MN Elderly Waiver Spenddown Study: Summary Findings and Recommendations Report

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1. Executive Summary

In order to better understand the trajectories Minnesotans experience as they move toward Elderly Waiver (EW) eligibility, and the factors that impact these trajectories, the Minnesota Department of Human Services (DHS) partnered with the University of Indianapolis Center for Aging & Community (CAC), Indiana University, and Sage Squirrels Consulting to complete key research activities that explored several questions about characterization of trajectories and ways to impact them. These activities included:

- review of related scientific and professional literature;
- a scan of related activities in other states;
- analysis of secondary data for participants of the EW program;
- creation and implementation of a survey of EW participants about their experiences; and
- creation and implementation of a survey of assisted living providers about their practices surrounding EW.

After completion of these research activities, convergences were assessed to identify themes across the results of all research activities. These themes were translated into areas of opportunity for impact.

1.1. Key Findings

- Two trajectories were identified for EW eligibility:
    - Individuals who had low personal resources long term with persistent Medical Assistance (MA) enrollment who then aged into eligibility for EW.
    - Individuals who relied on family or informal care as long as possible until needs were too high or too many to be met by informal support or until their assets met EW eligibility requirements.

- Across both trajectories, there is progressive need that builds over years before individuals join EW. This creates multiple contacts with the DHS system prior to eligibility and an opportunity to provide lower levels of support and guidance that may delay or prevent spenddown to MA or more costly support through MA/EW. Areas for opportunities in earlier supports include expanding existing programs such as Essential Community Supports and Alternative Care and expanding existing MA programs to provide earlier home- and community-based supports prior to EW eligibility.

- Family and informal caregivers play a critical role for EW clients with enrollment often triggered by family/informal caregivers reaching a tipping point or a lack of family/informal caregiver. Additional evaluation of the extent to which existing MN caregiver support programs, such as MN's Consumer Support Grant, Consumer-Directed Community Support, and Personal Care Assistant program could be expanded and enhanced to meet the need of informal caregivers is recommended.

- Options Counseling plays a role in helping Minnesotans access supports and services, but for many Options Counseling (particularly Housing Options Counseling) comes at the wrong time in the decision making process. Increasing the access and availability of Options Counseling, particularly earlier in the trajectory, well before they consider a move to AL, may help Minnesotans better understand their

options at a time when they are able to discern needs and make longer term decisions, thus better preventing spenddown and costlier forms of care.

- Enhanced access to information and education about long term services and supports may be beneficial in two areas. Broader education and access where people typically get their information (online, community, places of worship, health providers) and identification of an earlier stage in the planning process to provide targeted information will assist individuals in having the necessary information at the right point in the trajectory to make effective decisions. Broader outreach and education efforts should include healthcare providers across a variety of professions as individuals often look to these professionals for guidance along the trajectory.

- Assisted living providers are experiencing a period of significant instability due to COVID-19 impacts and new requirements under the Assisted Living Licensure (ALL). Survey responses were informative and additional survey of providers one to two years post ALL implementation is suggested to gather additional information on the best use of EW in AL.

2. 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 (Medicaid supported) care, have created pressure on the State to support the provision of cost-effective solutions outside of nursing facilities.

Minnesota's Elderly Waiver (EW) program, developed in the 1980's as an alternative to nursing home services has grown exponentially in response to the growing number of older adults needing affordable long-term services and supports (LTSS). Alongside the need for services has been the continued growth of the assisted living market, which has increased use of this service within EW.

In order to maximize the effective use of both State and individual resources and allow Minnesotans to receive support in the setting of their choosing for as long as possible, Minnesota's Department of Human Services (DHS) Aging and Adult Services Division engaged the University of Indianapolis Center for Aging & Community (CAC) to study the common trajectories that Minnesotans follow toward becoming eligible for EW. To answer the research questions detailed in Section 3 below, CAC, in partnership with Indiana University and Sage Squirrel Consulting, developed a multi-pronged research study. Research efforts included:

- review of related scientific and professional literature;
- a scan of related activities in other states;
- analysis of secondary data for participants of the EW program;
- creation and implementation of a survey of EW participants about their experiences; and
- creation and implementation of a survey of Assisted Living providers about their practices surrounding EW.

Research efforts were implemented in collaboration with DHS staff between March 2020 and September 2021. Each of these research activities culminated in a descriptive report that detailed research activities and findings and was submitted to DHS. Summaries of these activities can be found in Section 4 below and full reports can be requested from DHS.

At the culmination of all research activities, convergences and themes emerging across all five research activities were assessed. These were used to develop recommendations for DHS on policy and system changes and additional areas for study in order to maximize the use of resources to provide needed services and prevent or delay spenddown to Medical Assistance (MA) eligibility.

3. Research Questions

To guide research activities, MN DHS developed the following research questions:

- What are the LTSS market, economic, and demographic trends that impact spenddown patterns?
- What are the private resource spenddown experiences and patterns for individuals, both married and single, in assisted living settings that result in Elderly Waiver (EW) enrollment? How do these experiences and patterns differ based on demographic characteristics of people receiving services, and/or based on the characteristics of the setting?
- What are the private resource spenddown experiences and patterns for individuals, both married and single, purchasing home and community-based services in their own home, that result in Elderly Waiver (EW) enrollment? How do these experiences and patterns differ based on demographic characteristics of people receiving services, and/or based on the types of services they receive?
- 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?

4. Study Section Summaries

5.1. Literature Review

A review of the currently available literature shows that minimal research has been done in the area of spenddown patterns and decision-making processes. Some researchers and organizations have explored the overall economic and social trends that lead to a person spending down resources and reaching Medicaid eligibility, but none have looked into the individual decision-making processes that occur during this time or the factors that influence the decisions made.

Overall trends in population demographics and Medicaid utilization provide context for the work of this study. In 2018, MN DHS worked with the State Health Access Data Assistance Center (SHADAC) at the University of Minnesota to create a model to make projections about future long term services and supports (LTSS) in Minnesota. Demographic trends utilized by the model show that by 2050 older adults will have increased from 16% to 22% of the MN population with those aged 85+ more than doubling their overall percentage of the population (2.2% to 5.8%).[1]

Additionally, a study by Millsap et al. reports that state budgets are increasingly asked to cover more people under Medicaid. "According to Pew, more than twice as many people were enrolled in Medicaid in 2017 than in 2000. Some of this increase was driven by job losses due to the recessions of 2001 and 2007–2009, which caused incomes to fall and made more people eligible for government assistance."[2]

Several studies looked to characterize overall spenddown trends for those using long term care or long-term services and supports. Weiner et al. found those who spend down are a small portion of the overall population (9%) but they make up more than two-thirds of Medicaid users (64.2%) and are typically female, minorities, less educated, and with poorer health status and functionality.[3] As anticipated, this group also has fewer financial resources, with Yocom et al. reporting study participants typically having an annual income of $20,000 or less.[4]

Additionally, Weiner et al. found that not only do those in the spenddown population start at a lower income level, over the course of spenddown, "the income and assets of the spenddown population are either flat or decreasing while income and assets for the non-spenddown population increase substantially."[5] Length of stay

[1] Blewitt, L. A., Alarcon Espinosa, G., Hest, R., & Woodhouse, M. (2018). Minnesota Long-Term Services and Support Projection Model (Report). *Minneapolis, MN: State Health Access Data Assistance Center.*
[2] Millsap, A. (in press). Medicaid Spending Is Taking Over State Budgets. *Forbes*.
[3] Wiener J.W., Anderson W.L., Khatutsky, G., Kaganova Y. and O'Keeffe J. (2013). Medicaid spend down: New estimates and implications for long-term services and supports financing reform. http://www.thescanfoundation.org/rti-international-medicaid-spend-down-new- estimates-and-implications-long-term-services-and-supports.
[4] Yocom, C.L. et al. (2014, May). Financial Characteristics of Approved and Methods Used to Reduce Assets to Qualify for Nursing Home Coverage. https://www.gao.gov/assets/670/663417.pdf
[5] Wiener J.W., Anderson W.L., Khatutsky, G., Kaganova Y. and O'Keeffe J. (2013). Medicaid spend down: New estimates and implications for long-term services and supports financing reform. http://www.thescanfoundation.org/rti-international-medicaid-spend-down-new- estimates-and-implications-long-term-services-and-supports.

in a nursing home was also positively correlated with spending down resources to Medicaid eligibility.[6] Only one study addressed average length of time to spenddown, reporting the average as seven years with those using personal care services spending down slightly quicker and those using both nursing home and personal care services taking slightly longer.[7]

Collectively, the literature tells very little about trends, key events, or the decision-making processes for financial choices that do or do not lead to spenddown. McGarry et al. report that cognitive capacity is a key factor in decision making about purchasing long term care insurance,[8] which may help delay spenddown and a study by Hoffman et al. notes that "multiple participants mentioned the role of uncertainty, time, and values in making these decisions."[9] The Hoffman et al. paper highlights a group at Dartmouth College that is working with the local Aging and Disability Resource Center to create an online tool to support older adults in their decision-making processes around long-term services and supports, but reports no outcomes or key factors that influence the structure of their tool.

Each of these studies helps to provide context for additional work in this area. As indicated, additional research is needed into the "upstream" influences such as those mentioned by Hoffman et al. and the individual decision making processes that determine financial choices leading to spenddown. Knowing the trends and demographics for those experiencing spenddown helps to frame and guide additional research in this area.

[6] Gruman, Curry, C. L. (1999). Spend-Down Patterns of Individuals Admitted to Nursing Homes In Connecticut. https://portal.ct.gov/OPM/PDPD-HHS-Long-Term-Care/Researcher/Partnership-Researcher-Spend-Down-Study

[7] Wiener J.W., Anderson W.L., Khatutsky, G., Kaganova Y. and O'Keeffe J. (2013). Medicaid spend down: New estimates and implications for long-term services and supports financing reform. http://www.thescanfoundation.org/rti-international-medicaid-spend-down-new- estimates-and-implications-long-term-services-and-supports.

[8] McGarry, B. E., Tempkin-Greener, H., Grabowski, D. C., Chapman, B. P., & Li, Y. (2018). Consumer Decision-Making Abilities and Long-Term Care Insurance Purchase. *The Journals of Gerontology. Series B, Psychological sciences and social sciences*, *73*(4), e1–e10. https://doi.org/10.1093/geronb/gbx059

[9] Hoffman A.S., Bateman D.R., Ganoe C., et al. Development and Field Testing of a Long-Term Care Decision Aid Website for Older Adults: Engaging Patients and Caregivers in User-Centered Design. *Gerontologist*. 2020;60(5):935-946. doi:10.1093/geront/gnz141

5.2. National Scan

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 spenddown 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 10 states, based on information collected 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. Those organizations:

- 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 support their decision-making 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 10 states on the topics above as well as on 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.

5.2.1. 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 assistance 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.

5.3. Assisted Living Provider Survey

As part of a larger study of spenddown to Elderly Waiver (EW) eligibility in assisted living and in community-based settings, the Minnesota Department of Human Services, Aging and Adults Services Division wished to learn more about assisted living providers' perspectives of EW, and explore drivers of participation in the program as well as the providers' facilities' policies and practices for those using EW to pay for services. Specific factors of interest were participation in EW and reasons to participate (or not), which EW options facilities participate in (Customized Living, 24-Hour Customized living), the degree to which providers "market" or communicate about the EW option with prospective residents; how long residents pay privately for services in assisted living before applying for EW; policies and practices related to number of EW residents allowed; special requirements for residents using EW to pay for services; waiting lists for EW openings in facilities; and perceptions of state policies on EW practices in facilities. A survey of providers from a registered list of facilities that completed the Department of Health's 2019 Registration for Housing with Services renewal form and completed data for inclusion in the Uniform Consumer Information Guide was used to explore these topics. A total of 459 facilities completed the survey in the fall of 2020; of these, 85% reported participating in the EW program.

5.3.1. Key Findings

- Of the 68 facilities reporting they do not participate in the EW, the most common reason (53%) given for non-participation was the low payment rate, with the second most common reason (38%) that the program is complicated or cumbersome. These issues were also reflected in many of the open-ended comments.

- For those participating in EW, almost all (90%+) reported they discuss their facilities' policies around accepting EW with prospective residents, with most indicating they provide this information verbally during tours (92%) or information sessions, but also through several other means, including but not limited to: information in promotional materials (92%), the UCIG guide (83%), the Senior LinkAge Line® brochure on Long Term Care Options Counseling (63%). 91% indicate they specifically discuss the possibility of applying for and using EW once personal resources are exhausted.

- Providers report that the most common questions prospective residents and/or their families ask about financial options once they spend down their private resources are those related to how the EW program works, including how to apply, how long does it take, what resources can I keep, how much will the EW payment be, what happens if there is a delay in approval of my application. Most providers (83%) reported they have sufficient information to address these questions. But additional information providers said would be helpful focused on improved information about the program process, i.e., specific qualifiers spelled out plainly, step-by-step instruction on the process done in a very clear way, and "a straightforward application form and a cycle people can depend on," along with having access to a clear contact with whom residents and families can communicate.

- Of those participating in EW, 19% report they require new residents to have a minimum amount of income/assets at time of move in. The most commonly reported period for the minimum length of

private pay required by facility policies were between 19-24 months (reported by 40% of those responding). Less than 15% of those reporting said they required a private pay period of more than 24 months. The remaining 45% of facilities required less than this, with one to six months being the most common length of time their residents pay privately before eligibility.

- More than one quarter (26%) of facilities participating in the EW indicated they have a waiting list for prospective residents who would use EW at the time of move-in. Of these facilities, seven percent reported no current prospective residents on the waiting list for EW, and 60% reported five or fewer on this list. Of the few reporting how long prospective residents typically stay on the waiting list, the average time was less than one year.

- Fewer facilities reported having a waiting list for current residents, with only 10% indicating they have such a waiting list, and the number of residents reported on the list was quite small, with more than 61% having three or fewer current residents on the waiting list. The most common response to the average time current residents spent on the waiting list for EW was three months or less (29%).

- Slightly more than one-third of facilities report a limit on the number of residents who can be supported by the EW. Among these facilities, more than half (57%) report having a limit of 5 or fewer. These limits apply whether residents served are in traditional assisted living or memory care. Among the reasons given for limiting the number of residents supported by EW, the most common was the need to have a mix of private pay and public pay residents to generate enough revenue to cover costs. The second most common reason was the amount of money EW enrollees have to pay is too low. (This response category was general, and could be interpreted as referring to services or room and board coverage.)[10]

- Of facilities responding to their policies on shared units, 31% said their facilities have shared units, and of these, 34% indicated they do require residents using EW to reside in these units. Of two-thirds reporting units of varying sizes in their facilities, 44% report that residents supported by EW live in the smaller units.

- More than two-thirds of providers indicate they expect proposed changes from the new Assisted Living License will impact their policies and practices related to EW. The most common change expected is they will accept fewer EW residents or no EW residents, increase rates, and extend private pay period. They also voiced concern that reimbursement will not cover additional costs of the license and services.

- Many providers shared their views on the impact of COVID-19 on their facilities, beyond just any impact on EW policies and practices. These included dramatic increases in operational cost and reductions in census, and specifically in regard to EW, slower response times from case managers, delays in applications, and fewer onsite assessments. Some reported they are accepting more EW residents to try and make up for low occupancy, while others indicated they will delay participating in

[10] For context on state of MN's previous review of rates see the 2019 Legislative Report, with attention to pp. 15-24, which presents findings and DHS recommendations for many of the services provided through Elderly Waiver. https://edocs.dhs.state.mn.us/lfserver/Public/DHS-7850-ENG

the program due to low reimbursement rates and needing a higher number of private pay residents to recoup losses.

- In response to an opportunity to provide any additional comments, providers revisited themes seen in response to earlier questions, with concerns focusing on perceived inadequate reimbursement rates and issues with program processes and policies (e.g., problems with finding a reliable program contact, application problems, cost of meeting new license requirements). Other statements focused on specific positive relationships and program interactions unique to given counties, the importance of having this support for low-income older adults, and the desire to serve more EW residents but being hindered from doing so by financial considerations.

5.4. Secondary Data Analysis

As part of a larger study of spenddown to Elderly Waiver (EW) eligibility in assisted living and in community-based settings, the primary goal of the Secondary Data Analysis was to leverage existing data resources to better understand different patterns and trajectories of participants prior to enrollment on EW. Data from several sources were selected to represent EW clients who were enrolled in the waiver program at some point during the calendar year 2019. Data from four sources (Long Term Care Consultations, the Senior LinkAge Line®, Minimum Data Set Assessments, and MN Health Care Program enrollment and utilization) were compiled and matched by the MN Department of Human Services team then sent to the research team as a de-identified data set for analysis. Frequencies and means were used to describe the characteristics of EW clients and a cluster analysis identified six natural groupings within the data.

5.4.1. Key Findings

- New EW clients enrolling for the first time in 2019 represented 16% of clients enrolled at any point during that year and were younger and more likely to have an informal caregiver than the full client population.
- Clusters of new enrollee clients indicate that, at the time of referral for EW, the largest proportion of clients live alone, lack an informal caregiver, need low levels of assistance with ADLs and IADLs (particularly toileting), and have persistently low income/low assets.
- It is not clear what proportion of EW clients enroll having previously been living in an assisted living facility, however they were likely concentrated in the cluster of new enrollees who were in congregate living. These clusters were characterized by high ADL/IADL needs, high prevalence of cognitive impairment, and more recently qualifying for Medical Assistance (MA).
- Based on EW client data matched to Senior LinkAge line data, 24% of EW clients in 2019 sought information regarding a call for Housing Options Counseling, but for a large portion of EW clients in 2019 (62%) the call resulted in declined Housing Options Counseling.
- Linkage across other health-related data sets within MN, namely the SLL, MN Health Care Program data, and MDS data provided evidence that by and large, enrollees have engagement with MN programs prior to EW. For example, nearly two-thirds of EW clients from 2019 had some record of contact with the SLL, 36% had a skilled nursing facility (SNF) stay, and 57% had MA enrollment at least 1 month prior to EW.
- Congregate living clusters each had the lowest average months from first referral to EW and enrollment (1.7 and 1.2 months, respectively) compared to all other clusters.
- The timing of the SNF stays was observed such that, other than congregate living clusters, approximately 9-14% of clients had a SNF stay begin in the 90 days prior to EW enrollment. The frequency was considerably higher among the congregate living clusters, with approximately one-third

of clients in both the moderate and high need congregate living clusters having a SNF stay begin in the 90 days prior to EW enrollment.

- Emergency Department visits and hospitalizations were fairly common, with over 50% of clients in each cluster self-reporting a prior ED visit (nearly 25% had multiple visits), and between 40-60% of clients had a hospitalization. Also notable is the high frequency of reported falls, which was between 40-55% of clients. Although a sizable proportion of EW clients were observed to have MA utilization claims, gaps in these data are highlighted by the MDS SNF stay observations. For example, the number of hospitalizations is far lower than expected given the high proportion of SNF stays, which are generally preceded by a hospitalization.

5.5. Elderly Waiver Participant Survey

As part of a larger study of spenddown to Elderly Waiver (EW) eligibility in Assisted Living (AL) and in community-based settings, the Minnesota Department of Human Services (DHS), Aging and Adult Services Division wished to learn more about:

- how older adults make decisions about and pay for their care and services prior to application to EW;
- how they plan for future care needs;
- how they make the decision to use EW for either living at home or in AL,
- reasons for choosing AL or remaining in their home;
- reasons for applying for the EW;
- use of the Senior LinkAge Line® to speak to someone about Options Counseling; and
- patterns of payment for services in AL prior to EW eligibility.

For purposes of this survey, we define EW at Home as those who chose to remain in their own home rather than use the EW to purchase congregate care, specifically AL. We define EW in AL as new EW enrollees who either already were living in AL and became eligible to use the waiver to pay for AL services, or were newly eligible for EW at the time of their move into AL.

The participant perspective, gained from a telephone survey, gives insight into one aspect of the larger pattern of EW use to pay for AL services and spenddown to EW eligibility. Data sources used to provide this perspective included 231 completed surveys (64 EW at Home and 167 EW in AL) from participants or their proxies drawn from the study population of new Medical Assistance (MA enrollees within the last 90 days (enrollees must never have been on MA prior to this enrollment), pulled monthly between October 2020 and May 2021. This allowed the survey team to complete the survey in the six months between January and June 2021. Additional data were provided from Knowledge Services (KS), the survey vendor, and compiled to provide information on the efforts taken to reach the final respondent for each completed survey response. Data provided by the state on survey participant demographics and key program information for individuals on EW (e.g., gender, race, case mix, etc.) were merged with survey data for analysis using descriptive statistics.

5.5.1. Key Findings: EW at Home

- Almost one-third (32%) of EW at Home respondents reported thinking and talking (planning in advance) about how to pay for services once needed, with the most common concern reported being worried about having enough money to pay for help when needed. Very few had planned to use public programs to pay for services. Of those who reported they had done some planning for the future, most had done so with their families' involvement. More than 50% of total EW at Home reported having called the Senior LinkAge Line® or talked to someone at the state about programs as part of their planning.

- Almost 80% of EW at Home respondents reported needing help at home starting within the past two years; 41% said they had started needing help only within the last year. Family is the most frequently cited source of support when needing help, and the most frequently cited types of support are taking

care of one's home (such as cleaning or yard work) and rides to appointments, shopping, etc. Very few reported paying any informal support source such as family. Very few paid an agency for services. Of those who paid for help (6), three indicated they were able to pay for themselves longer than expected, and three were able to pay for a period shorter than expected. Costs of services and expensive repairs to the home or everyday expenses were the reasons most often cited for being unable to pay for one's own needs as long as expected.

- More than 75% of EW at Home respondents indicated they had considered AL, but the most frequently cited reason for not choosing AL was not being ready yet. In making their decision about place of residence, 53% of EW at Home respondents indicated they had called the Senior LinkAge Line® or the state about options, and 38% of those who said they had called indicated this information affected their decision to stay in their home.

5.5.2. Key Findings: EW in AL

- Forty percent (40%) of EW in AL respondents reported thinking and talking (planning in advance) about how to pay for services once needed, with the most common concern being worried about having enough money to pay for help when needed, but also thought they could get help from a government program. Indeed, 58% said they knew there were programs that could help for these services and of these, 80% said their plan including applying to the programs at some time. The most frequently cited help used to make a financial plan for services was family. Slightly more than 40% had also called the Senior LinkAge Line® or someone at the state about programs; 37% indicated they made other efforts to get information on what services might cost. Some had also prepared by looking closely at their finances, worked with an attorney, visited facilities, and taken other steps to be ready for a time when services would be needed.

- Less than one-fourth (22%) of EW in AL respondents reported starting to need help only in the past year, with 31% indicating they started needing help within the last one to two years. But almost one-fifth (19%) reported they started to need help more than 5 years ago. The primary source of help cited most frequently is family, with 91% of EW in AL respondents indicating family as their primary source of help. The most frequently reported types of help received were rides to appointments, shopping, etc., paperwork (like paying bills, rent, or banking), and taking care of one's home (such as cleaning or yard work). Slightly less than one-fourth (23%) indicated they paid an agency for services, with the most frequently reported services being cooking/meals, taking care of oneself (bathing, dressing, combing hair/cutting nails), and help with taking medications.

- When deciding on a place of residence, 95% of EW in AL respondents indicated family helped them make their decision, and family encouragement, along with needing too much help to stay in one's home, were most frequently cited reasons for choosing AL. Concerns about safety at home was also a frequently cited reason for this choice. In further exploration of the family's role in the AL decision, 49% of EW in AL respondents said the family made the decision, and another 45% said they (the participant) made the decision mostly on their own but family supported it. Slightly more than 40% of EW in AL indicated that prior to their decision to move to AL they called the Senior LinkAge Line® or talked to someone at the state about options for services (MN has a requirement that individuals call

the SLL before signing a contract with AL); of these, 40% said the discussion influenced their decision to move to AL.

- More than half (54%) of the EW in AL respondents reported living in the AL for less than one year. Thirteen percent (13%) of EW in AL respondents reported getting help from the EW at the time of move in; another 25% said they paid for themselves for less than one year before getting state support. More than one-third (34%) who paid for their services for some period of time after move in said the period was shorter than expected; another 41% said about what was expected, and for 25% the period was longer than expected. For those who said the period was shorter than expected, the most frequently cited reason was the costs of services were higher than expected. Most indicated they used their own money to pay before needing EW.

5.5.3. Key Findings: Across Groups

Few significant differences were found between EW at Home and EW in AL responses to common items in the survey. These are noted below.

- When reporting the types of planning prior to the time when one might need services, more of the EW in AL respondents indicated they thought they could get help from a government program (general), but a significantly higher percentage of EW at Home respondents thought they could pay for services specifically with Medicare.

- When asked about steps they had taken to prepare for the future, a significantly higher percentage of EW at Home reported having called the Senior LinkAge Line® or someone at the state and generally tried to find out about programs that might help them pay for services.

- EW at Home respondents were significantly more likely to report needing help at home for less than two years, compared to EW in AL who were more likely to report needing help at home for three years or more.

- EW in AL respondents were significantly more likely than EW at Home respondents to report family as a source of support once they started needing help. Small percentages of both groups said they paid for any informal support or support from an agency. In terms of the types of support provided by informal sources, EW in AL respondents were significantly more likely to cite getting help with paperwork, like paying bills, rent, or banking. Both groups frequently cited taking care of the home and help with transportation as services received.

- While a higher percentage of EW at Home respondents reported having contacted the Senior LinkAge Line® or someone at the state as part of their decision making on place of residence than did EW in AL, the differences are not significant. But, given the significant difference in the percent of EW at Home who had contacted one of these sources as part of prior planning before needing services, it may indicate that this group is more likely to have taken this step in making their decision to remain at home.

5. Trajectories to EW Enrollment

- We observed two general trajectories of entry to EW which are important to consider:
    - Low resources, persistent Medical Assistance (MA) enrollment, aged into eligibility
    - Enroll with substantial needs, relied on family/informal care until eligible
- Utilizing information for early identification could enable more closely tracking these trajectories as a means for making an impact

Drawing from the findings of the Provider Survey, National Scan, Secondary Data Analysis, and Participant Survey, we present some considerations regarding common trajectories of older adults as they age and develop needs for services. The synthesis of these findings identifies some potential points where policies and programs could have an impact on those applying for EW or who are considering a move to assisted living.

One trajectory for EW clients appears to be that of adults with limited resources, who are relatively young, and meet the necessary eligibility criteria for EW based on some specific needs. The Secondary Data Analysis identified over half (52%) of EW clients newly enrolled had overall relatively low ADL needs, were living alone or with friends or family, and residing in their own home at the time services were recommended. These clients also tended to be younger; 35% were under 70 years old and 56% under the age of 75. Additionally, among this group of clients, less than half had an informal caregiver and 70% were enrolled in MA at least 90 days prior to EW enrollment. The Participant Survey provided additional context to these findings, highlighting that those clients on EW while living in their home had a relatively new need for services. Specifically, among those receiving EW services in their home, 80% indicated they had begun needing help for less than two years and 40% less than one year. Likewise, these survey participants indicated much of this help was provided by friends and family. Therefore, older adults on this trajectory may benefit from programs or policies which are designed to extend informal caregiving or provide IADL support and address other targeted needs.

Another trajectory appears to be older adults who enroll in EW with substantial ADL and IADL needs and who have moved, or are imminently moving, to assisted living. Findings from the Participant Survey of those new to EW, new to MA, and living in assisted living indicate some level of help was needed for several years prior to qualifying for EW. In some cases, participants indicated the level of care needed reached a tipping point that prompted the move. Findings from the Secondary Data Analysis show clusters of enrollees on this trajectory typically have multiple ADL needs, however needing toileting and bathing assistance were nearly universal for these EW clients. For example, 34% of all EW clients newly enrolled in 2019 needed constant supervision or physical assistance during toileting, although this need was most concentrated among those currently living in congregate settings, where 50% had this need. Among clients newly enrolled in EW, those with the highest levels of need tended to be new to MA programs. Furthermore, nearly 70% of EW clients who lived in congregate settings at the time services were recommended were new to MA. Although the supply of AL providers could be a concern in the future, the Provider Survey and Participant Survey identified the policies and practices of providers impact the ability to receive EW services in AL. For example, the majority of providers surveyed stated they have limits on the number of residents that can use EW services (65%); just over a quarter (26%) use wait lists before EW enrollees can move in, and approximately one in five require a

minimum amount of income/assets at the time of move-in. Data from the participants surveyed corroborated the provider responses, such that over half of new EW clients who lived in assisted living had only done so for less than one year despite 44% saying they needed some level of help for more than two years. Therefore, older adults on this trajectory may benefit from programs or policies that educate about options for long-term care and housing and supports and services which could extend the time which clients can remain in their home.

Although each individual has their own aging journey, we provide conclusions based on data collected and analyzed from a variety of sources designed to represent commonalities across the aging population of Minnesota. Understanding the trajectories which older adults take before qualifying for EW is an important first step towards examining policies and programmatic changes that will ensure Minnesotans are optimally served. Although prospective identification of all older adults' trajectories may not be possible, understanding these commonalities can be useful in making data-driven programmatic changes. Furthermore, in some cases there will be opportunities to intervene at the individual level. For example, EW clients typically have multiple assessments, including formal Long Term Care Consultations (LTCCs), prior to the recommendation for services. By leveraging the coordination that already exists across DHS systems, potential/future EW clients could be identified when an LTCC is conducted, even when services are not recommended. Perhaps broadening the criteria or expanding the number of referrals for LTCCs could enable earlier identification as well as connecting with potential clients earlier. This could serve to provide more specific linkages to education (including Options Counseling) and caregiver supports. Furthermore, such information could be used to help estimate forecasting of EW enrollment. However, increasing the number of LTCCs conducted must be balanced between the administrative costs of the assessments with the benefits of tracking, forecasting, and referrals to other services/programs. Expansion of "upstream" services or programs that provide early interventions may also be an opportunity to delay spenddown and would enable earlier identification of future clients.

6. Areas of Opportunity for Impact

7.1. Upstream programmatic interventions

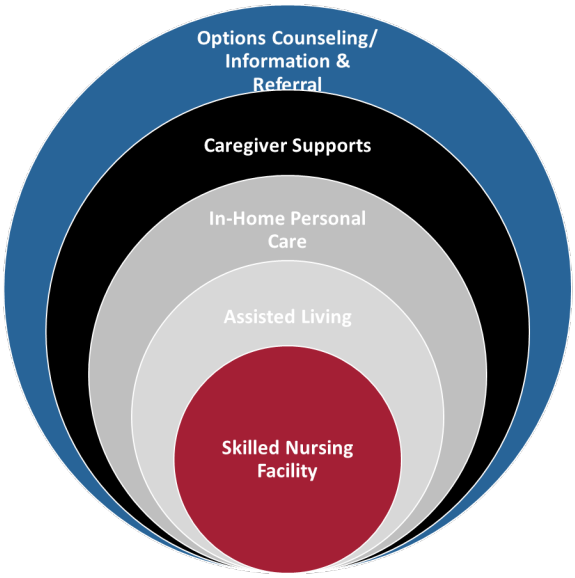
Opportunities for impact

- Utilize the contacts with the MN DHS system that frequently occur before Medical Assistance (MA) or Elderly Waiver (EW) eligibility to identify those who would benefit from early supports that can delay spenddown to MA or more costly supports through MA/EW
- Conduct robust research on costs and outcomes of these programs to discern their impacts on delay in facility-based housing and care and/or spend down to MA or EW eligibility
- Build on the existing Essential Community Supports and Alternative Care programs
    - Expand funding to include more people
    - Expand services to better align to the early supports needed to remain at home.
- Expand existing MA programs that provide supports before people reach nursing facility level of care, to help individuals stay in their home longer, and delay moves to more costly care settings

Rationale

Key informants from the National Scan stressed the critical role that programs designed to meet lower and earlier needs play in preventing or delaying spenddown to Medicaid eligibility and/or higher and more expensive care. As discussed in the National Scan Final Report, "one [key informant] 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."[11]

Figure 1. Visualization of Long-Term Services and Supports Model



Research activities in this project show a trajectory of needing assistance for several years prior to becoming eligible for EW as a common experience among those who ultimately apply for MA or EW,

[11] Snyder, Y., & Pierson, D. (2021). (rep.). *MN Elderly Waiver Enrollment Program Evaluation: National Scan*.

creating an opportunity for these kinds of programs to connect individuals and families with services earlier to prevent or delay more extensive needs/spenddown. The Participant Survey shows that needs start before individuals enroll in the Elderly Waiver (EW) with those at home most commonly saying they needed support one to two years prior and those in assisted living most frequently needing support as much as three to five years or more prior to EW enrollment. Earlier work by Wilder Research for MN DHS regarding the callers to Senior LinkAge Line® who were seeking assisted living (AL), found that "[a]pproximately one-third of consumers experienced a gradual change in their health condition prior to entering assisted living."[12]

The trajectory toward MA and EW programs may be impacted by the presence of informal support (and the level of that support) as well as particular acute health events (emergency department visits/ hospitalization/falls) that could result in additional short or long-term needs. In the Participant Survey, very few reported paying for needed services prior to joining EW, with most relying on informal support. For those without informal support, the need to rely on government programs is stronger and happens earlier, as shown in the Secondary Data Analysis where cluster analysis revealed that a sizeable portion of new EW enrollees had lower need for help with ADLs/IADLs, but lived alone and lacked an informal caregiver. The earlier noted Wilder Research report concluded that "concerns about the consumer's safety in the home, particularly as a result of their risk of falls"[13] was a driving factor for AL enrollment. Our Participant Survey data also showed that safety concerns were a factor in moving to AL. The Secondary Data Analysis showed that emergency department (ED) visits, hospitalizations, and falls were common occurrences prior to enrollment.

To maximize the benefit of early intervention programs, DHS must be able to identify and connect with these individuals at the right point in their trajectory through long term services and supports. The Secondary Data Analysis shows a high frequency of multiple contacts with the DHS system prior to EW enrollment, creating an opportunity for identifying and connecting with individuals and families in the earlier stages of needing assistance. By connecting with individuals at this earlier point in time, Options Counseling (discussed more below) and/or programs may be able to provide supports that address the lack of informal support, assuage fears about safety or falling, and provide lower level support earlier to prevent larger need later. Additional analysis of these early contact points would allow for more targeted and systematic identification and outreach.

As noted in MN 2030, The Future of the Elderly Waiver report prepared by the MN DHS in 2018, and revised in 2019,[14] the state already has multiple strategies in place to reach people early including the existing Essential Community Supports (ECS) and Alternative Care (AC) programs. These are a natural starting point for Minnesota to explore expanding early supports. These programs currently provide some home- and community- based services for individuals who are not eligible for MA and do or do not meet nursing facility level of care (AC and ECS respectively). The services needed prior to EW enrollment most commonly mentioned in the Participant Survey were taking care of the home, transportation, shopping, banking, and paying bills. Some of these, but not all, are already provided

[12] Wilder Research. (2017, May). *Experiences of Senior LinkAge Line® callers seeking assisted living*.
[13] Ibid.
[14] Minnesota Department of Human Services. (2019). *MN 2030: The future of Elderly Waiver*.

under ECS and AC. Additionally, both AC and ECS require that participants not be eligible for MA. The Secondary Data Analysis did not observe many enrollees to have prior utilization of these programs and found a large portion of EW enrollees had prior MA enrollment for several years prior to EW. This tell us that two ways of expanding these programs may be most beneficial:

- Growing the existing programs to cover more people and better aligning the necessary services; and
- Expanding existing Medicaid programs to provide some early home- and community-based supports prior to nursing facility level of care, but for individuals who are MA eligible.

Alongside expansion of AC and ECS, evaluation of program costs, a review of the patterns of use and outcomes on postponement of MA or EW eligibility, and timing of use of AL should be undertaken. This will help to guide advocacy for essential services, help policy makers analyze program funding and cost savings over time, and inform future planning.

The National Scan identified the Washington State 1115 waiver program as an example of these kinds of pre-eligibility supports that should be followed closely by MN to determine promising practices. Both of these programs have been implemented with the goal of delaying or preventing the need to move to more expensive types of care or delay spenddown to Medicaid eligibility. As both programs begin to evaluate the impact of efforts, additional information will become available on the most effective strategies for early supports and interventions.

7.2. Critical Role of Family Caregivers

Opportunities for impact

- Further study of the efficacy and gaps in existing supports and programs for family and informal caregivers
- Evaluation of the feasibility of expanding existing programs to individuals prior to Medical Assistance (MA) eligibility to provide early supports.

Rationale

The reliance on family and informal caregivers is well-known and the economic value of this care is substantial. The important role of family and informal caregivers was made apparent in each component of the research for this report, particularly the National Scan, Participant Survey, and Secondary Data Analysis. The key informants interviewed as part of the National Scan noted that maintaining family and informal caregivers was essential to prolonging the ability of older adults to live at home. In the Participant Survey, we noted that guardians and household members completed over half (54.8%) of the telephone surveys on behalf of the EW client. This highlights just how many enrollees have close involvement with family members/caregivers, regardless of whether or not the enrollee was physically or cognitively limited in their ability to answer the survey. Among the EW clients in assisted living who were surveyed, 95% reported family members helped them make decisions about their care and get the help that they need. Moreover, the lack of informal caregivers was noted in the Secondary Data Analysis as having implications for EW enrollment with lower care needs. Therefore, supporting family members and informal caregivers may be key strategies to planning for the future of HCBS.

As evident from the participants surveyed, many EW clients (or their proxies) in assisted living indicated they had moved to that setting because the level of care they needed had exceeded the capacity of family members. This “tipping point” may have been related to some specific needs. For example, findings from Secondary Data Analysis highlighted bathing and toileting as important ADL limitations of EW clients recommended for services; 58% of all new enrollees needed some assistance bathing and 34% needed supervision or physical assistance toileting. Receiving assistance for these ADLs from non-family members may be preferable. In some cases, the amount of needs and level of care a family member needs are too great to be handled at home, as was noted by 28% of respondents in the Participant Survey. This may be especially true following a hospitalization. Moreover, caregivers may be physically unable to provide care any longer. For example, caregivers may lack the strength to assist with some ADLs by themselves. Other comments from the Participant Survey indicated cognitive decline and/or memory concerns associated with behaviors, such as wandering, led family members to have safety concerns that required a move to assisted living.

Some EW clients lack anyone that can fill the role of caregiver. The Secondary Data Analysis observed that nearly 45% of new clients did not have an informal caregiver at the time EW services were

recommended, but the lack of caregiver was concentrated among EW clients with lower needs. The precise reasons behind not having an informal caregiver were not captured in these data. For instance, "no informal caregiver" may mean no one is present to provide help or care or they live too far away. Alternatively, it may mean that although someone is present, no friend or family member is able to provide *enough* help to be considered a caregiver. For example, they cannot miss work. This distinction has different implications. Responses of the Participant Survey were such that 78% of those at home and 91% of the assisted living respondents said they had relied on family members for help. Furthermore, few of the participants reported they had paid for services. Therefore, it is clear that family members are critical, as other sources of support services are uncommon among EW clients prior to their enrollment. Opportunities of future research may be able to better understand how frequently caregivers are completely lacking, versus caregivers who are unavailable to provide care, versus whose capacity has been exceeded. Such information may be helpful to identify gaps that services and supports can fill that caregivers cannot.

Minnesota has a robust set of programs designed to support informal caregivers. Among the programs offered, the Board on Aging provides family caregiver coaching and counseling, including specific information for memory care. Additionally, the Personal Care Assistant (PCA) and Consumer Support Grant Programs enable options for family members to be paid as a caregiver, while the Consumer-directed Community Supports (CDCS) program enables flexibility in the planning and responsibility for receiving services. Respite care and adult day care services are available to caregivers of EW clients. Previous research has demonstrated the use of Title III-E funds used to support caregivers.[15] The presence of an informal caregiver is assessed at multiple points, which includes when seniors are first assessed for services and at least annually thereafter. When an informal caregiver is present, additional information on the caregiver is collected. For those lacking caregivers, Minnesota manages the Direct Support Connect program to help connect individuals with those willing to provide care. The extent to which each of these services are utilized by informal caregivers, EW clients, or older Minnesotans as a whole, throughout the aging process as needs change is not fully known. For some informal caregiver programs, prior research has observed utilization may be lower than expected due to a lack of awareness of all the services available.[16]

Our analysis did not specifically identify gaps in the supports and programs for family and informal caregivers, and was not designed specifically to do so. However, our analyses do point to the level of support needed at the time of EW eligibility, the past history of informal care (or lack thereof), and how that level of care was exceeded by needs. We conclude that the lack of family caregivers and family caregivers' ability to provide care, or the level of care they can provide being exceeded, are important inflection points for receiving EW services. Whether additional programs and services to support informal caregivers could extend the time before more costly formal services are needed, like AL, remains unanswered. Additional research may consider the extent to which existing programs could be expanded beyond only those with Medicaid eligibility, such as is done with Hawaii's

[15] Wilder Research. (2017, May). *A Study of Title III-E Caregiver Services in Minnesota*.
[16] ibid

structured family supports program, Kupuna Caregivers Program.[17] Additional research could also specifically focus on gaps in supports and programs, or using the state-collected informal caregiver assessment information to better understand how to extend the "tipping point" for informal caregivers.

[17] Cobb, D. (2021, June 25). *Hawaii Kupuna Caregivers Program: Eligibility & benefits*. Payment Options & Financial Assistance for Senior Care. https://www.payingforseniorcare.com/hawaii/kupuna-caregivers.

7.3. Options Counseling

Opportunities for impact

Policy and practice considerations for improving the effectiveness of Options Counseling:

- Increase access and availability of Options Counseling to points before people have made decisions about how they want to receive LTSS.
- Educate healthcare professionals about referring people for Options Counseling as LTSS or other support needs become evident.

Rationale

As outlined in previous sections of this report, opportunities exist to intervene with targeted supports to people at lower levels of functional need or to caregivers and increase people's ability to age at home. Practically speaking, people must be able to learn about what supports are available in order to take advantage of them. Options Counseling is one avenue for this to occur. Robust Options Counseling is intended to help people formulate plans and connect to publicly or privately funded supports to help meet their LTSS needs.

In practice, Minnesotans can receive an offer of Options Counseling in three ways. First, an assessor can provide this type of information during a long-term care consultation conducted by a lead agency or a health risk assessment conducted by a managed care health plan. Second, anyone can call the Senior LinkAge Line® (SLL) to receive information and Options Counseling. Third, people who are required to call for Housing Options Counseling before they move into assisted living settings have the opportunity to receive counseling at this time.

As a result of the 2011 Special Session of the Minnesota Legislature, a revision of statute was adopted that required access to long-term care and Housing Options Counseling be offered and documented to those entering a housing with services setting, including AL facilities, regardless of payer source.[18] The intent of the revision was to ensure provision of information to those seeking care that would allow them to make the most cost-effective and least restrictive choice based on their needs; and at least for some considering entering AL, choose less costly home and community-based services. People are only required to be offered Housing Options Counseling one time.

Although an important service, there have been limited efforts to evaluate the role of Options Counseling on the timing and occurrence of residential care (including assisted living). Furthermore, although Minnesota requires access to Options Counseling, the extent to which this service is being used in the decision-making process for older adults and their families is not well-understood. As part of the National Scan, key informant interviews identified the service of Options Counseling as a key practice in preventing institutionalization; however data is limited and more research may be helpful.

[18] Amendments to Minnesota Statutes, section 256B.0911, subdivision 3c. https://www.revisor.mn.gov/statutes/cite/256B.0911. Accessed August 19, 2021

Of those who called for Housing Options Counseling, 62.5% declined Options Counseling—likely because they were planning a move to assisted living and simply needed to have an opportunity for Options Counseling to be provided as required by statute. This information suggests that for many, the decision to move into AL may have already been made at the time that participants called the Senior LinkAge Line® (SLL) and were offered Options Counseling. As noted in the National Scan, Options Counseling must be timely in order to support people's ability to plan for needs and weigh options. Survey results and Secondary Data Analysis indicate that Options Counseling at the point of just prior to moving into AL is not timely enough because the decision to move in may already be made based on family input, safety concerns, or the perception that needs are simply too high to be met at home. These results are congruent with the findings of a study conducted by Wilder Research on callers to SLL in 2017. Of the individuals who participated in that study and who declined Options Counseling prior to moving to assisted living, 92% stated that they had already decided to move into assisted living before calling SLL. Of those who accepted Options Counseling, 77% indicated that there was no change in their choice to move to assisted living.

In the Participant Survey, questions were asked about how people began considering their future need for services. When asked about steps they had taken to prepare for the future, a significantly higher percentage of EW at Home reported having called the Senior LinkAge Line® or someone at the state and generally tried to find out about programs that might help them pay for services. While a higher percentage of EW at Home respondents reported having contacted the Senior LinkAge Line® or someone at the state as part of their decision making on place of residence than did EW in AL, the differences were not significant. But, given the significant difference in the percent of EW at Home who had contacted one of these sources as part of prior planning before needing services, it may indicate that this group is more likely to have taken this step in making their decision to remain at home. The data is limited but suggests that there is an opportunity when people are still considering how to remain in their home for Options Counseling to provide information that is helpful in making that decision.

People tend to avoid long-term care planning for several reasons.[19] As it pertains to EW, it is possible that many do not perceive that they have options (e.g., who perceive their care needs to be beyond what can be done at home) and thus mandatory Options Counseling may be reconsidered. As described in the National Scan, the state of Wisconsin discontinued mandatory Options Counseling for persons seeking AL admission because it was perceived as detrimental by people who felt like they had no other options. Minnesota does not mandate that EW participants who have already received a long term care consultation conducted by an assessor receive the Housing Options Counseling service. Minnesota may use this data as an opportunity to re-evaluate the housing options counseling provided to potential AL residents, and examine how to reach potential AL residents earlier in their decision making process to ensure valuable state resources are being well spent.

Healthcare professionals were identified in the Participant Survey and the Secondary Data Analysis as key sources of information for LTSS needs. The role of health and human service professionals in providing information and helping people make choices about LTSS was also clear in the Wilder

[19] AP-NORC Center for Public Affairs Research. (2015) *Long-Term Care in America: Americans' Outlook and Planning for Future Care*. https://apnorc.org/wp-content/uploads/2020/02/AP-NORC-Long-term-Care-2015_Trend_Report.pdf

report.[20] However, healthcare professionals are not, and probably should not be, experts in LTSS. This is an important constituency that should be aware of the Senior LinkAge Line® and able to make referrals in a timely fashion; but that information must be received before people's concerns about their increased needs are actually driving their decision making. Education and outreach efforts, including to healthcare professionals, is discussed in more detail in the following section.

The scope of this project did not include an assessment of the effectiveness and accessibility of how Minnesota provides Options Counseling through the SLL but an assessment of that nature may also be of value to the state. Such an assessment could include learning about when and how people want to access LTSS-related information and the extent to which the Options Counseling meets that need. Based on available evidence it is unclear if Options Counseling is occurring too late to make a difference in people's choices; if changes need to be made to the service itself; or simply if the investment of state resources in the provision of Options Counseling, whether voluntary or mandatory, is not impacting people's decisions on the use of their personal resources or the choices they are making about where to receive LTSS.

[20] Wilder Research. (2017, May). *Experiences of Senior LinkAge Line® callers seeking assisted living*.

7.4. Enhancement of Education and Outreach

Opportunities for impact

- Broader upstream outreach and access to information where people typically get their information (online, friends, work, places of worship, health providers)
    - Public campaign
    - Targeted campaigns

- Review information given at time of contacts (when calls are received regarding how to pay in the future)
    - Opportunity to identify stage in planning and flag for further outreach
    - Include information on professionals with Medicaid-planning experience (elder law attorneys, medical social workers, state case workers and options counselors)
    - Include information on Enhanced Community Supports, Alternative Care

Rationale

In the Participant Survey, 32% of EW at Home respondents and 40% of EW in AL respondents indicated that prior to needing care, they and their families were thinking about the future and how they might pay for care when it was needed. During this planning period, 58% of EW at Home and 41% of EW in AL respondents said they had contacted the Senior LinkAge Line® or talked to someone at the state about programs to help them pay. In addition, EW at Home and EW in AL participants noted the most frequent steps they had taken when planning generally for future needs was to try and find out information about programs that might be available. So, even prior to looking for payment, there is a window during which time broader education and outreach about services and other resources available to support people as their needs change could be effective in promoting alternatives to more costly AL and other forms of congregate care. This education goes beyond payment options, focusing rather on the initial contact when these individuals are searching, and identifying what their needs are at this time, what is available to support and address those needs, and possible supports should those needs change in the future. The goal is that knowing the broad range of things that might be available, beyond AL or a nursing home, if effective, might postpone or delay spenddown of personal resources.

In addition, the role of family in planning for help, providing help when needed, and in decision-making at time of choosing assisted living was clearly seen in the survey results. So, even before the time when care is needed, there is opportunity for public education about planning for the time when the individual or their family members may need assistance to help the older individual remain living independently. There is a need to find the optimal “sweet spot” in timing (not too far in the future for family supports or after the older adults’ and their family members’ minds are made up) to connect people with the information about financial planning and counseling about options that could maximize personal resources and delay need for facility or in-home care funded by public programs.

Minnesota's DHS has developed a strong public education campaign, Own Your Future, to educate the public about the need to plan for long term care needs. Per the website, "Own Your Future aims to make Minnesotans aware of the importance of planning now to identify personal and financial options to meet their future long-term needs and to increase the number of Minnesotans who have taken action to address and provide for their future long-term needs."[21] It has not, however, been a sustained public awareness campaign, but rather receives press and other visibility only at certain times. Nor has there been evaluation of the effectiveness of the effort. There is potential to evaluate the effectiveness, build on existing efforts that are effective, and improve on areas where the campaign could be stronger and consistently maintained in the public's eye.

There are many publications aimed at caregivers, e.g., AARPs *Prepare to Care: A Caregiving Planning Guide for Families*[22], and while helpful once care is seen as needed, do not address longer-term, prior planning and financial planning in depth. There is an opportunity for MN DHS to continue to lead development of resources for the public with this focus on financial planning and the roles and limitations of public assistance. Targeting adults facing the position of being caregivers and who will face aging themselves (often this is the 45-64 demographic), whether through sustained public education campaigns, such as Own Your Own Future, and/or targeted campaigns, such as through employer HR programs that provide long term care planning education, could have an impact on encouraging financial planning as well as health care planning, and emphasize resources to help extend one's personal assets for as long as possible.

For all, education regarding the available programs, such as Essential Community Supports and Alternative Care, that support home- and community-based services to persons with modest assets but not yet eligible for Medical Assistance (MA), will become ever more important as baby boomers age. Data show that most baby boomers do not have sufficient assets in retirement[23] and carry debt and have greater debt balances[24] compared to earlier cohorts. Most desire to remain in their own homes. For the foreseeable future, this cohort is of most concern for efforts to extend existing assets for as long as possible and delay reliance on public programs. But, taking the long view, analysis of retirement savings in younger cohorts indicate millennials will have the hardest time saving sufficiently for retirement. And, they will be limited in being able to financially assist older parents.

The state should consider both broader public education campaigns as well as targeted campaigns for specific income, age or need groups that focus on planning for the time of needed services and supports and existing programs that help older adults remain in their homes and extend private resources.

In addition, targeted campaigns could focus on health care professionals as they are frequently where people express the need for support but professionals may have no idea where to refer people or

[21] Knatterud, L. R. (2019, November 15). *Own Your Future*. Own Your Future - Department of Human Services. Retrieved September 24, 2021, from https://mn.gov/dhs/ownyourfuture/.
[22] AARP. (n.d.). *Easy to download caregiving prepare to care guide*. Prepare to Care Planning Guide. https://www.aarp.org/caregiving/prepare-to-care-planning-guide/.
[23] Insured Retirement Institute. (2019) *BOOMER EXPECTATIONS FOR RETIREMENT 2019*. Accessed August 6, 2021.
[24] Stanford Center on Longevity. *Seeing Our Way to Financial Security in the Age of Increased Longevity*. Accessed August 4, 2021.

about the range of supports possible. Both the prior report prepared for MN by Wilder Research, "Experiences of Senior LinkAge Line® Callers Seeking Assisted Living" and our Secondary Data Analysis indicate that professional consideration – the influence of health care and human service professionals – influences housing and care decision making. But education campaigns must also go beyond physicians and should include occupational and physical therapists and hospital and rehabilitation facility social workers/care managers among others, as these providers are often assisting patients post-rehab or in home care when the opportunities to build a strong in-home system and monitor it over time is possible. Whether a broad public or targeted campaigns, this education effort must be sustained over time.

A more comprehensive review of Senior LinkAge Line® calls for information could be undertaken to determine if there are additional opportunities to identify patterns that could flag specific types of responses aimed at moving beyond payment to a broader discussion of services and supports. Many families may not have a full appreciation of all the resources available to older adults and their families enabling them to remain at home independently. Furthermore, it may be feasible for SLL to provide proactive follow-up to older adults that meet certain criteria signaling an increased likelihood of service need or changing service need in the near-future as a means to help extend individuals' resources further.

7.5. Provider Landscape

Opportunities for impact

- Survey providers one to two years post implementation of new licensure in August 2021
    - Assess impacts of new licensure requirements on EW policies and practices
    - Assess use of EW in facilities with new licenses

Rationale

The timing of this research came during a period of instability in the provider landscape. The impacts of COVID-19, while not fully known, reduced census in many facilities and reduced staff. Those impacts are ongoing and may permanently affect the views of older persons and their families on congregate living. Furthermore, facilities have been, and may continue to be, difficult to fully staff, exacerbating existing workforce shortages. In addition, the Assisted Living Licensure (ALL) became law on August 1, 2021, with new requirements for licensed facilities that provide EW customized living services.

The Provider Survey informed us that more than two-thirds of providers indicated they expected the proposed changes from the then-pending ALL would impact their policies and practices related to EW. The most common changes expected were that providers would accept fewer or no EW residents, increase rates (did not specify whether private rates or room and services), and extend required private pay periods. Providers also voiced concern that state program reimbursement would not cover the additional costs of the license and services.

The future of assisted living for EW enrollees is unclear at this moment in time, given the as yet unknown effects of COVID-19 and the ALL. Perceptions by older persons and their families of congregate living may reduce the demand for AL. Any of the expected changes reported by providers in response to the new ALL could reduce the supply of units to serve the EW in AL. Alternatively, changes in reimbursement could shift the use of EW, and perhaps decrease supply and thus increase demand. Some providers commented in the survey that they think the program is of great value and they would like to serve more residents using EW, but are hindered from doing so by financial considerations.

More than half (57%) of providers who responded to our survey stated that they limit the number of residents using EW to five or fewer, most have waiting lists for prospective residents paying with the EW at time of move-in, and overall there are fewer current residents waiting to use EW. Providers also provided insights on their view of the impacts COVID-19 has had on EW, namely slower response times from case managers, delays in applications, and fewer onsite assessments. Some providers reported they had relaxed some restrictions and were accepting more EW residents to try to make up for low occupancy. However, others indicated they would delay participating in the program due to low reimbursement rates and needed to increase the number of private pay residents in order to recoup losses. With so much uncertainty at the present time, it is difficult to predict the longer-term strategies facilities will use in order to respond to the pandemic and how this will affect EW in the post-pandemic era.

Reimbursement was identified as a significant limiter to providers' willingness to participate in the EW; rate increases might remove that barrier. The state of Minnesota has made some reforms in rates for many of the services covered by EW, AC, and ECS.[25] For example, rate setting reforms were passed by the Minnesota legislature in 2017, and additional increases of about 3.2% on average will be effective January 1, 2022. The 2021 Minnesota legislature also established a customized living rate floor (i.e., a minimum daily rate) for AL providers that serve 80% or more EW participants.[26] But even with these adjustments, the 2017 rate reforms are not fully funded. The effect of these increases and any further changes could be evaluated in another survey to assess the impact of those rates on provider policies and practices around EW.

We think there is value in surveying providers again in one to two years to assess whether the ALL impacts the providers expected on their EW policies and practices actually occurred, and the degree to which this affected EW use at move-in or post-residency. The survey could also explore participation in and use of EW in facilities obtaining first-time licenses under the new ALL. The survey may also serve to depict the long-term impacts of COVID-19 on provider operations and consumer views of congregate living and the demand for AL on the EW.

Two options are possible for survey implementation. One is to include some survey questions on license renewals. Basic data on EW participation, number of units, growth or contraction in EW units, impacts of ALL, and other factors would allow for monitoring of EW in AL over time. The other option is to do a point-in-time, cross-sectional survey (as was done in this project) to assess these same factors. These options are not necessarily mutually exclusive. The first option would be a long-term commitment and meaningful conclusions and trends could take time to be apparent. On the other hand, a point-in-time survey as described in option two could be used to provide data in real-time to assess impact.

[25] For context on state of MN's previous review of rates see the 2019 Legislative Report, with attention to pp. 15-24, which presents findings and DHS recommendations for a comprehensive study of rates for many of the services provided through Elderly Waiver. https://edocs.dhs.state.mn.us/lfserver/Public/DHS-7850-ENG

[26] Spuit, P., personal communication, August 13, 2021

7. Summary of Suggested Future Research

Each research activity in this effort made a significant contribution toward better understanding the trajectories people take toward the Elderly Waiver (EW) and the points and ways in which policy and programs can impact those trajectories. These efforts also highlighted areas that, beyond the scope of this project, would provide additional detailed and targeted information about effective ways to best support Minnesotans in efficient use of resources in receiving care in the choice of their setting with further study. These areas for additional study include:

- Robust research on costs and outcomes of the Essential Community Supports and Alternative Care programs to discern their impacts on delay in facility-based housing and care and/or spenddown to Medical Assistance (MA) or EW eligibility. These programs were identified as existing programs that could be enhanced to meet earlier needs that could delay or prevent spenddown/high levels of need and more information on how they are currently utilized (unavailable during this project) would help guide purposeful expansion and impacts of any expansion.
- Study of how frequently caregivers are completely lacking, versus where caregivers exist but are unavailable to provide care in a meaningful way, versus caregivers who are providing care, but whose capacity has been exceeded. Such information may be helpful to identify what needs services and supports can fill that caregivers cannot. Building on this information to determine how existing supports and programs for family/informal caregivers can be modified to best fill these gaps will maximize program efficacy. This should include the extent to which programs could be expanded to beyond those with Medicaid eligibility, such as is done with Hawaii's structured family supports program, Kupuna Caregivers Program.
- Assessment of awareness and effectiveness of how Minnesota provides Options Counseling, particularly Housing Options Counseling, including the timing of that counseling. Such an assessment could include learning about when and how people want to access LTSS-related information and the extent to which the Senior LinkAge Line® (SLL) meets that need. For Housing Options Counseling, additional study could include evaluation of the value added for the individual, particularly those considering AL. For each of these, evaluation will support the state in maximizing the effectiveness of the service in fully supporting people's LTSS planning and decision-making processes.
- A more comprehensive review of SLL calls for information could be undertaken to determine if there are additional opportunities to identify patterns or people at points where early interventions would be effective. Our research could not address directly ways in which SLL data could be used to better address opportunities for early intervention, flag individuals for follow up, or determine process improvements. Further study of this nature may allow SLL to provide proactive follow-up to older adults that meet certain criteria signaling an increased likelihood of service need or changing service need in the near future as a means to help extend individuals' resources further.
- Undertake an additional survey of assisted living (AL) providers in one to two years to assess the impacts of the Assisted Living Licensure on EW policies and practices and those impacts on utilization by AL residents. This survey could also be used to understand the short and longer-

term effects of the COVID-19 pandemic on provider operations and consumer demand for AL in EW.

- While the policy and program recommendations in this report do not target asset protection policies, there is value in monitoring the experience of the state of Washington as they move forward with implementation and evaluation of the new, publicly -long term care insurance program. Results from this program may inform future considerations in Minnesota for supporting the prolonged use of private resources prior to MA eligibility.