

ADRC OPTIONS COUNSELING:
WORKING WITH CAREGIVERS AS
CUSTOMERS



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EXECUTIVE SUMMARY

BACKGROUND

Caregivers are an important support for many elders and for adults with disabilities, enabling many Wisconsin residents to stay in their homes, transition to long term care or enjoy a better quality of life while in long term care. The focus of this study is to clarify the dynamics of providing options counseling to caregivers.

The goals of this project are to:

- ◆ Establish a baseline understanding of caregivers' satisfaction with options counseling;
- ◆ Gather staff feedback on best practices for performing options counseling, and implementing the options counseling standards, when working with caregivers;
- ◆ Refine and improve measures of quality customer service with particular attention to indicators related to the Administration for Community Living (ACL) interests of utility and economic impact of services.

METHODS

The evaluation research included both process and outcome measures within the framework of a quasi-experimental design. Data collection included staff and director interviews and a telephone survey of customers who are caregivers. A total of 36 staff from 29 Aging and Disability Resource Centers (ADRCs) participated in group interviews on four dates in June and July of 2013.

KEY TAKE-AWAYS

1. Wisconsin's caregiver population is vulnerable. One in three caregivers (35.5%) are 65 years of age or older, and almost one in four describe their health as "fair" (19.3%) or "poor" (3.9%). Almost one in three (29.6%) has a physical disability or limitation that makes it difficult to provide care. In the twelve months prior to contacting the ADRC, some caregivers had experienced a change in their own behavior, mood or mental health (36.2%) and/or physical health (33.1%). In addition, 27.6% had been to an emergency room or been hospitalized.
2. Caregivers reported offering an average of 41 hours per week of care; one in four (23.6%) spends 60 hours or more per week in caregiving activities. Half of the caregivers interviewed (49.8%) reported cutting back on the hours they spend working or volunteering in their community. Thus, caregiving activities, in addition to impacting the lives of individuals, also impact the community and local economy.
3. When asked what kind of support would help them to be able to continue providing care, caregivers mentioned respite care most frequently. Other needs included information or instruction on how to provide care (19.1%), particularly among caregivers who provide personal care (e.g., bathing, grooming or mobility in the home).
4. Almost one in three caregivers (30.1%) said that the meeting with the ADRC staff led to the discovery of previously unrecognized unmet needs for either the caregiver or care recipient (e.g., a need for adaptive equipment or home modification). Those who discovered an unrecognized need for making a decision were also more likely to feel the staff helped them to think about the future, stretch their money, and better understand their timeline. These respondents also rated the ADRC more favorably in terms of receiving help with their main issue of concern and for their overall experience.

5. About half of the caregivers surveyed (48.2%) said that the ADRC helped them to continue to offer care longer than they would have been able to had they not gone to the ADRC. Those who were helped to continue care longer than they otherwise might have were significantly more likely to say that the ADRC helped them to stretch their money, think about the future and understand their timeline. These three indicators, along with helping caregivers consider their options and those of their care recipient, consistently appeared among the drivers of positive outcomes (e.g., the ADRC helped them with their main issue of concern, a positive overall experience and willingness to recommend the ADRC to others).
6. Follow up has been shown in previous studies to be very helpful in improving the helpfulness of ADRC services. Among those who received a follow-up, 79.1% said the ADRC was very helpful, as compared to 53.1% of those who did not. Follow up conversations could provide an opportunity to make sure that customer questions or concerns around these issues have been addressed.
7. When asked to rate their agreement or disagreement, on a scale of one to four (one representing “strongly disagree” and four representing “strongly agree”) with a series of statements about the ADRC staff, caregivers rated staff very favorably on listening carefully, protecting customer privacy, and helping to evaluate options for the caregiver and care recipient (average ratings of 3.4 to 3.6). Although most caregivers agreed that the staff person understood their timeline (3.2) and helped them to think about the future (3.1), agreement was less strong than with the other characteristics. The level of caregiver agreement with the statement that the ADRC staff helped stretched one’s money (2.8) may offer an opportunity for improvement.

METHODOLOGY

The design for this study employed a mixed methodology that included both qualitative interviews of staff and directors at 29 ADRCs and a quantitative survey of ADRC customers who give care to another person. A total of 36 staff participated in the interviews and 602 customers completed the telephone survey. A pretest of ten interviews was also conducted, which included a cognitive testing designed to evaluate the wording and content of the survey instrument. Minor changes were made as a result of the pretest, and the interviews were included in the total of 602 completed interviews.

OBJECTIVES

This project was designed to assess the needs of caregivers who are customers of ADRCs in order to develop and refine the options counseling practices as they apply to this group. An interview guide for staff was developed and addressed the following topic areas:

- ◆ Understanding the Customer
- ◆ Decision Support
- ◆ Caregiver as a Customer
- ◆ Methods and Best Practices
- ◆ Development of Plans for the Next Steps
- ◆ Marketing and Outreach
- ◆ Referrals and Available Supports
- ◆ Goals and Outcomes
- ◆ Follow Up

The customer survey was developed based on the staff interviews, discussion with State staff, previous Wisconsin Options Counseling research results and the academic literature on caregiving and caregiver research. The topics covered by the customer survey encompassed many issues and included several broad, open-ended questions about the customer experience. Other quantitative measures in the instrument included the topics of the caregiver's relationship with the person to whom they give care, the caregiver's experience in the discovery and exploring options phases of options counseling, the caregiver's and care recipient's physical, mental and environmental circumstances immediately preceding their contact with the ADRC, the impact of caregiving on the caregiver's other activities and obligations, as well as a variety of outcome and satisfaction measures.

SAMPLE DESIGN AND METHODS

For the staff interviews, an invitation to participate, listing several available time slots, was distributed to staff and directors at all 41 Wisconsin ADRCs. Staff at 29 ADRCs participated in a group interview session. Interviews were recorded using a SmartPen, and portions have been transcribed for this report.

- ◆ Some ADRCs use the Social Assistance Management System (SAMS) for customer data management, whereas some use other management information systems. A few of the independent record keeping systems used did not record information that enabled reliable identification of caregivers. Therefore, a few ADRCs are not included in the chart below. A few ADRCs provided lists that included both caregivers

and care recipients. These lists were excluded when it became clear that care recipients were listed.

- ◆ A total of 602 customers completed a telephone interview. The table below shows the breakdown of interviews by ADRC and the number of contacts provided. The percentage of contacts completing the survey is not a response rate because once 600 interviews were completed, interviewing stopped, occasionally leaving additional contacts on the list who were not called for the survey.

ADRC	Survey Respondents	Number of Contacts	Percentage of Contacts Completing Survey
Adams, Green Lake, Marquette and Waushara	28	161	17.4%
Barron, Rusk and Washburn	41	140	29.3%
Brown	54	352	15.3%
Buffalo, Clark and Pepin	1	2	50.0%
Central WI	46	197	23.4%
Chippewa	10	21	47.6%
Columbia	1	2	50.0%
Calumet, Outagamie and Waupaca	54	330	16.4%
Dane	6	23	26.1%
Dodge	2	2	100.0%
Door	5	14	35.7%
Douglas	4	96	4.2%
Eagle Country	14	29	48.3%
Eau Claire	14	51	27.5%
Florence	1	12	8.3%
Fond du Lac	26	768	3.4%
Jefferson	17	99	17.2%
Kenosha	20	81	24.7%
Lakeshore	2	8	25.0%
Marinette	3	9	33.3%
Milwaukee ARC	0	10	0.0%
North	6	119	5.0%
Northwest	9	26	34.6%
Northwoods	0	19	0.0%
Ozaukee	20	50	40.0%
Pierce	8	44	18.2%
Portage	2	6	33.3%
Racine	13	56	23.2%
Rock	0	5	0.0%
Sheboygan	23	86	26.7%
Southwest	3	17	17.6%
Trempealeau	23	86	26.7%
Walworth	2	8	25.0%
Washington	12	39	30.8%
Waukesha	58	493	11.8%
Western	1	20	5.0%
Winnebago	55	721	7.6%
Wolf River Region	18	72	25.0%
Total	602	4273	14.1%

RESPONDENT CONFIDENTIALITY AND PROTECTION

Participation in this research is anonymous and confidential for customers. Respondents were randomly selected from each ADRC consumer listing. Transmission of the listings was made secure through password encryption and downloaded through the secure state system.

During the course of the research, a few consumers asked interviewers for ADRC services or follow-up. In these cases requests were forwarded to the ADRC for action. Although this action resulted in identifying a customer who had participated in the research, it did not identify the opinions of that respondent.

Staff participated in open forum-style interviews and facilitated feedback meetings. Four groups of staff interviews were conducted, as well as a group interview with ADRC directors and supervisors.

STATISTICAL SIGNIFICANCE REPORTING

In statistical analysis, a significance test indicates the probability of finding a particular relationship at random. Significant results are highly different from results we would expect from randomly generated responses. Researchers use a probability threshold of .05 to indicate that a relationship is meaningful, and not a random occurrence. For example, respondents who reported that the ADRC helped them to stretch their money were significantly more likely to say that the ADRC helped them continue providing care longer than they otherwise might have. The fact that the relationship is significant at the .05 level tells us that if the results were randomly generated, we would see this association less than 5% (.05) of the time. In other words, we are 95% confident that the observed relationship is not random, but is instead a meaningful result.

There are two drawbacks to the reporting of significance. First, if a variable is significant at .06, it has only a six percent chance of occurring randomly, yet is classified as not significant. Significance does not necessarily measure importance. An important or meaningful result should not be dismissed for lack of statistical significance when it is part of an overall pattern or meaningful result. For this reason, when a variable is close to significance but does not cross the threshold of .05, that result is reported and the lack of statistical significance noted.

The second limitation of focusing on statistical significance is that the measure contemplates one variable at a time and does not recognize meaningful patterns in the data. Several similar variables which indicate a trend may not show statistical significance individually, but when taken together the results become more meaningful. Where patterns are noted in sets of questions, statistical significance of each variable is noted, but sometimes overridden due to the meaningful pattern or trend.

DATA LIMITATIONS AND DRAWBACKS

Differences in Management Information Systems' records of customers who are caregivers resulted in some ADRCs being excluded or underrepresented where information identifying caregivers was unavailable. Results are unweighted and presented as an overall depiction of caregiver customers' perceptions and needs.

CAREGIVER PROFILE

CAREGIVER PROFILE

When asked about the relationship between the caregiver and care recipient, a large percentage of respondents (29.1%) said that their care recipient is their grandparent. One in five (20.1%) cares for a child (including adult children) and 10.5% care for a parent. One in ten gives care to a spouse. Among those who give care to a spouse, 82.5% are over the age of 65 years. Overall, 36.6% of the caregivers surveyed were over 65 years of age.

Wisconsin's caregivers are often in circumstances that may require assistance. One in three (35.5%) is 65 years of age or older, and while 25.8% rate their own health as "excellent", a majority describe their health as "good" (51%), "fair" (19.3%) or "poor" (3.9%).

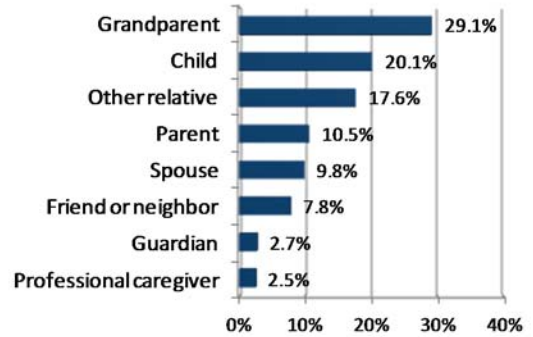
Almost one in three (29.6%) caregivers reported having a physical disability or limitation that makes it difficult to provide care.

In the twelve months preceding their visit to the ADRC, about one in three caregivers had experienced a change in their own behavior, mood or mental health (36.2%) and/or physical health (33.1%). In addition, 27.6% had been to an emergency room or been hospitalized.

Those caregivers who rated their own health as less than "excellent" or who had a disability or impairment that makes it difficult to provide care were significantly *more* likely to report that the ADRC was very helpful with their main issue of concern. However a caregiver's overall health or disability issues did not have an impact on overall satisfaction.

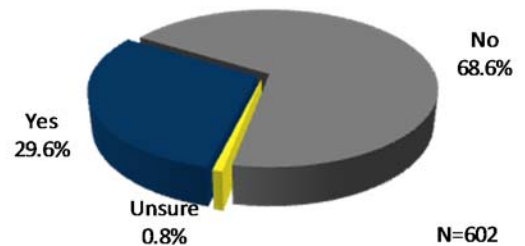
Just over half (52.3%) of the caregivers surveyed live with their care recipient, and of those care recipients who do not live with the caregiver, most (60.8%) live in a home or

**What is their relationship to you?
(They are my....)**



N=602

Do you have any physical disabilities that make it difficult to provide care?



N=602

In general, how would you rate your own health?

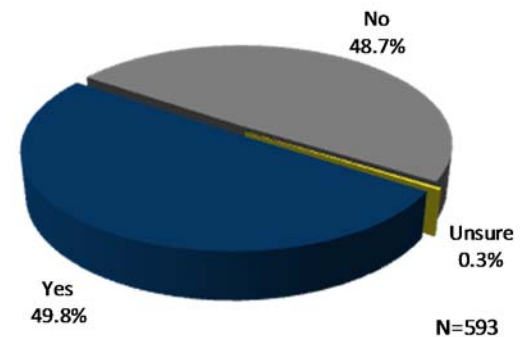


N=592

apartment. A substantial percentage of care recipients live in an assisted living facility (17.9%) or nursing home (16.8%).

Half of the caregivers interviewed (49.8%) said that they have cut back on the hours they spend working or volunteering in their community. Thus, caregiving activities, in addition to their impact on the lives of individuals, also have a direct impact on the community and local economy.

Have you cut back on the hours you spend working or volunteering?



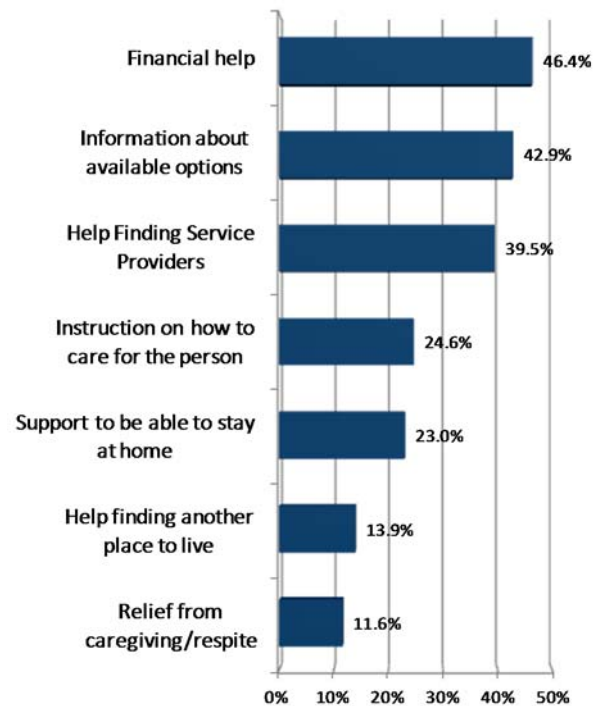
CAREGIVER NEEDS AND IDENTIFYING AS A CAREGIVER

Financial help (46.4%), information about available options (42.9%) and help finding service providers (39.5%) were the most common reasons customers contacted the ADRC.

About one in four caregivers (24.6%) reported looking for knowledge about how to better care for the care recipient. These respondents were most likely to offer help with mobility in the home, e.g. moving someone from a chair to a bed or with personal care.

When asked about the reason for contacting the ADRC, help finding a service provider was mentioned by over one in three caregivers (39.5%). Support in helping their care recipient stay at home was mentioned by 23% and help finding the person another place to live by 13.9%. A third (36.9%) of customers mentioned either maintaining their housing or moving as their primary reason for contacting the ADRC.

What prompted you to contact the ADRC?



N=602

TYPES OF CARE PROVIDED

The vast majority of customers provide care to a single care recipient, however more than one in 10 (12.9%) give care to two or more people.

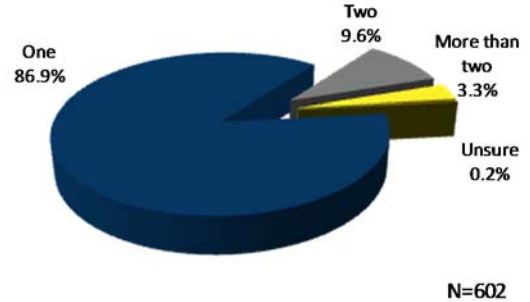
Caregivers reported providing an average of 41 hours per week of care, and one in four (23.6%) spends 60 hours or more per week in caregiving activities.

The majority of caregivers provide a range of services including checking to make sure things are okay (87.9%), arranging or attending medical appointments (85.6%), providing or arranging transportation (79.5%), managing finances (79.4%), preparing food or grocery shopping (75.9%), doing housework (67.4%) or managing medications (66.5%).

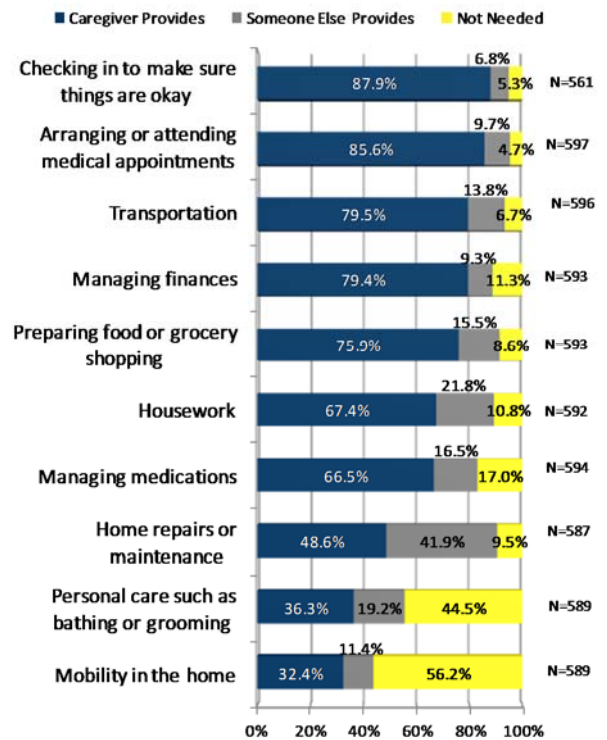
Caregivers were most likely to report that someone else provides home repairs or maintenance (41.9%), housework (21.8%) or personal care (19.2%).

Personal care (e.g. bathing, grooming, or helping with mobility in the home) was provided by approximately one in three caregivers (36.3% and 32.4%, respectively).

How many people do you provide care for?



What kinds of care are needed?



URGENCY OF THE CIRCUMSTANCES JUST BEFORE CONTACTING THE ADRC

Half of the caregivers surveyed (50.5%) said that the person they care for had a pressing concern or emergency prior to contacting the ADRC. About one in three caregivers (35%) reported experiencing a pressing concern or emergency.

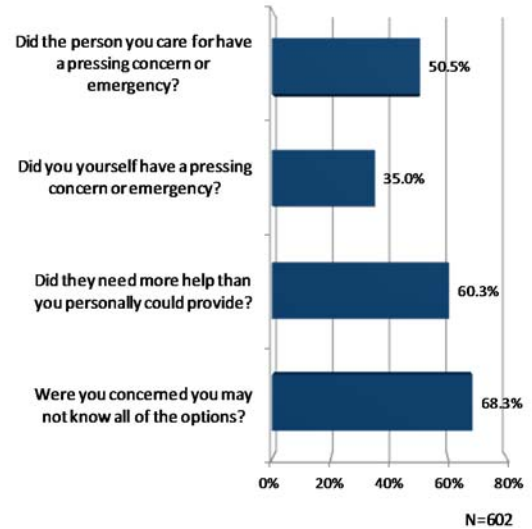
Almost two out of three caregivers said that just before contacting the ADRC, the person they care for needed more help than they personally could provide (60.3%), and 68.3% (almost seven out of 10 respondents), said that they were concerned they may not know all the options available to them.

Over half of respondents said there had been a change in the physical health (63.5%) or mood, behavior or mental health (54.8%) of the care recipient immediately prior to contacting the ADRC.

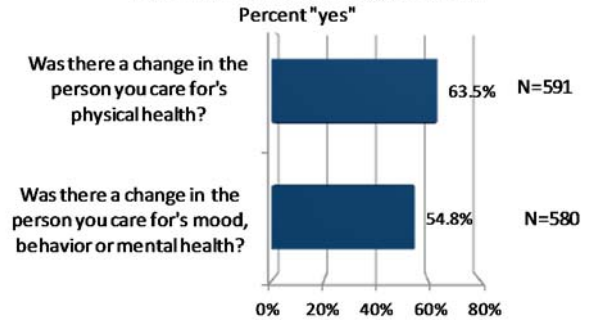
Those caregivers who reported that the person they care for needed more help than they could provide were significantly less satisfied overall with their ADRC experience (3.5 vs. 3.7 using a scale of one to four). Additionally, caregivers who reported that the person they care for had a pressing concern or emergency were also less satisfied overall with their ADRC experience (3.4 vs. 3.7 using a scale of one to four). Although the other measures of urgency did not show significantly lower satisfaction levels, caregivers who are “over their heads” with a care recipient who needs more care than they can provide or is in a state of emergency may require more concentrated attention.

Respondents who said the person they care for needed more help than they could provide did not rate the staff person or ADRC significantly less favorably on other important measures, including listening carefully and helping to evaluate their options.

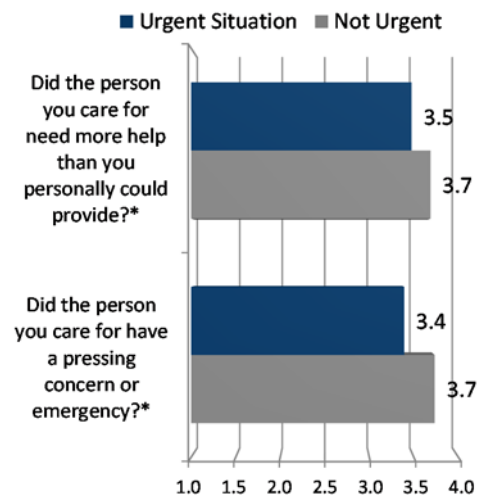
Just Before Contacting the ADRC



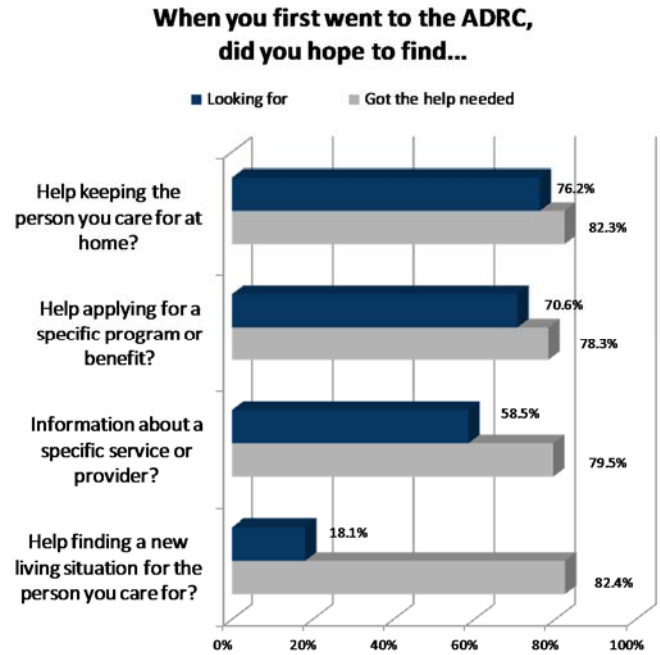
Just Before Contacting the ADRC



Urgent or Pressing Situations and the Impact on Satisfaction



When they first went to the ADRC for help, many respondents were hoping to find help keeping their care recipient at home (76.2%). Among those who were seeking help keeping someone at home, 82.3% found the help they needed at the ADRC. A large percentage of respondents were looking for help applying for a specific program or benefit (70.6%), and among those respondents 78.3% found the help they needed. Over half of respondents said they hoped to get information about a specific service or provider (58.5%), and among those who needed this type of help 79.5% said the ADRC helped them. A smaller percentage of respondents came to the ADRC hoping to get assistance in finding a new living situation for their care recipient (18.1%). Among these respondents 82.4% found the help they needed.

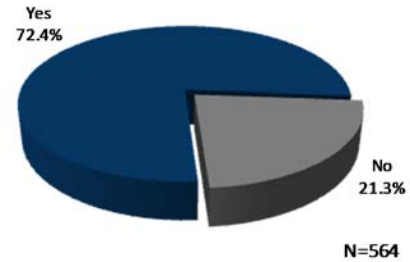


OTHER SOURCES OF INFORMATION

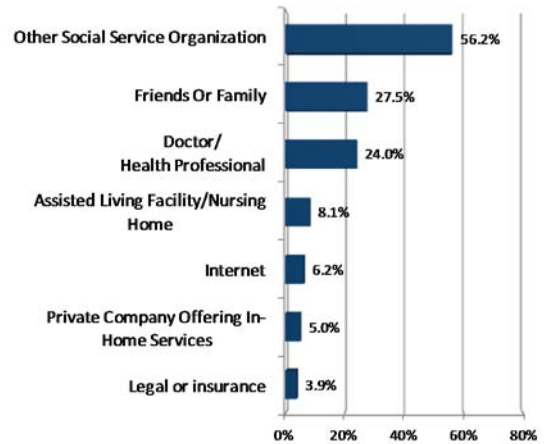
Most caregivers (72.4%) looked for information from another source before contacting the ADRC. Most often customers looked to a social service organization, a category that includes the Veterans' Affairs (VA) and local non-profit organizations (56.2%), friends or family (27.5%) or a doctor or other health professional (24%).

The vast majority of respondents said that knowing the ADRC offers information without selling anything or having a financial stake in the decisions they make is very important to them (83%). Just 2.4% said this is not important at all.

Did you look to anyone else for information?



Who did you look to for information?

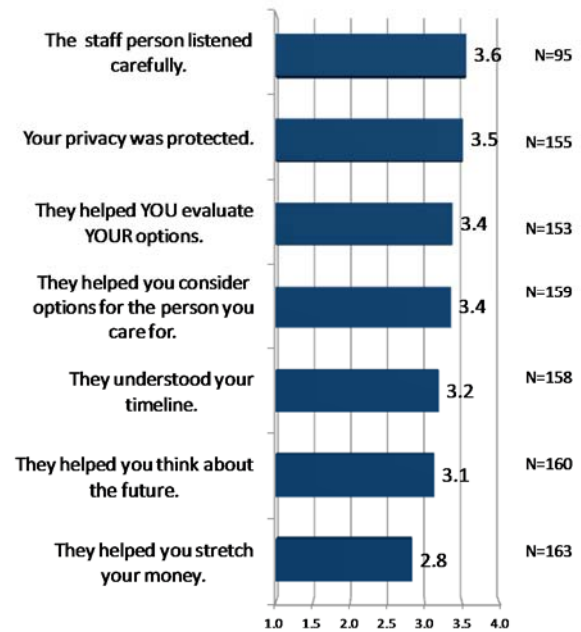


THE ADRC EXPERIENCE

Caregivers were asked if they agreed or disagreed with a list of attributes to describe the staff person who helped them and their experience with the ADRC. Once the respondent answered that they agreed (or disagreed) the interviewer asked "would that be strongly or somewhat?" Answers were calculated on a scale of one to 4, with one representing "strongly disagree" and four representing "strongly agree."

Caregivers strongly agreed that the ADRC staff person who helped them listened carefully (3.6) and that their privacy was protected (3.5). The ADRCs' ability to help caregivers evaluate their own options (3.4) and the options of their care recipient (3.4) gathered strong agreement. Most caregivers agreed that the staff person understood their timeline (3.2) and helped them to think about the future (3.1), although agreement was less strong than with the other characteristics. Lower ratings of helping customers stretch their money (2.8) may offer an opportunity for improvement.

Do you agree or disagree that...

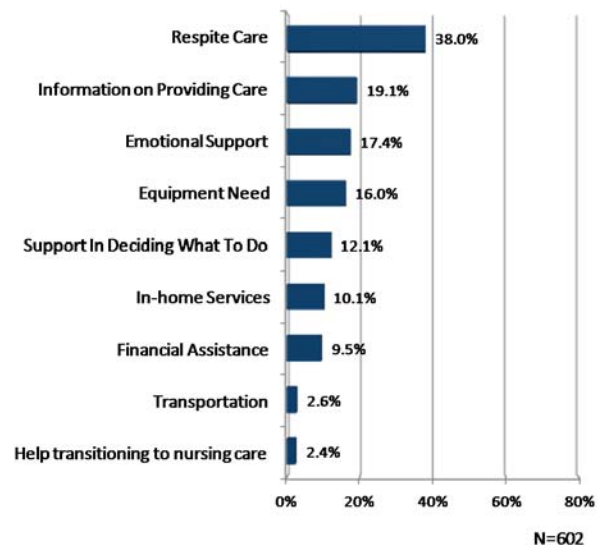


SUPPORT TO CONTINUE CAREGIVING

Respite care was the most frequently mentioned support to help caregivers continue providing care, named by over one in three respondents (38%). Many participants who mentioned respite care mentioned several specific needs, e.g. "someone to watch him while I do the grocery shopping" and "a break now and then". Several specific respite-related needs were counted only once as respite for the percentages shown. However, responses could cover multiple unique support areas, and the total of all responses does not equal 100%. This was an open-ended question that respondents answered in their own words, without pre-set answer categories.

Information or instruction on how to provide care was a frequently mentioned need (19.1%), and was significantly

What kind of support would help you continue to provide care?



more likely to be a need of caregivers who provide personal care, e.g. bathing, grooming or helping with mobility in the home.

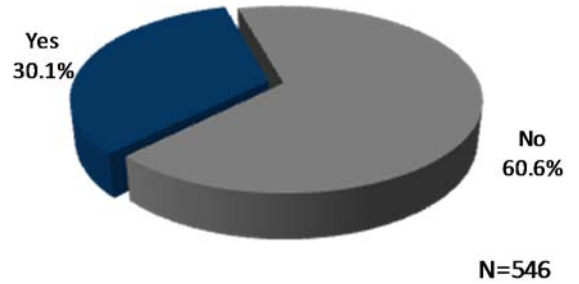
Some of the most frequently mentioned equipment needs included bars for the shower, bath or toilet, ramps, lifts and lift chairs.

Some caregivers (30.1%) said that when meeting with the ADRC, they or the staff person noticed a need that they did not realize they had. Those who discovered an unrecognized need were also more likely to strongly agree that the staff person helped them to think about the future (3.3 vs. 3.0), helped them to stretch their money (3.1 vs. 2.6), and understood their timeline (3.3 vs. 3.1). These respondents also rated the ADRC more favorably with regard to being very helpful with their main issue of concern (2.8 vs. 2.4 using a 3-point scale) and for their overall experience (3.6 vs. 3.4).

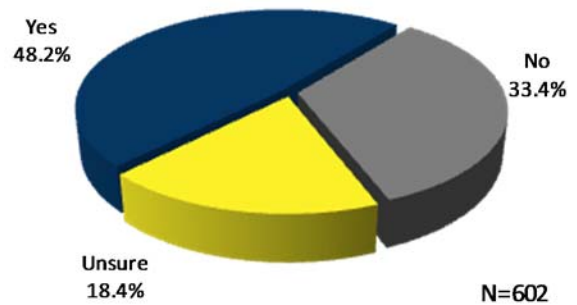
About half of the caregivers surveyed (48.2%) said that the ADRC helped them to continue to offer care longer than they would have been able to had they not gone to the ADRC.

Those who were helped to continue care longer than they otherwise might have were significantly more likely to say that the ADRC helped them to stretch their money (yes=3.05, no=2.33, gap=.72), helped them think about the future (yes=3.26, no=2.77, gap=.49) and that they understood their timeline (yes=3.37, no=2.91, gap=.47).

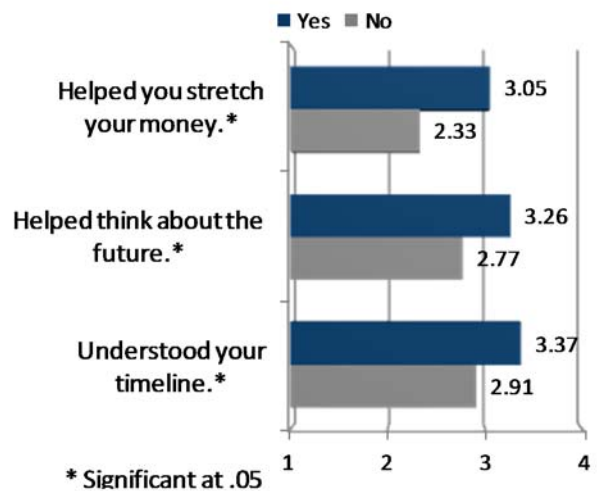
Did you or the staff person notice a need that you did not realize you had?



Did they help you continue to offer care?



Did the ADRC help you continue to offer care?



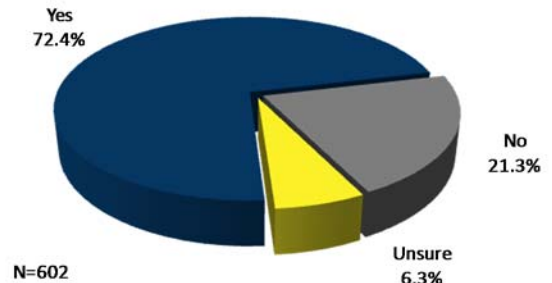
FOLLOW UP

Three out of four respondents (72.4%) said that the ADRC staff person followed up with them. Among those who did not receive a follow up, just 37.5% rated their experience overall as excellent, as compared to 65.4% of those who did receive a follow up. Although the vast majority of those who did not have a follow up would recommend the ADRC (87%), almost all of those who did receive a follow up (98.8%) would recommend the ADRC.

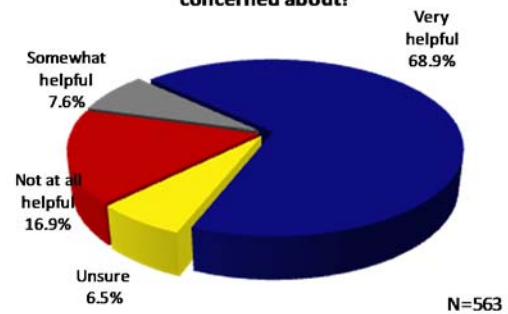
Over two out of three respondents (68.9%) said the ADRC was very helpful with the main issue they were concerned about. About one in six (16.9%) said the ADRC was not at all helpful.

Follow up has been shown in previous studies to be effective in improving the helpfulness of ADRC services. In this study, among those who received a follow-up, 79.1% said the ADRC was very helpful, as compared to 53.1% of those who did not. Further, over one in three respondents who did not receive a follow up said the ADRC services were not at all helpful, as compared with 14.4% of those who did receive a follow up.

Did the staff person you worked with follow-up with you?



Was the ADRC very, somewhat or not at all helpful with the key issue you were concerned about?



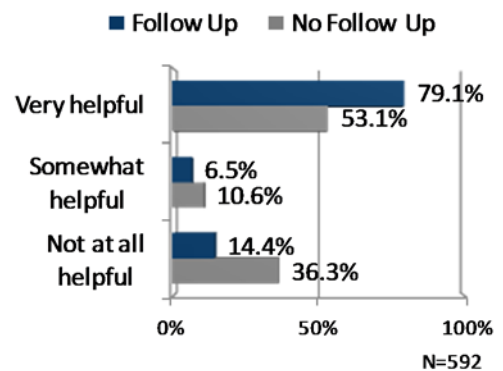
PROVIDING A HELPFUL EXPERIENCE

Among those respondents who said that the ADRC followed-up with them, 79.1% said that the ADRC was very helpful with the main issue that they were concerned about. In contrast, 53.1% of those who did not receive a follow-up said that the ADRC was very helpful. Over one in three respondents who did not receive a follow-up (36.3%) said that the ADRC was not at all helpful with their main issue of concern.

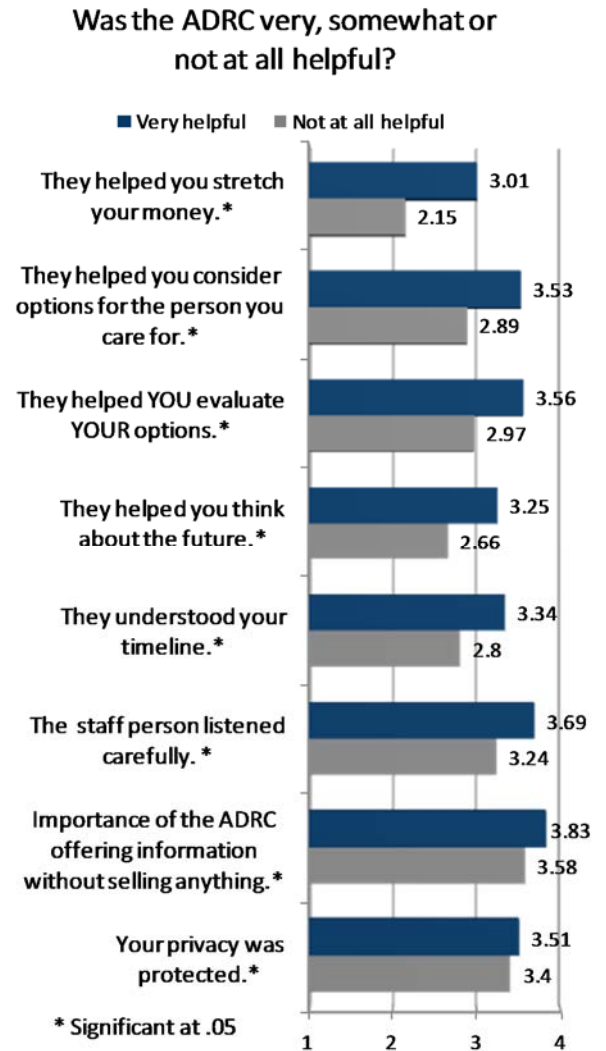
In addition to the follow up, several other elements of the options counseling experience were significantly associated with a more helpful experience.

Customers who said that the ADRC was very helpful were

How helpful was the ADRC with the main issue you were concerned about?



significantly more likely to agree that the ADRC helped them stretch their money as compared to those who found the experience to be not at all helpful (very helpful=3.01, not helpful=2.15, gap=.86). Customers who said they ADRC was very helpful were also significantly more likely to agree that the ADRC helped them to consider the options for themselves (very helpful=3.53, not helpful=2.89, gap=.64), to consider the options for the person they care for (very helpful=3.56, not helpful=2.97, gap=.60) and to think about the future (very helpful=3.25, not helpful=2.66, gap=.59). Follow up conversations could provide an opportunity to make sure that customer questions or concerns around these issues have been addressed.



DYNAMICS OF CAREGIVER SATISFACTION WITH ADRC SERVICES

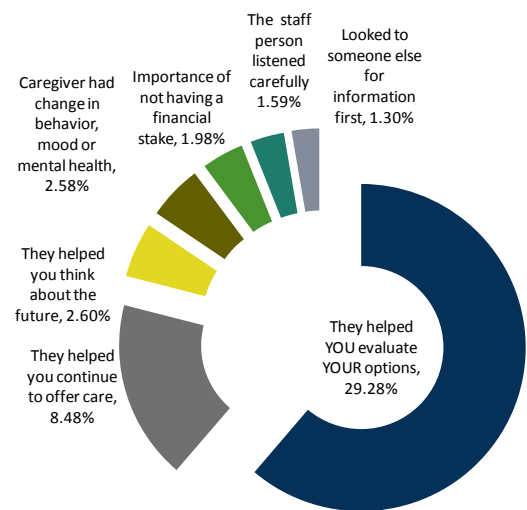
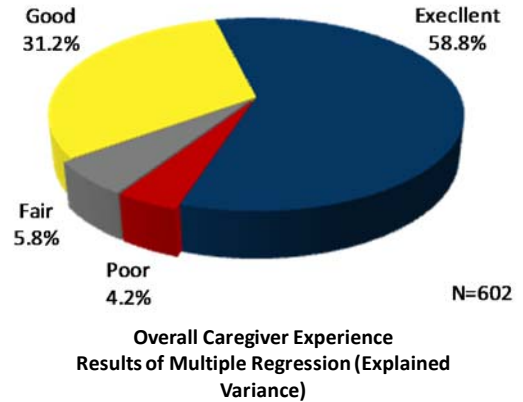
Nine out of 10 respondents rated their overall experience with the ADRC as either excellent (58.8%) or good (31.2%). The remainder were divided between fair (5.8%) and poor (4.2%). The vast majority (94.5%) said they would recommend the ADRC to someone else.

Multiple regression was used to identify the indicators of overall satisfaction that have the strongest independent impact on caregivers' perception of their overall experience. The donut chart (to the right, center) shows those indicators that are statistically significant predictors of overall satisfaction. The percentages represent the amount of explained variance, which offers two pieces of information. First, the total of explained variance (47.8%) tells us that the model as a whole accounts for about half of the factors that go into a respondent's rating of their overall experience. Second, the size of the increase in variance explained with the inclusion of each new variable is an indication of the strength of the impact each variable has on overall satisfaction.

The table shows the "beta scores" associated with the multiple regression. The staff person helping the caregiver to evaluate their own options, as distinct from their care recipient has the strongest impact on overall satisfaction and is the first variable entered into the model. Although the majority of caregivers come to the ADRC looking for help primarily for their care recipient, the ability to help the caregivers see their own options is key to a positive experience. The beta of .257 indicates that, for an increase in the rating of helping caregivers evaluate their own options of one point, from a rating of three (good) to four (excellent), one would expect the impact on overall satisfaction to be an increase of .257 (e.g., from 3.0 to 3.257.)

Helping the caregiver to continue to offer care longer than

How would you rate your experience overall?



Item	Beta
They helped YOU evaluate YOUR options.	.257
They helped you continue to offer care longer than you would have been able to if you hadn't gone to the ADRC.	.173
They helped you think about the future.	.173
Caregiver personally experienced a change in behavior, mood or mental health.	.154
Importance that the ADRC offers information without selling anything or having a financial stake in the decisions you make.	.107
The staff person listened carefully.	.098

they would have if they had not come to the ADRC is also central to a positive ADRC experience. Although generally focused on the needs of their care recipient, when caregivers described the reasons they first came to the ADRC, help for the caregiver and care recipient appear to be interdependent. When an ADRC provides help to the care recipient, the caregiver benefits. Similarly, when the ADRC provides needed options counseling to the caregiver, the care recipient also benefits. This interdependence is seen in the importance of helping the caregiver evaluate their options, continue to provide care and think about the future.