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Consumer Satisfaction with Aging & Disability Resource Connection of Oregon: Round 4

Confusion and Memory Loss: The ADRC Experience

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This is a companion report to the *Consumer Satisfaction with Aging and Disability Resource Connection of Oregon, Round 4* (2015) report that described the experiences of 306 consumers or family members who were in contact with the ADRC during a two to six week time period in the fall of 2014. This report focuses on a subset of consumers and family members who identified confusion or memory loss (CML) as a reason for contacting the ADRC (n=64) and/or indicated that they or a family member had confusion or memory loss that had been happening more or getting worse during the past 12 months (n=108). Forty-nine of those participants responded yes to both questions. In total, 123 (42%) of the Round 4 participants reported confusion or memory loss. Those who indicated they had noticed CML getting worse over the past 12 months were asked if they or their family member had received a diagnosis of Alzheimer's or a related dementia. Twenty-six participants responded yes (see Table 1). More than two-thirds of those 26 participants were family members (n=16) or friends/neighbors (n=2), and8 were consumers. For the majority of the CML sample (n=97), we do not know what condition is responsible for reports of CML. For example, we do not know whether there is an undiagnosed dementia, another medical condition, or whether these individuals are experiencing the normal cognitive declines associated with aging. Furthermore, it is also possible that people with cognitive impairment without confusion or memory loss are included in the no CML sample.

Table 1. Participants reporting CML

n=123* (42%)			
CML as reason for contacting the ADRC[a]	CML happening more[a]	Alzheimer's or related dementia diagnosis	CML condition unknown
n=64 (52%)	**n=108 (88%)**	**n=26 (21%)**	**n=97 (79%)**

[a]49 respondents answered yes to both questions

In this report we compare the ADRC experiences of the 123 participants (including consumers and family members of consumers) reporting CML to those who did not report CML (n=174)[1]. We also conducted analyses to determine whether consumers and family members in the CML participant group had similar or different responses to questions. We note in the tables and text when significant differences occurred. We also compared those reporting a diagnosis of Alzheimer's disease or dementia with those without a diagnosis, again specifying significant differences when they occurred. Please see the full report for detailed information

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[1] 9 participants from the original sample did not answer the two questions related to memory loss and are not included in these analyses.

about sampling, participant characteristics, and overall findings (http://www.oregon.gov/dhs/spwpd/pages/sua/ag-dis-resc.aspx).

Participant Characteristics

As reported in Table 2, the two samples were similar in terms of gender, age range, race/ethnicity, and education. In both CML and no-CML samples, consumers had lower household incomes than family. When calling the ADRC, family members were significantly more likely than consumers to identify CML. CML and non-CML family members' ages differed significantly; those calling on behalf of someone with CML were, on average, five years younger than family members calling on behalf of individuals without CML. As indicated in the full report (White & Elliott, 2015), half of those in the family category, which included 10 neighbors or friends, indicated the person they were calling about had CML. Although the proportion reporting a CML was lower in the consumer sample, the absolute number of consumers with CML was greater in this sample.

Table 2. Sample Characteristics

Circumstances	**Total Sample (N=297)[a]**			
	Confusion or Memory Loss (n=123)		**No Confusion or Memory Loss (n=174)**	
	Consumer	Family/Friend/ Neighbor	Consumer	Family/Friend/ Neighbor
Number	74	49	143	31
Women	81%	78%	76%	84%
Mean Age[b]	65	57	68	62
Age Range	29-92	23-80	29-92	37-87
Median Education	Some college	Some college	Some college	Some college
Median Income	$10,000-$20,000	$20,000-30,000	$10,000-20,000	$20,000-$30,000
Number/Percent White	85%	86%	89%	90%
Number/Percent reporting CML	74 (34% of consumers)	49 (61% of family)	143 (66% of consumers)	31 (39% of Family)

[a] Although the majority of those reporting CML are consumers, family, neighbors, and friends (61%) were significantly more likely to report CML than consumers (34%; p=.00).

[b] Family, neighbors, friends of people with CML were younger than family, neighbors, and friends of people without CML (p=.07).

Consumers with CML were significantly more likely to report receiving options counseling with a home visit than consumers without CML. No differences in use of Options Counseling were noted for family members of those with and without CML. Those with an Alzheimer's or dementia diagnosis were no more likely to receive Options Counseling or a home visit than others in the CML sample (Table 3).

Table 3. Sample by Options Counseling and Home Visit Categories

	Confusion, Memory Loss		No Confusion, Memory Loss		Total
	Consumer	**Family**	**Consumer (n=142)**	**Family (n=31)**	
Options Counseling, home visit	25 (35%)	8 (17%)	42 (30%)	7 (23%)	82
Options Counseling, no home visit	7 (10%)	4 (8%)	4 (3%)	2 (6%)	17
Call Center consumer, home visit	20 (28%)	18 (38%)	25 (18%)	10 (32%)	73
Call Center consumer, no home visit	20 (28%)	18 (38%)	71 (50%)	12 (39%)	121
Total	**72 (101%)**	**48 (101%)**	**142 (101%)**	**31 (100%)**	**293**

Note: percentages do not add 10 100% because of rounding.

Needs. Sixteen reasons have been identified for contacting the ADRC (Table 4). Assuming that these reasons reflect need, participants in the CML sample reported a significantly larger number of needs (average = 5.94) than those without CML (average=4.48). This was explained almost entirely by differences in self-reports between consumers with and without CML. For family members, no differences were noted in the number of reasons for contacting the ADRC between those in the CML and no-CML samples.

As shown in Table 3, CML sample participants were significantly more likely to report that help with activities of daily living (ADLs; i.e., personal care) and instrumental activities of daily living (IADLs; i.e., help at home, transportation, shopping and errands) were reasons for contacting the ADRC. This did not vary by participant type (i.e., consumer or family member). CML sample participants were also significantly more likely to be seeking caregiver respite or help in transitioning into a residential care setting (e.g., assisted living, adult foster care, nursing home). Although not statistically significant, the latter was more common when there was a diagnosis of Alzheimer’s disease. In contrast, those without CML were significantly more likely to report needing assistance with getting food stamps than those with CML.

Table 4. Reasons (Needs) for Contacting the ADRC

Service Type	Confusion, Memory Loss (n=123)	No Confusion, Memory Loss (n=174)
General information/advice	92 (75%)	117 (68%)
Physical health needs	81 (66%)	99 (57%)
Help at home (making meals, housekeeping, laundry, yard work)[a]	68 (55%)	72 (41%)
Help getting food stamps[b]	29 (24%)	58 (34%)
Help with Medicaid or paying for medical care	50 (41%)	64 (37%)
Help with Personal Care[a]	62 (50%)	56 (32%)
Help with transportation[a]	56 (45%)	56 (32%)
Help with medications	20 (27%)	38 (27%)
Help paying for energy bills	23 (19%)	34 (20%)
Help getting caregiver respite[a]	28 (23%)	24 (14%)
Dental care	25 (20%)	28 (16%)
Help getting shopping and errands done[a]	52 (42%)	50 (29%)
Help with housing: home modification	20 (16%)	18 (10%)
Help with housing: Finding subsidized housing	17 (14%)	19 (11%)
Help moving into an assisted living residence, adult foster home, or nursing home[a,c]	21 (17%)	11 (6%)
Total number of needs (average)	5.94	4.48

[a] Those with CML significantly more likely to report this need than those without CML.
[b] Those without CML more likely to report this need than those with CML (p=.06)
[c] Those with a diagnosis of Alzheimer's disease more somewhat more likely to report this need than those without that diagnosis

Pathways to the ADRC

Contact with the ADRC. No significant differences were found between CML and no-CML samples with respect to how they learned about the ADRC (see Table 5). However, within the CML sample, consumers were significantly more likely to have learned about the ADRC through a referral from another agency (32% for consumers compared to 21% for family) and Hospital/clinic/doctor/nurse (14% for consumers compared to 4% for family).

Table 5. How did you first learn about the ADRC?

	Confusion, Memory Loss (n=116)	No Confusion, Memory Loss (n=160)
Referral from another agency[a]	32 (28%)	35 (22%)
Friend	12 (10%)	24 (15%)
Hospital/clinic/doctor/nurse[a]	12 (10%)	20 (12%)
Family	14 (12%)	18 (11%)
Nursing home/assisted living	3 (37%)	3 (2%)
Phone book	--	3 (2%)
Recommendation/word of mouth	2 (2%)	2 (2%)
Brochure/flyer	6 (5%)	5 (3%)
Media/newspaper/TV/radio	1 (1%)	4 (2.5%)
Internet	9 (3%)	7 (4%)
Other (please specify)	25 (22%)	39 (24%)

[a] Within the CML sample, consumers were significantly more likely to have learned about the ADRC referrals from another agency or from health care providers than family members.

Both those with and without CML were most likely to have their first contact with the ADRC by telephone, although the percentage of those with CML was higher than for those without CML (Table 6). Significant differences were found within the CML sample between consumers reporting CML and family members. Family members (81%) were more likely than consumers (56%) to report first contact to be by telephone. Consumers with CML were more likely to go to the ADRC office (16%) than family members (4%). Consumers with CML were also more likely to report that the ADRC contacted them (19%) compared to family members (11%).

Table 6. How did you first come in contact with the ADRC?

	Confusion, Memory Loss	No Confusion, Memory Loss
By telephone[a]	77 (66%)	97 (56%)
Went to the office, in person[b]	13 (11%)	31 (19%)
They called me[b]	18 (15%)	16 (10%)
Through the website	1 (<1%)	1 (1%)
Other (please specify)	8 (7%)	20 (12%)

[a] Family members within the CML group were more likely to report their first contact was by telephone. [b] Consumers within the CML group were more likely to report their first contact involved going to the ADRC office, or receiving a call from the ADRC.

No statistically significant differences were found with respect to the phone being answered by a person or timing of a call back. However, family members of those with CML reported waiting a longer time for a call back than consumers with CML. This result is different from the overall findings in which all consumers (regardless of CML status) waited longer than the total family sample (White & Elliott, 2015).

No differences were found with respect to ever going to the ADRC building or ease of finding it. Significant differences were found in ratings of convenience of going to the ADRC, with the CML sample reporting it less convenient than the sample with no CML.

Information and Referral/Assistance (I&R/A)

Participants were asked whether the person they worked with at the ADRC spent enough time with them to understand their concerns. As reported in the full report, the vast majority answered affirmatively. No statistically significant differences were noted between CMI participants and participants with no CMI. Similarly, both groups reported receiving written materials relevant to their concerns at similar rates. Ratings of staff attributes also were similar, including those for being knowledgeable and respectful. Although positive, those in the CML group gave slightly lower ratings (p=.09)[2] for staff explanations about how to get the help or information they needed. On a 4-point scale (1=strongly disagree, 4=strongly agree), the CML sample average rating was 3.29 and the no-CML sample average rating was 3.49. It should be noted that there was a fair amount of variation in scores within each group.

Options Counseling (OC) or Home Visit Recipients

Eighty-two (67%) of the 123 survey participants in the CML sample received options counseling or a home visit (Table 2). This was a significantly greater percentage than the 50% of those with no CML (n=174; p = .00). However, those with a diagnosis of Alzheimer's disease were no more likely to receive OC or home visits than those without.

Those who received options counseling or reported that they had received a home visit were asked questions specific to home visits, their understanding about services, decision support, and perceived outcomes.

Home visits. With respect to home visits, those in the CML sample were more likely to receive a home visit than those in the no-CML sample (p=.07). Furthermore, within the CML sample, family members (88%) were significantly more likely to report a home visit than consumers (29%; p=.00). It is interesting to note how the responses from the options counseling sample versus responses from the call center sample varied. The options counseling consumers with CML were more likely to report a home visit than family members of those

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[2] p values indicate the likelihood that differences in scores between two or more groups do not occur by chance. Values of p < .05 are considered significant findings in this report. Values of p < .10, are reported because these are associations that indicate differences that the ADRC may want to track.

with CML. In contrast, for the the call center sample (i.e., no options counseling), family members of those with CML were the most likely to report a home visit. Differences regarding the presence of family members during a home visit were noted for those reporting a diagnosis of Alzheimer's disease. Consumers and family members who reported a diagnosis were more likely to have family members present during the home visit while consumers and family members who did not report a diagnosis were less likely to have a family member present during the home visit (73% compared to 45%; p = .04).

Decision Support. Significant differences were found in ratings of how much control the consumer had in making decisions (either reported by the consumer or the family member). Those in the CML sample indicated they or a family member with CML had less control than those who did not report CML.

No differences were found between CML and no-CML groups in any other ratings of OC services and staff, with overall positive ratings provided across both groups including the helpfulness of the staff, in:

- Understanding the service system
- Understanding about available options
- Exploring choices
- Having opinions, likes and dislikes considered
- Having choices supported
- Being talked into things not wanted

Action Plans and Follow-up. Overall, 60% of survey participants reported that the person from the ADRC helped them develop a plan listing their goals and next steps. Those with CML were less likely to report developing such a plan than those without (58% CML, 64% no CML), although this was not statistically significant. Those with a diagnosis of Alzheimer's disease were the least likely to report having developed a plan with the assistance of the ADRC (AD 31%, no AD 64%; p = .06).

Follow-up contact varied by CML. More of those in the CML group (58%) than the no-CML group (44%; p=.06) reported receiving a call from the ADRC to see how they were doing. Overall consumers with CML (67%) were significantly more likely than family members (41%) of those with CML to have reported this contact (p = .02). At the same time, those with a diagnosis of Alzheimer's disease were least likely to report having received a call (AD 31%; no AD 64%, p = .02). More of those in the CML group (54%) had initiated contact with the ADRC compared to those in the no CML group (35%; p = .01). Again, significant differences were found between reports by consumers and families, with 62% of consumers reporting contacting the ADRC compared to 40% of family members (p = .05).

Outcomes. Participants were asked how much they agreed or disagreed with seven questions related to outcomes (Table 7). Although not statistically significant, when these measures are summed, those in the CML sample had lower overall outcomes ratings (average = 2.51) than those in the non-CML sample (average = 2.71). Significant differences were found in the outcome related to independence, with those in the CML sample giving lower ratings. Interestingly, there were significant differences in consumer and family responses, with consumers giving higher ratings than family members; CML consumers reported feeling more independent than family members of those with CML. CML sample participants also gave lower ratings than the non-CML sample with respect to receiving enough support to meet needs and preferences. No significant differences were found in the other outcome measures.

Table 7. Outcome measures

	Confusion, Memory Loss (Mean, SD)	No Memory, Confusion (Mean, SD)
The services or information received have allowed me to live in the place I most desire.	3.04 (.916)	3.20 (.741)
I am receiving enough support to meet my needs and preferences[a]	2.72 (.974)	2.97 (.738)
I believe I am more independent as a result of the information and services I received[b]	2.67 (.928)	3.04 (.752)
I believe I am safer in my home as a result of the information and services I received	3.03 (.903)	2.97 (.694)
The services or information received have allowed me to expand or maintain activities outside of my home	2.57 (.947)	2.73 (.775)
The services or information received have helped me make the most of personal money and resources	2.76 (.806)	2.73 (.725)
I was eventually able to find help that I could afford[c]	2.85 (.923)	2.91 (.771)
Total Outcome Score[d]	2.51 (.825)	2.71 (.696)

Note: 1=strongly disagree, 2=disagree, 3=agree, 4 = strongly agree

[a] $p < .10$

[b] $p < .05$. Within the CML group, consumers were significantly more likely to agree or strongly agree than family members (consumers = 2.83; family = 2.32; $p < .05$)

[c] $p < .10$

[d] $p < .05$

Public Programs and Assistance

Participants were asked if they had made decisions as a result of their contact with the ADRC. If they had, they were asked whether those decisions had resulted in them receiving services. Of those who answered yes to making decisions, participants in the CML group (53%) were less likely than those in the no-CML sample (72%) to have received services. Having an AD diagnosis made no difference in whether they received services. However, those with CML (85%) were more likely to have had help with paper work to get services than the no-CML sample (70%) who received services. In addition, if those in the CML group did get services, they got more (average = 2.71), than those in the no-CML sample (average = 2.07; p = .004).

Almost half of those in the CML sample who received services, got three or more. In contrast, most of those in the non-CML sample received one (40%) or two (30%) services ($p \leq .10$). CML sample participants (37%) were significantly more likely than no-CML participants (18%) to have concerns that the ADRC had not addressed ($p < .05$).

Participants in the CML sample (51%) were significantly more likely to get information about or help with managing their health than those in the no-CML sample (23%; $p < .05$). No other statistically significant differences were noted between the groups for other types of services, though the number of people using these services may have been too small to detect meaningful differences.

Circumstances without the ADRC

All participants were asked what their circumstances would be without the ADRC. These open-ended responses were content analyzed and results are presented in Table 8. Descriptions of the ways these consumers' lives would have been worse were consistent with the overall population of respondents (see full report). Consistent with the quantitative data, many of those in the CML sample believed they are able to remain at home because they receive assistance with personal care, house cleaning, and meal preparation and delivery. Financial concerns were similar to those in the no CML sample as illustrated by CML participants who reported that they would be "financially distraught," and have "financial hardship," and be "unable to make it financially" without the help they received from the ADRC. Other participants said they would be sicker, unable to care for themselves, hospitalized, or would have died. Some found that they would be worse emotionally, feeling less safe, and "going nuts not knowing what to do." One consumer reported getting help moving to a safe home after experiencing "abuse, theft, and [being] broke."

Table 8. What do you think your circumstances would be now if you had not received information or services through the ADRC?

	Confusion, Memory Loss	No Confusion, Memory Loss
Worse	65%	61%
Worse emotionally	7%	11%
More difficulty with basic needs	28%	16%
Worse physically	11%	7%
Worse financially	9%	17%
A lot worse: general	4%	11%
A lot worse: would be homeless	2%	3%
Neutral, no difference	21%	33%
Negative ADRC experience; things worse	<1%	8%

Twenty-one percent of CML participants compared to one-third of all survey participants were neutral in their responses, and indicated that their circumstances would be the same without receiving services or information from the ADRC. These consumers believed that they were able to manage on their own, would have found what they needed elsewhere, or reported that “nothing has changed.” Two CML participants had decided to wait after having received information from the ADRC, and 3% said that the ADRC did not help them. One participant is still waiting to receive requested services. Only one participant (<1%) in the CML sample reported their circumstances had not improved, and described a negative experience with the ADRC versus 8% of total survey respondents. This person found the ADRC to be “disorganized,” and felt discriminated against even though he or she had received financial help and other services.

Consumer Recommendations and Overall Satisfaction

Overall, no-CML participants gave higher ratings for satisfaction than CML participants. Average scores were 3.50 and 3.30 respectively ($p <= .10$).

Most participants would recommend the ADRC to a friend or relative, though participants with an AD diagnosis were somewhat more likely to say they would not recommend the ADRC than those without (20% compared to 8%, $p < .10$).

Conclusions

Although we do not know a lot about the specific circumstances of the participants who reported CML, it does appear that the distinction provides useful information. Compared to the participants who did not report CML, the CML sample is clearly different in key areas of interest to ADRCs. Below, we highlight the key differences followed by a summary of similarities.

Differences:

Those with CML had different **pathways to the ADRC.** Consumers in particular were more likely to report receiving a referral from another agency. It may be that those with CML are more likely to be involved with services and providers in those agencies are helping to connect them to the ADRC, perhaps because they are recognizing a cognitive impairment. CML participants were less likely to learn about the ADRC from a friend or health professional. Those in the CML sample were more likely to report that the ADRC initiated the contact, again suggesting that their needs may be recognized by others who are contacting the ADRC on their behalf. CML participants, especially family members, were more likely to report first contact with the ADRC by telephone. This suggests there may be a greater urgency on the part of the CML sample to contact the ADRC directly. Similarly, CML participants were more likely than those in the no-CML sample to have ever visited the ADRC. However, they were more likely to report that it was inconvenient.

Needs. Not surprisingly, those in the CML sample identified a larger number of needs than those in the no-CML sample. As a group, they had more needs related to ADL and IADL services, respite care, and long-term residential housing. This is consistent with needs for those with cognitive impairments. The CML participants had fewer needs related to food stamps, though other financial, housing, and health care needs were similar to those in the no-CML sample.

Services. Those in the CML group were more likely to receive Options Counseling (OC) and home visits. This finding suggests that those who have the most need for decision support are receiving it. In the OC subsample, consumers were more likely to indicate they received home visits than family members. In contrast, family members of those receiving information and assistance only (not Options Counseling) were more likely to report receiving a home visit than consumers in this group. These family members were also more likely to report being present during the home visit. It is possible that family members were arranging personal and home care services for a cognitively impaired relative and are present when visits are made to set up those services. Family members reporting confusion, memory loss, or other cognitive impairment may be a population that could be targeted for options counseling.

Those in the CML sample, especially consumers, were more likely to have received a follow up call and to have initiated a subsequent call to the ADRC. This may indicate that the ADRC and/or options counselors recognize cognitive impairment and are prioritizing follow up calls with those who may need them the most. CML participants were also more likely to have assistance with paper work and help managing their health.

In spite of greater needs and use of OC and homes visits, however, CML participants overall received fewer services than might be expected for this group. When they did receive services, they received more than those in the no-CML group. However, a lower percentage got any services and more than a third reported concerns and unmet needs, twice the proportion of those in the no-CML sample. Consistent with this finding, CML participants also rated staff lower on helping them understand how to get help or information needed. This finding suggests that those with CML may be contacting the ADRC in larger numbers and identifying needs, but that the needs of many people with CML are not being met.

Outcomes. Overall outcome ratings were lower in the CML sample. This is consistent both with presence of a progressive cognitive impairment and with the inability to obtain needed services. Although participants did not report the reasons for not receiving services, possible explanations include a lack of available or affordable services. CML participants reported less consumer control in decision making, getting support required to meet their needs and preferences, and finding help they could afford. In contrast, CML consumers were more likely to report being more independent as a result of the ADRC. Those in the CML sample were more likely to report their basic needs would not have been met without the ADRC.

Overall satisfaction. Although those in the CML sample gave positive ratings for satisfaction with the ADRC, the scores were somewhat lower than those assigned by the no-CML sample ($p < .10$). As indicated above, they also provided poorer ratings for staff helping them understand how to get help or information.

Alzheimer's disease and dementia sample. Only 26 participants indicated that they or a family member had received a diagnosis of Alzheimer's disease or dementia, so it is difficult to draw conclusions from this survey. At the same time, it appears that this group is underserved. They were no more likely to have OC or a home visit than those in the no-CML sample. They were less likely to report an action plan and they were the least likely to report a follow up call. They were also less likely to recommend the ADRC to others. It is possible that cognitive impairment kept consumers from making accurate reports, but the majority of participants in this subsample were family, friends, or neighbors. When family members or consumers indicate an individual is experiencing confusion or memory loss, it would be important to ask if they have a diagnosis of Alzheimer's disease or other dementia, refer them to the Alzheimer's web site and facilitate connecting them to services.

Similarities:

Although significant differences were noted, the CML and no-CML participants also shared many **similar experiences** with the ADRC which indicate that the ADRC was responsive to individual need. This was apparent in the judgment that ADRC staff spend enough time with them, are knowledgeable, respectful, and provide relevant materials. Ratings of decision support were similar across the two groups, including having opinions, likes and dislikes considered; help to explore choices, being able to understand available options; having choices supported; understanding the service system; and not being talked into things not wanted (see White & Elliott, 2015, for details about these ratings).

Recommendations

1. 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.
2. 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.
3. Explore reasons why those with CML generally and those with a diagnosis of AD specifically are less likely to be getting needed services. 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.
4. 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.
5. Continue to listen, provide person-centered decision support, and share knowledge with this population.