of Social Services by the evaluators at the UConn Center on Aging, track the status of MFP benchmarks as well as other key data points.

- **Connecticut Home Care Program for Elders (CHCPE) Monthly Reports:** These monthly reports prepared by the Alternate Care Unit of the DSS include such information as number of participants on the various Medicaid HCBS programs and cost savings estimates.

- **Money Follows the Person Workforce Development Strategic Plan:** This plan, last updated in 2012, was developed by the Workforce Development Subcommittee of MFP… *"to build and support a robust LTSS workforce that is sustainable, respected and skilled. The workforce will support the dignity, choice and autonomy of older adult and persons with disabilities."*

- **State Plan on Aging:** The State Department on Aging (SDA) submits this plan every three years to the federal Administration for Community Living (which provides funding to SDA under the Older Americans Act). The most recent plan, submitted in October 2014, serves as a *"blueprint to goals and strategies to better serve older adults".*

Major Federal Initiatives to Support Rebalancing: To promote long-term services and supports (LTSS) rebalancing, the state of Connecticut has pursued and been granted numerous opportunities provided by the Federal Government, primarily the Centers for Medicare and Medicaid Services (CMS). In 2005, the Money Follows the Person (MFP) Rebalancing Demonstration, authorized by section 6071 of the Deficit Reduction Act was designed to reduce the deficit by assisting states to balance their LTSS systems and help individuals on Medicaid transition from institutions to the community. Then, in 2010, with the passage of the Affordable Care Act (ACA), states were afforded a number of new and expanded opportunities, including enhanced federal financing, to improve access to and delivery of Medicaid LTSS. Though working across state departments, as the state Medicaid agency, the Connecticut Department of Social Services (DSS) is the lead for these initiatives. The following is a simple list of these initiatives of which Connecticut has or is in the process of implementing. *For more information on these initiatives go to the Medicaid Medical Assistance Oversight Council website, which posts DSS presentations on these efforts.*

- **Medicare-Medicaid Enrollee (MME) Demonstration for Integrated Care:** DSS is working with CMS and stakeholders on designing this demonstration project aimed at integrating medical, behavioral and non-medical services and supports to MMEs. The demonstration seeks to improve access to primary care and specialists and provide coordination among doctors, hospitals and other providers. Financial incentives will be given to participating providers that achieve health and client satisfaction outcomes**.**
- **Money Follows the Person (MFP) Program**: This is a CMS federal demonstration grant intended to rebalance the LTSS system so that individuals have the maximum independence and freedom of choice regarding where they live and receive services. Since 2007, hundreds of millions of dollars have been invested by the federal government into MFP (at DSS) and Connecticut's rebalancing efforts. In addition to transitioning individuals out of insitutional settings and into the community, MFP is has also been engaged in several initiatives aimed at rebalancing, including nursing home diversification (via $40 million in grant and bond funding through 2017 for nursing homes interested in diversifying their scope to include HCBS), housing access, workforce development, an HCBS presumptive eligibility pilot, nurse delegation of medication, and other efforts.
- **Balancing Incentive Program (BIP)**: The federal government via CMS, offers states enhanced Medicaid funds to implement structural changes, including a no wrong door/single entry point system, conflict-free case management services, and the development of a core standardized assessment instruments. Connecticut DSS received $73 million from the federal CMS for these efforts. As part of the agreement, Connecticut must use the funds to provide new or expanded HCBS.
- **Community First Choice (CFC):** Connecticut DSS is applying for a state plan amendment to include Personal Care Assistant services as part of Medicaid. Connecticut will receive an enhanced 6% federal medical assistance percentage for this service.
- **Demonstration Grant for Testing Experience and Functional Assessment Tools (TEFT):** Connecticut DSS is participating in this CMS federal demonstration project to develop and utilize a core assessment and personal health records for LTSS.

Major State-Funded Home and Community-Based Services (HCBS): State-funded programs that support people in their homes and communities are often utilized in concert with available federal programs and cobbled together to provide the most effective use of dollars. Rarely are state and federal programs utilized in isolation of each other. And rarely are various programs funded solely by either state or federal dollars. For example, Medicaid is jointly funded by the federal government and the participating state government, with federal "matching" funds dependent on state compliance with a myriad of federal requirements. Accordingly, the HCBS landscape is complex, difficult to navigate, and constantly changing to leverage opportunities presented by changing laws and funding. Specifically in Connecticut, continued changes are occurring as a result of the various federal initiatives moving forward as outlined earlier in this report in the section entitled "Major Federal Initiatives to Support Rebalancing" on page 7.

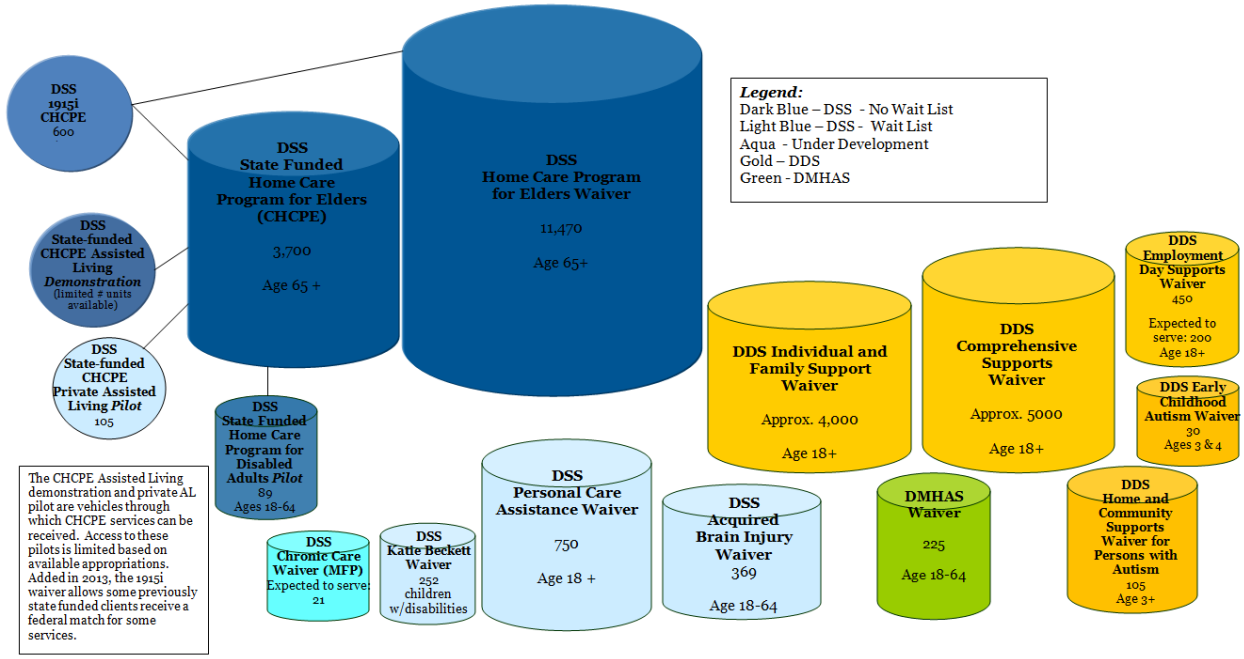
Major HCBS programs for older adults and persons with disabilities include, but are not limited to:

- CT Home Care Program for Elders (state & waiver)
- State funded Assisted Living Services and Pilot
- CT Homecare Program for the Disabled
- Medicaid HCBS Waivers
- Older Americans Act Programs
- State Respite Care Program
- Veterans Affairs

For a comprehensive inventory of state LTSS in Connecticut see Appendix G of the 2013 Long-Term Care Plan.

Connecticut Medicaid HCBS Waivers (& state-funded programs and pilots)

Prepared by: Connecticut's Legislative Commission on Aging



Connecticut Home Care Program for Elders (administered by the Department of Social Services (DSS) and serves approx. 15,000 people): The Connecticut Home Care Program for Elders (CHCPE) provides wide-ranging home health and non-medical services to persons age 65 and older who either are at risk of institutional placement or are at risk of staying in an institution unless home care services are made available. Which services are to be provided is determined by access agencies conducting in-home needs assessments, establishing care plans, and then monitoring these plans over time. The program has a three-tiered structure, and individuals receive home care services in amounts that correspond to their financial and functional needs. Two of the categories are funded primarily with state funds and serves 3,550 people; the third is funded under a Medicaid HCBS waiver which serves 11,230 people. Each category has eligibility requirements. There is no formidable enrollment cap for CHCPE, but there has been a prolonged financial eligibility determination process that inhibits expeditious access to the program. DSS is putting in place several new processes to help ease and expedite eligibility, such as a new HCBS centralized eligibility process and the MFP demonstration that is piloting a presumptive eligibility process. If the pilot is deemed successful, it may be incorporated in the larger HCBS waiver eligibility processes (DSS, Alternate Care Unit, 2014).

State-Funded Assisted Living Services and Pilots (administered by the Department of Social Services): The Connecticut Home Care for Elders Program (CHCPE) offers assisted living services to CHCPE consumers in a variety of ways (e.g. private assisted living pilot, congregate assisted living services, etc.) Assisted living is designed for people who want to live in a community setting and who need help with the activities of daily living (e.g., light housekeeping, laundry, meals and service coordination). Consumers must meet all eligibility criteria for the CHCPE and funding cannot be used for room and board.

State Funded Home Care for Disabled Adults (administered by DSS and serves 98 individuals). The Home Care Program for Disabled Adults program mirrors in both eligibility and services the state-funded portion of the Connecticut Home Care Program for Elders program. The Home Care Program for Disabled Adults was piloted after a significant gap in coverage was identified for persons under the age of 65 (therefore not eligible for the home care program for the elderly) but with similar functional needs due physical and/or a degenerative neurological condition (e.g. Multiple Sclerosis). The program was originally funded for 50 slots, and all 50 slots were utilized within the first year of the pilot. There has been an average of approximately 50 people on a waiting list for this program. The fiscal year 15-16 budget allocated funding for additional slots for the program. The addition of these slots has alleviated the waiting list, according to DSS.

Other Medicaid HCBS Waivers: Medicaid in Connecticut offers an array of programs to help individuals pay for long-term services and supports while living in the community. Each Medicaid HCBS waiver program is associated with distinct age, diagnostic or disability-specific eligibility criteria. They have been woven together over time, according to strict federal eligibility criteria often with a cap on the number of people

they can serve at one time. Historically, these HCBS Waiver programs generally have waiting lists and serve a relatively small number of people. In the 2014 Session of the Connecticut General Assembly, some of the caps were expanded on these HCBS waiver programs (such as for Personal Care Assistance waiver, the Katie Beckett waiver, and the Acquired Brain Injury waiver).

Older Americans Act (administered by the State Department on Aging): The Older Americans Act (OAA) was enacted in 1965 to promote the well-being of people 60 years of age and older and help them remain independent in their communities. The OAA provides federal funds, administered through the State Department on Aging, to pay for information and referrals, counseling, chronic disease self-management, outreach, congregate meal sites and home-delivered meals, the long-term care ombudsman program, and the national family caregiver program, among other services. These federally funded programs are not entitlement programs, meaning that services are not guaranteed but instead are available subject to funding. Federal Older American Act appropriations continue to be reduced, making it increasingly difficult for various OAA-funded programs to meet the growing demand for them.

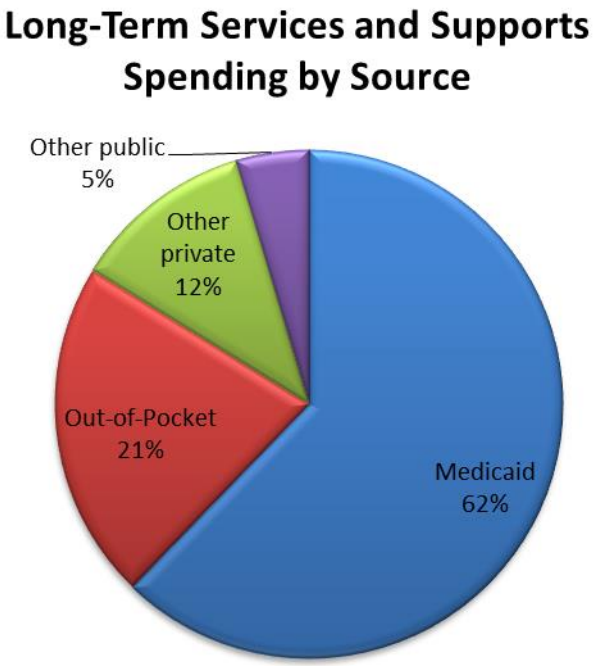
Connecticut Statewide Respite Care Program: The Connecticut Statewide Respite Care Program—the result of a joint partnership between the State Department on Aging, the Area Agencies on Aging, and the Connecticut Chapter of the Alzheimer's Association—offers various services to certain individuals who are caring for an individual with Alzheimer's Disease or other forms of dementia. Eligible families may apply for daytime or overnight respite care services, including but not limited to adult day care, home health aides, or self-directed care. Among other criteria, the applicant cannot be receiving services under the Connecticut Home Care Program for Elders. The program pays for up to $7,500 in respite care services per family per year. A 20% co-payment for the cost of services is required but may be waived due to financial hardship.

Veterans Affairs: Veterans with service-related disabilities or those meeting certain other eligibility criteria receive services funded by the federal Department of Veterans Affairs (VA). These services include nursing facility care, at-home care, and other long-term services and supports. In Connecticut, the federally VA-funded Veteran-Directed Home and Community Based Services program, administered by the SDA, allows veterans self-direction of their care and receipt of services in their home by a caregiver. For veterans with chronic and disabling medical conditions, the Connecticut State Veterans' Home provides long-term, quality health care. The facility also provides end-of-life care, palliative care and respite care.

Paying for Long-Term Services and Supports (LTSS)

In reference to paying for LTSS, this study addresses: 1) the state and federal financing of LTSS, 2) the private (out-of-pocket) sources for paying for LTSS, 3) the cost effectiveness of HCBS from the state's perspective, and 4) the affordability of LTSS from the private payer perspective.

State and Federal Financing of LTSS: Spending on LTSS represented 8% of all personal health care spending in the U.S., estimated at a total of approximately $210.9 billion in 2012. Medicaid is the primary source of payment of LTSS representing 62.3% (or $131.4 billion) expenditures. Out-of-pocket payments represent 21.6% (or $45.5 billion) and other private and public sources of make up the remaining (16.0%) (Robert Wood Johnson Foundation, 2014). *In addition to these expenditures, the national figure unpaid care provided by family members and other caregivers is estimated at approximately $5.8* billion (AARP, 2014)



NOTES Totals do not add due to rounding. Medicaid includes nursing homes, continuing care retirement communities, home health care services, intermediate care services for people with intellectual disabilities, HCBS waiver program, and Children's Health Insurance Program spending for nursing homes and home health. "Out-of-pocket" includes deductibles, copayments, and amounts not covered by health insurance for nursing home and home health services. "Other private" includes private long-term care insurance, other health insurance, and other private spending. "Other public" includes Department of Veterans Affairs, state and local programs and general assistance for nursing homes and home health services, and federal spending for home health services. It does not include Medicare skilled nursing and home health care spending because Medicare pays for such services only when they are medically necessary and not as part of traditional long-term care (O'Shaughnessy, 2013).

Medicaid as the Primary Payer of LTSS: The Medicaid program, jointly funded by the state and federal government, is the primary payer for LTSS nationally and in Connecticut. It helps individuals who do not have sufficient income and assets to pay for their needs or because they have 'spent down' their assets due to the high costs of care and have become nearly impoverished. For example, many older adults become eligible for Medicaid as a result of depleting their assets to pay for nursing home care that Medicare does not cover (with the private pay daily rate for a nursing home averaging $390) (Office of Policy and Management, 2013).

The Connecticut Medicaid program spent $2.8 billion on LTSS in 2012. These Medicaid LTSS expenditures represent 47% of all Medicaid spending and 14% of the State budget and serving 5.8% of the total Medicaid population. (Long-Term Care Planning Committee, 2014).

This number of people expected to need Medicaid LTSS will rise as a result of the rapidly growing aging population. By 2025, more than 48,600 individuals in Connecticut are expected to need Medicaid LTSS – an increase of more than 9,800 individuals over current levels. (LTC Planning Committee, 2013)

Looking at Connecticut's expenses for Medicaid LTSS in more detail, 43% was spent on home and community-based services and 57% on institutional care. Of that 43% for Medicaid HCBS expenditures, services for the developmentally disabled account for 26% of all LTSS expenses and 8% for the Elder, Personal Care Assistance, Katie Beckett, Acquired Brain Injury, and Mental Health waivers combined. (LTC Planning Committee, 2013)

Medicare: Medicare is a federal program that provides health care coverage for people age 65 and older and individuals under age 65 with disabilities. Medicare primarily pays for medical acute care, such as doctor visits, drugs, and hospital stays, and does not, generally, pay for LTSS. Long term nursing facility stays are not covered by Medicare. Medicare only pays for nursing facility stays for up to 100 days following an inpatient hospital stay of at least three days, paying for all of the first 20 days and a portion of the next 80 days. Assisted living costs are not covered. Home health care coverage is limited by type and duration. Some skilled nursing care, therapy services or intermittent home health care is covered if the individual is homebound (as defined per regulation) (LTC Planning Committee, 2013).

Older Americans Act (OAA): Another source of federal LTSS funds is the OAA. The federal Administration on Community Living provided $17.6 million in federal fiscal year 2011 to Connecticut's (State Department on Aging (SDA). Of these funds, $16 million were distributed by formula to the Area Agencies on Aging, who in turn contract with community-based organizations to provide social and nutritional services. The remaining $1.6 million of these funds were special grants received by SDA, including Aging and Disability Resource Centers, Empowering Older People to Take Control of Their Health, Respite Care and Elder Abuse Prevention. (LTC Planning Committee, 2013).

OAA funding is relatively small ($1.88 billion for all states in 2014), especially compared to Medicaid, which spent roughly $136 billion on LTSS in fiscal year 2011 (or $2.8 billion in CT in 2012). However, Medicaid serves low-income people with minimal assets. Many older adults are ineligible for Medicaid but cannot afford the high cost LTSS on their own. (AARP Public Policy Institute, 2014)

Cost Effectiveness of Home and Community-Based Services (HCBS) ~ from the State's Perspective:

The shift toward prioritizing HCBS policies, programming and funding allocation is driven by consumer choice and rights, and cost savings.

A consistent conclusion from research on Medicaid HCBS waivers is that these services provide savings over care in institutional settings over the long term. The data analysis from the Money Follows the Person Program demonstrates that the average cost of serving a Connecticut Medicaid participant in the community is approximately *one third* of the average cost of serving someone in an institution (though this doesn't take into account some types of supports such as housing and transportation).

Further, a cost-effectiveness model for home and community-based care, developed by the Department of Social Services while *evaluating the CT Home Care Program for Elders, calculates annual savings of nearly $113 million compared with serving participants in a nursing facility* (DSS Alternate Care Unit, 2012).

The Connecticut Home Care Program for Elders results in an annual ***savings of nearly $113 million*** *compared with serving participants in a nursing facility. According to the Department of Social Services.* (DSS Alternate Care Unit, 2012)

Accordingly, over time, the proportion of Medicaid LTSS expenses for HCBS has increased from 23% in SFY 1996 to 43% percent in SFY 2013 (Department of Social Services, 2013).

This shift in the proportion of LTSS expenditures toward HCBS is especially prudent given the projections of LTSS expenditures. By 2025, assuming current ratios of institutional and community care and a five percent annual inflation rate, Connecticut can expect Medicaid LTSS expenditures to grow from $2.8 billion in 2012 to $6.368 billion in 2025 (LTC Planning Committee, 2013).

Private Sources of Paying for Long-Term Services and Supports (LTSS):

Nationally, approximately 21.9 percent ($45.4 billion) of LTSS spending was paid directly by individuals in 2010. Out-of-pocket payments for LTSS were the second largest source of LTSS financing (LTC Planning Committee, 2013). These payments include deductibles and co-payments but do not include the valuable amount of uncompensated care provided by unpaid caregivers, which in Connecticut has an estimated value of $5.8 billion (AARP, 2014).

Paying for LTSS is a difficult issue for individuals and families to discuss and understand. Many people mistakenly believe that Medicare and other health insurance programs will cover their LTSS expenses. Planning in advance to create a strategy for LTSS enables individuals to utilize their finances most effectively (less likely to deplete savings) and makes it far more likely that care preferences will be realized.

Private Insurance Spending: In 2010, coverage from private insurance (including Medicare supplemental coverage, traditional health insurance and private long-term care insurance) and other private spending for nursing facilities and home health services represented 11.6% of LTSS expenditures in the U.S. (LTC Planning Committee, 2013).

Private Long-Term Care Insurance: Long-term care insurance covers services for individuals who need support to perform every day activities of daily living. These are services that are generally not covered by Medicare or other health insurance because they are not acute in nature but rather due to a chronic condition. Depending upon the policy, services can be provided in a variety of places, including: a person's home, a nursing facility, through community-based services (i.e., adult day care) and in a variety of assisted living settings (i.e., continuing care retirement communities, residential care homes, assisted living facilities).

Connecticut Partnership for Long-Term Care*:* Administered by the Office of Policy and Management, the Connecticut for Partnership for Long-Term Care is alliance between State government and the private insurance industry. It helps individuals plan for their LTSS needs without risk of impoverishment; enhances private long-term care insurance standards; educates the public about long-term care; and conserves State Medicaid funds. Connecticut Partnership policies have a Medicaid Asset Protection feature, available only for Partnership policies. For every dollar of pay-out in benefits by a Partnership policy, a dollar of assets is protected from Medicaid spend-down rules.

As of January 2014, there were over 57,000 Partnership policies sold in Connecticut. Purchasers of Partnership policies range in age from 20 to 88 years old, with the average age at purchase being 57 years old. Over 1,700 Partnership policyholders have utilized benefits under their policies, with over $133 million in benefits paid. Only 116 Partnership policyholders have accessed Medicaid utilizing the Asset Protection earned under their policies. This has helped the Partnership save the State over $15.3 million in Medicaid long-term care funding (CT Office of Policy and Management, 2014).

Still, despite the success of the Partnership program and the high likelihood of needing of long-term services and supports, only 7-8% of individuals have long-term care insurance. Accordingly, long-term care insurance plays a small role in the private financing of LTSS (Robert Wood Johnson Foundation, 2014).

Reverse Mortgages: Some people might tap into the equity of their homes to pay for LTSS. Home owners who are at least 62 years old may be able to get money to pay for LTSS (or anything else) by taking out a reverse mortgage. Reverse mortgages are designed specifically for older adults so that they can borrow a percentage of the equity in their home as liquid cash without having to either move or make regular loan repayments. They permit house-rich but cash-poor older adults to use their housing equity to, for example, pay for home modifications. Many older adults are now looking to the reverse mortgage as a way to help fund their retirement and/or to purchase long-term care insurance. The loans do not have to be repaid until the last surviving borrower dies, sells the home or permanently moves out. In a reverse mortgage, the homeowner receives a sum of money from the lender, based largely on the value of the house, the age of the youngest borrower, and current interest rates. The lower the interest rate and the older the borrower, the more that can be borrowed.

Financial Planning: Securing adequate financing for long-term services and supports requires investment from several sources, including individuals. Personal financial planning plays a partial but important role in helping individuals prepare for the strong likelihood of out-of-pocket, long-term care costs.

Overall, the costs of LTSS can be staggering and people by and large are not saving for their LTSS needs. The 2006, the legislatively mandated Connecticut LTC Needs Assessment found that 40% of baby boomers (people born between 1946 and 1964) cannot afford to pay anything for the LTSS needs (Center on Aging, UConn Health Center, 2007). In terms of income, according to the national AARP scorecard (2014), though much less expensive than institutional care, the cost of HCBS would exhaust nearly the entire income of the typical older, middle-income family in most states. In Connecticut, the typical cost of home-care services would consume 77% of median income, compared to 47% of median income in the District of Columbia (the most affordable jurisdiction), 111% of median income in Rhode Island (the least affordable state), and 84% of median income nationally (AARP, 2014).

In an attempt to address the problems associated with paying for LTSS, the Affordable Care Act of 2010 created the Community Living Assistance Services and Supports (CLASS) Act, a voluntary public long-term care insurance program. After actuaries concluded the program would not be financially self-sustaining, Congress formally repealed CLASS.

With Medicaid as the primary payer of LTSS, the state and federal government have a vested financial interest in the affordability of home and community-based services for private payers (in addition to those on Medicaid). To the extent state funded programs

and policies help those paying privately to be able to utilize their personal resources in the community for longer, spend down their funds at a slower rate and delay or alleviate the need for Medicaid, the state ultimately saves money.

Alzheimer's Disease and LTSS Costs: Among the biggest challenges for people living with Alzheimer's Disease and their caregivers is the financial burden of care (e.g. home care services, respite services, institutional care). Like other progressive diseases, every stage of the disease has costs associated with it that can become increasingly difficult to absorb as resources dwindle. Consequently, people living with Alzheimer's Disease often rely heavily on Medicaid. As Alzheimer's Disease progresses to later stages and end-of-life care is needed, many individuals turn to hospice care, a covered Medicare benefit that provides comfort, care and support services for people with terminal illnesses in their home or in an institutional facility.

Actual Private Pay Cost of LTSS:

- **Nursing homes:** The average cost of nursing home semi-private room daily rate in Connecticut is $389.62 (Office of Policy and Management, 2013).

- **Assisted Living**: The average cost of assisted living in Connecticut is $4,475 per month in 2012. This cost is the base cost for a one-bedroom assisted living unit in Connecticut. Additional fees beyond the base rate may apply. The monthly base rate for Connecticut assisted living is typically higher when compared to neighboring states and also more expensive compared to the national average (Genworth, 2014).

- **Home and Community-Based Services:** (Office of Policy and Management, 2014)

Type of Service	Average Charge
Adult Day Care (full day)	$85/day
Adult Day Care (half day)	$54/day
Chore Services	$21/hour
Homemaker Services	$20/hour
Companion Services	$19/hour
Live-in Companion	$211/day
Home-delivered meal (single)	$7
Home-delivered meals (double)	$10
2-way Personal Emergency Response System (installation)	$47
2-way Personal Emergency Response System	$44/monthly
Skilled Nursing Visit	$137/visit
RN	$60/hour
LPN	$49/hour
Home Health Aide	$30/hour
Physical Therapy	$142/visit
Occupational Therapy	$142/visit
Speech Therapy	$145/visit

Challenges and Recommendations

The identified challenges and the scope of these recommendations are related to the specific framework of directives mandated in the authorizing legislation for this study (Special Act 14-06) as follows: 1) "the private sources of funding available to elderly persons and persons with Alzheimer's disease in need of home or community-based care", 2) "the availability of programs funded by the state that provide home or community-based care to elderly persons and persons with Alzheimer's disease in need of home or community-based care"; and 3) identified expansion of state HCBS programs. Several of these recommendations reflect concepts put forward in similar plans that are related to the scope of this study. *For policy recommendations across the vast LTSS landscape, refer to the comprehensive plans listed on page 6.*

Availability of HCBS Funded by the State: Home and community-based services represent a combination of funding streams (e.g., federal, state, local). There are few HCBS programs in the state that are supported merely by state dollars. For example, the largest HCBS program in the state for older adults is the Connecticut Home Care Program for Elders (two of the categories are funded primarily with state funds; the third is funded under a Medicaid waiver. Each category has eligibility requirements. Another example is the Elderly Nutrition Program, which is also funded by federal Older Americans Act dollars with the state funding enhancements. The system of LTSS programs and policies are interrelated and highly complex. Therefore, when change happens in the Medicaid LTSS system, it has a ripple effect across all LTSS systems.

Expanding State HCBS Programs: There are a variety of ways to expand programs for people in need of HCBS, including modernizing policies, streamlining processes and building capacity, which will benefit older adults, persons with Alzheimer's Disease and other forms of dementia, caregivers, and people of all ages and disabilities in need of LTSS.

1. **Support for Informal Workforce (Caregivers):** Informal caregivers are the backbone of the LTSS system. It is estimated that the economic value of the care provided by unpaid caregivers is $5.8 billion in Connecticut. Supporting caregivers is a cost effective means of reducing the reliance on costly formal care system. Without support caregivers are likely to become emotionally and physically "burnt-out" and find few options yet to turn to institutional care.

   Recommendations:

   - **Create caregiver tax incentive**: Amend the state tax code to include a Dependent Care Credit where the tax filer can receive a credit for care expenses incurred while a caregiver is working. Home care and adult day care costs are examples of work-related expenses that may be eligible.
   - **Support the Caregiver Advise, Record, Enable (CARE) Act:** The CARE Act would inform and support informal caregivers when an individual goes into the hospital or a rehabilitation facility. The Act requires the hospital or rehabilitation facility to: 1) record the name of the informal caregiver upon admission to a hospital or

rehabilitation facility (as specified by the patient), 2) notify the caregiver if the individual is to be discharged to another facility or back home, and 3) provide the caregiver with an explanation and live instruction of the medical tasks - such as medication management, injections, wound care and transfers - that the informal caregiver will perform at home.

- **Establish paid sick leave for those caring for an aging parent or other relative:** Connecticut enacted legislation (Public Act 11-52) to support families by requiring certain employers to provide paid sick days to service workers. Connecticut's law allows paid sick leave to be used for the service worker's own illness or injury, or to care for the worker's child or spouse; it does not, however, cover workers who care for a parent or other relative. *The Connecticut Family and Medical Leave Act, different from the paid sick leave law, generally allows employees of certain employers to receive up to 16 weeks of unpaid leave in a 24-month period in order to, among other allowances, care for the employee's spouse, child or parent. Conn. Gen. Stat. Section 31-51ll(c).*

- **Promote flexible work schedules:** Studies have shown that flexible work schedule policies are not only an important way to support a caregiver but also benefit the employees. Policies that allow for flexibility enhance productivity, reduce absenteeism and reduce costs. They also positively affect recruitment and retention efforts.

2. **Build, Support and Enhance Quality of the Formal (Paid) Direct Care Workforce:** Understanding and leveraging the informal caregiver workforce, while making the direct care field an attractive option for job seekers, is a necessity.

   Recommendations:

   - **Professional development is needed to align with changing demographics** including geriatric behavioral health training, end of life care and cultural competence around LGBT issues, ethnicity and language. This will build upon legislation (PA 14-194) passed in the 2014 session of the Connecticut General Assembly requiring expanded training for those who serve people with Alzheimer's Disease and dementia.

   - **Increase synergy with Connecticut's workforce system** and support their efforts to create a pipeline of direct care workers with opportunities for career ladders and lattices to health, human and social services professions.

   - **Monitor implications and/or effectiveness of the US Department of Labor's Final Rule concerning domestic service workers under the Fair Labor Standards Act (FLSA), effective January 2015.** This rule brings minimum wage and overtime protections to the workers who, by their service, help older adults and persons with disabilities to continue to live in their homes and communities. Any analysis should include the effect on both the "consumer" (the individual receiving the care) and the worker. The countervailing concern is that HCBS will become less affordable.

3. **Explore Various Methods to Increase the Private Sector's Greater Involvement and Financial Ability as a Payer of LTSS, while Maintaining Individuals' Economic Security.** Private long-term care insurance can make private pay services affordable for those with policies, but market penetration is low.

   Recommendations:

   - **Explore the possibility of incenting employer-based long-term care (LTC) Insurance Coverage**. Explore the possibility of incentivizing businesses to offer LTC insurance policies to their employees. In 2009 almost 25,000 employers in the U.S. offered long-term care insurance to their employees. This market segment remains small and accounts for just over 35% of the roughly 7.5 million policies in force today (The SCAN Foundation, 2012).

   - **Establish a federal tax deduction**: Encourage the Connecticut Congressional delegation to work towards passage of a federal "above-the-line" tax deduction for the premiums paid for a private LTC insurance policy.

   - **Continue to establish rate stabilization provisions**, so that people can be assured that their premiums will not rise too quickly before any benefit is received. The cost of premiums is cited as a main reason for not buying LTC insurance.

4. **Make Reverse Mortgages a More Viable Option:** Explore and vet recommendations of the Reverse Mortgage Task Force (Public Act 14-89), whose work will conclude by January 1, 2015, co-terminus with the deadline of this report.

5. **Preserve funding for the Older Americans Act (OAA):** Although older adults may receive services under many other federal programs, OAA provides a substantial amount of social and nutrition services to people 60 years of age and older living in the community. Work with the federal government to preserve and enhance funding and modernize OAA programs.

6. **Access to Information and Referral:** Access to information about the types of programs and services available to consumers and caregivers continues to be a challenge as families and providers try to connect to both privately and publicly funded services. This complex system is difficult to navigate under the best of circumstances. However, consumers are often not seeking the information until a crisis has occurred, complicating the situation further.

   Recommendations:

   - **Implement a No Wrong Door (NWD) approach:** Offer multiple points of contact for those seeking LTSS information: online, over the phone and in person. As part of NWD, provide training to community-level access points that are often disconnected from the information flow. Many training curriculum have already been developed for Money Follows the Person staff, including some on-line training modules. Extend these training opportunities to community partners.

- **Continue development and implementation of a universal assessment tool** to determine functional eligibility, and integration of systems such as No Wrong Door, MyPlaceCT, ConneCT, and others to increase access and efficiency in providing long term services and supports.

- **Engage individuals and families in advance care planning** (health, prevention, legal, estate and financial): Assure that an inventory of culturally and linguistically appropriate community resources is maintained through state, local and private resources.

7. **Home Modifications and Assistive Technology to Help People Age in Place:** Home modifications are environmental accessibility adaptations to structural elements of the interior or exterior of an individual's home that enable them to function with greater independence in the home, remain in the community and reduce the need for human assistance. Simple modifications include adding nonslip strips to bathroom floors or other smooth surfaces, improving lighting, providing telephones with large numbers and letters, and installing grab bars. More complex (and expensive) modifications include installing ramps, chair lifts, stair glides, widened doorways, roll-in showers, and lowered countertops.

   Recommendations:
   - **Authorize the $6 million in bond money for home** modifications and assistive technology allocated in the 2014 Session of the Connecticut General Assembly (PA 14-98 Section (i)) to build upon the Tech Act administered by the State Department of Rehabilitation Services.

   - Through regional cooperation, **compile a listing of vetted home repair and home modification contractors and programs** to help older adults and persons with disabilities adapt their homes to meet their changing needs.

   - **Standardize access to home modifications across Medicaid HCBS waivers** for parity and maximum efficiency

8. **Enhance Community Spouse Protections:** Allow the community spouse (someone living independently with a spouse in an institutional setting paid for by Medicaid) to keep the $50,000 or half the couple's combined assets up to the federal maximum. (In 2014 in Connecticut, a community spouse was able to keep $23,448.) By doing so, it will better allow the spouse to maintain his or her independence and continue to live in the community, which is a less expensive alternative to institutionalization.

9. **HCBS Provider Issues:** As the landscape of LTSS changes and the population ages, the HCBS provider network is challenged to evolve. Funding adjustments have been slow to align.

Recommendations

- **Establish adequate and sustainable provider reimbursement levels and quality requirements across the LTSS continuum and quality requirements** in order to ensure capacity to meet the evolving needs, preferences and demographics. Connecticut HCBS providers have received 1% in the 7 years. (Note: that Public Act 14-217, Section 78 requires the Department of Social Services (DSS) to analyze the cost of providing services under CT Home Care Program for Elders and CT Home Care Program for Disabled Adults and to issue a report, due January 2015, with recommendations concerning adequate reimbursement to providers). Reimbursements should be adjusted annually to reflect cost of living adjustments.

- **Establish Telehealth Parity to enhance access:** Telehealth is a mode of delivering health care, public health and certain non-clinical services using electronic communications technology. It represents an opportunity for Connecticut to improve access to care, coordination, quality and outcomes for individuals, all while reducing cost, promoting local economic health, and offering a patient-centered approach. Connecticut should join at least 21 other states that have telehealth parity laws for private insurance, meaning that providers can collect reimbursement for telehealth services.

- **Support efforts that seek to integrate health care services and LTSS** while maintaining person-centeredness and valuing a social model (vs. an entirely medial model). This would help ensure better continuity of care and coordination. This is a provider issue as well as a payment and systems issue.

10. **State Funded Home Care Programs for Elders and Disabled Adults and Medicaid HCBS Waiver:** The improvements to LTSS Medicaid system, policies, funding and programs will spur positive change for those paying privately as well.

Recommendations:

- **Continue to implement the consolidation of new processes at** DSS to help expedite eligibility for the state funded Connecticut Home Care Program for Elders, Home Care Program for Disabled Adults and all HCBS Medicaid Waivers, including implementation of a centralized unit for processing all Medicaid waiver applications and piloting a presumptive eligibility process (through Money Follows the Person).

- **Consider design of a consolidated waiver for older and adults and persons with disabilities** and analyze cost implications.

- **Incorporate Respite Care across various HCBS Waivers**: Incorporate respite services across the various HCBS waivers. Redesign of this benefit not only helps family caregivers trying to support their family member at home, but also is a cost effective intervention since it reduces reliance on the formal system. In doing so, evaluate the effectiveness of the Informal Caregiver Support Pilot through the MFP Demonstration.

11. **Explore the Development of Social Impact Bonds for LTSS** in Connecticut. Social impact bonds are pay-for-success arrangements, actualized by partnerships between government, private investors, and nonprofit service providers. In this partnership, private investors provide the upfront capital to pay for social programs, and the government only pays the organizations if the program meets specified performance outcomes.

12. **Address Service Challenges Specific to Housing, Transportation and Behavioral Health**: Lack of affordable housing, rigid transportation services and insufficient behavioral health services present formidable barriers to successful aging in place. Accordingly, a broad range of accessible, creative and supportive housing and transportation options and behavioral health services are necessary to address present challenges.

    Recommendations:

    - **Accelerate investments in alternative, supportive, community housing models for older adults and persons with disabilities**, to complement bringing HCBS to residents of traditional housing.

    - **Invest in growing the stock** affordable housing for all residents.

    - **Develop or enhance mobility management programs** to help older adults and other community members learn how to access and navigate transportation options.

    - **Conduct walkability audits** to assess sidewalks, crosswalks, accessibility and pedestrian linkages to essential services and places for community engagement and employment, and invest in necessary streetscape improvements.

    - **Explore the use of taxi vouchers, public and private paratransit services, paid and volunteer driver services, on-demand car rental services** and other forms of transportation in the growing "shared mobility" economy.

    - **Formalize partnership between health care, public health and social services leaders and professionals** to ensure an integrated system that comprehensively meets the wide-ranging behavioral health needs of older adults and persons with disabilities, including addressing social isolation, loss and mental health issues.

13. **Enhance Community Integration and Connection**: Livable communities offer affordable, accessible and diverse housing and transportation options and public spaces and buildings; supportive community features and services; and vibrancy and opportunities for community engagement. Through its statutory charge to lead the state's livable communities initiative (Public Act 13-109), the Commission on Aging is facilitating public-private partnerships to enhance community integration and connectivity for all residents. See full Livable Communities report with recommendations.

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