

Alaska Division of Senior & Disabilities Services

Aging & Disability Resource Center

ADRC CONSUMER FEEDBACK INTERVIEWS

ADRC Expansion Project: Empowering Individuals to Navigate their Health
& Long-Term Support Options

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*A Report for the
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ADRC CONSUMER FEEDBACK INTERVIEWS

Introduction

The Aging & Disability Resource Center (ADRC) in Alaska is managed at the State level through Alaska's Division of Senior and Disabilities Services, under the Department of Health and Social Services. The Department/Division uses a competitive grant application process to fund regional ADRC sites. A Health Program Manager (ADRC Manager) in the Division oversees the ADRC system, and acts as a referral agent for regions not directly covered by a regional grantee. Currently, Alaska has four ADRC grantees: Bristol Bay Native Association (BBNA), Independent Living Center (ILC), Municipality of Anchorage (MOA), and Southeast Alaska Independent Living (SAIL). BBNA was the youngest and least developed of the grantee sites at the time of this report. MOA was the next most recently formed ADRC site.

An ADRC Expansion project for Alaska was funded by the U.S. Administration on Aging (AoA) in collaboration with the Centers for Medicare and Medicaid Services (CMS) beginning in October 2009. One of the aims of that project was to increase the capacity of Alaska's ADRC system to provide Long Term Support Options Counseling. The purpose of the ADRC Consumer Feedback Interviews was to gather information from people who received this service within the timeframe March through June 2012. Three of four ADRC grantees were providing Options Counseling during that timeframe. BBNA did not yet have staff trained in providing the service, and so was not included in this evaluation activity.

Method

On 6-September-2012, the ADRC Manager provided names and phone numbers to the evaluator for 39 contacts who had received Options Counseling from ILC or SAIL during the targeted timeframe. Another 12 eligible contacts were provided directly to the evaluator by MOA on 24-October-2012, for a total of 51 potential participants. Even though all these contacts were not received at exactly the same time, the same level of effort was invested in reaching people.

In seven cases, a recommended contact was a caregiver, parent, spouse, or other family member involved with the client in the service. In these cases, the clients were not as capable of responding directly due to their personal circumstances. Information about the personal circumstances of potential respondents was not shared with the evaluator.

Short interviews were conducted over the phone using a 7-item instrument (see Appendix). As interviews were conducted, responses were entered without identifiers into an online survey using Survey Monkey (surveymonkey.com), rendering the saved data anonymous. Lists of contacts were destroyed at the completion of this report.

Results

Participants

Of the total 51 eligible respondents, nine were unreachable by phone at the time of this evaluation activity. Reasons persons were not reachable included disconnected phone numbers (1-MOA, 1-SAIL), no longer residing at a place with the listed phone number (1-MOA, 1-SAIL), inability to respond due to current medical condition (1-SAIL), or the evaluator was unable to reach a person after ten attempts at varying times of day on both weekdays and weekends (2-ILC, 2-SAIL).

Two additional persons were reached by phone, but did not complete the interview. One declined to participate (MOA) and the other was in an emotional state that made it inappropriate to conduct the interview (MOA). The evaluator secured permission from the latter respondent to contact the ADRC on her behalf, and the ADRC responded very quickly to address her immediate need.

Forty consumers of ADRC services receiving Options Counseling within the timeframe March through June 2012 participated in interviews for an overall response rate of 78% as detailed below. Table 1 shows the response sorted by ADRC grantees and their service areas. No demographic information was collected from respondents, but information they offered indicated that most of them were seniors.

Original Target Population	51
Made contact	42
Ineligible	0
Opted out or did not respond (O)	2
Eligible completed responses (R)	40
No contact (N)	9
<hr/>	
Response Rate = R / (R + O + N) = 0.78431... or 78%	

Table 1: Response sorted by ADRC grantees and service areas

ADRC Grantee	Service Area(s)	Eligible	% of Eligible	Response	Rate	% of Response
Municipality of Anchorage (MOA)	Anchorage	12	23.5	8	67%	20.0
Independent Living Center (ILC)	Kenai Peninsula Borough, Copper River Basin, Valdez, Cordova, Mat-Su	27	52.9	23	85%	57.5
Southeast Alaska Independent Living, Inc. (SAIL)	Juneau Borough, Haines, Ketchikan, Sitka	12	23.5	9	75%	22.5
TOTAL		51	100	40	78%	100

Note: Percentages reported in tables are rounded and may not add up to exactly 100%

Responses to Interview Questions

Actions Taken & Changes to Life Situations

Respondents were asked whether or not they had made changes to their situations since they started working with the ADRC. If they said “yes” they were asked an open-ended question about what they had done. If they said “no” they were asked if they were more confident they knew where to go for services. Even though the latter was a yes-no question, people typically offered reasons why their situations had not changed.

Twenty-five respondents (62.5%) indicated they made positive changes to their situations since they started working with the ADRC. A number of these respondents suggested that they were still in ongoing relationships with the ADRC and anticipated making more positive changes and adjustments. The following summary is based on information provided by respondents indicating how ADRC assistance helped them change their lives. Numbers reported below are not discrete. That is, any single respondent could have done more than one thing.

- Seven respondents (17.5%) were able to successfully secure Medicaid or Medicare related funding or services, including waivers, care coordination, personal care assistance, and/or medication assistance.
- Seven (17.5%) were able to make their homes accessible, arrange food delivery, or make other disability accommodations in their homes.
- Five respondents (12.5%) were able to secure housing or financial assistance for utilities.
- Five (12.5%) were able to secure items such as glasses, hearing aids, wheelchairs, or walkers.
- Five (12.5%) were able to secure transportation.
- Four (10%) were able to resolve financial problems.
- Four (10%) were able to increase their own knowledge and skills, which enabled them to manage things and make positive changes.

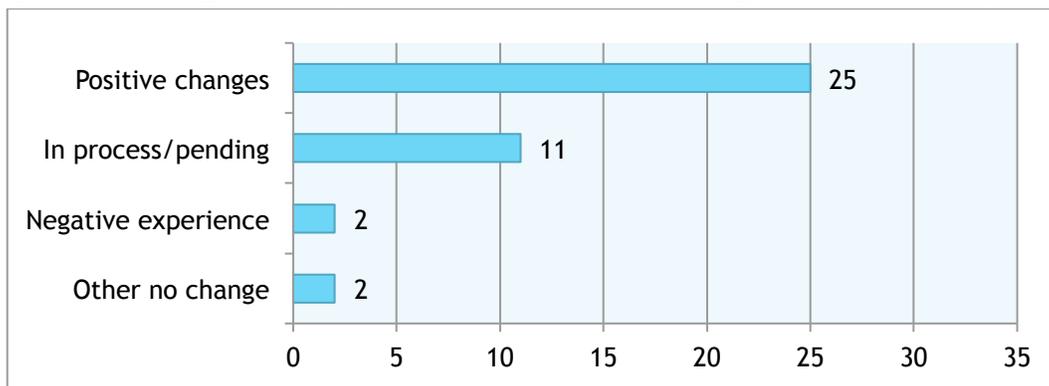
Fifteen respondents (37.5%) indicated they had not yet made changes to their situations since they started working with the ADRC. Most of these respondents (11 or 73% of this group) indicated they were confident they knew where to go for services. They tended to describe how attempts to make changes were in process, not yet resolved, or that they had not yet started to follow through on referrals. Some indicated this interview was a good reminder to get back to work on that process.

Of the four remaining respondents who had not yet made changes, one indicated not knowing where to go for services, but expressed a desire to go back to the ADRC to get a referral. One respondent wanted the evaluator to understand that a

lack of change had nothing to do with the quality of work done by the ADRC, and stated that the ADRC had done all that could possibly be done.

Two respondents blamed the ADRC for a lack of change in their situations. In one case the respondent stated ADRC staff did not return a call in a timely manner, which had negative consequences on a situation that needed quick attention. In the other case, ADRC staff assisted the respondent to apply for a type of government assistance, which was denied. The respondent was clearly frustrated and stated that ADRC staff did not know what they were doing. Figure 1 shows a summary of the types of responses given to this question.

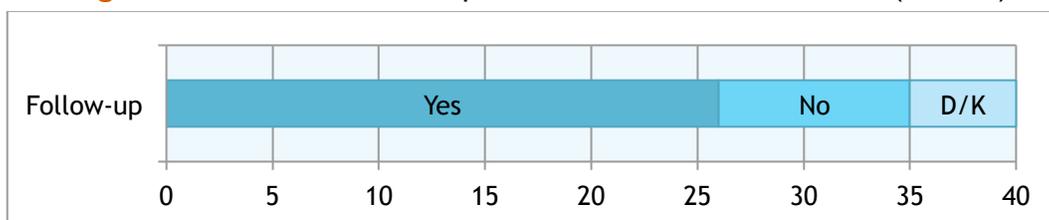
Figure 1: Changes to respondent's lives since working with the ADRC (N = 40)



Follow-up Activity

Respondents were asked if they received a follow-up call or email from the ADRC to see how things were going. Five respondents (12.5%) stated they could not remember. Twenty-six (65%) indicated they had received a follow-up call, and nine (22.5%) indicated they did not receive a follow-up call or email. Figure 2 summarizes responses to this question.

Figure 2: Received follow-up call or email from the ADRC (N = 40)



It eventually became known over the course of some interviews that respondents had repeated contacts with ADRC staff even if they said they did not receive a follow-up call or email. For example, some people mentioned periodic visits from ADRC staff, especially if they lived in more rural or outreach communities. Respondents who mentioned these visits expressed how grateful they were to ADRC staff for stopping by to see them. Some respondents also mentioned seeing ADRC staff

at health fairs, and this venue may have provided additional opportunities for ADRC staff to check in with contacts and ask how they were doing.

Helpfulness of Assistance

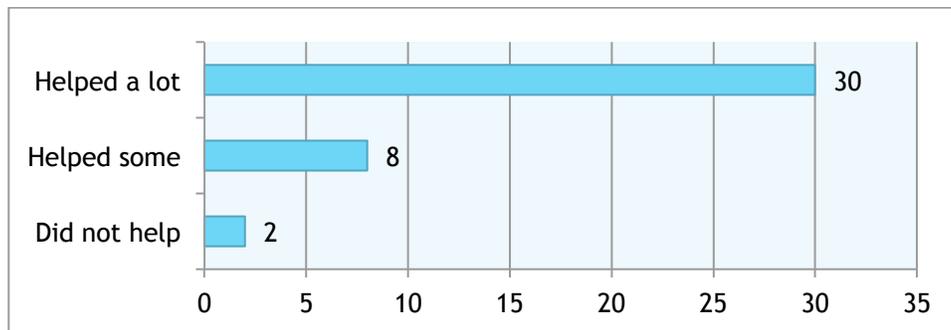
Respondents were asked to indicate the helpfulness of the assistance they received from the ADRC. There were four response choices: Helped a lot, Helped some, Did not help, or Made things worse.

Thirty respondents (75%) indicated the ADRC had “helped a lot” and they tended to say it with great enthusiasm. Many wanted to keep talking about their personal circumstances and how happy they were with assistance they received from the ADRC.

Eight respondents (20%) indicated the ADRC “helped some.” Several of these respondents indicated what they needed was not entirely within the scope of what the ADRC could do, and they wanted the evaluator to know the ADRC was not at fault for not helping them more. One repeatedly referred to ADRC staff as “saints.” Some respondents in this group offered constructive suggestions for how the ADRC could have helped them more, which are included later in this narrative.

Two respondents (5%) indicated the ADRC did not help them. No one indicated that the ADRC made things worse. Figure 3 summarizes response to this question.

Figure 3: Helpfulness of assistance from the ADRC (N = 40)



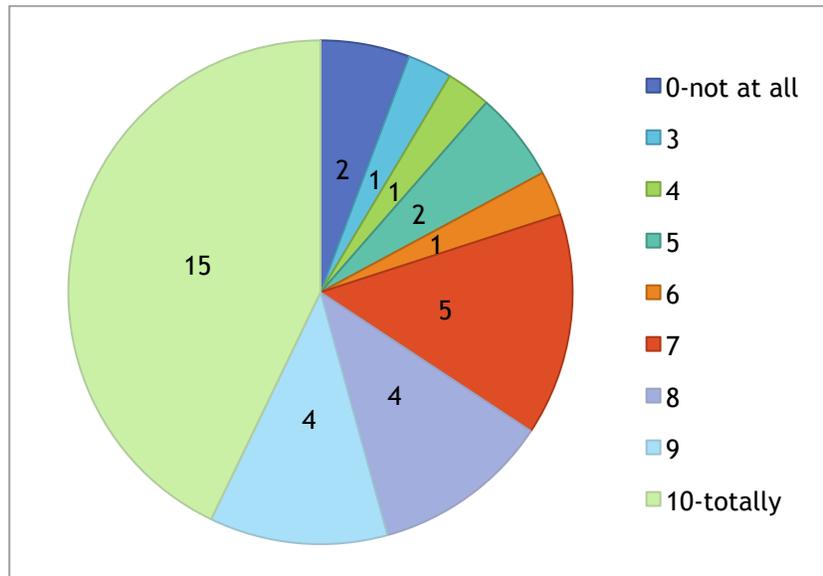
Staying in One’s Home

Respondents were asked to rate how confident they were that they could stay in their own homes as long as they wanted. This item used an interval scale from 0 (not at all confident) to 10 (totally confident). Three respondents seemed to have difficulty answering the question or seemed reluctant to answer it, and in these cases the question was skipped. Two respondents indicated this question was not applicable to their circumstances.

For the 35 respondents who answered this question there was an **average rating of 7.89**. The most frequent rating was 10, chosen by 15 respondents (42.8% of those who responded).

Another way to look at this data is that the vast majority of this group (29 or 82.9%) placed their confidence above the center point of the scale (> 5). The remaining 6 respondents (17.1%) placed their confidence at the center point or below (<= 5), with two indicating they were not at all confident they could stay in their homes. Figure 4 illustrates the distribution of responses to this question.

Figure 4: Ratings of confidence (0 to 10) in ability to stay in one’s home as long as desired (n = 35)



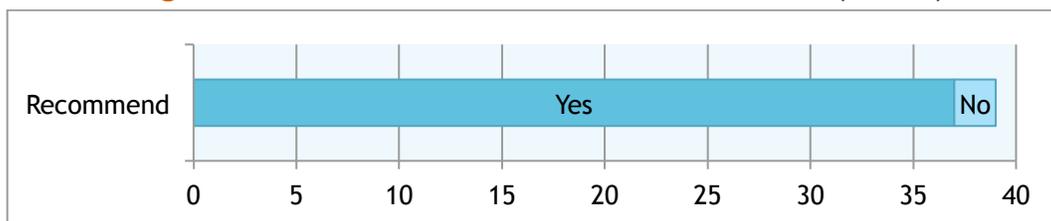
Note: No respondents chose ratings 1 or 2.

Recommending the ADRC to Others

Respondents were asked whether or not they would recommend the ADRC to others. One respondent did not answer this question. Thirty-seven respondents (92.5%) said they would recommend the ADRC to others, and many added that they had already done so.

Understandably, two respondents who felt the ADRC did not help them said they would not recommend it to others. Two respondents who felt the ADRC had “helped some” hesitated, but still gave an affirmative response. The rest of respondents who had not made changes to their lives stated without hesitation that they would recommend the ADRC to others, indicating confidence in the ADRC as a resource. Figure 5 summarizes response to this question.

Figure 5: Would recommend the ADRC to others (n = 39)



Suggestions & Other Comments

The last question in the interview asked respondents if there was anything that would have been more helpful, anything they would like to suggest. Eleven respondents (27.5%) indicated everything was great and they could not think of anything to make it better.

Twenty-nine respondents (72.5%) added a comment. Sixteen of these (55.1%) used the opportunity to say more positive things about the ADRC. Common themes were how grateful they were for the existence of the ADRC and how lost they would have been without the assistance. Two respondents used the opportunity to reinforce their frustration with the ADRC. Eleven of those who added a comment (37.9%) gave specific constructive suggestions summarized below.

- Do more advertising and marketing to increase awareness of the ADRC and what it can do for people
- Inform the Office of Children's Services and the local child protection offices about the ADRC and how it can help families with children who have disabilities so they can refer families to the ADRC for information and assistance
- Explore more ideas for covering medical expenses when people do not qualify for Medicaid or Medicare
- Gather more information about what resources are available to middle-income people, especially for those dealing with Alzheimer's
- Gather detailed information about assisted living resources so that each individual does not have to independently investigate these options
- Hire seniors, part-time or full-time, or use volunteer seniors because only they can really understand what it is like to be elderly
- Expand the use of in-home services, and use the cost-savings to expand eligibility for in-home services to a broader population
- Inform legislators about needs and advocate for positive changes in policy to improve access to services and resources for seniors
- Advocate to increase the distance covered by transportation services
- Provide handouts with lists of resources
- Provide lists of resources by email, including URL links
- Increase information resources available in Braille
- Increase regular communication and other regular contact with clients
- Find a resource that can do free consultations for financial trusts
- Find an effective resource that will help people get and use assistive technology for computers

Discussion

Feedback from 78% of those eligible to participate in this evaluation activity generally lends a high level of confidence in reliability of results. It was clear that as a group these clients received an invaluable level of service. Interviews required only about 5 minutes of a respondent's time if the conversation was limited to simply answering the questions, but some calls lasted closer to 30 minutes as respondents used the opportunity to talk about their lives and how the ADRC had helped them. Sixty-three percent had already made positive changes in their lives, and another 28% were in the process of making changes or at least knew what they were going to do. In combination, that represents about 90% of respondents. Similarly, 95% of respondents indicated the ADRC had helped them, either "a lot" (75%) or "some" (20%), and 93% said they would recommend the ADRC to others. These are very high and noteworthy results.

Two respondents expressed frustration with the ADRC. In the case where a return call was not timely, the ADRC is responsible for something falling through the cracks. In the other case, holding the ADRC responsible for benefits denied by a government agency seems unwarranted. Some respondents had applications that were accepted, others had applications that were denied. Generally, respondents blamed denials on the limits of eligibility criteria.

Confidence in staying in one's own home as long as desired ran high for respondents as a group, with an average of 7.89 on a scale of 0 to 10, with 10 being by far the most frequent response. The vast majority of respondents were elderly, and assistance from the ADRC probably increased their confidence in this regard, as people were able to make their homes accessible, secure assistance to pay for utilities, set up meal deliveries, and make disability accommodations. They were able to increase mobility with wheelchairs and walkers, as well as with transportation assistance. A number of people received types of assistance that improved their financial situations, particularly their ability to pay for medical needs.

An obvious concern for some respondents was how to meet needs if they were not eligible for Social Security, Disability, Medicaid, Medicare, or waivers for in-home services. People in this position generally felt the government should expand eligibility that would include them, or that there needed to be something else available to them. Some of the options people thought they might ultimately face were onerous, such as divesting themselves of their current resources and going bankrupt in order to qualify. One issue brought up was "the marriage penalty" where people can qualify for everything if they are single, but nothing if married. Avoiding marriage or getting a divorce should not be the most viable means to get medical care. These issues fall into the arena of policy, and one respondent suggested the ADRC should work in the policy arena to advocate for positive changes.

A potential lesson learned from this evaluation activity is that respondents who were slower to implement change or to follow through on referrals probably could have benefited from further follow-up contact from the ADRC. This applies to over a

quarter of those who responded. Some respondents stated that even contact from the evaluator reminded them to get back to work on what they knew they needed to do. Those respondents who had experienced multiple contacts with ADRC staff expressed enjoying this contact, and one person suggested increasing frequency of contact.

ADRC sites have very few employees at this time and it is unrealistic to expect ongoing communications with previous contacts under these constraints. However, one suggestion was to employ or use volunteer seniors to talk with people. The expressed perception was that only seniors really understand the challenges faced by the elderly. Bringing in one or more volunteer seniors and providing them with guidance to touch base with previous contacts, might be a relatively easy expansion of ADRC capacity to meet a need that currently may be under-addressed.

Several people felt that there was not enough awareness about the ADRC. One respondent made the specific suggestion to make sure OCS and its satellite offices knew to make referrals to the ADRC when a child has a disability. This same logic could be expanded to other agencies, organizations, and practitioners, beyond the obvious ones that deal most directly with seniors or disabilities.

In a similar vein, “branding” or “name recognition” is a function of marketing. Only the respondents in the MOA service area recognized “Aging and Disability Resource Center” or “ADRC.” In both the SAIL and ILC service areas, respondents did not know what the evaluator was talking about unless the name of the grantee organization was mentioned.

And on a final note, a few respondents mentioned things about computers and email, but it became very clear that as a group, the seniors who participated in these interviews had little or no access to the Internet, including email. Because the Internet has become such a useful tool for information, communication, and social participation, increasing access to this resource could make a positive difference for seniors. The ADRC may want to explore resources to help seniors overcome the barriers that prevent them from accessing and effectively utilizing the Internet.

Appendix: Interview Content

1. ADRC:

ILC - Independent Living Center

MOA - Municipality of Anchorage

SAIL - Southeast Alaska Independent Living, Inc.

2. Have you taken any action or made any changes in your situation since [ADRC] started working with you?

(If yes) What have you done?

(If no) Are you more confident you know where to go for services?

3. Did you receive a follow-up call or email from [ADRC] to see how things were going?

4. Do you feel that the assistance and any services you received...

Helped a lot Helped some Did not help or Made things worse?

(“don’t know” is a possible answer)

5. On a scale of 0 to 10, where 0 is “not at all confident” and 10 is “totally confident” how confident are you that you can stay in your home as long as you want?

(“not applicable” is a possible answer)

6. Would you recommend [ADRC] to others?

7. Is there anything that would have been more helpful? Anything you would like to suggest?

Thank you very much for your feedback!