

# Family Caregiving Grant Project

*Delaware Department of Health and Social Services -  
Division of Services for Aging and Adults with Physical Disabilities*

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**A P R I L 2 0 2 2**

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## Executive summary

The needs of family caregivers and the importance of this role are gaining attention as caregiving is recognized as the largest source of direct care for people of all ages, from children to older adults. In fact, caregivers are widely viewed as the backbone of the long-term care system, managing increasingly complex tasks for care recipients with increasingly complex conditions. Many older adults prefer to remain in their homes for as long as possible, and families often prefer to care for their children and other family members at home. The higher cost of care in institutions, along with the potential impact on Medicaid, Medicare, and other government resources, requires that family caregivers continue to do much of this work. But caregiving is stressful and can have a negative impact on caregivers' health and well-being. Supporting caregivers and helping them to continue in their caregiving roles is critically important.

## Focus group and stakeholder engagement project

The Delaware Department of Health and Social Services (DHSS), Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) received a grant from the National Academy for State Health Policy to fund the Focus Group and Stakeholder Engagement project. The goal of the project was to hear directly from unpaid or family caregivers in Delaware. While DSAAPD, in name, administers programs for older adults and adults with disabilities, this study was expanded to discover more about the needs of caregivers of people across the lifespan, including children.

With firsthand information about caregivers' experiences, DSAAPD expects to respond through policy and programmatic efforts in order to identify ways to engage caregivers and improve and expand a range of supports for caregivers in Delaware across the lifespan. Project partners include Caregiver Resource Centers Network (part of DSAAPD), Delaware AARP, Easterseals Delaware & Maryland's Eastern Shore, and Delaware Division of Medicaid & Medical Assistance. Wilder Research was selected to complete the project.

The pool of potential focus group participants was defined as caregivers age 18 or over residing in Delaware. Based on information about existing service gaps, the demographic diversity of Delaware caregivers, the unique needs of particular caregiver groups, and the financial and time resources available, DSAAPD also prioritized focus groups for caregivers to persons with Alzheimer's disease and related dementias (ADRD), and caregivers who identify as Black or African American. While not designated as specialized populations, DSAAPD was also interested in learning about the experiences of caregivers living in rural areas, and caregivers identifying as people of color or LGBTQ. Participants who said they were caring for children discussed additional unique circumstances, and their comments are included as applicable. Caregivers were recruited through the promotion efforts of DSAAPD and program partners with a flyer, social media posts, emails to partner organizations, and information shared with state legislators.

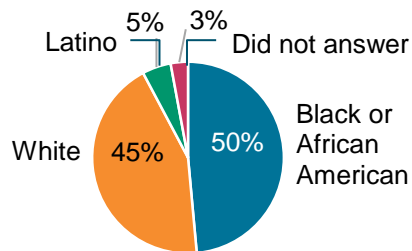
Wilder Research completed eight focus groups with 38 participants. All focus groups were completed via online video platform (some joined by phone only), and were scheduled for a variety of days and times. Participants were offered a gift card to thank them for their time.

# Characteristics of participating caregivers and their care recipients

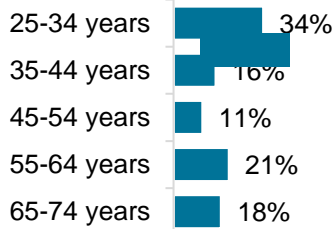
## Key characteristics of focus group participants:



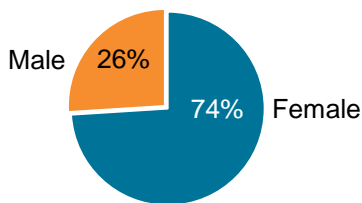
### Race of caregivers



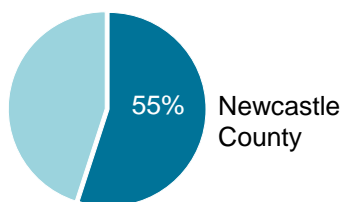
### Age of caregivers



### Gender of caregivers



### Where most caregivers live



53% of caregivers said they are employed.

## Key characteristics of care recipients:



### Who caregivers are providing care to



37%

A parent or parent-in-law

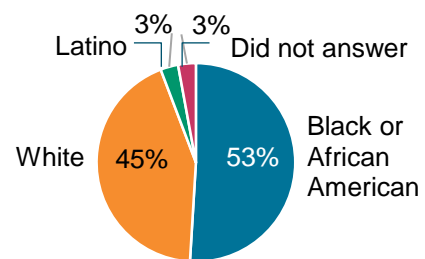


24%

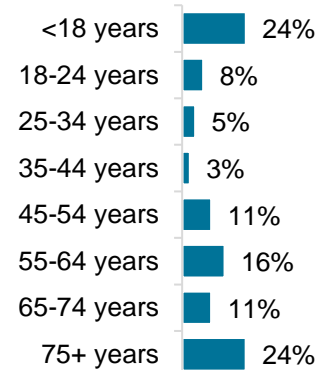
A child or grandchild



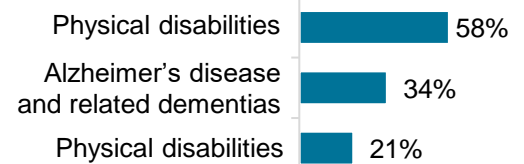
### Race of care recipients



### Age of care recipients



### Diagnoses of care recipients



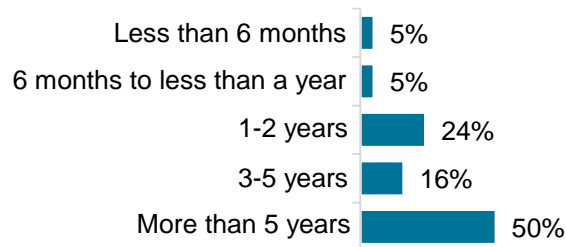
58% reported that their care recipients qualified for Medicaid.

Note: Medicaid qualification status was self-reported by focus group participants and is not an indication that the Delaware Division of Medicaid and Medical Assistance officially confirmed eligibility.

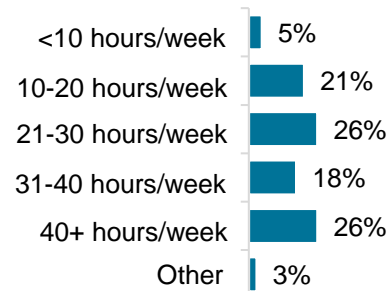
## Information about caregivers' experiences:



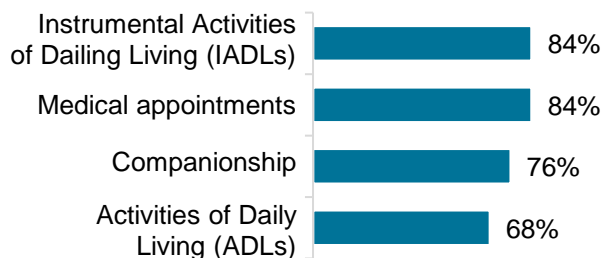
Years caregivers have been providing care



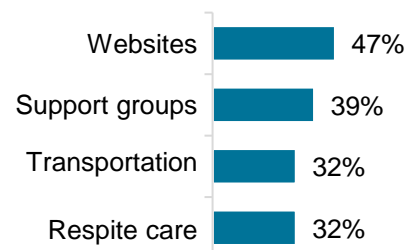
Hours of care provided each week



Activities caregivers are helping with



The supports most often used by caregivers



89% of caregivers said they share a home with the person they care for.

The results reported here reflect the individual voices of the caregivers who participated in these focus groups and cannot be considered as representative of all caregivers or groups of caregivers in Delaware.

## Key observations

Five **main themes** emerged from the focus groups with the diverse set of family caregivers.

### ■ Family caregivers' characteristics and experiences

According to the report, *Caregiving in the United States 2020* (AARP, 2020) caregiving cuts across generations, race and ethnicity, income, and family composition, among other identifiers. The characteristics of the caregivers who participated in these 8 focus groups affirms this observation. Even so, the information shared by caregivers in these focus groups also illustrates the uniqueness of the caregiving experience, which can be influenced by the personal characteristics and circumstances of both the caregiver and the care recipient, as well as by the characteristics of the community, the trajectory of the conditions, and interpersonal dynamics. There is no one “typical” caregiver and no one “typical” caregiver experience. Needs and expectations vary and can be constantly in flux.

- **Lack of awareness of services**

Focus group participants revealed that a lack of full information about what services might be available to them is one of the most common barriers to accessing supports. They simply do not know where to begin.

- **Difficulty finding useful information**

Focus group participants feel frustrated with the amount of time and effort required to navigate systems and find supports. Incomplete information, misinformation, and red tape add another layer of burden to their efforts.

- **Concerns about the reliability and quality of services**

Focus group participants talked about difficulties in arranging for services. Many factors contribute to this, including the limited availability of paid staff, costs of care, uncertainties about whether caregivers can trust the information or abilities of paid staff, and care recipients' reluctance to have unfamiliar people care for them.

- **Financial impact of caregiving**

Families are asked to make difficult choices about finances and managing necessary care. Medical care is expensive, insurance does not cover all their costs, and paid employment is difficult to manage in the face of caregiving responsibilities.

*For me it is literally a lack of information and not knowing where to get started. I know there are programs for the aging, I just don't know where to look for that.*

*We hear this all the time that there are services available. Ok, what are they?*

*If I knew of availability [of services] in the area that would be great. I just don't know what there is in the immediate area.*

*You have to do a lot of research to find something that is available.*

**Other themes** identified by Black and African American caregivers, caregivers in rural areas, and caregivers for children include:

- **Caregivers who identify as Black or African American**

A common theme among the caregivers in African American groups was their reliance on community members as sources of trusted information. Advice and recommendations from friends and family members, as well as other professionals they know, can provide assurance of the quality of the services or supports that can meet the needs of their care recipients.

- **Caregivers in rural areas of Delaware**

A lack of services or fewer options, the greater distance to reach organizations that may provide supports, and a lack of privacy in small towns are among the concerns mentioned by caregivers about accessing or arranging for services in rural areas.

## ■ **Caregivers for children**

Caregivers for children discussed the limited resources available for youth and believe that families are being overlooked or under supported. Peer support is particularly important for many of the caregivers of high-needs children.

## Suggestions from family caregivers

Caregivers shared **four key themes** addressing the current challenges facing caregivers and the system of supports that help them provide unpaid care for their family members or friends.

### ■ **Funding that allows self-directed care or covers gaps in coverage**

Caregivers would like to have a structure that would allow them to decide which resources to access and use in a way that works for them, as well as funding sources that can help them fill the gaps in the real costs of caregiving.

### ■ **Developing new facilities and programs, especially for children**

Many of the facilities and programs mentioned by caregivers that would better support them were specific to children and included extended long term care, care for children with chronic conditions and disabilities, and expanded mental and behavioral health resources.

### ■ **Funding staff positions and changing structures at DSAAPD**

Caregivers suggested that adding or adjusting staffing and structures at DSAAPD could help meet their needs, including designated staff for addressing issues related to access or specific conditions. Caregivers also believe they would benefit from improving the quality of information that is available and building inter-division collaborations at DSAAPD.

### ■ **Dissemination of information for caregivers in multiple ways**

Caregivers recommended that sharing quality information in a variety of ways could boost overall awareness of the resources that are available and reach a range of caregivers. The methods they mentioned include social media, brochures and flyers, postcards, information packets from medical staff, and advertisements in print media.

## Recommendations

The observations and experiences shared by caregivers in the focus groups suggest some key directions to consider.

### ■ **Continue operating with the *No Wrong Door Approach*, but improve the reach of service availability information by diversifying dissemination approaches.**

As evidenced by the DHSS and DSAAPD webpages, DSAAPD does provide multiple entry points into its system of information, services and supports, as well as multiple resources to

residents of Delaware. However, many caregivers seem unaware of how to get started and lack an understanding of what may be available.

Caregivers have suggested that DSAAPD could intentionally provide accurate information in a broad variety of formats, including boosting the use of social media and exploring other methods for widely and simultaneously sharing more information via advertising (social media and perhaps radio), posters and signs, existing channels such as medical clinics, and mailed information (e.g., included with utility bills). DSAAPD could also consider producing materials in a variety of languages. When using multiple communication methods, it would be especially important to update information regularly to ensure its relevance and accuracy.

- **Improve DSAAPD’s systems navigation processes, increase support staff knowledge, and create accessible population-specific materials.**

Regardless of the efforts currently implemented by DSAAPD to produce useful information, caregivers have indicated that they are frustrated by the effort required to find accurate and helpful information. Caregivers for children spoke about struggling to find information and support.

Potential steps to address this could include updating or revising DSAAPD internal structures to support systems navigation, providing staff with training on accurate information and practices, and establishing clear pathways and protocols for caregivers who require additional assistance.

Staff may also want to consider the current difficulty of finding information related to children and youth, and to long term care. Researchers noted that a specific pediatrics focus appears to be lacking on the DHSS and DSAAPD websites (aside from Child Protective Services, foster care, and criminal justice). It is also difficult to find the link for information about children with medical complexity, as it is located on the Division of Medicare and Medicaid (DMMA) webpage. The Long Term Care Medicaid Programs information appears equally difficult to find on the DMMA webpage.

- **Partner with leaders in a variety of communities who may function as trusted champions and sources of information, and may also provide insight on community needs and resources outside of DSAAPD’s typical purview.**

Many caregivers in the Black or African American focus groups emphasized the frequency with which they rely on community members, including friends and family, to share information and resources they can trust.

Building on informal networks, DSAAPD could work to establish connections with trusted community leaders (e.g., elders, faith leaders, health care providers) to share information about available caregiver supports, how to access them, and who can deliver them in culturally relevant ways. It may also be important to present information and provide services that are relevant to a variety of cultural norms and practices. In the same way, seeking input from trusted community leaders can continue to inform the work of DSAAPD in meeting the needs of caregivers in a variety of communities.

It is important to note, of course, that meeting caregivers and care recipients in the community is an important component of providing person-centered care, regardless of a person's race, ethnicity, location, or medical needs.

- **Explore ways to support caregivers with self-directed grants.**

Caregivers discussed their frustrations with arranging services that do not meet their particular needs (e.g., type of care, amount of care, schedule) and lamented the one-size-fits-all caregiver services and supports that do not address the unpredictable nature of caregiving. Several caregivers mentioned that other states provide funds that caregivers can use to customize the supports they receive. In each case, others in the groups stated that this sounded very appealing and wondered why this was not available in Delaware.

Implementing a method in Delaware that would support customizable services would augment the person-centered approach to supporting caregivers and care recipients.

- **Develop or sponsor opportunities for robust peer-to-peer support.**

Caregivers frequently mentioned the value they find in peer-to-peer support. They spoke about the ways in which they rely on others in similar situations or communities to share helpful suggestions and advice, offer real time moral support, and ease the burden of isolation. DSAAPD could take advantage of this medium and contribute, by providing accurate and current information and expanding the reach of resources available through DSAAPD.

- **Pursue additional activities to understand the needs and strengths of all caregiver populations in Delaware.**

The smaller numbers of participants, combined with the obvious interest of caregivers in contributing to DSAAPD's understanding of their needs, suggests the value of additional research into the needs of caregivers. Focused outreach, with targeted recruitment of participants (based on specific characteristics of caregivers or health conditions of care recipients, for example), or further review based on findings of interest in this report or peer-reviewed literature, could yield additional insights to guide DSAAPD's efforts.



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# Background

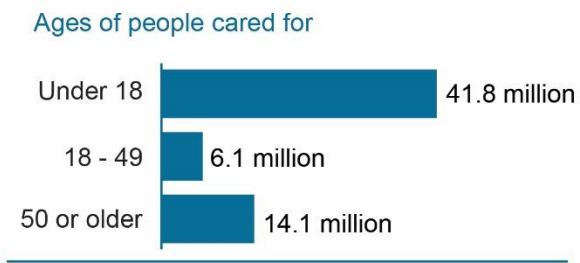
The needs of family caregivers and the importance of this role are gaining attention as caregiving is recognized as the largest source of direct care for people of all ages, from children to older adults. In fact, caregivers are widely viewed as the backbone of the long-term care system, managing increasingly complex tasks for care recipients with increasingly complex conditions. Many older adults prefer to remain in their homes for as long as possible, and families often prefer to care for their children and other family members at home. The higher cost of care in institutions, along with the potential impact on Medicaid, Medicare, and other government resources, requires that family caregivers continue to do much of this work. But caregiving is stressful and can have a negative impact on caregivers' health and well-being. Supporting caregivers and helping them to continue in their caregiving roles is critically important. Recent statistics reinforce this imperative:

“There are only four kinds of people in the world.  
 Those who have been caregivers.  
 Those who are currently caregivers.  
 Those who will be caregivers, and those who will need a caregiver.”  
 - Former First Lady Mrs. Rosalynn Carter

2020



Approximately **53 million** Americans provided unpaid care for another person.

Source: AARP & National Alliance for Caregiving, 2020

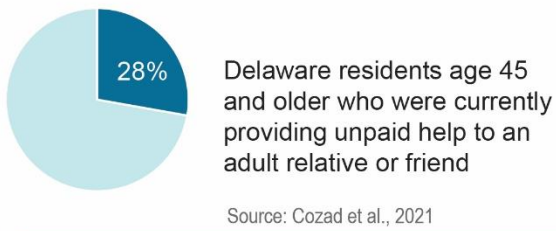


2017

**Delaware**

-  129,000 caregivers
-  108 million hours of care

Source: Reinhard et al., 2019



The economic value of unpaid, informal caregiving in Delaware was estimated to be:

Source: Reinhard et al., 2019



However, supporting caregivers is not a one-size-fits-all proposition. The caregiving experience is complex and dynamic, and depends on a number of factors, including the characteristics and trajectories of diseases or conditions, and the configurations and dynamics of individual family systems. As the population of the United States (and Delaware) grows increasingly diverse, it will also be more important than ever to address conditions for caregivers related to group identity, family obligations, and additional obstacles related to language and systemic barriers (Scharlach et al., 2006).

## DSAAPD’s current service delivery approach<sup>1</sup>

Services and supports currently administered by DSAAPD emphasize a person-centered approach, with a goal of coordinating access for all services throughout the community. DSAAPD’s **core services** include:

- Nutrition
- Adult day
- Caregiver supports
- Home health
- Attendant services
- Legal assistance

**Additional services and supports** provided through DSAAPD include:

- Aging & Disability Resource Center (services & supports)
- Adult protective services
- Case management and options counseling
- Home and community-based services
- Community nursing
- Long-term care in the Delaware Hospital for the Chronically Ill

In addition to general information and news, **the landing page for DSAAPD** provides information about numerous services, including:

- A link to the publication *Guide to Services for Older Delawareans and Persons with Disabilities* (downloadable 126 page document)
- Live links to Aging & Disabilities information for:
  - Services
  - Publications
  - Alzheimer’s Toolkit
  - Caregiver information
  - Brain injury information
  - Information for professionals
  - Advance directives
  - Laws and regulations
  - State-run long term care facilities
  - FAQs
  - Useful links

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<sup>1</sup> Information retrieved from <https://dhss.delaware.gov/dsaapd/>

## Project overview

Wilder Research was selected by the Delaware Department of Health and Social Services (DHSS), Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) to conduct the Focus Group and Stakeholder Engagement project through the National Academy for State Health Policy (NASHP) grant.

DSAAPD is interested in hearing directly from caregivers in Delaware, in order to learn about their caregiving experiences, identify ways to engage caregivers, and configure services in ways that allow caregivers to derive maximum benefit from the range of supports available now and looking to the future. The findings from this study will be used by DSAAPD to improve and expand supports for unpaid or family caregivers across the lifespan in Delaware through policy and programmatic efforts.

Two key evaluation questions guided the project work:

1. What services do caregivers in Delaware currently use, and what services do they say they need?
2. In what ways could caregivers in Delaware be better served by currently available resources?

Other project partners working with DSAAPD (in addition to the Caregiver Resource Centers Network) include Delaware AARP, Easterseals Delaware & Maryland's Eastern Shore (Easterseals), and Delaware Division of Medicaid & Medical Assistance.

The focus group results outlined here reflect the individual voices of the caregivers in Delaware who participated in this series of focus groups. In these discussions, all held virtually by online video platform (some joined by phone only), caregivers had an opportunity to describe their own experiences and hear about the experiences of others, discuss the forms of help and support that have assisted them, and suggest ways that they and other caregivers could be supported in the future.

The experiences shared by caregivers in this study cannot be considered as representative of all caregivers or groups of caregivers in Delaware. As such, these results should be combined with knowledge gained through additional sources, such as population-based surveys or reports from community organizations.

# Focus group outreach, registration, and implementation overview

From December 9, 2021 through January 4, 2022 Wilder Research completed eight focus groups with 38 caregivers. Based on the priorities of DSAAPD and their knowledge of existing service gaps, the demographic diversity of Delaware caregivers, the unique needs of particular caregiver groups, and the financial and time resources available, it was determined that focus groups would include those for the following caregiver populations:

1. Caregivers of any type in Delaware
2. Caregivers to persons with Alzheimer’s disease and related dementias (ADRD)
3. Caregivers who identify as Black or African American

While not designated as specialized populations, DSAAPD was also interested in learning about the experiences of caregivers living in rural areas, and caregivers identifying as people of color or LGBTQ. Participants who said they were caring for children discussed additional unique circumstances.

The multi-step process, from outreach with information about the focus groups to participation, was time-intensive and included the following steps:



The numbers of individuals included at key points in the process are shown below. A detailed discussion of the outreach and recruitment, registration, format and attendance, and participation for the focus groups is located in Appendix A.

## Caregiver sign-up process by the numbers



# Characteristics of caregivers and care recipients

Caregivers' responses on the registration form and brief survey were summarized to provide a description of their background characteristics, employment and income status, and caregiving profile, as well as the background characteristics of care recipients.

## Characteristics of focus group participants

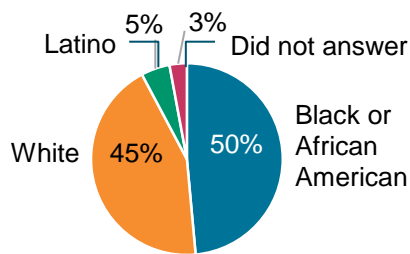
Participants were asked to share basic information about their background characteristics, including demographics, their work and income status, and details about their caregiving. Detailed results are located in Appendix B.

### Demographic and background characteristics (Table B1)

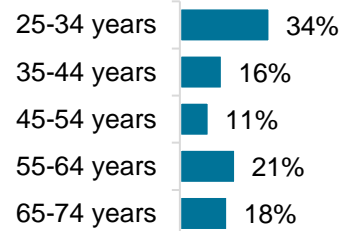
Highlights of their demographic characteristics include:



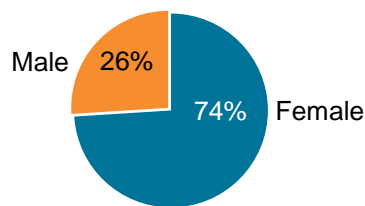
#### Race of caregivers



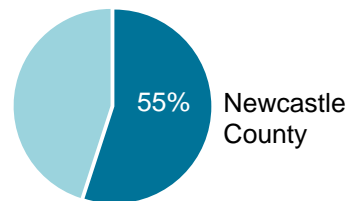
#### Age of caregivers



#### Gender of caregivers



#### Where most caregivers live

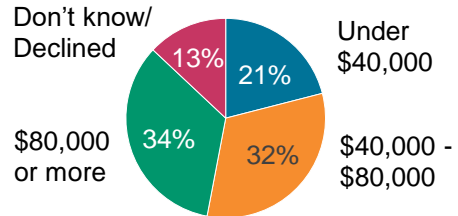


## Employment and income status of caregivers (Table B2)

**Highlights** about focus group participants' employment and income status include:



### Reported income of caregivers



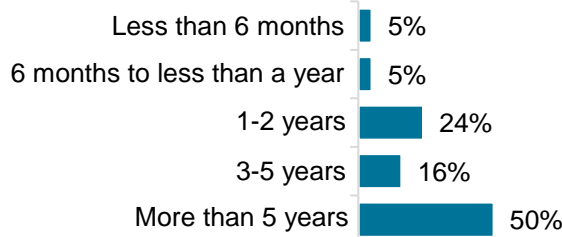
## Caregiving profile of caregivers (Table B3)

Caregivers were asked to share information about how long they have been providing care, the amount of time they provide each week, whether they live with their care recipient, supports they provide, and other services they may use to help them in their roles.

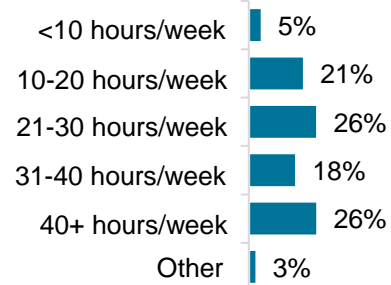
**Highlights** include the following:



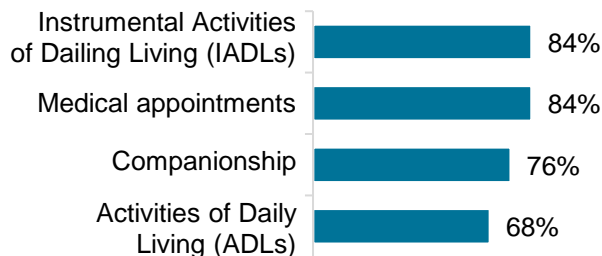
### Years caregivers have been providing care



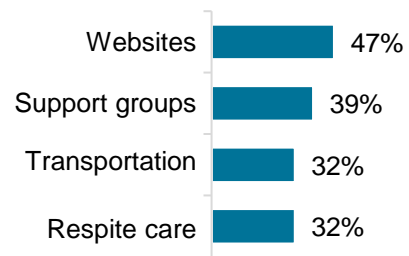
### Hours of care provided each week



### Activities caregivers are helping with



### The supports most often used by caregivers



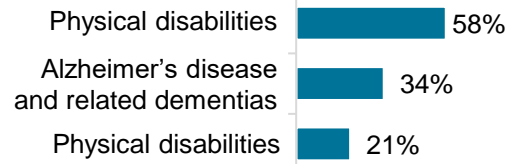
89% of caregivers said they share a home with the person they care for.

# Characteristics of care recipients (Table B4)

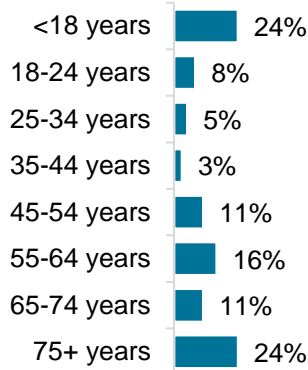
Highlights of the information about care recipients include:



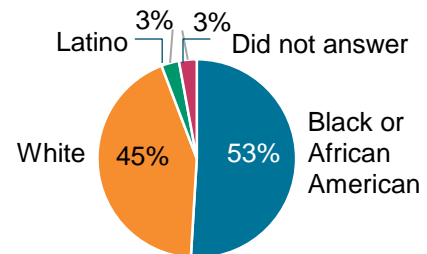
## Diagnoses of care recipients



## Age of care recipients



## Race of care recipients



58% reported that their care recipients qualified for Medicaid.

Note: Medicaid qualification status was self-reported by focus group participants and is not an indication that the Delaware Division of Medicaid and Medical Assistance officially confirmed eligibility.

**National profile of caregivers.** The AARP and National Alliance for Caregiving report, *Caregiving in the United States 2020*, outlined the profile of caregivers in the United States. In general, caregiving “occurs among all generations, racial/ethnic groups, income or educational levels, family types, gender identities, and sexual orientations” (p. 5).

Compared to the national results, a greater proportion of the Delaware focus group participants were:

- Female (74% vs. 61% nationally)
- Black or African American (50% vs. 14% nationally)
- Living with their care recipients (89% vs. 40% nationally)



## Findings from the focus groups

During the focus groups, participants shared a range of experiences and perspectives about caregiving. Although there were commonalities, no two stories about caregiving were identical. The findings from the focus groups are presented here, according to several main topics:

- The caregiving experience
- Challenges and frustrations in caregiving
- Unique challenges faced by caregivers in rural areas, those from Black, Indigenous, people of color (BIPOC) communities, and those who care for children
- Resources and changes that caregivers believe would help

In addition to summaries of the themes within each topic, quotations from the caregivers are shared abundantly to illustrate the perspectives they shared. Often the comments and stories we hear directly from the caregivers are the most powerful.

In the course of the discussions, many caregivers engaged in real time peer-to-peer support, exchanging contact information for later follow-up; sharing ideas and advice, program or organization contacts, and web links; and generally encouraging and sympathizing with each other. They also expressed appreciation for the opportunity to tell their stories to other caregivers, as well as to the researchers.

### The caregiving experience

In the first part of the focus group, participants shared information about their caregiving, as well as from whom and where they find support. While many did report receiving support from other family members, as well as outside sources such as home health care and support groups, **the majority of caregivers believe that they are doing this work on their own and accepted this as a matter of course.**

Caregivers had the following to say about support from others and doing the work of caregiving on their own:

*I'm the sole caregiver...When I can't get help I just try to do my best.*

*I don't have a lot of options, so I just have to be with my grandmother by myself.*

*I receive help from my siblings. They all work, but they give me money for what I do by taking care of our grandfather.*

*I don't feel there is great support. I feel very alone.*

Caregivers also shared information about the types of external supports they have used. One caregiver of a person with ADRD said they attended Savvy Caregiver, a program they learned about through Easterseals. **Participants also reported that they have found online support groups particularly helpful.** The support groups function as a means to receive advice from others, as well as to learn about options available for their care recipients. It should be noted that many of the support groups described by caregivers do not match the more traditional model of a discussion group at a set time, facilitated by a moderator with some background in the topic. Rather, these support groups are often discovered on social media platforms and involve participants sharing frustrations and successes, asking questions, gaining useful information, and identifying resources on an ad hoc basis as they interact with peers based on ongoing needs and their own schedule availability. Other caregivers said they learned about resources from their primary care physicians or the clinic staff. **Many caregivers depend on informal networks of family members and friends to learn about services that may help them.** Outside of their immediate communities, caregivers also report relying on technology and people in similar situations to find information.

Two caregivers said the following about the value of peer-to-peer support:

*I use Facebook. I have joined private groups that are specific to the condition I care for. That is a good tool for me to find support and connect with people who are experiencing what I am going through.*

*The support group helped me know about dementia patients apart from my doctor. I get to know what carers like me are facing. After the group it gave me some reassurance that my father's behavior is common for people of his kind.*

According to AARP's *Vital Voices* report (Cozad et al., 2021), 41% of Delaware residents age 45 and over said that "connecting with other caregivers in similar situations would be extremely or very helpful (p. 10)."

## Challenges and frustrations experienced by caregivers

Even when caregivers understand that they and their care recipients could benefit from external support, a number of issues can stand in the way of finding and using these services. **Their challenges and frustrations cover several main themes, including the financial impact of caregiving, looking for information and services, and finding the right services.** A number of caregivers also identified unique challenges they have experienced due to living in more rural counties, as well as due to their race or ethnicity, or as caregivers to children. The focus group with caregivers to people with ADRD was very small and did not reveal unique themes.

## *The financial impact of family caregiving*

Participants frequently mentioned the **real costs** associated with caring for someone (e.g., out-of-pocket costs for medications, travel for medical care) and the **inadequacy of funding** to cover those real costs. This imbalance leads to significant **financial strain**, which can be difficult to resolve through increased employment alone. Several participants mentioned the **dilemma of work versus caregiving** that has been an impossible Catch-22. The need for income or financial resources requires some caregivers to work, but at the same time being a caregiver can make it difficult to obtain and maintain employment that will provide sufficient levels of financial support and income. Some caregivers have returned to work in order to receive an income and benefits, while others have had to leave the workforce to provide the necessary care for their care recipient.

Caregivers had the following to say about the general financial impact of caregiving:

*Financially, caregiving wrecks your life.*

*We have good medical insurance, but it does not cover hotels, gas and food [when we travel to get medical care]. It adds up after a while, and it is all on me.*

*Financially this is close to bankrupting me. I need help understanding finances and how to navigate that.*

*It is a three-hour drive for us to access [specialized] healthcare. Our insurance does not do any reimbursement for the hotel stays or gas.*

Caregivers shared the following comments about the ways in which caregiving has superseded or affected their employment opportunities:

*I have not been able to go back to work. I tried for a brief time, but it did not work out. [Care recipient] needs constant supervision.*

*I cannot work full-time because my [care recipient's] health condition is so sporadic. I would never know when I would have to take off work to get them to a specialist.*

*I could only work part-time because you never know when the [paid home health worker] is going to call off or when you'll be up all night at the hospital. Whatever jobs I could take had to be very flexible.*

*How am I going to get work if you are not sending me a nurse [for my care recipient]? This makes me unemployable.*

One caregiver shared this example about how the need for income has affected their caregiving role:

*I am at the point where I have to work now. I went to full time in the last 6 months because I had to. That is why my [care recipient] has to stay in the hospital, because they can't get nursing to cover his [intensive needs]. It is a really traumatic experience when you have to choose.*

The AARP and National Alliance for Caregiving report, *Caregiving in the United States 2020*, presented the following information about finances and caregiving:

- “The majority of caregivers—about two in three for each—feel an income tax credit (68 percent) or program to pay caregivers to provide care (65 percent) would be helpful to defray the financial costs of care (p. 7).”

In addition, the AARP study, *Caregiving out-of-pocket costs study* (Skufca & Rainville, 2021) stated the following:

- “This study demonstrates the importance of supporting family caregivers with not only resources and education but financial assistance as well. The coronavirus pandemic has only heightened the need for caregivers and shone a light on both the emotional and financial sacrifices family caregivers make every day to help their family member or friend they care for. (p. 6).”

### *The burden of finding and accessing caregiver support services*

The line between supports for caregivers and supports for care recipients is not always clear. Caregivers often put the needs of their care recipients first, and the well-being of their care recipients becomes their primary orientation. So focused are they on their responsibilities and the pressing needs of their care recipients that sometimes caregivers may not be fully aware that they also have needs. In addition, supports that may be received by the care recipients, can also, by extension, be perceived by caregivers or function as supports for themselves—direct care for the care recipients may ease the responsibility and caregiving burden experienced by caregivers. In the focus groups, caregivers’ comments about finding and accessing care did not distinguish who the care was for.

Many of the caregivers in the focus groups indicated that they are aware, to some degree, of the existence of services or the importance of finding support. However, regardless of who the services are for, caregivers do not always go on to access those services for the following reasons:

- They do not know where to begin to find help
- Researching options is daunting and time-consuming, even if they do have a sense of where to begin looking
- Sometimes when they reach providers or other organizations with questions, they are not connected with the right people who can give them clear and accurate answers

Overall, caregivers feel tired and overwhelmed, and needing to work so hard for information just adds another layer of frustration.

Two caregivers summarized their experiences in the following way:

*There are way too many dots and not enough connections in Delaware.*

*There are resources in Delaware, but getting to them and knowing about them is a real problem in Delaware.*

According to AARP's *Vital Voices* report (Cozad et al., 2021), 61% of Delaware residents age 45 and over said that "information about available resources for caregivers in [their] community would be extremely or very helpful (p. 10)."

Comments about not knowing how to start looking for any type of help include the following:

*For me it is literally a lack of information and not knowing where to get started. I know there are programs for the aging, I just don't know where to look for that.*

*We hear this all the time that there are services available. Ok, what are they?*

*If I knew of availability [of services] in the area that would be great. I just don't know what there is in the immediate area.*

Comments about the effort required simply to search for information include the following:

*You have to do a lot of research to find something that is available.*

*A lot of caregivers are overtired and the last thing they want to do is search or do more searching. It is just a very exhausting thing, and we feel very alone.*

*We do not have a lot of time. We are all taking care of our loved ones. You don't relax until later—and then it is my time. So you cannot sit on the computer all night looking for resources.*

*It sucked the life out of me just trying to figure out how to get through the paperwork.*

*I have been doing 20-30 hours per week just on administrative work (insurance, medical supplies, getting services set up, therapy, managing money), and then add in being the nurse.*

Comments about receiving unclear or inaccurate information related to their care recipients' needs include the following:

*Every time I call to get help I get pushed to someone else, or I get sent somewhere and nobody responds.*

*I have looked into some things but they want a [test] done, but they don't say where I could take her to get them done.*

*There are way too many gatekeepers. It seems like a lot of them are like, "I don't know." It is a bit ridiculous.*

*Cutting through the red tape is so exhausting, and you get different answers from different people.*

*It was always "no" after the first 10 asks until you ask the right person who could give you a "yes" for whatever service you were looking for.*

*With case managers, if you don't ask you don't receive... There is a definitely a disconnect between the whole medical team. The doctor wrote an order for PT and OT, but no one told me I had to call the different companies to set it up.*

The AARP and National Alliance for Caregiving report, *Caregiving in the United States 2020*, included the following about information and services used by caregivers:

- Many caregivers “are recognizing that some services or supports, like respite care, would be helpful to their own situation, though actual use of supports and services remains low (p. 7). “
- [Caregivers] “may find themselves in need of information, resources, benefits, or programs—but these things are often difficult to find or access, or too expensive to afford.” (p. 8)

### ***Finding reliable and trustworthy supports for care recipients***

Caregivers are asked to provide increasingly complex medical care for their care recipients. This is part of the push for home and community-based services, which reflects both the financial pressure on government resources and the desire of many people to remain in their own homes. To do this, family caregivers often rely on paid staff (e.g., hired through an agency) to fill in the gaps and provide higher intensity medical care by licensed and trained staff. Many caregivers in the focus groups also recognized the value in respite care that can give them a much needed break or down time. Even respite care, which benefits caregivers, must be provided by paid, licensed staff in cases where the care recipients require care for more medically complex or specific conditions.

Many caregivers who found and used external supports still experienced additional challenges in obtaining appropriate supports suitable for their unique situations and which are also high quality, affordable, and trustworthy. Caregivers identified an overall lack of capacity in the formal caregiver support system, but especially as it relates to paid, formal caregivers. They also identified the ways in which these limitations render the paid, formal caregiver support system unable to meet their needs:

- There is poor availability of paid care providers (particularly skilled nursing care) through agencies
- Paid caregivers through an agency can be cost prohibitive, particularly when the care is private pay and not covered by other sources
- Paid care providers may not always meet caregiver expectations when it comes to appropriate job training, professionalism, and reliability
- There is not enough familiarity between care recipients and paid care providers or the organizations that provide them, resulting in a lack of trust and reluctance to have them in the home providing care.

Comments that illustrate the challenges associated with agency capacity include:

*I have two different agencies that I use right now. They just cannot fulfill the hours that I need.*

*There are a couple programs in Delaware that offer respite services...but there is never anyone available and no one I know.*

*I have had several agencies come in. They call, I do an assessment, but they say they do not have anyone with the hours I need.*

Comments that illustrate the challenges associated with the cost of care for the care recipients include:

*The skilled care infrastructure in the community base is getting lost. How are we going to compete when hospitals are paying \$50 per hour and the nurses taking care of [care recipient] are being paid \$25 per hour [through the agency]?*

*If I want to hire a skilled nurse through the agency it costs me \$50-\$60 per hour. If I do it on my own, I can do it for \$30 an hour.*

*We need to pay home health care people a good wage, as opposed to us paying double their salary [through an agency] and then they get paid so little. I hate that and everybody is short staffed right now.*

Comments that illustrate challenges with finding high quality support they can trust include:

*I have found that a lot of CNAs are not trained for clients that have dementia. This is concerning.*

*Some [outside support people] are not as reliable as you might want. They appear one day and are gone the next. Finding reliable, dependable services is a barrier.*

*[Care recipient] has very medically complex issues. Sometimes we [the family members] have to train the people who come and take care of him.*

Comments about care recipients not wanting unfamiliar people caring for them include:

*It is really intrusive to have others that aren't family existing in your home [while providing care].*

*My mother is very reluctant to let anyone else help her.*

*My daughter does not have faith and trust in having other people caring for her.*

### **Special challenges experienced by caregivers in rural areas of Delaware**

While more than half of focus group participants (55%) live in more populated Newcastle County, those who do not were quick to point out their unique challenges due to living in more rural locations in Kent and Sussex counties. **A lack of services or fewer options, the greater distance to reach organizations that may provide supports, and a lack of privacy in small towns** are among the concerns mentioned by rural caregivers about accessing or arranging for services.

Examples of their comments include:

*If I were in a more urban area I could find people who have enough experience to care for my grandad.*

*[Organization] is 20-25 minutes from me. So it is not so close to me where I could just decide to go there today.*

*Because I'm in a small town, everybody knows everybody and wants to be in your business. The minute they find out something then it's all over. I'm a private person.*

*[Rural county location] may not be a long drive, but when you care for more than one person it is a long drive.*

*I was doing group therapy sessions, but I stopped using it because I had to travel for a long distance before getting to the place.*

### **Unique experiences reported by caregivers of color**

A common theme among the caregivers in the Black and African American groups was their **reliance on community members as sources of trusted information**. Advice and recommendations from friends and family members, as well as other professionals they know, can provide assurance of the quality of the services or supports that can meet the needs of their care recipients. They had the following to say about sources of trusted information:

*I received assistance from one of my church organizations.*

*You must be very careful with the information you divulge online. You can't talk to just anyone.*

*If a friend or family member has tested an organization and can vouch for them that this is very reliable and authentic I won't hesitate to go to that organization.*

*Finding resources here for my elders has been quite difficult. Some information might not be true.*

*I contact the medical personnel taking care of my parents and ask if there is anything that would help them heal faster.*

*For me as a caregiver, I would definitely want to give [caregiving service] a try, because you are a very good friend of mine and you recommended it to me.*

*I haven't tried the services because of the reputation. I try to do the research and talk to other people, see their comfort level to see what they think of the services, especially if it's someone I trust with similar challenges*

One caregiver mentioned that **the lack of interpreters** for their family member's particular language needs made finding and receiving assistance more difficult. Another caregiver who identified as Latino in the focus group specifically called out their family's experience with **medical racism**. Their family member was released from the hospital without access to critical equipment, and they struggled to obtain the resources available to other families in similar situations.

*I had to navigate and plead to get help. Finally another parent told me she didn't understand why my child didn't have nursing. I think a lot has to do with a lot of bias. There are barriers for us being a minority.*



**Caregiving in BIPOC communities.** Cultural norms and practices within many BIPOC communities tend to emphasize a family-centered approach to caregiving, and for many, caregiving is just what you do to care for family members. In fact, it is not unusual for members of these communities to not recognize what they are doing as “caregiving.” Community members rely on trusted resources, including people and organizations, to seek help.

### *Unique experiences of caregivers for children*

Nearly a quarter of focus group participants (24%) were providing care for a child or grandchild. While DSAAPD, in name, administers programs for older adults and adults with disabilities, this study was expanded to discover more about the needs of caregivers of people across the lifespan, including youth.

While many needs of caregivers can be considered more universal, participants in the focus groups who care for children were very vocal about their unique needs. Diagnoses they discussed include a range of medically complex conditions, developmental disabilities, and emotional and behavioral health conditions, many of which co-exist for the youth. Caregivers discussed the **limited resources available for youth**, and believe that **families are being overlooked or under supported**. **Peer support** is particularly important for many of the caregivers of high-needs children.

Examples of the comments shared by caregivers about limited resources include:

*My child has a rare condition. There are only 12 specialists in the U.S. that treat [it in] pediatrics. It is still a three-hour drive to access health care.*

*I find there is a lack of mental health care for children. We could not get [care recipient] into an institution until age 13, even though the problems started at age three.*

*The adult world has more services than the pediatric world.*

Two caregivers had the following to say about the importance of peer-to-peer support:

*In the pediatric world, one of the things they teach you is other parents. Other parents who have been there, done that. They are the best ones to tell you.*

*There are a lot of private groups on social media. There is a Facebook site which has been very helpful. When I did not know what to do, it was easy to ask questions and get answers there.*

### *Experiences of caregivers for people with Alzheimer's disease and related dementias (ARD)*

There were only three participants in the group with a topical focus on the experiences of caregivers of people with ARD. All care recipients were over the age of 50. While they acknowledged that caregiving can be challenging and that the ARD diagnosis can require more vigilance, no unique themes emerged related to their needs.

## Caregiver suggestions to improve services

In the final portion of the focus groups, participants were asked how they would spend a hypothetical one million dollars to help caregivers. While some caregivers adhered closely to the assignment, others shared more broadly about what could change to provide better support for caregivers.

### *Participants' plans for spending a hypothetical one million dollars*

Caregivers shared a broad range of ideas for creative solutions for current challenges facing caregivers and the system of supports that help them provide unpaid care for their family members or friends.

#### **Funding that allows self-directed care or covers gaps in coverage**

A common theme shared by caregivers was creating a structure that would allow them to decide which resources to access and use in a way that works for them. Caregivers described this in the following ways:

*Create a grant that people could apply for based on their individual needs.*

*Consider a caregiver allowance that doesn't require us to sign up with a home health agency.*

*I'd come up with a small group and they could carry out surveys for qualification to join the program. Then we can partition the money to cover different needs.*

*Ask caregivers what they want for like \$1000, just as a reward for the caregiving. Maybe pay some medical bills, medications. Maybe a vacation for the caregiver.*

Caregivers also mentioned creating funding sources to fill the gaps in the real costs of caregiving:

*We need to have supports in place and raise money so it is not such a financial burden on the families so they can get support to stay at hotels.*

*A tax credit or social security credit to cover all the retirement benefits that I give up for caregiving for 40 hours a week and not earning money and putting it into social security.*

*Create grants for caregivers that have to take time out of work to provide for their care recipients.*

According to AARP's *Vital Voices* report (Cozad et al., 2021), 63% of Delaware residents age 45 and over said that "getting a credit on [their] income tax for expenses related to caregiving would be extremely or very helpful (p. 10)," and 89% of Delaware residents age 45 and over said they "would support a state income tax credit to family caregivers who incur caregiving expenses (p. 11)."

## Developing new facilities and programs

Many of the facilities and programs caregivers said they would develop with their million dollars were specific to children. In addition to building residential programs for young care recipients and their caregivers, caregivers also outlined programs they would develop including:

- extending long term care for children
- for children with chronic conditions or disabilities
- augmenting mental and behavioral health resources for children

Other caregivers mentioned general programs such as support groups, transportation, and respite care. One caregiver specified the following:

*I would like to see programs that pay me to take care of my [care recipient]. Some states pay for people to stay home and care for their families. Delaware does not do that.*

## Funding staff positions and changing structures at DSAAPD

Caregivers shared a range of ideas about what they would change at DSAAPD with the million dollars, in order to better assist caregivers. Several caregivers suggested that they would **fund additional staff positions**. Two examples include:

*How about funding an ombudsman for people who are getting the run around? A third party to call.*

*What if there were caseworkers who work specifically with the caregivers of people with specific types of challenges? Those caseworkers could run support groups for those interested parties and refer them to the right kinds of services.*

Caregivers also shared their thoughts on a need for changing the structures at DSAAPD, commenting on the persistent lack of adequate funding and staffing. They also suggested a need for **reducing the bureaucracy and restructuring processes**. Examples include:

*I would make a magical application filler outer program.*

*Is a single point of entry or repository the answer? I don't know. They tried with the 211, but the thing is they have to stay on top of it. The data is only as good as what is put in.*

*Train their case managers and those gatekeepers on what is really available and ways to reach those final goals that you may have for your person.*

*I would restructure DHSS and have people talk to each other because all the people on this call are not the first to have family members who have more than one issue or concern. The divisions don't all serve people with limitations, but they all have information that would benefit people. Some of the divisions have very innovative systems going, and others have no idea.*

*Streamline your process, make this easy when people come to you [DSAAPD] and they need help. Make it so they don't have to fight so hard.*

## **Participants' suggestions to increase DSAAPD service awareness**

As discussed previously, caregivers expressed frustrations about the lack of complete information or even knowing where to begin to find information. In general, they believe that the **information needs to be disseminated in multiple ways to increase awareness**. Using social media outlets was the most commonly suggested method for sharing information. Other suggestions included brochures or flyers, postcards, packets distributed by medical clinics, and advertisements in a variety of specialized and local newspapers or newsletters.

One caregiver specified using the hypothetical million dollars on an information campaign:

*I would heavily invest in an information campaign to get that knowledge out, to make it more user friendly for people to understand how to get the services, how to get started, what resources do they have. Obviously there are so many ways to spend a million dollars into this kind of issue, but I feel like information is a good start.*

Examples of other suggestions include the following:

*What about putting information in Delaware Power? Use flyers with the utility bills, send a postcard to every home saying "visit our website and these are the kinds of things you can find out about."*

*The best way to share this information is have it spread throughout social media so people can have this kind of awareness.*

*Make use of online stuff like social media and having flyers that will help create awareness. I also think signs and posters will help, with a call center where people can reach out if they need help.*

*Apart from online and community, there could be flyers given to everyone in hospitals and health centers.*

*There are different social media platforms that promote awareness using a lot of advertisements, catchy advertisements. Come into a particular community and organize conferences and seminars for caregivers who are interested.*

*The best way to get information to me or my community is by creating an African American community group on social media. Posting flyers on these social media pages will go a long way in letting people know about a particular support.*

## Recommendations

The observations and experiences shared by caregivers in the focus groups suggest some key directions to consider.

- **Continue operating with the *No Wrong Door Approach*, but improve the reach of service information by diversifying dissemination approaches.**

As evidenced by the DHSS and DSAAPD webpages, DSAAPD does provide multiple entry points into its system of information, services and supports, as well as multiple resources to residents of Delaware. However, many caregivers seem unaware of how to get started and lack an understanding of what may be available.

Caregivers have suggested that DSAAPD could intentionally provide accurate information in a broad variety of formats, including boosting the use of social media and exploring other methods for widely and simultaneously sharing more information via advertising (social media and perhaps radio), posters and signs, existing channels such as medical clinics, and mailed information (e.g., included with utility bills).

DSAAPD could consider producing materials in a variety of languages. When using multiple communication methods, it would be especially important to update information regularly to ensure its relevance and accuracy.

- **Improve DSAAPD's systems navigation processes, increase support staff knowledge, and create accessible population-specific materials.**

Regardless of the efforts currently implemented by DSAAPD to produce useful information, caregivers have indicated that they are frustrated by the effort required to find accurate and helpful information. Caregivers for youth spoke about struggling to find information and support.

Potential steps to address this could include updating or revising DSAAPD internal structures to support systems navigation, providing staff with training on accurate information and practices, and establishing clear pathways and protocols for caregivers who require additional assistance.

Staff may also want to consider the current difficulty of finding information related to children and youth, and to long term care. Researchers noted that a specific pediatrics focus appears to be lacking on the DHSS and DSAAPD websites (aside from Child Protective Services, foster care and criminal justice). It is also difficult to find the link for information about children with medical complexity, as it is located on the Division of Medicare and Medicaid (DMMA) webpage. The Long Term Care Medicaid Programs information appears equally difficult to find on the DMMA webpage.

- **Partner with leaders in a variety of communities who may function as trusted champions and sources of information, and may also provide insight on community needs and resources outside of DSAAPD’s typical purview.**

Many caregivers in the Black and African American focus groups emphasized the frequency with which they rely on community members, including friends and family, to share information and resources they can trust.

Building on informal networks, DSAAPD could work to establish connections with trusted community leaders (e.g., elders, faith leaders, health care providers) to share information about available caregiver supports, how to access them, and who can deliver them in culturally relevant ways. It may also be important to present information and provide services that are relevant to a variety of cultural norms and practices. In the same way, seeking input from trusted community leaders can continue to inform the work of DSAAPD in meeting the needs of caregivers in a variety of communities.

It is important to note, of course, that meeting caregivers and care recipients in the community is an important component of providing person-centered care, regardless of a person’s race, ethnicity, location, or medical needs.

- **Explore ways to support caregivers with self-directed grants.**

Caregivers discussed their frustrations with arranging services that do not meet their particular needs (e.g., type of care, amount of care, schedule) and lamented the one-size-fits-all caregiver services and supports that do not address the unpredictable nature of caregiving. Several caregivers mentioned that other states provide funds that caregivers can use to customize the supports they receive. In each case, others in the groups stated that this sounded very appealing and wondered why this was not available in Delaware.

Implementing a method in Delaware that would support customizable services would augment the person-centered approach to supporting caregivers and care recipients.

- **Develop or sponsor opportunities for robust peer-to-peer support.**

Caregivers frequently mentioned the value they find in peer-to-peer support. They spoke about the ways in which they rely on others in similar situations or communities to share helpful suggestions and advice, offer real time moral support, and ease the burden of isolation. DSAAPD could take advantage of this medium and contribute by providing accurate and current information and expanding the reach of resources available through DSAAPD.

- **Pursue additional activities to understand the needs and strengths of all caregiver populations in Delaware.**

The smaller numbers of participants, combined with the obvious interest of caregivers in contributing to DSAAPD's understanding of their needs, suggests the value of additional research into the needs of caregivers. Focused outreach with targeted recruitment of participants (based on specific characteristics of caregivers or health conditions of care recipients, for example) or further review based on findings of interest in this report or peer-reviewed literature, could yield additional insights to guide DSAAPD's efforts.

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# Appendix A: Focus group methodology

Included in this section of the report is an outline of the guidelines, outreach and recruitment, registration, format, and follow-up methods used during the completion of the focus groups with caregivers. A total of 38 caregivers participated in the eight focus groups. The attendance rate amongst those who completed the registration form was 34%.

All activities (meetings, focus groups, etc.) completed for this project occurred virtually, via online video platform, with some participants joining by phone only. The COVID-19 pandemic poses many challenges, especially when working with populations experiencing increased strain, such as caregivers for people who may have special health concerns or limitations. Technologies that support online interactions have become common and familiar. Other communications were completed via text messages and emails.

## Outreach and recruitment

DSAAPD took the lead on outreach and recruitment of participants for the focus groups. Wilder developed promotion materials for DSAAPD to distribute to partner organizations and key stakeholders, including a flyer and script examples for emails and phone calls (Appendix C). DSAAPD shared the flyer and focus group information across the state, relying on social media posts, emails to partner organizations, and information shared with state legislators to boost the message.

The outreach flyer included information about the purpose of the focus groups, eligibility for participation, and next steps for registration. A link to the registration site was also included on the flyer.

### **Source of information about the focus groups**

Caregivers were asked who gave them information about the focus group and suggested that they sign up.

<b>Source</b>	<b>Number</b>
Someone from DSAAPD	13
Someone from Easterseals	6
Someone from a Caregiver Resource Center	4
Family member or friend	4
Online	4
Someone from AARP	2
A case manager or social worker	2
Senator	1
Supervisor	1
Don't know	1

# Registration

Potential participants were invited to visit a webpage set up for registration, answer a number of screening questions, and indicate their preferences for specific dates and times for scheduled focus groups (Appendix B). All caregivers had the option of participating on any of the scheduled dates. Potential participants who identified as Black or African American and/or were caring for someone with ADRD could also register for a group reserved for caregivers identifying in those specific ways. Names of potential participants were removed from the list in cases where they did not provide working contact information (email or phone numbers), or were otherwise unresponsive. By using this type of voluntary, opt-in format for recruiting potential participants, DSAAPD and Wilder were able to avoid a lengthy IRB process.

Following the successful registration of potential participants, Wilder staff responded to caregivers with specifics about the dates and times of the groups they were assigned to, and included a link to a brief survey with additional questions about their backgrounds, their care recipients' backgrounds, and their experiences with caregiving (Appendix D). Caregivers were asked to complete the survey in advance of the focus groups (per a deadline included in the emails) so that the group time could be used more efficiently and provide as much time as possible for participants to share their perspectives. Once they completed the survey, they received the formal invitation with Zoom link for the focus group.

Multiple focus group dates and times were offered to participants via the registration link. As dates and times reached capacity, registration was capped and participants were redirected to alternative dates and times. For times and dates with too few registrations or none, participants were rescheduled and those times were closed. Some potential participants indicated their interest in joining a focus group, but were not available to attend during the scheduled times. These participants were added to a tentative wait list.

Multiple attempts were made to reach potential participants who did not complete the brief survey, in order to verify their participation and request that they complete the survey. One to two days before each scheduled focus group, participants were contacted with a reminder about the date and time. An additional group of names of potential participants were removed from the focus group schedule in cases where they were unresponsive or did not complete the survey. On the day of each focus group, Wilder staff finalized confirmations, and cancellation and reschedule requests via phone calls, text messages, and emails.

## *Efforts to reduce barriers and encourage participation*

In order to encourage participation and avoid turning away participants, DSAAPD and Wilder staff addressed potential barriers in the following ways:

- **Technology.** Caregivers who indicated on the survey that they did not have access to technology that would allow them to participate online were contacted by DSAAPD to discuss alternative accommodations, pre-arranged by program partners.
- **Respite care.** If caregivers requested additional information about respite care that would allow them to participate in the focus groups, they were contacted by Easterseals to make arrangements.

- **Schedule.** Support groups were scheduled for a variety of days of the week and times of the day in order to accommodate the caregivers’ responsibilities and care recipients’ needs.
- **Group capacity for caregiver participants.** Wilder created multiple break-out sessions during one focus group time to accommodate the large number of caregivers who wanted to participate, and offered another date to further accommodate additional participants.
- **Incentive for participation.** Participants were offered a gift card to thank them for their time.

## Focus group format and attendance

In order to accommodate participants’ schedules and caregiving responsibilities, eight focus groups were held at a variety of times during the day (Table A1).

### A1. Focus group schedule and participation

<b>Focal population</b>	<b>Date</b>	<b>Time</b>	<b>Number of participants</b>
All caregivers	December 9, 2021	11 am-noon	4
All caregivers	December 10, 2021	10-11 am	7
All caregivers	December 13, 2021	3-4 pm	6
Black or African American caregivers	December 20, 2021	7-8 pm	14
Black or African American caregivers	December 29, 2021	3-4 pm	4
Caregivers for people with Alzheimer’s disease and related dementias	January 4, 2022	9-10 am	3
			<b>38</b>

Note: There were an unexpectedly high number of registrations and confirmed participants for the December 20th Black or African American caregiver group who were not available for other focus group dates. To avoid participants disengaging due to delays with rescheduling or having a discussion group that was too large, Wilder invited all confirmed caregivers to the focus group on December 20 and created three simultaneous break-out sessions (with capacity for four groups, if needed), facilitated by Wilder staff leads and note takers.

At the beginning of each focus group, the facilitator described the purpose of the study and explained that the participants' comments would be kept confidential. With the permission of the participants, each focus group was recorded in order to guarantee that the full range of comments and opinions were captured by the researchers. One staff person from Wilder Research facilitated each focus group. For seven of the groups, one staff person also took notes; for the remaining group only the facilitator was present.

One standard focus group protocol was developed for the focus groups (Appendix F). Modifications to the focus group introduction and question emphasis were tailored to the particular focus of the groups. Questions related to the ways in which race or ethnicity, gender or sexual identify, and urban or rural location affect caregivers' access to services and supports were appended to the focus group instrument. The numbers of caregivers in the groups that represented various races or ethnicities and gender or sexual identity were small. Group facilitators approached those topics carefully to avoid singling out participants on the basis of those identifiers and to ensure their privacy.

Degrees and types of participation varied among caregivers in these groups. Several caregivers spoke freely and with their cameras on. Many others spoke only a few words or sentences, and did not turn on their cameras. Others neither spoke nor turned on their cameras, and instead contributed to the focus group via the chat function. In some cases, participants logged in to the meeting and disregarded facilitators' requests to identify themselves through audio or chat, and contributed no content.

Due to their limited participation (e.g., no camera, no speaking) or sometimes vague contributions, it was not possible to verify that all of the participants were, in fact, caregivers, or familiar with caregiving or with the types of services mentioned in the course of the focus groups. (Nor was it possible to verify the accuracy of information shared on the registration form or online survey.) The \$35 incentive may have persuaded individuals, who were not caregivers, to register. A lack of trust in the system may have influenced participants' reluctance to appear on camera. Limited English skills for others, or access to reliable technology may have reduced their ability to contribute to the conversation.

## Focus group follow-up

Caregivers were offered a \$35 gift card as an incentive to increase the likelihood of participation. After each focus group, Wilder issued gift cards to caregivers who participated, to compensate them for their time and effort. Participants chose from three different gift card options—Amazon, Walmart, or Wawa—and selected the method for delivery—electronic or U.S. mail.

Table A2 shows the types of gift cards and methods for delivery.

### A2. Gift card requests and delivery (N=38)

<b>Gift card</b>	<b>Electronic delivery</b>	<b>U.S. mail delivery</b>
Amazon	30	0
Walmart	4	2
Wawa	2	0

Wilder shared the names of caregivers who requested respite in order to attend the focus groups with Easterseals, who then contacted these caregivers to facilitate arrangements. Following each focus group, Wilder completed a form provided by Easterseals to confirm each person's attendance and ensure that they received the respite benefit.

## Appendix B: Demographics

All data is presented in aggregate form in order to protect the anonymity of the focus group participants and care recipients.

### B1. Demographic characteristics of focus group participants (N=38 caregivers)

Characteristics	Number	Percentage
<b>Race*</b>		
Black/African/African American	19	50%
White	17	45%
Latino	2	5%
Preferred not to answer	1	3%
<b>Age</b>		
25-34 years	13	34%
35-44 years	6	16%
45-54 years	4	11%
55-64 years	8	21%
65-74 years	7	18%
<b>Gender</b>		
Female	28	74%
Male	10	26%
<b>LGBTQ identification</b>		
Yes	6	16%
No	30	79%
Declined to respond	2	5%
<b>County of residence</b>		
Kent	14	37%
Newcastle	21	55%
Sussex	2	5%
Other (Work in Delaware)	1	3%

Note: Percentages may not total 100 due to rounding.

\*Multiple responses possible

## B2. Employment and income status of caregivers (N=38)

Employment and income	Number	Percentage
<b>Employed</b>		
Yes	20	53%
No	17	45%
Declined to respond	1	3%
<b>Hours worked/week (N=20)</b>		
40 hours or more	8	40%
<40 hours/week	12	60%
<b>Income</b>		
Less than \$16,000	1	3%
\$16,000 to under \$25,000	1	3%
\$25,000 to under \$40,000	6	16%
\$40,000 to under \$60,000	6	16%
\$60,000 to under \$80,000	6	16%
\$80,000 to under \$100,000	5	13%
\$100,000 to under \$150,000	6	16%
\$150,000 or higher	2	5%
Don't know	1	3%
Declined to respond	4	11%

Note: Percentages may not total 100 due to rounding.

### B3. Caregiving profile of focus group participants (N=38)

Caregiving profile	Number	Percentage
<b>Length of time as a caregiver</b>		
Less than 6 months	2	5%
6 months to less than a year	2	5%
1-2 years	9	24%
3-5 years	6	16%
More than 5 years	19	50%
<b>Number of hours/week caregiving</b>		
<10 hours/week	2	5%
10-20 hours/week	8	21%
21-30 hours/week	10	26%
31-40 hours/week	7	18%
40+ hours/week	10	26%
Other (Family members rotate care for months at a time)	1	3%
<b>Share home with care recipient</b>		
Yes	34	89%
No	4	11%
<b>Type of care provided for care recipient</b>		
Instrumental activities of daily living (e.g., managing finances, transportation, communication, medications, shopping and meal preparation, housecleaning, and home maintenance)	32	84%
Medical appointments	32	84%
Companionship	29	76%
Activities of daily living (e.g., walking, personal hygiene, bathing, getting dressed, toileting, eating, transfers)	26	68%
Other (religious observance and medical condition research)	2	5%
<b>Services used by caregivers</b>		
Website	18	47%
Support groups	15	39%
Transportation	12	32%
Respite care	12	32%
Chore services	9	24%
Counseling	9	24%
Coaching	6	16%
Group classes	4	11%
Hotline	4	11%
No services used	7	18%

Note: Percentages may not total 100 due to rounding.



#### B4. Characteristics of care recipients (N=38)

Characteristics	Number	Percentage
<b>Relationship to the caregiver (N=40)*</b>		
Parent/in-law	17	45%
Child/grandchild	9	24%
Spouse	5	13%
Sibling	4	11%
Grandparent	3	8%
Friend	2	5%
<b>Age of care recipient</b>		
<18 years	9	24%
18-24 years	3	8%
25-34 years	2	5%
35-44 years	1	3%
45-54 years	4	11%
55-64 years	6	16%
65-74 years	4	11%
75+ years	9	24%
<b>Race/ethnicity of care recipient*</b>		
Black/African/African American	20	53%
White	17	45%
Latino	1	3%
Preferred not to answer	1	3%
<b>Qualify for Medicaid<sup>a</sup></b>		
Yes	22	58%
No	12	32%
Don't know	4	11%
<b>Diagnosis that requires care*</b>		
Physical disability (e.g. due to injury, old age)	22	58%
Alzheimer's disease or related dementias	13	34%
Developmental disability	8	21%
Terminal neurological disease (e.g., ALS, Parkinson's, MS)	7	18%
Chronic health condition (e.g., COPD, heart disease)	6	16%
Traumatic brain injury	4	11%
Cancer	3	8%
Mental illness	2	5%

Note: Percentages may not total 100 due to rounding. \*Multiple responses possible

<sup>a</sup> Medicaid qualification status was self-reported by focus group participants and is not an indication that the Delaware Division of Medicaid and Medical Assistance officially confirmed eligibility.

# Appendix C: Outreach flyer

ARE YOU AN  
UNPAID CAREGIVER  
FOR A FAMILY  
MEMBER OR FRIEND?



WE WANT TO  
HEAR FROM YOU!

The Delaware DHSS Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) wants to improve services and supports for unpaid caregivers like you!



## WHO

Adults (age 18 and over) who are unpaid caregivers for relatives or friends (e.g, spouse/ partner, parent, neighbor)



## WHEN

The 1 hour discussions are being scheduled for December and January



## COMPENSATION

Participants will receive a **\$35 gift card for Amazon, Walmart, or Wawa** following the discussion

[Sign up below to learn more](#)

## 3 easy steps...



1. Sign up online. Go to:

<http://wilderresearch.org/go/DelawareDSAAPDFocusGroup>



2. Answer some screening and background information questions. Someone from Wilder Research will call you to confirm the details.



3. Join the focus group at your scheduled time and share your perspectives.

You may be eligible to receive **free respite services** during this time

## Other important information:

- The focus group is confidential. All of your answers will be private. No one will know who participated in a focus group or what they said.
- **Please sign up as soon as possible.** Focus groups are being scheduled for December and January.
- Focus group results will be used to improve and expand support for caregivers in Delaware.
- DSAAPD is working with staff from Wilder Research to schedule and complete the focus groups.

## Questions?



**Christin Lindberg** at Wilder Research:  
612-501-9408  
christin.lindberg@wilder.org



**Geralyn Aellis** at DSAAPD:  
302-255-9380  
geralyn.aellis@delaware.gov



DELAWARE HEALTH AND SOCIAL SERVICES  
Division of Services for Aging and Adults with Physical Disabilities

## Appendix D: Registration form

[Landing Page for information about the study]

**Are you an unpaid caregiver for a family member or friend?**

### WE WANT TO HEAR FROM YOU!

The Delaware DHSS Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) wants to improve services and supports for unpaid caregivers like you!

**Sign-up to participate in an online focus group and let us know your thoughts about services and support for unpaid caregivers.**

#### Who?

- Adults (age 18 and over) who are unpaid caregivers for relatives or friends (e.g, spouse/partner, parent, neighbor)

#### When?

- The 1 hour discussions are being scheduled for December and January

***You may eligible to receive free respite care during this time.***

#### Compensation?

- Participants will receive a **gift card for \$35** from **Amazon, Walmart, or Wawa** following the discussion

#### 3 easy steps to participate...

- Sign up online. See below.
- Answer some screening and background information questions.
- Join the focus group at your scheduled time and share your perspectives.

Other important information:

- The focus group is confidential. All of your answers will be private. No one will know who participated in a focus group or what they said.
- Please sign up as soon as possible. Focus groups are being scheduled for December and January.
- Focus group results will be used to improve and expand support for caregivers in Delaware.
- DSAAPD is working with staff from Wilder Research to schedule and complete the focus groups.

#### If you have any questions

Geralyn Aellis at DSAAPD: 302-255-9380 or [geralyn.aellis@delaware.gov](mailto:geralyn.aellis@delaware.gov)

Christin Lindberg at Wilder Research: 612-501-9408 or [christin.lindberg@wilder.org](mailto:christin.lindberg@wilder.org)

**We hope you take this opportunity to help us better understand what resources and services are most important to you and/or those you care for!**

Continue



**DELAWARE HEALTH AND SOCIAL SERVICES**

Division of Services for Aging and Adults with Physical Disabilities

[Note: Document formatted for online completion]

Are you currently providing unpaid care to a family member or friend (e.g., a spouse/partner, parent, neighbor)?

- Yes
- No → It looks like you are not eligible for this study. Thanks for your interest. [END]

1. Are you 18 years of age or older?

- Yes
- No → It looks like you are not eligible for this study. Thanks for your interest. [END]

2. Who is the main person that you care for?

- Spouse or partner
- Sibling
- Friend
- Parent, step-parent or in-law
- Child
- Grandparent
- Neighbor
- Other relative (describe: \_\_\_\_\_)
- Other (describe: \_\_\_\_\_)

3. What diagnosis for your [care recipient] makes it necessary for you to be a caregiver? (*Check all that apply*)

- Alzheimer's disease or related dementias
- Physical disability (e.g., due to injury or old age)
- Terminal neurological disease (e.g., ALS, Parkinson's, MS)
- Traumatic brain injury
- Cancer
- Mental illness
- Developmental disability
- Chronic health condition (e.g., COPD, heart disease)
- Short term illness or rehabilitation services
- Other (Please describe: \_\_\_\_\_)

4. What is your race or ethnicity? *(Check all that apply)*
- American Indian/Alaskan Native
  - Asian/Asian American
  - Black/African/African American
  - Hispanic/Latino/Latina
  - Native Hawaiian/Pacific Islander
  - White
  - A race or races not listed here (Please specify) \_\_\_\_\_
  - Prefer not to answer

**You are eligible to participate in our study about the needs of caregivers!**

Continue

## Supports for your participation

DSAAPD wants to help eliminate barriers to participation for eligible caregivers. These next questions are about your access to internet connections and need for respite care during the focus group.

5. Do you have internet technology that will allow you to participate online in the focus group? (e.g., internet on a phone or computer with connections to Zoom or a similar online platform)?
- Yes (Go to Q 7)
  - No → Would you be able to go to a site outside your home (e.g., Caregiver Resource Center or other community location) to participate in the focus group?
    - Yes → We will use the contact information below to be in touch with you to discuss options that may be available to you.
    - No → We will use the contact information below to be in touch with you to discuss options available to you.
6. DSAAPD is arranging free respite care services to help eligible caregivers participate in the focus groups. This could be either an in home or out of home service that would provide care for your care recipient. Would you like further information about respite care services that would help you participate?
- Yes → We will use the contact information below to be in touch with you to discuss options that may be available to you.
  - No

## Scheduling

7. Below you will see the dates and times of the discussion groups you are eligible to participate in. If more than one group is listed, please check which would be best for your schedule.

FG 1	FG 2	FG 3	FG 4	FG 5	FG 6	FG 7	None of these times work for my schedule
Tuesday Jan 4 9-10 am	Monday Dec 20 7-8 pm	Thursday Dec 9 11am-noon	Friday Dec 10 10-11 am	Monday Dec 13 3-4 pm	Wednesday Dec 15 7-8 pm	Saturday Dec 18 3-4 pm	Thank you for letting us know.  [Go to next page]

[For anyone marking FG1-7]

**Please provide us with your contact information so that we can reach you to confirm your participation and share more information with you.**

Name:

Email address:

Preferred method for contact

Cell phone number:



Home phone number

[For anyone marking the last option (i.e., not FG1-7)]

I would be interested in participating in a focus group at a different time.

- Yes →
- No

Pop up: Thank you! Please click “continue” to enter your contact information. We’ll be in touch with you to discuss another time that may work for you.

Continue

**Please provide us with your contact information so that we can reach you to discuss a time that may work for you and to share more information with you.**

Name:

Email address:

Preferred method for contact

Cell phone number:

Home phone number

## Appendix E: Online survey

### Delaware DSAAPD Focus Group Participant SAQ

*[Note: Will be formatted for online completion and sent via electronic link to all participants]*

**Thank you for completing this form before participating in the focus group about caregiving.**

Your responses will help us understand the background characteristics of caregivers and care recipients, and may help you and other caregivers access services that can best meet their needs. Completing these questions now will allow us to spend our time in the focus group hearing more about your experiences as caregivers. All responses will be kept confidential and grouped with all the other participants' responses for reporting.

---

#### **YOUR CAREGIVING ROLE**

1. Who do you care for? *(Check all that apply.)*

- Spouse or partner
- Sibling
- Friend
- Parent, step-parent or in-law
- Child
- Grandparent
- Neighbor
- Other relative (describe: \_\_\_\_\_)
- Other (describe: \_\_\_\_\_)

1a. [If multiple care recipients checked] Which one is your primary care recipient?

The following questions are related to [primary care recipient/care recipient identified above].

2. How old is your [care recipient]?

- Under 18
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75 +
- Prefer not to answer



3. What is your [care recipient's] race/ethnicity? *(Check all that apply.)*
- American Indian/Alaskan Native
  - Asian/Asian American
  - Black/African/African American
  - Hispanic/Latino/Latina
  - Native Hawaiian/Pacific Islander
  - White
  - A race or races not listed here (Please specify) \_\_\_\_\_
  - Prefer not to answer
4. For how long have you been providing care to your [care recipient]?
- Less than 6 months
  - 6 months to less than a year
  - 1-2 years
  - 3-5 years
  - More than 5 years
5. About how many hours per week do you spend providing care?
- Less than 10 hours
  - 10 to 20 hours
  - 21 to 30 hours
  - 31-40 hours
  - More than 40 hours
  - Other (Please describe: \_\_\_\_\_)
6. Do you share a home with the person you care for?
- Yes
  - No
7. What types of care do you provide for your [primary care recipient]? *(Check all that apply.)*
- Activities of daily living (e.g., walking, personal hygiene, bathing, getting dressed, toileting, eating, transfers)
  - Instrumental activities of daily living (e.g., managing finances, managing transportation, shopping and meal preparation, housecleaning and home maintenance, managing communication, managing medications)
  - Companionship
  - Accompany to medical appointments
  - Other (Please describe: \_\_\_\_\_)

8. Does your [care recipient] qualify for Medicaid?
- Yes
  - No
  - Don't know
9. Have you ever used any of the following services designed for caregivers? *(Check all that apply.)*
- Support group
  - Group class
  - Help with chores/housekeeping
  - Help with transportation
  - Respite services (e.g., in-home or off-site care to give caregivers short-term relief)
  - Coaching or consultations
  - Counseling services
  - Telephone hotline about services
  - Website with information
  - Other (Please describe: \_\_\_\_\_)
  - Have not used these services or supports

---

## **SOME INFORMATION ABOUT YOU**

10. In which county do you currently live?
- Kent
  - Newcastle
  - Sussex
11. What is your age group?
- 25-34
  - 35-44
  - 45-54
  - 55-64
  - 65-74
  - 75 +
  - Prefer not to answer

12. What is your gender identity?
- Female
  - Male
  - Non-binary/third gender
  - Prefer to self-describe: \_\_\_\_\_
  - Prefer not to answer
13. Do you identify as LGBTQA?
- Yes
  - No
  - Prefer not to answer
14. Are you currently employed?
- Yes
  - No
  - Prefer not to answer
- 14a. [If yes] How many hours do you work per week?
- 40 or more hours per week
  - Less than 40 hours per week
15. What was your household's income before taxes from all family members and all sources in 2020?
- Less than \$16,000,
  - \$16,000 to under \$25,000
  - \$25,000 to under \$40,000
  - \$40,000 to under \$60,000
  - \$60,000 to under \$80,000
  - \$80,000 to under \$100,000
  - \$100,000 to under \$150,000
  - \$150,000 or higher
  - Don't know
  - Prefer not to answer
16. Is there anything else you would like to tell us about you or your care recipient? (Please describe.)

17. Who gave you information about the focus group and suggested you sign up? (Check all that apply.)

- Someone from Division of Aging and Adults with Physical Disabilities (DSAAPD)
- Someone from AARP
- Someone from Easter Seals
- Someone from a Caregiver Resource Center
- A case manager or social worker
- Someone else (Please specify \_\_\_\_\_)

Now we need some information about which \$35 gift card you would like and the way you want to receive it. Please note, if you do not participate in the focus group you will not be eligible to receive the \$35 gift card.

Please indicate which type of gift card you would like as a thanks for participating in the focus group.

- Amazon
- Walmart
- Wawa

How would you like to receive your gift card? *Please note:* Electronic gift cards can be sent to you with a few days of completing the focus group. Gift cards sent in the US Mail could take several weeks to arrive. If selected, Wawa gift cards sent via US Mail will be delivered as one \$10 and one \$25 gift card.

- Electronically via email —→ Please add your email address here

Email

- Via US Mail —→ Please add your mailing address here

Address

City/State/Zip

[if 'Via US Mail'] Would you prefer:

- Regular US Mail
  
- Certified US Mail (requires you to be present at the mailing address listed above and provide your signature when it arrives)

# Appendix F: Focus group protocol

## Delaware DAASPD: Caregiver Study

### *Focus Group Protocol*

Welcome. Thank you for joining us. My name is \_\_\_\_\_ and this is [name]. We are on the research team at Wilder Research in St. Paul, Minnesota.

For this study we are partnering with the Division of Aging and Adults with Physical Disabilities at the Delaware Department of Health and Social Services. Wilder Research has been around for over 100 years, and is one of the nation's largest nonprofit research and evaluation groups dedicated to the field of human services. Our team has expertise in working with caregivers in the community to understand their experiences and share that information with program and policy makers to help better support caregiving efforts. We are using these focus group formats to hear directly from caregivers.

Informal/unpaid caregivers have been called the “backbone of long term care.” AARP reported in 2019 that 41 million informal caregivers provided an estimate of 34 billion hours of unpaid care. As caregivers spend their time meeting the needs of the person they are caring for, they often have to put their own needs second or third or even lower on the list in order to meet the basic needs of their care recipients. It can be rewarding work, but we also know it can be stressful and difficult. Delaware DSAAPD wants more information about how to support caregivers like all of you.

The primary focus of our questions today is:

**What do unpaid caregivers need to be effective and supported in their role? And are the services available to caregivers today a good match for the needs that you have?** You will probably hear me state these questions in several different ways during our discussion today.

As a focus group participant, you should think of yourself as a kind of expert witness. You know things that people who have not been caregivers simply don't know because they have not walked in the same shoes or down the same path you have walked.

We would like you to offer your thoughts and guidance to us and to the leaders of the Delaware Department of Human and Social Services about how—and in what ways—they can best provide support to the people who are caring for their family members or friends. Before we start our discussion, I want to let you know a few things:

- First, we are using this information for research purposes only. We are hosting a number of focus groups as part of this project, and when we write our report we do it in such a way that no participants are referred to by name, or in any other way that would identify you. Please be assured that your comments today will be kept confidential.

- Second, we want to hear what everyone thinks. Sometimes, you might have an idea that is very different from another person’s idea. That’s O.K. We are here to listen to what everyone has to say. We only ask that you please wait to share your comments until someone has finished talking. I will make every effort to be sure that we hear from everyone, even those of you who might feel a little shy. But not everybody will answer every question. Because our time is so short today, I may also keep the conversation moving so that we can get to all the questions.
- Third, as you have heard, you will receive a \$35 gift card for participating in the focus group. When you completed the online survey before this group, you provided us with your name and contact information so that we can send the gift card to you (electronic or regular/certified mail) and you also let us know what kind of \$35 gift card you wanted (Amazon, Walmart, Wawa). You will receive the gift cards in the next couple of weeks.
- [Notetaker] will be taking notes while we’re talking; because they may not type as fast as you can talk, we would also like to audio record this discussion so that we don’t miss any opinions that are shared. Is that O.K. with everyone here?
- Finally, I want to mention a few special things to consider since we are having this discussion virtually.
  - With virtual groups it may be difficult to know if someone wants to speak. Please use the “raised hand” icon feature or simply raise your hand if you want to speak. If you agree with someone speaking, you may use one of the reactions buttons like the “clapping hand” or “thumbs up” rather than nodding or gesturing so the note taker may capture that.
  - We encourage everyone to keep their video on for this discussion, since it helps us know who is talking. If you feel more comfortable or are having technology issues you should feel free to turn your video off.
  - Please stay muted until you are ready to speak; this will block out any background noise.
  - Lastly, please only use the chat function if you want to share a question or comment privately with the facilitators.

(START AUDIO RECORDING IF IT IS OK WITH EVERYONE).

So, let’s start with very brief introductions. [Show intro slide] Please share with us:

- Your first name
- Who you provide care to (a parent? a spouse?); and
- How long you’ve been a caregiver to that person

*[Note: Facilitators were alert for comments related to race, identification as LGBTQA, less urban counties, and probed as appropriate. See questions at the end of the protocol.]*

Our first questions are about the help you may receive for the caregiving you do.

1. Do you receive any help with caregiving from other family members or friends?  
*(Show of hands)*
2. Do you receive any help with caregiving from sources other than your family or friends right now? I'm mainly thinking of professionals, organizations, or others that might be involved. Sources of assistance may include things like counseling, coaching, support groups, individual and group training, in home and out of home respite, home modifications, homemaker, chore and transportation help, assistance in accessing services, and telephone reassurance.
  - a. If participants say "yes," follow-up probes include:
    - Who provides that assistance?
    - How did you find out about that? (What are your sources for information?)
    - How is that working for you? (Is it helpful?)
  - b. If participants say "no," follow-up probes include:
    - Do you feel you need or want outside assistance?
    - Have you heard about services that could help you/caregivers? (If yes, where?)
3. Sometimes caregivers are also reluctant to use outside supports, even when they are available. Has this ever been true for you?
  - a. What keeps you from using outside assistance?
  - b. What do you think might make you want to use these services?  
*Probe: What should be changed or different so you would want to use them? How could they be delivered differently?*
4. Are there any services or supports you have tried to use, but couldn't or stopped using because they were difficult to access or they weren't helpful?  
*Probe: What services were those? Why did you stop using them or not use them at all?*
5. Are there any services you know you need but are unable to find? *Probe: What are they? What do you do when you cannot get the help you need?*
6. Of all the help you receive (both from family or friends and outside organizations), what would you say is the most helpful to you? *Probe: Why is it the most helpful to you?*

7. Now I would like you to get creative. Imagine if Melissa Smith, the head of the Division of Aging and Adults with Physical Disabilities, gave you about a million dollars to spread around to help caregivers, how would you use the money to ensure that caregivers are supported?
- What services will caregivers use that will make it more likely that they can stick to the job and not wear down their own health while caring for someone?
  - What would make YOU want to use one of these services?
  - How would you ensure that caregivers who need the services know about them and can access them?

**Additional questions related to culturally specific groups or other identifiers**

*[Note: These questions were included in the group discussions, as relevant and appropriate.]*

We understand that inequalities that stem from [race/gender or sexual identity/urban vs. rural location] characteristics may have a significant effect on the experiences of caregivers, especially in finding and using services that may support them in their role. These next questions are related to those unique experiences.

Do you think that your **race/ethnicity** affects your access to services and supports as a caregiver?

*Probe: In what ways?*

*Probe: How has that lack of access affected you as a caregiver?*

*Probe: What do you think should be done to change that?*

Do you think that your **gender or sexual identity** affects your access to services and supports as a caregiver?

*Probe: In what ways?*

*Probe: How has that lack of access affected you as a caregiver?*

*Probe: What do you think should be done to change that?*

Are there special issues that affect your access to services and supports as a caregiver that are related to your more **rural location/living in Kent or Sussex counties**?

*Probe: What are those issues?*

*Probe: How has that lack of access affected you as a caregiver?*

*Probe: What do you think should be done to change that?*

**Conclusion:**

That was the last question of our discussion today.

Is there anything else you would like us to know before ending? Also if you think of anything else after we are done here, please feel free to send an email to us. *[Share email address]*

Keep your eyes open for your \$35 gift card, which you should receive soon [depending on via email or US mail] in the next couple weeks.

Thank you all so much for sharing your experiences with us today!



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