

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

Part 6. Confusion and Memory Loss: The ADRC Experience

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

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Part 6 of the ADRC consumer satisfaction survey report focuses specifically on comparisons between participants who indicated they or a family member had an issue with confusion or memory loss (CML) and those who did not. This focus was added in Round 4 (2014). Having CML concerns is a combination of responses to two questions: CML as reason for contacting the ADRC and experiencing increasing CML in the past 12 months. As shown in Table 6.1¹, the percentages responding “yes” to either or both questions was similar to or the same as responses in Rounds 4 and 5. A higher percentage of participants in Round 6, however, than in previous years indicated CML was a reason for contacting the ADRC; this percentage of affirmative responses has increased steadily over the past three surveys. Consistently, about one-third of participants have reported that they or a family member has experienced increased confusion or memory loss over the past 12 months. Those who reported they had experienced more CML were asked whether they had received a diagnosis of Alzheimer’s disease (AD). Twenty-three participants, just 18% of the CML group, reported a diagnosis of Alzheimer’s disease. This percentage is similar to that reported in 2014, but significantly lower than in 2015. The severity, cause, and anticipated progression of memory loss of the vast majority of those reporting CML in Round 6, therefore, is unknown.

Participant Characteristics

As displayed in Table 6.2, the CML and no-CML samples were similar in terms of age and gender, although participants in the CML sample had an older age range and consumers with CML were less likely to be women. Median education and income levels were similar for consumers regardless of whether or

¹All tables presenting Round 6 data are at the end of this report and in Appendix B.

not they were experiencing CML. Family members of those without CML on average had more education and lower incomes than family members of those with CML. Participants for all groups were predominantly White, although the no-CML group, especially family members, were somewhat more diverse. As in previous years, family members were much more likely to report concerns about CML than consumers were to describe themselves having CML issues. Seventy percent of family members reported CML concerns compared to 35% of consumers and 70% in 2015.

Consumers and family members reporting CML concerns were somewhat more likely to report receiving a home visit, regardless of whether or not they received options counseling (OC). These differences, however, were not statistically significant. Eight, or about one-third, of those with an Alzheimer's or dementia diagnosis received OC services; five received a home visit as part of OC services and three did not. Another five (22%) Call Center participants, who were all family members, reported having a home visit. Ten of those with a diagnosis of Alzheimer's disease (about 43%) were not OC participants nor did they receive home visits at the time of the survey. Note that the total numbers in Table 6.3 do not match the total numbers in Table 1.4 (see Appendix B) because not all participants answered questions about CML. The distribution of responses, however, is virtually the same.

Needs. Sixteen reasons for contacting the ADRC were identified from open-ended questions during the first round of interviewing in 2011-2012. As described in Part 1, four additional reasons were added in 2019. All of these are listed in Table 6.4 and provide an indicator of need among those who reach out to the ADRC. Participants in the CML sample reported nearly twice the number of needs (average = 8.21) than those without CML (average = 4.56). Although those with CML concerns have consistently reported more need, the level of need reported in 2016 is considerably higher in Round 6. Most of the differences in need between the two CML groups are explained by consumer rather than family responses. At the same time, those family members with concerns about CML

were also significantly more likely to identify needs for personal care and caregiver respite than family members without CML concerns.

Services. Consistent with need, those with CML received significantly more services than those without CML concerns, with an average of 3.25 compared to 2.13 services. With respect to specific services, those with CML concerns were significantly more likely to receive personal care, housekeeping, information about managing health, and services to prevent eviction or homelessness than those without CML concerns.

Decision Support, Outcomes, and Circumstances without the ADRC.

Decision support ratings were similar for those with and without CML concerns. Both groups found staff to be helpful in listening to their needs, providing information needed to make decisions, helping to explore options, and supporting decisions made by the consumer. Both groups also reported greater understanding of the social services system after working with staff from the ADRC. Consistent with previous years, significant differences were found with respect to control over the decision making process. Those with CML reported that they had less control in making decisions than those without CML concerns.

No significant differences were found in participant-reported outcomes between the two groups (Table 6.5). Although mean scores were typically lower for the CML versus the no-CML group, none reached statistical significance. A different pattern emerges with questions about what their circumstances would have been without the ADRC (Table 6.6). Consumers also report their medical condition would be worse, they could not meet their basic needs, would be more stressed, and they would be more isolated from the community. It is interesting to note that both family members and consumers with CML concerns were significantly more likely to agree that they or their family member would be dead without the ADRC.

Consumer Recommendations and Overall Satisfaction

Those with CML concerns reported that the ADRC had been somewhat helpful, though this is significantly lower rating than those without CML who were more likely to report the ADRC had been very helpful. Thirty-six people (12%) of the total sample indicated that they would not recommend the ADRC to a friend or family member. Almost all of these individuals were consumers and over half of these participants were in the CML group.

Conclusions and Recommendations

The same percentages consumers and family members reported an issue with confusion or memory loss (CML) in 2019 as did in 2015. As in previous years, family members were more likely to report a CML issue than consumers; over two-thirds 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 one-third of the consumers. The greatest numbers of those reporting CML issues came from the consumer group. This is not surprising given that more than 75% of the total sample was composed of consumers.

Those with CML have greater needs and are more vulnerable than consumers without CML. Even more than in 2015, Round 6 consumers with CML reported significantly more service needs than those without CML. Those with CML concerns were likely to report receiving significantly more services (3.24 compared 2.13) than those without CML. However, the patterns of OC service use were different in Round 6. Those with CML were no more likely to receive OC services or home visits than those without CML. Fewer people reporting CML concerns also had a diagnosis of Alzheimer's disease in 2019.

The CML group, especially consumers, identified more needs overall than the no-CML group. The CML group called the ADRC for help with personal care and caregiver respite at significantly 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. Consumers in the CML group were significantly less likely to feel they were in total control of their decisions.

In spite of these differences, the two groups shared similarities. In addition to OC services, 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 were also similar.

Recommendations

- 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. Emphasize the importance of a diagnosis for future planning.
- 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 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 (including 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 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 and appropriate to their cognitive status.

Part 6. Confusion and Memory Loss: The ADRC Experience

Table 6.1. Participants reporting Confusion or Memory Loss (CML)

	CML – reason for contacting ADRC <u>and/or</u> CML increased over 12 months	CML as reason for contacting the ADRC^a	CML happening more^a	Alzheimer’s or related dementia diagnosis	CML, but cause unknown
2014	n=123; 41% of all participants	n=64 (52% of CML group)	n=108 (88% of CML group)	n=26 (21%)	n=97 (79%)
2015	n=138; 44% of all participants	n=78 (56% of CML group; 25% total sample) 17 said yes to this, but not to CML happening more	n=121 (88% of CML group; 38% of total sample) 60 said yes to happening more, but not need	n=35 (30% of CML group) 11% of total sample	n=83 (70% of those with need or observed)
2019	n=142; 44 % of all participants	n=102 (72% of CML group; 28% total sample) n=23 said yes to this, but not to CML happening more	n=120 (71% of CML group; 36% total sample) n=48 said yes to happening more, but not need	n=25 (18% of CML group) 7% of total sample	n=117(82% of those with need or observed)

Table 6.2. Sample Characteristics Related to Confusion or Memory Loss – 2019

Circumstances	Total Sample (n=308) ^a			
	Confusion or Memory Loss (n=131)		No Confusion or Memory Loss (n=177)	
	Consumer	Family	Consumer	Family
Number	83	48	156	21
Women	40 (48%)	33 (70%)	105 (67%)	17 (81%)
Mean Age ^b	69	65	70	61
Age Range	32-95	37-94	27-95	27-89
Median Education	Some college or post-secondary education	Associates or technical degree	Some college or post-secondary education	Some college or post-secondary education
Median Income	\$10,000 - < \$20,000	\$40,000 - < \$50,000	\$10,000 - < \$20,000	\$20,000 to < \$30,000
Number/Percent White	74 (89%)	42 (88%)	128 (82%)	16 (76%)

^a Participants from the total sample who did not answer both questions related to confusion or memory loss and are not included in these analyses.

Table 6.3. Sample by Options Counseling and Home Visit Categories - 2019

	Confusion, Memory Loss		No Confusion, Memory Loss		Total N (%)
	Consumer (n=81)	Family (n=46)	Consumer (n=152)	Family (n=21)	
Options Counseling, home visit	#17 (21%)	7 (15%)	23 (15%)	4 (19%)	51
Options Counseling, no home visit	8 (10%)	6 (13%)	11 (7%)	2 (10%)	27
Call Center consumer, home visit	17 (21%)	16 (35%)	28 (18%)	4 (19%)	65
Call Center consumer, no home visit	39 (48%)	17 (37%)	90 (59%)	11 (52%)	157
Total	81 (100%)	46 (100%)	152 (99%)	21	300

Note: Percentages do not add to 100% due to rounding. Those with CML were more likely to receive OC services or home visits, but these differences were not statistically significant.

Table 6.4. Reasons for Contacting the ADRC (Needs)

Service Type	2014		2015		2019	
	Confusion, Memory Loss (n=123)	No Confusion, Memory Loss (n=174)	Confusion, Memory Loss (n=138)	No Confusion, Memory Loss (n=171)	Confusion, Memory Loss (n=142)	No Confusion, Memory Loss (n=177)
General information/advice ^a	92 (75%)	117 (68%)	109 (80%)	103 (59%)	104 (75%)	104 (57%)
Physical health needs ^a	81 (66%)	99 (57%)	40 (29%)	76 (43%)	110 (78%)	118 (64%)
Help at home (making meals, housekeeping, laundry, yard work) ^a	68 (55%)	72 (41%)	73 (53%)	65 (37%)	77 (55%)	61 (34%)
Help getting food stamps	29 (24%)	58 (34%)	28 (20%)	62 (36%)	36 (26%)	59 (32%)
Help with Medicaid or paying for medical care	50 (41%)	64 (37%)	58 (43%)	59 (34%)	61 (44%)	66 (36%)
Help with personal care ^{a,b}	62 (50%)	56 (32%)	65 (47%)	47 (27%)	84 (60%)	52 (28%)
Help with transportation ^a	56 (45%)	56 (32%)	54 (39%)	58 (33%)	71 (51%)	50 (27%)
Help with medications ^a	20 (27%)	38 (27%)	36 (26%)	35 (20%)	64 (45%)	54 (29%)
Help paying for energy bills	23 (19%)	34 (20%)	15 (11%)	41 (24%)	38 (27%)	45 (25%)
Help getting caregiver respite ^{a,b}	28 (23%)	24 (14%)	43 (32%)	14 (8%)	48 (34%)	24 (13%)
Dental care ^a	25 (20%)	28 (16%)	18 (13%)	29 (16%)	34 (24%)	23 (13%)
Help getting shopping and errands done ^a	52 (42%)	50 (29%)	49 (36%)	43 (25%)	69 (49%)	45 (24%)

Service Type	2014		2015		2019	
	Confusion, Memory Loss (n=123)	No Confusion, Memory Loss (n=174)	Confusion, Memory Loss (n=138)	No Confusion, Memory Loss (n=171)	Confusion, Memory Loss (n=142)	No Confusion, Memory Loss (n=177)
Help with housing: home modification ^a	20 (16%)	18 (10%)	21 (15%)	21 (12%)	35 (25%)	25 (14%)
Help with housing: Finding subsidized housing ^a	17 (14%)	19 (11%)	28 (20%)	27 (15%)	35 (25%)	31 (17%)
Help moving into residential care ^b	21 (17%)	11 (6%)	30 (22%)	15 (9%)	33 (23%)	14 (8%)
Getting medical equipment or assistive devices ^a	-	-	-	-	55 (39%)	34 (19%)
Worries about eviction ^a	-	-	-	-	35 (25%)	27 (15%)
Worries about falling ^a	-	-	-	-	72 (51%)	43 (24%)
Worries about abuse or neglect ^{a, c}	-	-	-	-	22 (16%)	7 (4%)
Total number of needs (average) ^a	5.94 (out of 16)	4.48 (out of 16)	5.81 (out of 16)	4.20 (out of 16)	8.21 (out of 20)	4.56 (out of 20)

^a Consumers with CML concerns were significantly more likely to report these needs than consumers without CML in 2019; ^b Family members with CML concerns were significantly more likely to report these needs than family members without CML concerns. ^c Consumers with CML concerns rated concerns about neglect significantly higher than other areas of concern within the abuse/neglect categories.

Table 6.5. Outcome measures

	2014		2015		2019	
	Confusion, Memory Loss (Mean, SD)	No Confusion, Memory Loss (Mean, SD)	Confusion, Memory Loss (Mean, SD)	No Confusion, Memory Loss (Mean, SD)	Confusion, Memory Loss (Mean, SD)	No Confusion, Memory Loss (Mean, SD)
The services or information received have allowed me to live in the place I most desire.	3.04 (.916)	3.20 (.741)	3.17 (.862)	3.14 (.807)	3.04 (.836)	2.90 (.907)
I am receiving enough support to meet my needs and preferences	2.72 (.974)	2.97 (.738)	2.90 (.954)	2.94 (.842)	2.65 (.893)	2.87 (.833)
I believe I am more independent as a result of the information and services I received	2.67 (.928)	3.04 (.752)	2.95 (.917).	3.03 (.772)	2.80 (.884)	2.97 (.770)
I believe I am safer in my home as a result of the information and services I received	3.03 (.903)	2.97 (.694)	3.08 (.884)	3.04 (.835)	2.93 (.822)	3.03 (.734)
The services or information received have allowed me to expand or maintain activities outside of my home	2.57 (.947)	2.73 (.775)	2.75 (.940)	2.87 (.767)	2.54 (.854)	2.70 (.754)
The services or information received have helped me make the most of personal money and resources	2.76 (.806)	2.73 (.725)	2.75 (.898)	2.77 (.826)	2.66 (.991)	2.55 (.872)
I was eventually able to find help that I could afford	2.85 (.923)	2.91 (.771)	2.77 (.72)	2.83 (.904)	2.57 (.963)	2.65 (.791)
I believe I am less likely to fall as result of the information and services I received	--	--	--	--	2.72 (.881)	2.62 (.922)
I believe I am less likely to move into a nursing home as result of the information and services I received	--	--	--	--	2.88 (.761)	2.73 (.961)
I believe I am at less risk for abuse or neglect as result of the information and services I received	--	--	--	--	2.85 (.755)	2.78(.815)
Average Outcome Score (new variables not included for comparison purposes)	2.51 (.825)	2.71 (.696)	2.53 (.904)	2.58 (.832)	2.64 (.733)	2.79 (.705)

Note: 1=strongly disagree, 2=disagree, 3=agree, 4 = strongly agree. No significant differences were found on these measures between participants who reported CML and those who did not. The average outcome score for 2019 does not include new items to facilitate comparison across years.

Table 6.6. Circumstances *without* the ADRC

	2019	
	Confusion, Memory Loss	No Confusion, Memory Loss
I would not have the information I need to get help	89 (68%)	120 (70%)
I would be stressed about not knowing what to do ^a	98 (76%)	112 (63%)
I would not have had the help I need	80 (62%)	113 (67%)
I could not meet my basic needs ^a	63 (51%)	61 (36%)
I would be more isolated from the community ^a	70 (56%)	68 (39%)
My medical condition would be worse ^a	60 (50%)	63 (36%)
I would be in a nursing home ^a	29 (24%)	20 (12%)
I would be dead ^a	35 (29%)	17 (10%)
I would be worse off financially	59 (50%)	85 (49%)
I would be homeless	25 (20%)	27 (16%)
It has made no difference. I would be just the same	54 (46%)	82 (49%)
I would be better off without the ADRC	8 (7%)	12 (7%)

^aThose with confusion or memory loss significantly more likely to agree with the statement