

EVALUATION OF THE ACL TITLE VI PROGRAMS

YEAR 3 INTERIM REPORT



January 2020



BACKGROUND

WHAT IS TITLE VI?

In 1965, the Older Americans Act (OAA) was authorized to protect the well-being of older Americans. The OAA promotes community and home-based services to support independent living, physical and mental health, suitable housing, restorative services for those requiring institutional care, and retirement in “health, honor, and dignity” (OAA Title I, Sec. 101: 42 U.S.C. 3001).

In 1978, the OAA was amended to include home- and community-based supportive services for older American Indian, Alaska Native, and Native Hawaiian (AI/AN/NH) populations. This amendment, Title VI, recognizes that older AI/AN/NHs are a “vital resource entitled to all benefits and services available” (OAA Title VI, Sec. 602: 42 U.S.C. 3057a).

Title VI provides nutrition and supportive services for elders, including congregate and home-delivered meals, information referral services, transportation, and other services. The program also provides caregiver services for individuals providing care for elders or for elders raising grandchildren or caring for adult children with disabilities. Services include information and outreach, respite care, and other related services.

The Administration for Community Living (ACL), Administration on Aging (AoA), administers the Title VI Programs. In fiscal year 2016, ACL awarded 3-year grants for the following:

- ▶ 270 grants for Nutrition and Supportive Services
- ▶ 233 grants for the Caregiver Support Program

ICF has been contracted to conduct the Evaluation of ACL’s AI/AN/NH Programs (OAA Title VI) Title VI Grant Program under ACL contract #1600197A. This report presents a summary and findings from year 3 of the evaluation.

WHAT IS THE EVALUATION OF THE ACL TITLE VI PROGRAMS?

The Evaluation of the ACL Title VI Programs is an opportunity to understand the impact of the Title VI Programs on stakeholders, including elder program participants, caregivers of elders, and program staff. The evaluation consists of an implementation study and an outcomes study.

The evaluation uses a mix of information that grantees already collect (secondary data), as well as new sources of information (primary data) to describe the implementation and outcomes across nutrition services, supportive services, and caregiver support services.

SUPPORTING ELDER AND CAREGIVERS

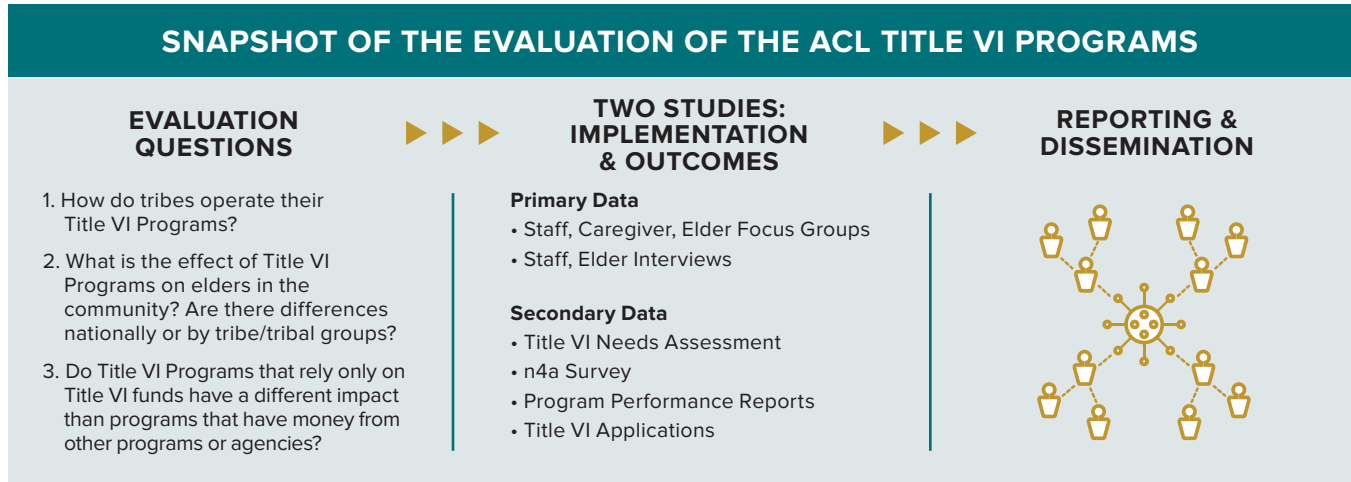
Title VI provides services through three programs: Part A (Indian Program), Part B (Native Hawaiian Program), and Part C (Native American Caregiver Support Program).

NUTRITION AND SUPPORTIVE SERVICES FOR ELDER	
Part A—Serves federally recognized tribes with at least 50 members ages 60 years and older.	<ul style="list-style-type: none">▶ Congregate and home-delivered meals▶ Information and assistance▶ Case management▶ Transportation▶ Health promotion▶ Other supportive services (e.g., homemaker, personal care, legal assistance)
Part B—Serves public or nonprofit organizations that serve Native Hawaiians and represent at least 50 individuals ages 60 years and older.	
CAREGIVER SUPPORT SERVICES	
Part C—Serves all programs with Parts A or B, providing support to caregivers of elders, elders caring for adult children with disabilities, and grandparents raising grandchildren.	<ul style="list-style-type: none">▶ Information and outreach▶ Access assistance▶ Counseling, training, and support groups▶ Respite services▶ Other supplemental services

»» **IMPLEMENTATION STUDY:** The purpose of this study is to understand the context of the Title VI Programs, including barriers and facilitators to program implementation.

»» **OUTCOMES STUDY:** This study assesses the impact of the Title VI Programs, particularly on elders and the community.

With the help of a stakeholder advisory committee (Steering Committee) representing tribal, local, state, and national partners to the ACL Title VI Programs, the evaluation is grounded by a medicine wheel representing the four quadrants of indigenous practice: spiritual, mental, emotional, and physical (see Appendix A). Each quadrant of the medicine wheel reflects the expected outcomes of the Title VI Programs on program participants.

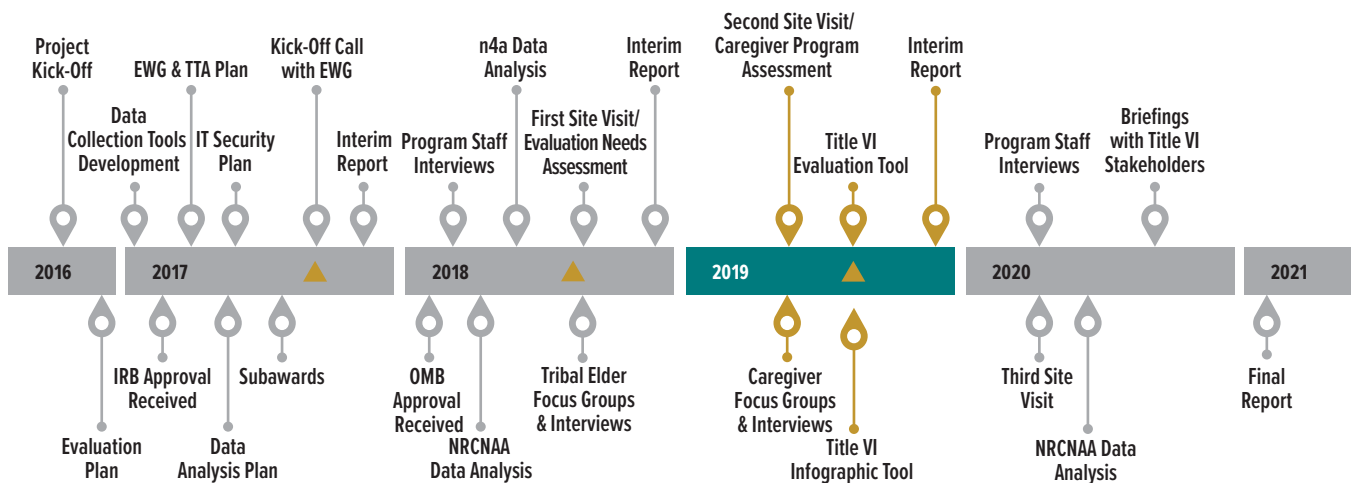


EVALUATION GRANTEES

Twelve Title VI grantees representing 5 Title VI regions and 6 states are participating in the Evaluation of the ACL Title VI Programs. Each grantee identified two to three people from its Title VI Program, including the Title VI program director, to serve on the Evaluation Working Group (EWG). The EWG guides and informs all stages of the evaluation, including data collection instruments, recruiting participants to take part in focus groups and interviews, and local data collection and technical assistance needs.

EVALUATION TIMELINE

The third year of the evaluation focused both on data collection to better understand the implementation of the Part C Caregiver Support Services and training and technical assistance (TTA) to support evaluation grantees in using their program data.



▲ EWG In-person Meetings

KEY ACHIEVEMENTS IN YEAR 3 OF THE EVALUATION OF ACL TITLE VI PROGRAMS

2019

January 15

The ICF Institutional Review Board (IRB) approved the Continuing Review of the Evaluation of the ACL Title VI Programs.

February 27

ICF hosted a webinar for the EWG, *Preparing for Your Second Site Visit*.

March 19–May 21

ICF staff conducted site visits to all evaluation grantees. Site visits included focus groups and interviews with caregivers, an evaluation needs assessment, and a caregiver program assessment.

June 17

ICF staff shared a summer e-letter update with the ACL Title VI Evaluation Steering Committee.

August 12

ICF hosted an in-person, full-day training with the EWG in conjunction with the National Title VI Training and Technical Assistance Conference.

October

ICF staff conducted quarterly evaluation calls with Title VI Evaluation grantees.

November 26

ICF staff shared a fall e-letter update with the ACL Title VI Evaluation Steering Committee.

January 29

ICF hosted a webinar for the ACL Title VI Evaluation Steering Committee, *An Update on the ACL Title VI Evaluation*.

March

ICF staff conducted quarterly evaluation calls with Title VI Evaluation grantees.

June

ICF staff conducted quarterly evaluation calls with Title VI Evaluation grantees.

July

ICF staff developed the Title VI Evaluation Tool and User Guide and the Title VI Infographic and User Guide.

August 15

ICF hosted a meeting with the ACL Title VI Evaluation Steering Committee during the National Title VI Training and Technical Assistance Conference.

October 30

ICF hosted a webinar for the EWG, *Using the Title VI Evaluation Tool and Infographic*.

TRAINING AND TECHNICAL ASSISTANCE

As part of the evaluation, the ICF evaluation team provides TTA to the EWG to ensure understanding and use of program data for program monitoring and improvement. The TTA includes skill-building resources and tools, such as one-page guidance documents on using focus groups and interviews to better understand elders' and caregivers' needs and satisfaction with program services. Through evaluation TTA, evaluation grantees have learned how to identify themes within their program data and use these findings to inform their programming.



During this year's site visits, the evaluation team worked with program staff to understand their local evaluation needs. Across the evaluation grantees, program staff shared a common need to understand whether and how their program services are meeting the needs of elders and caregivers, as well as a need to showcase the depth and breadth of their local Title VI program. To address these needs, the evaluation team developed two resources to support grantees in conducting local program evaluation and engaging stakeholders. The Title VI Evaluation Tool and the Title VI Infographic were shared with the EWG in August. As the EWG uses the tools, their feedback will be compiled and used to refine the tools before they are shared with the broader Title VI community.



TITLE VI EVALUATION TOOL AND USER GUIDE

"Appreciate the development of the various tools and products! They are all very useful and will definitely be used and implemented with our program."
—Title VI grantee

The Title VI Evaluation Tool and User Guide is a ready-to-use resource for Title VI program staff. The tool includes:

- ▶ **Two Surveys** (Part A/B, Nutrition and Supportive Services, and Part C, Caregiver Support Services)—to assess elder and caregiver use and satisfaction with program services.
- ▶ **Survey Response Spreadsheet**—to help program staff analyze survey responses through use of data visualizations (e.g., tables and charts).
- ▶ **User Guide**—to help program staff review and use evaluation findings with support of step-by-step guidance from planning to data collection.



TITLE VI INFOGRAPHIC AND USER GUIDE

"The infographic ... will help me paint a picture for leadership. Data such as numbers, raw data, is good but to have visualizations for them to relate to is awesome." —Title VI grantee

The Title VI Infographic and User Guide is designed to help Title VI program staff summarize and share their program data in a visual and engaging way. The Title VI Infographic brings together program data that Title VI grantees already collect, including their Program Performance and Reporting (PPR) data as well as data from their Elder Needs Assessment. The infographic includes four core sections:

- ▶ **Overview of the Title VI Program**—includes a description of services provided.
- ▶ **Elder Profile**—summarizes health characteristics of elders in the community.
- ▶ **Program Delivery and Participation**—summarizes the number of units and clients served for each Title VI service.
- ▶ **Program Improvement**—summarizes program quality improvement practices, including trainings and evaluation.

WHAT WE'VE LEARNED

The Evaluation of the ACL Title VI Programs uses mixed methods, including quantitative and qualitative data sources to answer the Title VI evaluation questions.

This year, the evaluation team focused on understanding the Title VI Part C, Native American Caregiver Support Program, from the perspective of caregivers. The evaluation team analyzed multiple data sources, including interviews and focus groups with informal (unpaid) caregivers, in order to understand the implementation and impact of the Part C Caregiver Support Program (see Appendix B: Methods). The following sections include a summary of emerging themes from the evaluation based on data collection and analysis in 2019. These themes include the variability of Part C caregiver support services across Title VI grantees and caregivers' met and unmet needs.

»» 2019 EVALUATION DATA SOURCES

- ▶ Caregiver Focus Groups and Interviews
- ▶ Caregiver Program Assessment
- ▶ National Resource Center on Native American Aging/University of North Dakota's Identifying Our Needs: A Survey of Elders (Elder Needs Assessment)
- ▶ n4a Title VI Survey

WHAT IS PART C?

The Native American Caregiver Support Program (Part C) supports unpaid family caregivers in caring for an elder family member, a grandchild, or an adult with disabilities. The Older Americans Act authorizes grantees to provide caregiver support services including: Information; Assistance; Counseling, Support Groups, and Training; Respite; and Supplemental Services.



Information—Provides information to caregivers on available services. It is often provided through public service announcements, health fairs, and program brochures.



Respite—Provides temporary support to give caregivers a break from caregiving.



Assistance—Includes hands-on support to help caregivers access services. Assistance includes one-on-one support and case management.



Supplemental Services—Offered on a limited basis, these may include home modifications (e.g., handrails), assistive technologies, or consumable supplies (e.g., gloves and adult diapers).



Counseling, Support Groups, and Training—Supports caregivers in decision making and problem solving related to their role as caregivers. Trainings often focus on stress relief and financial literacy.

»» While the OAA defines Part C as delivery of all five of these services, not all Title VI grantees are implementing these services.

PROGRAM CONTEXT AND DELIVERY

Staffing and Resources

Caregiver services have been funded under Part C for varying lengths of time across the evaluation grantees. The range of caregiver services provided did not depend on the length of time grantees had been receiving Part C funding.



Half of the evaluation grantees have received Part C funding for **more than 10 years**.

The other **half** have received Part C funding for **5 years or less**.

To meet the needs of caregivers and their families, elder programs rely on a mix of funding sources. While half of the evaluation grantees' caregiver support services are funded fully by Title VI funds, the remaining evaluation grantees receive supplemental funding to support their caregiver programs.



34%

of evaluation grantees have a designated caregiver program coordinator.

The staffing structure for the caregiver program varies by grantee. More than one-third of the evaluation grantees (34%) have a designated staff coordinator for their caregiver program. For others, caregiver program duties are spread across the program director, assistants, and other staff. In addition, many programs have experienced recent staff turnover. One-third of the evaluation grantees have new program directors or staff as of this year.

PROGRAM PARTICIPANTS

One in 3 elders have family caregivers.

One in 10 elders are a grandparent raising grandchildren.

One in 15 elders reported that they use caregiver services.

Less than 1 in 30 elders reported using respite care.

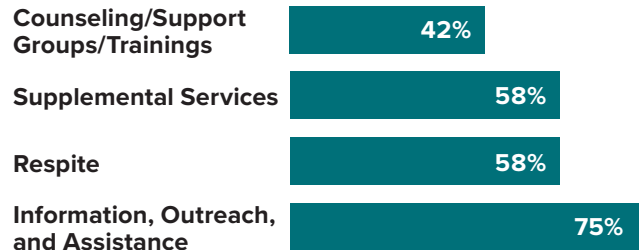


Data Source: Elder Needs Assessment

Service Delivery

The range of Part C Caregiver Support Services provided varies across the evaluation grantees. The majority of the evaluation grantees provide information, outreach, and assistance in accessing services to caregivers. Counseling, support groups, and training are less frequently provided.

PART C SERVICES PROVIDED BY EVALUATION GRANTEEES



Data Source: Caregiver Program Assessment

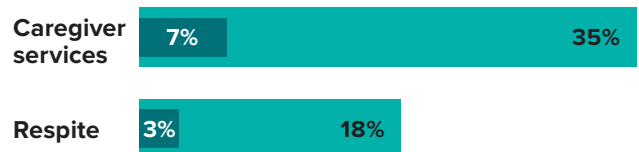
13 caregivers served, on average, in 2019, by the evaluation grantees that maintain a roster of caregivers.

Program Monitoring and Evaluation

The majority of the evaluation grantees do not have a systematic process in place for using Part C program data (e.g., PPR or elder needs assessments) to inform program planning. Instead, program planning is informed by staff observation of available resources to meet caregivers' needs.

»»» Across the evaluation grantees and all Title VI grantees, reporting for the Part C PPR is inconsistent. This may be due to a lack of clear definitions and guidance by ACL.

PERCENTAGE OF ELDERS CURRENTLY USING VERSUS WOULD USE CAREGIVER AND RESPITE SERVICES



■ Elders now using services ■ Elders who would use services

Data Source: Elder Needs Assessment

More elders report that they would use caregiver and respite services than are actually using those services.

WHAT IS WORKING

Caregivers who receive caregiver support services shared that the services helped them in important ways, particularly by providing relief from the stress of caregiving and helping to improve their overall quality of life.



Information and Assistance

Caregivers appreciate that local program staff are there to support them. Staff share useful resources and information about available caregiver services and provide referrals to ensure better care for them and their family members.

*“They’ve got tons of information. Anything you want to know, they bend over backwards and get it for you. If they aren’t able to have somebody come in for you, they give you information to rural resources or things like that.”**

*The staff member “is so caring, and she always gets right back with you. That’s important because you’re already frustrated or lacking sleep, and she always tries to find a resource for you. That’s what I like about her. And she comes out to visit. She checks up on the person that needs the care and the providers, as well, to see if there’s anything she could help out with.”**



Counseling/Support Groups/Training

Of the programs that offer caregiver support groups, caregivers shared that this resource helped them to manage the stress of caregiving. The support groups helped them learn from other caregivers who face similar issues and gave them renewed strength to continue providing care.

*“It’s most helpful for us as caregivers to take time away from our home, away from our clients or patients that we care for. I’m a 24/7 caregiver and to just get away for those few minutes over here and then to share our difficulties amongst ourselves. And as a caregiver, how to survive and take care of our self.”**

*“So I thoroughly appreciate coming [to the caregiver group]. Because ... of course, everything that we share amongst each other and all that stays here. And leaves that here for us to again kind of begin to be whole and start our journey again.”**

ACL RESPONDS

After learning of grantee confusion around the Part C program, ACL has begun developing clear guidelines to better support Title VI grantees.



Respite

For the programs that offer respite services, caregivers described that this service provided them an opportunity to take a needed break from the challenging work of caregiving and attend to other aspects of their lives.

*“I know as a caregiver, I need time for myself. It’s hard to take care of somebody else and not take care of yourself. How do you be strong for them when you can’t even take care of your own self? With mom, it’s good that somebody else comes in. And, that I take time out for me, and I go do what I need to do.”**

*“My mom liked to argue, especially when her dementia got worse, and [the respite] gave me a little bit of a break from her. I hate to say that.”**

PROGRAM STAFF PERSPECTIVE

One-third of evaluation grantees believe they are meeting caregivers’ needs for respite services.



Supplemental Services

A few caregivers described that the Title VI program provided equipment for them, such as wheelchairs or walkers. This was a simple but critical resource that helped them support their care recipient to remain as independent as possible.

*“This last week, she needed a walker. They provided that ASAP, and we didn’t have to worry about spending our own money, having to run around town and find it. ... That walker enables her to be independent instead of having to rely on somebody to help carry her to the bathroom.”**

PROGRAM STAFF PERSPECTIVE

Several programs shared that collaboration with other tribal or community organizations to support lending closet supplies has increased over time.

WHO IS A CAREGIVER?

Many caregivers shared that they do not consider themselves to be a “caregiver.” They view caregiving as a natural extension of their responsibility to their family. As a result, caregivers may not consider themselves to be eligible for caregiver services or support.

*“I think, number one, the caregivers don’t really know that they’re caregivers in the community. They’re just so used to taking care of somebody that they don’t consider themselves to be that precious to that individual. So they need to be identified, I think.”**

Many caregivers also described falling into the role of being a caregiver without any training or knowledge to support them in the role. As a result, they struggled when faced with issues such as how to safely lift and move a family member with a disability, administer medical care at home, navigate medical or insurance processes, or recognize the signs of depression in a loved one suffering from chronic illness.

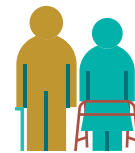


CAREGIVERS ARE FAMILY

Many caregivers described that “family takes care of family.” Caregivers shared that they work hard to meet the needs of family members with an illness or disability to avoid placing loved ones in a care facility.

*“If we don’t take care of our husbands, they go in a nursing home, so we do everything. We change them when it’s the end of their time, and we do everything ... change their bed all the time, we bathe them. Otherwise, if we don’t, then they go in a nursing home. So we keep going no matter what.”**

*“All of us kids and grandkids, we just kind of pull together, and my older sister got a group going where, ‘whose taking care of mom this day,’ ‘whose with mom in the evening.’”**



CAREGIVERS ARE ELDERS

In many cases, caregivers are themselves elders caring for other elders (e.g., spouse, siblings, or cousins) as well as grandparents raising grandchildren.

*“I think a lot of the problem is people are living too long now, and now it’s people like us that are actually old that are taking care of people that are older.”**

*“Well, my baby is 35 so it’s been that long since I raised a baby and ... I had to learn ... I’ve had both of them since they were infants and one is already a 9th grader in high school ... it’s hard, I say it’s very hard. Me and my husband, we’ll see other elders come out of places, no worries. You know, they’re just by themselves. I said, we should be like that. ... But we have to rush home because she’s coming home on the bus. ... You know, it kind of robs us of our livelihood.”**

CAREGIVING: A REWARDING BUT CHALLENGING EXPERIENCE



PHYSICALLY

Caregiving can be physically exhausting as caregivers attempt to handle the routine duties of their lives while also providing care. Many described depriving themselves of sleep or other self-care.

*“I drive back and forth to take my husband three times a week [to dialysis treatment]. And, his chair time starts at 3:00 a.m., so we leave home ... at midnight to get out to dialysis, and he’s done about 7:30, 8:00 a.m., and then I drive him back home. You know, it’s not only enduring the treatment time, but it’s the 6-hour commute time.”**



FINANCIALLY

Caregiving can be expensive. Many caregivers face travel-related costs driving to frequent medical appointments, sometimes requiring overnight stays in a motel. Caregivers also struggle with whether to leave a job or reduce to part-time in order to care for their family member.

*“I had to leave my job about 4 years ago when my husband’s kidney failed and he’s now in dialysis. So I’ve been a 24/7 caregiver for him. I left my job and everything ... and I left it to take care of my husband because he lost one side of his eyesight, and the other side is slowly diminishing.”**



EMOTIONALLY

Caregiving can be emotionally overwhelming. Caregivers often worry about the recipient of care as well as their caregiving duties. Some experience tension between family members regarding caregiving decisions. All caregivers experienced the need for, and lack of, personal breaks.

*“I was doing this from the time I was 17 until I was 22. And the amount of stress I was under during those times was just insane. And even when I was at home at night I couldn’t really rest because I was so worried about my grandma.”**

* Title VI Caregiver

GRANDPARENTS RAISING GRANDCHILDREN

For grandparents raising grandchildren, many are “starting all over”—taking on the role and responsibility of being a parent when they are often in need of greater support themselves. Grandparents described the time required to care for and raise a child; the related expense, when most are now retired; and that managing the many tasks needed to raise a child requires energy and mobility.

*“Well, my own children have been out of school for 7 years, and starting all over, it feels like ... It’s challenging at times, but we’re doing the best we can.”**



CARING FOR ELDERS WITH DEMENTIA

Caregiving for family members with dementia presents its own challenges. Caregivers described ongoing tension with the elder, whose illness may result in confusion, anger, and resistance to care.

*“It’s hard to reason with somebody who is adamant that she puts something there, and 10 minutes later, it’s not there. She can’t help it, she’s sick.”**

*“For people that have relatives with dementia ... you know a lot of them suffer the sun downers, and that was just ... really stressful to have to be up all night and work all day and take care of your own family and household. So that was a challenge.”**



* Title VI Caregiver

OPPORTUNITIES FOR GROWTH

While grantees are working to support the caregivers in their communities, caregivers and program staff each identified the need to increase caregivers' awareness of existing services as well as to expand the services provided. For some grantees, this may mean expanding their services to include all of the five required Part C services.



Information and Assistance

Many caregivers were interested to learn more about the types of caregiver services available and how to access them. Caregivers also expressed a need for information on the signs and symptoms of mental and physical illnesses and how to care for others with conditions such as dementia or depression.

*"At some point in time, I will be using that [caregiver] service and I need to find out what's available and how to go about getting it."**

*"It'd be helpful to learn some stuff about the one you're caring for, signs to look for to be aware of. That would be nice."**

PROGRAM STAFF PERSPECTIVE

Program staff reported a lack of awareness among caregivers about available services. Some program staff shared that they have increased outreach as a result.



Counseling/Support Groups/Training

Many caregivers spoke about the need for counseling and caregiver support groups that would provide an opportunity for them to share experiences and learn from one another.

*"So I think it's just offering these sessions to the families going through these situations and letting them know that it's normal to feel this way. But offering them the support and the tools they need to not, at the end of the day, break when it comes to these situations."**

*"And I love my grandkids, he's my grandkid, the little one. And, I have four other ones too. But ... I really need to talk to somebody, yeah, get my stuff out. And, I just need somebody to listen to and at least give me a little bit of advice, where to go or who to talk to."**

PROGRAM STAFF PERSPECTIVE

The majority of program staff expressed they did not understand the required elements of the Part C program.



Respite

Many caregivers described respite as a crucial resource. For those caregivers currently receiving respite, they expressed a need for additional hours of respite, available over a longer period of time.



1/3

of the evaluation grantees do not provide respite services.

PROGRAM STAFF PERSPECTIVE

Program staff shared that, in some cases, their tribal clearance process (e.g., background checks) for respite providers delays the availability of these services to caregivers in need.



Supplemental Services

Caregivers also described a need for supplemental services and supplies including hygiene, incontinence, and first aid supplies.

*"It's kind of hard when you get low [on supplies]. ... Because I'm taking care of two of them ... I really need a mask and the gloves."**

PROGRAM STAFF PERSPECTIVE

One grantee shared that services have decreased over time due to a decrease in tribal support that supplemented their Part C funding.

WHAT'S NEXT?

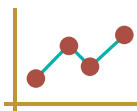
The fourth year of the evaluation marks the third and final year of data collection with the evaluation grantees. During year 4, ICF will conduct a third site visit with the evaluation grantees to collect program data and provide evaluation TTA. Following the site visits, ICF will begin synthesizing all data gathered across the three years of data collection with the evaluation grantees. Year 4 evaluation activities will include the following:



Final Site Visits

ICF staff will work with grantees to schedule a one-day site visit in the spring of 2020. The site visits will be an opportunity for:

- ▶ One-on-one TTA with grantees
- ▶ Conducting small group interviews with program staff



Evaluation Tools Dissemination

Using feedback from the EWG, ICF staff will refine the Title VI Evaluation Tool and the Title VI Infographic to better meet the needs of Title VI grantees. The revised tools will be shared with all Title VI grantees to enhance the ability of all Title VI programs to conduct local program evaluation for program monitoring and improvement.



Summative Analysis

The evaluation team will synthesize and summarize all data gathered through the three years of data collection, using it to address and answer the questions that have guided this evaluation.



Briefings With Stakeholders

The ICF evaluation team will brief stakeholders on findings from the evaluation. The briefings, delivered virtually, in-person, and through written posts, will be an opportunity to share what has been learned through the evaluation and gather feedback as to what it may mean from the local program perspective.

FOR MORE INFORMATION, CONTACT:

Kristen (Krissy) Hudgins, PhD

Social Science Analyst, Office of Performance and Evaluation
Administration for Community Living
Telephone: 202-795-7732
Email: Kristen.Hudgins@acl.hhs.gov

Gretchen Clarke, MPH

Manager, Title VI Evaluation
ICF
Telephone: 907-747-7124
Email: Gretchen.Clarke@icf.com