

Evaluation of the AT Home with Dementia Program

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PROGRAM DESCRIPTION

The AT Home with Dementia program focuses on increasing the quality of life for clients with dementia. Through an in-home consultation with specialists, the program addresses the home safety needs of the client and provides assistive technology support items and recommendations for daily living. Assistive technology items can support and enable clients with dementia to live more independently, while also providing caregivers with necessary reassurance. Such items can address concerns related to home safety, medication management, memory aids, communication devices, and items to support leisure activities and comfort.

The goals of the program focus on the physical and emotional health of both client and caregiver. The program aims to increase the well-being and safety of the client through emphasizing the client's independence in order to lengthen the time they can remain at home. The program works to increase a positive experience for caregivers by providing the tools necessary to reduce stress, maintain safety, and offer peace of mind.

At Home with Dementia is a collaborative project involving partners from NEW Curative Rehabilitation, Inc, Options for Independent Living, and the Aging & Disability Resource Center of Brown County (ADRC). Each agency brings experience and expertise to form this dynamic program. The team meets regularly and shares responsibilities of the management and implementation of the program. Along with agency funds, At Home with Dementia is supported by funding through the Greater Green Bay Community Foundation.

PURPOSE AND METHODS

In this section, we outline the characteristics of the sample and the measures employed in the evaluation. This program intended to achieve the following outcomes for caregivers and the client in their care:

- Client maintains functional abilities.
- Client increases independence.
- Safety in the home is improved.
- Client/ Caregiver utilize adaptive technology (AT) equipment as recommended.
- Caregiver is self-assured in caregiving role.
- Caregiver increases peace of mind in the caregiving role (reduces stress).
- Caregiver reduces burden of caregiving.
- Caregiver has opportunities to pursue desired activities.

The purpose of this evaluation is to assess the effectiveness of the AT Home with Dementia program relative to these outcomes. We employed a basic pretest-posttest design, where we obtained baseline information from caregivers before they participated in the program and again after one to two months.

SAMPLE

One hundred caregivers of clients referred to the AT Home With Dementia program were surveyed at baseline. Then, one to two months after the home visit, 75 caregivers completed the follow up survey. **Seventy-two percent of participating caregivers were female, and 53% were in the 51 to 64 age category. Another 29% were in the 65 to 74 year age group.**

Clients in the At Home with Dementia program can be diagnosed with dementia along with other dual diagnoses including depression, anxiety and more. Clients were classified into separate severity rating scores, following the 3 stage model of Alzheimer's Disease:

Stage 1: (Mild) characterized by memory loss, impaired logic, inappropriate use of words or dress, broad mood swings, repetition of questions, getting lost in familiar places, decreased motivation and attention. This is typically when the client and family first start to identify a problem beyond just forgetfulness

Stage 2: (Moderate) existing symptoms continue to become more severe and professional and social functioning are further deteriorating. More pronounced memory loss is experienced, including forgetting names or recognizing loved ones. Safety becomes an important issue during this stage.

Stage 3: (Severe) almost complete memory loss is experienced and assistance is often required for all basic activities for daily living. Ability to communicate is lost almost entirely, the brain begins to lose abilities to carry out the normal biological functions necessary to sustain life.

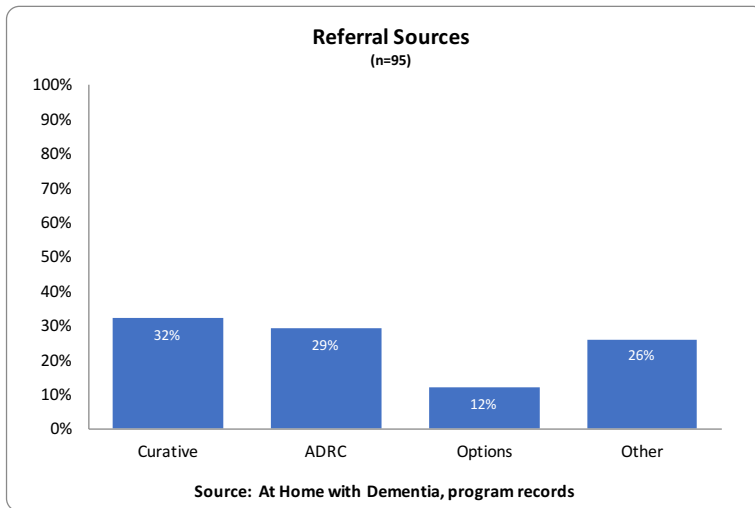
Program staff scored the severity of illness for each of the clients they assessed. Unfortunately, our data are incomplete for 53% of clients at intake, where no severity score was assigned, and another 28% were not assessed for severity when surveyed after the home visit.

MEASURES

The baseline and follow up surveys were conducted by agency staff and caseworkers through a structured telephone interview with a caregiver. The baseline contained two survey scales measuring 1) the caregiver's sense of the person with dementia's level of functioning relative to the activities of daily living and 2) the level of concern the caregiver currently experienced regarding the person with dementia. Demographic data, referral source, and living situation were gathered at intake, and caseworkers coded the severity of the client.

The delayed treatment group completed the two survey scales again after approximately 30 days (no other questions were administered), and then received the AT home visit. After receiving AT home visits, all caregivers repeated the two survey scales along with several additional questions (approximately 30 days following their visit). We employed the retrospective pre-post survey question format, where the caregiver was asked to reflect on 1) the client's independence and 2) the caregiver's self-assurance level before and now (after the home visit). This type of questioning accounts for frame of reference changes in the person providing care. A series of questions related to satisfaction with the home visit were also asked.

REFERRAL SOURCES



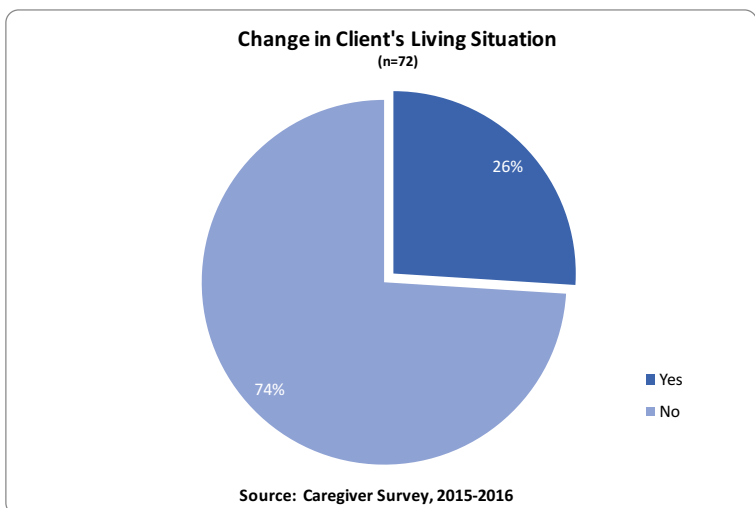
At Home with Dementia relies on its own outreach along with agency referrals to drive program participation. Considering the three main agency partners as possible referral sources: Curative is the largest source of referral for the program (32%), followed by the ADRC (29%) and Options for Independent Living (12%).

Additional outside sources, perhaps family members, friends, or other community organizations account for 26% of the referral sources. This is a growth in the amount of outside referrals compared to the data collected from the formative study (9%).

RESULTS

We present survey results to determine whether caregivers reported changes between the baseline assessment and the home visit.

CHANGE IN LIVING SITUATION



Caregivers were asked whether there was a change in the individual's living situation since the baseline survey took place.

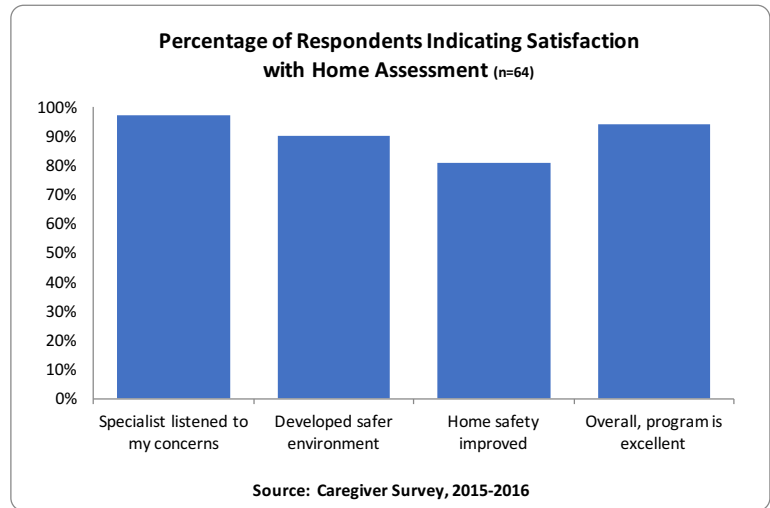
A majority of clients had remained in their homes (74%), while a quarter of caregiver respondents reported a change in client location of residence (26%). Of those, thirty-two percent of respondents reported the client had moved to a more supportive living situation (assisted living or specialized care), 26% of clients had moved into a nursing home or hospice, 16% were deceased, and 26% did not specify.

SATISFACTION WITH AT-HOME PROGRAM

Caregivers who completed the posttest were asked about their general satisfaction with the AT Home with Dementia program.

Overwhelmingly, caregivers responded they were satisfied with the program and they believed the home visit and AT items had improved their environment in terms of safety and support for the person in care.

Eighty-one percent of caregivers agreed home safety had improved after the visit, despite the likely hesitation they might have felt to admit safety had not been adequate prior to the home visit. Appendix 2 shows the detailed response patterns for these questions.

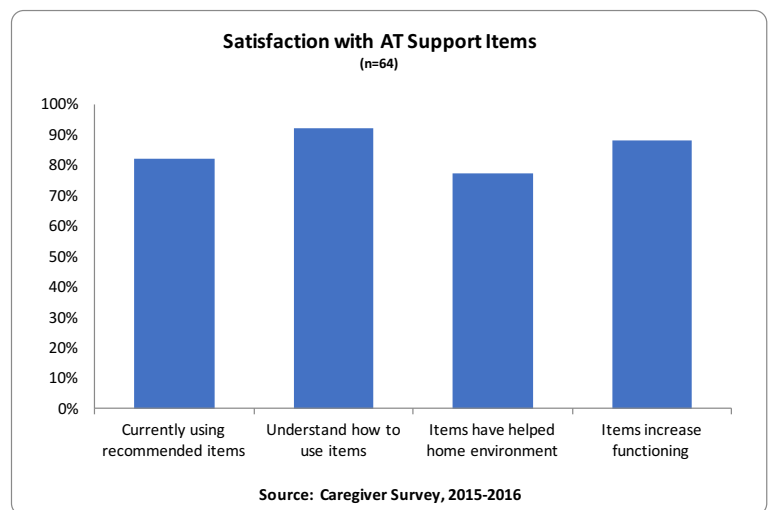


USE OF ASSISTIVE TECHNOLOGY

Responding caregivers reported satisfaction with the assistive technologies items provided by the specialists at the home visit. Eighty-two percent of respondents reported using the assistive items.

Ninety-two percent said they understood how to use the recommended support items, 77% of caregivers felt the AT items had helped to improve the clients' home situation, and 88% indicated the technologies enabled the individual to function better at home.

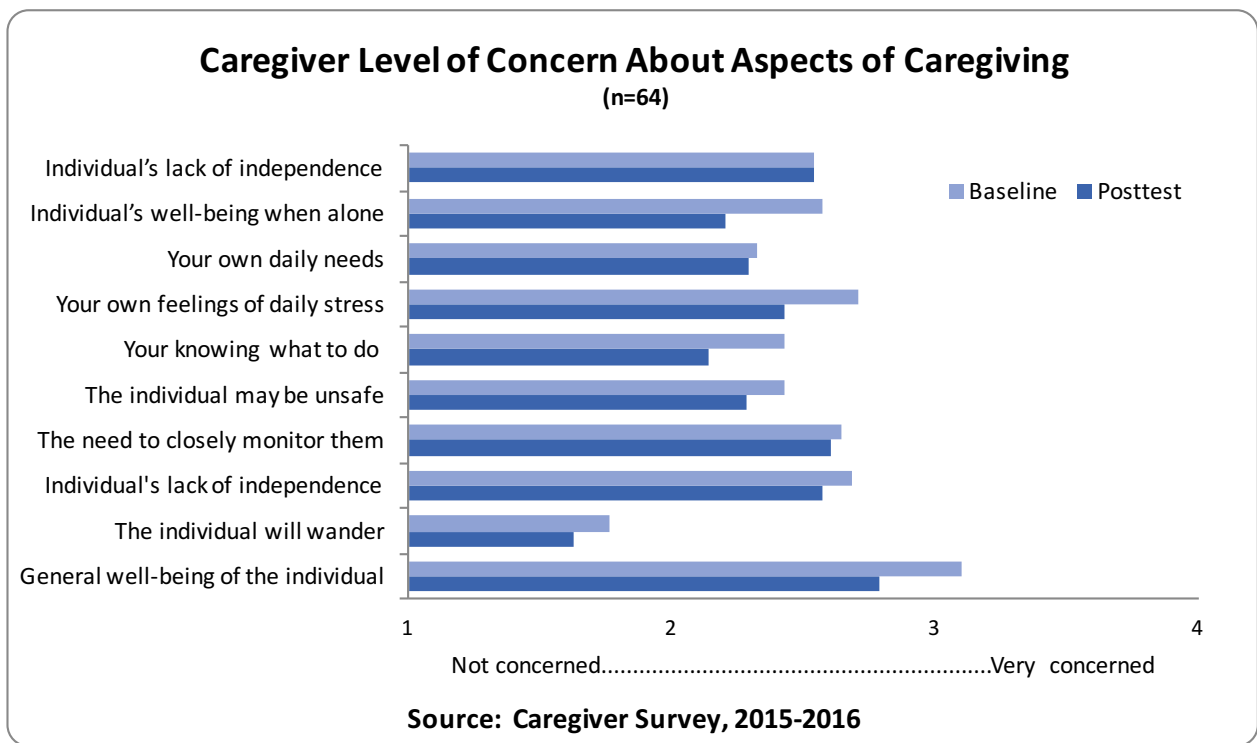
Only a small fraction of respondents disagreed when asked about the helpfulness of the items. Those who offered no opinion are likely families who either did not utilize any AT support items, or had no items recommended for their use.



CAREGIVER CONCERNS ABOUT ASPECTS OF CAREGIVING

At baseline and again 30 or more days after having received the assistive technology and instructions, caregivers responded to ten statements about the things that may concern them (Appendix 3 provides the mean responses). They indicated whether they were “not concerned, slightly, moderately, or very concerned” about the aspect of caregiving it described. After receiving the assistive technology, caregivers showed much less concern about the following:

- The individual’s well-being when caregiver was not home
- The general well-being of the individual
- Knowing what to do to meet the individual’s needs
- His or her own feelings of daily stress



INDIVIDUALS' INDEPENDENCE AND ACTIVITIES OF DAILY LIVING

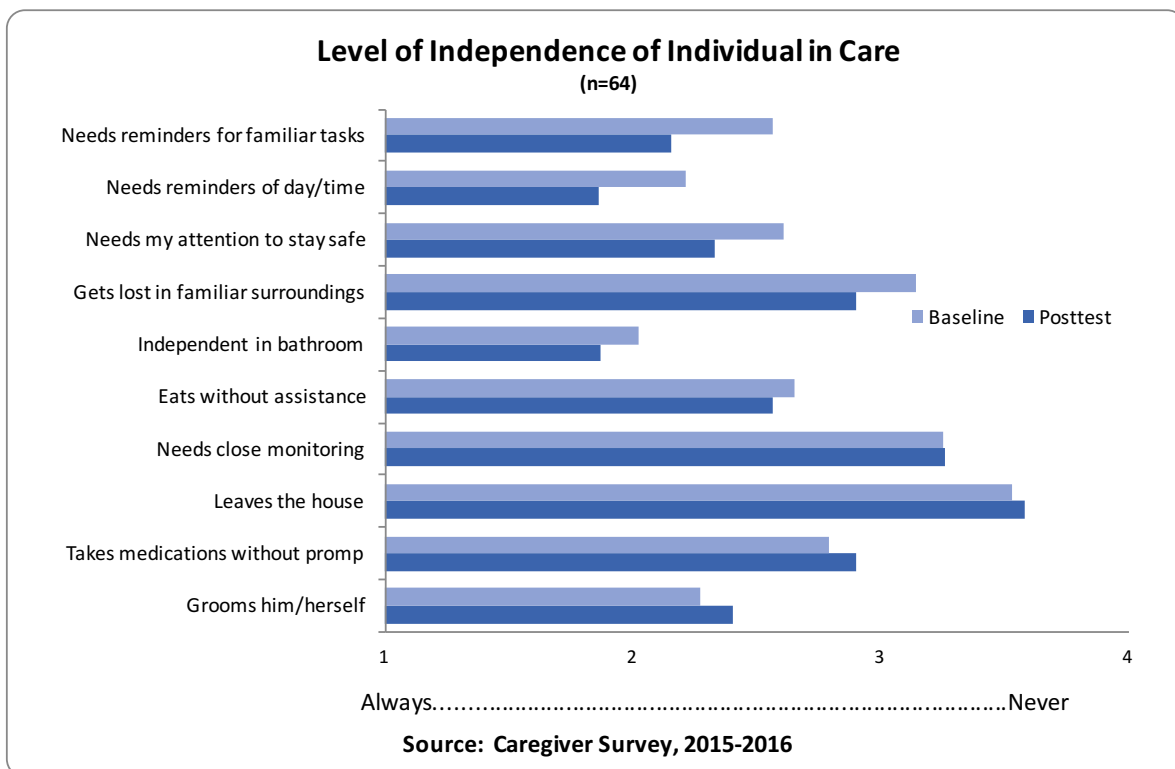
At baseline and one to two months after the home visit, caregivers assessed the status of the individual in their care with regard to activities of daily living that are sometimes impacted by dementia, such as getting something to eat, knowing the day and time, knowing where you are, using the bathroom, and other everyday tasks.

After the home visit where the case worker distributed assistive technology, several daily living activities showed improvement:

- Less often needed reminders to perform familiar tasks
- Less often needed reminders to track the day and time
- Less often needed a great deal of caregiver attention to stay safe
- Less likely to get lost in familiar surroundings

The following items showed minor improvement between baseline and posttest:

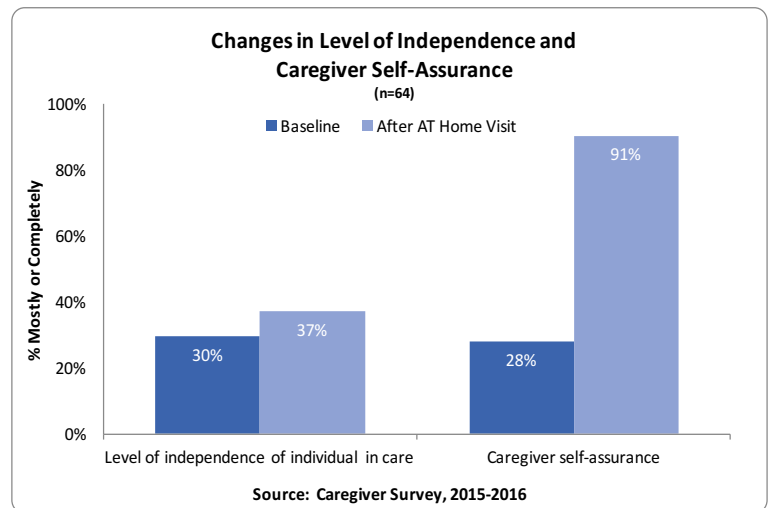
- Functions independently in the bathroom
- Can get something to eat without assistance



CAREGIVER SELF-ASSURANCE AND PERCEPTIONS OF INDIVIDUAL'S INDEPENDENCE

On the posttest, caregivers were asked to think back to before they received the home visit or assistive technology support items and rate the individual in care's independence and their own self-assurance from the vantage point of all they have learned since that time.

Before the AT Home program, 30% of caregivers reported the individual in their care was mostly or completely independent. After the home visit and receipt of technologies, 37% rated the individual independent. Twenty-eight percent of caregivers rated themselves mostly or completely self-assured before the home visit. A remarkable 91% reported being mostly or very self-assured following participation with the program.



CONCLUSIONS ABOUT THE EFFECTIVENESS OF THE PROGRAM

Survey results indicate the AT Home with Dementia program achieved most of the outcomes which were intended for persons with dementia and their caregivers (outlined on page 2). Ninety percent of caregivers reported the program contributed to a safer environment and even more, 94% agreed overall, the program is excellent.

Here we summarize the findings relative to the intended outcomes.

- ▶ **CLIENT MAINTAINS FUNCTIONAL ABILITIES AND INCREASES INDEPENDENCE.** Based on survey results, caregivers reported improvement among individuals in their level of independence in functioning at home daily. This included less need for reminders for familiar tasks or day/time, less need for constant caregiver attention to keep them safe, and less likelihood of getting lost in familiar surroundings. The percentage of caregivers who assessed the individual as mostly or completely independent increased from 30% before the AT Home program to 37% after it had been delivered.

- ▶ SAFETY IN THE HOME IS IMPROVED. We have little direct information about this outcome, as our home assessment data collection procedures proved too unwieldy a practical level. However, after receiving the assistive technology and home visit, 81% of caregivers agreed with the statement “safety of the individual in my care improved since the home assessment. Caregivers showed slight reduction in their level of concern for clients doing things that may be unsafe or wandering, and reduced concern about the need to monitor the person in their care at all times.

- ▶ CLIENT AND CAREGIVER UTILIZE ADAPTIVE TECHNOLOGY (AT) EQUIPMENT AS RECOMMENDED. Survey results indicate the achievement of this outcome. On the follow up survey, eight in ten or more of the caregivers agreed or strongly agreed they were using the AT items currently and knew how to use them.

- ▶ CAREGIVER IS SELF-ASSURED IN CAREGIVING ROLE. The major increase in caregiver self-assurance is one of the most compelling findings of the evaluation of the AT Home with Dementia program. Caregivers dramatically increased their feelings of self assurance after receiving the home visit and AT items. A full 91% of caregivers reported being mostly or completely self-assured in providing care to the individual after the AT home visit, compared to only 28% before receiving the care. On another question, caregivers showed gains after the home visit in “knowing what to do to meet the individual’s needs.”

- ▶ CAREGIVER INCREASES PEACE OF MIND IN THE CAREGIVING ROLE (REDUCES STRESS), AND REDUCES BURDEN OF CAREGIVING. Some evidence shows this outcome was achieved. Several survey questions asked about the stress associated with caregiving and the impact of the AT Home with Dementia program. At baseline, 44% of caregivers reported slight or no concern with “your own feelings of daily stress,” rising to 54% on the posttest.

- ▶ CAREGIVER HAS OPPORTUNITIES TO PURSUE DESIRED ACTIVITIES. Results for this outcome are unclear; only one survey item asked caregivers about their concerns of not having enough opportunities to “do the things you need to do in your daily life.” At baseline, caregivers expressed generally low level of concern about this aspect of caregiving, and on the posttest, the level remained at the same low level.

Based on this evaluation, the AT Home with Dementia program appears to have directly helped individuals with dementia in aspects of their daily lives—aspects where technology can directly assist, such as reminder tools, safety devices, and aids for daily living. The program clearly provides support and reassurance for caregivers, bringing more confidence and less concern into their everyday lives.

APPENDIX 1 CAREGIVER SURVEY – POSTTEST VERSION

1. Please indicate if there have been any changes in your loved one’s living situation since the home assessment:
Yes / No

If so - what was the change?

- Moved to a Nursing Home
- Moved in with another family member/caregiver
- Deceased
- Other, please specify: _____
- No change

Please share more information about your home assessment visit experience.

	Strongly Agree	Agree	Disagree	Strongly Disagree	No Opinion
The person completing the home assessment listened to my concerns and needs					
The home assessment helped us to develop a safer environment for our home					
Safety of my loved one has improved in the home since the home assessment					
Overall, I found this service to be excellent					

Comments (optional):

Please share information about your Assistive Technology (AT) support items:

	Strongly Agree	Agree	Disagree	Strongly Disagree	No Opinion
We are currently using most of the assistive technology (or AT) support items in our home in the ways that were recommended.					
We understand how to use all of the AT support items that we received.					
The AT support items have improved our home situation.					
The AT support items enable my loved one to function better at home.					

Comments (optional):

Please share information about your loved one and how this program may have affected their life. Think back to before you received the home assessment or AT support items. Before receiving the support items, how would you have rated your loved ones safety at home?

- Not at all Concerned
- Slightly Concerned
- Moderately Concerned
- Very Concerned
- Extremely Concerned

And what about now - currently what is your level of concern for your loved ones safety at home?

- Not at all Concerned
- Slightly Concerned
- Moderately Concerned
- Very Concerned
- Extremely Concerned

Next consider your loved one's level of functioning in regard to their ability to do things independently for themselves.

Think back to before you received the home assessment or AT support items - how would you have rated your loved ones level of functioning at home.

- 4 - Very Well Functioning Independently
- 3
- 2
- 1 - Not Functioning Well Independently
- No Opinion

And what about now - currently where would you rate your loved ones level of functioning independently at home since the home assessment?

- 4 - Very Well Functioning Independently
- 3
- 2
- 1 - Not Functioning Well Independently
- No Opinion

Please indicate in what ways, if any, did the home assessment and AT support items affect the overall quality of life for your loved one:

Please share information about your role as a caregiver.

Think back to before you received the home assessment visit or AT support items - please indicate how assured you felt in your caregiving role

- Not assured at all
- Slightly assured
- Quite assured
- Extremely assured

And what about now - currently, how assured do you feel in caring for your loved one.

- Not assured at all
- Slightly assured
- Quite assured
- Extremely assured

As a caregiver, please indicate how the following items affected your home life, if at all, after the home assessment and AT support items were placed in your home.

	Strongly Agree	Agree	Disagree	Strongly Disagree	No opinion
Since receiving the AT support items, I have a greater peace of mind in taking care of my loved one.					
Many of my safety concerns in the home have not changed since receiving the AT items (reverse coded)					
I can rest assured when I am away from the home while my loved one is there.					
My time to engage in leisure activities has increased since receiving the AT support items.					
I have utilized one or more of the resources recommended to me during my home assessment					
I feel I have greater support in my role as a caregiver					

Comments (optional):

Now that time has passed since your home assessment, if it was available, would be interested in having a follow up visit in your home?

Yes / Maybe / No

Please share what, if anything, about this program has been the most helpful in caring for your loved one:

Please feel free to leave any additional comments or suggestions about the services of this program (optional):

Thank you so much for your feedback, you and your satisfaction with our program is very important to us.

APPENDIX 2 DETAILED RESPONSE PATTERNS TO SCALE ITEMS

Satisfaction With Home Assessment & AT Items (n=64)	Strongly Agree	Agree	Disagree	Strongly Disagree	No Opinion
a. The person completing the home assessment listened to my concerns and needs	81%	16%	0%	0%	3%
b. Since the assessment, we have a safer environment for our home	45%	45%	0%	2%	8%
c. Safety of my loved one has improved in the home since the home assessment	45%	36%	2%	5%	13%
d. Overall, I found this service to be excellent	72%	22%	2%	2%	3%
e. We are currently using most of the AT support items in our home in the ways that were recommended.	50%	31%	3%	2%	14%
f. We understand how to use all of the AT support items that we received.	67%	25%	0%	0%	8%
g. The AT support items have NOT improved our home situation.	9%	5%	19%	58%	9%
h. The AT support items enable my loved one to function better at home.	44%	44%	2%	2%	9%

Client Independent Functioning Frequencies Pretest n=100, Post30 n=64 Valid percent (missing excluded)	Always	Mostly	Sometime	Never	No opinion
a. Is able to get something to eat without assistance	18% 24%	25% 20%	31% 27%	26% 25%	- 5%
b. Functions independently in the bathroom.	41% 39%	28% 36%	19% 14%	12% 6%	- 5%
c. Needs to be closely monitored to prevent wandering.	13% 11%	4% 8%	22% 14%	53% 52%	8% 16%
d. Needs reminders to track the day/time.	31% 41%	26% 27%	34% 22%	9% 3%	- 8%
e. Grooms him/herself on their own.	34% 23%	21% 27%	27% 27%	17% 17%	1% 6%
f. Takes medications as prescribed with little prompting.	23% 19%	14% 17%	23% 14%	39% 45%	1% 5%
g. Needs a great deal of my attention in order to stay safe.	24% 28%	13% 20%	34% 23%	24% 17%	5% 11%
h. Needs reminders to perform familiar tasks.	17% 30%	22% 27%	43% 28%	14% 8%	3% 8%
i. Leaves the house without my knowledge.	5% 5%	3% 2%	23% 19%	62% 61%	7% 14%
j. Gets lost in familiar surroundings	11% 13%	12% 11%	20% 28%	47% 28%	10% 20%

Caregiver Level of Concern Frequencies Pretest n=100, Post30 n=64	Not concerned	Slightly Concerned	Moderate concerned	Very concerned	No opinion
a. The general well-being of the individual.	7% 5%	18% 33%	33% 36%	42% 22%	- 5%
b. The chance the individual will wander outside the home.	57% 52%	14% 16%	7% 14%	14% 3%	8% 16%
c. The inability of the individual to do things for him/herself.	14% 16%	34% 33%	25% 23%	26% 23%	1% 5%
d. The need to closely monitor the individual.	21% 13%	29% 31%	21% 31%	26% 19%	3% 6%
e. The individual may try to do things that are not safe.	23% 23%	35% 36%	21% 22%	21% 14%	- 5%
f. Your knowing what to do to meet the individual's needs.	15% 28%	39% 38%	29% 13%	14% 14%	2% 8%
g. Your own feelings of daily stress.	11% 16%	33% 38%	30% 28%	26% 14%	- 5%
h. Your having enough opportunities to do the things you need to do in your daily life.	28% 25%	21% 30%	32% 23%	13% 14%	6% 8%
i. The individual's well-being when I am away from home.	22% 30%	23% 30%	20% 9%	27% 19%	8% 13%
j. The individual's lack of independence in daily life.	20% 16%	31% 31%	20% 25%	26% 20%	2% 8%

APPENDIX 3 MEAN RESPONSES TO SCALE ITEMS

Client Independent Functioning Means “no opinion” responses not included 1=Always, 4=Never	Mean at Intake (standard dev.) n=100	Mean at Post30 (standard dev.) n=61
a. Is able to get something to eat without assistance	2.65 (1.06)	2.56 (1.13)
b. Functions independently in the bathroom.	2.02 (1.04)	1.87 (0.90)
c. Needs to be closely monitored to prevent wandering.	3.25 (1.07)	3.26 (1.09)
d. Needs reminders to track the day/time.	2.21 (1.00)	1.86 (0.90)
e. Grooms him/herself on their own.	2.27 (1.11)	2.40 (1.06)
f. Takes medications as prescribed with little prompting.	2.79 (1.20)	2.90 (1.21)
g. Needs a great deal of my attention in order to stay safe.	2.61 (1.12)	2.33 (1.12)
h. Needs reminders to perform familiar tasks.	2.56 (0.95)	2.15 (0.98)
i. Leaves the house without my knowledge.	3.53 (0.80)	3.58 (0.79)
j. Gets lost in familiar surroundings	3.14 (1.07)	2.90 (1.06)

Caregiver Level of Concern Means “no opinion” responses not included 1=Not Concerned, 4=Very Concerned	Mean at Intake (standard dev.) n=100	Mean at Post30 (standard dev.) n=64
a. The general well-being of the individual.	3.10 (0.94)	2.79 (.86)
b. The chance that the individual will wander outside the home.	1.76 (1.12)	1.63 (.90)
c. The inability of the individual to do things for him/herself.	2.68 (1.03)	2.57 (1.04)
d. The need to closely monitor the individual.	2.64 (1.03)	2.60 (0.96)
e. The individual may try to do things that are not safe.	2.40 (1.06)	2.28 (1.00)
f. Your knowing what to do to meet the individual’s needs.	2.43 (0.92)	2.14 (1.03)
g. Your own feelings of daily stress.	2.71 (0.98)	2.43 (0.94)
h. Your having enough opportunities to do the things in your daily life.	2.32 (1.05)	2.29 (1.04)
i. The individual’s well-being when I am away from home.	2.57 (1.15)	2.20 (1.14)
j. The individual’s lack of independence in his/her daily life.	2.54 (1.10)	2.54 (1.02)