

# RESPIRE SERVICES:

The Experiences and Recommendations of Service Providers and Racially, Ethnically, and Culturally Diverse Family Members



**PREPARED BY**

Georgetown University National  
Center for Cultural Competence

2024

# FINAL REPORT

Respite Services:  
The Experiences and Recommendations of Service Providers and Racially, Ethnically,  
and Culturally Diverse Family Members

Submitted to:  
ARCH National Respite Network and Resource Center

Submitted by:  
Georgetown University National Center for Cultural Competence

Submitted on:  
March 12, 2024



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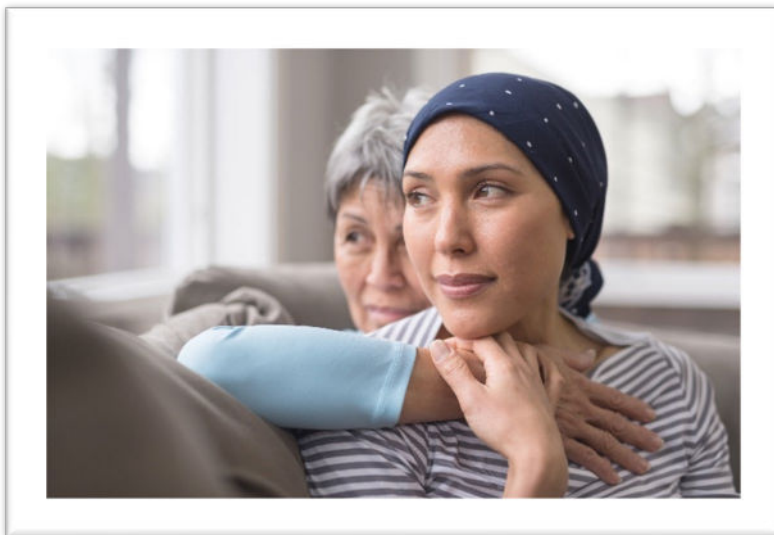
## OVERVIEW

The mission of the ARCH National Respite Network and Resource Center is to “assist and promote the development of quality respite and crisis care programs in the United States; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums” (2022). According to the Lifespan Respite Care Act, respite is defined as “planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers” (Public Law No: 109-442). Recognizing that many ethnic, racial, and cultural groups face challenges accessing or achieving desired respite outcomes, ARCH contracted with the Georgetown National Center for Cultural Competence (NCCC) to learn more about the experiences of these caregivers and what they would recommend to respite providers to improve services. The NCCC also gathered information from respite service providers to document their efforts in the provision of supports and services to racially, ethnically, culturally, and linguistically diverse family members and to elicit their suggestions for improvement. This paper examines the results of listening sessions with family caregivers from diverse racial, ethnic, and cultural groups, service providers, and key constituents to help inform improvement within respite programs funded by the Administration for Community Living (ACL), US Department of Health and Human Services (HHS).



## REVIEW OF THE LITERATURE

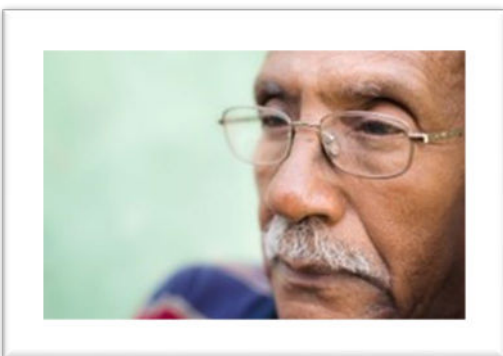
Research has shown that respite services help prevent caregiver burnout, reduce stress, and enhance overall well-being; however, they are underutilized by families (Wayne et al., 2023). Based on a survey of 1,392 caregivers, the National Alliance for Caregiving and the American Association of Retired Persons (AARP) reported that only 14% used respite (2020). There is sparse research on the pattern of respite use by families across diverse racial, ethnic, cultural, and linguistic groups. Findings among this limited body of literature, which was reviewed for this report, reveal variations in use, need, and intensity of respite services by race and ethnicity. This report uses racial and ethnic terms and categories as cited by the researchers conducting the studies. A study of Asian, Hispanic, and non-Hispanic White American family caregivers in California found that Hispanic caregivers used respite care services less than non-Hispanic White caregivers. However, there were no statistically significant difference found between Asian and non-Hispanic White caregivers (Miyawaki, 2016). Another study found that African American caregivers for persons living with dementia were 69% less likely to use respite than White caregivers (Parker & Fabius, 2020).



A number of studies documented underutilization among specific racial and ethnic groups, but also a greater need for respite supports and services. For example, findings revealed that care situations of African American and Hispanic caregivers were often more high



intensity when compared to caregivers who are White and Asian American (Choula et al., 2020; Cohen et al., 2017). According to the National Alliance for Caregiving and AARP, high intensity caregiving is defined as situations where the caregiver is the primary care provider, living with the care recipient, and providing care for an average of 49 hours weekly for an average of 5 years (2020). A secondary analysis study of national surveys showed that Black caregivers provided higher levels of care than White caregivers in daily activity measures and spent an average of 28.6 hours more per month in that role (Cohen et al., 2019). Notably, Black female caregivers provided higher levels and more hours of care than White females and males (Cohen et al., 2019).



A study of caregiving needs in American Indian communities indicated a high need for personal care and respite service (Aldrich, n.d.). A face-to-face survey of 169 Pueblo Native American caregivers in New Mexico showed significant levels of perceived burden on individual caregivers and the community as a whole (John et al., 2001).

Although third generation Asian and Hispanic caregivers used respite care the least, they spent more caregiving hours compared to Non-Hispanic Whites (Miyawaki, 2016). The National Alliance for Caregiving and AARP found that higher levels of emotional strain reported



by Asian American and White caregivers than African American or Hispanic caregivers (2020).

The underutilization of respite services by diverse racial, ethnic, and cultural groups may be tied to agencies' limited capacity to provide culturally and linguistically competent services and more research is needed to better understand this dilemma. In the article, *One-size-Doesn't-Fit-All: Recognizing Diverse Caregiver Experiences*, the authors underscore that family caregiving is deeply embedded in cultures and noted the following:

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*“While caregivers of color may be referred to as a single similar group, the experiences and cultural values, including how they choose to care for family — and where they care for them — vary widely.”*

*Choula et al., 2020*

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## PURPOSE AND METHODOLOGY

The purpose of this report is to provide ARCH National Respite Network and Resource Center a summary of the lived experiences of caregivers from diverse racial, ethnic, and cultural groups receiving or in need of respite services. To accomplish the purpose, the NCCC convened five virtual listening sessions for parents and family caregivers from racially, ethnically, and culturally diverse backgrounds to listen to and document their experiences with respite care for their family members. Additionally, two virtual listening sessions were convened to discover the challenges and successes of respite providers and State Lifespan Respite Grantees and State Coalition representatives in providing respite care to older adults and persons with disabilities across diverse racial, ethnic, and cultural groups. This report highlights the themes from these data collection efforts. (See Appendix A for description of the methods and data analysis).

This report was used to help inform the development of the Cultural and Linguistic Competence Assessment for Respite Organizations (CLCARO). The CLCARO was developed to support State Agency Lifespan Respite grantees and State Respite Coalitions to: (1) plan for and incorporate cultural and linguistic competence into their core functions; (2) enhance the quality of respite services, supports, and information provided to culturally and linguistically diverse communities; (3) advance cultural and linguistic competence as essential approaches to reduce disparities and promote equity among the diverse populations in need of respite services across the life span; and (4) meaningfully engage persons and families in need of respite services in public policy efforts.

## SUMMARY OF FINDINGS FOR FAMILY CAREGIVERS

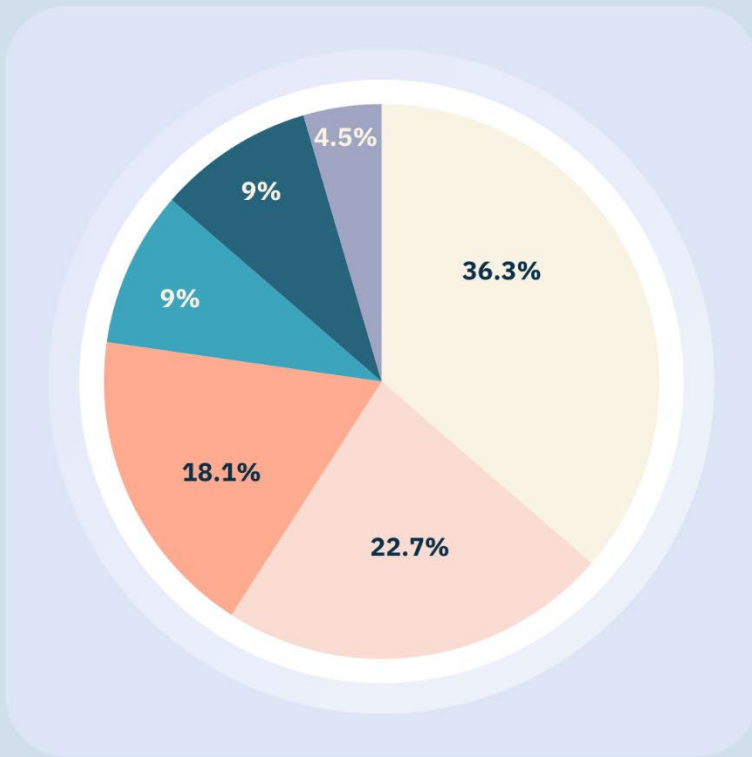
This section of the report summarizes themes and illustrative comments that emerged from the family caregiver listening sessions. A total of 22 family members<sup>1</sup> participated in the listening sessions. Participants were from 11 states including: California, Illinois, Massachusetts, New Jersey, New Mexico, New York, Ohio, Oklahoma, Texas, and Wisconsin. It is important to note that the majority of participants (95%) were women. Figures 1- 5 provide the summary demographics of family caregivers who participated in the five listening sessions.<sup>2</sup> Regarding caregiving roles, most participants were family caregivers of children/youth with disabilities and not currently receiving respite services (see Figure 1). Most of the participants identified as Hispanic/Latino (see Figure 2). Additionally, the majority of participants were married or in a domestic partnership (see Figure 3). In terms of employment status, the majority of participants were employed either full-time or part-time (see Figure 4). The age range of participants revealed that most were in the age groups of 45-54 and 35-44 (see figure 5).

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<sup>1</sup> In presenting the survey findings, drawn from a relatively small sample size of 22 family members, the NCCC has opted to use percentages instead of raw numbers. Despite the limitations of a small sample size, this approach offers a more standardized and comparable result (Sauro & Lewis, 2023). It is important to note that the percentages may not always sum to exactly 100% due to rounding.

<sup>2</sup> Supplemental material for enhanced accessibility: See [full data](#) of family caregiver demographics.

- 36.3% of the participants were caregivers of a child/youth with disabilities NOT currently receiving respite services
- 22.7% of the participants were caregivers of an adult with disabilities receiving respite services
- 18.1% of the participants were caregivers of an adult with disabilities NOT currently receiving respite services
- 9% of the participants were caregivers of a child/youth with disabilities receiving respite services
- 9% of the participants were caregivers of an older adult NOT currently receiving respite services
- 4.5% of the participants were caregivers of an older adult receiving respite services

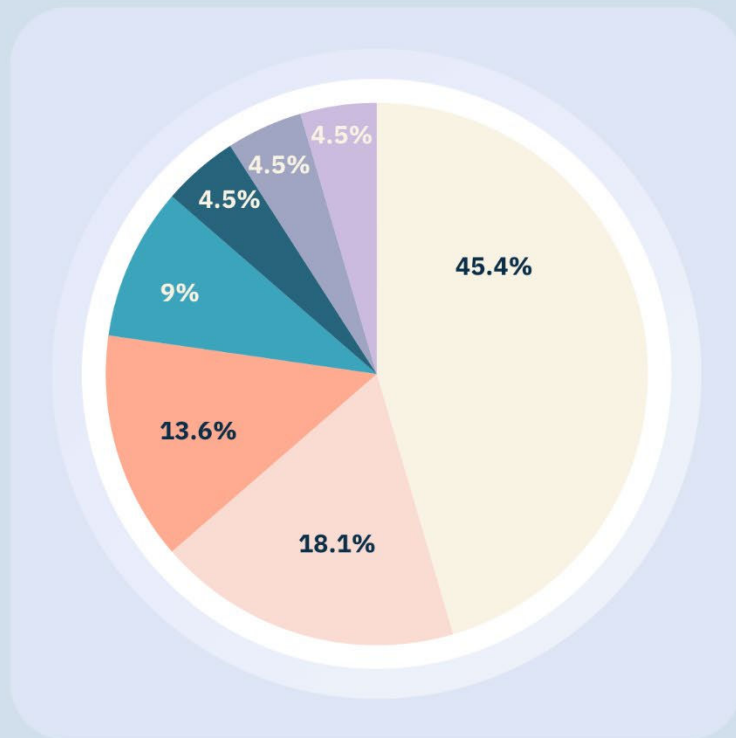


**FIGURE 1.**  
*Caregiving role and status of respite use of participants*

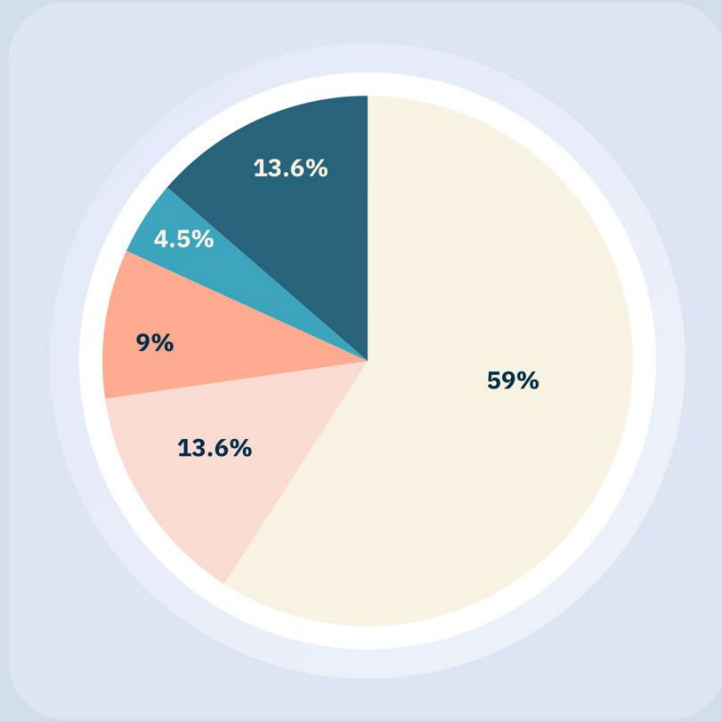
**FIGURE 2.**

*Self-identified race/ethnicity of participants*

- 45.4% of the participants self-identified as Hispanic/Latino
- 18.1% of the participants self-identified as White (non-Hispanic)
- 13.6% of the participants self-identified as being two or more races
- 9% of the participants self-identified as being Black or African American (non-Hispanic)
- 4.5% of the participants identified as Asian
- 4.5% of the participants self-identified as Native American or Alaskan Native
- 4.5% of the participants self-identified as some other race



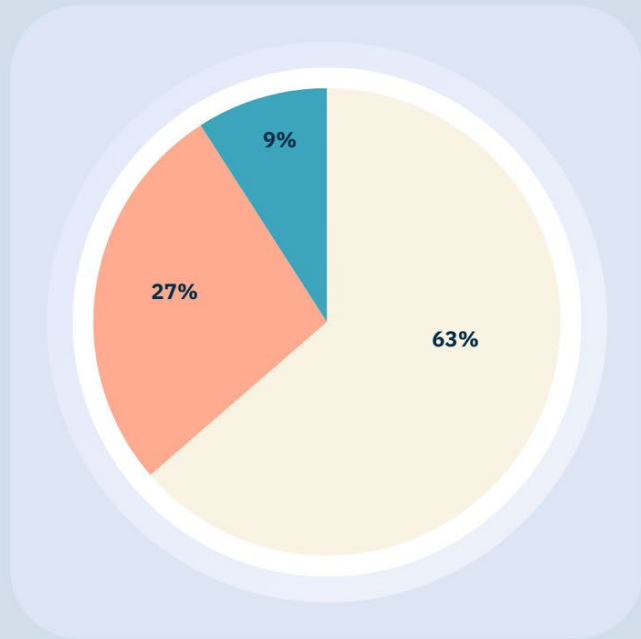
- 59% of the participants were married or in a domestic partnership
- 13.6% of the participants were single/never married
- 9% of the participants were divorced
- 4.5% of the participants were separated
- 13.6% of the participants chose not to answer



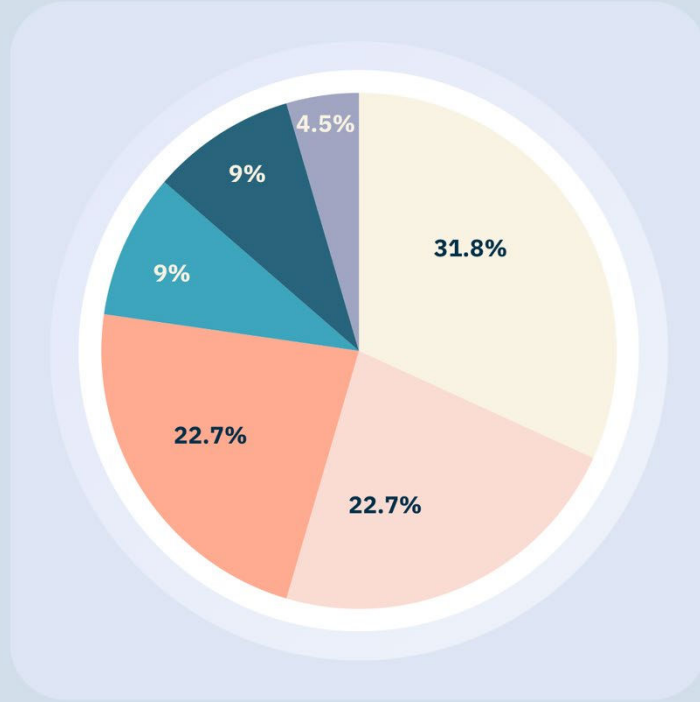
**FIGURE 3.**  
*Marital status of participants*

**FIGURE 4.**  
*Employment status of participants*

- 63% of the participants were employed either full time or part-time
- 27% of the participants were unemployed and NOT looking for work
- 9% of the participants were unemployed and looking for work



- 31.8% of the participants were between the ages of 45-54
- 22.7% of the participants were between the ages of 35-44
- 22.7% of the participants were between the ages of 64-74
- 9% of the participants were between the ages of 25-34
- 9% of the participants were between the ages of 55-64
- 4.5% of the participants chose not to answer



**FIGURE 5.**  
Self-reported age range of participants

Data analysis yielded nine key themes, some of which are overlapping.

### Theme 1: Importance of respite services to family members

All participants indicated that respite services were extremely important for both themselves and their families. Families reported that respite care made it possible for them to have time to complete household tasks and address their health needs and self-care.

Participants commented:

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“They're pretty important because they allow my mom, especially, to get the time to do things that she has to do away from my siblings...sometimes they don't like to go outside or grocery shop, so it gives her the time to be able to go do those things.”

“They were hugely important for my family. I'm a single parent of a son and I had so much difficulty accessing respite services that at times I thought if I didn't get a break, I would go right out of my mind...Because he was, by his account also, an extremely difficult child. He had number of issues going on at once and...I suffer from chronic migraine headaches, so I only had so much gas in the tank and I really needed the break, but I could not find respite services.”

“So, for me respite will be so important because I will love to go to my backyard and feed my plants and stay in my hammock, and I can't do that because my children don't go outside because of their condition. So, it is just as simple as me sitting outside with a cup of tea and a book in order for me to read.”

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## Theme 2: Need for cultural and linguistic competence in respite services

As reported in theme #1, when asked about the importance of respite services, families indicated that they were extremely important. However, families reported that much improvement is needed for services to be culturally and linguistically competent. Families stated there is a need for recruitment and hiring of more diverse and bilingual staff. When asked what service providers need to do to meet the interests and needs of families, participants commented:

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“The only other thing I would say would also be trying to hire more people of different backgrounds, because sometimes there's that lack of... people who don't speak Spanish or don't speak their particular language and it's really hard for them to communicate with whoever comes and does a service...there's a language barrier.”

“Try hiring people from other backgrounds because sometimes there is a lack of people who speak Spanish or their particular language and it's really hard for them (the family) to communicate with whoever comes and does a service. There's a language barrier, so it kind of affects the service, I feel, because, like the provider can't really tell the family what's going on, or if the child share something or says something and if they can't communicate that with them, it makes it kind of hard, I feel, to do their job, or at least to let the family know what's going on. And that's something I see a lot of people don't they can't find like Spanish speaking providers to help at their house and some families just feel more comfortable with people who speak their own language.”

“Sometimes you go and ask for help, or you don't know how to speak English, or you can't pronounce it right or how it is. And sometimes they look at you wrong. Or sometimes, they tell you, "Give me your information and wait for a call" or they put you on hold. On hold. That was my case, when my child was one year old, because it had to be a very long process and, because there were a lot of families on hold. And I really didn't know anything about the programs at that time.”

“I think that that is a struggle, a little bit I am part of that organization that serves the Latino community with children with disabilities, and we have seen that there is a struggle in that area because lots of families will either feel like there is a language barrier where they want to try and get services they need...”



“...I don’t think anybody’s thinking about that. I think that in general, if you get assigned a care provider, is just they’re available...I don’t see any kind of professional development happening or capacity development happening at all. I don’t think there’s any consideration of cultural needs in that process.

“I think that the ratios for when it comes to being of color like if Hispanic American, it’s very low compared to white to white individuals.”

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### **Theme 3: Build trust in diverse communities**

Providers must acknowledge the harm that individuals from minoritized communities have experienced due to institutional racism and discrimination. The need to re-establish trust when harm has occurred was a recurrent theme among family caregivers. Participants stated:

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“I need to trust you, and in order to trust you got to build some type of relationship and it's going to take time...it's going to take time for the children, it's going to take time for the workers, the pairing process is really important, and even that should be explained a little bit more in details, because if you don't pair with a child...You can't force that relationship, so I think that's one of the things that they're pretty good at, but it's going to take time”

“Having somebody who knows my child already so that it's not just some random person showing up, that's the reason I would not drop them off at services, because he has specific care needs and specific communication needs that I would want somebody who can understand those. And then making sure that those services have a quality aspect to them and that someone is checking on the quality, checking with me about my thoughts on the quality, and not just sending someone out and hoping everything goes okay.”

“I guess it depends how good they can relate to the client, because I think that sometimes you get providers that come to your home and they can't necessarily click with the client. They have a lot of trouble being able to communicate with them or guide them...with my brother...he has like a really hard time trusting people.”

“And I also think it is necessary for them to know that if we are requesting this service, it is not because we want to abuse the system. Or we want something extra, it's that it's a need for our children as well as for ourselves. It is not because we want to abuse and get more things, and that they give us, that they give us, that they give us. I mean, no, it is a mere (true) necessity.”

“I would say just have patience with our parents, especially being a new parent with this diagnosis that we have and just being patient with us and realizing that we're understanding, trying to understand, and like everyone's been saying it's just a dump of information, it's overwhelming when you're trying to juggle life at the same time.”

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#### **Theme 4: Disparities in respite service availability and access**

According to Choula, Snyder, and the John A. Hartford Foundation:

“Caregivers are often encouraged to enroll in formal training or respite programs to receive support. But for caregivers of color living in under resourced communities without such programs, where are they supposed to turn? If programs do exist, but all the materials are in English when Spanish is the primary language of caregivers in the community, what good does that do?” (2020)

Family caregivers indicated that there are disparities in service availability and that wealthy families have better access to respite providers. Participants indicated that service availability is impacted by staff shortages, geography, limited capacity of providers to serve those with diverse diagnoses, and failure to tailor services to the racial, ethnic, cultural, and linguistic needs of families. However, it should be noted that family caregivers believe that service providers could adjust their services and increase their capacity if they have the funding and staffing. Participants stated:

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“I definitely feel there's a disparity in who has access to information under services. So by that I mean if you're wealthy and you have gold plated insurance...you're put on top of list sometimes and I worked professionally as well as have a personal story with my own son so I can see it from both lenses...And I like the word she used, gatekeepers, because that's kind of what I feel like it is... there's like a vetting process of who are we going to give the little bit that we have to ...”

“I have tried and we live out of the city limits so individuals would still have to drive 20 miles one way to get to our home. And we live in a subdivision, which I would say we're kind of remote and because of the distance from the city, it just puts an extra burden on trying to find that person...it's hard to find respite.”

“I got discouraged. Because when they told me that the areas were far, for example, [City], or areas far from [City] or from where I lived, and that they couldn't go there [to our home]. I kept going to the next one, and it was more and more, and I kept getting discouraged, because there wasn't one near where I lived. And they gave me more problems, it was more difficult, it was. There was no help.”

“Mentioning how important is to have funding like many ways, federal funding or state funding towards the services, because there is clearly a shortage with the state. There are only like three within the city, there is only like three places where they could provide respite services...”

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### **Theme 5: Navigable, accessible, and multi-formatted respite service information**

Family caregivers reported that they need information so that they can navigate the respite system. This includes, but is not limited to, information about how to complete applications and to learn about available providers. Family caregivers recommended that service providers improve accessibility of materials by including resource listings and offering documents in plain language and in a variety of formats. Participants recommended:

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“A step by step guide on how you access the services is so important. One of the things I find families get very lost in the bureaucracy. And they can't always sort out on their own, ‘how do I get these services, what do I do now, what steps do I need to take’...I think it needs to be in plain language, everything should be in plain language. We have people of all abilities within our groups, parents and the clients included, and so we need to really be looking at how to make everything completely easily understood and how to follow those steps to get to that objective of having respite.”

“Certainly, an online directory would help as we look up to find licensed providers. If we were to put them in group homes, there should be some kind of directory, as well as places that offer respite services.”

“Have the education, if you don’t research because it’s so overwhelming, intimidating process and there’s so much that’s going on your end, that’s kind of like the last thing you’re thinking of because you’re worried about your child’s well-being and just receiving the services that you get is very overwhelming...been going through the application process, itself was horrible. I went to college and have my masters, but this whole process is absolutely overwhelming...”

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## **Theme 6: Increased support for respite system navigation**

Caregivers requested that there be staff members assigned the responsibility of serving as system navigators. Participants recommended:

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“Just someone to help guide me through all the big terminology, I mean I even went to college and I have my masters, but this whole process is absolutely overwhelming...and this, this is not my background at all, so I don't know what's even out there are available for me and my family.”

” Oh, I used to talk to so many robots...the pharmacy was a robot, the providers office was a robot...I'd like to talk to humans, because everybody's using robots to call you. It's like could I speak to a human, please very human voice that would be so nice.”

“If there could be some sort of educational thing periodically at schools where parents who have children, who are recently diagnosed, could get together and share information, we wouldn’t have all these parents doing this stuff on their own. And they have parental support groups and all that kind of stuff which helps a little bit, but it’s not the same thing as walking into those meetings and feeling that you know nothing and they know everything and they hold all the cards. So that has always frustrated me immensely.”

“...Providers should make a request about respite services as part of every exit, every visit. I think that one keeping it as a regular question so that families are aware of it and bringing it to the forefront, I think, it one of the key things they could do so that could be part of the checklist of which services are you getting when you are in your physician’s office or even in your school setting to make sure that families are adequately connected to the services that they need.”

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## Theme 7: Expansive community engagement and information dissemination

During the listening sessions, many participants indicated that they were not aware of services because the current methods of informing the public are limited. Family caregivers stressed that multifaceted efforts should be employed to reach and actively engage the diverse populations in need of respite services, including those for whom English is not their primary language. This may include but is not limited to traditional media such as television, social media, ethnic media, school venues/special education information campaigns, and other culturally and linguistically appropriate approaches. Traditional methods such as advertising in newspapers would appeal to older caregivers as that may still be the mode by which they receive information.

Participants indicated:

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“I think it would be really helpful to attend virtual or in person provider expos...purchasing some ads on Facebook, because our age group are the ones that are using Facebook...A lot of TV shows that are on the weekends that are community-based programming, they'll give free airtime to these organizations to come in and talk about it [respite].”

“It would be better to advertise more, like in the children's schools, and with the special service programs, to inform the parents, so that they can find out what the service is like, what it is about. Because many times we hear about respite services, but who knows what they are or what they are like. And I've heard about it because I've gone into other Zoom, but otherwise I wouldn't have much information about it.”

“...many times, we hear about respite services, but who knows what they are or what they are like. And I've heard about it because I've gone into other Zoom, but otherwise I wouldn't have much information about it.”

“Have the education, if you don't research because it's so overwhelming, intimidating process and there's so much that's going on your end, that's kind of like the last thing you're thinking of because you're worried about your child's well-being and just receiving the services that you get is very overwhelming...been going through the application process, itself was horrible.”

“And I, for example, I go into Facebook and Instagram groups a lot, and all that. And there are times when they only give you information in English. And I copy and paste it into the (Google) translator and that's why I find out more things. But I think moms don't have the time to translate those things or they don't know how to translate it and that's why they don't know.”

“...No one, no counselor, no educator that we've been seeing has even told us about respite services, so we were unaware of it. I had to do my research...

“I think reaching out to the county boards and making sure that they're aware of what services are available, making sure that case managers have their information so that if a family calls and says, I need respite they can say ‘Oh, I have a whole list of providers, here you go, find one that you're comfortable with.’ I really think the onus falls a lot on these big organizations like the ARCH and different groups like that to make sure that people are connected and understand what services are available.”

“I also wanted to think about the fact that providers should make a request about respite services as part of every exit, every visit. I think keeping it a regular question so that families are aware of it and bringing it to the forefront. I think it's one of the key things they could do so that could be part of the checklist of which services are you getting when you are in your physician's office or even in your school setting to make sure that families are adequately connected to the services that they need.”

“We definitely have to shop around for ourselves, but with like no good master list.”

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## **Theme 8: Enhanced provider capacity, training, and knowledge to better serve families**

As previously described, family caregivers made comments about the lack of respite providers. This staff shortage was exacerbated by COVID-19 pandemic and its endemic phase as many providers left the profession. Family caregivers suggested that there be increased recruitment of staff and efforts to make the job more attractive such as increased pay and the addition of benefits. When asked to make recommendations for respite agencies or organizations to better serve them, participants recommended more training to improve staff knowledge of available service options and their cultural and linguistic competence.

Participants indicated:



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“...We all are aware of the big shortage of respite providers and provider agencies and stuff like that, so perhaps also awareness that there is actually a need for that type of profession...a lot of people I know they have asked, ‘Oh, what is a respite provider I don't know what that is’...they don't even know what it is”

“...It's been three months, and I'm still waiting for this organization to call me back to come to my home and do the service.

...I would say training, because if you're trained in a good way, you're going to go in and feel confident in what you are doing. But if you're not going to want to do the job you'd rather go and look for a job somewhere else that's going to provide more benefits, training and the ability you know to get higher position, like at McDonalds.”

“I think there should be good training and I think it should be specific to the type of respite provider, you want to be, if you want to work with autistic individuals, I think you know your training should be focused on all the things that come with working with an autistic person and then additional training directly from the family, so that it's personalized and you know tailored to fit that individual's needs.”

“I would say that all those who are providers should be well trained, super trained, as several moms said, that they want help with their children to socialize. Because there are times when providers send people to our homes to take care of the children. ...Because if it's like sitting (in the home), then, they don't help the children to progress. Asking, if the child wants to go outside, if the child wants to go outside and play, “or do you want us to play with your toys?” So, I think that you have to be highly skilled at working with (our) children.”

“Right now, I am trying to get the providers to pay the respite and the in home provided at least \$15 an hour...they're getting 10 bucks, \$10.50, which is still not enough and we couldn't even get anybody to do it for \$10.15. It used to be \$9.00. I have a care provider, been with me for 20 years start off with from \$4.50 and she'd been taking care of my daughter for almost 20 some years. But, to be honest with you, I have to help supplement her income from my own money to appreciate her for all this hard work, I do have to use my own resources for her to be with me this long.”

“I'd love to see just the pay increase across the board, I think every provider that comes into your home deserves benefits and a good living wage, because here for an aide it's \$11.96 an hour, I think. Who can live on that? My one friend, her aide keeps calling off because she can't put gas in our car, you know, so...it's tough”

“COVID especially has exacerbated the shortages in that the in-home care that we've been able to get we went from having 16 hours of nursing a day plus two five hours respite a month, where we can have like a date night or something like that, to now being down to generally zero hours a week, most weeks. So, he still requires the same level of care, we have to do what we can, which is really forgo sleep and our own wellness to be able to manage that care.”

“I just think that the services were very minimal, and then COVID definitely almost extinguished them for many families and then now they've made a comeback...maybe back to where they were before. But the way that I look at it, we have so far to go to climb to what families need. So, I think it was kind of was like not great, then terrible and then now we're back to not great...I feel awful saying it but it's just you know I'm being truthful and transparent is you know with what we've experienced.”

“...It's just challenging because you can be approved for 20 hours a week of help, but they can tell you I don't have any help for you, you'll have to try to find a provider yourself...”

...there just aren't the providers, that I want that are available typically...They are very much newbies...and so they aren't good fits a lot of the time, or they quit really fast, you know because they just don't have the skill set or the experience level to handle children that are above and neurotypical...it's really a challenge across the board to get trained people...”

...I would definitely say that training, because you sometimes hear families that say, “Oh, they don't know what they're doing; they just come here and they don't do anything....”

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## Theme 9: Respite services to accommodate a wider range of diagnoses

Family caregivers were very concerned about how the respite eligibility requirements keep them from being able to receive services. They recommended changes in policies and procedures so that this important service is available to all who need it. Participants said:

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“I could not find respite services that would cater to him...because he doesn’t have ... at the time, he was not diagnosed with a developmental disability...his Autism/Asperger’s diagnosis came later, so I was really, really all alone.”

...It can just be this narrow definition of you know developmental disabilities or even intellectual disabilities, because there are many children who have other diagnoses and needs and the parent are just as stressed and just as strung out and just as needy of you know, the break that respite provides.

“I think there should be some kind of policy change as it relates to persons eligible for such care because, basically, right now, those that suffer with mental illness they’re kind of out of luck...”

“...the previous speaker highlighted some of the issues with diagnosis for certain developmental disabilities. That is even more highlighted in that we know there’s an equity issue in terms of correct diagnosis for certain developmental disabilities. He had it (autism) all along, they didn’t diagnose him properly, was not eligible for services based on the wrong diagnosis or not having a complete diagnosis....”

“It depends on the child’s disability and how much personnel they have so if your child has a lot of medical needs or behavioral issues, they might not be available to help you so those are state funded, so yes, there’s got to be more funding towards respite.”

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## SUMMARY OF FINDINGS FOR RESPITE CARE PROVIDERS

This section of the report summarizes themes and illustrative comments that emerged from the listening session convened with respite care providers. A total of four respite care providers participated in the listening session. They represented and provided services in four states – Florida, New Jersey, North Carolina, and Wisconsin. Two of the participants had been providing services for less than 5 years, one participant for 10-15 years, and one participant providing services for over 20 years.

The data analysis of the respite care providers' session revealed the following five themes.

### **Theme 1: Description of service options**

Respite care providers reported a wide array of options that are offered to caregivers of children with disabilities and special health care needs including but not limited to, social visits, educational and recreational activities, and standard respite relief services. Respite care providers also indicated that they offered services to caregivers of older adults and adults with disabilities, including social visits, emergency overnight assistance, and standard respite relief services. Some programs reported going beyond respite care and offering additional support to families, such as providing food and emergency funds to support the entire family unit in times of need. The efforts shared by providers focused not only on addressing the caregiving responsibilities but also supporting the overall well-being and stability of families they serve.

## Theme 2: Provider successes in engaging and serving diverse family caregivers

Providers reported the value of having a culturally and linguistically diverse volunteer base, the importance of longevity of presence in communities served, and the importance of networking and partnering with other organizations to reach a broader audience.

Participants said:

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“I would also say a success is the diversity of our volunteer pool as well. We can't always match, you know, an Indian family with an Indian volunteer, but we certainly, if we can, and if that seems like a good match and fit, we do try to do that, but we're not always able to do that. So, you know, we have some Spanish speaking volunteers, but we don't have enough to cover everyone that is Spanish speaking, so that would be a barrier and a challenge...and a success, I think, too, because we were able to do that some of the time.”

“I would say our successes are... we've been around a long time and we're still educating the community that we're here, but I feel like we get a ton of referrals now. I feel like the professionals know about us. We also get a lot...I mean we give you a professional referral or a family caregiver themselves can make the referral so...but we get a lot from home health, we get a lot from hospital discharge...But a lot of caregivers call us directly, so I feel like the word is out there, so that's good. I mean we always want to reach out to as many people as possible, but we work with the main agency on aging for the county, so they refer a lot of people our way, so a lot of the big organizations know about us.”

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## Theme 3: Barriers in engaging and serving diverse family caregivers

Providers reported gender imbalances in caregiving, as caregivers are mostly females and that respite service providers are also generally female. Providers also reported cultural and linguistic barriers such as difficulty tailoring training to diverse communities, lack of accessible resources, and the reluctance and delay of family members in help-seeking.

Participants commented:

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“It's a female heavy, female dominated field. But we really had a push in our community with men getting involved, the father's getting involved, and there have been a lot of initiatives like that happening...we are fully staffed now, but when we were hiring, we were looking for male caregiver or male providers, because we need some positive male role models for some of our men that don't have that positive male role model. So, gender, it's a work in progress, but I think we're in the right direction, but we are serving up what our population needs in our community.”

“As far as male versus female, in the past, I had seen a lot more female. I'm seeing more males, recently. I think there has historically been a lack of willingness on the men's part to ask for the help. And there's also a pride issue like the Italians believe you take care of your own, so there's been that pride issue.”

“We're working very hard and trying to tailor all these kind of trainings to the Latino Community because it's very different even within the Latino community we serve, we are different groups. People come from Mexico, which is divided in different regions. It's very different in North Mexico to South Mexico, Central Mexico and different kind of things. So, we need to learn these kind of values... there are people coming from Central America and Puerto Rico so we see with our different kind of families with different values. Even though we speak the same language...we need to be very careful when a specific word would be offensive to another family or not appropriate.”

“And there's a language barrier, it seems that the access to services is a little bit harder for different cultures, different languages.”

“And barriers...it's definitely...I think access to some resources on our side is also part of a barrier. Some of our families have resources, but accessing those resources on our side from times is hard. My assistant manager, she joined me about two years ago and she used to be a sign language interpreter. I have learned a lot about the policies and politics around having a translator and having an interpreter, and in the past, a lot of times for Spanish speaking families, I've used the children in the home to translate (interpret) when in reality, that's not exactly appropriate.”

“I'm seeing more of a trend of folks contacting me later in age when they're really starting to fall apart, and that's kind of across the board in our entire organization...With help with transportation and grocery shopping, even when they have children that could be doing some of these things, because what I hear a lot of is “I don't want to ask them for too much help because, if I do they're going to tell me it's time for us to move into an assisted living or nursing home” So that's really been a bit sad.



#### Theme 4: Collaboration with ethnic- and cultural-specific Community-Based Organizations

Most providers reported working primarily with ethnic and cultural-specific community-based organizations. Overall, providers emphasized the importance of building relationships, and collaborating with community partners, faith-based organizations, and other organizations and programs to address barriers and improve caregiving services for racially, ethnically, culturally, and linguistically diverse populations. Participants said:

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“Yes, I feel like we're pretty lucky here in [this county]. My program is currently funded by the juvenile welfare board, which is a local taxing authority or local taxing agent here. And the cool thing about that is that the juvenile welfare board has their hands in a lot of different programs around [this county], which is cool because it brings everybody together. So, they are in the Hispanic communities that hit Hispanic outreach centers. So anytime there's an event happening at the Hispanic outreach center, they'll send emails out to all their community partners to show up...and we also partner with a lot of the faith-based communities”

“We partner with the majority of the congregations in our area. And that's been...we've been in operation for 20 some odd years and that's always been the strategy of the organization is to partner with the congregations, and that seems to work pretty well.”

“We don't really partner with a whole lot of other organizations. We've been intentionally working on this, but we did make a connection with a missionary Baptist Church, which is a largely Black/African American church in the area, so we were able to make a connection there and we do caregiving classes, like caregiver support type classes...But in terms of other...I don't know, we don't really have a lot of partnerships per se”

“I would say some successes that we've had, since we are trying to expand our educational knowledge and everything, we partnered with some organizations around our community. Through these new networking opportunities that were meeting, we are partnering with a lot of agencies in the community, so we have some Hispanic outreach centers in our community. So, we're partnering with folks some of the local agencies like that to reach some of the folks that are harder to reach.”

“The cultural and language barriers, we're partnering with some of those local community agencies to try to reach some of those Participants that we're not reaching yet. So, I don't think it's a success yet, but it has been in the works, so I hope to see an impact in our community in the near future with that.”

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## Theme 5: Technical assistance recommendations for enhanced supports and services in diverse communities

Overall, providers emphasized the importance of learning what is needed to provide culturally and linguistically competent services and support. Specifically, providers expressed the value of knowledge sharing between respite care organizations and providers serving these diverse populations, and assistance with having marketing materials in multiple languages for diverse communities. Providers requested technical assistance for updating technology and information management systems for efficient tracking and assessment of families and populations in need of and receiving services. Participants stated:

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“I know for me let's say if I could be partnered with someone who is serving the exact opposite population of mine, I think I would learn so much from that person. I know personally when I walked into the [person's name] house, I didn't know what the heck to do. I didn't know...do I keep the shoes on, do I take the shoes off?”

“Marketing to different communities, and having the materials that would be helpful, you know and in different languages as well...to have more languages, because we have Hindi and Chinese and Spanish, so that comes to mind.”

“I would almost say a culturally diverse support system for us providers so there is somewhere to turn if we have questions...I don't know, that is a tough question.”

“I would love a way to streamline track my people and do my assessments and have it all just roll into one instead of keeping 87 different lists and trying to retrofit a database system to keep track of folks and how often I need to be checking in.”

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## SUMMARY OF FINDINGS FOR STATE LIFESPAN RESPITE GRANTEES AND STATE RESPITE COALITION MEMBERS

This section of the report summarizes the themes and illustrative comments that emerged from the listening session convened with State Lifespan Grantees and Coalition representatives. A total of six grantee and coalition representatives participated in the listening session. They represented five states – Arkansas, Arizona, Mississippi, New York, and Washington. There were three participants in the roles of program coordinator/program development, two participants in the role of grant manager, and one participant in a project director role. The representatives provided the following related to their years of experience and service in respite care.

<i>Frequency</i>	<i>Years in Role or Position</i>
1	Less than 12 months
3	1 – 4 years
1	5 – 10 years
1	More than 10 years

The data analysis of the State Lifespan Grantees and State Respite Coalition representatives' session revealed the following five themes.

### **Theme 1: Description of service options**

Grantees and coalition representatives reported a wide array of services that are offered to caregivers, such as respite voucher programs, and collaboration with organizations, agencies, and programs that provide services and supports based on age and/or disability type and family needs. Due to the COVID-19 pandemic, some programs reported updating their policies to allow family caregivers to have in-home care, providing more flexibility, being responsive to the changing interests and needs of families, and adhering to the challenges of a national public health emergency.

## Theme 2: Grantee and coalition successes in engaging and serving diverse family caregivers

Several grantees and coalition representatives reported collaborating with community partners, family caregivers, and community-based organizations. They reported other approaches that have been used to respond to the diversity of the populations in need of or receiving respite services. In some instances, providers cited advancing equity. These approaches included: 1) hiring outreach coordinators, 2) increasing the number of staff from racially, ethnically, culturally, and linguistically diverse groups, 3) adapting communication strategies to fit the preferences and needs of populations served, 4) implementing cultural- and language-specific programs and activities, and 5) strengthening communication and coordination across state-wide respite programs. Participants said:

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“One of the provider organizations that came on board with us and has been super active in the coalition is a centrally located agency that works almost exclusively with children and they provide a huge range of services for kids with all types of disabilities and they have a specific respite program, but they also offer so many activities and all the children are monitored either one on one or one on two, which means that parents can safely leave their children in an appropriate setting and they are founded by a former migrant person and as a result, they have done, extensive outreach in the community to bring parents, whose children have these issues into their services”

“We have a state-wide family caregiver conference, really, I feel like is a great outreach opportunity... I believe that that outreach has allowed us to connect with new partners to then participate in the coalition, so I really think that's a success”

“So, it's been incredibly helpful having that outreach coordinator, specifically, we also do a lot of Spanish content now on our social media pages because social media has been one of our biggest drives in trying to get more people into our program.”

“Especially on the technologies side ...we did a newspaper ad, of lot of our aging population came from those newspapers' ads. We ran them for about five to six weeks...certain populations still read the newspaper, maybe not my age, we probably scroll and see it on social media site. But that age, they really are using the service and taking advantage of the service...newspaper ads were just great, they love it”

“We obviously like so many coalitions had to move virtual but even pre-pandemic we offered a hybrid meeting platform...I really do think that has assisted us with participation. Because even though many times it's better to be in person in terms of building those relationships, and getting to know each other, maybe more on a personal level, to work together, even professionally. But I've been really pleased that utilizing the virtual format quarterly our participation has been good, so I think that has helped our representation.”

“There is a program and that's down in the [name of region] of our state, and it is, I think, one of the only Spanish speaking social adult day programs in their community and with the impacts of COVID and some of the services kind of pivoting during that time...they actually had an increase in their membership. But we were able to connect the coalition with them, and it was just so wonderful because when we did the introductions and we had just a little kind of meet and greet in and talked about how we might be able to collaborate, meaning the coalition...and I just was amazed by their willingness to help in any way with translating material. They were like send it to us we'll get it translated for you, and, of course, they had interest in connecting with the other organizations that are part of the coalition membership to try to branch out and do some of their own networking.”

“We recently this...over the past six months, we have done what we've called family caregiver retreats and we had an overnight stay sometimes two nights or one night. Our team worked intentionally to try to have representation of all race and ethnicities in participation of these retreats and it just increased my awareness of course we're always looking at data...”

“A real strength of our coalition is to have a respite subcommittee. And so, it allows our state-wide respite voucher programs, not just lifespan but those with developmental disabilities.... veterans... we have about 13 different state-wide programs...to serve those that fall in the gap... so that coalition respite committee really helps those coordinators in each of those programs to coordinate across programs.”

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### Theme 3: Barriers in engaging and serving diverse family caregivers

Grantees and coalition representatives reported various barriers in efforts to engage and provide services to minoritized populations and communities within their respective states. Cited barriers included : 1) an overall lack of staff representative of diverse racial, ethnic, cultural, and linguistic groups; 2) lack of trust among members of marginalized communities; 3) culturally-defined stigma associated with caregiving; 4) lack of resources exacerbated by the COVID-19 pandemic; 5) isolated populations due to geographic locale and related challenges; and 6) lack of knowledge about the meaning and role of family caregivers based on their lived experiences (i.e., culturally defined beliefs about disability and aging, racial and ethnic identities, languages spoken, social location and positionality, SES status, immigration status).

Participants stated:

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“Part of it is our staffing...the staffing of our agency as a whole is very state representative in terms of diversity, but we are so lean right now. There are three of us who do the entire state and we all happen to be White women so that's just kind of random”

“Another barrier that we have had is a lack of trust too and I'm sure other people can attest to this on the call but especially within the indigenous communities, Hispanic and Latino communities...there is a lack of trust going to non-profit organizations, especially when, unfortunately, the non-profit organizations or governments are typically white representatives, white employees, and so there's a lot of mistrust, too”

“I understand how the mistrust of government and things like that goes but it's another level with tribal communities, and I understand they want someone that looks like them to explain what resources that they have so that's a barrier we're trying to break”

“Maybe perhaps some of the barriers...everyone is overextended...that's just the truth of the matter. We're living in a quite difficult time than ever before in terms of additional challenges that our families have had to face and endure...That has changed all of our lives”



“We don't have caregivers staffed which is kind of a bit of a barrier for some people. Especially as it's been mentioned before, the struggle with finding caregivers, paid respite providers, there is a shortage. And even just trying to find someone in care.com it's a little bit difficult for individuals, so we try to do whatever we can provide whatever resources we can to help people”

“Individuals don't want to classify or categorize themselves as family caregivers because there is a lot of negative stigma surrounding family caregiving. So, that's a huge barrier we come across as a whole. We have found that even more so in the Hispanic and Latino communities, the native American/indigenous communities, because within their culture having that family caregiver stigma...you don't identify as a family caregiver...what we found is that they just care for family and again it's typically the women in those cultures that are caring for the family members.”

“One of the issues that our program has had over time, is that we have extremely...there are extremely limited options outside of our voucher program for families of children and adults with disabilities.”

“One of the really isolated populations in our state is in central [region of the state] ...it is a temporary home to a great many migratory farmworker families and they are about 100% Spanish speaking from...most of them have been in this country for quite a while, but they move around quite a bit and mostly originally from Central America and...they just have real problems getting access to things.”

“And the barriers that we kind of experience...we have a hard time connecting with those who are parents caring for children with developmental disabilities or grandparents caring for grandchildren, ...the biggest barrier we see across the board is lack of education about family caregivers what it means to be a family caregiver.”

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#### **Theme 4: Collaboration with ethnic- and cultural-specific Community-Based Organizations**

Overall, grantees and coalition representatives emphasized the significance of collaborating with community organizations to support caregivers effectively. They highlighted the benefits of various approaches such as embedding coordinators, building strong community partnerships, and being responsive to the specific interests and needs of racially, ethnically, culturally, and linguistically diverse communities within their states. However, they also

recognized the room for improvement in actively seeking and forming more intentional partnerships with ethnic- and cultural-specific community-based organizations.

Participants stated:

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“We have team members across the state that are embedded at the county level, so they are working with families, one on one and they have firsthand information about each of those community resources and partners...so there's a real strength to having embedded coordinators across the state...And so, our team has really done a great job and knows the importance of building and having community partners, there's no way we could do what we do without those community partners, and I believe it starts there and then continues to strengthen up to the state level.”

“We also have a quarterly meeting with what we call the [name of state] respite network, and that is with all of our partner organizations, and this is a topic that we do try to tackle and we have some individuals from government agencies from other local non-profits and we have a very diverse group of individuals in the respite network who also can help us in navigating trying to connect with caregivers in those specific communities.”

“This is specific to the tribal communities in [this state], they really did not want to be part of the standard lifespan coalition. They wanted to have their own representation with their own person up at the state level, so we developed that with them. And when I say we it isn't really my agency it's up at the aging and long-term services division level, at the state level. So, they have developed their own respite programming. But we do stay in touch with them a lot. We're invited to state wide and local meetings and conferences which have been remote, but in the past have been very in person and they're always very welcoming but they're always very clear that as a partnership that they have their own needs and they respectfully ask that we meet their needs, on their terms, which I think we are doing...But I do feel that we don't do any intentional partnering and I maybe feel a little defensive about that.”

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## Theme 5: Technical assistance recommendations for enhanced supports and services in diverse communities

Grantees and coalition representatives highlighted the needs for studies and technical assistance on effective strategies to reach and support diverse and minoritized populations in the provision of respite services. In particular, case studies were recommended as effective ways to: 1) provide real-life examples across diverse racial, ethnic, cultural, and linguistic groups; 2) deepen insight and knowledge of cultural beliefs and practices about disability and aging including stigma and language associated with caregiving; and 3) develop culturally and linguistically competent practices. Participants said:

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“Having assistance with developing language around caregiving to ensure the language we are using represents everyone and reduces the stigma of family caregiving.”

“Case studies of how Lifespan Programs have learned about needs and then how they proceeded.”

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## KEY FINDINGS AND RECOMMENDATIONS

Across the listening sessions, numerous perspectives were shared about engaging and providing respite services to the racially, ethnically, culturally, and linguistically diverse populations of family caregivers in the United States. Key findings and recommendations are as follows.

### **Key Finding and Recommendation 1**

A key finding is that efforts should be made to diversify staffing and representation within respite care organizations and programs. State Respite Grantee and Coalition representatives are acutely aware of the complexity involved to increase staff diversity due to factors such as low wages, associated stigma within some marginalized communities, and geographic challenges. Increasing staff diversity is a long-term effort that will require: 1) the commitment of policy makers (federal, state, and local levels); 2) heightened awareness of and coordinated action to address the critical need for respite services in general and within minoritized communities in particular; and 3) engagement of multiple sectors of the community (e.g. faith-based, advocacy and legal representation, ethnic- and cultural-specific organizations, business and chambers of commerce, community-based and social justice organizations). The complexity of the staffing challenge should not be underestimated. Plans to address this seemingly intractable challenge must be addressed over time with additional resources invested in the capacity to track and evaluate outcomes, public reporting to affected communities, policy makers, and other constituents.

## **Key Finding and Recommendation 2**

Family caregivers who participated in the listening sessions described experiences of:

1) marginalization and discrimination based on race, ethnicity, and languages spoken; 2) delayed or no access to services; 3) lack of cultural and linguistic competence across service systems and providers; and 4) other barriers when seeking and/or receiving services. While some of these experiences involve allocation of resources to increase capacity, others can be addressed by consistent implementation of culturally and linguistically competent policies and practices. Cultural and linguistic competence are evidence-based practices that help to decrease disparities and promote equity. Addressing systemic causes of inequities are too much for any one respite organization or program to undertake. However, each State Lifespan Grantees and State Respite Coalitions could give consideration to conducting an organizational assessment of cultural and linguistic competence and developing an action plan to implement supportive policies and practices to evaluate services from the perspectives of families. The CLCARO, developed by the NCCC, is designed specifically for this purpose.

## **Key Finding and Recommendation 3**

State Lifespan Grantees and State Respite Coalitions reported continued struggles with engaging minoritized and geographically isolated populations and communities in their respective state. Concerted and sustained efforts must be undertaken in order to rebuild trust when harm has occurred, and to establish authentic relationships within racially, ethnically, culturally, and linguistically diverse communities. State Lifespan Grantees and State Respite Coalitions should create and implement community engagement action plans. This will involve but is not limited to: 1) defining values for community engagement, 2) aligning policies and

practices with said values, 3) allocating resources (fiscal, personnel, and volunteer) to embed culturally and linguistically competent practices in community engagement efforts, and 4) tracking progress over time and public reporting of outcomes.

#### **Key Finding and Recommendation 4**

Family caregivers who participated in listening sessions reported the complexity of navigating systems ranging from available information about respite services, to understanding eligibility and completing the necessary documents to apply for respite services, and communicating in general with providers of such services including in languages other than English. State Lifespan Grantees and State Respite Coalitions should consider convening accessible community forums to identify problems and brainstorm solutions in partnership with family caregivers from marginalized communities and other constituents within the state. Create action plans to implement over time including tracking progress and public reporting of outcomes. Additionally, there is limited information on respite care utilization, therefore collecting data on processes and outcomes, disaggregated by demographics is essential to pinpoint disparities and for determining root causes.

## CONCLUSION

An analysis of data gleaned from the listening sessions revealed the day-to-day reality of family caregivers across racial, ethnic, and cultural groups seeking and/or receiving respite services and the experiences of respite programs attempting to respond to the interests and needs of these populations. It should be noted these findings represent a limited number of participants from states and communities nationally. These findings may be limited due to several factors that influence the context of respite care and caregiving across different regions and population. These factors include differences in demographic makeup and socio-cultural factors related to disability and aging that affect knowledge and use of respite services and supports. Additionally, respite care is subject to state-specific policies and regulations that govern its implementation with varying resource allocation at both the federal and state levels. Variation in these policies can result in differences in availability, accessibility, acceptability, quality, and utilization of respite services across states.

Overall, the findings indicate that efforts should be made to diversify staffing and representation within caregiving organizations and address the shortage of respite providers. It is important to foster collaborative partnerships, increase education and awareness, and build trust with communities served through culturally and linguistically appropriate approaches. It is also crucial to recognize the unique needs of specific communities, such as those who are geographically isolated, and work collaboratively to develop tailored caregiving programs. Overall, improving caregiving efforts for diverse populations required a multifaceted approach that includes cultural sensitivity, trust-building, collaborative partnerships, and the provision of accessible resources and supports.

Given these findings about the caregiving and service experiences of families, it is important for organizations that provide services to caregivers of diverse racial, ethnic, culturally and linguistic groups to employ efforts designed to guard against institutional inequities that contribute to the challenges of caregiving. It is important to note that “one size does not fit all” when addressing challenges faced by caregivers of color. According to Choula, Snyder, and the John A. Hartford Foundation, “the ability to care and advocate for their family member is often impeded by the larger context of institutional racism, implicit bias and inequities that affect people of color in every aspect of their lives” (2020). Addressing the disparities in respite care utilization among underserved communities requires tailored efforts. Increasing awareness and education about respite care services and supports, ensuring cultural and linguistic competence in service provision, and building trust through community engagement and collaboration can help improve access. It is essential to provide culturally and linguistically competent respite care options that meet the unique needs and preferences of underserved caregivers. Additionally, there is limited information on respite care utilization, therefore collecting data on processes and outcomes, disaggregated by demographics is essential to pinpoint disparities and for determining root causes.



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## APPENDIX A

### METHODS

The NCCC and ARCH were especially interested in learning about the experiences of parents and family caregivers of individuals with disabilities and older adults from diverse racial, ethnic, cultural, and linguistic groups in accessing and using respite services. A total of five listening sessions were conducted for families who expressed an interest in participating in a session. Family caregivers received a \$25.00 gift card for their participation. Listening sessions were conducted in English with family caregivers of (1) children and/or youth with disabilities, (2) adults with disabilities and (3) older adults. Additionally, two separate listening sessions were conducted in Spanish for family caregivers of children and young adults with disabilities. Descriptive statistics of the family caregiver demographics are provided in this report on pages 9 to 12.

NCCC faculty researched the role and function of: 1) respite service providers; 2) State Lifespan Respite grantees and, 3) State Coalition representatives to prepare for listening sessions with these three participant groups. Two listening sessions were conducted to elicit the experiences of providers about the challenges and successes of providing respite care to diverse racial, ethnic, cultural, and linguistic populations. One session was convened for respite care providers, and a session was convened with the State Lifespan Respite grantees and State Coalition representatives combined.

Each listening session was scheduled to last approximately 90 minutes. Participation in all listening sessions was voluntary. Flyers were disseminated by the ARCH via their national network to recruit participants for the listening sessions. The flyers included a phone number for individuals to contact the NCCC and leave a message with their contact information. After receiving the messages, the NCCC team called interested volunteers and conducted a participant intake process. The purpose of the intake process was to ensure participation of a diverse population by state and other relevant demographics, specifically for the family caregivers:

The following information was gathered as part of the intake protocol:

- Providers provided their contact information, their role (service provider, grantee, coalition representative), and their location of services (State/city).
- Family caregivers provided their contact information, their caregiving role, their race/ethnicity, their primary language, and whether they needed accommodations

During the intake process, the NCCC provided an overview of the study, presented the informed consent documents, and obtained verbal consent from all eligible participants. All listening sessions were submitted to and approved for exemption by the Georgetown University Institutional Review Board.

## DATA COLLECTION AND ANALYSIS

A total of seven listening sessions were conducted in August 2022 via Zoom. The average length of the listening sessions was 71 minutes, with a maximum of 91 minutes and a minimum of 56 minutes. The transcripts from the interviews were downloaded and corrected for accuracy. From September, 2022 – October, 2022, NVivo was used to complete the qualitative data analysis for a set of 6-9 themed questions, some containing multiple related probes. Each response was analyzed for its manifest content. The codes for each question were geared at emphasizing, on a surface level, the content of participant responses to the interview questions without investigating latent themes based on the interpretation of NCCC team members. Results were presented to the ARCH including the code structure, frequency of codes, demographics, and participant quotes that best illustrated those codes for each question. Response frequency was based on the number of occurrences of the theme, or how often it surfaced within and across participant responses. For example, if asked to give recommendations on how to best meet the interests and needs of family caregivers, participants may have mentioned three recommendations for that single question. If each recommendation is coded, this would register in NVivo as a code that's been referenced three times. For questions that were particularly extensive, the NCCC team identified illustrative quotes to accurately represent the common responses to those questions. These illustrative comments are also presented in this report within the themes.

## **ABOUT THE GEORGETOWN UNIVERSITY NATIONAL CENTER FOR CULTURAL COMPETENCE**

The mission of the Georgetown University National Center for Cultural Competence is to increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address growing diversity, persistent disparities, and to promote health and mental health equity.

### **SUGGESTED CITATION (APA)**

Harrison, S., & Yimer, B. E. (2023). *Respite Services: The Experiences and Recommendations of Service Providers and Racially, Ethnically, and Culturally Diverse Family Members*. Washington, DC: Georgetown University National Center for Cultural Competence.

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### **FUNDING FOR THIS PROJECT**

This publication was supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,647,597 with 75 percentage funded by ACL/HHS and \$549,200 amount and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.