

APPENDIX B

TITLE VI EVALUATION METHODS



Methods

The Evaluation of the ACL Title VI Programs uses a mixed-methods approach to assess the impact of the Title VI Programs on stakeholders, including elder program participants, caregivers of elders, and program staff. As the evaluation is implemented over time (2018–2020), various data sources will be used to describe and demonstrate the implementation of the Title VI Programs and outcomes across nutrition services, supportive services, and caregiver support services. As described in the year 3 interim report, the evaluation design includes two interconnected studies to assess the Title VI Programs:

The **implementation study** is designed to understand the extent of implementation of the Title VI Programs at the national and tribal levels, contextual factors that affect implementation, and the barriers and facilitators to program implementation.

The **outcomes study** is designed to assess the impact of program implementation, including the proximal and distal program outcomes outlined in the program logic model.

Primary and secondary data collection and analysis approaches are designed to ensure that the objectives of the evaluation are achieved. The evaluation is designed to address the following questions:

- What is the context of the Title VI Programs at the national and tribal levels? How do tribes operate their Title VI Programs?
- What are the outcomes and impact of Title VI Programs, nationally and by tribe or tribal groups? What is the effect of the Title VI Programs on elders in the community, and are there differences nationally or by tribe/tribal group?
- Do Title VI Programs that rely only on Title VI funds have a different community impact than programs that have money from other programs or agencies?

The data sources used to inform the year 3 interim report in 2019 are described in the following sections.

Data Sources

QUALITATIVE

Primary Data—Caregiver Focus Groups/Interviews

During site visits held in March, April, and May of 2019, the ICF team conducted focus groups and interviews with caregivers participating in the Title VI Program. The purpose of the data collection was to understand caregivers' experiences with the Title VI Program, including met and unmet needs related to spirituality; social connectedness and isolation; physical, mental, and emotional health and wellness; and independence and quality of life. ICF collaborated with ACL and the Title VI Evaluation Steering Committee to design moderator and interview guides to elicit information related to the evaluation questions (the guides appear at the end of this summary).

Caregivers were asked to describe the length of time they had participated in the Title VI Program, the services they had received through the program, what they liked best about the services, how the program helps them, and the ways in which they would change or enhance the program. Before the site

visits, ICF held a webinar presentation with the grantee program staff to share the purpose of the site visits and coordinate planning of the data collection activity. Caregivers were identified and recruited for the focus groups and interviews with assistance from local Title VI Program staff. During the site visits, the ICF team conducted focus groups or interviews with caregivers receiving caregiver services at each grantee program. Incentives were provided to caregiver participants by local Title VI program staff and varied across grantee programs (e.g., incentives often included a meal or a gift card). All interviews and focus groups were audio recorded and transcribed for analysis. As a backup data source, ICF staff took notes during the interviews and focus groups and met to debrief after data collection activities to document the content and initial impressions of the findings. In all, the team conducted 8 focus groups and 11 interviews. The focus groups lasted an average of 56 minutes, and the interviews lasted an average of 20 minutes. Participants were primarily unpaid family caregivers; however, at one grantee site, the participants were formal, paid caregivers who also had experience as informal caregivers for their own families. Participants ranged in age from early adult to elder and included adults caring for their aging parents, husbands or wives caring for their spouse, siblings caring for another sibling, adults caring for a disabled family member, and grandparents caring for grandchildren.

Caregiver Program Assessment

The ICF team developed the caregiver program assessment—an Excel workbook that catalogs information related to grantees' caregiver programs, including program participants, services provided, and program monitoring and evaluation. The caregiver program assessment was designed to support a thorough understanding of the Part C Caregiver Support Program as it is implemented at the local level. The caregiver program assessment was conducted through conversations with program directors and other program staff as well as through direct program observation during site visits held in March, April, and May 2019.

QUANTITATIVE

Secondary Data—Elder Needs Assessment

The *National Resource Center on Native American Aging/University of North Dakota (NRCNAA/UND) Identifying Our Needs: A Survey of Elders* (Elder Needs Assessment) survey and data is administrated by NRCNAA, located at the Center for Rural Health at UND. Cycle VI data were collected from April 2014 to March 2016 and include information related to the health status of all elders receiving services through the Title VI Programs. It covers domains such as demographics, overall health and wellness, healthcare access, weight and physical activity, social functioning, social connectedness, and social supports and housing of all program recipients. The Elder Needs Assessment also includes domains related to caregiving, including whether elders have a family caregiver, whether they are raising grandchildren, as well as their current and anticipated future use of caregiver services. To the extent that survey participants are elders, responses pertaining to the caregiver experience are assumed to reflect the experience of elders who are themselves caregivers (of other elders or of grandchildren) and/or their perception of their family caregiver's experience. As the evaluation grantees

Caregiver Program Assessment Topics

- Overall caregiver program description, including participants, staff, and services provided
- History of the program
- Community partnerships and collaborations
- Program challenges and facilitators
- Program monitoring and evaluation
- Grantee Part C questions/concerns

are representative of all Title VI grantees (as detailed on page 4 of the [Year 2 interim report](#)), in this report our sample for data analysis was the evaluation grantees.

Prior to receiving frequency tables from UND, ICF undertook the following steps to ensure data agreements and protections were in place:

1. **Tribal resolutions.** ICF worked with each of the 12 evaluation grantees to secure a tribal resolution to access their tribal level Elder Needs Assessment data. ICF staff sent an advance notification email to the Title VI evaluation grantee program directors to inform them of the purpose of the request for a tribal resolution. ICF staff followed this with personal calls to each program director to address any questions or concerns related to data sharing and to identify the tribal resolution process for their tribe. To assist with the tribal resolution, ICF developed an optional resolution template for grantees. The template clearly stated what data were requested, how the data would be used, and who would have access to the data. ICF received tribal resolutions from each grantee.
2. **Data use agreement (DUA).** ICF established a DUA with NRCNAA/UND. The DUA described the purpose of the evaluation; the proposed usage of the Elder Needs Assessment data; data access, transfer, and storage; how local level approvals (tribal resolutions) were obtained; and noted that only aggregated data would be reported.

Secondary Data—n4a Title VI Program Survey

The n4a Title VI Program Survey is collected and administered by Scripps Gerontology Center (Scripps). The survey gathers information from program staff about which services are available, how the services are delivered, partnerships established to support service delivery, strategies for record keeping and budgeting, and challenges experienced with Title VI implementation. In order to access the Title VI Program Survey data for the 12 evaluation grantees, ICF undertook the following steps:

1. **Informed consent.** In November of 2017, ICF staff worked with Scripps to develop an informed consent letter to the Title VI evaluation grantee program directors to inform them of the purpose of the request for their Title VI Program Survey data. This letter explained the purpose of the evaluation, the risks and benefits to sharing the data, who would have access to the data, and how the data would be stored and transferred. The letter was emailed to the program directors in January 2018.
2. **Program data.** In January 2018, Scripps sent a PDF version of each tribe's completed 2016 Title VI Survey to each of the 12 evaluation grantees. ICF staff then reached out to each of the grantees to answer any questions.
3. **Data access.** ICF supported grantees in sharing their 2016 data with the evaluation team.
4. **Data extraction.** ICF extracted data for each grantee manually and consolidated the data in an Excel file based on data cleaning and management plans. Following ethical procedures, only aggregated data for the overall evaluation sample is ever reported.

Secondary Data—Title VI Program Performance Report (PPR)

The Title VI Program Performance Report (PPR) is maintained by the Administration on Aging/Administration for Community Living (AoA/ACL). The PPR collects information on the number of clients and Title VI service units for nutrition, supportive, and caregiver support services delivered by each Title VI grantee.

Data Analysis

QUALITATIVE

Caregiver Interviews and Focus Groups

ICF's approach to the qualitative analysis of interview data and focus group data included the following steps:

- 1. Data capture and management.** Three team members working on the analysis managed a comprehensive data inventory in Excel to monitor and track for each grantee: dates of data collection activity, number of participants per data collection effort, number and type of data files (i.e., digital recordings, notes, transcripts), and steps and progress related to monitoring data quality. The analysis team reviewed transcripts and notes for completeness and to minimize errors before the analysis process began. All data files and documents produced or collected before, during, and after data collection activities (e.g., interview and focus group notes, proprietary documents associated with a grantee, digital recordings and transcripts) were stored in password-protected electronic files accessible only by the ICF project team members.¹ Audio recordings from each interview and focus group were transcribed and imported into the qualitative software package ATLAS.ti v7.5.18, useful for facilitating the organization and management of textual data. Three ICF team members used this software to analyze the data for themes, patterns, and interrelationships relevant to the evaluation questions.
- 2. Codebook development.** Codebook development was a multistep and iterative process involving the development and definition of codes and pretests to refine the codes and definitions. A draft codebook, with an initial set of codes, was first developed on the basis of evaluation questions. Next, each of the three team members reviewed the transcripts and developed summary memos to document initial impressions of the findings. This process helped to inform the development of new codes to capture unexpected issues and themes not included in the preliminary coding scheme. Upon completion of a revised codebook, team members separately coded a single transcript and then came together to discuss how they applied the codes to the document. Through these discussions, codes were added, removed, or refined to best capture emerging themes. This process was repeated through a similar review of a single transcript. Team members debated confusion or disagreement over code definitions or applications until all members had the same analytical understanding of the codes as measured by sufficient intercoder reliability. The final codebook included codes, subcodes, definitions, and links to evaluation questions; a version of the codebook, excluding sub codes (for brevity), is presented in Table 1.
- 3. Code application.** Following codebook development, each team member created their own Hermeneutic Unit (HU) in ATLAS.ti, where they uploaded the transcripts and codebook. Team members applied the codes to the transcripts to facilitate data analysis using ATLAS.ti software. ICF team members coded at the level of a whole sentence or paragraph.
- 4. Analysis and documentation of themes.** Upon completion of the coding process, team members used ATLAS.ti to search for, retrieve, and classify the coded data. The team produced output documents associated with each code and sub code. Two team members participated in

¹ See additional detail about security procedures in the section titled "Ethnical Considerations and Regulatory Review."

a thematic analysis approach in which each team member conducted an in-depth review of a set of output documents reflecting groupings of interrelated codes and sub codes. Next, each team member produced a comprehensive summary memo providing an assessment of key themes and relationships among themes for the assigned set of output documents. Following this process, team members met to discuss the analysis, findings, and themes, some of which were identified by a single analyst and some by multiple analysts. Team members then compiled and reduced the results of the output review in preparation for developing a triangulated approach to reporting, featuring multiple data sources. Themes in responses that were posed repeatedly by interview and focus group participants are presented in the year 3 interim report. Themes that were more subtle or less often voiced are also described. Ultimately, the analysis facilitated the development of explanatory narratives related to Title VI Program staff and elders' experiences with and insights about the Title VI Program.

Table 1. ACL Title VI Caregiver Interviews and Focus Groups: Codebook

Code	Definition	Related Evaluation Question(s)
Caregiver service availability	<p>Discussion of availability of caregiver resources and supports in the community and surrounding area.</p> <p><u>Non-Title VI</u>: Availability of caregiver services offered through other programs.</p> <p><u>Lack of</u>: Discussion of lack of caregiver resources.</p>	<ul style="list-style-type: none"> • What is the context of the Title VI Programs at the national and tribal levels?
Caregiver awareness of services	<p>Discussion of caregivers' awareness (or lack of awareness) of services, resources, and supports for caregivers; how caregivers are currently recruited or provided information about services/supports; and how respondents think caregivers should be recruited or informed.</p> <p><u>Current Outreach</u>: References to how the respondent learned about Title VI caregiver services and/or how outreach and information occurs currently.</p> <p><u>Suggestions for Outreach</u>: Respondents' suggestions for outreach strategies to build awareness of caregiver services and resources (i.e., how respondents suggest getting the word out).</p> <p><u>Lack of</u>: Discussion of lack of awareness of resources or supports for caregivers in the community among caregivers.</p>	<ul style="list-style-type: none"> • What is the context of the Title VI Programs at the national and tribal levels?

Code	Definition	Related Evaluation Question(s)
Caregiver role	<p>Description of caregiving duties, individual(s) receiving care, and caregiver characteristics.</p> <p><u>Caregiver-Elder</u>: An elder providing informal care for another elder or for an individual of any age with Alzheimer’s disease or a related disorder.</p> <p><u>Caregiver-Adult</u>: An adult (non-elder) providing informal care for an elder or for an individual of any age with Alzheimer’s disease or a related disorder.</p> <p><u>Grandparent</u>: Grandparents raising grandchildren.</p> <p><u>Disabilities-Elder</u>: Elder providing informal care for an adult with disabilities.</p> <p><u>Note</u>: When the details are not specific enough to select a sub code, simply use “caregiver role.”</p>	<ul style="list-style-type: none"> • What is the context of the Title VI Programs at the national and tribal levels?
Caregiver experience	Description of what it’s like to be a caregiver and how the caregiver is impacted.	<ul style="list-style-type: none"> • What is the context of the Title VI Programs at the national and tribal levels?
Key quotes	Use to document key quotes.	
Length of time at program	Discussion of how long caregiver has been receiving Title VI services or has been a caregiver.	<ul style="list-style-type: none"> • What is the context of the Title VI Programs at the national and tribal levels?
No Title VI	Description of what would happen or what caregivers would miss if Title VI services went away.	<ul style="list-style-type: none"> • What are the outcomes and impacts of the Title VI Programs, nationally and by tribe or tribal groups? • What are the met and unmet needs of consumers and program stakeholders?
Services received—Part C	<p>Description of services that caregivers receive that are designed for caregivers and appear to be supported by Part C.</p> <p><u>Information and Outreach</u>: A public and media activity that conveys information to caregivers about available services, which can include an in-person interactive presentation to the public.</p> <p><u>Assistance</u>: Helping caregivers access services, including through:</p>	<ul style="list-style-type: none"> • How are the Title VI Programs implemented at the national and tribal level? • What are the program inputs, resources, and activities implemented through Title VI? • How are nutrition, supportive, and caregiver support services provided through the Title VI Programs?

Code	Definition	Related Evaluation Question(s)
	<ul style="list-style-type: none"> • Individual one-on-one contact linking family caregivers with services, supports, and other opportunities. • Follow-up to ensure services are received. • Case management—Caregiver Assessment, wrap-around services, person-centered planning. <p><u>Counseling, Training, or Support Groups for Caregivers</u>: A service designed to support caregivers and assist them in their decision-making and problem solving.</p> <ul style="list-style-type: none"> • Individual counseling, organization of support groups, and caregiver training to assist the caregivers in the areas of health, nutrition, and financial literacy, and in making decisions and solving problems relating to their caregiving roles. <p><u>Respite Care</u>: A service for caregivers that offers temporary, substitute supports or living arrangements for care recipients in order to provide a brief period of relief or rest for the caregivers. Also includes opportunities for caregivers to “get a break” via fieldtrips or other activities</p> <p><u>Supplemental Services</u>: (meant to be provided on a limited basis)</p> <ul style="list-style-type: none"> • Home Modifications • Assistive Technologies • Emergency Response Systems • Equipment • Incontinence Supplies • Transportation 	<ul style="list-style-type: none"> • What is the array of Title VI practices available to caregivers?
Services received—Part A/B	<p>Discussion of services provided through Part A/B (e.g., meals, transportation) or provided in other ways through the elder center.</p> <p><u>Supports Respondent</u>: Respondent sees service as helping them generally—e.g.,</p>	<ul style="list-style-type: none"> • How are the Title VI Programs implemented at the national and tribal level? • What are the program inputs, resources, and activities implemented through Title VI?

Code	Definition	Related Evaluation Question(s)
	<p>they directly benefit as a participant in the meal, transportation, or activity.</p> <p><u>Supports Respondent as Caregiver:</u> Respondent recognizes that service helps them to be a better caregiver by relieving them of the stress, worry, and responsibility of meal preparation, finding transportation, etc.</p>	<ul style="list-style-type: none"> • How are nutrition, supportive, and caregiver support services provided through the Title VI Programs? • What is the array of Title VI practices available to caregivers?
Services received— Other	Discussion of services that caregivers receive that seem to be non-Title VI services.	<ul style="list-style-type: none"> • What is the context of the Title VI Programs at the national and tribal levels?
Challenges	<p>Description of challenges associated with caregiving in general or caregiver program implementation.</p> <p><u>Aging Population:</u> As individuals are living longer, elders are now caring for older elders. There is a growing need for long-term care and in-home nursing.</p> <p><u>Dementia:</u> Discussion of prevalence of and impact related to caring for individuals with dementia, Alzheimer’s, and related illnesses.</p>	<ul style="list-style-type: none"> • What is the context of the Title VI Programs at the national and tribal levels?
Title VI-like best	Description of what caregivers like best about the Title VI Program that supports them in their caregiving role.	<ul style="list-style-type: none"> • What are the outcomes and impacts of the Title VI Programs, nationally and by tribe or tribal groups? • What are the met and unmet needs of consumers and program stakeholders? • What are the physical, emotional, mental, and spiritual outcomes of the Title VI Programs?
Ways program helps	<p>Description of the various ways in which the program helps caregivers. Consider the medicine wheel:</p> <ul style="list-style-type: none"> • Spiritual • Mental • Emotional • Physical 	<ul style="list-style-type: none"> • What are the outcomes and impacts of the Title VI Programs, nationally and by tribe or tribal groups? • What are the met and unmet needs of consumers and program stakeholders? • What are the physical, emotional, mental, and

Code	Definition	Related Evaluation Question(s)
		spiritual outcomes of the Title VI Programs?
Wish list	Description of other services or supports that respondent wishes for, that could be provided for caregivers (either by the elder center or by other entities in the community in general).	<ul style="list-style-type: none"> • What are the outcomes and impacts of the Title VI Programs, nationally and by tribe or tribal groups? • What are the met and unmet needs of consumers and program stakeholders? • What are the physical, emotional, mental, and spiritual outcomes of the Title VI Programs?
Cultural-community	<p>Discussion of cultural or community norms, expectations, trends, or other issues rooted in culture that affect caregiving, attitudes about caregiving, or help-seeking among caregivers.</p> <p><u>Reluctance to Seek Help</u>: Reluctance of caregivers to seek or access services or ask for help (e.g., embarrassment, stigma, desire to maintain independence).</p> <p><u>Women Caregivers</u>: Notion that women should provide caregiving.</p> <p><u>Family Caregivers</u>: It is the family's responsibility to provide caregiving to avoid facility care or, for various reasons, families end up providing caregiving (e.g., often family members take shifts to cobble together care for a parent).</p> <p><u>Identity-Caregiver</u>: Sense that people don't identify as a caregiver because it's just part of their job as a family member.</p>	<ul style="list-style-type: none"> • What is the context of the Title VI Programs at the national and tribal levels?

Caregiver Program Assessment

ICF staff reviewed the caregiver program assessment results to identify commonalities and areas of divergence among the grantees. Findings were organized by topical area.

QUANTITATIVE

Elder Needs Assessment

ICF program staff revised frequency tables generated by NRCNAA/UND containing evaluation grantees' data and consolidated the variables of interest for Title VI Part C (Table 2). Then, for each variable of

interest, ICF generated an average percentage for all evaluation grantees. As the Elder Needs Assessment survey categorizes questions related to “respite” and “caregiver services”—including all other caregiver services—separately, findings are presented in the report using this approach to categorizing services.

Table 2. Elder Needs Assessment Data Title VI Year 3 Evaluation Indicators

Elder Needs Assessment Survey Question
Q69. Are you an enrolled member of a federally recognized tribe?
Q50. Do you have a family member who provides care for you?
Q51. Do you take care of grandchildren?
Q52. Are you the primary caregiver of grandchildren?
Q59. Are you now using or, if at some point you became unable to meet your own needs, would you be willing to use the following services? <ul style="list-style-type: none"> • Caregiver Program • Respite Care

n4a Title VI Program Survey

In April 2018, ICF received the dataset for the 12 evaluation grantees’ Title VI Program Survey responses. ICF staff developed a codebook with key questions aligned with the evaluation plan and consolidated responses in one aggregated dataset containing recoded responses for all grantees. The recoded responses included both objective and descriptive answers. Table 3 includes a list of the selected survey questions used in this report along with a description of the data management approach for each.

ICF focused on an initial descriptive analysis (frequencies, means). Data cleaning (e.g., excluding invalid entries) and examination of missing data and out-of-range values were performed prior to data analysis. Additional recoding and transformation of variables were conducted and values were collapsed into meaningful categories. Due to the nature of many “multiple response” items on the survey, data were analyzed based on multiple response sets for the relevant questions. Therefore, the sum of percentages may add up to more than 100%.

Table 3. n4a Data Title VI Year 3 Evaluation Indicators

n4a Survey Question	Data Management
Q9. Which services are Title VI funded, wholly or partly— Respite care	Responses recoded to categorical Title VI funds = 1
Q9. Which services are Title VI funded, wholly or partly— Family caregiver support services	Provided partly with Title VI funds = 2 Provided through non-Title VI funds = 3 Not available = 0
Q10. Rate the capacity of services to actually meet the needs of your elders—Family caregiver support services	Responses recoded to categorical Significant unmet needs = 0 Some unmet needs = 1 Needs met = 2
Q10. Rate the capacity of services to actually meet the needs of your elders—Respite care	
Q10a. Please identify up to five of the most significant unmet needs—Respite care	Responses recoded to categorical Family caregiver support services =19 Respite care = 20
Q10a. Please identify up to five of the most significant unmet needs—Family caregiver support services	
Q26a. Evidence-based program has been offered through Title VI or another program within the last two years—The Savvy Caregiver in Indian Country	Responses recoded to dichotomous Not familiar with this program = 0 Familiar with this program = 1
Q26a. Evidence-based program has been offered through Title VI or another program within the last two years— Powerful Tools for Caregivers	
Q31a. What information does the Title VI program maintain about each elder? Caregiver/informal support information	Responses recoded to dichotomous Yes = 1 No = 0

PPR

In June 2019, the Title VI Part C Performance Data Report for fiscal years 2010–2017 was shared with ICF. Review of the data identified extreme variances within and across grantees' data, suggesting an overall lack of reliability. In consultation with ACL, the evaluation team determined to exclude Part C PPR data from data synthesis.

Ethical Considerations and Regulatory Review

Office of Management and Budget (OMB) Clearance

In 2017, ICF prepared, in consultation with ACL, an Evaluation of the ACL Title VI Programs OMB Information Collection Request (ICR) package. The OMB package included standard forms, a comprehensive supporting statement, 60- and 30-day Federal Register notices (FRNs), and a list of attachments such as data collection instruments. The summary statement described the objectives of the Evaluation of the ACL Title VI Programs, the evaluation questions being pursued, and the domains and/or data elements to be collected. The statement included clear descriptions of each data collection activity and instrument as well as burden estimates. The 60-day FRN was posted for public comment in the Federal Register. Comments were solicited over a 60-day period on the need for and proposed use of the study, respondent types, and annualized burden. No comments were received at the conclusion of the 60-day comment period. ICF then resubmitted the package, along with the 30-day FRN, to ACL for review and approval. ICF worked with the contracting officer's representative to obtain necessary approvals and otherwise move through the approval chain for submission to OMB. OMB approval was received on February 5, 2018.²

Institutional Review Board (IRB) Review and Approval

To ensure the protection of human subjects, including the confidentiality of data compiled and collected during the Evaluation of the ACL Title VI Programs, evaluation data collection protocols and instruments were reviewed and approved by the ICF IRB prior to the collection of protected data. This review ensured compliance with the spirit and letter of U.S. Department of Health and Human Services (HHS) regulations governing such projects.

The ICF IRB is committed to protecting the rights, welfare, and privacy of individuals who participate in ICF-supported research and evaluation studies, as well as the confidentiality of the data. The IRB's approach to protecting human subjects is guided by the ethical principles and guidelines outlined in the Belmont Report: respect for persons, beneficence, and justice. The ICF IRB (IRB00000954; expires July 12, 2023) complies with all requirements specified in the Code of Federal Regulations (45 CFR 46) on the protection of human subjects and has a Federalwide Assurance (FWA00000845). In addition to the Federal regulations, the IRB takes into consideration any State or local laws regarding human subjects that may be more protective than the Federal statutes. It is the responsibility of the IRB, as well as the evaluation team, to ensure that these regulations and other applicable laws are followed in the conduct of ICF-supported research and evaluation.

² OMB No.: 0985-0059, Expiration Date: 02/28/2021

To ensure the protection of human subjects in this evaluation, ICF undertook the following steps:

1. Respondents were given the opportunity to refuse to answer questions or to stop the focus group or interview or leave the focus group at their discretion.
2. Focus group moderators were trained about their responsibility to maintain the privacy of respondents' answers. Moderators were instructed not to disclose any information obtained during the focus group to any other individual outside of the evaluation team.
3. Interviewers were trained about their responsibility to maintain the privacy of respondents' answers. Interviewers were instructed not to disclose any information obtained during the interview to any other individual outside of the evaluation team.
4. To minimize the risk of emotional or mental distress or general discomfort related to the topics discussed, all focus group moderators and interviewers received in-depth training on how to ask questions and respond appropriately, particularly regarding sensitive topics.
5. Focus group moderators were trained to conduct focus groups in private locations with only the respondents, the moderator and the note-taker(s) present.
6. Interviewers were trained to conduct interviews in private locations with only the respondent and interviewer present.
7. The Evaluation Working Group (EWG) received human subjects protection training at the EWG in-person meeting prior to beginning data collection.
8. Comments made during the focus groups and interviews were not attributed to any one respondent.
9. Focus group and interview digital recordings and notes are kept in password-protected electronic files at ICF.
10. All evaluation reports and publications that result from these data include only group-level analyses that fully protect the confidentiality of individual participants.

Approval for the Evaluation of the ACL Title VI Programs was obtained from ICF's IRB, including both an original protocol (approved on March 1, 2017) and a modified protocol (approved on February 9, 2018). ICF received continuing review approval on January 15, 2019. The submission to the IRB included a summary statement addressing the key required criteria for the IRB outlined above and the evaluation protocol, including data collection instruments. Data collection did not begin until the ICF team member had reviewed the informed consent form with all eligible respondents, including program staff and tribal elders. All participants received a copy of the informed consent form, which emphasized the voluntary nature of participation and the right to stop participating at any time, and noted that all individual data would be kept private. Focus groups and interviews were audio recorded with the permission of the participants.

Local-Level IRB Review and Approval

In addition to ICF IRB, ICF worked with each evaluation grantee to identify and obtain the local level approval(s) necessary to participate in the Evaluation of the ACL Title VI Programs through an IRB, institution at large, or other governing or advisory body, such as the tribal council. Each of the evaluation grantees obtained a tribal resolution confirming their tribe's commitment to participate in the evaluation as well as share their Title VI data with ICF. All grantees received a copy of ICF's 1) approved IRB package/application, 2) IRB approval letter; 3) summary page of IRB steps; 4) instruments and informed consents; and 5) summary of instruments by research question.



Title VI Tribal Caregiver Focus Group/Interview Moderator Guide

Evaluation of the ACL Title VI Programs

Title VI Tribal Caregiver Focus Group/Interview Moderator Guide

Questions	Probes	Time Guidelines
Introduction of Moderator/Guests and Purpose of Focus Group/ Logistics		5 minutes
Read Consent Form/Confirm Verbal Consent/ Confirm Permission to Audio Record		5 minutes
Opening Question 1. Please tell us your first name and how long you have been using Title VI (or local program name) services.		5 minutes
Introductory Question 2. Tell me a little bit about the services you get as a caregiver.	Provide examples of services specifically provided by the program: <ul style="list-style-type: none"> ▪ Information ▪ Counselling ▪ Education ▪ Support group ▪ Respite care ▪ Grandparent support 	10 minutes
Transition Questions 3. What do you like about the caregiver program?	<ul style="list-style-type: none"> ▪ Why is that? What about that service makes you say that? ▪ Can you give me an example or tell a story about it? 	10 minutes
Key Questions 4. How does the program help you as a caregiver?	<ul style="list-style-type: none"> ▪ How does the program help you with stress, time, resources, etc.? ▪ How/does the program ease mental overload? ▪ How/does the program improve your quality of life? ▪ How/does the program improve the quality of life of the person you care for? ▪ Are there other ways that the program helps you feel connected to your community? 	10 minutes
5. What else do you wish the program had for caregivers?	<ul style="list-style-type: none"> ▪ What other types of information might be valuable to you as a caregiver? ▪ What other types of services might you want to receive? 	10 minutes
6. If you could change something about the program for caregivers, what would that be?		10 minutes

<p>7. What would happen to you as a caregiver if you didn't have this program?</p>	<p>Components to talk about:</p> <ul style="list-style-type: none"> ▪ Employment ▪ Stress ▪ Difficulty with providing care ▪ Chances to socialize/visit with others ▪ Getting out of the house, etc. ▪ Not be able to continue providing care ▪ Not be able to provide as good care 	<p style="text-align: center;">10 minutes</p>
<p>8. If you were telling a friend about the experiences you've had as a caregiver with the program, what would you would tell them?</p>		<p style="text-align: center;">10 minutes</p>
<p>Ending Question</p> <p>9. Thank you so much for sharing your stories with us today. Is there anything that we have missed? Is there anything that you came wanting to say that you didn't get a chance to?</p>		<p style="text-align: center;">5 minutes</p>
<p>Total Time</p>		<p style="text-align: center;">90 minutes</p>



Title VI Caregiver Program Assessment

Title VI Caregiver Program Assessment, Codebook

Topic	Description
General Program Description	
Who participates in the caregiver program	<ul style="list-style-type: none"> ▪ Understand who receives services and verify that the participating caregivers are unpaid. <p><u>A caregiver can be:</u></p> <ol style="list-style-type: none"> 1) An unpaid family member, friend or neighbor that cares for an elder. 2) Grandparents caring for grandchildren as the primary care provider. <p>(Definition is stated briefly here; see additional details in the caregiver chapter of the Title VI manual).</p>
Number of caregivers in the program	<ul style="list-style-type: none"> ▪ Understand how many caregivers are served, including how many of which caregiver type (i.e., family members, grandparents caring for grandchildren)
Caregiver outreach—how caregivers are identified	<ul style="list-style-type: none"> ▪ Explore how grantee programs identify caregivers and the process for recruitment and enrollment into the program. <p><u>Related description from caregiver chapter of Title VI manual:</u></p> <ul style="list-style-type: none"> ▪ “In Indian Country, the most likely caregivers are family members (spouses, daughters, granddaughters, and occasionally, male relatives), friends of the family, neighbors, or members of a church or social club who are close to the person needing care. Word of mouth is the best way to find caregivers, but many caregivers don’t identify themselves as such. Since caring for elders is a traditional activity in Indian Country, caregivers are simply doing what needs to be done.”
Caregiver services provided	<ul style="list-style-type: none"> ▪ Describe whether the program includes some, all, or none of the five caregiver services (listed below), and which services are most often used. ▪ Describe what each service type looks like. ▪ Describe types of services provided to grandparents caring for grandchildren. ▪ Describe types of services provided for family members or friends caring for elders. <p><u>The five types of caregiver services include:</u></p> <ol style="list-style-type: none"> 1) Information and outreach (information to caregivers about available services) 2) Assistance to caregivers in accessing the services 3) Counseling or support groups for caregivers and caregiver trainings 4) Respite care (i.e., allows the caregiver to be relieved of their duties) 5) Supplemental services like lending closets (e.g., supplies like toiletries or school supplies) or home modifications (e.g., install a wheelchair ramp at front entrance) <p>(Description is stated briefly here; see additional detail in the caregiver chapter of the Title VI manual).</p>
Who provides caregiver services	<ul style="list-style-type: none"> ▪ Describe whether caregiver services are provided by the program director, other staff, volunteers, partner agencies, or others.
How often services are provided	<ul style="list-style-type: none"> ▪ Describe how the program is organized in terms of frequency of service provision. Specify for all five types of caregiver services. For example, if respite services are provided, note the frequency of service provision for that specific service (e.g., two hours per week).

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	<ul style="list-style-type: none"> Describe whether all caregivers in the program are provided the same services at the same frequency or if there is any variation depending on caregiver type or other factors (and if so, why).
Where services are provided	<ul style="list-style-type: none"> Describe where services are provided. Specify for each of the five caregiver service types.
History of the Program¹	
When caregiver services began	<ul style="list-style-type: none"> Describe when the grantee began providing caregiver services and how long caregiver services have been provided (specify for all five types of caregiver services).
How caregiver services have changed over time (if at all)	<ul style="list-style-type: none"> Provide a description of the changes. Describe reasons or context for the changes.
If some or all caregiver services are not provided	<ul style="list-style-type: none"> Describe perceived barriers to providing caregiver services. Describe what it would take, from the grantee’s perspective, to provide such services.
Partnerships/Collaborations	
Caregiver program partners	<ul style="list-style-type: none"> Describe agencies, organizations, tribal departments or other entities that serves as a partner to the grantee in the provision of caregiver services (e.g., the transportation department may provide transportation services for respite care workers).
Other caregiver service provider in the area/region	<ul style="list-style-type: none"> Describe whether other caregiver services are provided in the local area or region. <p><u>Related description from the caregiver chapter of the Title VI manual:</u></p> <ul style="list-style-type: none"> “The OAA requires that caregiver support funds supplement, and not supplant, any federal, state, or local funds for caregiver services. In other words, if some other program was paying for caregiver support services, funds from the Native American Caregiver Support Program cannot be used for those same services. However, Title VI, Part C funds can be used to provide additional services.”
Use of volunteers	<ul style="list-style-type: none"> Explore whether the grantee uses local volunteers to help deliver the program. <p><u>Related description from caregiver chapter of Title VI manual:</u></p> <ul style="list-style-type: none"> “In addition to the required (caregiver) services, the 2005 Amendments to the OAA require the programs to use trained volunteers to expand the required services. If possible, you are to coordinate with organizations that have experience in providing training, placement, and stipends for volunteers, such as programs administered by the Corporation for National and Community Service. These would include VISTA Volunteers and Senior Corps Volunteers.”
Program Challenges & Facilitators	

¹ Note: many of our program directors are relatively new in their position and may not be able to provide much insight into the history of the program. If this is the case, just note as such. Do not press on the issue or require the director to go in search of the information.

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<p>Challenges providing caregiver services</p>	<ul style="list-style-type: none"> ▪ Describe challenges the grantee identifies related to providing caregiver services (e.g., engaging caregivers, getting them to participate, securing background checks).
<p>Solutions/strategies attempted to address challenges identified</p>	<ul style="list-style-type: none"> ▪ Describe any solutions grantees have found related to the challenges or strategies they have tried to address the challenges (if any).
<p>What helps grantees provide services</p>	<ul style="list-style-type: none"> ▪ Describe what helps grantees provide the caregiver services (e.g., partners, particular outreach strategies).
<p>Program Monitoring and Evaluation</p>	
<p>How the grantee tracks their caregiver program</p>	<ul style="list-style-type: none"> ▪ Describe how the grantee tracks their caregiver program, building off of what we learned last year as part of the data needs assessment (e.g., caregiver needs assessment, approaches to monitor caregiver services provided, number of participants served, caregiver satisfaction with services).
<p>How collected data informs programming</p>	<ul style="list-style-type: none"> ▪ Describe how the grantee uses the program monitoring/evaluation data they collect to inform their program, if they do (again, building off of what we learned last year).
<p>How program decisions regarding services are made</p>	<ul style="list-style-type: none"> ▪ Describe how program decisions regarding services are made (e.g., how priorities are identified, how decisions are made about service approach given limited resources, who participates in decision-making).
<p>Grantee Questions/Concerns/Ongoing Needs</p>	
<p>Questions the grantee may have about the program</p>	<ul style="list-style-type: none"> ▪ List any questions the grantee has about the caregiver program (e.g., this may include questions about what should be included as a part of caregiver services, how to implement a particular service, how to request support).
<p>Current needs of caregivers in the grantee community</p>	<ul style="list-style-type: none"> ▪ Describe the current needs of caregivers in this community based on the perceptions of the program director or other staff. ▪ Note how caregiver needs are identified by the grantee (relates to program monitoring and evaluation). <p><u>Related description in caregiver chapter of Title VI manual:</u></p> <ul style="list-style-type: none"> ▪ “The Native American Caregiver Support Program can help caregivers in a variety of ways. It is important to ask caregivers what would help them best. The suggestions included here are just suggestions. Be certain to include clinic staff and churches in your discussion of what caregivers need. Both may be able to support your programs with training, volunteers, and identifying caregivers.”
<p>Resources or assistance the grantee needs to implement their caregiver services more fully</p>	<ul style="list-style-type: none"> ▪ Describe the resources or assistance the grantee needs to implement their caregiver services more fully (specify whether the resource identified was identified by the grantee or by the site visitor/liaison). <p><u>Technical assistance areas of need may include:</u></p> <ul style="list-style-type: none"> ▪ Starting a caregiver program ▪ Strengthening or expanding their caregiver program ▪ Additional information or expertise (e.g., best practices in providing caregiver services) ▪ Training needs for staff ▪ Other issues identified by the grantee

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Additional Liaison Observations/Questions	
General notes	<ul style="list-style-type: none">▪ Add any notes here about the grantee's caregiver program that do not seem to belong elsewhere in the excel file.