Final Report 2019

Consumer Satisfaction with the Aging & Disability Resource Connection of Oregon: Round 6

Part 1: 2019 Survey Participants

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Consumer Satisfaction with Aging & Disability Resource Connection (ADRC) Services: Round 6

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Part 1. Introduction and 2019 Survey Participants

This first section of the 2019 (Round 6) ADRC consumer satisfaction report describes revisions to the ADRC Consumer Satisfaction survey, the methods used to conduct the evaluation, the sample characteristics of those interviewed, and the needs they identified as reasons why they contacted the ADRC. This is the sixth consumer satisfaction survey conducted by Portland State University (PSU) and follows the Round 5 survey conducted in 2015. The survey instrument can be found in Appendix A. The tables referred to in this report are presented at the end of this section, and in Appendix B. Many tables include comparisons of findings across the six rounds of data collection as well as tables featuring findings from new questions added to the Round 6 survey. This project was approved by the PSU Institutional Review Board.

Measures

Several new questions were added to the survey in 2019 (See Table 1.1 on the following page). These changes were made in response to recommendations from the consultants from Compelling Reason who had been hired to develop a business case for the ADRC and calculate the return on investment. In addition, new questions addressed ADRC services that had not been covered adequately in prior surveys (e.g., specific information about health promotion activities and services). New items were discussed by PSU project staff, representatives from

Table 1.1. Changes to the Survey in Round 6

New Questions

- Reasons for contacting the ADRC. Worries about:
 - o Getting medical equipment or assistive devices
 - Eviction or homelessness
 - o Falling
 - Abuse or neglect (including specific types of abuse)
- Services received to address:
 - Abuse or neglect
 - Housing to prevent eviction or homelessness
 - Fall prevention classes (with specific types of classes listed)
- Outcomes—As a result of the ADRC:
 - o I am less likely to fall
 - o I am less likely to move into a nursing home
 - o I am at less risk of abuse or neglect

Question with a New Format: Circumstances without the ADRC

- I would not have the information I need to get help
- I would be stressed about not knowing what to do
- I would not have had the help I need
- I could not meet my basic needs
- I would be more isolated from the community
- My medical condition would be worse
- I would be in a nursing home
- I would be dead
- I would be worse off financially
- I would be homeless
- It would be no different
- I would be better off

Compelling Reason, Community Services and Support staff, and Business Case Steering Committee. In addition, we quantified a question that had been asked previously only as an open-ended question: What would your circumstances be without the ADRC? The major themes were listed based on data from prior years and each person was asked to indicate their agreement with the statements (yes/no).

Other items were
eliminated so as not to add
burden to the participants.
Previous surveys averaged
about 20 minutes and we
wanted to keep the length
of the survey within this
range. The group jointly
agreed on questions to
eliminate, including how
participants learned about

the ADRC, whether they used the website, and whether they visited the ADRC

building. In spite of these changes to the survey, most of the Round 6 survey questions remained the same as those in previous years.

Sample Selection

As in previous surveys, two groups were targeted: those only using ADRC Call Center services and recipients of Options Counseling (OC) services. The Call Center sample was selected from a random sample of ADRC Call Center consumers stratified by region and consumers from all Centers for Independent Living (CIL). The consumers sampled had been in contact with the ADRC Call Center from January 25 – February 8, 2019 (n=2,468). At the time the sample was drawn, none of these individuals had received Options Counseling services. The two-week window was used so that participants would be interviewed within one month of their contact with the ADRC. This decision was made after earlier survey rounds when it became apparent that many Call Center participants had difficulty recalling their specific ADRC experiences after one month.

The OC sample consisted of everyone who had used Options Counseling services between December 26, 2018 and March 12, 2019 (N=475). This longer time frame was used for OC consumer interviews because fewer consumers receive OC services and the largest sample possible was needed to reach the goal of 135 completed interviews. In addition, fewer consumers were in the OC sample received than in the past. For comparison, the total OC sample received in 2015 was 636. Furthermore, because OC consumers generally have more frequent or intensive contact with the ADRC than Call Center consumers, more confidence can be placed in OC consumer survey responses over the two and a half-month window.

The sampling frame is presented in Table 1.2¹. The goal for Call Center consumers was 190 completed interviews stratified to represent the ADRCs and

¹ Tables 1.2 – 1.8 are at the end of this report; all tables are presented in Appendix B

CILs across the state; all CILs in Oregon were included. Targets were not reached for CILs; only three names were received and none could be interviewed. In addition, targets of 13 completed interviews were not met in four ADRCs (Central Oregon, Douglas County, South Coast, or Eastern Oregon). However, the overall sampling goal was met by oversampling for Lane, NW Senior & Disabled Services, and the Metro ADRCs. The Metro ADRC sample was significantly larger than in previous years. As a result, only a segment of those interviews are included in this report to make results more comparable to previous rounds. The Metro sample included in this report was selected randomly from all the completed interviews.

The goal for the OC consumer sample of 135 was not met. The target number reflected the number of OC consumers interviewed in 2015, but only 80 interviews were completed in this round. This is a result of the smaller sample received from the ADRC program (see Table 1.2). One reason for the smaller sample is that only those who were enrolled and had been in contact with the Options Counselor were included in the sample. In previous years, all of those actively enrolled were included, regardless of whether or not they had been in contact with the Options Counselor.

Interview procedures

Telephone interviews were conducted by the Social & Economic Sciences Research Center at Washington State University. Interviews were conducted between February 27 and April 5, 2019. Interviews averaged about 26½ minutes, more than five minutes longer than previous surveys, reflecting the addition of the new questions. Of the 2,867 unduplicated numbers received from the ADRC program, 1,104 were deemed to be appropriate numbers (38%). This means that when the number was called, a contact was made. Interviews either were completed, partially completed or an interview was not conducted. The completion or partial completion rate was 36%. Reasons for not conducting the interview were due to refusal (n=314; 28% of appropriate numbers), contact with the ADRC-named person was not made (n=196), the person was not available for the interview (n=7), the person had died (n=22), they were physically or cognitively unable to participate in an interview (n=23), or there was a language problem $(n=40)^2$.

It is unknown whether some numbers were connected to the ADRC consumers because in spite of multiple calls, no contact was made (n=1100; 38%). This included phones with answering machines only (n=836), no answer (n=105), call blocking (91), or regularly busy (n=63).

Other numbers were inappropriate numbers (24%); that is, the numbers were not connected to an ADRC consumer. The largest categories for ineligible numbers were no eligible respondent in the household (n=275), nonworking numbers (n=111); numbers had changed (n=90), and disconnected numbers (n=77).

The final options counseling sample was 80 completed and 13 partially completed interviews. After adjusting for the oversampling of the Metro ADRC, the final Call Center sample described in this report is 239 completed interviews and 34 uncompleted interviews. Each table contains the number of participants who answered the specific questions addressed in the table.

Sample Characteristics

Of the 367 participants in this sample, 250 (78%) were consumers of services, defined here as the direct recipient of services. This is a similar percentage reported in previous years. The remaining 22% was made up of 69 family members (Table 1.3).

² The languages of those not interviewed were Spanish (14), Chinese (7), Asian not specified (5), Russian (2), Japanese (1), Somalian (1), unknown/unspecified (8).

Sample characteristics are consistent with those found in previous surveys. The majority of participants were women, although by lower percentages than in previous years (61% of consumers, 64% of family members); this is consistent with the trend for reaching more men noted in 2015. Two people, one consumer and one family member, identified themselves as gender neutral. The average age of consumers was 69 years of age compared to 64 years for family; each group was slightly older than consumers and family members in 2015. Consumer ages ranged from 27 to 95 years, with a similar age span for family (27-94 years). The median education level for consumers was "some college" and the median education level for family was an associate's degree. The median income for consumers was the \$10,000-20,000, which has been the same in all rounds of the survey. The median family income was in the \$20,000-30,000 range, considerably lower than in 2015. The sample continues to be dominated by Whites; 85% of consumers and 84% of family members. When asked whether they had concerns with memory loss, 28% of consumers and 62% of family members answered affirmatively (Table 1.3), which are larger percentages than all previous years this question has been asked.

Of those receiving OC services, 66% received a home visit (17% of the entire sample). Nearly one third of Call Center consumers (31%) also reported a home visit (23% of the overall sample). All OC consumers and family members (regardless of whether or not they received a home visit) and Call Center consumers who reported a home visit (n=167) were administered a long version of the survey which included questions about home visits, decision support and perceived outcomes related to their involvement with the ADRC (Table 1.4).

Needs

Participants were asked to describe why they had come into contact with the ADRC. The interviewer then read a list of 20 possible reasons, including the four new items about concerns with housing, falls, abuse or neglect, or help with medical equipment and they were asked if any of these had been a reason why they contacted the ADRC.

Patterns of need were similar to or higher than those found in previous rounds (Table 1.5). In 2019, higher percentages of participants indicated needs related to energy bills, help with medications, and physical health needs. With respect to the new items, 128 participants (40%) indicated concerns about falls, 102 (28%) needed assistance with getting new medical equipment or assistive devices, 70 (20%) had concerns about eviction from housing or homelessness, and 35 (10%) had concerns about abuse or neglect. As shown in Table 1.5, the primary abuse concern was emotional abuse (88%), followed by neglect (69%), financial exploitation (57%), abandonment (47%), physical abuse (40%), and sexual abuse (22%).

The 20 people who reported worries about financial exploitation were asked how much money was at risk. Of the 16 people who responded, only a few provided specific dollar amounts, which ranged from \$200 – \$6,000. Others indicated it was "a lot of money," or "large amounts." Others said someone got "whatever they could get," "a monthly social security benefit," "my mother's home," and others were not sure. One person indicated her caregivers were stealing from her.

As in previous surveys, many participants had multiple needs. About twothirds of participants contacted the ADRC to obtain information or advice. Well over two-thirds participants (71%) indicated they or a family member had physical health needs that resulted in a need for services. Need for help at home with tasks such as making meals, housekeeping, laundry or yard work were each identified by 44% of participants and the same percentage indicated a need for personal care. The need for Medicaid assistance was reported by 40%, followed by transportation (38%), medications (36%), and help getting errands and shopping done (36%). Close to 30% of participants indicated needs related to

food stamps (28%) and confusion or memory loss (28%), Some reported needs related to paying energy bills (26%), help finding subsidized housing (20%), home modification (19%), dental care (18%), moving into residential care (15%), or "other" needs (18%). When asked what other needs they had, most of those identified fit into the categories described above.

A greater percentage of family members (81% compared to 61% of consumers), contacted the ADRC to get information or advice. In addition, family members were significantly more likely to report physical health needs, needs for personal care, getting assistance for caregivers, and moving a person into a residential care setting. Family members were also significantly more likely to report that the care recipient was experiencing confusion and memory loss. As in previous years, family members, therefore, were contacting the ADRC on behalf of a consumer who required assistance with activities of daily living (ADL), instrumental activities of daily living (IADL), and a variety of health care issues. As before, consumers were more likely to be calling about food stamps or getting assistance with energy bills.

Differences between needs identified by Options Counseling and Call Center consumers were identified. Options counseling consumers were significantly more likely than other consumers to report physical health needs, needs for personal care, and help getting shopping and errands done. Call Center consumers were significantly more likely to report needs with respect to Medicaid or paying for medical care, food stamps, and concerns with eviction or homelessness.

The number of needs was summed for each participant. Of a possible 20, the number of needs reported ranged from 0 to 20. Families reported more needs, but differences were not statistically significant. To compare needs to previous years, the original 16 areas of need were summed. In 2019, the average number of needs reported was 5.4, somewhat higher than the 4.9 needs reported in 2015.

To identify possible cognitive impairment, participants were asked: *During the past 12 months, have you experienced confusion or memory loss that is happening more or is getting worse?* Percentages of those responding affirmatively are similar to previous years, although slightly lower (Table 1.6); 28% of consumers and 62% of family. As before, families were significantly more likely than consumers to report confusion and memory loss. Of those indicating these cognitive challenges, only 4 consumers (6%) and 19 (45%) reported the consumer had received a diagnosis of Alzheimer's disease (Table 1.7). The following comments reflect participants' concerns, needs, and reasons for calling the ADRC in 2019.

To look into respite care and what kind of assistance is available for my mother.

I was having some issues finding housing. That's basically what I was looking for and they've been doing a good job looking for housing resources. They've done their best so far.

I'm getting concerned about my ability to continue limping alone. I'm losing balance I'm making mistakes like leaving the burner on and I flooded the bathroom. I'm concerned about myself and my abilities so I wanted to start looking at the option of me not living alone.

I needed help with energy assistance because they turned my lights off.

I needed some new dentures and I don't make enough to afford them.

Homeless, 77 years old, a kidney failure.

My husband has PTSD so we were looking for assistance because we were getting overwhelmed. I was trying to take care of him and a disabled child.

I was trying to see if I could get help paying bills and if so, who could help me with that.

I am 74 years old, at the time I was falling down and I wasn't able to clean house.

I had a cognitive test performed by my doctor, which showed some possible early dementia symptoms, I also get short of breath and they think that might be causing me some confusion from lack of oxygen. So I wanted to see what services that the ADRC has available if I need something in the near future.

I need to get my brother in memory care and I can't financially do it myself. My brother has Alzheimer's.

Conclusions

The 2019 sample is less representative of the state of Oregon than in 2015, with more regions of the state having few participants in the sample. Fewer options counseling consumers were recruited for this survey reflecting the smaller sample available from the ADRC program.

It is useful to compare family and consumer responses. As in past years, family members are calling the ADRC requesting support for their care recipients 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.

Questions added to the survey in 2019 reveal a sizeable number of participants who have worries about falling and need assistance obtaining medical equipment and assistive devices. One in five participants reported concerns about eviction or becoming homeless, reflecting the growing housing crisis for older adults. Not surprisingly, there is significant overlap with consumers who were seeking help finding subsidized housing and concerns with eviction or homelessness. Finally, concerns with abuse or neglect reflect some national estimates of abuse experienced by community dwelling elders.³

³ Teaster, P. B., Wangmo, T., & Vorsky, F. B. (2012). Elder abuse in aging families. In R. Bliezner & V. H. Bedford (Eds.) Handbook of Families and Aging (second edition). pp. (409-429). Praeger: Santa Barbara, CA.

Table 1.2 2019 Sampling Frame

	Sample	Sample	Actual
	Received	Goal	Completes ^a
ADRC Call Center			
Lane COG	298	19	30
NW Senior & Disability Services	626	24	67
Oregon Cascades West COG	344	24	26
Metro (Multnomah, Clackamas, Columbia, Washington)	1000	42	84 ^b
Central (Central Oregon Council on Aging)	11	13	1
South Coast	78	13	10
Rogue Valley COG	17	14	15
Douglas (DCSDS)	29	13	4
Eastern Oregon (CCNO)	62	13	2
Centers for Independent Living	3	15	0
Subtotal	2,468	190	239
Options Counseling			
Lane COG	53	13	13
NW Senior & Disability Services	30	13	4
Oregon Cascades West COG	106	13	13
Metro (Multnomah, Clackamas, Columbia, Washington)	200	37	37
Central (Central Oregon Council on Aging)	6	9	0
Rogue Valley COG	23	9	4
Douglas (DCSDS)	5	9	0
Eastern Oregon (CCNO)	26	9	5
South Coast	2	9	1
Centers for Independent Living	24	15	4
Subtotal	475	136	80
Total	2,943	326	319

^aAn additional 47 interviews were partially complete and are used in analyses throughout the report when data are available for the specific question

b119 Although oversampling has occurred in every year in the Metro area to achieve our sampling goals, the Call Center interviews completed in 2019 were nearly 3 times the goal for the Metro area. To keep the distribution comparable to other years, 84 completed interviews are included in this report.

Table 1.3 Round 6 Sample Distribution by respondent type

ADRC	Option Cou (n=82	_	Call Cer (N=23		Total sub	Total	
	Consumer	Family	Consumer	Family	Consumer	Family	
Lane COG	11	2	21	9	32	11	43
NW Senior & Disability Services	1	3	49	17	50	20	70
Oregon Cascades West COG	8	5	21	5	29	10	39
Metro (Multnomah, Clackamas, Columbia, Washington)	32	5	78	8	108	13	121
Central (Central Oregon Council on Aging)			1	0	1	0	1
Rogue Valley COG	2	2	11	4	13	6	19
Douglas (DCSDS)			2	2	2	2	4
Eastern Oregon (CCNO)	2	3	1	1	3	4	7
South Coast	1	0	7	3	8	3	11
Centers for Independent Living	4	0	0	0	4	0	4
TOTAL	61	20	189	49	250	69	319

Table 1.4 Sample Characteristics

Participants	Total Sample (N=319)							
	Consumer	•	Family					
	#	%	#	%				
Number	249	78%	68	21%				
Gender Neutral	1	.3%	1	1.5%				
Women	153	61%	50	74%				
Age	Average: 69 years Median: 69 years		Average: 64 years Median: 65 years					
Age Range	27 - 95 years		27 – 94 years					
Median Education	Some college		Associates degree					
Median Income	\$10,000 to < \$20,000	48%	\$20,000 to < \$30,000	16%				
Number/Percent White	212	85%	58	84%				
Concern about memory loss/confusion last 12 months	68	28%	43	62%				

Table 1.5 Sample by Options Counseling and Home Visit Categories

	20	12	2012		2014		2015		2019	
	20		2013		2014		2015			
	N=297	%	N=292	%	N=300	%	N=326	%	N=343	%
Options Counseling, home	57	19%	73	25%	82	27%	87	27%	59	17%
visit	37	1570	,	23/0	02	27/0	67	27/0	33	17/0
Options Counseling, no	14	5%	27	9%	19	6%	ΕO	150/	20	9%
home visit	14	J/0	21	9%	19	0%	50	15%	30	9%
Call Center consumer,	64	22%	45	1 5 0 /	7.0	250/	٦.	170/	70	220/
home visit	04	22%	45	15%	76	25%	56	17%	78	23%
Call Center consumer, no		55%	1.47	F00/	122	410/	122	410/	176	F10/
home visit	162	JJ%	147	50%	123	41%	133	41%	176	51%

Note: Not all percentages add to 100 due to rounding

Table 1.6 Reasons for Contacting the ADRC

Service Type	2012	2013	2014	2015	2019
,	N (%)				
Physical health needs ^{a,c}	161	177	188	202	258
	(54%)	(60%)	(61%)	(62%)	(71%)
General information/advice ^c	222	212	215	222	227
	(73%)	(71%)	(70%)	(68%)	(64%)
Help at home (making meals, housekeeping,	113	103	147	143	159
laundry, yard work) ^a	(37%)	(35%)	(48%)	(44%)	(44%)
Personal Care ^{a,c}	87	95	126	117	156
	(29%)	(32%)	(41%)	(36%)	(44%)
Medicaid or paying for medical care ^b	104	100	118	122	143
	(35%)	(34%)	(39%)	(37%)	(40%)
Falls	_	_	_	_	128
- uns					(40%)
Transportation ^a	99	92	114	116	139
Transportation	(33%)	(31%)	(37%)	(36%)	(38%)
Help getting shopping and errands done ^a	53	68	108	98	128
Theip getting shopping and entands done	(18%)	(23%)	(35%)	(30%)	(36%)
Medications	78	73	80	73	132
Wiedications	(26%)	(25%)	(26%)	(23%)	(36%)
Food stamps ^{b,d}	105	80	90	95	105
Tood stamps	(35%)	(27%)	(30%)	(29%)	(29%)
Confusion or moment loss ^{3,0}	74	71	69	84	102
Confusion or memory loss ^{a,c}	(25%)	(24%)	(23%)	(26%)	(28%)
Help getting new medical equipment or					102
assisted devices	-	-	_	-	(28%)
E Bill d	64	47	58	60	93
Energy Bills ^d	(21%)	(16%)	(19%)	(18%)	(26%)
	62	70	52	61	82
Help getting caregiver support or respite ^c	(21%)	(24%)	(17%)	(19%)	(23%)
Frieties frame annual bears and bears and					70
Eviction from current home or homelessness d	_	-	-	-	(20%)

Service Type	2012 N (%)	2013 N (%)	2014 N (%)	2015 N (%)	2019 N (%)
Help with housing: finding subsidized	50	57	36	58	72
housing ^d	(16%)	(19%)	(19%)	(18%)	(20%)
Dontal care	58	31	53	49	66
Dental care	(19%)	(10%)	(17%)	(15%)	(18%)
Halp with housing, home modification	50	41	39	45	69
Help with housing: home modification	(17%)	(14%)	(14%)	(14%)	(19%)
Help moving into residential care ^c	36	42	33	47	53
Help moving into residential care	(12%)	(14%)	(14%)	(14%)	(15%)
Abuse or neglect					35
Abuse of fleglect	_	1	1	1	(10%)
Did you contact ADRC to get help with	57	43	37	57	60
anything else that we did not already cover?	(19%)	(15%)	(12%)	(17%)	(18%)

^aOptions counseling consumers significantly more likely than call center consumers to report this need (p<.05)

Table 1.7 Areas of abuse or neglect that are of concern

Туре	2019 N (%)
Physical abuse	14 (40%)
Emotional abuse	30 (88%)
Financial exploitation*	20 (57%)
Sexual abuse	7 (22%)
Neglect	22 (69%)
Abandonment	15 (47%)

^bCall center consumers significantly more likely than options counseling consumers to report this need (p<.05)

^cfamily members significantly more likely than consumers to report this need (p<.05)

dconsumers significantly more likely than family members to report this need (p<.05)

Table 1.8. During the past 12 months have you experienced confusion or memory loss?

	Consumer				Family/Friends				Total			
	2013	2014	2015	2019	2013	2014	2015	2019	2013	2014	2015	2019
	(n=69)	(n=218)	(n=231)	(n=244)	(n=25)	(n=80)	(n=85)	(n=69)	(n=94)	(n=298)	(n=316)	(n=313)
Yes	20	64	69	68	12	45	54	43	32	109	123	111
	(29%)	(29%)	(30%)	(28%)	(48%)	(56%)	(64%)	(62%)	(34%)	(37%)	(39%)	(36%)

Note: In 2013 only OC consumers and family were asked this question; in subsequent years all have been asked this question. In all years, family members were significantly more likely to report confusion or memory loss than consumers.

Table 1.9 Have you received a diagnosis of Alzheimer's disease?

	Consumer			Fan	nily/Frie	nds	Total			
	2014 (n=64)	2015 (n=66)	2019 (n=67)	2014 (n=44)	2015 (n=53)	2019 (n=42)			2019 (n=109)	
Yes	8 (12%)	9 (14%)	4 (6%)	18 (41%)	26 (49%)	19 (45%)	26 (23%)	35 (29%)	23 (21%)	

Note: in all years, family/neighbors were significantly more likely to report a diagnosis of Alzheimer's disease than consumers.