

Final Report
2016

Consumer Satisfaction with Aging & Disability Resource Connection of Oregon: Round 5

Executive Summary

Submitted to
Oregon State Unit on Aging, Department of Human Services



Diana L. White, PhD
Sheryl Elliott, MUS

Consumer Satisfaction with Aging & Disability Resource Connection (ADRC) Services: Round 5

Diana White and Sheryl Elliott
Portland State University Institute on Aging
March 31, 2016

Executive Summary

This report describes the fifth round of consumer satisfaction surveys that were conducted with people who had been in contact with the Aging and Disabilities Resource Connection (ADRC) of Oregon Call Center for Information & Referral/Assistance (I&R/A) services or received Options Counseling (OC) services. Data for this survey were collected between October 29 and November 14 in 2015. Detailed information reporting results of this survey is presented in 10 separate documents:

- Part 1: Introduction and 2015 Survey Participants
- Part 2: Pathways to the ADRC
- Part 3: Information and Referral/Assistance
- Part 4: Options Counseling
- Part 5: Public Programs and Assistance
- Part 6: Confusion and Memory Loss
- Part 7: Consumer Recommendations and Overall Satisfaction
- Appendix A: 2015 Consumer Satisfaction Survey Questions and Script
- Appendix B: Tables of Findings from 2011-2015
- Appendix C: Final Status Report: ADRC 2015 Phone Survey

This Executive Report summarizes findings from these individual reports, including conclusions, and recommendations for the ADRC program. Some recommendations are directed to the ADRC, such as issues related to customer service or outreach, and some are directed to policy makers and administrations and are related to capacity of the organization to provide needed services.

Measure. Most survey questions have been asked across all rounds of data collection, which allows comparisons across time. Some new questions were added over time. Most recently, questions were added in 2014 (Round 4) about confusion and memory loss and a diagnosis of Alzheimer's disease. As before, a short version of the survey was administered to

Call Center participants and a longer version to those who received OC services or were Call Center participants who reported receiving a home visit. Detailed information about the development of this measure can be found in previous reports.

1. 2014 Survey Participants

Sample characteristics. Two populations were targeted for this survey:

- 1) ADRC Call Center users between September 8 and September 24, 2015 selected from a stratified random sample (n=190).
- 2) All those who used Options Counseling services between August 3 and September 24, 2015 (n=138).

Of the 328 people interviewed, 240 (73%) were consumers of services, defined as the direct recipient of services and 87 (27%) were family members. The OC sample met targets for the first time in 2015 and was more representative of the state than in past rounds.

Participant needs. Patterns of need were similar to those found in previous rounds. Most participants contacted the ADRC to obtain information or advice, and well over half indicated they or a family member had physical health needs that required assistance. The need for help with activities of daily living (ADL) and instrumental activities of daily living (IADL), healthcare, housing, and financial and legal assistance were identified by consumers and family members alike. A list of reasons for contacting the ADRC was provided. Of a possible 16, the average number of needs reported was 4.9, with family members reporting significantly more needs (6.00) than consumers (4.54). Family members increasingly are reporting issues of confusion and memory loss, 64% in 2015. The frequency of other reported needs has been similar across all years of the survey.

Conclusions. The 2015 sample is more representative of the state of Oregon than in past years and contains a higher proportion of OC recipients, although the numbers of people receiving Options Counseling remains low in some parts of the state. Family members are calling the ADRC requesting support for their members who have significant disabilities, including cognitive decline. They are arranging for services to support ADL and IADL needs, to find the most appropriate levels of care, and to find the resources to pay for those services. Although they are experiencing disability and the need for ADL and IADL services, consumers are more likely than family members to be looking for financial assistance in the form of food stamps and energy assistance, a consistent pattern over time.

2. Pathways to the ADRC

Nearly 50% of referrals to the ADRC came from agencies, hospitals, and clinics, an increase from 2014, indicating that outreach efforts to partner with these organizations continue to be successful. Access to services has improved over time. The ADRC Advisory Committee established consumer-based standards and expectations for accessing services. These standards were met in 2015. Furthermore, although the number of respondents reaching a person when they contacted the ADRC decreased in 2015, a greater number of consumers and family members alike indicated that the wait time for a return call was prompt or reasonable, an improvement from 70% in 2014 to 96% in 2015. This is significant progress. It is important to note, however, that these data do not reflect consumers who reached a voice mail or automated system and did not leave a message.

Recommendations include:

- Continue outreach to health and social service providers.
- Continue efforts to improve response time for returning telephone calls.
- Outreach efforts through news media, and awareness of ADRC services through brochure distribution continue to be low relative to other sources. Increase media outreach to consumers, including information about the website, and distribute print material more widely.
- Increase training efforts to help older adults and people with disabilities learn to use the website.

3. Information & Referral/Assistance (I&R/A)

Almost all of the participants indicated that they received all or some of the information they needed when they contacted the ADRC. Most participants received written materials and reported the materials were relevant to their concerns. The overwhelming majority of participants continued to report that the staff person they talked with had spent enough time with them. Virtually all participants indicated the person they talked with was knowledgeable. Those receiving Options Counseling rated staff knowledge significantly higher than those receiving I&R/A services only. Similar ratings were given to the respectfulness of the staff. The majority of participants rated staff as excellent or good in explaining how to get the help that they needed. Fewer participants than in previous years assigned ratings of fair or poor.

Recommendations include:

- Continue to communicate with consumers in empathic, respectful ways that foster greater understanding of how to access available resources.

- Continue efforts to make information about how to contact the ADRC and how to navigate the website more available through outreach efforts, provide consumer training on finding services on the website, and provide a wider distribution of print material.
- Continue to answer calls in a prompt and timely manner.
- Continue to assist consumers who are eligible for services by answering questions, assist with completing paperwork, and provide help navigating the complex social insurance and social service system.

4. Options Counseling (OC)

The ADRC Options Counseling program is clearly providing important and valued services. Sixty-four percent of OC recipients reported receiving a home visit. Wait times for the home visits have increased, although most participants reported that wait times were reasonable. Most consumers reported the visit had been very helpful in addressing their concerns and that they were very comfortable with the person who came to their home. The person who came to their home typically identified additional types of help that could be provide and participants generally agreed with the assessment. Participants reported the visit had been helpful.

Those with home visits were significantly more likely to get all of the information they needed. Additionally, they reported more needs, used significantly more services, rated outcomes more positively, and were generally positive about the assistance they received in understanding the service system.

The ADRC was rated as good or excellent in helping consumers to explore choices, and excellent in supporting their decisions, meeting these benchmarks as well. The majority of participants indicated that the ADRC is doing a good or excellent job of considering their opinions, and likes and dislikes before recommending services, key indicators of a person-centered approach to service. Half of participants reported they had total control of making decisions about what to do next. Those with confusion or memory loss were significantly less likely to report being in control.

Assisting consumers to develop actions plans is among the professional standards for Options Counselors. Over half of the participants reported receiving this service. More consumers reported receiving a follow-up call in 2015 than in the previous two years. Half of participants reported that they had contacted the ADRC again.

Several indicators of positive outcomes are included in the survey. Overall, these measures indicate that the ADRC is meeting its goals of supporting people in the least restrictive environment. Below are the 2015 responses to the following statements:

- *The services or information have allowed me [my family member] to **live in the place I [he/she] most desire.*** 38% strongly agreed, 45% agreed.
- *I am [my family member is] **receiving enough support to meet my needs and preferences.*** 29% strongly agreed, 42% agreed.
- *I believe that I am [I believe that my family member is] **more independent** as a result of the information and services I received.* 29% strongly agreed, 47% agreed.
- *I believe I am [I believe that my family member is] **safer in my home** as a result of the information and services I received.* 34% strongly agreed, 42% agreed.
- *The services or information received has allowed me [my family member] **to expand or maintain activities outside of my [her/his] home.*** 23% strongly agreed, 40% agreed.
- *The services or information received have helped **make the most of personal money and resources.*** 18% strongly agreed, 48% agreed (Family members gave significantly more positive ratings than consumers).
- *I was eventually able to **find help that I could afford** [My family member was eventually able to find help that she/he could afford].* 24% strongly agreed, 43% agreed.

Qualitative responses strongly support the value of the ADRC for these participants. The majority ADRC consumers and their family members say their circumstances would have been worse or much worse without the ADRC. This includes having more difficulty meeting basic health and ADL needs, being worse off financially, and being more distressed emotionally.

Recommendations include:

- Continue to make home visits a priority.
- Continue to decrease the wait time for OC home visits. It is likely that consumers receiving OC services have support needs that are more urgent.
- Options counselors are doing an excellent job in providing decision support. Continue to provide and expand person-centered support to consumers in exploring choices, considering their opinions, likes and dislikes, and supporting consumer decisions.
- Approximately one-third of those receiving OC services reported not having an action plan. Identify reasons for this (e.g., timing of the interviews, consumer decision) and strengthen this aspect of the program.

- Increase follow-up calls with consumers to determine whether additional information and support are needed.
- Although well over two-thirds of consumers indicate that they a) have support to meet their needs and preferences, b) are more independent, c) are safer, and d) have preserved their resources, this doesn't achieve many of the higher standards set during year 2 of the ADRC program. Whenever possible, increase the number of consumers who are receiving enough support so that they are able to live more independently and safely in their homes.
- A significant number of consumers are unable to locate affordable services. Increase efforts (e.g., increase access, expand eligibility, create more public/private partnerships) to assist these individuals in finding services that fit their budgets.

Part 5. Public Programs and Assistance

The services described in this report addressed the importance of streamlined eligibility determination for public programs. All participants – both Call Center and OC consumers – were asked what decisions they had made after their contact with the ADRC, and whether these decisions resulted in receiving services. Some participants had not yet made decisions and others were in the process of seeking and obtaining services. Consumers who reported making decisions to seek services in 2015 increased from 2014, and most indicated the ADRC support they received was somewhat helpful or very helpful.

When read a list of 10 services, 140 (43%) of participants reported receiving one or more of those services. Many of these participants received more than one service; the average number was 2.48. About 25% received 4 or more services, an increase over prior years. Consistent with previous surveys, Options Counseling participants received significantly more services, averaging 2.90 services compared to the average of 1.98 services reported by Call Center participants. Over all rounds of surveys, participants reported receiving fewer services than reported needing assistance.

Service use increased for housekeeping services, information to manage health, and transportation services. Transportation services use showed the greatest increase. The number of participants who reported receiving financial assistance decreased slightly from 2014.

Timeliness of services were rated positively. The most marked improvement was in timeliness of receiving a return phone call when they first contacted the ADRC. Improvements in promptness of services (compared to Round 4) also were found for seeing someone at the ADRC building and meal services. In contrast, participants reported

increased wait times for help getting benefits, transportation, managing health, and personal care services.

Recommendations include:

- Continue efforts to eliminate the gap between needs and services.
- Increase capacity to provide housekeeping services, home modifications, transportation, health management support, and financial services.
- Continue efforts to return consumers' calls and provide services a timely manner.

Part 6. Confusion and Memory Loss

Although confusion and memory loss (CML) has been listed as a possible reason for contacting the ADRC in all rounds of data collection, participants were asked explicitly in 2014 (Round 4) if they or their family member had experienced more or worse confusion or memory loss during the past 12 months. If they said yes, they were asked if they or the family member they were calling about had a diagnosis of Alzheimer's disease.

In 2015, more consumers and family members reported an issue with confusion or memory loss (CML) than participants did in 2014. This may be explained by the greater proportion of participants who were receiving OC services (42% in 2015, compared to 34% in 2014). This may also be a result of extensive outreach efforts to reach this population in recent years. Those with CML were more likely to have OC services with home visits. Thirty-five of those in the CML group (30%) had received a diagnosis for Alzheimer's disease, an increase over 2014. We do not know whether others without a diagnosis had been assessed for cognitive impairment. Presence of a diagnosis of Alzheimer's disease was not related to service use.

As in 2014, family members were more likely to report a CML issue than consumers; 2/3 of family members surveyed indicated they contacted the ADRC because of CML and/or that they had observed increasing difficulties with CML over the past year, compared to about 1/3 of the consumers. The greatest numbers of those with CML issues came from the consumer group. This is not surprising given that almost 75% of the total sample was composed of consumers.

The CML group, especially consumers, identified more needs overall than the no-CML group. The CML group also called to get general information and caregiver respite at higher rates than the no-CML group. This was true for both family and consumers. Most differences between CML and no-CML responses, however, were accounted for by consumers. For example, consumers (but not family members) in the CML group were more likely to be calling about physical health, personal care, or for assistance moving into residential care. They were also more likely to report learning about the ADRC from another agency or that someone from the ADRC contacted them first. This likely reflects high levels of physical and cognitive impairment in the people family members were supporting. Consumers in the CML group were significantly less likely to feel they were in total control of their decisions, but they were more likely to report that someone from the ADRC helped them develop a plan listing their own goals and next steps.

In spite of these differences, the two groups had more similarities than differences. With the exception of OC, the numbers and types of services actually received reported by participants was similar for the CML and no-CML groups. The two groups gave similar ratings with respect to the timeliness of receiving services and the helpfulness of those services. Most responses to questions about staff attributes, decision support, and outcomes (including

assessments of what their circumstances would be without the ADRC), and overall satisfaction were also similar.

Recommendations include:

- Be prepared to talk with consumers and especially family members about confusion and memory loss.
- When those calling the ADRC have specific questions about confusion and memory loss, encourage them to obtain a complete medical checkup.
- Be knowledgeable about person-centered support services for people with dementia.
- Incorporate questions about confusion and memory loss into conversations with those who contact the ADRC. Ask if there has been a diagnosis of Alzheimer's disease (AD) or a related disorder and encourage those who haven't to talk with a healthcare provider about their confusion and memory loss.
- Prioritize options counseling for those who report CML (include both consumers and their family caregivers), especially if they have a diagnosis of AD or a related disorder.
- Explore reasons why those with CML generally, and those with a diagnosis of AD specifically, are not getting more services than those without CML. Many needs identified were for ADL, IADL, caregiver respite, and assistance with transition to residential care settings. Identify gaps in services that need to be addressed to assure that those with CML get those services in a timely way.
- Maintain and enhance efforts to develop action plans and follow up with those with CML. Continue to help those with CML to complete paper work for services. Consider additional resources which simply and clearly provide information and direction to those with CML so that they know what they can do to get help if needed.
- Continue to listen, provide person-centered decision support, and share knowledge with this population regardless of their cognitive status.

Part 7. Consumer Recommendations and Overall Satisfaction

All participants were asked if they had concerns that had not been addressed by the ADRC and 25% did, a consistent response over time. When asked about those concerns, about one-third of those with concerns indicated a general need for services and resources. Many others expressed frustration with the lack of follow-up and other issues related to customer service.

Similar to previous ADRC reports, participants described specific needs related to the original reasons for their contact with the ADRC. Many participants reported needing help with transportation, housing, health concerns, and help with Instrumental Activities of Daily Living (IADLs). Of those, approximately 28% expressed financial needs, while others required assistance with discovering available resources, and identified the need for increased eligibility and funding sources for services.

Participants offered suggestions and comments for ways to improve ADRC services. These included making ADRC contact information easier to locate, improving staff knowledge, and providing a more convenient location for the ADRC building. Many expressed the desire for more services, improved coordination and quality of services, expanded eligibility and funding, and additional staff to manage what some perceive to be an unreasonable workload. Participants reported a need for calls to be returned in a more timely manner. Some requested more assistance accessing and navigating the service system to locate available resources. Still others suggested the ADRC staff behave more respectfully, and show more empathy when providing support to consumers and their families.

The ADRCs continues to provide important services and access to resources that are valuable to consumers and their family members. The importance of Call Center and OC staff cannot be overstated. Positive ratings of staff are most strongly associated with overall satisfaction with the ADRC. For OC consumers, who have greater overall need and represent the most vulnerable consumer group, the association is particularly striking. Positive ratings of OC staff are associated with higher scores on receiving needed information, levels of understanding of the service system, and outcomes. A similar pattern is seen with ratings of Call Center staff and measures of understanding and receiving information, although the association is not quite as strong. Note that Call Center consumers were not asked questions about outcomes.

Although a minority of ADRC consumers had concerns or areas of dissatisfaction, it is important to use their feedback in quality improvement efforts. Talking to a person, and receiving information and assistance in a timely manner are critically important to older adults and those with disabilities, especially those with cognitive impairment. Continued efforts are needed to help these consumers understand and navigate the system.

ADRCs need to continue promoting ways to increase awareness and provide access to the ADRC, build capacity to meet the growing demand for resources, and to address concerns of consumers who are not able to locate and afford services that meet their needs. This includes increasing and coordinating community partnerships, increasing follow up, continuing to decrease response times, and continuing staff development.

Recommendations include:

- Continue to improve customer service where needed through staff training and mentoring.
- Continue to build skills and resources to communicate with consumers who may have limited capacity to understand the service system.
- Continue to build partnerships, coordinate services, and expand service availability. Widely distribute print material that provides information about the ADRC including telephone and internet contact information.
- Continue the good work of respecting consumers, providing person-centered decision support, and contributing a vital service.