



# EVALUATION OF THE OREGON PROJECT INDEPENDENCE EXPANSION PILOT PROJECT

REPORT SUBMITTED TO THE OREGON  
DEPARTMENT OF HUMAN SERVICES

*Consumer characteristics and experiences,  
lessons learned from the Area Agencies on  
Aging, and cost estimates for statewide  
implementation*



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# EXECUTIVE SUMMARY: OPI-E PILOT STUDY

Consumer Characteristics, Service and Cost Estimates, and  
Lessons Learned

## Introduction

The Oregon Project Independence Expansion (OPI-E) pilot project was established in 2014 to serve adults with disabilities in seven Area Agencies on Aging (AAA).

These AAAs were:

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The Community Action Program of East Central Oregon (CAPECO)

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Lane Council of Governments (LCOG)

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Multnomah County Aging, Disability, and Veterans Services (MCADVS)

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Northwest Senior and Disability Services (NWSDS)

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Oregon Cascade West Council of Governments (OCWCOG)

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Rogue Valley Council of Governments (RVCOG)

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Washington County Department of Disability, Aging, and Veterans  
Services (WCDAVS)

## Part I. Comparison of OPI-E consumers: 2014 and 2015-2017

Part I is a comparison of the initial data collected about the program following its first year (2014) with data collected over the next biennium (2015-2017). The OPI-E pilot program grew from 398 in 2014 (a 12-month period) to 581 people served during the 2015-2017 biennium, a 46% increase, suggesting that the program is growing to capacity. During that time, consumers served by the program were more evenly distributed throughout the seven AAAs that were participating in the

Three of the four AAAs had a waiting list for OPI-E consumers, because demand in those communities has exceeded the allocation for those AAAs.

expansion as reflected by the decreasing percentage of OPI-E consumers served in Multnomah County from 45% in FY 2014 to 32% of those served during FY 2015-2017.

Three of the four AAAs had a waiting list for OPI-E consumers, because demand in those communities has exceeded the allocation for those AAAs. As presented in Part II, three AAAs may not have wait lists because they are at or near capacity and do not have active outreach activities.

Many OPI-E consumer characteristics have remained similar over time, including percentages of women and men served, the age distribution of OPI-E consumers, and the racial and ethnic distribution.

OPI-E consumers have also had similar levels of need as reflected in service priority levels and risk assessments which were similar for consumers in 2014 and 2015-2017. OPI-E consumers in 2015-2017 differed somewhat from 2014 OPI-E consumers in some areas, including those in recent years having a higher level of assets and somewhat higher costs per consumer.

In addition to age, OPI-E consumers differed from traditional OPI consumers during 2015-2017 with respect to somewhat larger percentages of men and people of color served in the younger age group. A higher percentage of OPI-E consumers were served between 6 and 24 months compared to traditional OPI, likely due to the short time in which OPI-E has been operating. The service priority levels (SPL) reported by the two OPI programs differed, but with no clear pattern. Older adults appear to have a wider range of SPL compared to younger adults

who clustered in the middle range. Younger adults experienced less change in SPL scores during this time period compared to older adults who were more likely to see their needs increase.

## Part II. Lessons Learned by AAA Staff

During the first year of the pilot, AAA staff working with consumers participated in monthly conference calls. The purpose was to facilitate the exchange of information and capture lessons learned over time. These lessons were revisited with the current evaluation through interviews conducted in June and July 2018 with 23 staff from all seven of the AAAs who participated in OPI-E. They include interviews with 3 AAA directors, 4 program managers, one quality assurance staff, and 15 case managers or service coordinators. Findings from interviews with AAA staff with respect to those lessons include:

**Outreach:** OPI-E services are known within the aging network, but more needs to be done beyond it. Systematic outreach is limited in many AAAs.

**Service provider capacity:** The lack of home care services (both through home care workers and home care agencies) remains a major challenge. Major concerns include lack of availability, training, and transportation.

**Unique characteristics:** Many similarities to older adult needs noted. However, in most AAAs, younger adults were reported to have more behavioral needs. Responses varied considerably among AAA staff independent of AAA.

**Data:** Majority of staff are able to easily access information to determine eligibility. Most challenges are related to cumbersome data systems and inconsistencies in maintaining data across AAAs.

**Challenges for rural Oregon:** Geographical distances increase challenges accessing home care services and meeting consumer transportation needs.

New “lessons learned” themes from the interviews include: the value of OPI services for this age group and how even low levels of service go a long way, the importance of relationships with consumers, empathy, flexibility and creativity, challenges in finding and enrolling eligible consumers. Virtually everyone interviewed said that OPI-E should be expanded statewide.

## Part III. Consumers' Experience with OPI-E

In July 2018, all OPI-E consumers (N=268) received a mailed survey which measured the importance of specific services for consumers' health and well-being, satisfaction with their OPI-E case manager, satisfaction and experiences with in-home care workers, outcomes resulting from OPI-E services, and overall satisfaction. Consumers were given three choices for taking the survey: mail it back in the envelope provided, take the survey online, or request a phone interview. All who completed the survey within the time available received a \$10 gift card. The survey was completed by 126 consumers (47% response rate).

The consumers surveyed are very similar to those described in Part 1. Both qualitative and quantitative data show that consumers value OPI-E services. The majority stressed their appreciation and gratitude for the program, with several using terms such as "lifesaving" in their comments. Consumers reported that OPI-E contributes significantly to their independence, their ability to remain at home, and often support family members who also provide care. Most consumers rated their case managers quite positively.

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*"I would not be able to live at home if I didn't have OPI – even if I have only 19.5 hours per month. I am in a wheelchair and have paralysis in my hands. I don't have enough hours. I have no other options."*

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-OPI Consumer

All of the services received were rated by consumers as important or very important with most rating services they received as very important. The most common service received was personal and home care services and, not surprisingly, this was the service identified as most important. The majority of respondents had very favorable views of their home care workers (HCWs), although comments reveal that finding, hiring, and supervising care workers was very challenging and stressful, particularly for those with limited energy. Those who had difficulties finding appropriate help wished for more guidance and assistance from the OPI-E program in doing this.

Nearly half of the 89 consumers in this sample who provided comments were related to needs that had not been met. In the comments provided by consumers,

the most frequently identified area of need was for more hours of care. Arguably, with more hours some of these needs could be met. Another theme emerging from the open ended responses to the survey was uncertainty about other services and benefits available. The list of possible services was eye-opening to some consumers who were not familiar with services listed on the survey and thought they might benefit from them. Other consumers expressed concerns about their future – what will happen when they turn 60? How do they get questions answered?

## Part IV. Estimated Need and Cost Estimates to Expand OPI-E Statewide

Traditional OPI and OPI-E are based on an intra-state funding formula that includes elements of geographic size of the AAA and the population of the particular age groups. PSU was asked to estimate the need and costs estimates to expand OPI-E statewide. The purpose of these estimates is to provide information to legislators and policy makers in planning future allocation for these programs. This report documents the final cost estimates and describes methods and data sources used in the calculating the estimates. In addition to the data available to us about the current OPI-E program, data sources for the estimates included the American Community Survey and the National Health Interview Survey.

The final total cost estimates to expand OPI services to those aged 18-59 ranges from \$6.3 to \$22 million<sup>1</sup> for FY2019-2020. The median estimate is \$12.54 million for the 2019-2020 biennium, with monthly costs per participant ranging from \$403 in 2019 to \$413 in 2020. Based on these estimates, the program budgets would range from \$2.95 to \$11.14 million for 2019 and \$3.38 to \$11.58 for 2020.

The median estimate for legislative consideration is \$12.54 million for the 2019-2020 biennium, with monthly costs per participant ranging from \$403 in 2019 to \$413 in 2020.

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<sup>1</sup> All monetary values are expressed as nominal (not inflation-adjusted), but cost estimates are adjusted for price increases in health care services using CMS Personal Health Care Price Index (see text for details).

The estimate range is large because data available for the estimates were limited, the service needs of non-participating and potentially eligible population are unknown, there is significant statewide variation in the potentially eligible population, and there is variability in outreach to increase awareness and encourage participation.

The historical average costs per participant likely reflect the lower end of the estimates considering it was a pilot program and some counties did not offer all services. Additionally, consumers in some counties not currently served may have higher needs compared to consumers in the pilot counties. Each AAA decided how they would allocate the limited resources based on various factors. At the same time, average costs per participant that we have seen in the past may be due to a few consumers who have required unusually high expenditures for services. Because the total number of participants are small, these few consumers with high needs may have artificially elevated average costs. To obtain better estimates in the future, we fully support a system of collecting individual level data consistently across all AAAs.

## Recommendations

The OPI Expansion pilot is valued by virtually everyone who was interviewed or surveyed, including staff and consumers alike. The consensus from AAA staff is that the OPI-E has been able to address previously unmet needs in a vulnerable population and should continue statewide. The following recommendations emerged from the program data, interviews with AAA directors and case managers, consumer experiences, and estimated costs.

OPI-E has been able to address previously unmet needs in a vulnerable population and should continue statewide.

## Summary of Key Recommendations

### **Fund the continuation of OPI and OPI-E statewide**

- Allocate statewide funding for both OPI-E and traditional OPI programs based on population. Include costs for travel time for staff outreach and assessment activities into the allocation.
- Maintain separate funding for OPI-E so that this younger population is not subsumed and lost in the larger program.

### **Increase access to supports and services for consumers with greater needs**

- Expand the number of hours in-home care service for consumers with greatest needs.
- Increase access to in-home care and reduce the burdens of limited hours on those who provide in-home. Address issues of transportation costs, particularly for HCWs in rural areas.

### **Provide support and training for consumers, AAA staff, and in-home care workforce**

- Provide basic behavioral health training to AAA staff.
- Increase awareness of both AAA staff and consumers about the Employer Resource Connection (formerly the STEP program).
- Continue efforts to build and support the in-home care workforce, including helping consumers develop skills in hiring and supervising workers.
- Develop systems to check in more frequently with consumers to answer questions and provide information.

### **Enhance partnerships and opportunities for collaboration**

- Partner with Behavioral Health Specialists who provide training and complex case consultation that includes a focus on adults with disabilities. For more information on this resource, please visit the [Institute on Aging website](#).
- Partner with the Community Services and Support Unit and AAAs to increase outreach for OPI-E to determine a more accurate estimate of need.
- Explore closer partnerships to enhance communication between APD and Type A AAAs to streamline determination of OPI eligibility and services.
- Support and prioritize ongoing efforts to improve state and local data systems and to improve information sharing.

# EVALUATION OF THE OPI EXPANSION PILOT PROJECT

## Introduction

Oregon Project Independence (OPI) was established in 1975 with the aim to support adults 60 years old and over in their homes to avoid or delay the need for residential long-term care services (e.g., nursing home, assisted living). The intent was also to help individuals to optimize personal resources and natural supports to preserve their assets for as long as possible and prevent the need for Medicaid. OPI is funded through Oregon general funds and is administered by the 17 Area Agencies on Aging (AAA) throughout Oregon. OPI is considered a key component of AAA services.

In 2005, the Oregon State Legislature amended the Oregon Revised Statutes (ORS 410.435) so that OPI could serve individuals younger than 60 who would otherwise qualify for OPI services. The Legislature authorized the OPI pilot for younger adults with disabilities in 2014 through HB 5210. In July 2014, an expanded OPI for younger adults was piloted in seven AAAs:

- Community Action Program of East Central Oregon (CAPECO)
- Lane Council of Governments (LCOG)
- Multnomah County Aging, Disability, and Veterans Services (MCADVS)
- Northwest Senior and Disability Services (NWSDS)
- Oregon Cascade West Council of Governments (OCWCOG)
- Rogue Valley Council of Governments (RVCOG)
- Washington County Department of Disability, Aging, and Veterans Services (WCDAVS)

NWSDS served as the lead for the pilot program and produced a report describing the results, including numbers of individuals served, client characteristics, services provided, and lessons learned<sup>2</sup>.

The OPI expansion pilot (OPI-E) has continued to be funded in these seven AAAs. In 2018, Portland State University (PSU) Institute on Aging (IOA) received a contract from the Oregon Department of Human Services (DHS) to evaluate, review, and summarize data compiled by the pilot AAAs and DHS for the biennium 2015-2017. This report is presented in four parts. Part I contains a summary of consumer data collected by the AAAs and DHS replicating, to the extent possible, the report produced by NWSDS after the first year of the pilot project. Part II describes results from interviews conducted with AAA directors, or their designees, and OPI-E case managers. The voices of current OPI-E consumers are presented in Part III and are based on surveys completed by consumers. Finally, Part IV provides a cost estimate to expand the OPI-E program for those younger than 60 statewide.

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<sup>2</sup> 2014-2015 Expansion of Oregon Project Independence Report. June 30, 2015.

# PART I. CONSUMER DATA

Characteristics of OPI-E Consumers between July 2015 and June 2017<sup>3</sup>

## Number of consumers served and service areas

From July 2015 through June 2017, 3,824 unduplicated consumers were served by the traditional OPI program and 581 unduplicated consumers received services through the OPI-E program. Table 1-1 displays the total number of new consumers enrolled by service start date. Of the traditional OPI consumers, 77 percent were receiving services before July 2015. In contrast, 46 percent of OPI-E clients had started receiving services before the start of the biennium, likely representing the growth of the expansion program during 2015-2017.

**TABLE 1-1. NUMBER OF OPI CONSUMERS BY AREA AGENCY ON AGING (AAA) AND PROGRAM TYPE: FY2015-2017**

Service start date	Traditional		Expansion Pilot	
	#	%	#	%
<b>Prior to July 2015</b>	2,952	77	270	46
<b>2015 Q3</b>	280	7	73	13
<b>2015 Q4</b>	159	4	61	10
<b>2016 Q1</b>	83	2	43	7
<b>2016 Q2</b>	36	1	25	4
<b>2016 Q3</b>	66	2	29	5
<b>2016 Q4</b>	70	2	40	7
<b>2017 Q1</b>	94	2	25	4
<b>2017 Q2</b>	84	2	15	3
<b>Total</b>	<b>3,824</b>	<b>100</b>	<b>581</b>	<b>100</b>

Table 1-2 shows the number and share of the total consumers served by program type (traditional or expansion) through each Area Agency on Aging (AAA).

<sup>3</sup> Consumer data reported here were provided by the Oregon Department of Human Services in consultation with the IOA. The data sources were Oregon Access and RTZ.

All 17 AAAs across Oregon provided services to traditional OPI consumers and seven of these AAAs participated in the OPI-E program. Of the 3,824 traditional OPI consumers, a quarter (27%) were served by Multnomah County Aging, Disability, and Veterans Services (MCADVS), followed by Northwest Senior and Disability Services (NWSDS; 12%). Of the 581 OPI-E consumers, a third (32%) were served by MCADVS, and Lane Council of Governments (LCOG) and Rogue Valley Council of Governments (RVCOG) served 17 percent each. In comparison, during the first year of the expansion in 2014, MCADVS served 45%, Lane County 12% and RVCOG 12.5%.

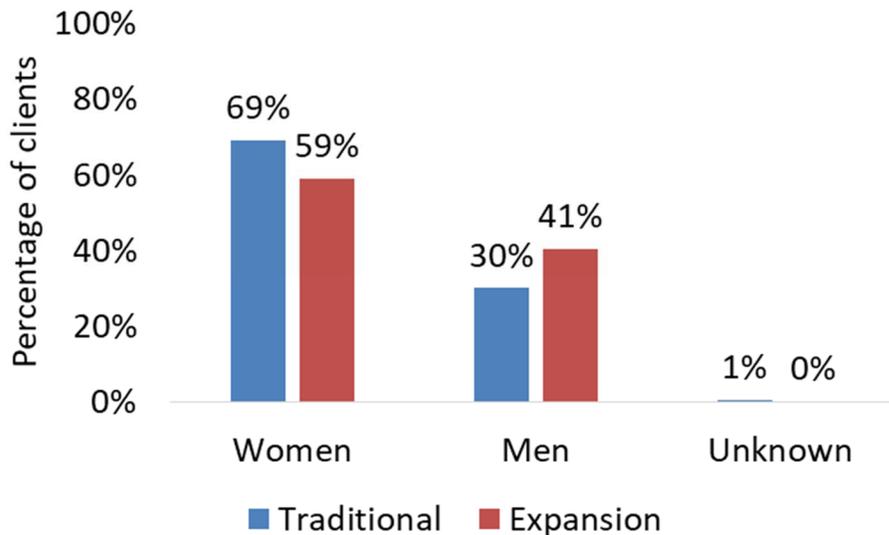
**TABLE 1-2. NUMBER OF OPI CONSUMERS BY AREA AGENCY ON AGING (AAA) AND PROGRAM TYPE: FY2015-2017**

AAA (counties served)	Traditional		Expansion	
	#	%	#	%
CAPECO (Morrow, Umatilla)	93	2	21	4
CAT (Columbia)	68	2	-	-
CCNO (Baker, Grant, Wallowa, Union)	116	3	-	-
CCSS (Clackamas)	261	7	-	-
COCOA (Crook, Deschutes, Jefferson)	92	2	-	-
DCSSD (Douglas)	119	3	-	-
HCSCS (Harney)	23	1	-	-
KLCCOA (Klamath, Lake)	85	2	-	-
LCOG (Lane)	358	9	97	17
MCADVS (Multnomah)	1,050	27	187	32
MCCOG (Hood River, Gilliam, Sherman, Wasco, Wheeler)	78	2	-	-
MCOACS (Malheur)	48	1	-	-
NWSDS (Clatsop, Tillamook, Marion, Polk, Yamhill)	474	12	41	7
OCWCOG (Benton, Linn, Lincoln)	260	7	78	13
RVCOG (Jackson, Josephine)	317	8	100	17
SCBEC (Coos, Curry)	129	3	-	-
WCDAVS (Washington)	253	7	57	10
<b>Total</b>	<b>3,824</b>	<b>100</b>	<b>581</b>	<b>100</b>

Notes: Dash (-) indicates no consumers were served under the program by that AAA.

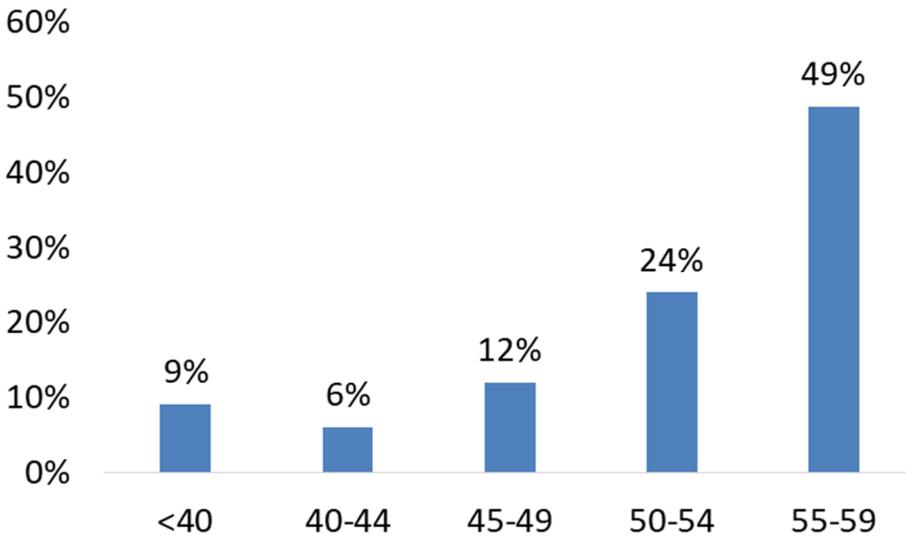
## Consumer demographics

Figure 1-1 below shows that the majority of both traditional and OPI-E consumers were women (69% and 59%, respectively). This is the same percentage of women as reported in the OPI-E in 2014.



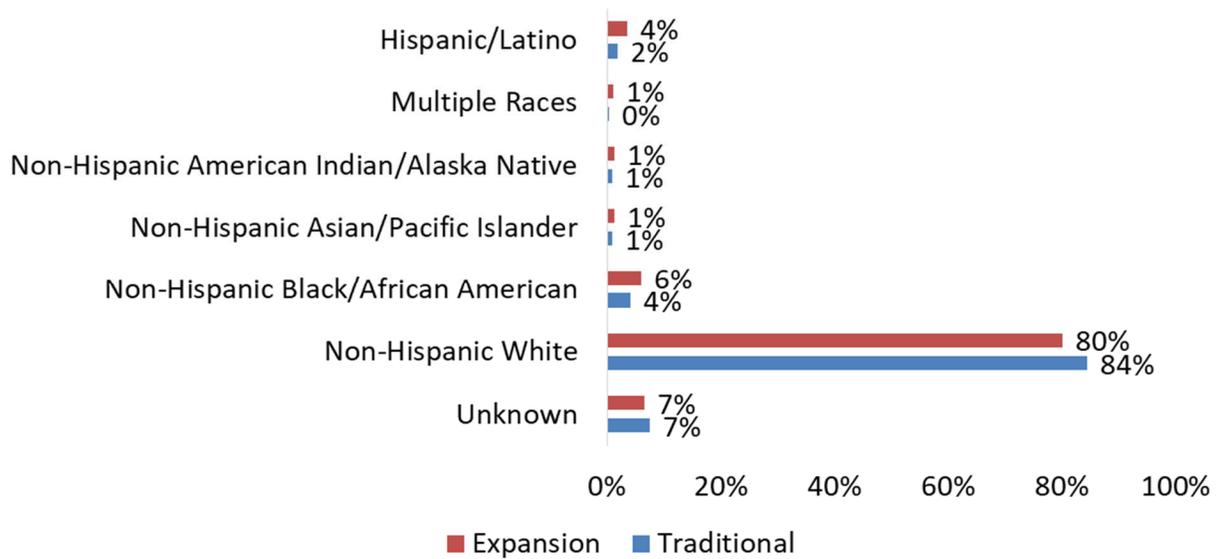
**FIGURE 1-1. OPI CONSUMERS BY GENDER AND PROGRAM TYPE: FY2015-2017**

Half of all traditional OPI consumers were 78 years and older and half of all OPI-E consumers were 54 years and older. Nine percent of OPI-E consumers were younger than forty years old (see Figure 1-2). This is very similar to the age profile for the 2014 OPI-E consumers when 46% were in the 55-59 age group and 8% were younger than 40 (OPI-E Report, 2015).



**FIGURE1- 2. OPI-E CONSUMERS BY AGE GROUP: FY2015-2017**

Including the 7% missing data about race/ethnicity, 84% of traditional OPI consumers and 80% of OPI-E consumers were non-Hispanic White (see Figure 1-3). Two percent of all traditional OPI consumers and four percent of OPI-E consumers were Hispanic/Latino of any race. Four percent of all traditional OPI consumers and six percent of OPI-E consumers were non-Hispanic Black/African American. These statistics indicate that OPI-E consumers have a higher percentage of men and are slightly more diverse than the traditional OPI consumers. Men in both OPI programs are underrepresented when compared to the general population. The racial/ethnic profile of OPI-E consumers is very similar to that reported in 2014 (OPI-E Report, 2015).



**FIGURE 1-3. OPI CONSUMERS BY RACE/ETHNICITY AND PROGRAM TYPE: FY2015-2017**

## Consumer Service Priority Levels

Eligibility for OPI services is determined by establishing a consumer’s service priority level (SPL). This is done through an annual assessment of a consumer’s functional abilities in terms of activities of daily living (ADL) and instrumental activities of daily living (IADL). ADLs include abilities related to basic functioning such as eating, dressing, mobility, elimination, and cognition. IADLs refer to abilities related to managing tasks such as housekeeping, laundry, shopping, transportation, and medication management. The assessment identifies how much assistance is needed for each ADL and IADL: requires full assistance, substantial assistance, assistance, minimal assistance, and no assistance. Priority levels range from 1 (requires full assistance in mobility, eating, elimination, and cognition) to 18 (independent but requires structured living or supervision for complex medical problems or a complex medication regimen) (ORS 411-015-0010).

SPL levels for OPI consumers tend to cluster around 5 levels and indicate the following levels of dependence:

- SPL 3 indicates that full assists are needed in ADLS related to mobility, cognition, or eating.
- SPL 7 is an assist with inside the home mobility, such as with transfers or ambulation, and an assist with elimination
- SPL 10 means substantial assist with mobility, such as transfers or ambulation, within the home
- SPL 15 refers to minimal assistance with mobility and ambulation outside of the home
- SPL 17 is assistance with bathing or dressing.

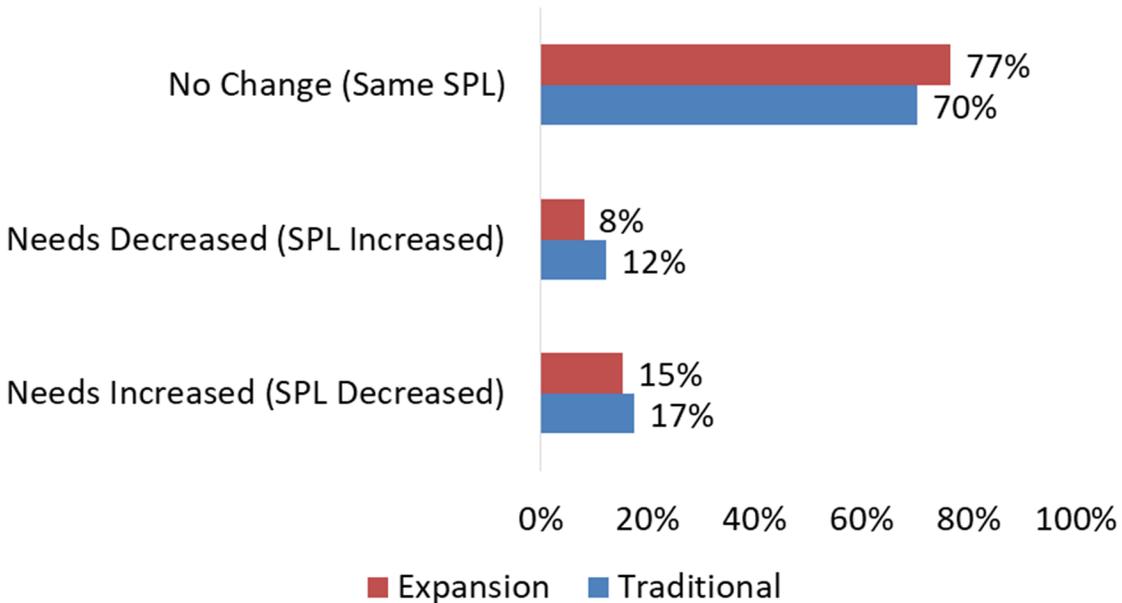
Cognition is not considered in rules related to SPL until full assists are required. A lower SPL broadly indicates higher consumer needs. Table 1-3 shows first SPL value recorded for consumers in the biennium by program type. Forty-eight percent of OPI traditional and forty-seven percent of OPI expansion consumers had SPL values of 13 or below. The distribution of SPL priority scores presented here are similar to those reported for the first year of the expansion. At that time fifty percent of OPI-E consumers had SPL values of 13 or lower (OPI-E Report, 2015).

SPL	Traditional		Expansion	
	#	%	#	%
1	32	1	1	<1
2	1	<1	-	-
3	466	12	37	6
4	64	2	5	1
5	32	1	5	1
6	18	<1	5	1
7	361	9	77	13
8	7	<1	-	-
9	4	<1	-	-
10	538	14	111	19
11	138	4	10	2
12	19	<1	1	<1
13	150	4	19	3
14	13	<1	2	<1
15	981	26	116	20
16	73	2	5	1
17	620	16	128	22
18	307	8	59	10
<b>Total</b>	<b>3,824</b>	<b>100</b>	<b>581</b>	<b>100</b>

**TABLE 1-3. OPI CONSUMERS BY FIRST SPL RECORDED IN THE BIENNIUM AND PROGRAM TYPE: FY2015-2017**

*Notes:* Dash (-) indicates no consumer in that program had an SPL of that value.

Figure 1-4 shows the change in the first and last SPL values recorded during the biennium. Seventy percent of traditional OPI consumers and 77 percent of OPI-E consumers experienced no change in SPL. The percent of consumers who experienced an increase in needs (SPL decreased) were 17 and 15 percent for traditional and OPI-E consumers, respectively.



**FIGURE 1-4. CHANGE BETWEEN FIRST AND LAST SPL ASSESSMENT DURING THE BIENNIUM: FY2015-2017**

The majority of consumers (67%) in traditional OPI lived in one or two person households, compared to about half of OPI-E consumers (Table 1-4). The pattern of household size is different in the 2015-2017 biennium compared to the 2014 fiscal year (OPI-E Report, 2015), when nearly three quarters of OPI-E consumers lived in one-person households with another 18% in two person households. Note, however, the large number of “unknowns” with respect to household size, so these findings must be interpreted with caution.

OPI-E consumers have lower incomes than consumers in traditional OPI; 70% and 51% respectively having monthly incomes of \$1,500 or less. In 2014, 77% of OPI-E consumers had monthly incomes of less than \$1,500. This is also reflected by the percentages of those enrolled in Social Security Disability Insurance (SSDI); 81% of OPI-E consumers compared to 10% of traditional OPI consumers received SSDI. A slightly higher percentage of OPI-E consumers (81%) received their health

insurance through Medicare compared to traditional OPI consumers (77%). This is somewhat higher than the 77% for OPI-E consumers in 2014 (OPI-E Report, 2015). Income and benefits information was less likely to be reported for the traditional consumers compared to OPI-E consumers.

**TABLE 1-4. CONSUMER CHARACTERISTICS BY PROGRAM TYPE: FY2015-2017**

Characteristic	Traditional		Pilot	
	#	%	#	%
<b>Household Size</b>				
One	1,993	52	230	40
Two	583	15	60	10
Three	33	1	9	2
Four or more	6	0	8	1
Unknown	1,209	32	274	47
<b>Monthly Income</b>				
\$1,000 or less	652	17	166	29
\$1001-\$1,500	1,313	34	236	41
\$1,501-\$2,000	750	20	69	12
\$2,001-\$3,000	416	11	61	10
\$3,000 or more	221	6	15	3
Unknown	472	12	34	6
<b>Social Security Disability Income</b>				
Yes	401	10	472	81
No	2,987	78	78	13
Unknown	436	11	31	5
<b>Medicare</b>				
Yes	2,927	77	495	85
No	461	12	55	9
Unknown	436	11	31	5
<b>Total</b>	<b>3,824</b>		<b>581</b>	

## Risk Assessment Data Summary

Table 1-5 on the right presents data from the RTZ system used by Oregon’s AAAs. Included here is information about liquid assets, risk assessment, fall history, and perceived caregiver stress. Note that for each category, more than one-third of the data are missing. As a result, these tables need to be interpreted with caution.

According to these data, most OPI-E consumers have assets of \$10,000 or more for an individual or \$15,000 or more for a couple. The pattern of risk scores are similar to those reported in 2014, with the highest percentages having moderate risk followed by high risk. The

percentage of those with no risk was lower in 2015-2017 (1%) compared to 2014 (15%) (OPI-E Report, 2015). Percentages of caregivers being overwhelmed or stressed were nearly the same over time (30-31%).

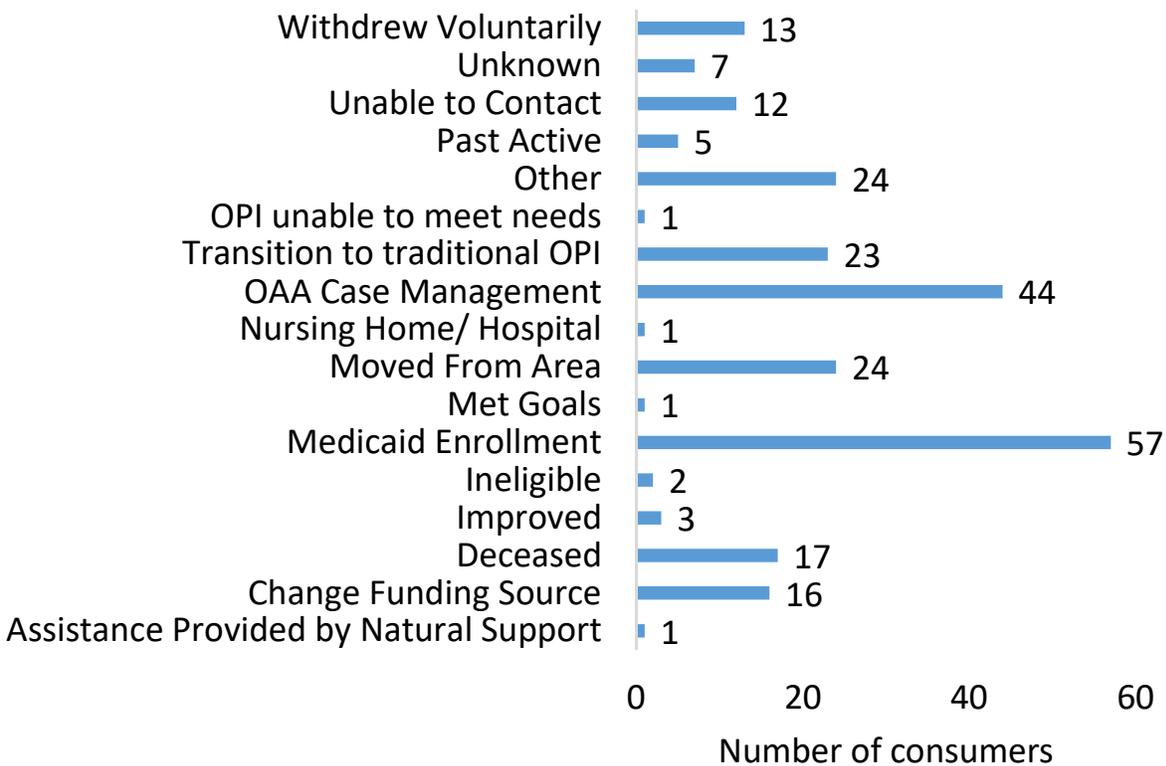
**TABLE 1-5. RTZ DATA FOR OPI-E CLIENTS ONLY: FY2015-2017**

<b>Characteristic</b>	<b>#</b>	<b>%</b>
<b>Liquid Assets</b>		
<b>Less than \$10,000 (\$15,000 for a couple)</b>	340	5
<b>\$10,000 or more (\$15,000 for a couple)</b>	27	59
<b>Unknown/missing</b>	214	37
<b>Risk Assessment</b>		
<b>No Risk (N)</b>	4	1
<b>Low Risk (L)</b>	61	10
<b>Moderate Risk (M)</b>	188	32
<b>High (H)</b>	125	22
<b>Missing</b>	203	35
<b>Recent Falls with Injury</b>		
<b>Yes</b>	130	22
<b>No</b>	245	42
<b>Missing</b>	206	35
<b>Caregiver Overwhelmed or Stressed</b>		
<b>Yes</b>	124	31
<b>No</b>	251	43
<b>Missing</b>	206	35

## Service closure

From the data available, the reasons for service closure for 251 OPI-E consumers are displayed below in Figure 1-5. The major reason was Medicaid enrollment (n=57; 23%) followed by OAA case management assuming responsibility (44; 18%). Twenty-four moved out of the area and another 24 left for unspecified reasons (n=24). A similar number (23) aged into the traditional OPI program.

The pattern was somewhat different in 2014 (OPI-E Report, 2015); 77 left the program. As in 2015-2017, the major reasons for leaving was enrolling in Medicaid (n=30; 40%). However proportionately more withdrew voluntarily (n=17; 22%), or died (n=13; 17%) in 2014.).



**FIGURE 1-5. NUMBER OF OPI-E CONSUMERS BY SERVICE CLOSURE REASON (EXCLUDING 330 MISSING CASES): FY2015-2017**

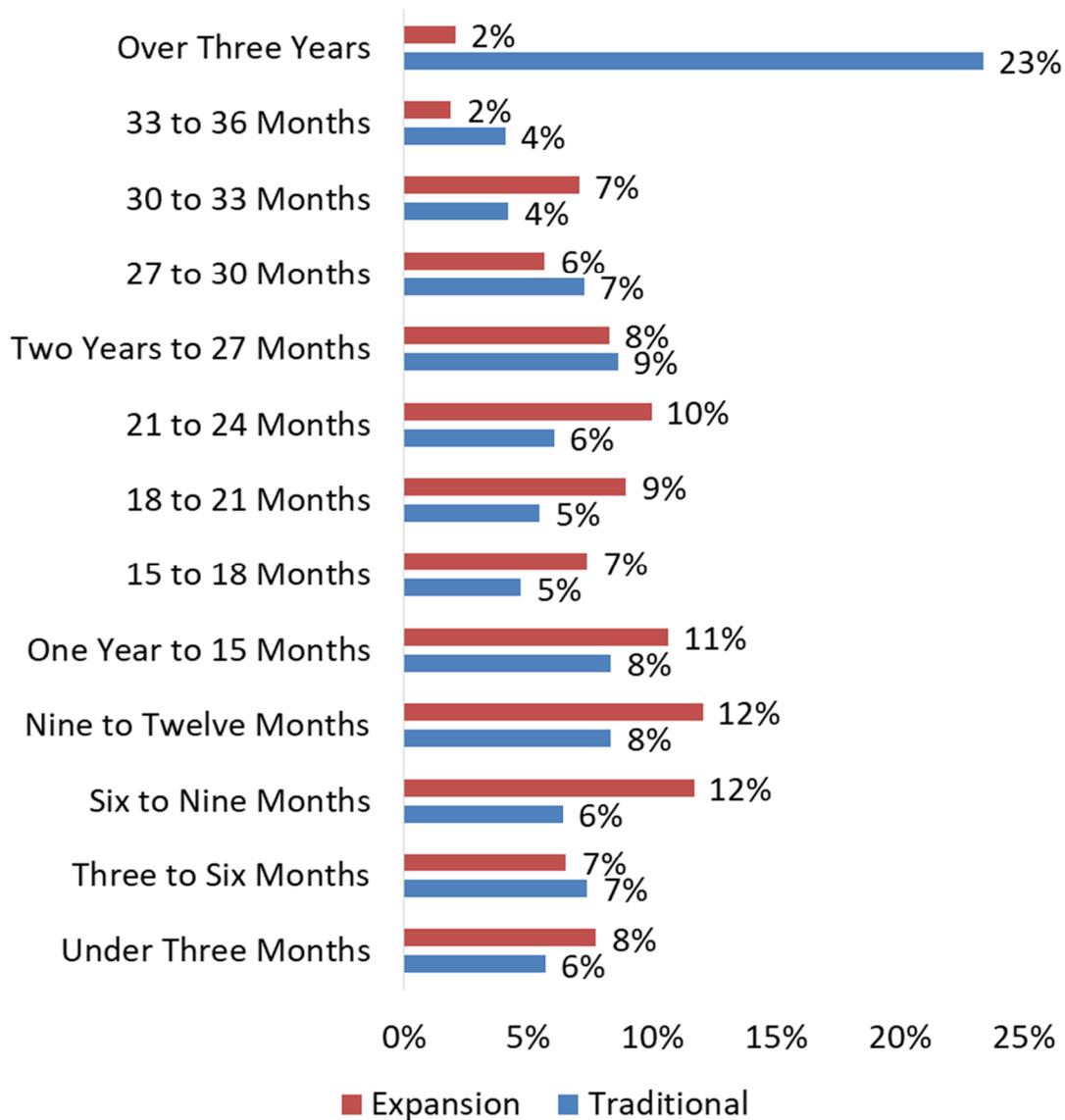
## Service and Costs

The monthly average cost for FY2016-2017 biennium was \$243.69 for traditional OPI and \$393.24 for OPI-E consumers. However, there was large variation across AAAs in terms of average costs, reflecting different services provided as well as cost of services (e.g., labor costs). The costs for OPI-E consumers were somewhat higher in 2015-2017 compared to 2014, when the average cost reported was \$335 per month (OPI-E Report, 2015).

The total cost of services was \$5,024,247 for OPI-E during FY2016-2017. A third of the total cost (31.06%) was spent for home care workers, followed by case management (25.22%) and Home Care through In Home Care Agencies (IHCA; 12.74%). Other sizable costs included area plan administration (8.98%), HDM (8.43%), and personal care IHCA (6.64%). The remaining cost categories were health and medical equipment (1.97%), options counseling (1.90%), transportation assistance (1.51%), chores (<1%), adult day care (<1%), caregiver training (<1%), and transportation (<1%).

## Service Length

Not surprisingly, significantly more traditional OPI consumers have been in the program longer than three years compared to OPI-E consumers (Figure 1-6). This is due to relatively short time that the OPI-E program has been operating. A larger percentage of OPI-E consumers have been served between 6 and 14 months compared to the traditional OPI clients.



**FIGURE 1-6. OPI CLIENTS BY SERVICE LENGTH AND PROGRAM TYPE: FY2015-2017**

## Summary

The OPI-E pilot program grew from 398 in 2014 (a 12-month period) to 581 people served during the 2015-2017 biennium, a 46% increase, suggesting that the program is growing to capacity in the seven AAAs piloting the program. During that time, consumers served by the program were more evenly distributed throughout the seven AAAs that were participating in the expansion as reflected by the decreasing percentage of OPI-E consumers served in Multnomah County from 45% in FY 2014 to 32% of those served during FY 2015-2017. Three of the four AAAs have a waiting list for OPI-E consumers, because demand in those communities has exceeded the funding allocation for those AAAs.

Over the course of the expansion, many OPI-E consumer characteristics have remained similar, including percentages of women and men served, the age distribution of OPI-E consumers, and the racial and ethnic distribution. Over these two time periods (2014 and 2015-2017), OPI-E consumers have also had similar levels of need as reflected in service priority levels and risk assessments.

OPI-E consumers in 2015-2017 differed somewhat from 2014 OPI-E consumers in some areas, including those in recent years having a higher level of assets and somewhat higher costs per consumer.

In addition to age, OPI-E consumers differed from traditional OPI consumers during 2015-2017 with respect to somewhat larger percentages of men and people of color served in the younger age group. A higher percentage of OPI-E consumers were served between 6 and 24 months compared to traditional OPI. This is likely due to the short time in which OPI-E has been operating. The service priority levels (SPL) reported by the two OPI programs differed, but with no clear pattern. Higher percentages of older adults had service priority scores indicating high needs but also lower levels of needs when compared to younger adults.

# PART II. LESSONS LEARNED FROM THE AREA AGENCIES ON AGING

Experiences of Area Agency on Aging Directors, Program Managers, and Case Managers between June and July 2018

## Introduction

The Oregon Project Independence Expansion (OPI-E) pilot project has been conducted in seven Area Agencies on Aging (AAA) since 2014. In Part II of this report, we focus on data collected through open-ended interviews with AAA staff who are most involved with the program either as case managers (which includes staff with titles of service coordinators) and program administrators including AAA directors or program managers. As described below, staff were asked to reflect on their current experience with OPI-E, which were then compared with those reported in the 2015 NWSDS evaluation report.<sup>4</sup> All of the findings in this section of the report represent the opinions and perceptions of AAA staff about the OPI-E program in the summer of 2018. As noted throughout this section, some findings represent major themes (identified by half or more of the staff across multiple AAAs) and common themes (identified by at least 20% of staff from at least two AAAs).<sup>5</sup> It is interesting to note, that while major and common themes emerged from the interviews, the responses to questions varied across staff and often within the same AAA. This variability is partially explained by the number of OPI-E clients served by the AAA and/or case manager; some case managers only had one consumer on their caseloads and as a result had little experience with the program. Some AAAs served very few OPI-E consumers and

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<sup>4</sup> 2014-2015 Expansion of Oregon Project Independence Report. June 30, 2015

<sup>5</sup> Numbers and percentages of staff are not generally reported because they can be misleading in qualitative analysis. It is noted when only one or two people made a comment. These comments are included because they may be helpful to program directors and policy makers in identifying ways to improve training and other support to AAAs.

others served large numbers. Length of time AAA staff had been on the job and previous work experiences also appeared to be a factor in the range of responses.

## What We Did

Findings from the previous report included lessons learned by pilot project staff. These lessons emerged from monthly calls held during 2014. The purpose of the calls was to facilitate the exchange of information and capture lessons learned over time. As described in 2015, five themes emerged from these calls and were revisited in the summer of 2018:

1. Outreach to the referral network
2. Service provider capacity (including in-home care services)
3. Unique characteristics of younger individuals
4. Converting Medicaid eligibility to MAGI (modified adjusted gross income) based standards
5. Challenges for rural Oregon

As part of the evaluation of the OPI-E pilot from 2015 to the present, these lessons were revisited to determine the extent to which issues described at the end of 2014 had been resolved or continued to represent challenges to the program. Structured open-ended interviews were conducted in June and July 2018 with 24 staff from all seven of the AAAs that participated in OPI-E.

Interviews included questions addressing the five original themes. In addition, AAA staff were asked about length of stays for consumers and reasons for closure, collecting and accessing data about program participants, and expanding the program statewide. Finally, they were asked generally about lessons learned and advice they would offer to other AAAs seeking to implement OPI-E services (see Appendix A for the interview questions).

Information provided by the AAA staff was reviewed by three members of the evaluation team, each of whom had conducted several of the interviews. Analysis consisted of identifying themes found in responses from multiple AAA staff and coming to agreement among members of the evaluation team on those themes and the conclusions drawn.

## OPI-E Pilot AAAs

The seven AAAs all serve adults 59 years and younger who meet general program requirements for activities of daily living (ADL) support using Client Assessment and Planning System (CAPS). Each AAA has the flexibility to implement the program in slightly different ways, including specific inclusion criteria, number of hours available, and types of services provided. The AAAs participating in the pilot project included both Type A and Type B agencies and were located in both rural and urban areas of the state. The total number of OPI-E consumers served by the AAAs during FY 2015-17 ranged from 21 to 187, with the average number of consumers served at any one time averaging 5 to 71 (Table 2-1).

The type of AAA is provided because this influences the extent to which the AAA is directly involved in Medicaid assessment and case management.<sup>6</sup> In general, Type A AAAs administer Older Americans Act (OAA) and OPI program services. Medicaid, financial services, adult protective services, and regulatory programs are administered by local Aging and People with Disability offices in those service areas. In contrast, Type B AAAs administer all services: to OAA and OPI services, Type B AAAs provided all of these services. Knowing the type of AAA helps interpret similarities and differences between the experiences of OPI-E pilot AAAs.

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<sup>6</sup> For more information about Type A and Type B AAAs, please see [https://www.oregon.gov/DHS/SENIORS-DISABILITIES/SUA/AAABusinessTraining/Agency\\_Type\\_Overview%2007-2017.pdf](https://www.oregon.gov/DHS/SENIORS-DISABILITIES/SUA/AAABusinessTraining/Agency_Type_Overview%2007-2017.pdf)

**TABLE 2-1. PILOT AAAs AND OPI-E CONSUMERS SERVED**

<b>AAA</b>	<b>AAA type</b>	<b>Counties served</b>	<b>Total # of consumers served FY 2015 – 17</b>	<b>Range, avg # of OPI-E consumers served monthly Nov 2017 – Aug 2018</b>
<b>CAPECO</b>	Type A	Umatilla, Morrow, Gilliam, Wheeler <sup>7</sup>	21	Range 3-6; average 5
<b>LCOG</b>	Type B	Lane County	97	Range 41-63; average 52
<b>MCADVS</b>	Type B	Multnomah County	187	Range 65-79; average 71
<b>NWSDS</b>	Type B	Marion, Polk, Yamhill, Tillamook, Clatsop	41	Range 13-25; average 20
<b>OCWCOG</b>	Type B	Linn, Benton, Lincoln	78	Range 30-38; average 35
<b>RVCOG</b>	Type B Contract	Jackson, Josephine	100	Range 38-52; average 46
<b>WCDAVS</b>	Type A	Washington County	57	Range 24-29; average 28

<sup>7</sup> Beginning in October 2018, subsequent to data collection, Sherman, Wasco, and Hood River Counties have been added to the planning and service area for CAPECO.

## Who We Interviewed

The 24 people who were interviewed included three AAA directors and four program managers who supervised and managed the OPI-E program, 16 case managers or service coordinators who worked directly with OPI-E consumers, and one quality assurance staff person who provided training and program review. Directors or program managers, and case managers or service coordinators represented all seven of the pilot AAAs. One participating case manager had recently left her position. Three case managers on the original list to interview did not participate: One was no longer with the agency, one was brand new to the agency and did not respond to requests to participate, and one was on vacation during data collection. Table 2-2 provides additional information about the people who filled these roles.

**TABLE 2-2. DESCRIPTION OF AAA STAFF INTERVIEWED**

<p><b>Case Managers (13), Service Coordinators (3), Quality Assurance (1)</b></p> <p>Time in the job</p> <ul style="list-style-type: none"><li>• Range: 6 weeks – 4 years (i.e., from the beginning)</li><li>• Average: 2 ½ years</li><li>• Median: 3 years</li></ul> <p>Primary roles</p> <ul style="list-style-type: none"><li>• 14 supported consumers in multiple programs (e.g., OPI-E plus traditional OPI, Medicaid)</li><li>• Two case managers (two AAAs) served OPI-E consumers only</li></ul> <p><b>AAA Directors (3) and Program Managers (4)</b></p> <p>Time in the job</p> <ul style="list-style-type: none"><li>• Range: 9 months – 7 years</li><li>• Average: 3.89 years</li><li>• Median: 3 ½ years</li><li>• Most had been working at the agency and involved with OPI and OPI-E in roles held prior to their current leadership role.</li></ul> <p>Primary roles</p> <ul style="list-style-type: none"><li>• Management, oversight of case managers</li><li>• Communication, including facilitating communication between case managers and the state program</li></ul>
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## Status of the 2014 “Lessons Learned” in 2018

### Outreach and referral network

In 2014, AAA staff reported that internal and community referral sources were critical (OPI-E report, 2015). They found that dedicated staff time to deliver in-person outreach was most effective in building referral relationships. They also received very positive feedback from the community referral partners about the expansion of OPI to younger adults.

**Awareness.** In 2018, most of the AAA staff reported having a very strong referral network through the Aging and Disability Resource Centers (ADRCs). In this way the OPI-E program was well integrated into AAA services. Beyond the Aging Services Network, however, the perceived awareness of the referral network about the OPI-E program was mixed. For example, staff in some AAA reported that the ADRC Information and Assistance staff knew a lot about the program but that those working in disability services did not. Other staff noted that more effort was needed to reach adults with disabilities who are employed, hospital discharge planners, medical professionals, and the general community. Still other staff expressed concern that more community awareness could result in greater demand for program than the AAA’s capacity to meet it.

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*“It still surprises me how many people don’t know about the pilot. [We have] offered that opportunity everywhere we go. Three of us do presentations at conferences . . . [we] talk on resources available-including this program. [We do] tabling, networking, intentional movement within our organization.”*

*-AAA Director*

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**Outreach.** The ongoing outreach by AAAs for the OPI-E pilot varied considerably. Differences were associated with the numbers of OPI-E consumers served (both currently and historically), the capacity of the agency to serve more, whether or not there was a waiting list, adequate staffing for case management and/or outreach, and the agency’s overall approach to outreach. For most of the AAAs, ongoing outreach was provided by the ADRC or designated staff who

regularly promoted multiple programs offered through the AAAs and their key partners. One of the AAAs felt they had steady referrals plus a waitlist, so they were not doing ongoing outreach. Another did very little outreach and relied on word-of-mouth through the community. Regardless of the extent of outreach, this was clearly an ongoing challenge that requires major agency commitment.

## AAA Capacity to Provide OPI-E services

In 2014, capacity of local service providers to serve the pilot consumers was one of the topics discussed by AAA staff. Concerns included contractors for one-time services (e.g., heavy housekeeping, assisted transportation, and construction of ramps). The lack of home care services were also issues, particularly in one AAA. (OPI-E Report, 2015). In 2018, we asked specifically about experiences with home care workers (HCWs) and in-home care agencies with the OPI-E population. We were also interested in the AAAs' capacity to serve OPI-E consumers at this stage of program development. Specific questions focused on the ability of their AAA to serve OPI-E eligible clients, the strengths and limitations of their agencies related to the OPI-E pilot, adequacy of training, and organizational support (both from the AAA and state agencies).

**In-home care capacity.** OPI and OPI-E relies on two types of providers, HCWs who are employed directly by the consumer and are required to be listed in the registry of the Oregon Home Care Commission, and in-home care agencies who employ, train, and schedule workers. The consumer chooses the in-home care provider, although choices may be limited in a particular community. The information presented in this section is based on the knowledge of AAA staff who work with consumers and their insight into consumer experiences. In 2018, a major theme identified in all AAAs was limited access to home care services as a major challenge in serving OPI-E (and traditional OPI) consumers, “across the board it’s difficult,” “there are not enough of them [HCW or agencies].”

Case managers reported that both HCW and agency home care staff can work well for consumers, but there are challenges with each. A major challenge regardless of type of home care is the small number of hours of work available for each consumer compared to the Medicaid in home program. A common issue reported by AAA staff is that agencies are not willing to schedule workers for less than four or five-hour shifts allocated to the consumer. This is a similar issue with HCWs who AAA staff find reluctant to work for consumers with limited hours.

The reluctance to work for less than four hours is related to time and costs related to transportation. Although these experiences were common across all AAAs, it was especially challenging in rural communities where distances to and between consumers are great. Turnover in home care workers is another challenge reported by AAA staff and occurs across employee types.

AAA staff reported that HCWs are preferred by some of the consumers they serve. Reasons given by AAA staff were that a HCW may provide the consumer with more autonomy, may be known to the consumer, and may be more willing to work within the constraints of the OPI program. At the same time, case managers observed that HCW can be very challenging for consumers. They reported many consumers find it difficult to navigate the registry, screen, hire, and manage the HCW, although the Employer Resource Connection (formerly the STEPS program) is available to help consumers to learn these skills.<sup>8</sup> Although some case managers found this resource to be of limited help for consumers, others reported it was extremely helpful.

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*“We have the STEPS<sup>8</sup> program to help with that [finding and hiring a HCW] but you can’t increase a person’s cognitive abilities.”*

*-Program Manager*

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<sup>8</sup> STEPS is currently called “Employer Resource Connection.” For more information see <https://www.oregon.gov/DHS/SENIORS-DISABILITIES/HCC/Pages/Steps.aspx>

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*“Boy, some clients that I’ve worked with, particularly [those] with behavioral health issues...I’ve been so resistant to encouraging them to hire their own [HCW], feared they wouldn’t make good decisions. I’ve been fooled, they’ve done great. Our STEPS worker here is great.”*

-Case Manager

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Although the choice of HCW is up to the consumer, a common theme from the case managers was concern that many HCW are not well trained in basic caregiving and are not prepared to work with the unique needs of their clients. Some case managers felt this group was less reliable than in-home care agency staff. Although rare, a couple of case managers provided examples where either the consumer or the HCW had been taken advantage of by the other. For these reasons, some case managers expressed preferences for working with in-home care agencies. They felt workers were better trained and that

issues with an individual worker could be addressed more easily.

Although lack of in-home services predominated the discussion of capacity, AAA staff indicated that other needed community-based care services were lacking as well. Lack of these services limit the ability of AAAs to expand OPI-E (and traditional OPI) services even if they had the staff and funding to do so. This will be discussed further in the subsection of this report describing the unique characteristics of OPI-E consumers.

**AAA program capacity.** The number of people being served by each AAA in the pilot program at the time of the interviews (June 2018) ranged from six to about 74 and was based on the agency budget for the program. In contrast, the number of traditional OPI consumers during this same time ranged from 37 to over 408. The reported capacity to serve OPI-E consumers varied significantly by AAA. Generally, and not surprisingly, the AAAs serving the largest number of OPI-E consumers were larger AAAs and indicated their organization had the capacity to serve this population. In contrast, AAAs in rural communities who also were serving the fewest consumers through OPI-E reported more limited capacity.

Three AAAs had a waitlist at the time of the interviews. One AAA had a total capacity to fund 20 OPI-E consumers and a waitlist of 20. ADRC staff regularly checked in with those on the waitlist and gave priority to those with the greatest need when a slot opened. This agency indicated that they had the staff and expertise to serve more if they had had more funding specifically for the program. Two of the AAAs had waitlists associated with being short-staffed; one was more than 100. Staff from both of these AAAs indicated they had new hires and were quickly working through the waitlist. They expected to be able to serve everyone on the waitlist who met eligibility criteria once new staff were fully trained and able to work independently.

Four of the agencies had no waitlist. Of these, one AAA reported that ongoing outreach was needed to keep enrollment at current levels, even though they had capacity to serve more. Another reported that not enough people in their service area were eligible for the program. One AAA indicated that potential clients had needs that could not be met through the program, such as a need for housing or complex care. The fourth indicated that although they had no waitlist, they were at capacity and accepted only internal agency referrals. Differences in those meeting eligibility criteria reflect, in part, differences in choices among AAAs about the types of services they provided. AAAs generally reported they had some excess capacity to serve OPI-E consumers, unlike the traditional OPI program which has long lists of people waiting for services in most of the AAAs.

**Program strengths.** The OPI-E program appears to be fully integrated into almost all of the AAAs with case management staff and other AAA staff fully understanding and embracing the program. Five of the pilot AAAs are Type B agencies. In many of these, the OPI-E case manager also does Medicaid assessments and provides case management for Medicaid and OPI consumers. If a person does not meet Medicaid eligibility requirements for services, these case managers are able to tell them about OPI or OPI-E as well as other services they might qualify for. Other case managers have both traditional and OPI-E caseloads. Three of the AAA have at least one case manager dedicated primarily to OPI-E clients. These are the agencies serving the largest numbers of OPI-E consumers.

A major theme from the AAA staff was that OPI-E had helped to address a previously unmet need in their communities, reporting that these few hours of services per month made a difference in the lives of these younger consumers. When discussed, AAA staff reported they were able to meet the needs of most OPI-E consumers with the hours of services available. At the same time, the need for additional hours for some consumers in both OPI-E and traditional OPI was a common theme.

A major theme from most AAA staff included their ability to use all of the budget allocations within their programs effectively. As noted above, most AAA did not have waitlists. The consensus across agencies was that once an OPI-E consumer was enrolled in the program, the AAA was able to get services started promptly. Most felt the OPI-E program was well funded even as many of the staff indicated they could serve more people with more funding, and others noted limited community resources as described below. It is important to note that one of the reasons some AAAs did not have wait lists is likely related to lack of outreach which contributes to the lack of awareness in the community about OPI-E. With its long history, traditional OPI may be better known.

**Program limitations.** Although most AAA staff reported that the OPI-E program was adequately funded in their agencies, several staff also indicated that need exceeded available funds. This was reported by all staff in one of the AAAs with a waitlist but also by staff in other AAAs. Examples of funding limitations included inadequate staffing, including staffing for outreach, and time for identifying needed services that could supplement OPI-E services. A reduction in funds to the program resulting in service reduction for some consumers was also reported.

Although lack of funding was an issue for OPI-E, it was less so than for traditional OPI, with some staff noting greater funding per person for the OPI-E program. Several of the staff described long waitlists for those over 60. One person described situations of two siblings who were two years apart and had similar levels of ADL need. One could be served by OPI-E right away, but the other had been placed on a waitlist for traditional OPI.

Limitations identified by AAA staff also involved community capacity and limitations for client care which are beyond the scope of OPI programs. Limited availability of in-home services, as discussed above, was a major concern as were housing, transportation, and mental health services. These services are not funded through OPI.

**Training.** Most of the AAAs' case managers, directors, and program managers felt that the case management staff was well trained. Some noted their agencies commitment and investment in staff training, often conducting the training themselves. In addition, they feel case managers are well supported in their work. Staff from other AAAs suggested that it had taken time and persistence to accomplish this.

Most staff wanted more training and a few noted weaknesses in training. Sometimes it was inadequate. For example, changes in the HCW voucher system and CAPS tool was challenging in spite of webinars and peer-to-peer training. Most who made these comments indicated that training had been improving as these changes had become more integrated into the programs. Some staff (both management and case managers) felt that specific training on the OPI-E program would be helpful, such as identifying how the two OPI programs were different. A case manager in one AAA, where there had been extensive staff turnover, indicated that extensive training about the program was needed for all staff. Learning details of the program through co-workers was beneficial for some, as opposed to more formal training.

**Organizational support.** Case managers were asked about support that they received from their agencies. Most of the case managers indicated that their agencies were supportive or very supportive. For example, some of the comments from these case managers included: "[agency staff] love OPI and do their best to support the program," "I can go to my supervisor any time. This is an above and beyond kind of thing," "all see it as valuable and needed by the population." Only two indicated lack of support. One case manager suggested that it was difficult for some staff to focus on a population younger than 60 and also indicated a preference for services offered under the Older Americans Act. This person did not feel the AAA was committed to OPI, but this was not the perception of other

staff from this agency. Another case manager said agency turnover had presented challenges because new staff were less familiar with the program.

AAA directors and program managers were asked about support from Aging and People with Disability and/or the Community Services and Supports Unit (CSSU). Many indicated that they received good support, particularly from the CSSU staff who responded to questions and communicated well (e.g., getting information into the field). Areas where more assistance from the CSSU was desired included marketing the program and outreach to agencies outside of the aging network. Some other comments included tight budgets and desires for more flexibility in using funds.

## Unique Characteristics of Individuals Younger than 60

In 2014, AAA staff described the OPI-E population as having different life priorities than older adults. Some were still working and had strong desires to stay independent. They were described as more likely to have natural and community supports. At the same time, they were described as having more complex needs related to physical disability and co-occurring mental health disorders or intellectual disabilities.

In 2018, AAA staff were again asked about the similarities and differences between the older and younger populations served through the OPI programs. They were also asked whether these two consumer groups had different expectations about services. Responses to these two questions varied by AAA and by AAA staff within the AAAs.

Before exploring differences, however, it is important to note the similarities in these populations. Consumers in both groups were described by some staff as grateful for services (as well as both groups being described by other staff as being more demanding than the other). Both populations have activities of daily living (ADL) and/or instrumental activities of daily living (IADL) needs requiring in-home support (e.g., bathing, housekeeping, meals), and transportation). Both groups have complex needs related to chronic illness and/or disability, behavioral health and/or dementia, and various socioeconomic conditions. These complex needs typically require long-term services. As described by one program manager, they are both, “living on the edge, often borderline eligible for Medicaid or are experiencing declining health.” Others noted that consumers in both programs

are at risk for social isolation and loneliness, and both populations have unmet need. At the same time, staff generally felt that both groups are well served by the limited services and hours provided through OPI; these services serve to stabilize situations that would otherwise continue to deteriorate. In spite of the similarities ADL and IADL need, many of the conditions leading to OPI services appear to be quite different in these two age groups.

As in 2014, the most frequently noted difference with younger adults focused on behavioral health. Other differences involved the type of physical disability experienced, and different priorities related to life and family stage in life. Differences were also noted in the presence or absence of a social support system.

### Behavioral health needs of OPI-E consumers

When AAA staff were asked to compare the needs of consumers younger than 60 years with the traditional OPI consumers (60 years and older), seven of the 24 people interviewed (29%) from four different AAAs reported more behavioral health needs in the younger population compared to traditional OPI consumers. Two of these AAAs serve the highest numbers of OPI-E consumers, and two served among the lowest numbers. It is important to note that responses to the general question about differences between the two OPI populations varied widely within many AAAs, with some staff identifying behavioral health as an issue and others not.

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*“We have experienced that with a few clients. I don’t think it is any more challenging than dealing with ADL/IADL needs of the older adult population – they have cognitive and behavioral health issues, too, so there isn’t a major difference in the delivery of in-home care.”*

*-Program Manager*

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When asked specifically about behavioral needs, however, 67 percent of those interviewed – all of the staff in five AAAs, and half of those interviewed in a sixth – agreed that behavioral health was an issue for at least some of the consumers they served. Some with the largest caseloads estimated the prevalence at 40-60 percent. The more OPI-E consumers served by the staff person, the more likely

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*“Some people can make it more challenging to provide services, so that adds a layer of complexity just trying to keep services in place.”*

-Program Manager

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they were to report having a consumer with behavioral health needs. In only one of the smaller AAAs did all of the staff interviewed report no behavioral health needs among the OPI-E consumers they served.

The challenges described associated with serving consumers with behavioral health needs varied by staff and AAA. A few staff indicated that although behavioral health needs might be more present in the younger population, meeting these consumers’ needs were not any more complicated than meeting the needs of older adults. For example, one case

manager pointed out that younger adults might have mental health disorders and that older adults might have dementia. Each condition requires identification of specific needs, supports available, and resources to address those needs. This view was also captured by a AAA program manager. A few noted challenges of supporting people with a behavioral health needs. At the same time, many of those interviewed expressed concern about the general lack of behavioral health services within a community. This is true regardless of whether a person qualifies or does not qualify for OPI.

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*“The challenge is helping them maintain services in their homes. The home care workers (HCWs) switch out a lot because this group is honestly difficult to serve.”*

-Case Manager

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Several of the staff indicated that they tried to connect individuals to behavioral health services. Some staff who had backgrounds in behavioral health or ongoing partnerships with behavioral health providers described successes in working with OPI-E consumers who also had behavioral health needs.

*“We help to connect them with behavioral health services, which are limited . . . There is a lot of unmet need.”*

-Program Manager

*“. . . There are no behavioral health services available unless they have Medicaid. We’re instructed to send them to mental health. Well, there is no mental health.”*

-Case Manager

*“[Behavioral health needs are] common for a lot of people with disabilities, they are more likely to have experienced abuse or trauma, mental health needs that go unmet. . . . There are limitations in being able to address [these needs] because of the program’s limitations . . . People need access to behavioral or mental health.”*

-Case Manager

*“Mental health should have their own OPI program. As far as behavioral needs, it needs to grow more towards mental health and having those counselors or skills trainers for a lot of the people.”*

-Case Manager

It should be noted that OPI is not intended to serve individuals whose primary need is driven by a behavioral health issue. The fact that there are so many individuals with behavioral health conditions is indicative of the lack of mental health services throughout the state, especially for individuals who need in-home supports.

**Physical disabilities.** Participants who described differences in physical abilities and disabilities were fairly evenly split in describing younger OPI consumers as more disabled or less disabled than older consumers; no clear themes emerged from the interviews. These different perspectives were present within many of the AAAs. Some of the staff who viewed younger consumers as more disabled, described them as recovering from a surgery or a temporary disability. Others described younger consumers as more disabled because of a long-term disability (whether due to chronic illness, birth defects, or accident).

For the most part, these individuals had lived with the condition successfully without OPI support for a long time. The reason these younger adults began receiving OPI-E services was that their health or physical abilities were declining and they could no longer manage on their own or with the supports they had used in the past. This group of consumers were described as most interested in maintaining their independence and/or struggling with coming to terms with their loss of function. Some AAA staff reported younger consumers are less likely to need or want physical hands-on care compared to older users, finding transportation to be especially important.

These different views about the disability are indicative of the wide range of need that the OPI-E program addresses as well as the variation in AAA staff experiences. Those who had served only one or two consumers were limited to observations from those experiences.

**Social support.** As with physical disabilities, AAA staff reported a wide range of experiences with OPI-E consumers and their social support systems. Consumers were described by some staff as having more natural supports and by other staff as having less compared to traditional OPI consumers. One case manager indicated that availability of natural supports varies widely for the younger population. This may be associated, in part, with the extent to which the person has a history of behavioral health needs. One notable difference between younger and older OPI consumers is who provides natural support services. According to the staff who discussed social support, older adults tend to get support from adult children whereas younger adults receive support from a spouse or partner.

**Life priorities.** A few of the AAA staff indicated that younger and older OPI consumers may have different priorities based on their age and life stage. Some, particularly those without behavioral health needs, may be working or trying to

maintain a job. They may own property. As a result of increasing ADL and IADL need, housing and financial needs may be greater for OPI-E consumers. Some of the younger OPI consumers may be raising children. AAA staff reported that this added another worry for some of the OPI-E consumers, who worried that Child Protective Services might take their children if the agency determined the parent was no longer able to provide care.

**Expectations.** Participants also were asked if OPI-E consumers had different expectations for services than traditional OPI consumers. Again the response was mixed, though most of those who noted differences indicated that younger consumers were more demanding and had higher expectations for services. At the same time, other staff framed the issue differently, indicating that younger adults were more clear about their needs, may have had more experiences with and understanding of the service system, and therefore better able to advocate for themselves. At the same time, a few staff indicated that younger consumers had less history with the service system, many may not know about services, and that prior to OPI-E had not been eligible for services. These individuals were described as especially grateful for the OPI-E program.

## Medicaid and OPI and State Data Systems

It is important to emphasize that those receiving support from Medicaid are not eligible for either the traditional OPI or OPI-E programs. The expansion of Medicaid, due to the Affordable Care Act, during the implementation of OPI-E in 2014 changed the projected needs for OPI-E as more consumers became eligible for Medicaid services. More recently, the CAPS assessment program which determines eligibility for both Medicaid and OPI was revised, resulting in additional challenges to AAAs and case managers as they learned to navigate these changes. In 2014, AAA staff found it difficult to access and communicate with the state's data systems about a consumer's status with Medicaid. In the 2018 interviews, we asked AAA staff about difficulties with accessing and obtaining information needed to determine OPI eligibility to assure no conflict with Medicaid. We also asked about any challenges experienced by AAA staff in obtaining and recording data needed to track and evaluate the program.

**Determining eligibility.** The vast majority of AAA staff indicated that they easily were able to access and obtain information they needed to determine eligibility for OPI and ensure that prospective OPI consumers were not eligible for Medicaid. This was especially true for Type B AAAs, which also manage Medicaid services. In many of these programs, the person doing the assessment is the same for Medicaid, traditional OPI, and OPI-E consumers. If a person does not qualify for Medicaid, they are informed about the OPI programs. In some AAAs, staff indicated they could use Oregon ACCESS to learn of a person’s Medicaid status. A few staff indicated training had been very important in helping them understand different types of Medicaid services and what that meant for their work. A few people indicated that they found the system archaic. One staff found it “a pain” and not always possible to get into the system to check the Medicaid status of an individual. Another reported using precious time in obtaining information, which often required a call to APD in Salem. No distinctions were made in these comments between the two OPI programs.

**Challenges in obtaining and recording data.** A minority of the staff noted difficulties obtaining consumer data. Most of the issues had to do with getting accurate information from consumers. Although, according to one staff, “not a lot of documentation from consumers is required” by the OPI-E program, most of the issues related to obtaining consumer data involved getting accurate information. Some consumers did not want to complete forms while the person doing the intake was there or consumers had difficulties coming up with concrete numbers. Getting accurate information was also difficult when someone had a cognitive impairment.

Although the data system seemed satisfactory to some AAA staff, a common theme was a desire for a more streamlined system. More than one-third of the staff expressed frustration in having to record data in multiple places, often recording

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*“Having to enter duplicate data into multiple systems, one of which is not the system that actually activates their eligibility, so that second set of data entry is easy to forget or delay entry due to other workload priorities or demands.”*

*-AAA Director*

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the same information in two or more different systems. One person suggested that forms could be consolidated to reduce redundancy. One database was described by a staff person as “real old, complicated, and stupid.” Oregon ACCESS is used for needs and services plans. RTZ and spreadsheets or paper files developed by the agency were used to record and track other information (CAPS assessments, HCW time sheets, financial information). Getting aggregated reports of data submitted by the AAA was another challenge identified by several staff. Some relied on their own agency’s tracking system. For some, it was a workload issue, not having the time or “bandwidth” to generate and review reports. More often was the inability of the OPI or AAA program staff to generate the reports, instead relying on the state. According to one program manager, “Our small program is low on the state priority for pulling reports, so we don't get information back.” Others relied on their own tracking systems within their agency to track the program.

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*“We have people 50 miles out of town. We assign mileage for grocery shopping and that absorbs a lot of dollars. It’s difficult to find home care workers who will travel that far so sometimes we can’t open these clients.”*

*-Case Manager*

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## Challenges for Rural Oregon

In the 2014 report, AAA participants identified two major challenges for providing services in rural Oregon. The first involved characteristics of the consumer, namely being highly independent. AAA staff found telephone screenings to be misleading at times. Geographical distances limiting provider capacity and availability also were identified, especially for consumers who cannot drive (OPI-E report, 2015).

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*“Definitely not finding enough. I feel like the standards aren’t high enough. There’s a lack of training in the HCWs. There’s not really any oversight. If there’s an agency I think it works different. It’s just kind of the bare minimum with HCWs.”*

-Case Manager

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In 2018, none of the AAA staff identified consumer independence as a challenge for rural communities. However, geographical distances in every county, but particularly in the rural and frontier counties contributed to multiple challenges as described below. These challenges lead to the inability of AAAs to provide services to those who qualify for them.

**Home care services.** Issues related to provider capacity and service availability were identified by every AAA. Almost everyone interviewed identified the limited availability of home care providers by both agencies and home care workers (HCW). This is especially challenging in rural communities because of the travel time required for the few hours of work for each provider. Some consumers live more than an hour away from

available home care services. Some AAAs have been creative in contracting for higher hourly wages for in-home care agency providers, but this option is not available for HCWs. It appears that reimbursement for time available to HCWs in some circumstances<sup>9</sup> was not being accessed; none of the AAA staff mentioned this resource. Instead, travel time and mileage expenses were reported as barriers to providing services.

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*“Yes, getting in-home care agencies and HCW can be challenges, especially in [rural parts of the] county. Some people may know and request a HCW and that's great. The problem when we can't find home care services is not being able to keep the case open.”*

-Program Manager

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<sup>9</sup> HCW with a schedule of contiguous consumers supported DHS services (e.g., OPI, Medicaid, Developmentally Disabled, Mental Health) may receive reimbursement for mileage and travel time to consumers.

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*“We have enough caregivers through the agency we use, but it’s for such different needs – some tasks under cognitive skills. We don’t get to train these HCWs – it’s up to the client or the agency itself. I would guess a lot of these caregivers don’t have a lot of training or experience supporting people with more emotional needs. Agencies have a target market of older adults with more financial resources, so their training for caregivers is limited in this way.” -Case Manager*

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Additionally, this is not an option for all AAAs. The issues of travel to consumers is not the only concern. An added challenge noted by AAA staff is the limited pool of qualified HCWs and of in-home care agencies in these rural communities. As a result, staff reported that some consumers who are eligible for OPI, regardless of age and program cannot be served by the program.

### Transportation services.

Transportation was a close second in terms of challenges in rural communities identified by AAA staff. Multiple participants from every AAA identified transportation as a barrier. This included a lack of public transportation, especially door-to-door services. Some identified lack of medical transportation. One case manager described consumers who lived over an hour from the grocery store.

Although shopping was included as an OPI service, the time required for the shopping trip meant that other tasks needed by the consumer could not be addressed. Lack of medical transportation was another challenge identified by a case manager.

**Limited resources.** In addition to limited home care and transportation services, several of those interviewed working in rural areas identified lack of availability of other needed services. Those mentioned were meal services, home maintenance and repair services, durable medical equipment, and adult day services. Social isolation and loneliness was another unmet need. Some AAA staff expressed a desire for a warm line or volunteers who could be in contract with these people. Some described the shortage of physicians and general difficulty in finding providers who accept Medicare.

**Challenges for agencies.** In addition to the difficulties finding and providing services, AAA staff also experience challenges related to distance and small populations. This includes limited ability to do outreach for services (which in essence may not be available in many communities). Some of the case managers talked about their efforts to schedule visits with multiple consumers who live close together to maximize efficiency.

## Length of stay and reasons for closure

In general, once a person is on OPI, they stay until they have a change in condition or, in the case of OPI-E, they age into the traditional program. The exceptions are the few consumers who are enrolled in the program while they are recovering from an injury or surgery. The majority of AAA staff interviewed had been serving the same consumers throughout their tenure with the program. AAA staff were asked to identify the major reasons for closure when it did occur. Note that these numbers do not match the numbers reported in Part I. Part I provided data from all consumers during the 2015-2017 biennium and the numbers below are perceptions reported by the AAA staff participating in 2018 interviews. The interviewers read the following list which is organized by frequency of mention by AAA staff.

- Became eligible for Medicaid (16)
- Moved onto traditional OPI (12)
- Moved out of the area (8)
- Consumer met their goals (6)
- OPI-E was unable to meet consumer needs (6)
- Consumers withdrawing from the program (4)
- Consumer died (4)

Some of the staff offered other reasons for closure including: Not qualifying for services with the new CAPS assessment, consumer did not want to pay for OPI-E services anymore, and staff were unable to contact the consumer or their natural support system.

## 2018 Lessons Learned

Toward the end of the interview, we asked AAA staff to identify the major lessons they had learned providing OPI-E services. Four major themes emerged: The value of the program, relating to consumers, unmet need, and organization of the program.

**Value of the program.** About one-third of the AAA staff indicated that participating in the pilot gave them appreciation for the importance of the program for this age group. They felt that it is a good program. One case manager called it “very eye-opening.” Prior to OPI-E, very few services were available for this age group if they did not meet full eligibility requirements for Medicaid. Others emphasized how a little bit of service goes a long way as reflected in these comments.

*“A little goes a long way. This level of service makes a big difference. What we offer is usually enough.”*

-Case Manager

*“It’s a huge benefit to the community, meeting people who haven’t had a tangible option for basic tasks like keeping your house clean. Support to people with chronic issues, makes consumers feel validated in their issues.”*

-Case Manager

*“I’ve learned that a little bit goes a long way. Longer than I thought it would. Working with people who are younger, falls into “an ounce of prevention is worth a pound of cure.” . . . The pilot gives people a glimmer of hope. They don’t have to be down and having someone care about them really lightens their load... It’s nice to see people have hope.”*

-Case Manager

Relating to consumers. The lessons learned that seemed to resonate most with AAA staff (especially case managers) centered on the way they related to consumers. Just over 40% made comments that fell into this category. Many went on to say that learning to relate to OPI-E consumers led to their own personal growth. Some of the insights from staff included the importance of not making assumptions.

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*“Don’t go in and assume you know what clients will need based on their age. Each client is different whether they are 45 or 85 their needs are different.”*

-Program Manager

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*“That what you see is not always what you get. Everybody’s journey is different.”*

-Case Manager

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Some of the staff discussed ways of interacting and being with consumers. This included the need to build rapport, especially with people with behavioral health issues. More generally, many of the staff also indicated that they had learned the importance of empathy, flexibility, and creativity as well as the importance of consumer self-determination.

## CASE MANAGERS SAID...

*“Understanding the emotional aspect of what it means to lose function. It has changed the way I work. I help reframe, help them find peace with the change.”*

*“[Being] more patient as far as personal growth. Listen to them, and advocate for them in the community. . . Kind of expanding [boundaries of the program] and to be able to do your own type of case management and know what you can provide.”*

*“I learned to ask in a lot of creative ways what kinds of insurance they have, as it relates to eligibility.”*

*“Need to practice a lot of empathy. I’m learning more advocacy skills, mostly honoring self-determination. This has been a major eye opener. With family members, it’s respecting the person’s decisions. With agencies it’s getting them to be more flexible with their scheduling and worker assignments to meet client needs. Like finding a worker willing to care for the cat.”*

*“Being honest, being more patient. Just doing it differently. That they’re capable in some areas and finding what areas they’re really not capable. Writing it up in a way that they’re still in [the primary] role.”*

**Unmet need.** In spite of the value of the program, many staff saw needs that could not be met. Those making this observation referred to some of the themes discussed previously in this report, such as the complexity and wide array of needs, lack of behavioral health services for adults who do not meet full eligibility for Medicaid, and finding home care providers.

**Program logistics.** Those in leadership roles commented on lessons related to the program as a whole. Two people talked about the difficulty of finding and enrolling qualified consumers. As one stated:

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*“It goes back to that it’s actually more difficult than we thought to recruit individuals to the program. Thought there would be a lot of demand, but it is difficult to find right individual.” –AAA Director*

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Another person commented on the importance of having a separate program for this population, presumably as opposed to folding it into the OPI program. This person stated that:

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*“[AAAs] Have to be thoughtful when serving small numbers to make sure to maintain program integrity -- having the program serving a unique population through a separate program has worked well.” – AAA Director*

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Although the following comment could be categorized “relating to consumers theme,” it speaks to the training and preparation of case managers and service coordinators who work with this population. One of the case managers said that to work effectively with OPI-E consumers:

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*“[I had] to learn how things are different for this age group, relearning [overcoming] the indoctrination of Medicaid.” –Case Manager*

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## Recommendations

### Implementing OPI-E statewide

Virtually everyone interviewed said that OPI-E should be expanded statewide, with many saying “definitely,” or “absolutely.” Four were surprised that it was not already. The major reason given for expansion was that the program has been successful in the pilot counties, that OPI-E addresses an unmet need, and that the program is cost effective. Issues of equity were also at the heart of some comments as captured by these two Program Managers:

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*“This should be a state program. Services should be uniform across the state.”*

-Program Manager

*“It is always frustrating to me when different services are offered in different areas, especially publically funded services. These all should be available statewide.”* -Program Manager

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Two staff indicated that sufficient resources needed to accompany expansion. Only one person indicated that the program should be changed in any way if it were to be expanded and that person though the SPL should be lowered from 18 to 15.

### Advice from OPI-E staff

AAA staff were asked to offer advice to other AAAs or to case managers to prepare them to expand OPI services to younger consumers. Responses fell into five major categories:

- Know the population
- Work differently
- Outreach
- Assessment
- Training

**Know the population.** About one-fourth of the comments stressed the importance of knowing population under 60 years of age, with an emphasis on not making assumptions about need based on age or disability. As described earlier in this report, many of the AAA staff noted that OPI-E serves a different population with different needs than the older adult population. Specific comments included the importance expanding knowledge about emotional or behavioral health needs. Others indicated that to be effective, the case manager also need to develop or strengthen relationships with behavioral health providers and use release of information forms to assure that various providers can talk with one another.

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*“Expand your knowledge of emotional health needs to understand why people might seem why they aren’t making a lot of progress in their life. Have empathy and compassion for people. Empower people to continue asking for help; listen for other issues.”*

*-Case Manager*

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**Work differently.** In a similar vein, some of the AAA staff suggested that OPI staff needed to work differently to serve this population. Mostly this referred to the need for greater flexibility than many case managers are used to. Examples included allowing more funds for transportation, checking in more frequently with consumers, and unlearning the very prescribed processes used for working within the Medicaid program.

**Outreach.** Outreach is essential when beginning to serve this population. As one AAA Director stressed, it is important to “realize how much outreach it’s going to require.” Many of those interviewed indicated that they could be doing more outreach themselves. Some recommended that AAA OPI staff seek opportunities to make presentations about the program to educate the health care sector, including physicians and hospital staff. Another staff emphasized the importance of increasing public awareness about the service. Still another who works in a rural community emphasized the importance of being alert to the needs of the community through every day interactions.

**Assessment.** Although the population may be different, the assessment process and eligibility criteria are similar. One case manager from a Type B AAA suggested always screening for Medicaid first. If the person does not qualify for Medicaid, they may qualify for OPI. Because they do not do Medicaid assessments, Type A AAA providers might need additional training in assessment or documentation and may need to partner more closely with the local APD office.

One person emphasized the importance of doing a thorough assessment, noting that for many OPI-E consumers, this is the first time they have received formal services and so the assessment is especially important to make sure that things do not get missed.

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*“Know you can be the first service this person experiences and they will really need you to assess needs and make referrals. I know I'm the first in line, so I have to be aware, I'm the first eyes on this.” -Case Manager*

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**Training.** A few of the AAA staff emphasized the importance of having well-trained staff. Training that focuses on the population (including content about behavioral health) must be available, but also must include information on the technical aspects of the job, such as assessment and documentation.

## Summary and Recommendations

The OPI expansion pilot is valued by virtually everyone who was interviewed, especially by those who worked with more than a handful of consumers. The consensus is that the OPI-E has been able to address previously unmet needs in a vulnerable population and should continue statewide. Here are recommendations emerging from the data that should be considered in this expansion.

### Recommendation

1. Allocate funding for both OPI programs based on population and include costs for travel time for staff outreach and assessment activities into the allocation.
2. Increase funding for OPI to reduce the waitlists for those 60 years and over; maintain separate funding for OPI-E so that this younger population is not subsumed and lost in the larger program.

The variation in responses was striking, both within and between AAAs. Consistent with the variation in AAA programs throughout the state, variability was noted between the pilot sites. This was true for eligibility criteria. For example, at least one AAA appeared to exclude those with behavioral health needs while others provided significant support. Within agency differences were seen in staff assessments of unique characteristics of the population, including their needs and expectations.

Consistently, the message is that the needs of OPI consumers are typically complex, with a range of need that include changes in ability due to declines in physical and cognitive function and increased risk of social isolation and loneliness. At the same time, those in the OPI programs can be stabilized by relatively low levels of service. When differences between the two OPI populations were noted, a major theme from AAA staff was the presence of behavioral health issues in the physically disabled younger age group. Consumers with behavioral health needs could be especially challenging for case managers who may have little knowledge of the population or relationships with behavioral health providers.

## Recommendation

3. Provide basic behavioral health training to AAA staff.
4. Partner with Behavioral Health Specialists who provide training and complex case consultation that includes a focus on adults with disabilities.<sup>10</sup>

Another area of difference between AAAs was the amount and type of outreach conducted specific to the program. Although most AAAs indicated that their referral network (e.g., ADRC and partners) were aware of the program, some of the AAAs noted specific limitations. For example, many of those interviewed found little awareness from the general public or from health providers. Some AAAs had limited capacity for outreach. At the same time, some of those interviewed expressed concern that more outreach could lead to wait lists and an inability to meet need.

## Recommendation

5. Partner with the Community Services and Support Unit and AAAs to increase outreach for OPI-E to determine a more accurate estimate of need.

Assessment procedures varied by AAA. Some of those in Type B AAAs described the benefits of assessing first for Medicaid. Someone not able for Medicaid may be eligible for OPI and so OPI can be offered as an alternative.

## Recommendation

6. Explore closer partnerships enhance communication between APD and Type A AAAs to streamline determination of OPI eligibility and services.

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<sup>10</sup> For more information on this resource, see: <https://www.pdx.edu/iaa/older-adults-with-behavioral-health-needs>

Staff reported that both in-home care agency staff and HCW have provided positive experiences for consumers they serve. From these data, no one type of provider necessarily is better than another, although many staff found that in-home care providers tended to have better training. Also noted were difficulties some consumers experienced in hiring and managing HCW. At the same time, examples were provided where HCW provided more flexibility and were more able to meet consumer needs.

Staff from all AAAs also reported that finding in-home care providers, particularly in rural areas was challenging, for both traditional OPI and OPI-E. Some consumers could not be served because no care workers were available. In large part, this stems from the limited hours of service allowed through OPI as well as uncompensated transportation and travel time.

### **Recommendation**

7. Increase awareness of both AAA staff and consumers about the Employer Resource Connection.

8. Increase access to in-home care as well as reduce the burdens of limited hours on those who provide in-home services by increasing hours and addressing transportation issues. This is particularly important in rural communities and downtown Portland.

Data collection and data reports is challenging for AAAs, and not just for OPI services. Staff must enter data in multiple systems often requiring duplicate entry which reduces the quality of data.

### **Recommendation**

9. Support and prioritize ongoing efforts to improve state and local data systems and to improve information sharing.

# PART III. CONSUMER EXPERIENCES

## A Survey of Current Consumers in July 2018

### Introduction

In Part III of the evaluation we focus on the experiences of consumers of OPI-E services. This perspective had not been captured in previous evaluations of the OPI-E program. Hearing directly from consumers is the best way to understand how the program is working for individuals and to identify ways to improve the program.

In consultation with Oregon DHS, the IOA team decided to field the consumer satisfaction survey to OPI-E consumers who were still receiving services. This decision was based on concern that finding and identifying consumers described in Part I of this report would be challenging and that problems about recall would be extensive. All OPI-E consumers receiving services as of July 2018 (n=268) were asked to complete a survey about their experience with the program. This study was approved by Portland State University's Institutional Review Board. All quotes in this section of the report are those of OPI-E consumers.

### Methods

#### Study Design

A questionnaire was designed by the IOA in consultation with Oregon DHS. Questions measured the importance of specific services to the consumers' health and well-being, satisfaction with their OPI-E case manager, information about experiences with in-home caregivers, outcomes as a result of receiving OPI-E services, and overall satisfaction. Space was provided for comments. A \$10 gift card was provided for each consumer who completed the survey by the time data collection closed. Options were provided so that the consumer could complete and return the survey in a pre-postage paid envelope, complete the survey online, or request to do the survey by phone.

Because PSU does not meet IT standards for HIPAA compliance, PSU and DHS arranged to have DHS send packets containing survey materials directly to consumers (e.g., cover letter, survey, form to complete for receiving the gift card, and return envelope). Packets to all 268 OPI-E consumers were mailed on or about August 28, 2018. Two weeks later DHS sent postcard reminders to all consumers reminding them to complete the survey if they had not already done so and thanking those who had. As written surveys were returned, the information sheet with identifying information for the gift card (i.e., name and address) was removed from the survey to preserve anonymity.

## Sample Characteristics

Of the 268 questionnaires that were sent out by the Oregon Department of Human Services, IOA received information from a total of 126 respondents, a response rate of 47 percent. Most replied by mail (n=96; 76%), though several elected phone interviews (n=18; 14%), and some completed the survey online (n=12; 10%). Table 3-1 below compares selected characteristics of all OPI-E consumers during FY2015-17 with the consumers who completed the survey.

Overall, the sample largely mirrored all OPI-E consumers who received services in FY2015-17. Sixty-three percent of the survey sample was women compared to 59 percent for all OPI-E consumers in FY2015-17. Only seven percent were younger than 40 (9% among all OPI-E consumers) and half were between ages 55 and 59 (which was 49% among all OPI-E consumers). A large majority (91%) of respondents reported receiving Medicare compared to 90 percent of all OPI-E consumers. About a quarter of the respondents in the sample (28%) reported receiving services starting in 2018 and 38 percent had started receiving services before 2016. Finally, six percent of respondents were veterans.

A little over half (56%) of survey respondents lived alone compared to three quarters (75%) of all OPI-E consumers (see Table 3-1). Among respondents who lived with others, about 46 percent (24 out of 52 respondents) reported that they were responsible for at least one more person and 24 percent (13 out of 54 respondents) had someone under the age of 18 living with them.

## Help completing the survey

It is perhaps not surprising to find that the survey sample were more likely than the OPI-E sample as a whole to live with others. Living with others may have made it more likely for the consumer to complete the survey. Twenty percent of consumers (25 out of 124 respondents; two missing) received help completing the survey. Some of the people who provided help to consumers to complete the survey were relatives (e.g., mother, daughter, and spouse) and others (e.g., caregiver, roommate).

## First service start month/year

A large share of respondents (29 percent; 37 out of 126 respondents) did not know/remember when they first began to receive OPI services. Only 54 respondents (43 percent) reported the exact month and year of their service start date. Among the latter group, as of September 2018, average time since first service start was 21 months, ranging from zero to 57 months. Half of these respondents had first started receiving services 23 months or earlier. This suggests that these consumers had extensive experience with the OPI-E program.

**TABLE 3-1. COMPARISON OF CHARACTERISTICS OF OPI-E CONSUMERS FY2015-17 AND CONSUMER SURVEY RESPONDENTS**

	<b>All OPI-E Consumers FY 2015-17</b>	<b>Consumer Survey Respondents</b>
<b><i>Gender</i></b>		
<b>Women/Female</b>	59%	63%
<b>Men/Male</b>	41%	37%
<b>Other</b>	n/a	<1%
<b>Unknown/Missing</b>	0%	0%
<b><i>Age</i></b>		
<b>&lt;40</b>	9%	7%
<b>40-49</b>	18%	17%
<b>50-54</b>	24%	24%
<b>55-59</b>	49%	50%
<b>Unknown/Missing</b>	0%	2%
<b><i>Household Size (non-missing only for OPI-E)*</i></b>		
<b>One</b>	75%	56%
<b>Two</b>	20%	24%
<b>Three or more</b>	5%	19%
<b>Unknown/Missing</b>	n/a	1%
<b><i>Medicare (non-missing only for OPI-E)*</i></b>		
<b>Yes</b>	90%	91%
<b>No</b>	10%	8%
<b>Unknown/Missing</b>	n/a	1%
<b><i>Veteran</i></b>		
<b>Yes</b>	n/a	6%
<b>No</b>	n/a	93%
<b>Unknown/Missing</b>	n/a	<1%
<b><i>Service start date</i></b>		
<b>Prior to 2016</b>	69%	38%
<b>2016</b>	23%	20%
<b>2017</b>	7%	14%
<b>2018</b>	n/a	28%

*\*Note: Because there were a lot of unknown/missing values here for OPI-E data, these figures were recalculated to show the percentages for the known group only.*

## Results

Both qualitative and quantitative methods were used to analyze the data. Quantitative data is displayed first. Where appropriate, quotes from consumers are provided in italics and provide further information about the numbers appearing in the tables. Summaries of the qualitative data are presented at the end of the results section.

### Services received

We asked respondents which of 11 services provided by OPI they have received.<sup>11</sup> As shown in Table 3-2, almost all OPI-E consumers received personal and home care services, followed by chore services, service coordination and case management, and assisted transportation. It is important to note that most consumers did not actually receive chore services which means “assistance such as heavy housework, yard work, or sidewalk maintenance provided on an intermittent or one-time basis to assure health and safety” (OARS 411-032-0000 Definitions, 14). It is likely that consumers interpreted chore services to mean tasks such as housekeeping and meal preparation. Therefore, this finding should be interpreted with caution. Very few respondents reported receiving registered nursing services, options counseling, or adult day care services.

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<sup>11</sup> Although the question was designed so that respondents would select services they have and have not received, some respondents chose to select only services they did receive and left the others blank. After team discussions, we consider the blank responses to mean “no.”

**TABLE 3-2. PERCENTAGE OF RESPONDENTS WHO REPORTED RECEIVING SERVICES**

<b>Service type</b>	<b>Percent Receiving Services</b>
<b>Personal and home care</b>	91%
<b>Chore services*</b>	79%
<b>Service coordination/case management</b>	58%
<b>Assisted transportation</b>	44%
<b>Assistive technology</b>	27%
<b>Home delivered meals</b>	21%
<b>Health promotions services</b>	16%
<b>Family caregiving services</b>	13%
<b>Registered nursing services</b>	10%
<b>Options counseling</b>	7%
<b>Adult day care</b>	4%

\*This is most likely an over count due to misunderstanding of the term “chore services.”

The number of services received by each OPI-E consumer ranged from zero to eight. Almost three-quarters of the OPI-E consumers reported receiving three or more services (see Table 3-3).

**TABLE 3-3. NUMBER OF SERVICES RESPONDENTS REPORTED RECEIVING**

<b>Number of services received</b>	<b>Percent Receiving Services</b>
<b>0</b>	2%
<b>1-2</b>	25%
<b>3-4</b>	44%
<b>5-6</b>	21%
<b>7-8</b>	8%

## Importance of services received to consumer health and well-being

We asked respondents who reported receiving a particular service how important that service was to their health and well-being. The four response categories ranged from 1=not at all important to 4=very important. We excluded cases where respondents selected multiple response categories from the analysis reported here. Overall, respondents rated the importance of these services very highly. No services received ratings of “not at all important” or “not important” for any of the services received. All average scores were above 3.5 out of 4 (see Table 3-4).

**TABLE 3-4. PERCENTAGE OF RESPONDENTS WHO REPORTED RECEIVING SERVICES**

<b>Service type</b>	<b>Number of consumers receiving a service</b>	<b>Mean (1-4)</b>	<b>Minimum and Maximum Selected</b>	<b>Percent Agree or Strongly Agree</b>
<b>Personal and home care</b>	113	3.9	3-4	100%
<b>Chore services</b>	97	3.9	3-4	100%
<b>Adult day care</b>	5	3.6	3-4	100%
<b>Family caregiving services</b>	14	3.7	2-4	93%
<b>Health promotions services</b>	17	3.6	2-4	94%
<b>Registered nursing services</b>	9	3.7	3-4	100%
<b>Home delivered meals</b>	25	3.6	2-4	92%
<b>Assisted transportation</b>	52	3.8	2-4	98%
<b>Options counseling</b>	9	3.9	3-4	100%
<b>Service coordination/case management</b>	68	3.5	2-4	97%
<b>Assistive technology</b>	34	3.6	2-4	94%

## Most important service received for health and well-being

Respondents were asked to identify the most important service they received. Responses reflect the type of services received. Of the 91% who responded to this question, two-thirds (67 percent) indicated personal care and home care services were most important. Nearly one in five (18%) felt that chore services, which in most cases likely referred to home care, were the most important and about six percent named assisted transportation. Other services that were most important included family caregiving services, home delivered meals, and medication management. Each of these areas were mentioned by three or fewer respondents. Four people indicated that all of the services received were most important.

## Consumers' ratings of OPI case managers

The survey included a series of statements about OPI case managers (defined as “the person from aging services who helped you sign up for OPI”) and respondents were asked to rate their agreement (1=strongly disagree to 4=strongly agree). We excluded cases where respondents selected multiple response categories from the analysis reported here. Overall, respondents rated their OPI case managers very highly with all average ratings over 3.2 out of 4 (see Table 3-5). The lowest rating was assigned to “easy to contact,” although 82% did agree or strongly agree.

**TABLE 3-5. CONSUMERS' RATINGS OF OPI CASE MANAGERS**

<b>My OPI case manager...</b>	<b>N</b>	<b>Mean (1-4)</b>	<b>Minimum and Maximum Selected</b>	<b>Percent Agree or Strongly Agree</b>
<b>a. Is helpful</b>	122	3.6	1-4	96%
<b>b. Is respectful</b>	122	3.7	1-4	98%
<b>c. Is knowledgeable</b>	121	3.6	1-4	94%
<b>d. Considers my opinions, likes, and dislikes</b>	121	3.5	1-4	93%
<b>e. Explains services clearly</b>	120	3.5	1-4	89%
<b>f. Helped find services to meet my goals</b>	120	3.4	1-4	88%
<b>g. Responds to my concerns</b>	120	3.5	1-4	89%
<b>h. Is easy to contact</b>	119	3.2	1-4	82%
<b>i. Supports my decisions</b>	117	3.5	1-4	93%

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*“I know that I truly benefit from the services of OPI. My case manager has been wonderful. I would have more life difficulties without OPI. Thanks!”*

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Consumer comments reflected their ratings of case managers, illustrating both positive and negative experiences. Seven of the 11 comments about case managers were negative. Some expressed the desire for more support from their case manager, most often in navigating the service system and knowing what is available to them. Several found it difficult to find a home care worker (HCW) from the list they were provided. Two

consumers indicated they needed follow up with the agency. Positive comments from consumers who were content with the services they were receiving demonstrate their gratitude for the program and for the role of their case manager.

## Receiving services from home care workers

Ninety-three percent of respondents (116 out of 124) reported currently receiving services from a HCW. When asked what type of services their HCW currently provides, 93 percent reported housekeeping, 72 percent personal care, and 63 percent meal preparation. Forty-seven percent of respondents reported receiving other services from their HCW, such as shopping and running other errands including picking up medications or food. Other activities mentioned were, “listening to me complain,” doing laundry, helping manage medications, and being flexible and helping with, “what I need that day.”

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*“My new OPI representative has not been helpful at all. I have only got a list of caregivers and numbers. I don’t know who is available or not. [It is] causing increased distress.”*

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*“When I was initially accepted to the program, I was given a list of HCWs and to get someone was a pain in the arse. The person I have now is the only one who got back to me out of all those I contacted. [...] I wish there was a point of singularity for all the programs. Better educating the client on other support that may be available.”*

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A quarter of respondents (23 percent; 22 out of 95 respondents) did not know/remember when their HCW/agency started helping them. Overall, 66 respondents (70 percent) reported the exact month and year. Among the latter group, as of September 2018, average time since first service start was 16 months, ranging from zero to 65 months. However, half of these respondents had first started receiving services eight months or earlier. The discrepancy between average and median length of service is due to one consumer who reported receiving services from their HCW for about eight and a half years. We assume that this consumer either paid privately for care prior to OPI, or this was a family member who had not been reimbursed previously.

## Consumer satisfaction with their current home care workers

We asked respondents who currently received services from a home care worker about their views on several characteristics of the paid care worker, such as promptness, dependability, respect for the consumer, among others (see Table 3-6 below). The four response categories ranged from strongly disagree to strongly agree. We excluded cases where respondents selected multiple response categories from the analysis reported here. Overall, respondents rated their current home care workers very highly with all mean scores over 3.5 out of 4.

**TABLE 3-6. CONSUMERS' RATINGS OF HOME CARE WORKERS CURRENTLY EMPLOYED**

The paid care worker who comes to my home...	N	Mean (1-4)	Minimum and Maximum Selected	Percent Agree or Strongly Agree
<b>a. Is prompt</b>	113	3.5	1-4	90%
<b>b. Is dependable</b>	114	3.6	1-4	95%
<b>c. Does work the way I want it done</b>	114	3.5	1-4	94%
<b>d. Is respectful</b>	113	3.7	1-4	96%
<b>e. Does a good job</b>	115	3.6	1-4	96%
<b>f. Makes me feel comfortable</b>	114	3.8	1-4	97%
<b>g. Helps me be in control of my day</b>	113	3.5	1-4	93%
<b>h. Meets my needs for support</b>	114	3.6	1-4	93%
<b>i. Makes me feel safe</b>	115	3.7	1-4	97%
<b>j. Helps me accomplish my goals</b>	113	3.5	1-4	94%

## Consumers' perceptions of home care workers in general

All consumers who received services from a HCW were asked to rate a list of five statements related to experiences with HCWs: turnover, backup plans, worry over personal belongings, who to contact when desire changes, and receipt of additional social support. The four response categories ranged from strongly disagree to strongly agree. We excluded cases where respondents selected multiple response categories from the analysis reported here. A sizable share of

consumers (39%) perceived a high turnover among paid in-home care workers (see Table 3-7). Only one-third (34%) of consumers reported having a backup plan if their in-home care worker did not show up. Few (17%) worry about personal belongings. A large majority (89%) reported knowing who to contact if they wanted to make a change. Finally, two-thirds (66%) of consumers reported that their family members or friends provided support in addition to the caregiver.

**TABLE 3-7. CONSUMERS' PERCEPTIONS OF HOME CARE WORKERS**

<b>The paid care worker who comes to my home...</b>	<b>N</b>	<b>Mean (1-4)</b>	<b>Minimum and Maximum Selected</b>	<b>Percent Agree or Strongly Agree</b>
<b>a. Paid in-home care workers change too often</b>	115	2.3	1-4	39%
<b>b. I have a backup plan if the in-home care worker does not show up</b>	114	2.1	1-4	34%
<b>c. I worry about personal belongings</b>	115	1.6	1-4	17%
<b>d. I know who to contact if I want to make a change</b>	114	3.3	1-4	89%
<b>e. Family members or friends provide additional support</b>	115	2.7	1-4	66%

## Experience with workers (firing and quitting)

Among respondents with valid information (ever hired workers and non-missing), 38 percent (45 out of 119 respondents) reported ever firing workers who were hired to help them in their home. A large majority of respondents who ever fired a worker reported firing only one (63%) or two (24%). One consumer, clearly an outlier, reported firing over ten workers.

Among respondents with valid information (ever hired workers and non-missing), 42 percent (52 out of 123 respondents) reported workers who were hired to help them in their home quit. A majority of respondents whose workers ever quit reported only one (48%) or two (33%) workers quitting. There was only one person who reported over ten of their workers quit.

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*“I feel that more people who use the services should be made aware of how to find a caregiver. I see postings online almost daily for people looking for a caregiver, and have no idea how to locate a qualified one, how to interview, how to recognize a quality caregiver. As such, they often end up with unreliable and untrustworthy caregivers, and go through a number of them. I think they should check in regularly to make sure the caregiver is doing a good job. Too many people think they are ‘stuck’ with a bad caregiver or have no idea how to get a new one.”*

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*“Because of my income I still pay 40-50% from the cost and administration fees. I wish the brackets are not so high that allow more deduction or consider the cost of OPI when they decide the deduction from the services.”*

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## Benefits of OPI services

We asked all respondents about their experience with OPI services and whether the services they received improved their lives in various ways (see Table 3-8 below for the list). The four response categories ranged from strongly disagree to strongly agree. We excluded cases where respondents selected multiple response categories from the analysis reported here. Respondents rated OPI services very highly in terms of allowing to live in the place the

respondents most desired (92%), making them safer in their home (91%), and giving them independence (95%). Although the majority (60%) indicated that OPI-E helped them avoid running out of money, it was the lowest rating for possible benefits. A sizeable number of consumers were concerned about their finances.

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*“I have asked a number of times to give me more hours. . . . I asked again [and] they took one more away. I pay for more hours on my own, but I don’t think it is fair. . . .”*

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**TABLE 3-8. BENEFITS AND OUTCOMES OF OPI SERVICES**

OPI services...	N	Mean (1-4)	Minimum and Maximum Selected	Percent Agree or Strongly Agree
<b>a. Have allowed me to live in the place I most desire</b>	122	3.5	1-4	92%
<b>b. Have provided me enough support to meet my needs and preferences</b>	121	3.1	1-4	82%
<b>c. Made me safer in my home</b>	123	3.3	1-4	91%
<b>d. Have given me more independence</b>	120	3.5	1-4	95%
<b>e. Kept me from moving into a care setting such as a nursing home, assisted living, care home, group home</b>	120	3.0	1-4	73%
<b>f. Helped me maintain activities outside my home that are important to me</b>	120	3.1	1-4	77%
<b>g. Helped me avoid running out of money</b>	120	2.8	1-4	60%
<b>h. Helped me find the help I needed</b>	122	3.2	1-4	84%

When asked if they would recommend OPI to a friend or a family member, almost all respondents (98%) replied positively. However, when asked if they had concerns that OPI had not addressed, 32 percent (39 out of 123 respondents) also replied that they had; 12 consumers identified more than one unmet need. Half of those responding

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*“Funds keep getting cut and [consumer describes difficulty paying bills for non-OPI services] . . . . My worker’s hours keep getting cut.”*

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*“They should allow caregivers to accompany clients to doctor’s visits.”*

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indicated a range of unmet needs including transportation (n=7), health services (n=4), and meals (n=3). Other needs were unspecified or covered areas such as deep cleaning and housing. Eight of the consumers indicated that they lacked knowledge about various OPI services, or at least the terminology to

describe those services. For example, some consumers did not understand the term “options counselors” and one person was not aware of the program name, although knew OPI services came through aging services.

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*“Since I live in a rural area, I do not get to have transportation assistance to appointments. . . Getting to medical appointments, grocery store, church, etc.”*

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Respondents also were given space to provide open-ended comments about their OPI experiences. Eighty-nine people made comments (70 percent of the participants), and more than 40 percent had comments that reflected two or more themes. Themes reflecting open-ended comments and concerns were similar and are displayed in Table 3-9.

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*“Without this service, during the times my 74-year-old parents got sick, I could not have gotten through. I can’t drive or vacuum as I am in a wheelchair. Just the extra help made me stay independent. I was in the hospital nine months and would rather not go back to the facility.”*

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*“My OPI experience has been helpful and an important element of my independence when care is consistent. I think this is a great program and that it continues! Thank you.”*

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As shown in Table 3-9, the majority of comments made were quite positive and reflected appreciation and gratitude for the OPI-Expansion service. This sentiment is reflected in these responses.

**TABLE 3-9. COMMENTS AND CONCERNS**

<b>Themes</b>	<b>General Comments (n=89) # (%)</b>	<b>Needs not Met (n=39) # (%)</b>
<b>Overall positive (e.g., great, helpful, lifesaver, appreciate)</b>	51 (57%)	--
<b>Need more hours</b>	16 (18%)	10 (26%)
<b>Unmet Needs</b>	13 (15%)	20 (51%)
<b>Caregiver</b>		
• <b>Positive</b>	14 (16%)	--
• <b>Ambivalent/mixed</b>	5 (6%)	1 (2%)
• <b>Negative</b>	6 (7%)	2 (5%)
<b>Case manager</b>		
• <b>Positive</b>	4 (4%)	--
• <b>Negative</b>	7 (8%)	
<b>Lack of knowledge about OPI and/or available benefits/services</b>	6 (6%)	8 (20%)
<b>Costs</b>	4 (4%)	1 (2%)
<b>Follow-up needed</b>	2 (2%)	6 (15%)

At the same time, many of the consumers indicated that they needed more hours of service. Some made this comment in response to the question of unmet need and others made the point in the open-ended question. It seemed especially challenging to those who had seen their hours of OPI services cut. Here are some comments that illustrate this need.

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*“More hours would help me as I continue to decline! And previous to my current great help, hiring and finding help has been hard.”*

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*“The main problem I had with this program is that I didn’t have the hours I needed. Between going to the doctor and wound care and so on, it didn’t leave much time if any for house work!”*

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*“Since becoming disabled I lost my job, long-term relationship and home. I had to rent a room from an acquaintance. I started receiving OPI shortly after. Because of OPI I have been able to get an apartment and live near my family member who is my care worker. My quality of life is far greater than it has been for a very long-time because of OPI. I am very, very grateful!”*

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Most of the comments regarding caregivers were positive, although a significant number had ambivalent or negative experiences as illustrated below.

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*“My helper is awesome. She really helps with anything and helps me keep on top of chores. I feel much more “present” and capable from her assistance. I am very, very appreciative of OPI.”*

*“. . . There is a certain amount of dysfunction between my caregiver and myself. She does a good job, she is late and slow. But she stays until she gets the job done. The fact that she is here rather late makes me feel less lonely. So, it is a trade-off!”*

*“My worker has changed constantly. I have had ten workers in about six years. When I call I am assigned a new worker every time. [It is] difficult if not impossible to get a response from a worker. [It’s] hard to keep workers, as they are constantly leaving for better pay elsewhere.”*

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Fewer comments focused on case managers than in-home care workers. Those that did were more likely to describe negative experiences. This comment also reflects another theme of being uncertain about available services and options.

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*“. . . [It has] been frustrating sometimes to find out if there’s anything else available to me. [I] only hear from [the case manager] once a year when it’s time to renew my benefits. That part is frustrating. She hasn’t always been nice. I’ll leave it at that. I learned that I could get help with my incontinence supplies, but not from my case manager. I wish she had let me know when I qualified.”*

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Some of the consumers have questions they would like to have answered and found case managers unresponsive. The survey itself alerted some respondents that services might be available for them that they did not know about.

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*“Going through this form is bringing to light other things I didn’t know were available. I wish the options counseling – wish there was a point of singularity for all the programs. Better educating the client of other support that might be available.”*

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Some of the consumers are worried about what will happen to them wants they age into traditional OPI.

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*“Am I going to lose my worker when I turn 60 next year? My worker is the one that does most of the chores and driving, as I have a bad back and get severe migraine headaches when I have to do the driving for some of my chores when she isn’t here. I thank you for the opportunity to have participated in this program! Is it going to end? What am I supposed to do if it does end services for me at 60 years?”*

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## Summary

The consumers surveyed are very similar to those described in Part 1. The survey provided additional information about the experience of consumers who receive this

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*“OPI saved my life.”*

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service. Both qualitative and quantitative data show that consumers value OPI-E services. The majority stressed their appreciation and gratitude for the program, with several using terms such as “lifesaving” in their comments. Consumers reported that OPI-E contributes significantly to their independence, their ability to remain at home, and often support family members who also provide care. Most consumers rated their case managers quite positively.

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*“I would not be able to live at home if I didn’t have OPI – even if I have only 19.5 hours per month. I am in a wheelchair and have paralysis in my hands. I don’t have enough hours. I have no other options.”*

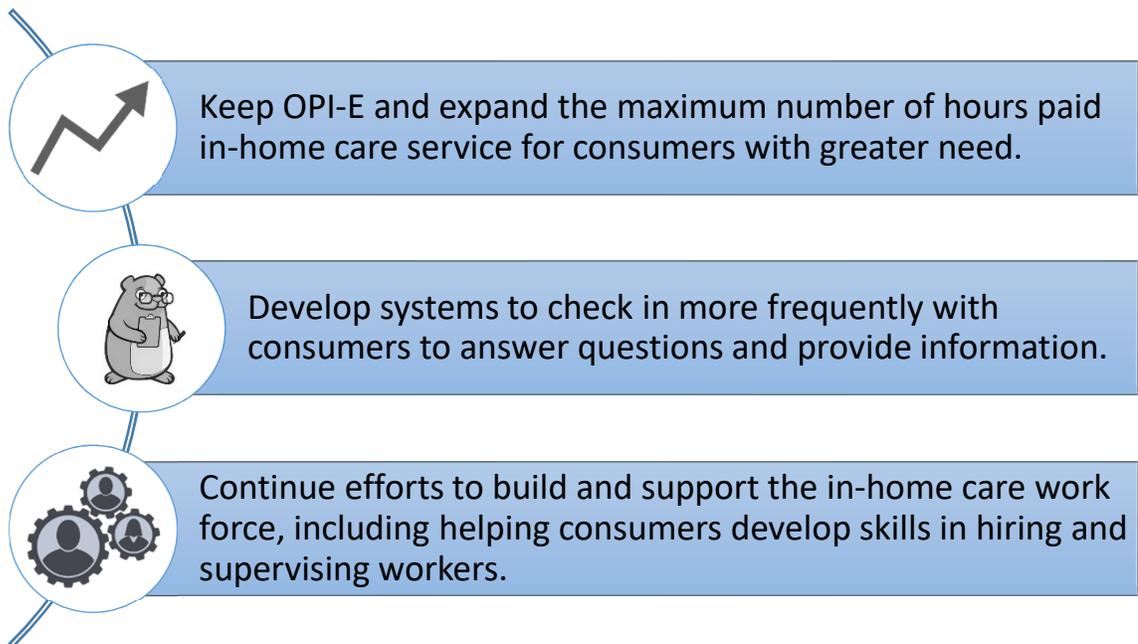
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All of the services received were rated by consumers as important or very important with most rated services they received as very important. The most common service received was personal and home care services and not surprisingly, this was the service identified as most important. The majority of respondents had very favorable views of their home care workers (HCWs), although comments reveal that finding, hiring, and supervising care workers was very challenging and stressful, particularly for those with limited energy. Those who had difficulties finding appropriate help wished for more guidance and assistance from the OPI-E program in doing this.

Many consumers in this sample, while very appreciative of the services received, had need for more hours of care. This was the area of need identified most in the comments provided by consumers. Similarly, and related to hours, many consumers indicated they had concerns that had not been addressed by OPI-E. Arguably, with more hours some of these needs could be met. Another theme emerging from the survey was uncertainty about other services and benefits available for the population. The list of possible services was eye-opening to some

consumers who were not familiar with services such as options counseling and thought they might benefit from them. Some consumers have concerns about their future – what will happen when they turn 60? How do they get questions answered?

## Recommendations



# PART IV. ESTIMATED NEED AND COST ESTIMATES TO EXPAND OPI-E STATEWIDE

## Introduction

This report documents the final cost estimates and describes methods and data sources used in the calculating the estimates for the population ages 18 through 59. In addition to the data available to us about the current OPI-E program, data sources for the estimates included the American Community Survey and the National Health Interview Survey. This part of the report estimates the need (number of consumers) and costs of expanding the Oregon Project Independence program to eligible Oregonians aged 19 and 59 across the state. This section of the report also provides documentation of methods and data sources used in the calculating the estimates.

The final total cost estimates to expand the OPI-E pilot ranges from \$6.3 to \$22 million<sup>12</sup> for FY2019-2020. The median estimate is \$12.54 million for the 2019-2020 biennium, with monthly costs per participant ranging from \$403 in 2019 to \$413 in 2020. Looking at both the lower-bounds and upper bounds of the estimate, the cost estimate per participant ranges from a low \$304 to \$626 in 2019 to a high of \$312 - \$641 in 2020. Overall, the program is expected to incur costs ranging from \$2.95 to \$11.14 million for 2019 and \$3.38 to \$11.58 for 2020. The cost estimates reported here do not take into account the potential fiscal benefits due to delayed participation of

The median estimate for legislative consideration is \$12.54 million for the 2019-2020 biennium, with monthly costs per participant ranging from \$403 in 2019 to \$413 in 2020.

<sup>12</sup> All monetary values are expressed as nominal (not inflation-adjusted), but cost estimates are adjusted for price increases in health care services using CMS Personal Health Care Price Index (see text for details).

eligible individuals in the Medicaid program, which has not been determined.<sup>13</sup>

The large range in the final estimates in this report reflects the underlying uncertainty in identifying the eligible population, population change, expected participation rate, and cost estimates. The large range in estimates is broadly attributable to four main sources of uncertainty:

- Scarcity of data sources necessary for estimation
- Unknown service needs of the currently non-participating, potentially-eligible population
- State-wide variation in potentially-eligible population and cost estimates
- The extent of future effort in reaching out to the potentially-eligible population by agencies (i.e., APD, AAAs) to increase awareness and to encourage participation

This report details the methods used to calculate the final estimates as well as the assumptions for each step.

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<sup>13</sup> Oregon Enterprise Data Analytics. (2016). *Describing differences between Oregon Project Independence & Medicaid Long-Term Care Consumers*. Oregon Department of Human Services and Oregon Health Authority.

## Eligibility Criteria for OPI Expansion

We begin first with a review of OPI-E eligibility criteria: “To qualify for OPI you must **need in-home assistance based on an assessment** and **not be receiving full medical coverage through Medicaid**, such as the Oregon Health Plan.” Here is how Oregon Administrative Rules define eligibility for “Pilot for Adults with Disabilities” (411-032-0050):

(A) To qualify for authorized services under this pilot, an individual must:

- (i) Be an **adult**<sup>14</sup> with a **disability**<sup>15</sup>;
- (ii) Be a resident of a designated pilot area and seek services at that location;
- (iii) Not be receiving Medicaid; and
- (iv) Meet the requirements of the long-term care services priority rules in OAR chapter 411, division 015.

## Methods: Data Sources and Assumptions for Cost Estimates

Several data sources were used and are presented in Table 4-1 along with the estimates (with a 95% confidence interval) calculated using these data sources. First, the American Community Survey (ACS) was used to calculate broad population estimates for Oregon. It is considered to be a reliable data source because ACS estimates of Oregon’s population were nearly identical to those of Oregon’s Population Research Center. The ACS was used to estimate the number of Oregonians age 19-59. The median estimate is 2,228,722. The table also presents of the range of estimates based on the 95% confidence interval. Large confidence intervals are due to low sample sizes in the state-level data and are unavoidable. They reflect the uncertainty in the estimates. ACS was also used to

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<sup>14</sup> "Adult" means, for purposes of this rule, any person 19 to 59 years of age.

<sup>15</sup> "Disability" means, for the purposes of this rule, a physical, cognitive, or emotional impairment which, for an individual, constitutes or results in a functional limitation in one or more of the activities of daily living defined in OAR 411-015-0006, or in one or more of the instrumental activities of daily living defined in OAR 411-015-0007.

estimate the population change multiplier. This multiplier is necessary to account for population increase and was calculated using the annual average growth coefficient in the past three years (2015-2017). It was calculated using the average growth coefficient, 1.4%, in the past three years (2015-2017). Finally, the ACS also was used to identify those between ages 19 and 59 who were not eligible for Medicaid, one of OPI-E's eligibility criteria.

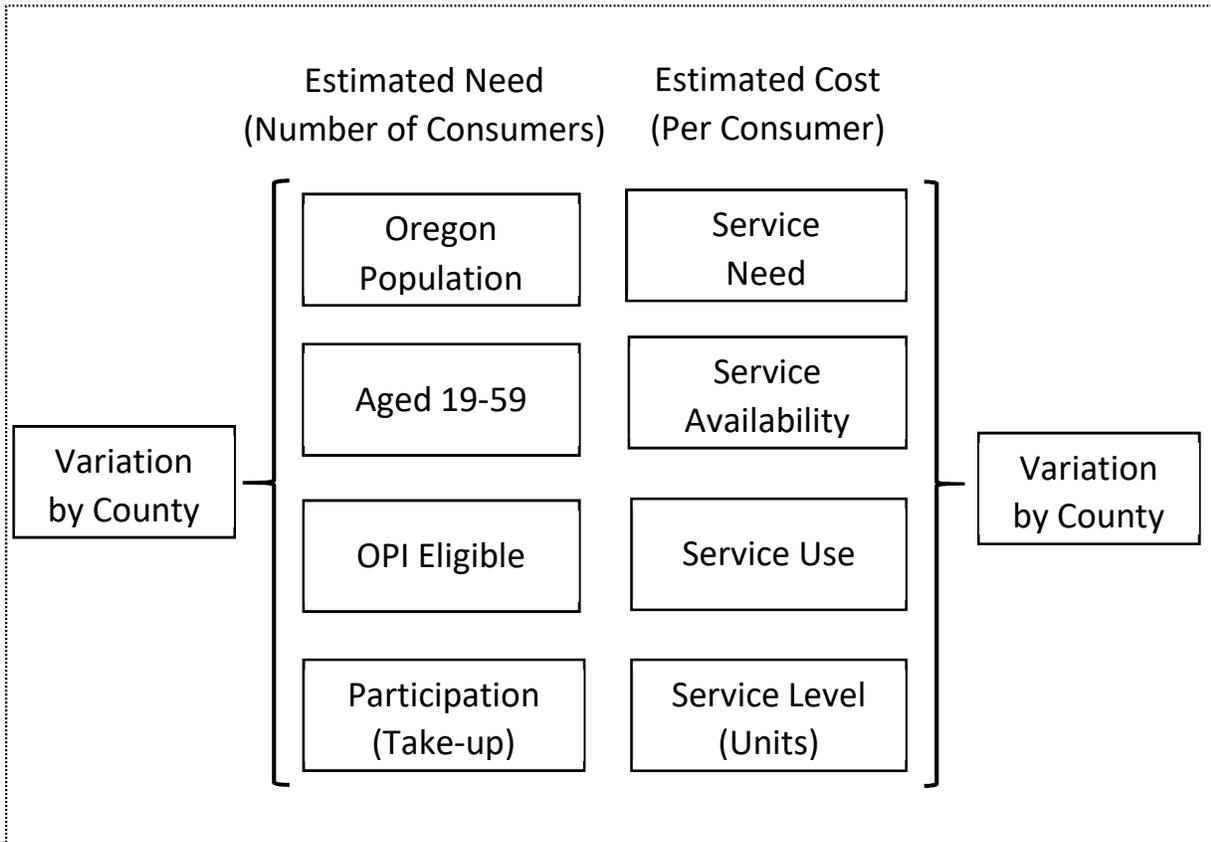
The National Health Interview Survey (NHIS) 2017 was used to estimate the need-based eligibility multiplier. This multiplier is used to ensure that only adults ages 19-59 with activities of daily living (ADL) or instrumental activities of daily living (IADL) needs are included in the eligible population. The NHIS includes questions about age, family income, and ADL and IADL needs. The sample was restricted to all respondents aged between 19 and 59. We created a binary variable to indicate whether a respondent reported any current ADL (eating, bathing, dressing, or getting around inside the house) or IADL (everyday household chores, doing necessary business, shopping, or getting around for other purposes) needs. Overall, 1.4% [CI 1.3%, 1.6%] of the population had at least 1 ADL or IADL need. Note that this is a national estimate. However, considering that no dataset that includes required information for calculating this multiplier exists at the state- or county-level, this serves as our best estimate. Using this data source, the median estimates for the number of eligible OPI-E participants is 25,438 people in 2019 and 25,794 in 2020. Note that the ADL and IADL measures that were used in the NHIS Survey may not reflect eligibility commensurate to the CAPS assessment used by Oregon AAA/APD.

**TABLE 4-1. DATA SOURCES AND ESTIMATES FOR ELIGIBLE POPULATION, PROGRAM PARTICIPATION RATE, AND EXPECTED NUMBER OF PROGRAM PARTICIPANTS**

	<b>Data Source</b>	<b>Estimate 2017 [95% CI]</b>	<b>2019 [LB; UB]</b>	<b>2020 [LB; UB]</b>
<b>Ages 19-59 – Oregon</b>	American Community Survey (ACS)	2,228,722 [2,190,821; 2,266,623]	Not needed	Not needed
<b>Population change multiplier</b>	American Community Survey (ACS) 2015-2017	1.4% [1.3%, 1.5%]		
<b>Ages 19-59 – Oregon Not Medicaid recipient</b>	American Community Survey (ACS)	1,791,882 [1,757,022; 1,826,742]	1,816,968 [1,779,863; 1,854,143]	1,842,406 [1,803,002; 1,881,955]
<b>Need-based eligibility multiplier</b>	National Health Interview Survey (NHIS)	1.4% [1.3%, 1.6%]		
<b>Estimated number of eligible Oregon residents</b>	Estimated number of Oregon residents aged 19-59 who may be eligible for services if OPI-E is expanded statewide		25,438 [23,138; 29,666]	25,794 [23,439; 30,111]
<b>Participation rate among eligible population</b>		5% 3.5%		
<b>Estimated program participants</b>			1,272 [810; 1,483]	1,290 [903; 1,506]

*Notes: CI indicates confidence intervals. LB=Lower bound estimate, UB=Upper bound estimate. Lower/upper bound estimates incorporate lowest/highest estimates for population sizes and each multiplier.*

Not all eligible individuals are expected to participate in the program; in fact, the rate has been and is expected to be much below 100 percent. Reasons include lack of perceived benefits, lack of awareness or knowledge, and social stigma against participation in public programs.<sup>16</sup> Figure 4-1 presents a summary of the process used to estimate needs and costs.



**FIGURE 4-1. PROCESS USED TO ESTIMATE NEEDS AND COSTS**

<sup>16</sup> Wright, B. J., Garcia-Alexander, G., Weller, M. A., & Baicker, K. (2017). Low-Cost Behavioral Nudges Increase Medicaid Take-Up Among Eligible Residents Of Oregon. *Health Affairs*, 36(5), 838–845

Benefits to signing up for OPI-E decrease somewhat linearly as household income increases due to the sliding scale cost-share structure. For those with over 400% of adjusted net income (as a percent of federal poverty guideline), cost share increases up to 100% of unit price.<sup>17</sup> Data from current OPI-E consumers with non-missing monthly income show that the majority (86%) had a monthly income less than \$2,000 (<200% FPG even for a single adult family). As such, we would expect very few eligible adults with incomes over 400% FPG to sign up for this program.

According to our calculations based on the State Health Access Data Assistance Center (SHADAC) suggested health insurance units and federal poverty guidelines using ACS data,<sup>18</sup> at least 50 percent of the eligible population would be above this threshold, thus reducing the expected number of participants by half. Moreover, even more publicly-recognized programs (such as Medicaid) encounter outreach and enrollment issues even among fully eligible population. For instance, estimates of take-up among the uninsured who are Medicaid-eligible in “Expansion” states implementing the Affordable Care Act range from 80% (among parents) to about 75% percent (among childless adults).<sup>19</sup>

To explore the potential participation rate, we matched the predicted number of eligible participants to the actual number of consumers served in three large counties (Multnomah, Lane, and Washington) in FY2017. We selected these counties because (1) American Community Survey provides county-level data for them and (2) OPI pilot program was administered in these counties solely by single AAA (hence we have number of consumers served for the county).

Table 4-2 below reports on estimated participation rates for these three counties, which ranged from 1 percent to 3.2 percent. These rates suggest an upper-bound participation rate of 5 percent among all eligible population to be reasonable.

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<sup>17</sup> <https://www.oregon.gov/DHS/SENIORS-DISABILITIES/SUA/Documents/OPI-Fee-Schedule-2018.pdf>

<sup>18</sup> <http://www.shadac.org/publications/using-shadac-health-insurance-unit-hiu-and-federal-poverty-guideline-fpg-microdata>.

<sup>19</sup> Haley, J.M., Kenney, G.M., Wang, R., Lynch, V., Buettgens, M., 2018. Medicaid/CHIP Participation Reached 93.7 Percent Among Eligible Children In 2016. *Health Affairs* 37, 1194–1199. <https://doi.org/10.1377/hlthaff.2018.0417>

Note that these counties may have served a larger number of consumers if they had a waiting list and adequate staffing and/or funding. As described in Part II of this report, AAA staff were interviewed in the spring and summer of 2018. At that time AAA staff in Multnomah County reported that they had a wait list, but those in Washington and Lane Counties did not. These two counties without a waitlist were able to serve consumers almost immediately if the county was aware of them and consumers met eligibility criteria. Staff interviewed from all pilot counties indicated that outreach beyond the aging network was limited due to issues of staffing and concern about not being able to serve people in most need of the program.

The estimated participation rate among the three major counties is generalized to all of Oregon. Although we allowed for higher participation rate than the highest estimated rate (5% vs. 3.2%), participation behavior may vary by county in unexpected and unknown ways.

**TABLE 4-2. ESTIMATED OPI-E PARTICIPATION RATES IN MULTNOMAH, LANE, AND WASHINGTON COUNTIES**

	<b>Estimated (2017)</b>	<b>Actual (FY2017)</b>	<b>Estimated Participation Rate among Estimated Eligible Population</b>
<b>MCADVS (Multnomah)</b>	5,710	130	2.3%
<b>LCOG (Lane)</b>	2,192	69	3.2%
<b>WCDAVS (Washington)</b>	4,193	42	1.0%

**TABLE 4-3. DATA SOURCES FOR COST ESTIMATES**

	<b>Data Source</b>	<b>Estimate [Min, Max]</b>
<b>Average monthly cost per participant FY2015-2017</b>	Oregon DHS (including administration costs and overhead)	\$393 [\$297, \$611]
<b>Cost adjustment*</b>	Centers for Medicare and Medicaid Services, Office of the Actuary –based on CMS Personal Health Care Price Index	2.5 [2018] 2.4 [2019]

**TABLE 4-4. MEDIAN COST ESTIMATE SCENARIO**

	<b>2019</b>	<b>2020</b>	<b>FY2019-20</b>
<b>Estimated monthly spending per consumer</b>	\$403	\$413	
<b>Estimated consumers</b>	1,272	1,290	
<b>Total estimated program cost</b>	\$6,151,392	\$6,393,240	\$12,544,632

**TABLE 4-5. LOWEST COST ESTIMATES SCENARIO**

	<b>2019</b>	<b>2020</b>	<b>FY2019-20</b>
<b>Estimated monthly spending per consumer</b>	\$304	\$312	
<b>Estimated consumers</b>	810	903	
<b>Total estimated program cost</b>	\$2,954,880	\$3,380,832	\$6,335,712

*Note: all lower-bound estimates, including costs.*

**TABLE 4-6. HIGHEST COST ESTIMATES SCENARIO**

	<b>2019</b>	<b>2020</b>	<b>FY2019-20</b>
<b>Estimated monthly spending per consumer</b>	\$626	\$641	
<b>Estimated consumers</b>	1,483	1,506	
<b>Total estimated program cost</b>	\$11,140,296	\$11,584,152	\$22,724,448

*Note: all lower-bound estimates, including costs.*

## Conclusion and Limitations

There are multiple caveats to these cost estimates in addition to those described throughout the report. During the pilot, not all counties were served. Moreover, not all counties provided the same set of services. Due to the scarcity of data, we could not separately estimate number of would-be eligible participants and their need levels separately for each county.

The historical average costs per participant likely reflect the lower end of the estimates considering it was a pilot program and some counties did not offer all services. Each AAA decided how they would allocate the limited resources based on various factors. Additionally, consumers in some counties not currently served may have higher needs compared to consumers in the pilot counties.

To obtain better estimates in the future, we fully support the recommendations from the Oregon Data Analytics report (p. 12)<sup>20</sup>, including “report service, cost, and consumer information at the individual level” and do this consistently across all AAAs.

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<sup>20</sup> Oregon Enterprise Data Analytics. (2016). *Describing differences between Oregon Project Independence & Medicaid Long-Term Care Consumers*. Oregon Department of Human Services and Oregon Health Authority.

## Appendix A – AAA Director and Case Manager Interview

*Note: questions marked with one asterisk (\*) were for AAA directors only; questions marked with two asterisks (\*\*) were for OPI Case Managers only*

### **Consent telephone script at the beginning of the interview:**

Hello, this is [name]. Thank you for talking with me today. We very much appreciate your time and learning about your experiences. As a reminder, this is a confidential interview. We will compile and summarize the information we receive from all of the pilot AAAs. We may ask your permission to include a quote or specific information if it could be connected with you and is helpful to the evaluation. Additional information was provided in our email, including your right to stop at any time and how to contact the Office of Research Integrity at PSU. By continuing with this interview, you are giving consent to participate in this research. Do you wish to continue? Do you have any questions? All right, let's begin.

### **Interview Questions - general**

1. How long have you been in your position? How long have you been working with OPI (traditional or pilot)?
2. Please describe briefly your role/participation in OPI Pilot Expansion.
3. What changes in the pilot program have you seen since you have been involved? (e.g., numbers served, changes in needs, changes in other consumer characteristics)

### **Questions based on “lessons learned” from 2015; Recommendations**

When AAA Directors and OPI case managers were interviewed about the expansion two years ago, several concerns and recommendations were made. I would like to ask you about those issues.

1. The first involved **referrals**.
  - a. At this time, how aware is your AAA referral network about OPI services for those younger than 60? (i.e., how much referral are you doing specific to this program? How well has it been integrated into your system of services?)

- b. Tell me about your outreach about this program (i.e., where have you gone, what have you done?).
2. Another issue was **AAA Capacity**.
- a. At this time, what is the capacity of your agency (AAA) to provide OPI services to those younger than 60? (ask: financial capacity, numbers served)\*
  - b. To what extent are you able to meet the needs of this population (i.e., do you have wait lists or unmet need)?
  - c. Where are your strengths and limitations with respect to capacity?
  - d. Do staff have the needed training to do this work?
  - e. What about AAA support?\*\*\*
  - f. What about APD support for the OPI Pilot? the State Unit on Aging support?\*
3. A third issue concerns **consumer characteristics**.
- a. How are the needs of younger OPI consumers different from those served in traditional OPI? How are they similar? Are there differences in unmet needs?
  - b. Do younger OPI consumers have different expectations than the traditional OPI consumers?
  - c. How effectively are you/is your AAA able to meet the unique needs of OPI consumers younger than 60?
  - d. Many younger adults with disabilities have behavioral health needs that have caused an ADL or IADL limitation. To what extent have you experienced this with the pilot consumers? To what extent are you able to meet their needs (listen for challenges, systems issues, limitations, etc.)?
4. Now I would like to ask about **eligibility**.
- a. Are you able to access and obtain information needed to determine eligibility (to assure no conflict with Medicaid programming)?
5. **Rural**. I know that you serve some rural communities. What are specific challenges in rural communities for this population (e.g., telephone screenings, travel distances)
6. **Providers**.

- a. What is your experience with home care workers and in-home care agencies with this population? (Are you finding enough? Are they adequately trained?)

**7. Other.**

- a. What other challenges have you experienced with the OPI pilot?
- b. Overall, what do you find as the most challenging aspect to providing this service?\*
- c. How about for the AAA as an agency?\*
- d. For consumers?
- e. Overall, what do you think has worked especially well through the OPI pilot program?

**8. Length of stay.**

- a. In your experience, about how long do you typically serve OPI pilot consumers?

**9. Closure.**

- a. What are the major reasons for service closure for pilot consumers in your AAA?
  - i. Medicaid enrollment
  - ii. Voluntary withdrawal
  - iii. Deceased
  - iv. Moved out of area
  - v. Unable to meet needs
  - vi. Consumer met goals
  - vii. Regular OPI enrollment
  - viii. Other

**Back to general questions:**

1. Overall, what are the major lessons you have learned in providing OPI pilot services?
2. Tracking consumer service needs, characteristics, and services provided is critical to program evaluation? What challenges do you experience in obtaining and recording data?
3. Should the OPI program for those younger than 60 be implemented statewide? Why or why not?
4. What advice would you give to other AAAs or OPI case managers to prepare to expand OPI services to those younger than 60.