

APPENDIX C

IN THEIR OWN WORDS: CAREGIVERS



IN THEIR OWN WORDS: CAREGIVERS ON THE TITLE VI PROGRAM

In the spring of 2019, the ICF team conducted focus groups and interviews with caregivers participating in the Title VI Program to improve understanding of their experiences with the program. Highlights of their experiences are presented below.

Title VI Part C – Providing a Vital Service

- “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... needing equipment and not being able to pay for it, I can always come to the Senior Center. And she'd always have something. 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.”

Information and Assistance

- “You know, I've never been offered or introduced to a program such as this. And it's like magic. And the workers, they're so on it. You know, I just love the reminders, the calls, and it's such a picker upper when you're a caregiver 24/7...”
- “I think I'm okay because if I have anything bothering me I know I can come to the program and talk to them. And they'll try to help me any way they can.”
- “What I need is information on how to help me... with [my grandchildren]. I know we got counselors up at the hospital... maybe once a month they come in or whatever, but sometimes I need it daily. If they had a pamphlet or information on how I can be a better grandparent, because I'm not young like I used to be, and I do need my rest.”

Counseling/Support Groups/Training

- “You know, I've talked to [program staff person] a lot of times, and he's been very supportive. He understands what... we go through. I mean, he says, I'm not in your shoes, and I really can't completely understand, but I have an ear. I can listen, I can hear you.”
- “For me, that was my first time having to take care of somebody like that. I don't know those things [related to caregiving]. And to be able to talk to somebody who's been through it would've been helpful.”
- “Sometimes he does bring somebody in from the outside to speak on either caregiving or... Alzheimer's,... like informational sessions.... And then they provide dinner, so we all sit and eat, and it's a great type of thing.”

Respite

- “It's just the time I need to free myself up to do the things that need to be done. Things that never go away. There are things to be done, and that's where I'm going to utilize this [respite care worker].”

- "You never know how wonderful respite is until you don't have it. And you know, I never knew, so I just adjusted my time and my life to caring for my husband. But now to have it, oh it's so lovely."

Supplemental Services

- "I think more supplies would be helpful. More funds would be helpful to get supplies for the clients that may have run low... personal care [supplies], like bedding supplies, like toiletries."
- "[Program staff have] a couple maintenance workers... they only work a few hours a week but go in and do some basic cleaning and stuff. Or take out their trash... it's only a few hours a week... That'd be nice if there were more services like that."

Caregiving: A Rewarding, But Challenging Experience

Physically and Emotionally Stressful

- "I'm a farmer, and my mom has congestive heart failure, and her lungs are only working at 40 percent. So, she's on oxygen and she's not supposed to be left alone. I have to wait until she goes to sleep at night so I can go out and do my work. So, I work at night most of the time, so I don't get a whole lot of sleep. Because, during the day I have to take care of her."
- "Our biggest thing was getting sleep at night. [My siblings] would take turns watching her between us three girls and my brother. And on those nights, we'd get very little sleep, and then still have to... come to work every day."
- "After taking care of her for all these years, it's stressful. It's really stressful, and it was hard for us to even consider sending her to a home, so we cared for her until she passed away."

Coping with Dementia and Other Disabilities

- "And with my mom, it's very challenging because she can't hear very well. And so... it's hard to talk to her. When she wants something, you try to figure out what it is, and you try to ask her, and if you talk loud she thinks you're yelling at her, then she gets mad. And so, it's kind of challenging."
- "I still take care of him because he's got dementia. And right now he's really stubborn where I can't tell him what to do legally.... So I just take care of him by making sure he's alright and has a place to stay. And, with his meds, I always make sure that he's got a refill, because he's got some heart issues and other health issues. So I take care of him."

Grandparents Raising Grandchildren

- "It's a 24/7 job, you know it's hard. Sleep with them, get them up in the morning, get them ready, like a mom... is supposed to be doing. But like I said, it's got to be done and I'm doing it, the best way I know how. Sometimes I lose it. I just get irritated and all that, you know, but that's age I guess."
- "Sometimes I get so mad but then I can't because those are my kids, they're my grandkids. I can't... That's the kind of information I would kind of like to receive, even through the mail. How to deal with stress. How to deal with kids of certain age. Just like, parenting."