

# MN Elderly Waiver Enrollment Program Evaluation: Participant Survey

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# 1. Executive Summary

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.

The participant perspective, gained from a telephone survey, is expected to give insight into one aspect of the larger pattern of EW use to pay for AL services, and spenddown 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.

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.

## 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, but 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 (like cleaning or yard work) and rides to appointments, shopping, etc. Very few reported paying any informal support source or 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.

## 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. To get help, the primary source 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 (like 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; 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.

## 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. In terms of the types of support provided by these 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.

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

Minnesota's 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 AL market, which has increased use of this service within EW. Yet, there has been little research to understand the patterns of use of EW to pay for AL, including the spenddown patterns of those using the program and policies and practices of providers in relation to EW.

As part of a larger study of spenddown to EW eligibility in 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.

The participant perspective, gained from a telephone survey, was expected to give insight into one aspect of the larger pattern of EW use to pay for AL services, and spenddown to EW eligibility.

### 3. Research Questions

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

- What are the private resource spenddown experiences and patterns for individuals, both married and single, in AL 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. Data and Methods

### 4.1 Data sources

The data included 231 completed surveys from EW participants (or their proxies) and data from Knowledge Services (KS) on the number of steps taken for each survey to reach the final respondent. 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.

### 4.2 Study Population

The study population consisted of new, first-time EW participants who enrolled in Medical Assistance (MA) for the first time within 90 days of starting EW 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. A total of 1,299 new enrollees were pulled during this period. Of these, 109 were removed from the first data pull because they had enrolled in Medical Assistance longer than three months prior to the pull date. During the course of the survey, 128 potential survey cases were removed because they did not have contact information, case manager did not provide contact information, or the participant had died. This left the final potential survey population at 1,062.

See Appendix A for monthly numbers of new enrollees and how these numbers compared to the year 2019. As shown in Appendix A, there were fewer new enrollees identified in the survey period than in 2019 due, in part, to lag in data entry into the system and that we used only those enrolled in the 90 days prior from October 2020-June 2021, i.e. less than one year of enrollees. Note, each new pull would delete any identified in the previous month to avoid duplications. In addition, the first sample pull (October) did not screen for only new MA enrollees; from that pull, we had to eliminate 217 who were not first-time MA enrollees from the potential survey population. The total then of new enrollees included in the correct population pull was 1,299. While we originally anticipated sampling from the monthly new enrollees, given the small number each month, the entire population was used as the sample.

Post survey, we also analyzed the demographics of the survey respondents to the similar population from 2019 (last full year available at the time of the study start). As Appendix B shows, the survey population is very similar to the new enrollees from the 2019 data, indicating a representative set of survey respondents for this population.

## 4.3 Methods

A telephone survey (see Appendix C, pg. 42) was used to explore the spenddown and decision-making around choice of living setting, either at home or in AL, of new Medical Assistance enrollees over a six-month period. The first step in the telephone survey process was to use a decision matrix developed by the CAC team in collaboration with DHS staff to determine if the individual enrollee could complete the survey or if a proxy would be needed. See 68 to view the decision matrix. This matrix was developed based on a sample of cases pulled prior to the survey to get a sense of who would be the primary contacts for those in this population. The decision starts with MN DHS staff using Long-Term Care (LTC) Assessment variables of orientation, hearing, able to use telephone, and/or needing an interpreter to develop cutoff scores to identify those who, based on these variables, were likely to need a proxy. The next screen was whether any in the eligible population, participants or likely to need a proxy, had a guardian. If no, participant or proxy could be contacted directly. If a guardian was in place, the guardian was the first contact. If not, a series of steps followed to determine the best respondent (refer again to Appendix D). In implementation, this process was followed based on the initial contact provided for each enrollee; these included Person, Household, Guardian, Case Manager. KS, the survey vendor, first attempted the initial contact, then based on response, would continue as the initial contact indicated, whether refused, identified a better contact, referred to a proxy, or completed the survey themselves.

While the decision matrix was the first guide, getting to the “best respondent” for each case was extremely challenging. When it was necessary to contact a case manager to find the best respondent, i.e., when participants were unable to complete a survey for any reason, it often took the KS team many attempts to reach a case manager, and many did not respond even after DHS staff presented the survey at several key events and emphasized the importance of case manager response to assist in finding someone who could complete the survey on behalf of the participants. The state system of separate eligibility and assessment staff distinct from case managers added to this challenge; for example, the first person reached by KS might be initial eligibility and assessment staff person who would then refer to the current case manager. Even when the case manager was reached and they identified a suitable proxy, reaching those people also involved multiple attempts. When participants were contacted who also said they could not complete the survey, KS asked them if someone could answer on their behalf. Then, the follow-up began to reach that person as well.

CAC asked KS to maintain a record of the stream of attempts (up to eight in some cases), although the cutoff for attempts was formally six. Analysis of the attempts shows that in almost one-third (32%) of completes, four or more attempts (up to seven) were needed. A full analysis of contacts and outcomes is shown in Appendix E. This information is very useful in analyzing the higher number of proxy responses. As shown in Appendix E, while in 68% of cases the first contact was the EW participant (person), only 30% of completions were by this person. So, in addition to our screening process which identified participants who would, a priori, be seen as needing a proxy, it is clear that many more of the participants were unable to respond on their own. We believe this information can inform future surveys with similar populations of the very old, in higher need of services, and who even when the first contact often referred surveyors to a proxy to answer on their behalf.

A total of 231 completed surveys, 64 EW at Home and 167 EW in AL, were completed, for a 21.7% response rate. Persons (participants) completed the survey in 62 cases; proxies completed the survey in 169 cases. Given the lower number of new enrollees during the study time frame (refer to Appendix A again for comparison of 2020-2021 to 2019), the higher levels of service need and age, especially of EW in AL participants, and the number of attempts needed to reach the appropriate respondents, we view this response rate as quite good. While lower than the often-quoted industry overall average of around 33%, and higher than the low of 9% currently seen for telephone surveys of the polling type, our response rate is slightly above the 18% average for telephone surveys<sup>1</sup> and nearer the 25% average KS reports from their survey experiences. We believe the extra efforts made by KS to identify and follow-up with often numerous contacts to reach the best respondent for each potential survey added to this success.

Data were analyzed, using descriptive statistics, in SPSS. Statistical comparison of proportions was conducted using  $\chi^2$  tests, including Fisher's exact test when cell counts were low, with an  $\alpha = 0.05$  to indicate statistical significance. When reviewing the results, it is important to note that skip patterns in the survey dictated different sample sizes for the questions. Some questions also allowed multiple responses and when these are reported, the percentages are based on the potential number of responses (sample for individual question).

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<sup>1</sup> Lindemann, N. (2021, August 12). *What's the average survey response RATE? [2021 Benchmark]*. Survey Anyplace. <https://surveyanyplace.com/blog/average-survey-response-rate/>.

## 5. Results – Demographics of Survey Sample

Selected demographic information on the program participants reflected in the survey (regardless of response type) is shown in Table 5.1. The demographic information is split to show comparison between program participants living at home versus in assisted living. As shown, the EW in AL survey participants are significantly ( $p < .05$ ) more likely to have high case mix, be older, widowed, and white.

**Table 5.1. Demographic Comparisons of EW Participants Represented in the Survey**

Demographics	EW at Home	EW in AL
Gender ( $\chi^2=5.339$ , $p=.069$ )		
Male	25 (39.1%)	41 (24.6%)
Female	39 (60.9%)	124 (74.3%)
Not Reported	0 (0.0%)	2 (1.2%)
Case Mix ( $\chi^2=15.78$ , $p=.000$ )		
Missing	0 (0.0%)	2 (1.2%)
Low	23 (35.9%)	22 (13.2%)
High	41 (64.1%)	143 (85.6%)
Age ( $\chi^2=15.79$ , $p=.003$ )		
60-69	12 (18.8%)	12 (7.2%)
70-79	24 (37.5%)	37 (22.2%)
80-89	17 (26.6%)	68 (40.7%)
90+	11 (17.2%)	48 (28.7%)
Missing	0 (0.0%)	2 (1.2%)
Marital Status ( $\chi^2=11.39$ , $p=.023$ )		
Single, never married	7 (10.9%)	11 (6.7%)
Divorced	10 (15.6%)	25 (15.2%)
Widowed	17 (26.6%)	81 (49.1%)
Married	19 (29.7%)	34 (20.6%)
Unknown	11 (17.2%)	14 (8.5%)
Race ( $\chi^2=11.56$ , $p=.041$ )		
Missing	0 (0.0%)	2 (1.2%)
Asian	2 (3.1%)	2 (1.2%)
Black/African-American	7 (10.9%)	3 (1.8%)
Black-African-American (Biracial)	0 (0.0%)	1 (0.6%)
Unable to determine	4 (6.3%)	10 (6.0%)
White	51 (79.7%)	149 (89.2%)

## 6. Results – EW at Home

### 6.1 Planning Before Help was Needed

The survey asked a series of questions about the time prior to needing help. The purpose of these questions was to explore how much thinking and planning individuals and families had done for a time when the older person might need help, and the extent to which they had specifically planned for paying for services when needed. In the first of these questions, we asked “before you needed help from anyone, were you and/or your family thinking and talking about how you might pay for help when you needed it?” Almost one-third, 20 (32%) said “yes.” For those who had begun this thinking for the future, we then asked whether a series of statements about paying for services applied to them. As shown in Table 6.1, the most frequently cited response was knowing they would have to pay and worrying about having enough money to do so.

*[NOTE: As described in the methods earlier, in Tables with multiple responses throughout the report, the percentage is of the total potential respondents, and these may vary based on skip patterns in the survey.]*

**Table 6.1. Planning and Paying for Help One Might Need in the Future (n=20, multiple responses possible)**

Considerations	N	%
I knew I would have to pay and was worried about having enough money	16	80%
Thought I could pay for services with Medicare	7	35%
Thought I could get help from a government program	6	30%
Knew I had to pay, and thought I had enough to cover what I would need	3	15%
Thought I could pay for the services I needed with long-term care insurance	1	5%

When asked if at the time they were thinking about possibly needing help or services, they knew there were programs that could help pay for services, 9 of the 20 (45%) said “yes.” Of these nine, six said their plan to pay for services included applying to the programs at some time. Of the same 20 who had planned, 11 (52%) reported someone helped them to think about or make a financial plan to pay for services when they were needed. Among those who helped were: family (10); estate planner (3); case worker (2); friend (1).

Finally, a series of statements describing possible ways people can prepare for when they may need help were presented to all EW at Home respondents, and they were asked to identify if they used any of these ways to plan. As shown in Table 6.2, the most frequently cited ways in which respondents had prepared for the future were to have called the state to explore programs, and or generally, in some way, tried to find out about programs to pay for their services when needed in the future.

**Table 6.2. Ways of Preparing for Future Needs (n=64; multiple responses possible)**

Preparations	N	%
Called the state Senior LinkAge Line or talked to someone at the state about programs	37	58%
Tried to find out about programs that might help you get and/or pay for services	36	56%
Gathered information about what services might cost	23	36%
Used estate planning	3	5%
Purchased long term care insurance	0	0%
Prepared in some other way	7	11%

Among the other ways in which people had prepared were:

- Called A Place for Mom, but referrals were unsuitable
- Insurance carrier for Medicare informed respondent of what services he was qualified for
- Hospital staff helped inform
- Saved money to have a little extra
- Tried to directly get enrolled through state Medical Assistance
- Prepared for the location ahead as she had worked there and had to move, this was her preference

## 6.2 Getting Help Once Needed Prior to EW

Once older adults need help, they often use a variety of sources to meet their needs prior to application for EW. We asked a series of questions about how long ago these EW at Home participants started to need help and from what sources they received the help needed. As shown in Table 6.3, 41%, said they had needed help for less than one year; another 38% reported needing help within the past one to two years. So, in total, more than 75% of EW at Home respondents had started needing care within the past two years.

**Table 6.3. How Long Ago the Person Started Needing Help at Home (n=64)**

Length of Time	N	%
Less than a year	26	41%
1 to 2 years	24	38%
3 to 5 years	6	9%
More than 5 years	2	3%
Unsure/Don't Recall	6	9%
<b>Total</b>	<b>64</b>	<b>100%</b>

To get the help needed, respondents turned to a variety of supports. As shown in Table 6.4, family was cited most often as the source of help once needed. Among the “other” responses were: biking club, case worker, home cleaning service, home health aide, hospice, and Lake County. When asked if they paid for any of this help, only seven of the 58 (12%) who could recall past service responded “yes.”

**Table 6.4. Sources of Help Once Needed to Take Care of Self or Home (n=64; multiple responses possible)**

Source	N	%
Family	50	78%
Friends or neighbors	10	16%
My faith community	2	3%
Other	6	9%

Next survey respondents were asked to identify the types of help they received from these multiple sources. As shown in Figure 6.1, the most frequently cited types of help were taking care of one’s home and transportation and shopping assistance.

**Figure 6.1. Types of Help Received When Started Needing Help (n=67; multiple responses possible)**



Among the “other” responses for types of help received were: an agency fixed outside of home, help to translate phone calls, haircuts and beard trim, help opening jars and other tasks as needed, help getting a cane and walker, and help buying a bigger, more accessible vehicle to accommodate scooter.

EW at Home respondents were also asked if when they started needing help, they paid an agency for services. As shown in Table 6.5, only eight (13%) indicated they paid an agency to help them. With the few respondents who reported paying an agency for services, the most common service – reported by all – was paying for help in maintaining their home. The one person responding “other” used this opportunity to note that she was only able to pay for an agency to “come a few times.”

**Table 6.5. Types of Services Paid an Agency to Provide (n=8; multiple responses possible)**

Services	N	%
Taking care of your home, like cleaning or laundry or yard work	8	100%
Taking care of yourself, like bathing, getting dressed, combing your hair/cutting your nails	5	63%
Cooking, meals	4	50%
Rides to appointments, shopping	3	38%
Taking your medications (prescriptions filled, reminders to take, helping to take)	2	25%
Paperwork, like paying bills, rent or banking	1	13%
Modifying your home (for example, putting in grab bars in your bathroom)	0	0%
Other	1	13%

When asked how they were paying for services, three responded “used my own money,” two said “my family was paying for some or all,” two said insurance or specifically outside insurance combined with Medicare/MA, and one said generally “government.”

EW at Home respondents were then asked if they could recall how long they were able to pay for these services before applying for help from the State. Of the five who could recall, three said “less than one year” and two said “one to two years.”

Of those who paid for some type of help, six responded to a question about how long they were able to pay for services themselves. Three indicated they were able to pay for themselves “longer than expected” and three responded “shorter than expected.” When asked about issues that were a part of why they weren’t able to pay for services as long as expected, the reasons cited are shown in Table 6.6.

**Table 6.6. Reasons Unable to Pay for Services as Long as Expected (n=6; multiple responses possible)\***

Reason	N	%*
<b>Overall Costs and Income Issues</b>		
Costs of services were higher than expected	4	67%
Cost of rent/living was higher than expected	1	17%
Had less income from investments than expected	1	17%
Had expensive home repairs or other everyday expenses	4	67%
<b>Medical or Insurance Issues</b>		
Long term care ended sooner than I thought it would	0	0%
Medicare didn’t pay for things I thought it would	0	0%
Medical bills for self	3	50%
Medical bills for spouse	0	0%
<b>Other Contributing Issues</b>		
Had my income fall due to death of my spouse or partner	1	17%
Had my income reduced for some other reason (pension ended, e.g.)	0	0%
I spend my money helping children and grandchildren	0	0%

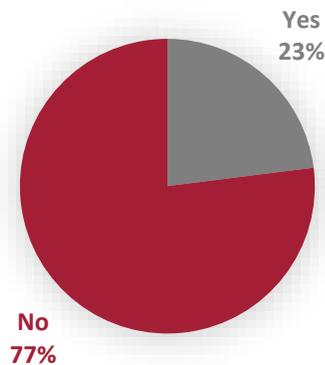
\*Due to very small number of responses, percentages should be interpreted with caution.

As shown in Table 6.6, higher than expected costs of services, having expensive home repairs or other everyday expenses, and medical bills for self were the most commonly cited reasons for EW at Home respondents being unable to pay for services as long as expected.

### 6.3 Decision Making About Place of Residence

A series of questions were asked of EW at Home respondents about their choice to remain in their home. First, they were asked if they had considered moving to assisted living. As seen in Figure 6.2, more than 75% said they had not considered assisted living.

**Figure 6.2. EW At Home Who Had Considered AL (n=64)**



As shown in Table 6.7, for the 15 who said they had considered AL, we followed up with a question regarding their reasons for choosing to remain at home. The most commonly cited reason was that the respondent was not yet ready to move to AL. Among the “other” responses were that lease for current apartment is still current, do not need AL yet, and that while still at home, respondent is planning a move to AL.

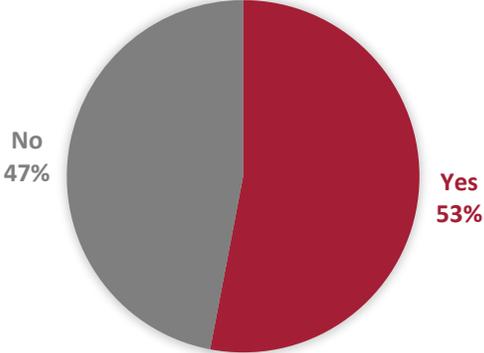
**Table 6.7. Main Reasons for Choosing to Remain at Home (n=15, multiple responses possible)**

Reason	N	%
Wasn't ready yet	6	40%
Didn't want to move	3	20%
Too expensive	3	20%
Wanted to try at home with more services	2	13%
Would take all of my money with nothing left for self	2	13%
Other	3	20%

Those living at home with EW were also asked whether at any time in making their decision about where to live and use the EW, they had called the Senior LinkAge Line or someone at the state about options for getting services, at home or in another setting. As shown in Figure 6.3, 34 (53%) said they had called to get information on options; this is slightly less than the percentage of EW at Home respondents (58%) who

reported having called during an earlier period when they were planning on how to pay for services when needed. Of the 34 who indicated they called to get specific information about getting services at home or in another setting, 13 (38%) said this call and the information gained influenced their decision to stay at home.

**Figure 6.3. EW at Home - Called Senior LinkAge or State as Part of Decision Process (n=64)**



## 7. Results – EW in AL

### 7.1 Planning Before Help Was Needed

As with the EW at Home participants, we asked EW in AL participants to reflect back to a time when they were in their own home and before needing help from anyone. In the first of these questions, we asked “before you needed help from anyone, were you and/or your family thinking and talking about how you might pay for help when you needed it?” Sixty-seven (40%) said “yes.” For those who had begun this thinking for the future, we then asked whether a series of statements about paying for services applied to them. As shown in Table 7.1, the most frequently cited response was knowing they would have to pay and worrying about having enough money to do so; almost half also said they thought they could get help from a government program.

**Table 7.1. Planning and Paying for Help One Might Need in the Future (n=67, multiple responses possible)**

Considerations	N	%
I knew I would have to pay and was worried about having enough money	36	54%
Thought I could get help from a government program	31	46%
Knew I had to pay, and thought I had enough to cover what I would need	21	31%
Thought I could pay for services with Medicare	9	13%
Thought I could pay for the services I needed with long-term care insurance	4	6%

When asked if at the time they were thinking about possibly needing help of services, they knew there were programs that could help pay for these services, 39 (58%) said “yes.” Of these 39, 31 (80%) said their plan to pay for services included applying to the programs at some time.

Of the same 67 who had planned, 40 (60%) reported someone helped them to think about or make a financial plan to pay for services when they were needed. Among those who helped were: family (34); legal advisor/estate planner (3); social worker (1); someone from the state (1), and someone from the county (1).

Finally, a series of statements describing possible ways people can prepare for when they may need help were presented to all EW in AL respondents, and they were asked to identify if they used any of these ways to plan. As shown in Table 7.2, the most frequently cited ways in which respondents had prepared for the future were called the Senior LinkAge Line or the State about programs, tried to get information about programs that would pay for services and generally gathered information about service costs.

**Table 7.2. Ways of Preparing for Future Needs (n=167; multiple responses possible)**

Preparations	N	%
Called the state Senior LinkAge Line or talked to someone at the state about programs	68	41%
Gathered information about what services might cost	61	37%
Tried to find out about programs that might help you get and/or pay for services	57	34%
Used estate planning	12	7%
Purchased long term care insurance	5	3%
Prepared in some other way	23	14%

The other ways in which people had prepared are summarized here under major themes, and examples of each follow.

*Family Assisted (6)*

- Brother set up an annuity
- Daughter sought counsel from an attorney
- Daughter is a social worker so she knew where to start looking for service

*Prepared Myself (17)*

- Gave away a vacation house when spouse died to prepare for retirement
- Had papers prepared with an attorney
- Looked around at some different facilities for good care so I would be in a nice facility
- Savings, annuities, 401(k), paid mortgage all to prepare
- Started to downsize
- Took out life insurance policies
- Assisted living providers help to find services

## 7.2 Getting Help Once Needed Prior to EW

As noted in the section 5, once older adults need help, they often use a variety of sources to meet their needs prior to application for EW. We asked a series of questions about how long ago the EW in AL participants started to need help and from what sources they received the help needed. As shown in Table 7.3, more than half (53%) started needing help at home within the last two years. But almost one-fifth (19%) had needed help for five years or more.

**Table 7.3. How Long Ago the Person Started Needing Help at Home (n=166)**

Period of Time	N	%
Less than a year	37	22%
1 to 2 years	52	31%
3 to 5 years	41	25%
More than 5 years	31	19%
Unsure/Don't Recall	5	3%
<b>Total</b>	<b>166</b>	<b>100</b>

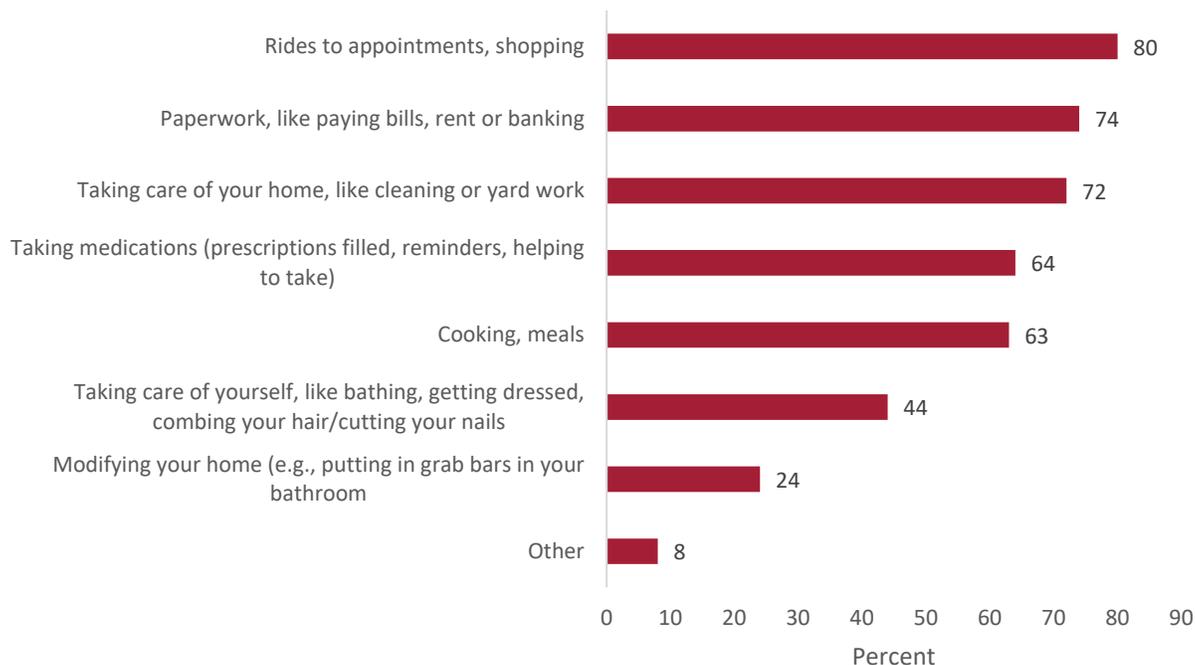
To get the help needed, EW in AL respondents turned to a variety of supports. As shown in Table 7.4, the primary source of help is family, cited by 91% of respondents. “Other” sources of support included agency or paid care (4), paid care and Meals on Wheels (1), and Alcoholics Anonymous (AA) group (1). When *asked if they paid for any of this largely informal help*, 17 (10%) responded “yes.”

**Table 7.4. Sources of Help Once Needed to Take Care of Self or Home (n=167; multiple responses possible)**

Sources	N	%
Family	152	91%
Friends or neighbors	34	20%
My faith community	6	4%
Other	8	5%

Next survey respondents were asked to identify the types of help they received from these multiple sources. As shown in Figure 7.1, the most frequently cited types of help were rides to appointments, shopping, paperwork, and taking care of one’s home. But, the number of respondents citing many of these types of help is an indication of the level of need among the AL participants prior to their moves to AL facilities.

**Figure 7.1. Types of Help Received When Started Needing Help**



Among the “other” types of help received were: companion services (1), emotional support from church (1), help with a catheter (1), medical and legal oversight at appointments (1), help with signing up for VA benefits (1), and senior center services, e.g., nurse and van (1).

EW in AL respondents were also asked if, when they started needing help, they paid an agency for services. Thirty-eight (23%) indicated they paid an agency to help them. As shown in Table 7.5 the most common service paid for was cooking/meals. Among the “other” responses were: companion services (4); OT and/or PT (3); basic health care (1), and adult day care (1).

**Table 7.5. Types of Services Paid an Agency to Provide (n=38; multiple responses possible)**

Service	N	%
Cooking, meals	14	37%
Taking care of yourself, like bathing, getting dressed, combing your hair/cutting your nails	9	24%
Taking your medications (prescriptions filled, reminders to take, helping to take)	8	21%
Rides to appointments, shopping	2	5%
Paperwork, like paying bills, rent or banking	2	5%
Modifying your home (for example, putting in grab bars in your bathroom)	0	0%
Taking care of your home, like cleaning or laundry or yard work	0	0%
Other	9	24%

## 7.3 Decision Making Regarding Place of Residence

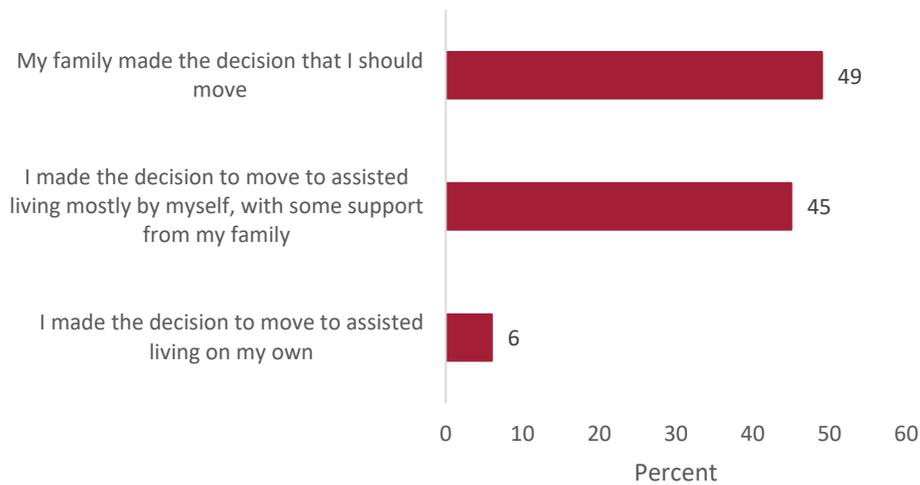
First, 95% of respondents indicated that the person on EW has family members who help them make decisions and get the support they need. Second, as shown in Table 7.6, this role of family is also reflected in the main reasons given for choosing AL, with “family encouraged it” the reason most often given, even if it is one of several reasons provided. Among the “other” responses remaining were driving issues, had friends in the facility, liked the facility and staff, to be closer to children, spouse became ill and moved as what was hoped to be a temporary way to get help during his treatment, and family concern for safety.

**Table 7.6. Main Reasons for Choosing Assisted Living (n=167, multiple responses possible)**

Reason	N	%
<b>Survey Closed Options</b>		
Family encouraged it	63	38%
After a hospital stay, I need too much help to stay at home	47	28%
Knew I needed help	27	16%
Didn't feel safe at home	25	15%
So family won't have to keep doing things for me	18	11%
My spouse needed care/memory care and I moved with him or her	13	8%
There weren't enough service providers for me/my spouse to get help in my home	6	4%
Lost my spouse	6	4%
Lost my main help/helper	4	2%
<b>Coded from "Other Reasons" where Multiple Responses Given</b>		
Level of care needed	13	8%
IADLs	12	7%
Fall risk	11	7%
Overall health	10	6%
Cognitive issues	10	6%
Spouse's needs	9	5%
Doctor recommended	9	5%
General- unable to care for self	9	5%
Dementia	8	5%
Need place to live	7	4%
ADLs	6	4%
Loneliness/isolation	5	3%
Rehabilitation	5	3%
Psychological/psychiatric issues	4	2%
Family changes	3	2%
Vision loss	2	1%
Safety	2	1%
Other	13	8%

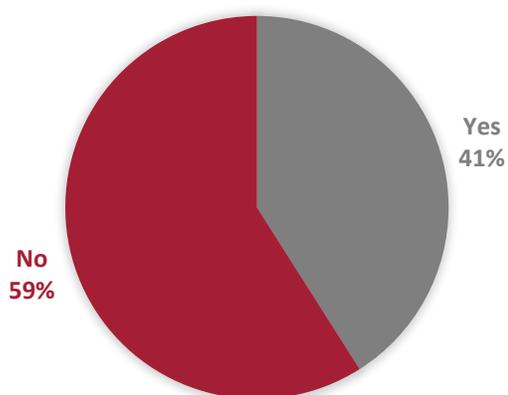
Delving further into the role of family, those who reported they had family who helped them make decisions were asked how they would describe the role of their family in the decision to move to AL. As shown in Figure 7.2, in 49% of cases respondents said family made the decision they should move, and in another 45% of cases, the family played a role in the decision even if respondent was the primary decision-maker.

**Figure 7.2. Family Role in Decision to Move to AL (n=157)**



Respondents were also asked if, as part of the decision to move to assisted living, they called the Senior LinkAge Line or talked to someone at the state about options for getting services, either at home or in assisted living. As shown in Figure 7.3, 41% said they had contacted one of these sources. Of the 68 who said they did contact one of these sources, 27 (40%) said this discussion made a difference in their decision to move to AL.

**Figure 7.3. Called Senior LinkAge or State as Part of Decision Process (AL) (n=165)**



## 7.4 Patterns of Spending in AL

As shown in Table 7.7, the majority (124, 75%) of AL residents had been in their facilities for 2 years or less, with more than half (54%) indicating they had lived in AL for less than one year.

**Table 7.7. Length of Residency in AL (n=166)**

Length	N	%
0 - 3 months	44	27%
4 - 11 months	44	27%
1 - 2 years	36	22%
3 - 5 years	28	17%
More than 5 years	14	8%
Total	166	100%*

\*Total not equal to 100% due to rounding

The AL residents were then asked how long they were able to pay for services themselves in the AL before applying for help (from EW). As shown in Table 7.8, 13% received support from the EW on move-in, and another 51% paid for services themselves for less than two years.

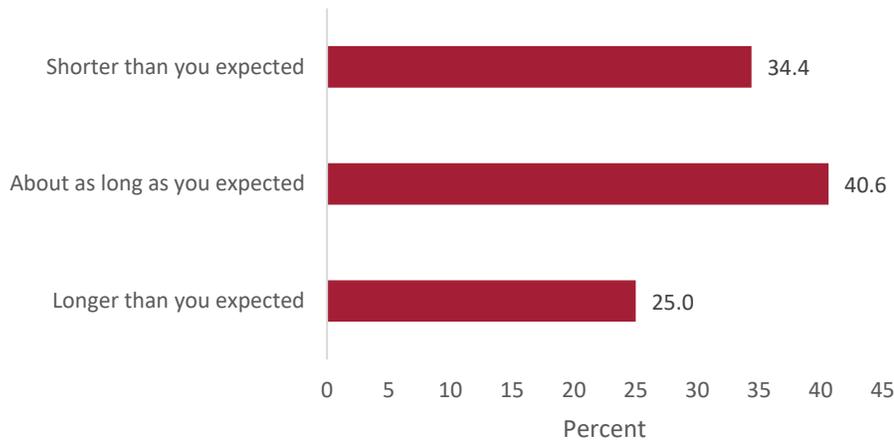
**Table 7.8. Length of Time of Self-Pay for Services Prior to EW Application (n=121)\***

Length	N	%
Started getting help from state at time of move in	16	13%
Less than one year	30	25%
1-2 years	31	26%
3-5 years	22	18%
More than five years	16	13%
Cannot Recall	6	5%
Total	121	100%

\*This question was only asked of those who reported having lived in the facility for 4 months or more in the previous question Table 7.7), and there was one missing response.

The survey respondents were then asked about the match between their expectations of self-pay period and what occurred. As shown in Figure 7.4, for slightly more than one third (34%), the length of time to self-pay was shorter than they expected. But for many, 41%, the time was about what they expected.

**Figure 7.4. Expectation of Self-Pay (n=96)\***



\*This question was asked of only those who did not report “I started getting help from the state right away,” or who could not recall in Table 7.8. Potential n was 99, and there were three missing cases.

For those who reported the self-pay period was shorter than expected, the following issues were seen as contributing to this early spenddown. As shown in Table 7.9, the most common issue cited was the costs of services in AL were higher than expected. Beyond this, a range of other issues contributed to earlier than expected spenddown.

**Table 7.9. Issues Contributing to Shorter Self-Pay Period Than Expected (n=33, multiple responses possible)**

Issues	N	%
<b>Overall Costs and Income Issues</b>		
Costs of services were higher than expected	28	85%
Cost of rent/living was higher than expected	7	21%
Had less income from investments than expected	5	15%
Memory care was a large change in cost	3	9%
<b>Medical or Insurance Issues</b>		
Medical bills for self	7	21%
Medicare didn't pay for things I thought it would	6	18%
Medical bills for spouse	4	12%
Long term care insurance coverage ended sooner than I thought it would	1	3%
<b>Other Contributing Issues</b>		
Had my income fall due to death of my spouse or partner	4	12%
Had my income reduced for some other reason (pension ended, e.g.)	2	6%
I spend my money helping children and grandchildren	1	3%

Two respondents reporting “other” noted that cost of living was more than anticipated at their age, and that the Medicare supplemental policy did not provide enough coverage to cover their medical costs.

For AL residents who reported a self-pay period that was shorter than they expected, we asked about the source of funds used to pay for their services. This question was erroneously asked only of those who reported their expectation of their private pay period was “shorter than expected” in Figure 7.4. As shown in Table 7.10, the most commonly cited source was one’s own funds. Among the “other” responses, were funding from the Veterans Administration pension and Social Security in combination, plus added from own funds, “Supplemental,” and sale of one’s home. Of those reporting a self-pay period, 44% indicated the AL setting required a private-pay period before applying for EW.

**Table 7.10. Source of Funds Used During Private Pay Period (n=33; multiple responses possible)**

Source	N	%
I used my own money	33	100 %
My family was paying for some or all	2	1%
Other	3	2%

## 8. Results Across Groups

Many of the questions related to planning prior to need, paying for services, and options counseling, were asked of both groups, EW at Home and EW in AL. In some of these questions, where multiple responses are possible, or if follow up questions were asked of only a subsample, cross-tabulations were not meaningful due to the small numbers in each “cell” of the analysis. So, in this section of the report, we present the combined data for the two groups on the common variables and, where cross-tabulation was meaningful (could be used robustly for determining significant differences –  $p < .05$ - among groups), it is reported.

### 8.1 Planning Before Help was Needed

In exploring whether participants in each group had planned for a time when they might need help or services in the future, 20 (30%) of EW at Home respondents said “yes,” and 27 (40%) of EW in AL also said “yes.” When presented with a series of statements about whether any of these applied to their planning, it is clear (see Table 8.1) that worrying about having enough money was a concern for all, but more so for those at home. More of the EW in AL respondents indicated they thought they could get help from a government program, and a significantly higher percentage of EW at Home respondents thought they could pay for services specifically with Medicare.

**Table 8.1. Planning and Paying for Help One Might Need in the Future (multiple responses possible)**

Considerations	EW at Home	(n=20)	EW in AL	(n=67)
	N	%	N	%
I knew I would have to pay and was worried about having enough money	16	80%	36	54%
Thought I could pay for services with Medicare	7	35%*	9	13%
Thought I could get help from a government program	6	30%	31	46%
Knew I had to pay, and thought I had enough to cover what I would need	3	15%	21	31%
Thought I could pay for the services I needed with long-term care insurance	1	5%	4	6%

\* $p < .05$

Of the 20 EW at Home who had planned, 11 (52%) reported someone helped them to think about or make a financial plan to pay for services when they were needed. Among those who helped were: family (10); estate planner (3); case worker (2); friend (1). Of the same 67 EW in AL who had planned, 40 (60%) reported someone helped them to think about or make a financial plan to pay for services when they were needed. Among those who helped were: family (34); legal advisor/estate planner (3); social worker (1); someone from the state (1), and someone from the county (1).

Next, a series of statements describing possible ways people can prepare for when they may need help were presented to all EW at Home and EW in AL respondents, and they were asked to identify if they used any of these ways to plan. As shown in Table 8.2, the most frequently cited ways of preparing, across groups, was to try and find out about programs, and/or specifically calling the Senior LinkAge Line or talking to someone at

the State about programs. A significant percentage of EW at Home respondents indicated each of these ways of preparing more frequently than their EW in AL counterparts.

**Table 8.2. Ways of Preparing for Future Needs (multiple responses possible)**

Preparations	EW at Home	(n=64)	EW in AL	(n=167)
	N	%	N	%
Called the state Senior LinkAge Line or talked to someone at the state about programs*	37	58%	68	41%
Tried to find out about programs that might help you get and/or pay for services*	36	56%	57	34%
Gathered information about what services might cost	23	36%	61	37%
Used estate planning	3	5%	12	7%
Purchased long term care insurance	0	0%	5	3%
Prepared in some other way	7	11%	23	14%

\*p<.05

## 8.2 Getting Help Once Needed - Prior to EW

As shown in Table 8.3, our analyses revealed statistically significant differences in the distribution of the length of time needing help at home. EW at Home respondents were more likely to report needing help at home for less than two years, compared to EW in AL respondents who were more likely to report needing help at home for three years or more.

**Table 8.3. How Long Ago the Person Started Needing Help at Home**

Length of Time	EW at Home	EW at Home	EW in AL	EW in AL
	N	%	N	%
Less than a year	26	41%	37	22%
1 to 2 years	24	38%	52	31%
3 to 5 years	6	9%	41	25%
More than 5 years	2	3%	31	19%
Unsure/Don't Recall	6	9%	5	3%
<b>Total</b>	<b>64</b>	<b>100%</b>	<b>166</b>	<b>100</b>

When asked about the sources of help once needed prior to EW, as Table 8.4 indicates, EW in AL respondents were significantly more likely than EW at Home respondents to cite family as a source of support.

**Table 8.4. Sources of Help Once Needed to Take Care of Self or Home (multiple responses possible)**

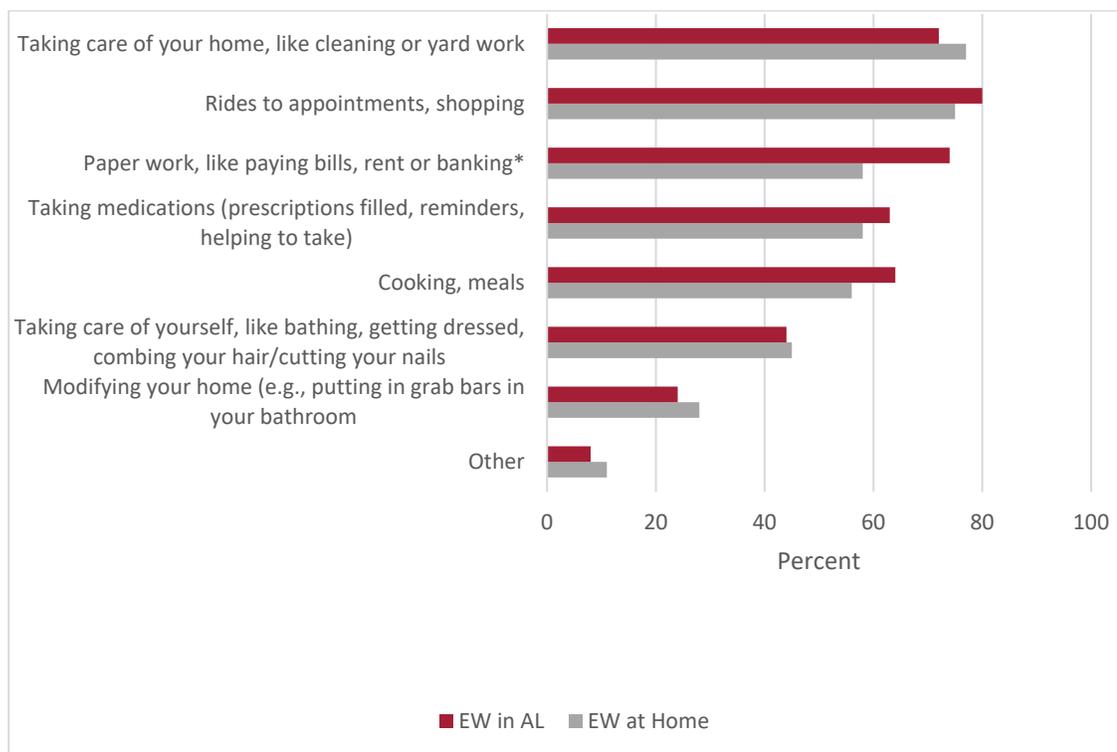
Source	EW at Home		EW in AL	
	N	(n=64) %	N	(n=167) %
Family	50	78%	152	91%*
Friends or neighbors	10	16%	34	20%
My faith community	2	3%	6	4%
Other	6	9%	8	5%

\*p<.05

For EW at Home, when asked if they paid for any of this informal help, only seven of the 58 (12%) who could recall past service responded “yes.” For EW in AL, 17 of 167 (10%) responded “yes.”

Next, survey respondents were asked to identify the types of help they received from these multiple sources. As shown in Figure 8.1, the only significant difference in responses between the two groups was for “Paperwork, like paying bills, rent or banking,” with EW in AL respondents significantly more likely to cite this type of help received.

**Figure 8.1. Types of Help Received When Started Needing Help**



\*p<. 05

EW at Home and EW in AL respondents were also asked if, when they started needing help, they paid an agency for services. Only eight (13%) of the EW at Home respondents indicated they paid an agency to help them; 38 (23%) of the EW in AL said they paid an agency for help. No significant differences were found between groups on the types of services they paid an agency to provide (see Table 8.5).

**Table 8.5. Types of Services Paid an Agency to Provide (multiple responses possible)**

Service	EW at Home	(n=8)	EW in AL	(n=38)
	N	%	N	%
Taking care of your home, like cleaning or laundry or yard work	8	100%	0	0%
Taking care of yourself, like bathing, getting dressed, combing your hair/cutting your nails	5	63%	9	24%
Cooking, meals	4	50%	14	37%
Rides to appointments, shopping	3	38%	2	5%
Taking your medications (prescriptions filled, reminders to take, helping to take)	2	25%	8	21%
Paper work, like paying bills, rent or banking	1	13%	2	5%
Modifying your home (for example putting in grab bars in your bathroom)	0	0%	0	0%
Other	1	13%	9	24%

Follow-up questions on expectation of length of time to pay and issues related to ability to pay for as long as expected were asked of both groups but in a different context; that is those on EW at Home were asked about paying for services at home prior to EW (see 6.2 Getting Help Once Needed Prior to EW) and EW in AL were asked about spending patterns for services in AL prior to the waiver (See 7.2 Getting Help Once Needed Prior to EW) These are different types of service and payment patterns and thus comparisons should be made with caution. In addition, having only eight EW at Home respondents who reported paying for any services and fewer (6) answering the follow-up questions precludes any meaningful comparison of reported spending.

We first asked if participants could recall how long they were able to pay for these services before applying for help from the state. Given the very small number of respondents in EW at Home, comparisons of percentages here are not robust. Only five of the eight EW at Home could recall, with three reporting “less than one year” and two reporting “one to two years.” For EW in AL, for those who could recall and did not get help from the state on move in, 30 (25%) said “less than one year,” 31 (26%) said “one to two years,” 22 (18%) said “three to five years,” and 15 (13%) said “more than five years. Given the very small number of respondents in EW at Home, comparisons here are not robust.

For those who reported paying, we next asked if the period of paying for services was the amount of time expected (responses in Table 8.6). Here, too, the small numbers of respondents in each group who responded to the expectation of payment question means meaningful comparison of percentages is limited.

**Table 8.6. Expectation of Payment Period**

Length of Time	EW at Home N	EW at Home %	EW in AL N	EW in AL %
Longer than you expected	3	50%	24	25%
About as long as you expected	0	0	39	41%
Shorter than you expected	3	50%	33	34%
<b>Total</b>	<b>6</b>	<b>100%</b>	<b>96</b>	<b>100%</b>

Next, a series of issues were presented, and those who said the period of paying for services was less than expected were asked if any of the issues contributed to this shorter time period. As with the previous questions regarding payment, the small numbers of respondents in each cell limits drawing meaningful comparisons. But, as shown in Table 8.7, costs of services being higher than expected was frequently cited as an issue by both groups, and that those living at home were more likely to cite costs related to home repairs.

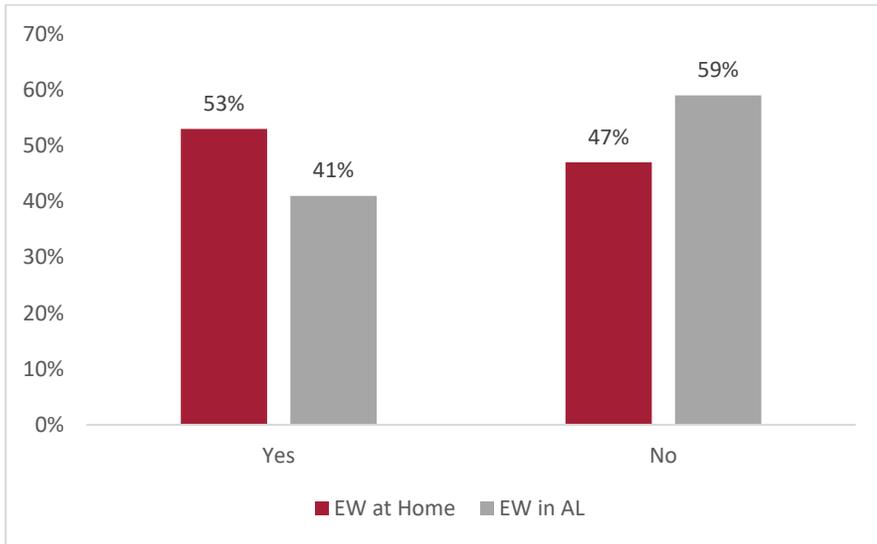
**Table 8.7. Issues Contributing to Shorter Self-Pay Period Than Expected (multiple responses possible)**

Issues	EW at Home N	(n=6) %*	EW in AL N	(n=33) %
<b>Overall Costs and Income Issues</b>				
Costs of services were higher than expected	4	67%	28	85%
Cost of rent/living was higher than expected	1	17%	7	21%
Had less income from investments than expected	1	17%	5	15%
Had expensive home repairs or other everyday expenses [Asked only of EW at Home]	4	67%	na	na
Memory care was a large change in cost [Asked only of EW in AL]	na	na	3	9%
<b>Medical or Insurance Issues</b>				
Long term care ended sooner than I thought it would	0	0%	1	3%
Medicare didn't pay for things I thought it would	0	0%	6	18%
Medical bills for self	3	50%	7	21%
Medical bills for spouse	0	0%	4	12%
<b>Other Contributing Issues</b>				
Had my income fall due to death of my spouse or partner	1	17%	4	12%
Had my income reduced for some other reason (pension ended, e.g.)	0	0%	2	6%
I spend my money helping children and grandchildren	0	0%	1	3%

## 8.3 Decision-Making about Place of Residence

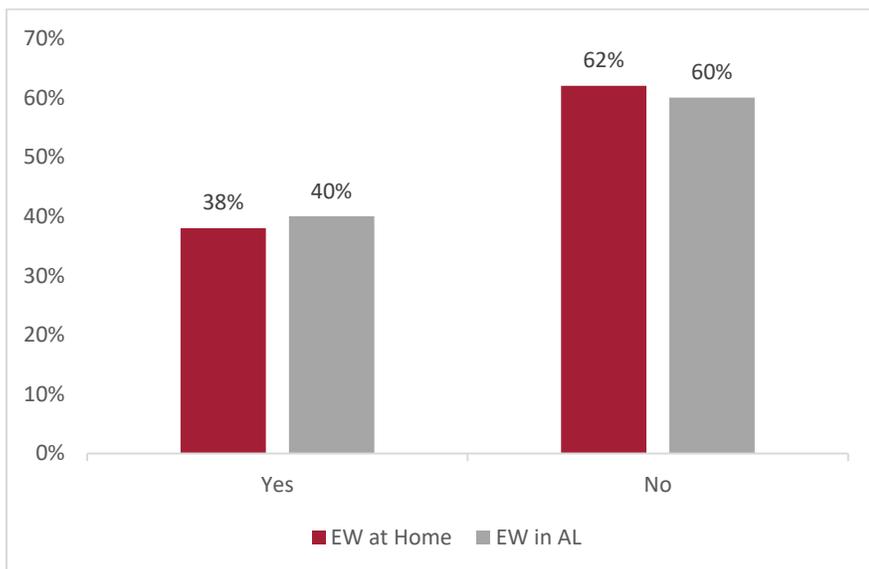
As part of the questions exploring the decision about their place of residence, both groups of respondents were asked about whether they, as part of their decision making, contacted the Senior LinkAge Line or the state, and if they did, whether it influenced their decision. As shown in Figure 8.2, a higher percentage of EW at Home reported having contacted one of these sources than did EW in AL, but the differences are not statistically significant.

**Figure 8.2. Called Senior LinkAge or State as Part of Decision Process (n=165, EW in AL; n=64, EW at Home)**



As shown in Figure 8.3, of those who call the Senior LinkAge Line or State as part of their decision, just slightly more of EW in AL respondents indicated “yes” the call influenced the decision. These differences, too, were not found to be significant.

**Figure 8.3. Call Influenced Decision Regarding Place of Residence (n=68, EW in AL; n=34, EW at Home)**



## 9. Study Limitations

As discussed in section 4.3 Methods, the most important limitation in the study was the smaller than expected population to survey. Based on prior estimates of enrollment, as noted in Appendix A, the total population was expected to be 24% higher. This is one factor contributing to the challenge in meeting our initial goal of survey completion. We cannot know with certainty the reasons for lower enrollment, although we expect the COVID pandemic played some part. The low population meant we used the entire population as the sample; even with this, the numbers of respondents, especially for EW at Home, and skip patterns in the survey itself, meant there were low numbers of responses on many survey items. This limited the meaningful statistical analysis possible across participant groups.

While not a clear limitation – we believe proxies provided sound responses on behalf of EW participants - we do think the high percentage of participants needing a proxy to complete the survey is important to consider for future research efforts. While the initial screen done by DHS in determining a need for a proxy was useful, we also saw that in 68% of cases the first contact indicated by DHS was the EW participant (person), but only 30% of completions were by this person. Self-report of spending and decision-making is thus challenging for a large portion of the study population.

# 10. Appendix A

## Comparison of Survey Enrollment Figures to Prior Two Years

### Elderly Waiver Participant Telephone Survey Enrollment Figures<sup>2</sup>

Elderly Waiver participants represented in these counts enrolled in EW for the very first time. With the exception of the "pull error" noted below, these participants also enrolled in the Medicaid health care program (i.e. Minnesota's Medical Assistance program) for the first time within 90 days of their Elderly Waiver enrollment. In addition to the variables discussed below the table, the pandemic may also have contributed to 200-2021 enrollments rates.

**Table 10.1. Enrollee Survey Figures Compared to Prior Enrollment**

Month of Enrollment	2018-2019	2019-2020	2020-2021*	% Change (2019-2020 to 2020-2021)
<i>Pull error**</i>	0	0	217	N/A
Oct	205	219	137	-37%
Nov	218	197	129	-35%
Dec	202	215	142	-34%
Jan	225	246	152	-38%
Feb	210	227	165	-27%
Mar	235	228	187	-18%
Apr	214	205	129	-37%
May <sup>^</sup>	242	183	41	-78%
<b>Total</b>	<b>1,751</b>	<b>1,720</b>	<b>1,299</b>	<b>-24%</b>

\*The lower values for 2020-2021 are partly due to data entry lag times. Data from the previous two years is much more complete. Also, due to the sampling time frames, Oct and May were only pulled once, and other months were pulled 2-3 times.

\*\*217 recipients had older MA enrollment dates and were pulled into the survey sample in error.

<sup>^</sup>The value for May 2021 is especially low due to administrative data entry lags. This data was pulled on June 1, 2021, which left little time for counties and health plans to enter new enrollees, especially in the later part of the month.

<sup>2</sup> Source: P. Spuit, personal communication, June 21, 2021

# 11. Appendix B

## Demographic Analysis: Survey Respondents to 2019 New Enrollees

**Table 11.1. Comparison of Survey Participants and Elderly Waiver Clients Newly Enrolled During 2019**

Demographics	Survey Participants, N (%)	Enrolled in 2019 and no prior MA, N (%)
Total	232	1,503
Age		
65 to 69	24 (10.3)	87 (5.8)
70 to 74	29 (12.5)	145 (9.7)
75 to 79	32 (13.8)	218 (14.5)
80 to 84	44 (19.0)	308 (20.5)
85 to 89	42 (18.1)	330 (22.0)
90+	60 (25.9)	415 (27.6)
Gender		
Male	68 (29.3)	405 (27.0)
Female	163 (70.3)	1,098 (73.1)
Race		
White	202 (87.1)	1,347 (89.6)
Black	11 (4.7)	24 (1.6)
Asian	4 (1.7)	16 (1.1)
Other	-	10 (0.7)
More than one race	-	2 (0.1)
Unknown	14 (6.0)	104 (6.9)
Hispanic Ethnicity	4 (1.7)	8 (0.5)
Marital Status		
Single, never married	18 (7.8)	65 (4.3)
Divorced	36 (15.5)	186 (12.4)
Widowed	98 (42.2)	686 (45.6)
Married	54 (23.2)	427 (28.4)
Legally separated	-	2 (0.1)
Unknown	25 (10.8)	137 (9.1)
Casemix High (A,L)	186 (80.2)	1,239 (82.4)
Casemix Low (B-K)	45 (19.4)	264 (17.6)
Housing		
Own home	142 (61.2)	832 (55.4)
Board & lodge	75 (32.3)	594 (39.5)
Inst. NF/cert boarding	8 (3.5)	30 (2.0)

<b>Demographics</b>	<b>Survey Participants, N (%)</b>	<b>Enrolled in 2019 and no prior MA, N (%)</b>
Inst. Hospital	3 (1.3)	16 (1.1)
Homeless	2 (0.9)	5 (0.3)
Non-cert boarding	1 (0.4)	13 (0.9)
Foster care	-	12 (0.8)
<b>Living Arrangement</b>		
Living alone	88 (37.9)	488 (32.5)
Living in congregate setting	86 (37.1)	660 (43.9)
Living with spouse/parents	28 (12.1)	216 (14.4)
Living with family/friends/SO	27 (11.6)	127 (8.5)
Homeless	2 (0.9)	5 (0.3)
Homeless without current/planned housing	-	7 (0.5)
<b>Informal Caregiver</b>		
Yes	117 (50.4)	831 (55.3)
No	77 (33.2)	490 (32.6)
Unknown	38 (16.4)	182 (12.1)

# 12. Appendix C

## MN Participant Survey FINAL version

---

Start of Block: Intro Questions Block

Q61 To Surveyor: What is the participant's StudyID?

---

Q61 To Surveyor: Is this survey being answered by a proxy?

Yes (if yes, what is the relationship to the participant?) (1)

---

No (2)

---

Display This Question:

*If To Surveyor: Is this survey being answered by a proxy? = No*

1 You have been contacted about this survey because you started receiving help from the State of Minnesota and the Elderly Waiver in the past few months to pay for some services that you need. This survey is being conducted by the Minnesota Department of Human Services and the University of Indianapolis to learn more about individuals receiving State help for services.

*(If needed, inform Participant they may have gone through their County to receive their services.)*

1. Your participation in the survey is completely voluntary.
2. You may choose to take part in as much of or as little of the survey as you wish. At the end of the survey we will join your responses with some basic information about you and what services you've used as provided by the State of Minnesota. Your responses are not tied to you individually and your services will not be affected by your responses in any way.
3. We are hopeful your response and others will help us learn more about the experiences of people receiving help from the State for needed services.

---

*Display This Question:*

*If To Surveyor: Is this survey being answered by a proxy? = Yes (if yes, what is the relationship to the participant?)*

3 You have been selected to respond on behalf of someone who is receiving help from the State of Minnesota and the Elderly Waiver to pay for some services that they need. This survey is being conducted by the Minnesota Department of Human Services and the University of Indianapolis to learn more about individuals receiving State help for services.

1. Your participation in the survey is complete voluntary.
2. You may choose to take part in as much of or as little of the survey as you wish. Your responses are not tied to the person receiving State help individually and their services will not be affected by your responses in any way.
3. We are hopeful your response and others will help us learn more about the experiences of people receiving help from the State for needed services.

---

4 Do you grant verbal consent to begin the survey over the phone? If you have questions, concerns or complaints please let me know and I will provide you with contact information for the appropriate party.

- Yes (1)
- No (2)

---

*Skip To: End of Survey If Do you grant verbal consent to begin the survey over the phone? If you have questions, concerns o... = No*

*Display This Question:*

*If To Surveyor: Is this survey being answered by a proxy? = Yes (if yes, what is the relationship to the participant?)*

5 The survey questions are designed to be answered by the person receiving the services. So, put yourself in their place and answer as if they were replying. Let us know if you have any questions or need clarification as we go through the survey.

---

6 Before starting our questions, do you currently live.

- At home (1)
- In assisted living (2)

7 Do you recall how long ago you first started needing help to take care of yourself or your home.

- Less than a year (1)
  - 1 to 2 years (2)
  - 3 to 5 years (3)
  - More than 5 years (4)
  - Unsure/Don't recall [Do not read] (5)
- 

8 When you started needing help to take care of yourself or your home, did anyone help you, such as:

*(To Surveyor: Read options; check all that apply)*

- Family (may include spouse) (1)
- Friends or neighbors (2)
- My faith community (3)
- Some other helper (Specify: \_\_\_\_\_ ) (4) \_\_\_\_\_
- No one (5)
- Unsure/Don't recall [Do not read] (6)

*Skip To: 11 If When you started needing help to take care of yourself or your home, did anyone help you, such as... = No one*

*Skip To: 11 If When you started needing help to take care of yourself or your home, did anyone help you, such as... = Unsure/Don't recall [Do not read]*

---

9 Did you pay for any of their help?

- Yes (1)
  - No (2)
  - Unsure/Don't recall [Do not read] (3)
- 

10 Did you receive help from friends, family, or your faith community with any of the following?

*(To Surveyor: Read options; check all that apply)*

- Taking care of yourself, like bathing, getting dressed, combing your hair/cutting your nails (1)
  - Taking care of your home, like cleaning or laundry or yard work (2)
  - Rides to appointments, shopping (3)
  - Cooking, meals (4)
  - Taking your medications (prescriptions filled, reminders to take, helping to take) (5)
  - Paperwork, like paying bills, rent or banking (6)
  - Modifying your home (For example, putting in grab bars in your bathroom) (7)
  - Some other kind of help (Specify: \_\_\_\_\_ ) (8)
- 
- Unsure/Don't recall [Do not read] (9)
- 

11 When you started needing help to take care of yourself or your home, did you pay an agency to help you?

*(To Surveyor: May need to remind not family, friend or faith community but someone for hire)*

- Yes (1)
- No (2)
- Unsure/Don't recall [Do not read] (3)

*Skip To: 20 If When you started needing help to take care of yourself or your home, did you pay an agency to hel... = No*

*Skip To: 20 If When you started needing help to take care of yourself or your home, did you pay an agency to hel... = Unsure/Don't recall [Do not read]*

12 Did you pay for help with any of the following kinds of services?

*(To Surveyor: Read all options; check all that apply)*

- Taking care of yourself, like bathing, getting dressed, combing your hair/cutting your nails (1)
- Taking care of your home, like cleaning or laundry or yard work (2)
- Rides to appointments, shopping (3)
- Cooking, meals (4)
- Taking your medications (prescriptions filled, reminders to take, helping to take) (5)
- Paperwork, like paying bills, rent or banking (6)
- Modifying your home (For example, putting in grab bars in your bathroom) (7)
- Some other kind of help (Specify: \_\_\_\_\_ ) (8)

---

- Unsure/Don't recall [Do not read] (9)

Display This Question:

If Did you pay for any of their help? = Yes

Or When you started needing help to take care of yourself or your home, did you pay an agency to hel... = Yes

13 You mentioned you have paid for services. How were you paying for these services?

(To Surveyor: Read all options; check all that apply)

- I used my own money (1)
- I used long term care insurance (2)
- My family was paying for some or all (3)
- Some other way (Specify: \_\_\_\_\_ ) (4) \_\_\_\_\_
- Unsure/don't recall [Do not read] (5)

14 Do you recall how long you were able to pay for services yourself before you applied for help from the state (or through the county)?

- Less than a year (1)
- 1 to 2 years (2)
- 3 to 5 years (3)
- More than 5 years (4)
- Unsure/Don't recall [Do not read] (5)

Skip To: 20 If Do you recall how long you were able to pay for services yourself before you applied for help fro... = Unsure/Don't recall [Do not read]

15 Were you able to pay for services yourself:

- Longer than I expected (1)
- About as long as I expected (2)
- Shorter than I expected (3)

*Skip To: 20 If Were you able to pay for services yourself: = Longer than I expected*

*Skip To: 20 If Were you able to pay for services yourself: = About as long as I expected*

---

16 I'd like to ask about some of the reasons you weren't able to pay for services as long as you expected to.

---

17

First, were any of these issues a part of why you weren't able to pay for services as long as you expected to?

*(To Surveyor: Read all options; check all that apply)*

- Costs of services were higher than I expected (1)
  - Cost of rent, living was higher than I expected (2)
  - Had less income from investments than expected (3)
  - Had expensive home repairs or other everyday expenses (4)
- 

18 Next, were any of these medical or insurance issues a part of why you weren't able to pay for services as long as you expected to?

*(To Surveyor: Read all options; check all that apply)*

- Long term care insurance coverage ended sooner than I thought it would (1)
  - Medicare didn't pay for things I thought it would (2)
  - Medical bills for self (3)
  - Medical bills for spouse (4)
- 

19 Finally, were any of these other things a part of why you weren't able to pay for services as long as you expected to?

*(To Surveyor: Read all options; check all that apply)*

- I spent my money helping children or grandchildren (1)
- Had my income fall due to death of my spouse or partner (2)
- Had my income reduced for some other reasons (pension ended, e.g.) (3)
- Someone took money from me (4)
- Or something else (Specify: \_\_\_\_\_ ) (5) \_\_\_\_\_

*Skip To: 23 If Finally, were any of these other things a part of why you weren't able to pay for services as lon... = I spent my money helping children or grandchildren*

*Skip To: 23 If Finally, were any of these other things a part of why you weren't able to pay for services as lon... = Had my income fall due to death of my spouse or partner*

*Skip To: 23 If Finally, were any of these other things a part of why you weren't able to pay for services as lon... = Had my income reduced for some other reasons (pension ended, e.g.)*

*Skip To: 23 If Finally, were any of these other things a part of why you weren't able to pay for services as lon... = Someone took money from me*

*Skip To: 23 If Finally, were any of these other things a part of why you weren't able to pay for services as lon... = Or something else (Specify: \_\_\_\_\_ )*

---

20 I'd like to ask about the reasons you applied for help from the state. First, were any of these issues a part of why you applied for help with paying for services?

*(To Surveyor: Read all options; check all that apply)*

- Costs of services were higher than I expected (1)
  - Cost of rent, living was higher than I expected (2)
  - Had less income from investments than expected (3)
  - Had expensive home repairs or other everyday expenses (4)
- 

21 Next, were any of these medical or insurance issues a part of why you applied for help with paying for services?

*(To Surveyor: Read all options; check all that apply)*

- Long term care insurance coverage ended sooner than I thought it would (1)
  - Medicare didn't pay for things I thought it would (2)
  - Medical bills for self (3)
  - Medical bills for spouse (4)
- 

22 Finally, were any of these other things a part of why you applied for help with paying for services?

*(To Surveyor: Read all options; check all that apply)*

- I spent my money helping children or grandchildren (1)
  - Had my income fall due to death of my spouse or partner (2)
  - Had my income reduced for some other reasons (pension ended, e.g.) (3)
  - Someone took money from me (4)
  - Or something else (Specify: \_\_\_\_\_ ) (5) \_\_\_\_\_
- 

23 Have you considered moving to assisted living?

- Yes (1)
- No (2)

*Skip To: 25 If Have you considered moving to assisted living? = No*

---

24 If yes, why did you choose not to move to assisted living?

(To Surveyor: Do NOT read all options, use some of the response options as a probe if participant is having trouble)

- There aren't any assisted living places in my area (1)
- Too expensive (2)
- No assisted living places had opening for someone getting help from the state (3)
- Didn't want to move (4)
- COVID (5)
- Wasn't ready yet (6)
- Wanted to try at home with more services (7)
- Some other reason (Specify: \_\_\_\_\_ ) (8) \_\_\_\_\_
- Unsure/Don't recall [Do not read] (9)

---

25 At any time, did you call the Senior LinkAge Line or talk to someone at the state about options for getting services, either at home or in another setting?

- Yes (1)
- No (2)

*Skip To: 27 If At any time, did you call the Senior LinkAge Line or talk to someone at the state about options f... = No*

---

26 Did your discussion with Senior LinkAge line or someone at the state make a difference in your decision to remain at home rather than move to Assisted Living?

*(To Surveyor: A probe, if needed: Did they tell you about home services available to you, etc.)*

Yes (1)

No (2)

---

27 Now, we've talked a lot about what kind of services or help you might have been getting before applying for help from the state. But, even before you needed help from anyone, were you and/or your family thinking and or talking about how you might pay for help when you needed it?

Yes (1)

No (2)

Unsure/Don't recall [Do not read] (3)

*Skip To: 33 If Now, we've talked a lot about what kind of services or help you might have been getting before ap... = No*

*Skip To: 33 If Now, we've talked a lot about what kind of services or help you might have been getting before ap... = Unsure/Don't recall [Do not read]*

---

28 When you started thinking or planning about paying for help you might need, would you say that:

*(To Surveyor: Read all options; check all that apply)*

I knew I would have to pay and was worried about having enough money (1)

Knew I had to pay, and thought I had enough to cover what I would need (2)

Thought I could pay for the services I needed with long-term care insurance (3)

Thought I could pay for services with Medicare (4)

Thought I could get help from a government program (5)

---

29 At the time you were thinking about possibly needing help/services, did you know there were programs that could help you pay for services?

- Yes (1)
- No (2)
- Unsure/Don't recall [Do not read] (3)

*Skip To: 31 If At the time you were thinking about possibly needing help/services, did you know there were progr... = No*

*Skip To: 31 If At the time you were thinking about possibly needing help/services, did you know there were progr... = Unsure/Don't recall [Do not read]*

---

30 Did your plan for paying for services include applying for help from these programs at some time?

- Yes (1)
  - No (2)
  - Unsure/Don't recall [Do not read] (3)
- 

31 Did anyone help you to think about or make a financial plan to pay for services you might need?

- Yes (1)
  - No (2)
  - Unsure/Don't recall [Do not read] (3)
- 

*Display This Question:*

*If Did anyone help you to think about or make a financial plan to pay for services you might need? = Yes*

32 If yes, who helped?

*(To Surveyor: Read all options; check all that apply)*

- Family (1)
  - Friend(s) (2)
  - Legal Advisor/estate planner (3)
  - Someone else (Specify: \_\_\_\_\_ ) (4) \_\_\_\_\_
- 

33 Finally, we know that in thinking about their possible need for help, older people may prepare in several ways. Did you do any of the following to prepare for when you might need help?

*(To Surveyor: Read all options; check all that apply)*

- Used estate planning (1)
- Purchased LTC insurance (2)
- Tried to find out about programs that might help you get and/or pay for services (3)
- Called the state Senior LinkAge Line or talked to someone at the state about programs (4)
- Gathered information about what services might costs (5)
- Prepared in some other way (Specify: \_\_\_\_\_ ) (6)  
\_\_\_\_\_

---

End of Block: At Home Question Block

Start of Block: Assisted Living Question Block

1 First, I'd like to ask you a few questions about your situation before you moved to assisted living. Do you recall how long ago you first started needing help to take care of yourself or your home?

- Less than a year (1)
  - 1 to 2 years (2)
  - 3 to 5 years (3)
  - More than 5 years (4)
  - Unsure/Don't recall [Do not read] (5)
- 

2 When you started needing help to take care of yourself or your home, did anyone help you, such as:

*(To Surveyor: Read all options; check all that apply)*

- Family (may include spouse) (1)
- Friends or neighbors (2)
- My faith community (3)
- Some other helper (Specify: \_\_\_\_\_ ) (4) \_\_\_\_\_
- None (5)
- Unsure/Don't recall [Do not read] (6)

*Skip To: 4 If When you started needing help to take care of yourself or your home, did anyone help you, such as... = None*

*Skip To: 4 If When you started needing help to take care of yourself or your home, did anyone help you, such as... = Unsure/Don't recall [Do not read]*

---

3 Did you pay for any of their help?

- Yes (1)
  - No (2)
  - Unsure/Don't recall [Do not read] (3)
- 

4 Did you receive help from friends, family, or your faith community with any of the following?

*(To Surveyor: Read all options; check all that apply)*

- Taking care of yourself, like bathing, getting dressed, combing your hair/cutting your nails (1)
  - Taking care of your home, like cleaning or laundry or yard work (2)
  - Rides to appointments, shopping (3)
  - Cooking, meals (4)
  - Taking your medications (prescriptions filled, reminders to take, helping to take) (5)
  - Paperwork, like paying bills, rent or banking (6)
  - Modifying your home (For example, putting in grab bars in your bathroom) (7)
  - Some other kind of help (Specify: \_\_\_\_\_ ) (8)
- 
- Unsure/Don't recall [Do not read] (9)
- 

5 When you started needing help to take care of yourself or your home, did you pay an agency to help you?

*(To Surveyor: May need to remind not family, friend or faith community but someone for hire)*

- Yes (1)
- No (2)
- Unsure/Don't recall [Do not read] (3)

*Skip To: 7 If When you started needing help to take care of yourself or your home, did you pay an agency to hel... = No*

*Skip To: 7 If When you started needing help to take care of yourself or your home, did you pay an agency to hel... = Unsure/Don't recall [Do not read]*

6 Did you pay for help with any of the following kinds of services?

*(To Surveyor: Read all options; check all that apply)*

- Taking care of yourself, like bathing, getting dressed, combing your hair/cutting your nails (1)
- Taking care of your home, like cleaning or laundry or yard work (2)
- Rides to appointments, shopping (3)
- Cooking, meals (4)
- Taking your medications (prescriptions filled, reminders to take, helping to take) (5)
- Paperwork, like paying bills, rent or banking (6)
- Modifying your home (For example, putting in grab bars in your bathroom) (7)
- Some other kind of help (Specify: \_\_\_\_\_ ) (8)

---

- Unsure/Don't recall [Do not read] (9)

7 Thanks, this is all very helpful. Now I'd like to ask you some questions about moving to assisted living. First, let's start with your decision to move to assisted living.

What were the main reasons you chose assisted living to meet your housing and service needs?

*(To Surveyor: Don't read all but can use as prompts)*

- So family won't have to keep doing things for me (1)
  - After a hospital stay, I needed too much help to be at home (2)
  - Didn't feel safe at home (3)
  - Lost my spouse (4)
  - Lost my main helper/help (5)
  - Family encouraged it (6)
  - Knew I needed help (7)
  - My spouse needed care/memory care and I moved with him or her (8)
  - There weren't enough service providers for me/my spouse to get help in my home (9)
  - Other (Specify: \_\_\_\_\_) (10) \_\_\_\_\_
  - Unsure/Do not recall [Do not read] (11)
- 

8 Do you have family members who help you make decisions and get the support you need?

- Yes (1)
- No (2)

*Skip To: 10 If Do you have family members who help you make decisions and get the support you need? = No*

---

9 Which of the following statements best describe the role your family played in your decision to choose Assisted Living?

- I made the decision to move to assisted living on my own (1)
  - I made the decision to move to assisted living mostly by myself, with some support from my family (2)
  - My family made the decision that I should move (3)
  - Not applicable (no family?) (4)
  - Unsure/Don't recall [Do not read] (5)
- 

10 As part of your decision to choose Assisted Living, did you call the Senior LinkAge Line or talk to someone at the state about options for getting services, either at home or in assisted living?

- Yes (1)
  - No (2)
- 

*Display This Question:*

*If As part of your decision to choose Assisted Living, did you call the Senior LinkAge Line or talk... = Yes*

11 Did your discussion with Senior LinkAge line or someone at the state make a difference in your decision to move to assisted living?

*(To Surveyor: Probe, if needed: Did they tell you about home services available to you, help you think about why assisted living would be a good fit, etc.)*

- Yes (1)
  - No (2)
-

12 How long have you lived in your current Assisted Living residence?

- 0-3 months (1)
- 4 to 11 months (2)
- 1-2 years (3)
- 3-5 years (4)
- More than 5 years (5)

*Skip To: 20 If How long have you lived in your current Assisted Living residence? = 0-3 months*

---

13 Now, I'd like to ask a few questions about paying for services at your assisted living. Do you recall how long you were able to pay for services yourself before you applied for help?

- I started getting help from the state right away when I moved in (1)
- Less than a year (2)
- 1 to 2 years (3)
- 3-5 years (4)
- More than 5 years (5)
- Unsure/Don't recall [Do not read] (6)

*Skip To: 20 If Now, I'd like to ask a few questions about paying for services at your assisted living. Do you re... = I started getting help from the state right away when I moved in*

*Skip To: 20 If Now, I'd like to ask a few questions about paying for services at your assisted living. Do you re... = Unsure/Don't recall [Do not read]*

---

14 Were you able to pay for assisted living services yourself:

- Longer than you expected (1)
- About as long as you expected (2)
- Shorter than you expected (3)

*Skip To: 20 If Were you able to pay for assisted living services yourself: = Longer than you expected*

*Skip To: 20 If Were you able to pay for assisted living services yourself: = About as long as you expected*

---

15 First, were any of these issues a part of why you weren't able to pay for services as long as you expected to?

*(To Surveyor: Read all options; check all that apply)*

- Costs of services were higher than I expected (1)
  - Cost of rent, living was higher than I expected (2)
  - Had less income from investments than expected (3)
  - Had expensive home repairs or other everyday expenses (4)
- 

16 Next, were any of these medical or insurance issues a part of why you weren't able to pay for services as long as you expected to?

- Long term care insurance coverage ended sooner than I thought it would (1)
  - Medicare didn't pay for things I thought it would (2)
  - Medical bills for self (3)
  - Medical bills for spouse (4)
-

17 Finally, were any of these other things a part of why you weren't able to pay for services as long as you expected to?

- I spent my money helping children or grandchildren (1)
  - Had my income fall due to death of my spouse or partner (2)
  - Had my income reduced for some other reasons (pension ended, e.g.) (3)
  - Someone took money from me (4)
  - Something else (Specify: \_\_\_\_\_) (5) \_\_\_\_\_
- 

18 Before you started getting help to pay for your services at your assisted living, how were you paying for assisted living services?

*(To Surveyor: Read all options; check all that apply)*

- I used my own money (1)
  - I paid with long term care insurance (2)
  - My family was paying for some or all (3)
  - Some other way (Specify: \_\_\_\_\_) (4) \_\_\_\_\_
  - Unsure/don't recall [Do not read] (5)
-

19 Did the Assisted Living setting where you live now require you to pay for services from your private funds for a specific period of time after you moved in?

- Yes (1)
  - No (2)
  - Unsure/don't recall [Do not read] (3)
- 

20 For this last group of questions, I'd like to think back to when you were in your own home and before you needed help from anyone.

Before you needed help from anyone, were you and/or your family thinking and or talking about how you might pay for help when you needed it?

- Yes (1)
- No (2)
- Unsure/don't recall [Do not read] (3)

*Skip To: 25-1 If For this last group of questions, I'd like to think back to when you were in your own home and be... = No*

*Skip To: 25-1 If For this last group of questions, I'd like to think back to when you were in your own home and be... = Unsure/don't recall [Do not read]*

---

21 When you started thinking or planning about paying for help you might need, would you say that:

*(To Surveyor: Read all options; check all that apply)*

- I knew I would have to pay and was worried about having enough money (1)
  - Knew I had to pay, and thought I had enough to cover what I would need (2)
  - Thought I could pay for the services I needed with long-term care insurance (3)
  - Thought I could pay services with Medicare (4)
  - Thought I could get help from a government program (5)
- 

22 At the time you were thinking about possibly needing help/services, did you know there were programs that could help you pay for services?

- Yes (1)
- No (2)
- Unsure/Don't recall [Do not read] (3)

*Skip To: 24 If At the time you were thinking about possibly needing help/services, did you know there were progr... = No*

*Skip To: 24 If At the time you were thinking about possibly needing help/services, did you know there were progr... = Unsure/Don't recall [Do not read]*

---

23 Did your plan for paying for services include applying for help from these programs at some time?

- Yes (1)
  - No (2)
  - Unsure/Don't recall [Do not read] (3)
-

24 Did anyone help you to think about or make a financial plan to pay for services you might need?

- Yes (1)
  - No (2)
  - Unsure/Don't recall [Do not read] (3)
- 

*Display This Question:*

*If Did anyone help you to think about or make a financial plan to pay for services you might need? = Yes*

25 If yes, who helped? [Read, check all that apply]

- Family (1)
  - Friend(s) (2)
  - Legal Advisor/estate planner (3)
  - Someone else (Specify: \_\_\_\_\_ ) (4) \_\_\_\_\_
- 

25-1 Finally, we know that in thinking about their possible need for help, older people may prepare in several ways. Did you do any of the following to prepare for when you might need help?

*(To Surveyor: Read all options; check all that apply)*

- Used estate planning (1)
  - Purchased LTC insurance (2)
  - Tried to find out about programs that might help you get and/or pay for services (3)
  - Called the state Senior LinkAge Line or talked to someone at the state about programs (4)
  - Gathered information about services might costs (5)
  - Prepared in some other way (Specify: \_\_\_\_\_ ) (6)
- 

End of Block: Assisted Living Question Block

---

Start of Block: End of Survey

Q63 Thank you so much for answering our questions; it will really help the state learn how to support people like you who need services and are looking for financial help to pay for them.

End of Block: End of Survey

---

# 13. Appendix D

## Survey Decision Matrix

**Table 13.1. Survey Decision Matrix**

Step 1: Pull EW Participants with EW Start date in the last 90 Days (sample data pull n = 313)

Step 2: Screen for ability to complete survey

Proxy not needed	Proxy needed
<ul style="list-style-type: none"> <li>• orientation (#1 or 2) and</li> <li>• hearing (#1 or 2) and</li> <li>• telephone (#1 or 2) and</li> <li>• Interpreter needed (no)</li> </ul>	<ul style="list-style-type: none"> <li>• orientation (#3 or 4) and/or</li> <li>• hearing (#3) and/or</li> <li>• telephone (#3 or 4) and/or</li> <li>• Interpreter needed (yes)</li> </ul>
<p>Participant (sample data pull n = 196) (63%)</p>	<p>Proxy (sample data pull n = 117) (37%)</p>

Step 3: Screen for Guardian

Proxy not needed; Does NOT have guardian	Proxy not needed; DOES have guardian	Proxy needed; DOES have guardian	Proxy needed; Does NOT have guardian	Proxy needed; Does NOT have guardian	Proxy needed; Does NOT have guardian
Contact person	Contact guardian	Contact guardian	Contact case manager; then contact person	Contact case manager; then contact proxy	Contact person; then contact proxy

Proxy not needed; Does NOT have guardian	Proxy not needed; DOES have guardian	Proxy needed; DOES have guardian	Proxy needed; Does NOT have guardian	Proxy needed; Does NOT have guardian	Proxy needed; Does NOT have guardian
<ul style="list-style-type: none"> <li>• Do they want to participate?</li> <li>• Schedule time for full survey call</li> <li>• Inform can have someone else with them</li> <li>• Prepare that during scheduling or once start survey participant may indicate can't remember, would rather have proxy (memory issues, language issues, hearing challenges, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>• Could person complete survey?</li> <li>• If no, who would be the best proxy (guardian or other, may say to ask case manager for suggestions)?</li> <li>• Assumes have guardian contact information from participant file. If do not have contact info, get from case manager</li> </ul>	<ul style="list-style-type: none"> <li>• Could person complete survey?</li> <li>• If no, who would be the best proxy (guardian or other, may say to ask case manager for suggestions)?</li> <li>• Assumes have guardian contact information from participant file. If do not have contact info, get from case manager</li> </ul>	<ul style="list-style-type: none"> <li>• Do they want to participate?</li> <li>• Schedule time for full survey call</li> <li>• Inform can have someone else with them</li> <li>• Prepare that during scheduling or once start survey participant may indicate can't remember, would rather have proxy (memory issues, language issues, hearing challenges, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>• Do they want to participate?</li> </ul> <p>**This is the preferred path, if IRB will allow for this waiver of direct consent from the participant</p>	<ul style="list-style-type: none"> <li>• Do they want to participate?</li> <li>• Schedule time for full survey call</li> <li>• Inform can have someone else with them</li> <li>• Prepare that during scheduling or once start survey participant may indicate can't remember, would rather have proxy (memory issues, language issues, hearing challenges, etc.)</li> </ul>
Participant does/does not give consent	Does guardian consent? <ul style="list-style-type: none"> <li>• If yes, call person.</li> <li>• If no, ask about a proxy. Obtain consent from proxy</li> </ul>	Does guardian consent? <ul style="list-style-type: none"> <li>• If yes, call proxy or complete with guardian if they are the proxy.</li> <li>• If no, ask about another proxy. Obtain consent from proxy</li> </ul>	Participant does/does not give consent	Obtain consent from proxy	Participant does/does not give consent to contact proxy <ul style="list-style-type: none"> <li>• If yes, call proxy, obtain consent from proxy</li> <li>• If no, attempt survey directly with participant, if consent obtained</li> </ul>

# 14. Appendix E

## Survey Contact and Completion Analysis

Total: 3,206 call attempts for a population of 1,062 enrollees.

**Table 14.1. Outcomes of Calls for Participant Survey**

Outcome	N	%
Completed	695	21.7%
Declined	328	10.2%
Unable to Locate	2,094	65.3%
Unable to Participate due to health	89	2.8%
<b>Total</b>	<b>3206</b>	<b>100%</b>

Among completions, here is the number of calls required:

**Table 14.2 Number of Calls Before Completion**

Calls	N	%
1	34	15%
2	61	27%
3	58	25.7%
4	27	12%
5	23	10.2%
6	19	8.4%
7	4	1.8%
<b>Total</b>	<b>226</b>	<b>100%</b>

In 69% of the time, the first person contacted was the enrollee themselves.

**Table 14.3. First Person Contacted for Survey**

Person	N	%
Guardian	42	4.0%
Person	732	68.9%
Household	97	9.1%
Case Manager	191	18.0%
<b>Total</b>	<b>1062</b>	<b>100%</b>

Among completions, the person (aka enrollee) was contacted first (164 / 226) 73% of the time.

**Table 14.4. First Person Contacted on Completed Surveys**

First person contacted	N	%
Guardian	13	5.8%
Person	164	72.6%
Household	19	8.4%
Case Manager	30	13.3%
<b>Total</b>	<b>226</b>	<b>100%</b>

However, the person who ultimately completed the survey was much different (only 30% completed by the person).

**Table 14.5. Person Who Completed Survey**

Person who completed the survey	N	%
Guardian	88	38.9
Person	68	30.1
Household	36	15.9
Case Manager	34	15.0
<b>Total</b>	<b>226</b>	<b>100%</b>