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Evaluation of Ohio's assisted living
Medicaid waiver program: Consumer
access and satisfaction

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Living Medicaid Waiver Program:**

Consumer Access and Satisfaction

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INTRODUCTION

In 2005, the Ohio Legislature authorized the development and evaluation of the Ohio Assisted Living Waiver Program. With approval from the Federal Centers for Medicare and Medicaid Services (CMS), the state's Medicaid waiver program began operations in July 2006. This study evaluates program performance for the initial implementation period July 2006 through March 2007. During that period the program enrolled 134 participants; by June 1, 2007, a total of 193 individuals had enrolled in the program.

The assisted living evaluation includes three topical reports and a final summary report. This report on *Consumer Access and Satisfaction* is accompanied by two other topical papers, one on *Assessment and the Service Plan Development Process* and another on *Program Costs*. These three freestanding reports are combined into a final summary document.

BACKGROUND

The implementation of the assisted living waiver represents a partnership between the Ohio Department of Aging (ODA), with day-to-day management responsibilities, and two other state agencies, the Ohio Department of Job and Family Services (ODJFS) and the Ohio Department of Health (ODH). ODJFS, as the single state Medicaid agency, has fiduciary responsibility for the program, whereas ODH is responsible for residential care facility licensure and data collection for the ODA certification of assisted living providers that participate in the program. A critical element of the program is the use of case managers, located in the 13 regional PASSPORT administrative agencies. Case managers assess applicant eligibility and assist the consumer in accessing and transitioning into an assisted living residence as part of the waiver program. After a consumer has enrolled, case managers are responsible for monitoring the consumer's condition and the services provided in the assisted living facility.

To be eligible for the assisted living waiver, participants must be either nursing home residents, who would remain in the facility without the assisted living option, or be currently enrolled in the PASSPORT, Choices, Ohio Home Care, or Transitions waiver programs. To enroll, an eligible consumer must find a facility that has been approved by ODH and is able to accommodate her/him. As of March 2007, 50 facilities had received approval to enroll Medicaid waiver participants. Program enrollment has been slower than originally anticipated; although this experience is typical for assisted living waiver programs nationally, this is in part a function of the relatively low facility enrollment rate. For example, more than 190 consumers are currently waiting to enroll, but report not having a facility available in their geographic area. Issues surrounding enrollment will be examined in depth in the final summary report mentioned earlier.

STUDY QUESTIONS AND METHODOLOGY

This report provides a profile of individuals who enrolled in the Assisted Living Waiver Program. Data on the demographic and functional health of residents and their satisfaction with services are presented for those who enrolled between July 2006 and March 2007. In addition, the report presents information on those who were found to be eligible, but chose not to enroll and those who left the program after moving into a participating facility. The data sources for this component of the study include the PASSPORT Information Management System (PIMS), which includes information on all individuals who enrolled into the program, telephone and in-person interviews with residents to assess consumer satisfaction, telephone interviews with those who left the program (or their proxies), and telephone interviews with individuals who were determined eligible (or their proxies), but who did not choose to enroll.

Profile of Assisted Living Residents

Characteristics of Enrollees

The basic demographic characteristics of those who enrolled between July 2006 and March 2007 are presented in Table 1. Ages ranged from 48-99 years, with an average age of 78 and a median age of 79.5 years. Most enrollees were female (78%), White (87%), and widowed (55%); approximately 10% were currently married.

Table 1
Demographic Characteristics of Enrollees
in the Assisted Living Waiver Program,
April, 2007

Characteristics	
Age	
46-59	9.0%
60-64	8.2%
65-69	7.5%
70-74	11.2%
75-79	14.2%
80-84	9.7%
85-90	23.1%
91+	17.2%
Average Age	78.03
Gender	
Female	77.6%
Males	22.4%
Race*	
Non-Whites	12.9%
Whites	87.1%
Marital Status	
Non-Married	90.1%
Married	9.9%
Sample Size	134

* Race data were only available on 70 of the 134 applicants.
Source: PASSPORT Information Management System (PIMS)

Data on the extent to which residents required assistance with the activities and instrumental activities of daily living are presented in Table 2. Activities of daily living (ADL) include such items as bathing, dressing, and grooming. Instrumental activities of daily living (IADL) include such tasks as shopping, meal preparation, and laundry. Two additional behavioral indicators were available from assessment data: whether the applicant was incontinent and whether the applicant required no, partial or 24-hour supervision.

The majority of residents required assistance with bathing (94%), mobility (89%) and dressing (64%). Almost four in ten participants required assistance with grooming (40%) and toileting (35%); one in ten required assistance with eating. Consistent with the broader gerontological literature, we expected that applicants to assisted living programs would require a great deal of assistance with IADLs and this is certainly the case. As Table 2 shows, for all the IADLs, almost all of the residents (98%) require assistance. In addition, almost one fourth of participants were identified as incontinent and one in five required some level of supervision; with 12% requiring 24-hour supervision.

Table 2
Functional Characteristics of Residents in the Assisted Living Waiver Program

	N	% Requiring Assistance
ADLs		
Eating	13	9.7%
Toileting	47	35.1%
Grooming	53	39.6%
Dressing	86	64.2%
Mobility	115	88.8%
Bathing	126	94.0%
IADLs		
Shopping	131	97.8%
Laundry	131	97.8%
Meal Preparation	132	98.5%
Community Access	132	98.5%
Environmental Management	134	100.0%

Source: PASSPORT Information Management System (PIMS)

Resident Satisfaction

To assess resident satisfaction, we identified 97 participants who had lived in assisted living for two months or longer and asked them to complete a survey about their experience enrolling in the program and residing in the facility. In February and March 2007, 41 telephone or in-person interviews were conducted with enrollees or their proxies. Many residents did not have a phone in their room; repeated attempts to contact these individuals yielded a response rate of 42%. Residents (or their proxies) were asked a series of questions to assess their perceptions of the quality of care and their satisfaction with the services that they were receiving at the assisted living residence.

In general, participants in the assisted living waiver program reported positive ratings about the help they received in moving in to the residence. The vast majority of residents (about 90%) responded with an “excellent” or “good” for items in this category (See Table 3). A handful of consumers did express concerns about the information received about the program services. The relatively small number of respondents in the sample limits our ability to further analyze these items.

A series of questions were also asked about participant satisfaction with life in the assisted living residence (see Table 4). Three questions were asked related to employee behaviors and residents appear relatively satisfied with assisted living facility employees; 86% allowed that employees always let residents do what they want for themselves, three of four residents found employees to be always courteous, and seven in ten described employees as always available to help. Two questions were asked about food and, in each case, more than two of three participants were satisfied that there was always choice in the selection of food and drink and that food was always served at the right temperature. It is worth noting that almost one in

Table 3
Ratings of the Quality Help in Moving Into an Assisted Living Residence

How would you rate the ...	Excellent	Good	Fair	Poor	TOTAL
information you received concerning the services here? (N = 30)	43.3%	43.3%	10.0%	3.3%	99.9%
financial information regarding the AL waiver program? (N = 26)	61.5%	34.6%	3.8%	--	99.9%
helpfulness of the staff during your move to the facility? (N = 34)	55.9%	35.3%	2.9%	5.9%	100.0%
helpfulness of the AAA case manager during your move to the facility? (N = 27)	55.6%	33.3%	7.4%	3.7%	100.0%
helpfulness of your family during your move to the facility? (N = 29)	62.1%	27.6%	3.4%	6.9%	100.0%

five respondents (18%) did complain that at their place of residence they hardly ever had choice in what to eat or drink.

Three of four residents responded that their belongings were always safe. Three additional questions were asked about the rules at their residential facility: 95% agreed that they could always go to bed when they liked, 76% asserted that the rules were always reasonable, and two-thirds responded that it was always acceptable to make a complaint at their residence.

Overall satisfaction with enrollees' residential care and services in the Assisted Living Waiver program was also examined (See Table 5). In general, it appears that the residents (or their proxies) interviewed were satisfied with their assisted living arrangements. Almost four of five indicated that they always get the care and services they need, and three of four revealed that they always feel comfortable in their residential setting. More than nine in ten enrollees always find their residence to be an appealing place for others to visit and 72% are always satisfied with the activities being offered. Finally, almost two of three residents like living in the current

Table 4
Resident Satisfaction with Care and Services in the Assisted Living Residence

	Yes, always	Yes, sometimes	No, hardly ever	No, never
Are the employees courteous to you? (N = 40)	75.0%	25.0%	--	--
Are employees available to help you if you need it? (N = 37)	70.3%	27.0%	2.7%	--
Do the employees let you do things you want to for yourself? (N = 36)	86.1%	13.9%	--	--
Do you have a choice of what to eat and drink? (N = 39)	69.2%	12.8%	17.9%	
Is your food served at the right temperature? (N = 36)	69.4%	25.0%	5.6%	
Are your belongings safe here? (N = 36)	75.0%	19.4%	2.8%	2.8%
Are the rules here reasonable? (N = 33)	75.8%	24.2%	--	--
Can you go to bed when you like? (N = 37)	94.6%	5.4%	--	--
Is it acceptable to make a complaint here? (N = 34)	64.7%	23.5%	5.9%	5.9%

facility and three in four would always recommend the residence to a family member or friend. In response to the latter two questions, 11% of enrollees “hardly ever” or “never” like living in their assisted living facility and 10% would “never... recommend this place to a family member or friend.” As sample size increases, more analysis will allow further examination of these findings.

Table 5
Enrollee Global Satisfaction with Their Residential Setting
in the Assisted Living Waiver Program,
April 2007

	Yes, always	Yes, sometimes	No, hardly ever	No, never
Do you get the care and services that you need? (N = 39)	79.5%	20.5%	--	--
Do you feel comfortable here? (N = 33)	75.8%	24.2%	--	--
Do you think this is an appealing place for people to visit? (N = 34)	91.2%	8.8%	--	--
Are you satisfied with the activities they offer here? (N = 32)	71.9%	21.9%	6.3%	
Overall, do you like living here? (N = 38)	65.8%	23.7%	2.6%	7.9%
Would you recommend this place to a family member or friend? (N = 40)	72.5%	17.5%	--	10.0%

Participants Leaving the Program

Over the first nine months of the waiver program, eight of the 134 assisted living waiver program participants left the program; three of these individuals died. During March 2007, we completed interviews with three of the five participants who chose to leave and/or their proxies. Individuals (or proxies) were asked, “What were your reasons for deciding to leave the assisted living facility?” The very small number of participants who left limits any analysis, but we present these data as a sample of future data collection efforts in this area. Individuals gave multiple reasons for disenrolling. Two individuals responded that the facility did not provide the services/activities that they required, whereas another indicated the specific need for a nursing home. One married respondent wanted to be reunited with the spouse, who had been placed in a

nursing home. We asked these individuals (or their proxies) whether they made the decision to leave on their own and, if not, who helped them. One individual stated that the decision to leave was made entirely on his/her own; the two others indicated receiving help from family members, primarily a spouse and adult children, and from a case manager. These same individuals were helpful in the decision about where to go once they left the assisted living facility. One individual went to live with a family member and two others went to a nursing home.

Non-Enrollees

As of April 2007, 44 applicants were assessed, deemed eligible for participation, but did not enroll in the Assisted Living Waiver program. The characteristics of these individuals were similar to those who did enroll; mostly female, non-Hispanic White, not married (widowed, divorced or single) (See Table 6). Their ages ranged from 48-87 years with an average age of 71, seven years younger than for the enrolled group (see Table 1 above). Those who did not enroll had similar levels of disability compared to assisted living program participants (see Tables 2 and 7). Again the limited sample size of this group make any findings preliminary in nature.

Telephone interviews were completed with 13 of the 44 non-enrolled applicants or their proxies between November 2006 and March 30, 2007. Many non-enrollees had moved from one location in which they lived at the time of their assessments and could not be reached. Applicants reported getting information about the Assisted Living Waiver Program in diverse ways including from a case manager, another long-term care professional, a family member or friend, through the PASSPORT program, from someone at the nursing home, an AARP flyer, and the newspaper.

Four of these non-enrollees or their proxies were able to visit an assisted living facility participating in the waiver program. Reasons why others were not able to visit a facility included

Table 6
Demographic Characteristics of Non-Enrollees
in the Assisted Living Waiver Program

Characteristics	
Age	
<65	35.7%
65-79	28.6%
80+	35.7%
Average Age	71.21
Gender	
Female	92.9%
Males	7.1%
Race*	
Non-Whites	16.7%
Whites	83.3%
Marital Status	
Non-Married	84.6%
Married	15.4%

* Race data was only available on 12 of the non-enrollees.
Source: PASSPORT Information Management System (PIMS)

the absence of a participating facility in their community (8), no transportation (2) or because they were too impaired or too ill to visit a facility (3); one of the non-enrollees did report that a family member or friend/neighbor was able to visit a participating facility in his/her stead.

Most of these non-enrollees (7 of 12) reported that they were able to get all the information they wanted before making a decision; others did not get that far as they assumed transportation would not be available to physician appointments and the like or that more care would be required than an assisted living facility could provide. When asked how satisfied they were with the information they did receive about the waiver program, five non-enrollees responded that they were “satisfied” (one even responded “very satisfied”) and three were dissatisfied; others did not know or refused to answer.

Table 7
IADLs, ADLs and Behavioral Indicators for
Non-Enrollees in the Assisted Living Waiver Program,
April, 2007 (N = 14)

	N	% Requiring Assistance
IADLs		
Meal Preparation	13	92.9%
Community Access	13	92.9%
Laundry	14	100.0%
Shopping	14	100.0%
Environmental Management	14	100.0%
ADLs		
Eating	1	7.1%
Toileting	6	42.9%
Dressing	9	64.3%
Grooming	10	71.4%
Mobility	11	78.6%
Bathing	13	92.9%
Behavioral Indicators		
Incontinence	3	21.4%
Requires Supervision	3	
24-Hour	2	14.3%
Partial	1	7.1%

Source: PASSPORT Information Management System (PIMS)

Non-enrollees (or their proxies) were asked to identify their reasons for not entering assisted living and these reasons are listed in Table 8. All responses were recorded, as a number of the non-enrollees had multiple reasons for not entering a facility in the waiver program.

Costs were among the most frequently cited reasons for not entering an assisted living facility in the waiver program, receiving a total of seven mentions from among non-enrollees, and this pattern was confirmed when respondents were asked to identify the most important reason for not entering an assisted living facility. Three respondents specifically identified having to pay their own costs, including co-pays and prescriptions; three identified the rent as being too high; and another was concerned that assisted living would use up all her money and she could not go along with that.

Table 8
Reasons Non-Enrollees did not Enter an Assisted Living Facility

Reasons for not entering an assisted living facility

- Had to pay own costs (e.g., co-pays, Rx).
 - The rent was too high.
 - Did not like the accommodations.
 - The facility did not have the services/activities needed.
 - The facility was too far from family.
 - The facility was too far from friends/neighbors.
 - Other
 - The facility was confining, too much like a nursing home.
 - Cable TV was not included in the package.
 - Unable to host family or have family sleep over.
 - Current place of residence is just fine.
 - Had used up all money in assisted living and could not move directly into the waiver program.
 - Would have taken all money and applicant didn't agree with that.
 - Loss of independence and unable to smoke.
 - Preferred to stay in community.
-

Two respondents did not like the accommodations (with direct and specific mentions given to the absence of a kitchen and the small size of the rooms) and two asserted that the assisted living facility available to them did not have the services/activities that were needed (A proxy for one non-enrollee was particularly adamant that with her Alzheimer's disease and insulin-dependent diabetes, more one-to-one care was required than could be provided in the assisted living facility). Other respondents also spoke indirectly to concerns about accommodations and an absence of services (e.g., "the facility was confining...;" "...unable to host family...;" "cable TV was not included ...").

Several respondents (3) also spoke to concerns about staying in the community; two expressed these concerns indirectly in remarking that the facility available to them was too far from family (1) or friends/neighbors (1), whereas a third spoke directly to the preference to stay

in her home community. Nine of the respondents indicated that the decision not to enroll was solely their own, with two others identifying family members (i.e., a daughter and extended family members) who helped make the decision.

Finally, we asked non-enrollees (or their proxies) to think back over the entire experience of applying, gathering information and trying to decide whether to enter the waiver program and rate the overall experience as excellent, very good, good, fair or poor. Only eight responded, with four indicating “very good/good” and four indicating “fair/poor.” We followed up by asking this group of non-enrollees what they would recommend to make the program better, and Table 9 lists their recommendations. Again, several respondents were at a loss to make recommendations, whereas others had a bounty of ideas. Cost issues appear to dominate – at least two non-enrollees offered that information about out-of-pocket costs associated with the waiver program should be provided earlier so that it could be factored into the decision-making process. Five respondents suggested that enrollees be allowed to retain sufficient money to purchase discretionary items and other necessities. Other recommendations included making sure that assisted living facilities participating in the program had available transportation for physician visits and other medical needs, allowing for larger rooms, and speeding up the application/eligibility assessment.

Table 9
Non-Enrollee Recommendations to Improve
the Assisted Living Waiver Program,
April 2007

Recommendations

Provide transportation (e.g., physician appointments or dialysis).
People should be allowed to keep enough of their money/resources to purchase cable TV or other needed items (e.g., eliminate co-pays).
Provide larger rooms (e.g., respondent dislikes twin beds).
If information about costs were provided first, the decision would have been made more quickly.
“It took too long to tell if I was eligible.”
People should be able to move from assisted living right into the waiver program.
Assisted living waiver was “not the right solution.”
Some services should be made available (e.g., hairdressing).

CONCLUSION

This report provides a first look at the consumers involved in the Ohio Assisted Living Waiver Program. As expected, participants have a high level of disability. On average, residents reported high levels of satisfaction with the transition process into the assisted living residence and with the quality of services provided. A very small proportion of those entering the program left during the early stage of the program. The slower than expected build-up and the short period of time for the evaluation limited the total number of subjects available for analysis. As the program builds enrollment over time, it will be important to re-examine program outcomes.