MN Elderly Waiver Enrollment Program Evaluation: National Scan

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- Nebraska: Cynthia Brammeier, Ben Stromberg
- Washington: Bea Rector
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Executive Summary

Demographic change and the growth of the number of older adults who need support and care have created pressure to develop cost-effective solutions outside of nursing facilities. As part of a larger study of spenddown to Elderly Waiver eligibility the Minnesota Department of Human Services, Aging and Adult Services Division wished to learn more about how other states’ policies and practices impact how people use their personal resources and make choices about how to meet their LTSS needs. This included interest in gathering more information on other states’ programs and practices that help shape participants’ experiences with spending down their personal resources on the trajectory toward Medicaid financial eligibility.

The national scan engaged colleagues across the nation who are involved in program planning and policy making around the topics of private pay spenddowns and Medicaid enrollment, and incentivizing in-home service arrangements as compared to residential service arrangements. This engagement was performed in two phases:

1. Interviews with national key informants to identify innovative state programs and practices;
2. Outreach to at least ten states, based on information gleaned through the literature review and key informant interviews, to delve into programs and practices that impact how people use their private resources and make choices to meet their LTSS needs.

The key informants represented a diverse set of organizations with different perspectives on state and national long-term services and supports. The key informants represented organizations that:

- work directly with states;
- work to translate federal policy to states;
- represent providers of services; and/or
- advocate for/with consumers of long-term services and supports and those that pay for services and supports.

Four primary topics emerged from the key informant responses:

1. State policies around **asset protection** play an important role in spenddown outcomes.
2. **Programs that target the “pre-Medicaid” population**, including both programs that are 100% state-funded or that are Medicaid demonstration programs, are essential components in slowing spenddown.
3. Maintaining **family caregivers** is key to avoiding placement in congregate residential settings, such as nursing facilities or assisted living.
4. It is important that states provide **robust and timely options counseling** to help people examine available LTSS options and make determinations about which are the best fit for their preferences, needs and personal resources.

Ten states were identified for closer review based on information from the national key informants. An outreach guide was developed to gather information from these ten states on the topics above as well as policies around assisted living coverage by Medicaid. Information was also gathered through publicly available data online. Challenges included the impact of the COVID-19 pandemic on state staff capacity to respond and the relative newness of this topic – not many states have studied this issue, making it difficult to obtain...
quantifiable information. However, through discussion with many state staff, interesting examples of how different states are rising to these challenges were identified.

Key Findings

- State policies around asset protection may impact how people make choices of where and how to receive services. New York has the highest asset limit in the country; this is worth further study to determine if those policies impact how people choose their Medicaid home and community-based services.

- Long term care insurance policies may help to preserve private resources and delay the trajectory to Medicaid. Washington State recently enacted a publicly funded long term care insurance benefit, funded with a payroll tax on all W-2 workers. Only people who meet certain conditions may opt out of this program. The state believes that this program could save $3.7 billion taxpayer dollars by 2052.

- Pre-Medicaid programs, whether state-funded or Medicaid-funded, can meet targeted needs at an earlier point and potentially delay or prevent full Medicaid eligibility. Indiana’s CHOICE program is an example of an older program that is being modernized to meet more targeted needs. The state of Washington is experiencing promising early results from a Medicaid 1115 Transformation waiver, the Medicaid Alternative and Targeted Supports to Older Adults program that was implemented in 2017, which seeks to provide targeted supports and caregiver resources to people who may not otherwise be eligible for Medicaid.

- Family caregivers play an enormous role in supporting people to remain in their homes and communities. The Washington 1115 Transformation waiver is one example of how states might provide Medicaid-funded caregiver supports. Hawaii has implemented the Kupuna Caregiver program that provides a cash stipend to support caregivers helping someone remain in their home and community. The Wisconsin Alzheimer Family Caregiver Support program provides counties with funding that they can use to build community resources or provide direct supports to caregivers providing supports to persons with Alzheimer’s or other dementias.

- The service of options counseling may be valuable in helping people evaluate available care options and make choices about how best to use their available financial resources. The state of Wisconsin was an early developer of Aging and Disability Resource Centers and the provision of options counseling. Wisconsin options counselors are available in every county of the state to provide structured high quality decision support and care planning to anyone who asks for it. They promote this program through doctor’s offices and other settings in hopes that people will “get to know them before they need them.”

- Nearly all of the targeted states provide Medicaid coverage for assisted living-type services. There is some evidence that other states are experiencing a significant increase in the percentage of people who are receiving Medicaid funded assisted living services, but no information was gathered that indicated why this might be the case.
1. Background

In the MN 2030: Future of Elderly Waiver report (MN 2030), Minnesota outlines some of the challenges the state faces in continuing to serve growing numbers of people with long term care needs in a sustainable fashion. Demographic change, particularly the anticipated growth of the baby boomer population and their need for long-term services and supports, and the growth of the number of older adults who need affordable (i.e. Medicaid supported) care have created pressure on the State to support the provision of cost-effective solutions outside of nursing facilities.

As part of a larger study of spenddown to Elderly Waiver eligibility in assisted living and in community-based settings, the Minnesota Department of Human Services, Aging and Adult Services Division wished to learn more about how other states’ policies and practices impact how people use their personal resources and make choices about how to meet their LTSS needs. Therefore, part of this project encompassed a scan of other national programs and practices that help shape participants’ experiences with spending down their personal resources on the trajectory toward Medicaid financial eligibility.
2. Research Questions

The national scan provides input to address some aspects of the following research questions (which guided the larger study of spenddown):

- What are some potential policy and system changes that might help extend older Minnesotans’ private resources available to help meet their needs in the community?
- What are some potential policy and system changes that might incentivize in-home service arrangements as compared to residential service arrangements?
3. Data and Methods

The National Scan engaged colleagues across the nation who are involved in program planning and policy making around the topics of private pay spenddowns and Medicaid enrollment, and incentivizing in-home service arrangements as compared to residential service arrangements. This engagement was performed in two phases:

1. Interviews with national key informants to identify innovative state programs and practices;
2. Outreach to at least ten states, based on information gleaned through the literature review and key informant interviews, to delve into programs and practices that impact how people use their private resources and make choices to meet their LTSS needs.

3.1 Key Informants Interviews Process

Sage Squirrel Consulting interviewed eight key informants from five national organizations providing services for older adults. The key informants were identified by the Minnesota Department of Human Services and Sage Squirrel Consulting based on their Medicaid LTSS subject matter knowledge across the country. The key informants represented a diverse set of organizations with different perspectives on state and national long-term services and supports. The key informants represented organizations that:

- work directly with states;
- work to translate federal policy to states;
- represent providers of services; and/or
- advocate for/with consumers of long-term services and supports and those that pay for services and supports.

Once identified, key informants were asked to participate in a telephone or video conference interview where they were asked the following questions:

1. What states do you believe are taking innovative approaches to helping families extend private resources to age in place in their communities?
2. What do you think may be different in how persons spend down to Medicaid when they are using assisted living (AL) vs in-home home and community-based services (HCBS)?
3. What policies or procedures are you aware of that might mitigate or exacerbate those differences?

Key informants included:

- Martha Roherty, Executive Director, ADvancing States
- Damon Terzagli, Senior Director of LTSS Policy, ADvancing States
- Allison Kusel, Director of Long Term Care claims, Genworth Financial
- Jackie Olcott, Director of Claims Analytics and Operational Risk, Genworth Financial
- Eric Carlson, Directing Attorney, National Center for Law and Elder Rights/Justice in Aging
- Gelila Selassie, Staff Attorney, National Center for Law and Elder Rights/Justice in Aging
- Howard Bedland, Vice President for Public Policy and National Advocacy, National Council on Aging
- Wendy Fox-Grage, Project Director, National Academy for State Health Policy
Four other national organizations were identified as potential sources for the national scan but were unable to participate in this process:

- National Consumer Voice
- National Center for Assisted Living
- AARP
- Leading Age

3.2 State Outreach and Information Gathering Methods

From the conversations with key informants, ten states were identified as leaders in one or more target topics for this project. Once the target states were identified, we developed a plan for information gathering and outreach. The initial plan was to approach each of the target states to gather information specific to the topic for which they were selected, but to also gather information from each of the target states relative to the other themes. The purpose of this is to develop quantifiable information from multiple states across the range of themes. The list of questions is included as Appendix A.

Before initiating outreach to the states, we researched publicly available information about programs and practices in the targeted states. This was an attempt to reduce the effort required from state program staff to respond to this request for information. Results from this effort were mixed. Some information, such as asset protection policies, was readily available from the Centers for Medicare and Medicaid Services (CMS) Medicaid website, but many states do not make detailed information about outcomes and expenditures or other administrative details about their programs publicly available.

Outreach to states began in February 2021. Using contact information from ADvancing States, we identified and emailed one or two individuals from each target state. Initial emails were followed by reminder emails and phone calls in case the original emails had gone to spam folders. In most states, the information sought crossed program and/or agency lines, necessitating repetition of the outreach process in multiple target states to connect to the program staff best equipped to respond to these inquiries. The states of New York and Hawaii never responded to multiple appeals for information and Delaware declined to participate.

While comprehensive information was sought from states to cover the key informant themes in detail, staff in state agencies and programs that serve older adults faced unprecedented challenges in 2020 and early 2021 as a result of the COVID-19 pandemic and we were unable to get full responses from many states. We are grateful to all of the states who responded and provided information as a result of this request. Despite the challenges collecting information, the responses received provided some valuable insights regarding HCBS programs/policies nationally.
4. Results

4.1 Key Informant Results

Four primary topics emerged from the key informant responses:

1. State policies around asset protection play an important role in spenddown outcomes.
2. Programs that target the “pre-Medicaid” population, including both programs that are 100% state-funded or that are Medicaid demonstration programs, are essential components in slowing spenddown.
3. Maintaining family caregivers is key to avoiding placement in congregate residential settings, such as nursing facilities or assisted living.
4. It is important that states provide robust and timely options counseling to help people examine available LTSS options and make determinations about which are the best fit for their preferences, needs and personal resources.

4.11 Asset Protection

Asset protection policies were mentioned as the single biggest contributor to people being able to slow the utilization of their personal assets and allow them to remain in their personal homes. Most of the key informants mentioned these policies and identified one state, New York, as an outlier compared to most of the rest of the states.

Another way that people are able to protect assets is by purchasing long term care insurance through state “Partnership” programs. One key informant pointed to practices by Nebraska that they believed were unique and to the Long-Term Services and Supports Trust that was enacted in the state of Washington in 2019.

4.12 Pre-Medicaid Programs

Pre-Medicaid programs provide lower cost supports intended to preserve the role of the caregiver or meet lower level needs and thereby prevent the escalation of need that might lead to Medicaid eligibility. Nearly all of the key informants mentioned these kinds of programs as key resources in preventing or delaying the slide to Medicaid eligibility, and one described a desirable LTSS model as one that is designed in “concentric circles” of LTSS with persons needing nursing facility level of care at the center and indicated state programs should be designed in such a way to meet needs at the outer edges of the circle.
Nearly all of the key informants mentioned the state of Washington’s Medicaid 1115 demonstration waiver that extends limited services to people who do not meet full Medicaid eligibility criteria and provides supports for the maintenance of informal caregivers. Hawaii was also identified by multiple informants as having an 1115 Medicaid demonstration program. Indiana’s state funded CHOICE program has been the subject of efforts to update the role it plays in supporting people in order to prevent or delay Medicaid eligibility. Massachusetts’ Home Care program is the oldest home care program in the nation and was regarded as a model program by one key informant.

4.13 Family Caregivers

Key informants talked frequently about the importance of caregivers; most referenced work done by AARP. While AARP declined to participate in an interview, that organization has produced large amount of resources on different aspects of caregiving, including studies on the importance of family caregivers to helping people remain at home and in their communities.

Hawaii’s Kupuna Caregivers Program, a state-funded cash stipend to caregivers, was noted by key informants as an innovative caregiver program. California was reported to have implemented a “master plan” on aging and created resource centers throughout the state for family caregivers.

4.14 Robust and Timely Options Counseling

In the estimation of two key informants, only a handful of states offer options counseling robust enough to accomplish the goal of helping to prevent institutionalization. Both discussed Wisconsin’s role in leading the development of the service of options counseling through their statewide Aging and Disability Resource Center (ADRC) network as well as the Virginia public/private ADRC partnership that relies on innovative technology to provide consumer information about long term care choices.

Based on the above themes and additional information from the key informants, ten states were initially targeted for outreach. Three additional states were explored during the process, but were unable to contribute additional information. Each of the states listed in Table 4.1 was selected for at least one specific program or practice associated with the relevant themes.
Table 4.1. Target States and Topics

<table>
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<tr>
<th>State</th>
<th>Asset Protection</th>
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4.2 State Outreach and Information Gathering Results

As noted by the key informants, states all take different approaches to meeting growing LTSS needs. We summarize below findings from the target states for each of the major themes and highlight programs that were identified as emerging or promising best practices. Despite the pandemic-related challenges in collecting information, the responses received provided some valuable insights regarding HCBS programs/policies nationally.

4.21 Asset Protection

The aim of this project was to determine what impacts choices that people make as they utilize or “spend down” their private resources to Medicaid eligibility. The term “spend down” is usually applied to state policies that determine Medicaid eligibility. Applicants for Medicaid are required to have limited income and assets. When people are over these limits, they are required to “spend down” their income and/or their assets in order to qualify for Medicaid.

States vary in their approach to how people are required to spend down income. Some create a “medically needy pathway” and allow people to spend excess income on medical expenses, including prescription drugs or insurance premiums. Some states have income caps and people are required to establish Qualified Income Trusts (“Miller” trusts) in which they deposit excess income. Funds in this trust are exempt from the income limit and are only available for limited medical purposes.

For purposes of this report, we focus on asset protection policies. In most states, the asset limitation for single applicants for LTSS is $2,000. Countable assets are generally those that can be easily converted to cash. Certain assets are excluded from consideration, such as one’s primary home, an automobile, personal items and certain insurance policies if below a stated value. If married couples are applying for Medicaid at the same time, most states allow combined countable assets of $3,000. If one spouse is applying for Medicaid long term care either in a nursing facility or for a home and community based waiver, the non-applicant spouse (the
“community” spouse) is generally able to retain a higher proportion of their combined assets, sometimes up to 100% if those assets are below a certain limit. This is called the Community Spouse Resource Allowance (CSRA) and is intended to prevent spousal impoverishment.

Loss of housing or inability to maintain one’s home was cited by most of the national informants as a reason for individuals to choose a nursing facility or assisted living placement. According to national key informants, the relationship between asset protection policies and how people utilize their personal resources on the path to Medicaid eligibility hinges on housing. People may retain their primary home, but asset protection restrictions may limit their ability to perform maintenance and repairs once they have spent down their assets and qualified for Medicaid.

Policies around asset protection vary widely by state. Spousal impoverishment policies and CSRA policies are even more variable. Medicaid eligibility requirements for all of the targeted states is included as Appendix B.

Most of the target states were at or close to the most common limitations. One state, New York, has significantly higher asset protection limits than all of the other states but we were unable to explore that as state officials did not respond to repeated outreach attempts.

4.211 Long Term Care Insurance
People with qualifying long-term care insurance plans can retain a larger share of their assets if they exhaust their long-term care plan benefits and become eligible for Medicaid-funded LTSS. Because of this, many states offer long term care “partnership” policies to incentivize uptake of long-term care insurance, with some states even offering reciprocity, making these policies portable. All of the target states, except for Hawaii and Massachusetts, offer Partnership plans. Currently, California has paused their program for study.

Nebraska was identified by one national key informant as having a unique billing arrangement between Medicaid and their qualified long term care insurance plans. A closer review of those practices in conversation with state officials revealed that Nebraska’s practices were similar to how most states handle third party liabilities for persons receiving Medicaid HCBS.

In 2019, Washington enacted the Long-Term Services and Supports Trust Act¹ to create a long-term care insurance benefit for eligible Washington residents. The plan is funded through a tax on all W-2 workers who reside in the state. The state will begin collecting the tax January 1, 2022 and the first benefits will be payable in 2025. It is an “opt-out” program instead of an “opt-in” for all W-2 workers, and the state offers an opt-in provision for people who are self-employed. There are certain criteria people must meet in order to opt-out, including people who purchase a qualifying private long term care insurance before November 1, 2021. People who opt-out are permanently barred from future participation. Some aspects of the program, including other exemptions, are still under development.

Washington is the first state in the nation to implement this kind of program. According to information from the state, this program will reduce pressure on the state’s Medicaid program, saving taxpayers approximately $3.7 billion by 2052 and prevent people from impoverishing themselves because of the need to rely on Medicaid. This is an emerging practice that will likely receive a great deal of scrutiny in coming years.

4.22 “Pre-Medicaid” Programs

Medicaid HCBS is most commonly offered as an alternative to nursing facility care through state “waiver” programs under Section 1915(c) of the Social Security Act. In order to qualify for these waivers, people must demonstrate that they meet the state’s level of care requirement to receive Medicaid-funded services in an institution. For older adults, this is often referred to as “nursing facility level of care” (NFLOC). While people with NFLOC may not need continuous skilled nursing, they generally are impaired in multiple Activities of Daily Living (ADLs) or Intermediate Activities of Daily Living (IADLs) and need extensive day-to-day supports and are at high risk for institutionalization.

Anecdotal evidence from the national key informants suggests that spending smaller amounts of money at earlier points in time or at lower levels of need can delay or prevent that increased risk of institutionalization and decrease the rate of expenditure. Two ways that states can achieve this are with state-funded programs or with Medicaid 1115 demonstration waivers. These programs may serve people with less stringent financial eligibility requirements or with cost-sharing based on income, or by providing services at a lower functional eligibility standard.

The national key informants pointed to both types as examples of programs that can delay or prevent the need to move to congregate residential settings such as nursing facilities or assisted living and slow the progression to full Medicaid LTSS eligibility. Two states that were identified with promising programs were: Washington’s 1115 demonstration waiver and Indiana’s CHOICE program.

Six states responded to our inquiries about pre-Medicaid programs. Three of the target states did not have any state-funded HCBS programs. California reported that they had rolled their state-funded program into Medicaid but did not say when this occurred. We found two state programs that hold promise, though neither program has fully developed the supporting evidence base at this time. Still, each provides examples of interventions which may slow the risk of Medicaid eligibility and promote community living.

4.221 Indiana – CHOICE Program

Indiana’s CHOICE (Community Home Options to Institutional Care for Elders) program was established in 1984 to provide in-home supports and case management to older adults at risk of institutionalization. The state appropriation for this program has been stable at $48 million, for several years; $18 million is transferred to the state Medicaid agency as a portion of state match dollars. The remaining $30 million is distributed to the state’s 15 Area Agencies on Aging, with a funding formula that mirrors the state’s Older Americans Act funding formula.

CHOICE recipients must be at least 60 years old or have a disability. Prior to 2015, CHOICE eligibility required an impairment in two ADLs, but legislation in 2014 updated eligibility to one or no ADL impairment if there is evidence of immediate risk of institutionalization. There is no income limit for CHOICE, but there is a cost-sharing formula and an asset cap of $250,000. CHOICE funds a range of services, including in-home supports, adult day, respite, case management, and options counseling.

2 All information self-reported by the state or contained in the Indiana Family & Social Services Administration CHOICE Pilot Report to the General Assembly, September 2016.
The legislation in 2014 was intended to make CHOICE a more flexible funding source, to catch and prevent people from becoming institutionalized when a targeted intervention could have prevented that from occurring. The legislation was based on the experience of two Area Agencies on Aging (AAAs) that used other grant funds to implement a service model called “Community Living” focused on eliminating waitlists and increasing the numbers of people served with limited service dollars.

Per legislative requirements, the state developed and implemented a pilot program in four of the state’s then 16 AAAs. The pilot program had five major elements:

1. The reduction in functional eligibility to allow CHOICE funding to be used where risk of institutionalization was present, even in the absence of clear ADL impairment;
2. A decrease in the asset cap from $500,000 to $250,000;
3. Implementation of a “needs-based” assessment instrument rather than the state’s traditional eligibility-based screening forms; and

In 2016, the state performed an evaluation of the pilot. Results were mixed.

1. Pilot areas reported dramatic decreases in waitlists but it was unclear that these were the results of the pilot or other activities.
2. The state measured preadmission screenings as a leading measure for institutional placement. Pilot areas did have a slightly lower percentage of preadmission screenings among CHOICE recipients vs non-pilot areas but that percentage change could have been attributed to the larger number of recipients based on the more flexible eligibility criteria.
3. CHOICE expenditures per person were lower in pilot areas. It was believed that this may have been attributable to the needs-based approach combined with more robust options counseling.

Following the pilot, in 2016, the updated CHOICE eligibility criteria were made permanent.

4.222 Massachusetts – Home Care Program
Massachusetts was the first state in the nation to establish a home care program, which began in 1972. One key informant noted this program because it was the first of its kind and a model for those that came after. The Massachusetts Home Care program was established long before Medicaid began paying for home and community-based services through 1915(c) waivers in 1983. According to state officials, the Home Care Program provides care management and in-home support services to help older adults, people with disabilities, and people with Alzheimer’s Disease or related dementia successfully age in place within Massachusetts. Eligibility for the Home Care Program is based on age, residence, and ability to carry out daily tasks. Care management and in-home services support adults 60 years and older or residents aged under 60 with early on-set Alzheimer’s disease or related dementia. Cost share amounts for supportive services through the Home Care program are determined based on income. Applicants must be living at home within Massachusetts outside of an institutional or Certified Assisting Living setting.

This program provides a wide variety of services to eligible participants and serves approximately 66,000 unduplicated individuals each year. Budget figures for this program were unclear and the state does receive some federal financial participation dollars for certain services on this program. The state does not collect any data about if or how this program might delay or prevent institutionalization or Medicaid eligibility.

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3 All information self-reported by the state.
4.23 Family & Informal Caregivers

As noted by the national key informants, maintaining family and informal caregivers is a central component of helping people remain in their homes and communities as they age and as their needs increase. Strikingly, in 2019, AARP calculated the economic value of that caregiving at $470 billion.⁴

According to AARP, nearly one in five Americans performs caregiving tasks for an adult with disabilities. Since their last report in 2015, the prevalence of caregiving has increased from 16.6% to 19.2% of Americans providing care to another adult in 2020⁵. They attribute this growing prevalence to some combination of the following factors:

- the increasing numbers of aging adults who need care;
- workforce challenges in state LTSS systems;
- increased reliance on HCBS in state LTSS systems; and
- increased awareness that the activities they are performing are actually caregiving.

In the AARP 2020 study, 23% of caregivers report that their own health has declined as a direct result of caregiving activities; 25% of caregivers also report that they find it difficult to take care of their own health.

The latest AARP report states, “[t]he shift in health care to community-based settings rather than traditional residential settings puts additional pressure on families to fill the gaps in LTSS.” They also state that the strain disease or disability puts on a family can endanger policy goals of improving healthcare outcomes and reduce costs in the overall system. Caregivers who are unable to care for themselves become unable to provide care for others.

Seven target states provided information on how they support family caregivers through a variety of programs, using both state and federal funds. All of the states cited the Older Americans Act Family Caregiver Support program as central to their efforts in this area with California and Nebraska reporting they rely exclusively on these programs. California provides caregiver supports through a network of “caregiver resource centers” across the state, where people can go to connect to resources such as respite, support groups, education and specialized information and referral services. Hawaii and Wisconsin have state-funded programs dedicated to maintaining family caregivers. Washington State includes caregiver supports as a major component of their Medicaid 1115 demonstration waiver. Taken together, these all represent different, but promising, approaches to increasing supports for family caregivers although none have been subjected to a rigorous evaluation for their effectiveness in reducing outcomes related to institutionalization or reliance on congregate settings.

One program, Hawaii’s Kupuna Care program, was named by multiple key informants as an innovative program for supporting working family caregivers. “Kupuna” is the Hawaiian word for elder or ancestor. The program is administered through the state’s network of aging and disability resource centers (ADRC). As

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⁵ National Alliance for Caregiving (NAC) and AARP Public Policy Institute, *Caregiving in the U.S.*, 2020 (Bethesda, MD: NAC; Washington, DC: AARP, 2020)
outlined on the state’s ADRC website, qualified caregivers may receive up to $350 each week to cover costs associated with care and services that can include: adult day, respite, transportation, home-delivered meals, handyman or homemaker services, or personal attendant care services. Funds are paid to the service provider, not the caregiver.

Hawaii’s Kupuna Caregiver program was established as a demonstration program in 2018, with passage of the Kupuna Caregivers Law. There are no income or asset restrictions on this program. To be eligible to receive these supports, the caregiver must be providing care to a U.S. citizen or legal resident who is at least 60 years old. The caregiver does not need to live with the care recipient but they must be employed for at least 30 hours a week. The care recipient cannot be living in any type of long term care facility and must require assistance with at least two ADLs or IADLs or have a substantive cognitive deficit.

4.231 Wisconsin’s Alzheimer’s Family Caregiver Support Program
Wisconsin was not identified as a state with exemplary caregiver programs, but revealed during the interview with state officials a long standing state-funded caregiver support program, established in 1985, called the Alzheimer’s Family Caregiver Support program. State funds are made available to each county in the state and counties can make up to $4,000 available per person. County aging offices choose what types of supports and services to provide in their areas. Examples include:

- counties may provide services such as respite, adult day care or in-home assistance;
- counties may purchase goods, e.g. nutritional supplements, security systems, home-delivered meals; and/or
- counties may fund public awareness or support groups or other community-based resources.

A person applying for this support must have a diagnosis of Alzheimer’s or another irreversible dementia. There is an income cap of $48,000 but expenses associated with the dementia can be deducted from gross income. The state currently expends about $5 million per year on these services and serves approximately 1200 people. Legislation is pending in 2021 to increase the budget and raise the income cap for this program.

4.232 Washington Medicaid Transformation Waiver
In the eyes of many, including the national informants interviewed for this project, the state of Washington is a national leader in the provision of long-term services and supports. Washington took strong steps in the early 2000s to “rebalance” their Medicaid spending away from nursing facility utilization. As LTSS utilization shifted to in-home services, the likelihood of people to enter nursing facilities dropped. In studies with two cohorts (see Figure 4.1), a slight decline was also observed in the percentage of participants who started in in-home services and then transitioned to community residential settings.

7 All information self-reported by the state.
8 All information self-reported or provided by the state.
In 2017 the state of Washington built on this success by implementing a Medicaid 1115 Transformation waiver with two major components:

1. Medicaid Alternative Care (MAC): a package of services for people who are eligible for Medicaid but who are not already accessing Medicaid-funded LTSS. Services are provided to unpaid caregivers and designed to support the caregiver’s health and well-being.

2. Tailored Supports for Older Adults (TSOA): a set of benefits for people who are at risk of incurring future Medicaid LTSS needs but who are not currently financially eligible for Medicaid. Services are designed to help people avoid or delay impoverishment and the need for Medicaid-funded LTSS.

According to the state, “The financial logic supporting the MAC and TSOA programs is founded on the same principles underlying the expansion of home- and community-based (HCBS) LTSS services: increasing service options can lead to reduced use of intensive services, creating savings for reinvestment in LTSS services.” According to the Washington State Medicaid Transformation Project demonstration Section 1115 Waiver Annual Report DY3 (2019), the state served 6850 participants in 2019 with expenditures of approximately $5.7 million. In November of 2020, the state released an analysis that demonstrated how the caseload for other in-home services on the Community First Choice program has grown at a slower than expected rate (see Figure 4.2) and concluded, “Although other factors may have affected trends, in-home service caseload trends are consistent with the MAC and TSOA programs achieving the level of savings necessary to be budget neutral from a State General Fund perspective. In fact, the estimated savings are sufficient to increase MAC and TSOA per cap expenditures to levels that would better support the long-term sustainability of the programs.”

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4.24 Options Counseling

One of the things noted by most of the national informants is that many people don’t identify the need for long term care until there is a crisis and then there is urgency involved in making decisions. They discussed how important it is that people are able to get thorough and timely information about their LTSS options and can make decisions about those options based on their preferences, their needs and their financial resources. Options counseling was identified as a key service by national informants in helping people get needed information and supporting them in making decisions about LTSS.

Options counseling was defined by the Administration for Community Living in 2010 as a “person-centered, interactive, decision-support process whereby individuals receive assistance in their own deliberations to make informed long-term support choices in the context of their own preferences, strengths and values.”

Options counseling goes well beyond traditional information and referral (I&R). Components include:

- an interview;
- assistance with identification of choices available, including examining available public and private financial resources;
- a facilitated decision-making process in which pros and cons are weighed for the various options;
- assistance with development of an action plan; and
- assistance with connection to resources as needed.

Options counseling is a relatively new service, with definitions and standards dating only from about 2010. While the Administration on Aging (later part of the Administration for Community Living) established standards and a definition for the service, there has not been a single dedicated funding source for options counseling. States have had to rely on existing funding sources or create new state funds to pay for it. In recent years, some states have begun identifying ways to receive Medicaid reimbursement for options counseling.

The Administration for Community Living (ACL) has funded a series of grants to states to develop a No Wrong Door system of access to LTSS anchored in a network of Aging and Disability Resource Centers (ADRCs). Person-centered counseling is a central component of these systems. In 2018, ACL announced a funding opportunity specifically for the purpose of working with states to develop ways to determine the return on investment (ROI) in the ADRC networks and NWD systems. A toolkit for states and ADRCs has been produced out of this process but conclusions have not yet been released about the ROI.

Seven of the target states responded to inquiries about options counseling. All of the responding states stated that they provide options counseling but the robustness of the counseling, eligibility, standards, and funding varied widely. There was consensus among responding states that the challenge is reaching people in a timely fashion – before they are required to make immediate decisions about how to meet LTSS needs. Wisconsin was targeted for further research by our team because of their lengthy investment in ADRC development and the state’s commitment to the provision of options counseling.

4.241 Wisconsin – Options Counseling and ADRCs

According to state officials, Wisconsin is the birthplace of ADRCs, where they began developing ADRCs for the purpose of preventing or delaying institutionalization in 1997. Wisconsin was also identified by multiple national informants as a national leader in this area. The state achieved statewide coverage in 2013, with ADRCs in every county of the state. According to the officials, their objective is to provide information at any time, hopefully prior to an actual need, with an informal slogan of “Get to know us before you need us.”

Options counseling is central to the state’s effort, including talking about financial resources and how to make them last as long as possible and keeping natural supports in place for as long as possible. The state promotes the ADRC network through physicians’ offices and ongoing marketing campaigns. The state does not mandate options counseling for anyone. They noted that the customer drives the decision about if, how, and where they would like to receive options counseling services. Previously, the state had mandatory options counseling for people entering assisted living but removed this requirement after receiving feedback about how few options some people actually had. State staff did note, “[b]y the time someone is in assisted living they are in crisis and it’s too late at that point.”

The state shared some data for 2019 and 2020, but noted that 2020 was an unusual year due to the COVID-19 pandemic. In 2020, options counseling was provided to approximately 14% of people who have contact with an ADRC; this was a decline from 2019. The state attributes the decline, in part, to the pandemic and the fact that in-person options counseling was suspended; and increased training and understanding by staff of what actually constitutes options counseling.

The state was unable to provide expenditure data on options counseling but shared that dollars to fund options counseling come from mixed sources. Approximately 1/3 of the funding is from Medicaid administrative claiming, 1/3 from state dollars, and the remaining 1/3 is from a mixture of other sources.

Wisconsin was one of the original pilot states for the development of the No Wrong Door system of access to LTSS. Wisconsin was also one of the states to receive a grant from ACL in 2018 to work on a No Wrong Door/Return on Investment Business Case. Using that grant the state recently completed a study showing that

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12 All information self-reported by the state.
customers who visit an ADRC have a reduced number of emergency department visits and 30-day hospital readmissions compared to people who do not visit an ADRC. They were not able to determine the effect of ADRC contact regarding admissions to SNFs or ALFs. They hope to continue the work of building out data in that area.

Organizational design was not part of this scan but it is noteworthy that the Wisconsin state unit on aging, which is responsible for oversight and administration of ADRC and options counseling, is housed in the state’s public health agency. Every county has a county aging office that works alongside county public health offices. There are active efforts for these offices to collaborate on building capacity to keep people in the community as long as possible and integrating aging issues into community health plans.

This trend holds potential for new practices in reaching older adults through proven and effective delivery of information and health services by public health agencies, and is consistent with CDC goals as outlined in the February 14, 2003 edition of the Morbidity and Mortality Weekly Report. In this report the CDC focused on public health trends associated with the growing numbers of older adults. Included in that report were five potential roles for the CDC (and by extension the nation’s public health system) to collaborate with the aging services network:

1) to provide high-quality health information and resources to public health professionals, consumers, health-care providers, and aging experts;
2) to support health-care providers and health-care organizations in prevention efforts;
3) to integrate public health prevention expertise with the aging services network;
4) to identify and implement effective prevention efforts;
5) to monitor changes in the health of older adults.

4.3 Assisted Living and Medicaid

Because of the focus on differences in trends between those at home and those in Assisted Living, it is important to note that there is no one standard of definition for the service or setting that is assisted living (AL). As noted in the 2015 Compendium of Residential Care and Assisted Living Regulations and Policy, “what follows the words assisted living can vary, including facility, community, residence, program and home.” If AL is licensed it is most commonly licensed as “residential care.” We see this same variance in the states that were surveyed for this report. This variability can make it challenging to make accurate comparisons about assisted living and how people experience it.

The majority of Assisted Living is paid for with private funds, but some states do allow for Medicaid funding of assisted living. As part of the state information gathering process, we also sought information about the inclusion of assisted living in state Medicaid HCBS programs. Of the ten targeted states, all but two, Virginia and Massachusetts, allow payment for assisted living-type services by Medicaid. For this topic, we examined publicly available information and sought information directly from state officials. Three states responded to

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questions about assisted living and Medicaid: Indiana, Washington, and Wisconsin. The National Center for Assisted Living published a State Regulatory Review in 2019\textsuperscript{15} that includes information about if and how states use public funds to pay for assisted living. Information about the target states is included in Appendix C.

Indiana and Wisconsin both reported increases in the percentage of people receiving services in assisted living settings in recent years. Indiana reported that the number of Aged & Disabled waiver participants who receive the waiver service of assisted living increased from 8.5% in 2016 to 16% in 2021. Wisconsin reported that the number of frail elderly receiving their services in a residential (assisted living) setting increased from 20.7% in 2013 to 26.7% in 2019. Washington has three different types of assisted living: Assisted Living, Adult Residential Care and Enhanced Adult Residential Care. That state provided caseload projections for these services that indicate, between the three AL-type services, stable caseloads.

Only Wisconsin provided information about Medicaid expenditures for assisted living. Wisconsin reports that in 2019, average annual expenditures for Medicaid participants in residential settings were $44,713 versus $21,538 for those receiving services in home settings (and $57,384 in nursing facilities).

5. Conclusion

Medicaid is one of the largest budget areas in every state in the union and is the largest payer of LTSS in the country. People who use long term care incur the largest Medicaid expenditures. Given the growing numbers of older adults, based on the aging of the baby boom generation and advances in longevity of the 20th century, the needs of older adults will pose a significant burden on state budgets. It is striking that only two of the target states answered the question, “Has your state developed strategies that were intentionally designed to delay or prevent Medicaid financial eligibility?” with a definitive “yes.”

There is consensus among key informants and state representatives that programs and policies around asset protection, pre-Medicaid interventions, caregiver supports, and robust options counseling have potential to slow people’s trajectory into institutional or other congregate residential settings and toward financial eligibility for Medicaid. There is an opportunity here for states or other organizations to conduct more rigorous evaluations of these programs to determine if there is a definitive return on investment.

Each of the states in our union are grappling with the implications of the growing numbers of older adults and how to meet increased needs for LTSS. The programs represented here are but a sampling of state efforts to meet those challenges.
6. Appendix A
Questions for State Officials

1. Have you had an intentional strategy around preventing or delaying Medicaid eligibility in the area of long-term care? (If no, skip to Question #8)
   2. If so, what strategies have you employed?
   3. What strategies do you plan to employ?
   4. Were there other strategies you considered but rejected? If so, why were they rejected?
   5. Are there strategies you employed but found not to be effective?
   6. Do have any data/results on the effectiveness of the strategies used?
   7. How long have the strategies been in place? (Jump to Question #8)
8. Have you had conversations about preventing or delaying Medicaid eligibility?
9. Do you collect any data around how long it takes individuals to spend down their private resources prior to Medicaid eligibility? If so, can you share that information?
10. Do you offer any Medicaid HCBS services as state plan services, 1915(l) or 1915(k)? If so, describe. (this information would likely come from pre-interview research but this is the spot where we would ask for any clarifications)
11. Any Medicaid covered services offered to individuals or their family caregivers pre-financial eligibility?
12. Do you offer assisted living under Medicaid HCBS programs? (may be under another name such as housing with services, supported living, etc.) (may know this information for pre-interview research but this is the trigger for additional questions) (If no, skip to Question #19)
   13. If so, what percentage of participants utilized the service 5 years ago and what percentage utilize it today?
   14. Does the state provide monetary assistance (state funded or otherwise) with room and board costs for individuals in Medicaid assisted living?
   15. What counseling is provided to individuals considering assisted living or other HCBS options even as private pay?
   16. Does Medicaid coverage for assisted living require that the individual has nursing facility level of care?
      17. If yes, describe your nursing facility level of care standard. (Skip to Question #19)
      18. If no, describe what the functional eligibility requirements are for Medicaid coverage of assisted living.
19. Have you had an intentional strategy to incentivize in-home service arrangements as compared to residential service arrangements? (If no, skip to Question #26)
   20. If so, what strategies have you employed?
   21. What strategies do you plan to employ?
   22. Were there other strategies you considered but rejected? If so, why were they rejected?
   23. Are there strategies you employed but found not to be effective?
   24. Do have any data/results on the effectiveness of the strategies used?
   25. How long have the strategies been in place? (Jump to Question #8)
26. Do you have a state funded HCBS program? (may know some or all of this information from pre-interview research) (If no, skip to Question #31)
   27. What are the financial eligibility requirements for the program?
28. What are the functional eligibility requirements for the program?
29. How long has the program existed?
30. Is assisted living a service covered by the state funded program?
31. Does the state participate in the Long-Term Care Partnership Program? (will know this from pre-interview research, here to trigger additional questions) (If no, skip to Question #37)
   32. What is the cost of living percentage required for a qualifying policy?
   33. What, if any, participation benchmarks have been established?
   34. Are those benchmarks met?
   35. Has participation increased or decreased in the past 10 years, 5 years?
   36. What is the relationship, if any, between Medicaid agency and partnership plan entities?
37. Do you provide options counseling to persons seeking LTC/LTSS information or resources? (If no, skip to Question #45)
   38. What entities provide options counseling?
   39. Do you have Medicaid reimbursement for options counseling? If not, how is it funded?
   40. When is options counseling typically provided?
   41. Are there any qualifications or criteria used in determining who receives options counseling?
   42. Does your state have a website that facilitates access to information? (may know this information from pre-interview research or previous questions, here to trigger additional questions) (If no, skip to Question #38)
       43. Can individuals complete self-assessment or screenings online?
       44. Does the website refer to in-person counseling if needed?
45. Do you have programs that support informal caregivers in your state? (If no, skip to Question #51)
   46. Does your state conduct caregiver assessments? (If no, skip to Question #42)
       47. If so, what assessment tool do you use?
       48. When is the assessment completed?
49. Does your state provide any kind of training for informal caregivers? If so, please describe.
50. How are caregiver supports/services funded in your state?
51. Anything else you would like to share that you think would be important for Minnesota to consider?
## 7. Appendix B
### State Eligibility Requirements

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<tr>
<th>Requirement</th>
<th>California</th>
<th>Delaware</th>
<th>Hawaii</th>
<th>Indiana</th>
<th>Massachusetts</th>
<th>Nebraska</th>
<th>New York</th>
<th>Virginia</th>
<th>Washington</th>
<th>Wisconsin</th>
<th>Minnesota</th>
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<td>44</td>
<td>550</td>
<td>52</td>
<td>72.8</td>
<td>60</td>
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<td>40</td>
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<td>none*</td>
<td>2,349</td>
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<td>none*</td>
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<td>1,063 (applicant)</td>
<td>1063 (applicant)</td>
<td>875 (applicant)</td>
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<td>2382 (applicant)</td>
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<tr>
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<td>none*</td>
<td>2,978</td>
<td>none*</td>
<td>2,349 (applicant)</td>
<td>1,437</td>
<td>1,437</td>
<td>1,284</td>
<td>4,698</td>
<td>4764 (2382 per spouse)</td>
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<td>1,468</td>
<td>1,985</td>
<td>1,224 (at home)**</td>
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<tr>
<td>(both spouses applying)</td>
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<tr>
<td>Medicaid Asset Limit -</td>
<td>2,000</td>
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<td>2,000</td>
<td>2,000</td>
<td>2,000</td>
<td>4,000</td>
<td>15,750</td>
<td>2,000</td>
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<tr>
<td>Single - Aged, Blind,</td>
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<tr>
<td>Disabled</td>
<td>3,000</td>
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<td>3,000</td>
<td>3,000</td>
<td>3,000</td>
<td>6,000</td>
<td>23,100</td>
<td>3,000</td>
<td>3,000</td>
<td>3,000</td>
<td>6000</td>
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<td></td>
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<td>Delaware</td>
<td>Hawaii</td>
<td>Indiana</td>
<td>Massachusetts</td>
<td>Nebraska</td>
<td>New York</td>
<td>Virginia</td>
<td>Washington</td>
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<td>Disabled (one spouse applying)</td>
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<tr>
<td>Medicaid Asset Limit -</td>
<td>3,000</td>
<td>3,000</td>
<td>2,000</td>
<td>3,000</td>
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<td>6,000</td>
<td>23,100</td>
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<td>3,000</td>
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<td>6000</td>
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<tr>
<td>Married - Aged, Blind,</td>
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<tr>
<td>Disabled (both spouses</td>
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<tr>
<td>applying)</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
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<td>Spousal Impoverishment</td>
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<tr>
<td>Protection for HCBS Waiver?</td>
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</tbody>
</table>

* In CA individuals must spend all personal income on care with exception of PNA and spousal allowance.

** In HI, individuals in adult foster care only retain $50 of their income, the rest goes towards room and board and to the provider
## 8. Appendix C

State Assisted Living Information

<table>
<thead>
<tr>
<th>Assisted Living Type Service Covered on Waiver?</th>
<th>California</th>
<th>Delaware</th>
<th>Hawaii</th>
<th>Indiana</th>
<th>Massachusetts</th>
<th>Nebraska</th>
<th>New York</th>
<th>Virginia</th>
<th>Washington</th>
<th>Wisconsin</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No - but personal care and case management are provided under state plan to persons living in ALs</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Adult Residential Care Services</td>
</tr>
</tbody>
</table>

| Number Receiving Medicaid Assisted Living Type Service | November 2020: 5017 with waitlist of 4513* | 4250* | 8918 | 5700* |

| If so, what percentage of participants utilized the service 5 years ago and what percentage utilize it today? | 8.5% in 2016 vs 16% in 2020* | 20% in 2013 to 27% in 2019 | State reported stable caseload among all AL services* | 20.7 in 2013; 26.7 in 2019 ("residential") |

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<table>
<thead>
<tr>
<th>State</th>
<th>California</th>
<th>Delaware</th>
<th>Hawaii</th>
<th>Indiana</th>
<th>Massachusetts</th>
<th>Nebraska</th>
<th>New York</th>
<th>Virginia</th>
<th>Washington</th>
<th>Wisconsin</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the state provide monetary assistance (state funded or otherwise) with room and board costs for individuals in Medicaid assisted living?</td>
<td>No</td>
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<tr>
<td>What counseling is provided to individuals considering assisted living or other HCBS options even as private pay?</td>
<td>No mandated counseling but Medicaid participants will receive options counseling prior to enrollment*</td>
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<tr>
<td>Medicaid Programs that cover AL</td>
<td>Assisted Living Waiver</td>
<td>Diamond State Health Plan</td>
<td>QUEST Integration benefit</td>
<td>A&amp;D Waiver</td>
<td>n/a</td>
<td>HCBS for Aged &amp; Adults &amp; TBI waiver</td>
<td>Assisted Living state plan program</td>
<td>Alzheimer's AL Waiver ended in 2018</td>
<td>Adult Residential Care on Medicaid state plan; Residential Support waiver;</td>
<td>Family Care Waiver</td>
</tr>
</tbody>
</table>