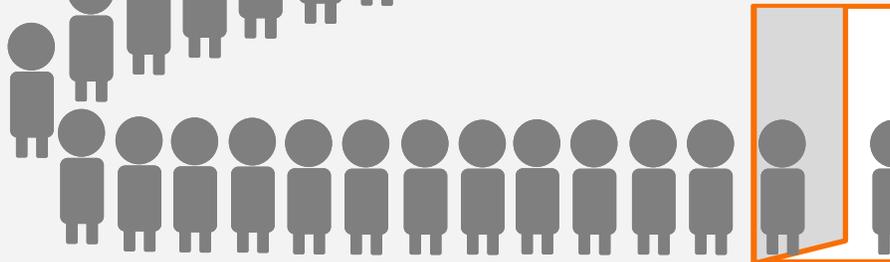


What Happens to Those on In-Home Service Wait Lists?

A study comparing outcomes for
older adults and adults with a disability
who remained on a wait list
for government-supported, in-home services
and those who began receiving in-home services
within two years.



Summary

The Area Agency on Aging 1-B (AAA 1-B) of southeastern Michigan provides state and/or federally-funded in-home services for older adults and adults with a disability. In 2008, due to a lack of public resources, 1,471 older adults and adults with a disability were placed on the AAA 1-B's wait list for in-home services. Two years later, the AAA 1-B followed up with these individuals in an effort to increasingly understand outcomes associated with remaining on a wait list without needed services compared with moving off the wait list and receiving necessary services. Notable findings are detailed in the following report and are highlighted below:

- *62% (441) died waiting to receive services. 27% (193) were still waiting to receive services. 11% (80) were no longer on the wait list and were receiving services.*
- *Of surviving individuals initially placed on the wait list, 71% (193) were still waiting at the time of this report. 29% (80) moved off the wait list and were receiving services.*
- *People remaining on the wait list lived in a nursing home more than five times more frequently than those receiving services.*
- *Those on the wait list have a 90% chance of moving to a nursing home facility instead of moving to another home/apartment.*
- *Of those remaining on the wait list who moved to a nursing home (n=38), 84% were forced to move because the participants' needs exceed their caregivers' capacity to provide care. Only one person who began receiving services moved to a nursing home because his or her needs exceeded his or her caregiver's capacity to provide care.*
- *Caregivers of those waiting to receive services reported caregiving responsibilities interfering with employment more than three times more frequently than caregivers of those receiving services.*

What happens when older adults who need in-home services cannot get them? What impact does the lack of vital support have in their lives and the lives of their caregivers? How do the outcomes of those who remain on the wait list compare to those who get services?

These questions guided the Area Agency on Aging 1-B's inquiry into the well-being of the individuals on their wait list for in-home services. In 2008, 1,471 older adults and adults with a disability were placed on the wait list for Michigan's Medicaid Elderly-Disabled Home and Community-Based Waiver (MI Choice) or other in-home services funded by the Older Americans Act or the state. The services they were waiting for include personal care, homemaking, and/or in-home respite.

Approximately two years later, the AAA 1-B took extensive efforts to determine the status of the 1,471 individuals placed on the wait list. The AAA 1-B located and discovered the status of 769 individuals, a response rate of 52%. Notably this study found individuals waiting to receive services were more likely to move to a nursing home, require emergency room attention, and/or die than their counterparts who began receiving services at some point during the two years. These, and other findings regarding those on the wait list, are detailed in this report.

Methodology

The AAA 1-B serves six counties in southeastern Michigan: Livingston, Macomb, Monroe, Oakland, St. Clair, and Washtenaw. This study interviewed or investigated all individuals aged 60 and older or adults with a disability, living in the AAA 1-B's service area, who were placed on the AAA 1-B wait list for in-home services in 2008. The survey was designed to provide information regarding outcomes associated with receiving and not receiving MI Choice or other in-home services, and the consequences of not receiving services for caregivers. The telephone survey was piloted prior to its use and administered by a contracted researcher. In instances where the wait listed individual died, the caregiver provided information regarding the date and place of death. Where no caregiver was available, public records were consulted to verify the individual's death.

In addition to the measures contained in the survey, variables providing health and demographic information for each respondent were obtained from the AAA 1-B Universal Intake Report and merged with the survey dataset. All statistical analysis was conducted in Stata 12.0.

Analysis involving statistical significance seeks to identify whether the sample population's results may be due to chance or are potentially applicable when

considering a larger population with similar traits. Statistical significance is indicated by a p-value, a measure of the likelihood that results are due to chance. P-values of less than 0.05 (noted as $p < 0.05$) indicate statistical significance, meaning there is a less than 5% likelihood results are due to chance. Conversely, this indicates a 95% likelihood that the relationship(s) between variables present in the sample population are real and may be applicable to a larger population. Unless otherwise noted, significance was tested at the $p < 0.05$ level in this study.

Results

The AAA 1-B connected with or determined the status of 769 individuals placed on the wait list for in-home services in 2008. Of these individuals, the status of 93% (714) was determined, 36% (273) individuals or caregivers completed the survey, 4% (34) terminated the interview before completion, and 3% (21) refused to participate. Demographic and health information regarding respondents is detailed in Table 1.

As depicted in Figure 1, of the 714 individuals whose status was determined:

- 62% (441) died waiting to receive services.
- 27% (193) were still waiting to receive services.
- 11 % (80) were no longer on the wait list and were receiving services.

Deceased Participants

Responding for deceased participants, 156 caregivers provided the waitlisted individual's place of death. The majority of deceased participants died while living in their own home or apartment (56%), followed by nursing home facilities as the second most frequent place of death (27%). Other responses are included in Figure 2.

Figure 1
Status of All Respondents at Time of Interview (n=769)

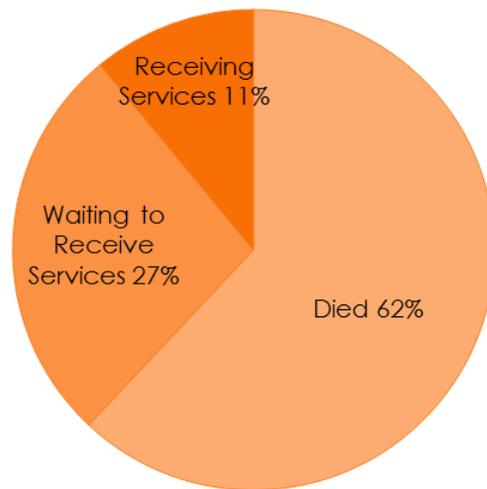


Figure 2
Deceased Participants' Place of Death (n=156)

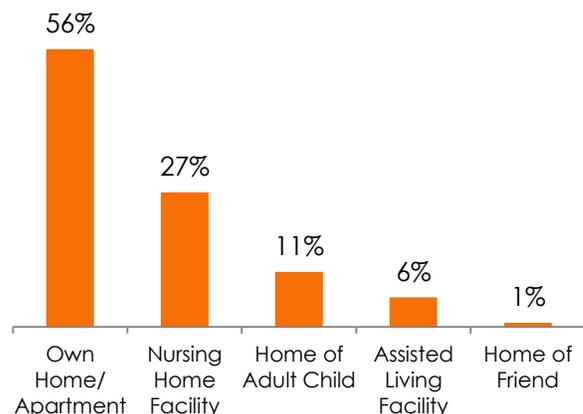


Table 1
Respondent Demographics

Measure	n	%
<i>Gender</i>		
Female	552	73%
Male	202	27%
<i>Race/Ethnicity</i>		
Asian	6	1%
Black	97	15%
Hispanic	3	0%
White	558	84%
Other	3	0%
<i>Marital Status</i>		
Divorced	110	15%
Married	219	29%
Separated	15	2%
Single/Never Married	55	7%
Widowed	356	47%
<i>Medicaid Status</i>		
Medicaid Recipients	127	17%
Not Medicaid Recipients	641	83%

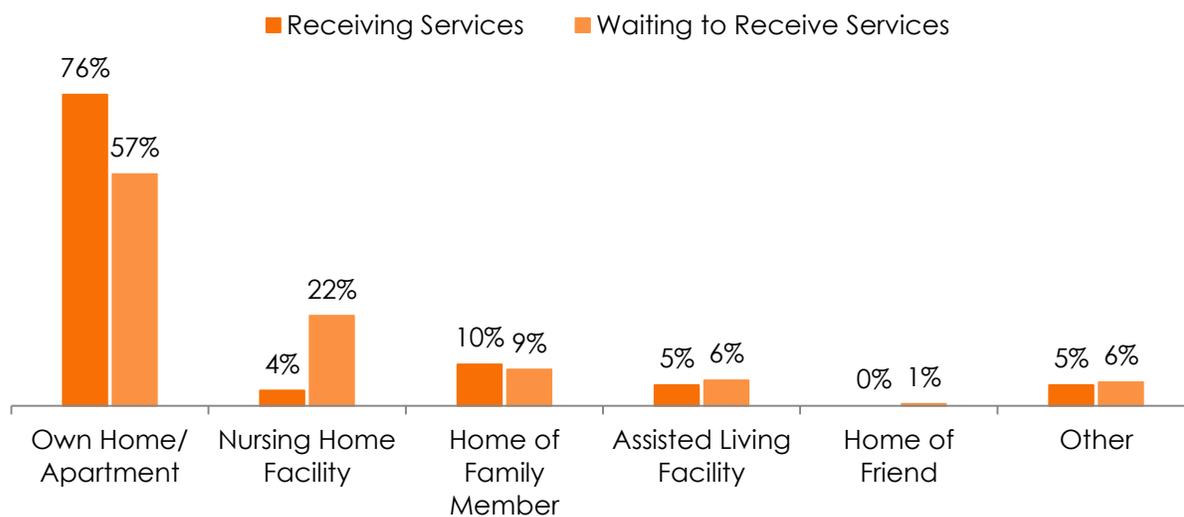
Measure	Mean	Range
Age	79	60 - 101
Monthly Income	\$1,106	\$0 - \$4,600
Number of Activities of Daily Living (ADL) Limitations ¹	4	0 - 12
Number of Instrumental Activities of Daily Living (IADL) Limitations ²	9	0 - 13
Number of Chronic Medical Conditions ³	2	0 - 8

¹ ADL limitations include bathing, bed mobility, bladder function, bowel function, dressing, eating/feeding, mobility, stair climbing, toileting, walking, and wheeling.

² IADL limitations include doing laundry, cooking meals, handling finances, heating their home, heavy cleaning, keeping appointments, light cleaning, reheating meals, shopping, taking medications, using the telephone, using private transportation, and taking public transportation.

³ Chronic medical conditions include Alzheimer's disease, arthritis, cancer, congestive heart failure, COPD, dementia, diabetes, emphysema, gall bladder, heart attack, high blood pressure, lung disease, mesothelioma, multiple sclerosis, Parkinson's disease, pituitary, prostate, psychiatric diagnosis, renal failure, skin problem, spinal cord injury, stroke, throat problem, and thyroid problems.

Figure 3
Place of Residence at Time of Interview (n=270)



Living Participants

At the time of the interview, 273 of the individuals initially placed on the in-home services wait list were alive and living in the AAA 1-B service region. The average age of this group was 79 years. **Of this group, 71% (193) remained on the wait list. In the approximate two years that transpired between being placed on the wait list and the interview, 29% (80) began receiving in-home services.** The average age of those remaining on the wait list was 76 years, while the average age of those receiving services was 74 years.

Emergency Room Visits

Survey respondents provided information regarding how often in the previous three months the person waiting for in-home services visited the emergency room (n=

221). Individuals remaining on the wait list reported a mean of 0.3 emergency room visits in the past three months. People receiving services reported using the emergency room twice as often as those remaining on the wait list, with a mean of 0.6 emergency room visits in the most recent three months. The difference between these groups is statistically significant (t-test, p<0.05).

Place of Residence

There is a statistically significant relationship between whether an individual began receiving services and where he or she resided (chi-square, p<0.01). The variances between those receiving services and those on the wait list are depicted in Figure 3. A greater proportion of those who received services lived in their own home at the time of the interview (76%) than those who remained on the wait list (57%). The greatest variance in

residence between those who did or did not receive services occurred in nursing home residence. Merely 4% of individuals who began receiving services resided in a nursing home, while 22% of individuals remaining on the wait list lived in a nursing home.

People remaining on the wait list lived in a nursing home more than five times more frequently than those receiving services.

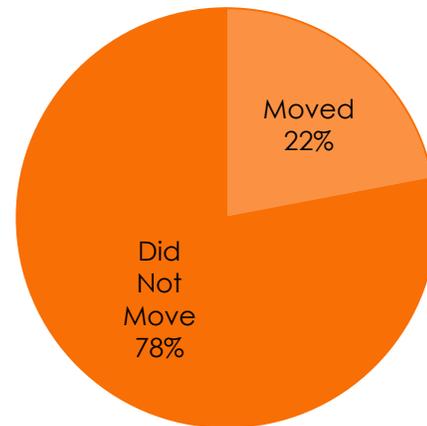
Additionally, individuals on the wait list were eight times more likely to live in a nursing home facility than their own home/apartment, when compared to their counterparts who received services. The statically significant (multinomial logistic regression, $p < 0.001$) association between these categories indicates **the risk of residing in a nursing home instead of a person's own home/apartment is approximately 80% greater when on the wait list than when receiving services.**

Participants also provided information regarding whether they moved after being placed on the wait list. Depicted in Figure 4, there is a statistically significant relationship between whether an individual moved and whether he or she received services (chi-square, $p < 0.01$). At the time of the interview, 22% of those receiving services had moved whereas 40% of those still on the wait list had moved.

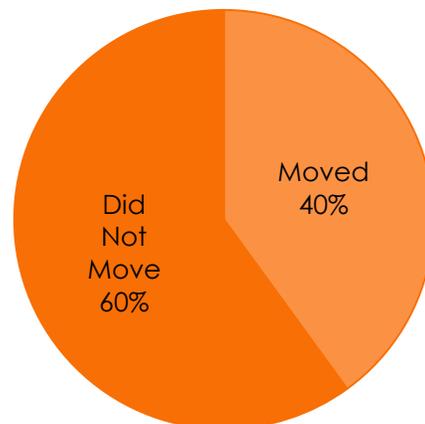
There is also a statistically significant relationship between where

Figure 4
Occurrence of Move (n=269)

Participants Receiving Services

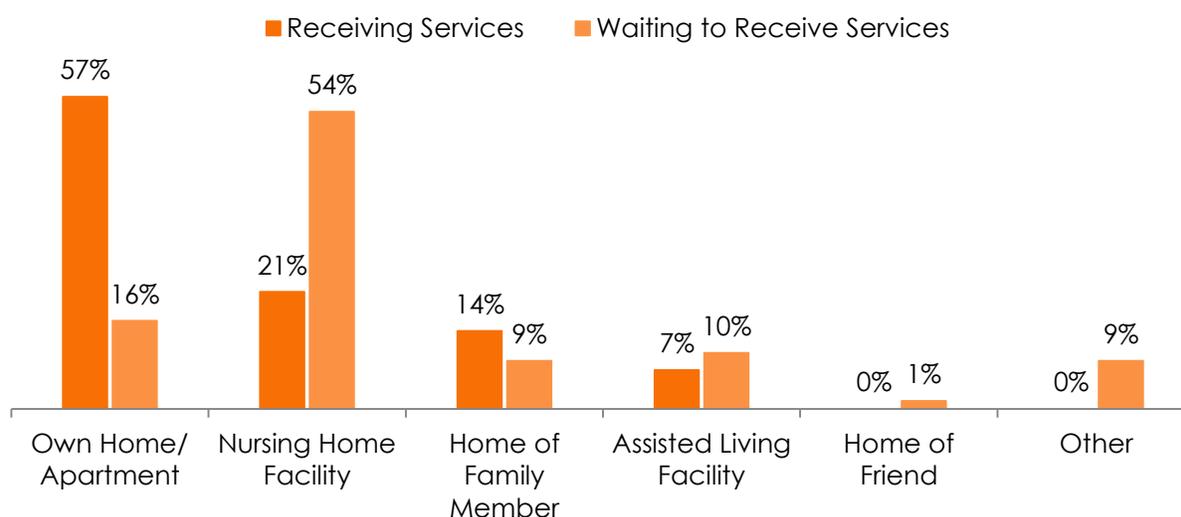


Participants Waiting to Receive Services



people moved and their status on the wait list (chi-square, $p < 0.05$). Participants' residences after moving are depicted in Figure 5. Of those participants who moved, a far greater proportion of people receiving services relocated to another home/apartment (57%), where as merely 16% of people still waiting for services moved to another home/apartment. More than half (54%) of the people remaining on the wait list who relocated moved to a nursing home

Figure 5
Participants' Residences after Relocation (n=82)



facility. Comparatively, 21% of those receiving services who also moved relocated to a nursing home facility.

There is a statistically significant association between not receiving services and moving to a nursing home rather than another home/apartment (multinomial logistic regression, $p < 0.01$). Individuals on the wait list who move within the previous two years are nine times more likely to move to a nursing home facility—instead of their own home/apartment—than their counterparts who receive services. In other words, **those on the wait list have a 90% chance of moving to a nursing home facility instead of moving to another home/apartment.**

Forty-one caregivers provided information regarding the cause of a participant's move to a nursing

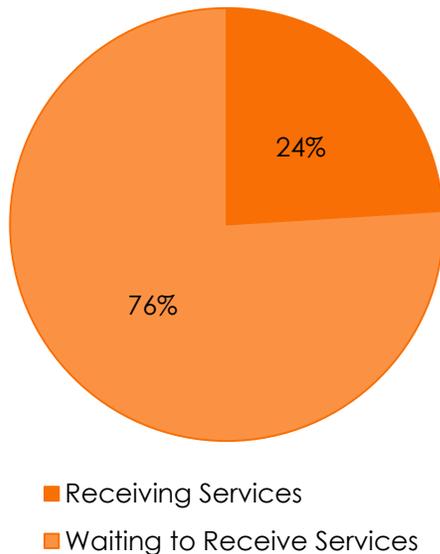
home. Of those remaining on the wait list who moved to a nursing home (n=38), 84% were forced to move because the participants' needs exceed their caregivers' capacity to provide care. **Only one person who began receiving services moved to a nursing home because his or her needs exceeded his or her caregiver's capacity to provide care.**

Caregiver Impact

In interviews where caregivers were the primary contact, they provided information about the caregiving experience in addition to providing an update regarding the person on the wait list. Of caregivers interviewed (n=164), 43% were employed full- or part-time. Nearly half of employed caregivers (46%) reported caregiving responsibilities interfering with their employment.

Caregivers of those waiting to receive services reported caregiving responsibilities interfering with employment more than three times more frequently than caregivers of those receiving services. As depicted in Figure 6, 76% of those reporting caregiving interferes with employment were providing care for someone on the wait list. Comparatively, 24% of caregivers reporting employment interference were providing care for a person receiving in-home services.

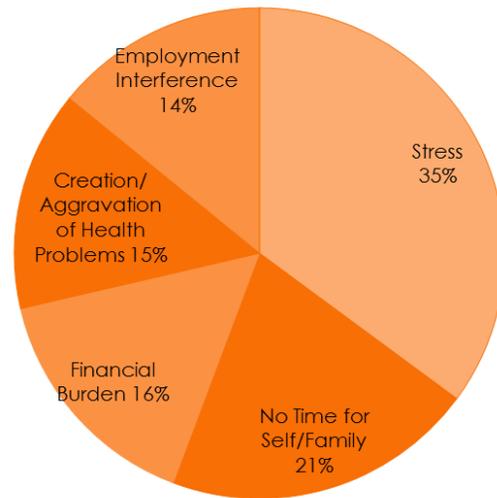
Figure 6
Caregiving Interfering with Caregiver's Employment (n=33)



Caregivers were also asked to comment on the burdens they experience because of caregiving. When asked about their greatest difficulties, the most frequent response was stress. Having no time for themselves or other family

members was the second most common response. The distribution of responses is depicted in Figure 7.

Figure 7
Caregivers' Greatest Difficulties (n=262)

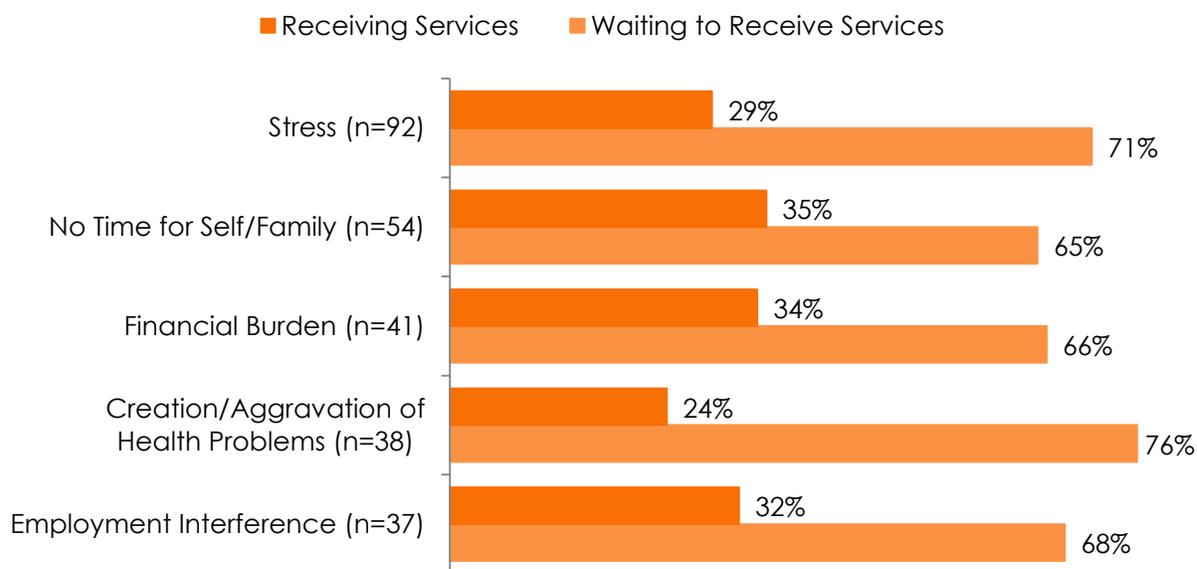


In each category, detailed in Figure 8, caregivers whose care recipients were still on the wait list for in-home services were far more likely to report difficulties than those whose care recipients were benefiting from services.

Conclusion

Many agencies, organizations, and government bodies face the difficult task of distributing limited resources to those in need. The AAA 1-B undertook this study in an effort to increasingly understand the consequences of people's needs exceeding available resources for in-home services funded by the state or Older Americans Act. This study documents the deleterious outcomes which occur when older

Figure 8
 Caregivers' Greatest Difficulties By Wait List Status (n=262)



adults and adults with a disability cannot gain access to the services their conditions necessitate.

Acknowledgements

The AAA 1-B would like to thank the many individuals and family caregivers who have turned to the agency for help in managing their long term care. The agency's staff deeply regrets being unable to provide help to all those in need due to lack of public resources. However, the findings of this report have been instrumental in advocating with state officials to increase public support for in-home services, and helped lead to Michigan's adoption of a pledge to make Michigan a "No Wait State" for in-home services for older adults.

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