

APPENDIX D

TITLE VI CAREGIVER FOCUS GROUP AND INTERVIEWS SUMMARY



Evaluation of the ACL Title VI Programs

Caregiver Focus Groups and Interviews Summary

October 14, 2019

This is a summary of the qualitative data collected during site visits with the evaluation grantees in 2019. It does not reflect synthesis with other data sources.

Methods

During site visits held in March, April, and May of 2019, the evaluation team conducted focus groups and interviews with caregivers participating in the Title VI Programs. 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. Caregivers were asked to describe the length of time they have participated in the Title VI Program, the services they have received through the program, what they like best about the program, how the program helps them, and the ways in which they would change or enhance Title VI Program services.

Evaluation Questions

The data collection was designed to address the following evaluation questions:

- 1) How are the Title VI Programs implemented at the national and tribal levels?
 - a. What is the array of Title VI practices available to caregivers?
 - b. What are the met and unmet needs of consumers and program stakeholders?
- 2) What are the outcomes and impacts of the Title VI Programs, nationally and by tribe or tribal groups? (What is the effect of the Title VI Programs on the caregivers in the community? Are there differences nationally or by tribe or tribal group?)
 - a. To what extent are caregiver expectations met through the Title VI service areas?
 - b. To what extent do caregiver experiences vary by program inputs, resources, and management models?
 - c. To what extent do caregiver experiences vary by tribal and grantee demographic, geographic, and other tribal contexts?
 - d. How accessible are Title VI nutrition and supportive services? How did this change through the Title VI Program?
- 3) What are the Title VI Program outcomes for programs that rely solely or primarily on Title VI funds, compared to cost-shared programs that receive a significant proportion of their resources from other programs/agencies? (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?)
 - a. What are the physical, emotional, mental, and spiritual outcomes of the Title VI Program?
 - i. Are there differences in outcomes by Title VI grantee characteristics and management models?

- ii. Are funding structures associated with Title VI Program outcomes?
- b. How has the Title VI Program led to improved health outcomes, such as an increase in the number of lives saved, or the number of elders returning from nursing homes?
 - i. How are Title VI Program “costs” associated with outcomes?

Design Development

ICF collaborated with the Administration for Community Living (ACL) to design a moderator/interview guide to elicit information related to data collection goals. Through consultation with ACL, ICF refined the guide with the aim of building rapport with caregiver participants and streamlined the approach, minimizing burden. ICF’s institutional review board approved the original protocol on March 1, 2017, and a modified protocol on February 9, 2018. In addition, ICF received continuing review approval on January 15, 2019. Office of Management and Budget approval was received on February 5, 2018.

Respondent Recruitment and Data Collection

The ICF evaluation team collaborated with program directors to develop a schedule for the site visits, including the focus groups and interviews, and requested assistance from program directors to identify a sample of potential caregiver respondents to participate. In March, April, and May 2019, the evaluation team conducted 1- to 2-day site visits with all Title VI evaluation programs. In each case, one or two evaluation team members attended, including ICF staff and, for some grantees, an ACL staff member. One team member moderated each focus group or conducted an interview while the other recorded notes. In the case of two grantees, the caregiver program had not yet been developed and implemented. Thus, ICF evaluation staff conducted a site visit in each case to understand the grantee’s related plans and needs but did not conduct interviews or focus groups with caregivers.

The total number of focus groups and interviews conducted per grantee was determined based on the number of caregivers willing and available to participate. 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, a sibling caring for another sibling, adults caring for a disabled family member, elders caring for other elders, and grandparents caring for grandchildren. Data collection did not begin until the ICF team member had reviewed the informed consent form with all participating caregivers, and caregivers had agreed to participate. Focus groups and interviews were audio recorded with the permission of the participants (all participants agreed to be recorded). Focus groups and interviews were transcribed and stored as Word documents, along with the audio files, on a secure ICF server.

Data Analysis

ICF’s approach to the qualitative analysis included initial transcript review and assessment of themes, codebook development, code application, and continued analysis and documentation of themes. Three ICF team members independently reviewed the transcripts to assess initial themes, patterns, and

interrelationships relevant to the evaluation questions and developed summary memos documenting the preliminary findings. The team developed a codebook to capture various categories of information connected to the data collection goals and related topics identified as part of the initial data review. To test the codebook and build intercoder reliability, three ICF team members separately coded two transcripts. The team members met to discuss coder agreement after coding each transcript and collaborated to refine the codes and code definitions and to ensure mutual understanding and consistency in code application. Through such meetings, codes were added, removed, or refined to capture themes emerging from the data. The team continued this process until a shared understanding of the codes was reached as measured by sufficient intercoder reliability. Using the revised codebook, each team member created a Hermeneutic Unit in the software package ATLAS.ti 7.0 and coded a set of the transcripts. Following coding, the ICF team used ATLAS.ti to search, retrieve, and classify the coded data. This process facilitated the comparison of themes and identification of relationships among themes. The team met to discuss themes identified, including responses posed repeatedly by respondents and responses that were more subtle or less often voiced.

Emerging Themes

Title VI Services Available for Caregivers

In answer to questions about the types of services they receive that support them in their caregiving role, caregivers often described a range of services spanning Title VI Program sections, including Parts A/B (nutrition and supportive services for elders) and Part C (services for caregivers). Responses suggest that many caregivers view their Title VI Program's services holistically and often do not distinguish between services specifically intended to support caregivers in comparison to services intended to support elders. This perspective may exist because many caregivers are also elders who may participate in the full range of Title VI services offered within each program.

Caregiver responses also suggested that while Title VI programs typically offer core Title VI nutrition and supportive services for elders, the caregiver services offered vary to a greater extent across programs. Specifically related to Part C, some caregivers reported receiving a variety of services that align with the five categories of caregiver services under Part C, while other caregivers reported a more limited range of services available to them. In addition, some caregivers described that they only recently learned about their Title VI Program's caregiver services and had not received caregiver services in the past but were in the process of gaining an understanding of available services. The Title VI Part C categories of caregiver services include: 1) information and outreach; 2) assistance; 3) counseling, support groups, and training; 4) respite care; and 5) supplemental services. The types of services that caregivers described receiving are summarized below by category.

- **Information and outreach:** Caregivers described a variety of outreach methods and information provided by the Title VI programs. Some caregivers described receiving information from their Title VI Program on a variety of topics related to providing care for others, such as insurance coverage, dementia, diabetes, and substance misuse. Some caregivers also receive notices about program events and guest speaker presentations, some of which focus on topics related to caregiving, and others receive information through a newsletter or community posting.

- **Assistance:** Some caregivers shared that program staff conduct home visits to assess the needs of both caregivers and recipients of care. A few caregivers shared that program staff helped them with accessing insurance, Medicare, or medical services and that they referred caregivers to local health clinics or other medical providers.
- **Counseling, support groups, and training:** Some caregivers described having the opportunity to participate in caregiver support groups and trainings focused on topics such as diabetes, dementia, and CPR. Some attended presentations focused on topics relevant to caregivers, such as stress management or emotional self-care. Those participating in caregiver support groups suggested that these groups provided an opportunity for caregivers to gather together and share their experiences and insights with other caregivers in a supportive environment.
- **Respite care:** Caregivers described receiving respite care services in different ways depending on the grantee program. In some cases, respite care services included payments to a respite care worker (often a family member) for a certain number of hours per week or per month.
- **Supplemental services:** A few caregivers described receiving supplies and equipment or that they were offered access to a “lending closet” to support them in their caregiving roles. A few other caregivers also described receiving a walker or wheelchair to support recipients of care.

Caregiver Awareness of Services

Caregiver awareness of Title VI caregiver services varied across programs and caregiver participants. As noted, while some caregivers participate in or receive one or more services that may be provided with the support of Title VI Part C funding, many caregivers expressed uncertainty about the types of caregiver services available to them through their Title VI Program. Some only recently became aware of the caregiver services provided through their Title VI Program. Many caregivers were interested to learn more about Title VI caregiver services, including types of services available, eligibility criteria, and how to access such services. In a few cases, respondents suggested that caregivers may be reluctant to seek information about services, in part due to this uncertainty or sense of embarrassment around inquiring.

Among caregivers who were aware of caregiver services offered through their Title VI Program, they often reported learning about such services through conversations with program staff. One caregiver describes: *One day, [the program director] approached me and told me, I know you're doing a lot for your parents and this and that. You need to start coming over. So, he invited me to come over, so I started coming over. I said wow, I was surprised that this was going on.*

In addition, some caregivers suggested that awareness of services could best be enhanced through “word of mouth,” particularly as some caregivers do not use social media or the internet. When asked about the best approach to build awareness, one caregiver responded: *I would say, word of mouth. I think a lot of people don't realize there is a program that can help.* Another responded: *Word of mouth. Because, I've been in this community for over 40 years, and if you send fliers or you go online and do it through Facebook or whatever, they don't read. They don't know, they're not technology savvy. So, word of mouth is the best because they know you, and they trust whatever you're going to tell them. Word of mouth is the best opportunity to get people to enroll.* Some caregivers recommended broader outreach to caregivers in the community to build awareness, particularly as some caregivers may not have the opportunity to visit their senior center or attend community events on a regular basis.

Caregiver Role/Characteristics

Caregivers who participated in the interviews and focus groups 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, a sibling caring for another sibling, adults caring for a disabled family member, elders caring for other elders, and grandparents caring for grandchildren. In some cases, caregiving is focused on a single recipient of care, such as a grandchild, adult with a disability, or elder spouse, while in other cases, caregiving is provided to multiple recipients at once, such as multiple grandchildren or both a grandchild and an elder family member.

Caregiving responsibilities vary in intensity depending on factors such as recipient needs and the extent of support caregivers receive, whether from other family members, friends, or the community, or through Title VI caregiver services. In addition, some caregivers provide care over a long period of time—either caring for one individual for many years or for one care recipient and then another over time—while others provide care for a short-term period. One caregiver describes, *I've been a caregiver for more than 25 years because I took care of my grandma back in the 90s, and now, it's my mom for almost 12 years now.* Among points of consistency, all caregivers reflected dedication to the role, concern for the well-being of the care recipient, and a focused approach in ensuring the recipients' needs were met. Most caregivers described that they provided care for a relative, while a few provided care for friends or others who were not relatives. Other themes observed include the following:

- **Caregivers often do not recognize that they may be eligible for caregiver services.** Many caregivers do not consider themselves to be a caregiver and/or they view caregiving as a natural extension of their responsibility to their family. As a result, often they do not consider that they may be eligible for caregiver service support, whether through Title IV Programs or community agencies or other entities that may assist them and alleviate some of the burden of caregiving. Caregivers provided the following responses:
 - *Just like me, I got this notice that I'm a caregiver. Am I a caregiver?*
 - *I really wish I would've known it was about "caregiving," because I did a lot for him.*
 - *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.*
- Caregivers believe "family take care of family," in part based on Native culture and tradition. Tied closely to the finding above, many caregivers described that family members expend considerable energy to meet the needs of an ill or disabled family member, in some cases coordinating with one another to create comprehensive support and to avoid placing loved ones in a nursing care facility. Some spoke to the desire to ensure that an elder family member can remain in their own home and with their family for as long as possible: *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 nursing home. So we keep going no matter what. Some*

also expressed that an additional key priority for family caregivers is to respect and abide by Native culture and tradition:

- *As a Native, I wouldn't want to put my mom—she passed away—but I wouldn't want to keep her in a home, when she's so used to the old ways where you want to feed them Native food and stuff and watch them as much as you can.*
- *Our Native people are... They would rather stay home than to go to a nursing home. It's out of their... what do you call it, their norms of life, to go into a community of all white people in a nursing home. So, they're very private about wanting to stay at home, or come home from a nursing home. They don't want to stay in nursing homes.*

Caregivers' Service Experience

What Caregivers Like Best

- **Dedicated staff.** Many caregivers expressed appreciation for Title VI program staff who are often kind, caring, and dedicated to providing services for both elders and caregivers. Caregivers described that program staff regularly check in on both caregivers and their care recipients, share useful resources or information, visit with caregivers and care recipients while delivering meals, and deliver meals regardless of challenges such as harsh winter weather or poor road conditions. Some described that a kind word from program staff can make a difference in caregivers' overall quality of life, particularly when caregivers are exhausted and stressed. Communication with program staff also helps strengthen social connectedness for caregivers who may be isolated and homebound while providing care. One caregiver appreciated that program staff put a priority on involving caregivers in planning Title VI program activities and including caregivers in the full range of program events and activities. Such inclusiveness conveys to caregivers that they are an important part of the community. Caregivers provided the following responses:
 - *[One program staff member] is always so compassionate. She 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.*
 - *I think the good part about the program is they have things, like they ask the elders what they want to do, and the caregivers are always involved with the planning or whatever activities they're having. And, I know they have potlucks every other month and birthday potlucks. The bingos and things like that, so... the caregivers are always a part of that. So I think... it's not just the elderly program, it's a community program, with the caregivers involved.*

Ways the Program Helps Caregivers

- **Respite care.** When asked which services were most helpful to them in their caregiving role, most caregivers who have received respite care services indicated that this service was the most helpful caregiving-related service offered to them. Some described that this service provided

substantial stress relief by allowing caregivers to attend to other aspects of their lives for short periods of time or simply to take a needed break from the challenging work of caregiving. Caregiver responses included the following:

- *I think the biggest [service] would be respite. Which helps a lot of people, especially if they do need to run those errands, because again...you're constantly running into those issues like, I need to pick up something from the grocery store or I need to go do this. Or, they might just need to have lunch on their own one day, whatever the case might be. So I think respite is one of the biggest things.*
- *I know when [my husband]... had a hospital bed, IV, the whole 9 yards in the house...they would come in and... help him so I could take a break. Then when I went, they completely, for like a week, they would come in every day and put on his support hose...respite came in and offered to cook him meals and do some laundry....It was very, very helpful...he feels safe and that he's taken care of, and yet I can get a break.*
- *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...it seems to work out for the 2–3 hours she's here. She preps a nice meal for mom, and they get along.*
- **Counseling or caregiver support groups.** Caregivers affiliated with one grantee that currently offers a caregiver support group once per month emphasized that the caregiver support group has helped them substantially to manage the stress of caregiving as well as gain insight from others facing similar issues about potential caregiver resources and strategies. They described that the opportunity to share experiences with fellow caregivers builds resilience and gives them renewed strength to continue in their role:
 - *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. That's some of the things that we get when we come here, because we talk about, amongst each other, about what problems or concerns that have come about around us, where we couldn't really share it with anybody but the care-group givers, as we have our meeting.*
 - *So, I thoroughly appreciate coming. Because, by the time we get out... and of course everything that we share amongst each other and all that stays here. And leave that here for us to, again, kind of begin to be whole and start our journey again.*

Caregivers who do not have access to such structured caregiver support groups shared that informal resource sharing with other caregivers has been beneficial to them. One caregiver appreciated guidance and insight from a friend related to understanding the stages of dementia: *I had to go out and get some resources. And I have a friend that's...going through the same thing, and... she'll help me [with] what to do next. The part that I don't understand, the doctor says they go through stages, so I ask, what are the stages? She said, well, they're going to get*

agitated, they're going to be confused. They're going to think they can do it, but, you know, they can't, so you cannot get mad. You just listen to them.

- **Assistance.** Connected to an overall positive feeling about the Title VI Program and the dedicated staff, some caregivers also spoke specifically about how they know they can rely on program staff to help them identify and access available resources or services to provide better care for their family members. One caregiver described that such assistance supports unpaid family caregivers in particular, as these caregivers often have limited financial resources or other supports or insight about caregiver services. Through assistance, including referrals, program staff help connect caregivers to important community resources.
 - *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.*
 - *So, I take care of my mom, who is an elder, and I think... I don't get paid to take care of her, I just... that's my mom, so I do it. And if I'm ever stuck...and needing equipment and not being able to pay for it, I can always come to the senior center to [program staff] and ask if she knew of those resources. And she'd always have something. She'd always figure something out. I know that I could always go to her to...find some type of resource. Anything I needed, she'd be able to help with. So I think, as a caregiver that doesn't get paid, it's nice to know there's people out there and somewhere that has these resources and has answers and is willing to help.*
- **Supplemental services.** A few caregivers described that the Title VI Program provided equipment for them, such as wheelchairs or walkers, which served as simple but critical resources for helping the care recipient remain as independent as possible. One caregiver describes: 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 after I got her out of the hospital... that walker enables her to be independent instead of having to rely on somebody to help carry her to the bathroom... that is the goal—we're trying to help them be totally independent and still remain who they were.
- **Nutrition and supportive services.** As noted under “Title VI Services Available for Caregivers,” many caregivers reflected on the way in which Title VI-supported nutrition and supportive services (Part A/B) offered through the Title VI Program supported them in their caregiving role. Some described that the opportunity to share a meal, socialize, and connect with others in the community, as well as other benefits, helped to reduce the stress that many caregivers experience and to support caregivers in diverse ways. More specifically:
 - For caregivers providing care for elders who receive Part A/B services, many reported that these services substantially supported their care recipient, which also helped to alleviate the burden of caregiving: *I'm able to just check in on mom, and... the services that the center provides are the meals that they give once a day. I don't have to worry about that, she manages those meals, and she can have them a couple times a day.*

- For caregivers who are also elders receiving Part A/B services, these services—including the opportunity to socialize, share resources, receive meals, and others—directly promoted caregiver well-being. *I think it's wonderful that there's that availability for people to get together at the [senior center]... just to be able to have a safe place to get to, and you know, get together with friends and acquaintances that you see, and maybe [you] just need to encourage sometimes and get encouragement from. And that's really, really good, I think.*

Challenges

- **An intensely stressful experience.** Many caregivers of all types—whether caring for grandchildren or an elder or disabled family member—described that the all-consuming nature of caregiving can become intensely stressful in various ways. Caregivers whose care recipient suffers from dementia suggested that such stress is particularly acute. One such caregiver described: *I helped take care of my mother up until she passed away last year in 2018. And that was off and on for the same amount of time. She had dementia, so that was, the past two years were really, really difficult.* Another described: *Yes, or even 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.* A third caregiver noted: *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.* Moreover, another caregiver noted: *It's hard to reason with somebody who is adamant that she put something there, and ten minutes later, it's not there. She can't help it, she's sick.*
 - **Physical stress.** Caregiving can become physically exhausting as caregivers attempt to handle the routine duties of their lives, such as work or other responsibilities, while also caring for grandchildren and/or an ill or disabled family member. Many described struggling and often depriving themselves of sleep or other self-care. One caregiver described working as a farmer at night in order to care for his aging mother during the day. In other cases, family members rotated the responsibility of staying up through the night to watch over and administer care to a loved one. One caregiver described: *I drive back and forth to take my husband 3 times a week [to dialysis treatment]. And, his chair time starts at 3:00 a.m., so we leave home here, we leave home...at midnight to get out to dialysis, and he's done about 7:30, 8:00, and then I drive him back home. And, I do it 3 times a week... You know, it's not only enduring the treatment time, but it's the 6-hour commute time.*
 - **Financial stress.** Caregiving often imposes substantial financial burden, such as those related to frequent medical appointments located at great distances. Caregivers struggle with decisions such as whether to place a loved one in a nursing care facility or leave a job or reduce their hours to part-time to be more available to provide care for a family member. One caregiver notes: *For my part, I've spent probably thousands of dollars on my own traveling to Boise and Caldwell, hospitals, and having to stay in a motel overnight. So, what we do now, if my wife has three appointments, we try to set them all on the same day. And, we get with the secretaries from these different clinics or*

whatever we have to go to and try to get...you know, sometimes we have an 11:00 appointment, 12:00 appointment, or 1:00 appointment...So, it's a lot of travel, a lot of expense.

- **Emotional stress.** Most caregivers described that caregiving can be emotionally overwhelming. In addition to coping with a loved one's illness or disability, for example, caregivers often worry about managing caregiving duties, and some experience tension between family members regarding caregiving decisions. Many experience isolation and loneliness. Universally, caregivers experienced both the need for, and lack of, personal breaks. Some also described that the responsibility of caregiving magnified the sense of loss and guilt experienced in a loved one's death. One caregiver describes: *Six months ago... I was washing dishes, and her voice started to get louder, and then came the accusation part. Okay, wait a minute. I turned off the water, got my bag, and went on the bus, and went for a good four hours. I took a break. I need to take time out for myself, because if I don't, then I get more stressed out, and it shows when I'm with her. I need to be more patient. I know that, because we all need to be more patient.*
- **An isolating experience.** As noted, compounding the emotional stress associated with caregiving, many caregivers described that caregiving can be an isolating experiencing, either as a result of being homebound while providing care or being caught in an unending cycle of routine tasks related to caregiving. One grandparent appreciated that program staff include grandparents raising grandchildren in events, as this provided a reprieve from isolation: *They had a little gathering for the grandparents that are taking care of their grandchildren, and then I came to that. And I think that's really good because, you don't feel like you know you're just so isolated.*
- **Challenges for grandparents raising grandchildren.** In addition to the stresses described above, grandparents raising grandchildren described additional challenges such as the difficulty of "starting all over," taking on the role and responsibility of being a primary caregiver for a child or adolescent, at a time when many grandparents are in need of greater support themselves related to declining health or mobility. Specific issues include the time required to care for and raise a child; the related expense, when financial resources may be at a low point; and the fact that managing the many tasks needed to raise a child requires energy and agility. Such tasks include providing meals, supporting routines, helping children with homework, attending to grandchildren's health care needs, and arranging for transportation to activities. Moreover, some grandparents described that raising a child in a modern world is very different from their own experience of growing up, as well as compared to the experience of raising their own children. One grandparent described: *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.*
 - **Additional factors.** For some grandparents, additional factors greatly intensify these challenges, and can include 1) caring for children who are less independent, including very young children; 2) caring for multiple children at once; and 3) caring for children or youth who struggle either with developmental disabilities or behavioral health issues, in some cases as a result of having been exposed to adverse childhood experiences (ACEs).

One grandparent described being concerned about whether her grandson, who struggles with behavioral health issues, could pose an unintentional danger to her husband, whose mobility and sense of balance was declining. She suggested that caring for both family members in the same household was stressful. Related to the issue of ACEs, grandparents shared the following:

- *My grandkid has been in a home where there was meth and a lot of abuse from their dad, verbal abuse and him assaulting their mother that they saw, so it's been very traumatizing to them. And to hear some of the stories... they say, it's hard.*
- *And I also took care of my grandsons. So that's a big challenge. You work with a lot of different people when you're taking care of children. Especially if there's problems of any kind. And, of course, the police and FBI and everybody that's getting involved if you have problems, so it's a big issue sometimes.*

- **Assuming a caregiving role without education, training, or other support related to caregiving.** Many caregivers described falling into the role of being a caregiver without the benefit of education, guidance, or insight from a peer/friend, counselor, support group, or other resource that would orient them to the common challenges, strategies, and experiences of being a caregiver. As a result, many described struggling when faced with such common challenges, such as how to lift and move a disabled family member, communicate with and support an elder losing vision or hearing, administer medical care at home, coordinate complex appointment schedules, navigate medical or insurance processes and decisions, or recognize the signs of depression in a loved one suffering from chronic illness. One caregiver described: *[My husband] got so depressed there, I didn't realize at first that that's what was happening. He was just sinking down further and further.... You don't say stuff.... 'You're talking in such a whisper, I feel like I'm talking to a dead person.' I said that. You don't say that to somebody that's depressed. I know that now, looking back.... For me, that was my first time having to take care of somebody like that. I don't know those things. And to be able to talk to somebody who's been through it would've been helpful.*
- **Providing care for family members who are reluctant to receive assistance outside of the family.** Although caregivers may seek support beyond family care providers (e.g., respite care from someone outside of the family) to help a care recipient, some caregivers report that elder care recipients in particular may be resistant or reluctant to accept such care, preferring instead to rely on help from a family member. This can create additional stress for a caregiver who is attempting to manage multiple caregiving responsibilities while respecting the preferences of an elder family member. One caregiver describes: *I did get... like a home care provider that came from Las Alamos to give her therapy and what not. But my mom, like some people, they don't want it. And then... Mom, I said, we're trying to do this, but you don't want it. Now, she's saying, we don't want this, we don't want that. You know, we're trying our best on the other hand to make it a lot easier for us.*

Caregiver Suggestions to Adapt or Enhance Title VI Services

When asked what they wish they could include or change about their Title VI Program, respondents provided a wide variety of suggestions, often focused on topics such as the following:

- **Information to support caregiving.** Some caregivers suggested it would be helpful to receive additional information to support them in their caregiving role. For example, several described that the individuals they care for are living with mental health or cognitive health issues such as dementia or depression—conditions that complicate caregiving in many ways. They requested information related to the signs and symptoms of mental or physical illness, stages of illness, and how to care for others with certain conditions. Some grandparents suggested that guidance related to caring for youth, particularly youth who may have experienced trauma and/or may struggle with behavioral health issues, would be helpful.
- **Assistance with referrals.** Caregivers suggested that referrals to outside services would help them to navigate systems of care and identify new resources. Caregivers described having difficulty identifying and accessing appropriate services and securing appointments. Some also requested guidance in understanding related medical terminology, the implications of diagnoses, and care procedures. One caregiver described: *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. Like, talk with somebody for support, to know what my patient is going through.*
- **Counseling or caregiver support group.** Many caregivers spoke about the need for and anticipated benefit of counseling and caregiver support groups that would provide an opportunity for caregivers to share experiences and learn from one another. One caregiver described: *So I think it's just like 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. A caregiver for grandchildren also noted: 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. What to do?*
- **Enhanced respite care.** Many caregivers suggested that respite care is a crucial resource for caregivers and often expressed a desire either to be able to receive respite care in general or to receive such support for additional hours or over a longer period of time. A few respondents suggested that an adult day care program or other dedicated temporary support for care recipients would be a valued resource, allowing time for caregivers to attend to errands, appointments, or self-care. One caregiver for grandchildren described needing: *Somebody I could call when I need to go to my appointments or last minute appointment or something.... I'm scrambling around to find somebody at least to keep an eye on the kids until I get back. So I don't feel rushed and overwhelmed, because I always feel that!*
- **Access to supplemental services.** Several respondents suggested that additional supplemental services and supplies would help them to meet their caregiving needs (e.g., supplies related to hygiene, incontinence, first aid). A few respondents requested assistance related to routine home maintenance or transportation.