



Office for
the Aging

Caregiver Focus Group Report

2021



2021 Caregiver Focus Group Highlights and Summary

Executive Summary

Utilizing a focus group model, NYSOFA and partners gathered input and recommendations from caregivers on ways to better serve their needs and connect them to services through enhancements and expansion of caregiver-directed respite service delivery models. The following is a summary of this input process, corresponding research, and key recommendations for developing a flexible model of caregiver-directed respite.

Background

Caregivers help their loved ones remain independent and live meaningful lives by providing vital assistance to the care receiver to meet a wide range of needs. Responsibilities can include personal, financial, medical, legal, emotional, social supports, and everyday activities of daily living. While they can feel positive effects from taking care of their loved ones, caregivers often feel highly strained, overwhelmed, and are at a much higher risk for chronic loneliness and adverse health effects than the non-

caregiving population. Most family caregivers receive little instruction or support. Oftentimes caregivers may recognize the need for respite care or legal help, but they might not know services are available to them or how to obtain the services (Office for the Aging, n.d.). Caregiving is becoming increasingly more complex and caregivers have reported an increased difficulty in coordinating care (AARP Public Policy Institute, 2020). Additionally, more caregivers report they are now providing care for more than one person at a time (AARP Public Policy Institute, 2020). The population of family caregivers will continue to grow, and they need assistance to address their needs.

In 2020, there were an estimated 53 million caregivers in the United States, an increase from 43.5 million in 2015 (AARP Public Policy Institute, 2020). This means that today, more than one in five people in the United States are caregivers (AARP Public Policy Institute, 2020). In the next two years, 20.1% of non-caregivers can expect to become a caregiver (CDC, 2018). In New York State's population of more than 20.2 million people, around 4.1 million are informal caregivers (Office for the Aging, n.d.; US Census Bureau, 2021). Many caregivers do not self-identify as a caregiver, which leads to an underestimation of the true number of caregivers. If caregivers do not self-identify, they likely will not access the benefits or services they may need or may be eligible for. Family caregivers provide approximately 80 percent of all long term services and supports (LTSS) while balancing work, care, and other responsibilities (Reinhard et al., 2019). In New York State, this equates to an estimated 2.1 billion hours of unpaid care, which is valued at \$31 billion (Reinhard et al., 2019).

While many caregivers feel their role has given them a sense of purpose or meaning, these positive emotions often coexist with feelings of stress or strain (physical, emotional, and financial) (AARP Public Policy Institute, 2020). One out of five caregivers self-rate their health as fair or poor, an increase from 2015 (AARP Public Policy Institute, 2020). One in four caregivers felt alone in caregiving, and 36 percent report having high emotional stress. Loneliness and high levels of stress can lead to adverse health effects which has further implications on caregiving. Almost 37 percent of caregivers age forty-five or older report having two or more chronic diseases (CDC, 2018). As highlighted in the 2021 Alzheimer's Disease Facts and Figures Report, over half of caregivers in New York State who are caring for an individual with dementia report having a chronic condition and many report feeling depressed and being in poor physical health (Alzheimer's Association, 2021).

Along with physical health, the stresses of caregiving can affect caregivers' mental health substantially. It has been reported that 6 percent of the general population use substances to cope, while 33 percent of caregivers use substances to cope (*Help For Working Caregivers* | Office for the Aging, n.d.). Around 3 percent of the general population has contemplated suicide while 31 percent of caregivers have contemplated suicide (*Help For Working Caregivers* | Office for the Aging, n.d.). The economic effects of family caregiving can result in financial strain. One in five caregivers report having high financial strain as a result of their caregiving role (AARP Public Policy Institute, 2020).

These statistics show how caregiving can be extremely stressful and can lead to a decline in the caregiver's mental health.

How Respite Can Help

Everyone needs a break sometimes, especially caregivers. Caregivers are constantly care planning for the care receiver and are trying to meet their various needs. As a result, caregivers may neglect their own needs simply due to the lack of time. Caregiving takes a lot of time and energy. Caregivers are often busy with work, other family members, other responsibilities, or even their own health issues. Respite allows for caregivers to take a much-needed break to be able to care for themselves. Caregivers can use respite care to attend a doctor's appointment, visit with friends or family, shop, get a haircut, exercise, take a vacation, etc. Respite care provides caregivers with a short-term break to de-stress from their caregiving responsibilities and meet their own needs. If caregivers can take a break, their stress levels will decrease, resulting in better health outcomes (Mariotti, 2015; Zarit et al., 2017). When family caregivers are well supported, data show that receivers of their care are able to stay in their homes longer and can have a better quality of life (Mittelman et al., 2006).

The National Family Caregiver Support Program (NFCSP)

The National Family Caregiver Support Program (NFCSP) was established in 2000 to fund support programs to assist informal caregivers in caring for their loved ones (*Section 373 of the Older Americans Act of 1965, as amended, Title III-E*). The New York State Office for the Aging (NYSOFA) administers the program through its fifty-nine Area Agencies on Aging (AAAs). The AAAs must establish and operate a caregiver support program that meets the needs of the caregiver, enhances the supports given to the care receiver, helps the caregiver become a better advocate and more confident in assisting the care receiver with their needs, deters placement in a long-term care facility, and promotes continuing care within the home and/or alternative community settings for as long as possible. The program also helps provide support to older relatives who are caregivers for children or individuals with disabilities, if desired.

The intent of the NFCSP is to focus on and provide support to the caregiver, which in turn supports the care receiver. The caregiver-directed service delivery model provides consumers (the caregiver) and the care receiver with more control and choice in the delivery of the care they receive. Expanding the caregiver-directed respite model under the NFCSP will offer caregivers and their care receivers greater flexibility, with a person-centered approach. Under this model, the caregiver is the consumer. The caregiver will be able to recruit, hire, schedule, supervise, train, and dismiss the in-home provider/service worker of their choice to provide supports to their loved ones for respite services. The caregiver will be able to choose when respite will be provided, and the setting that will best meet their needs.

Caregiver-Directed Respite under the NFCSP

As stated earlier, the purpose of this report is to provide an overview and rationale when considering expansion of the caregiver (consumer)-directed respite model under the NFCSP. Currently, under the caregiver-directed model, Title III-E funds are only allowed to be used to provide in-home respite services, and to date, twenty AAAs have implemented caregiver-directed respite under the NFCSP. Other forms of non-caregiver directed respite are allowable under the NFCSP and caregivers benefit when there are options and flexibility to meet their respite care needs. The caregiver-directed in-home respite option, while important as a service delivery model, does not currently offer flexibility and choice to help meet the unique needs and preferences of caregivers who may want to direct their own respite services.

Representatives from NYSOFA and the New York State Caregiving and Respite Coalition (NYSCRC) have explored other states' caregiver-directed respite models and have consulted AAAs and State Respite Programs on what the expanded caregiver-directed respite model under the NFCSP should include. Additionally, the needs and preferences of informal caregivers were identified through a series of focus groups hosted by NYSOFA and the Westchester County Department for Senior Programs and Services. The data collected from these focus groups will be used to help inform decisions when considering the expansion of the NFCSP caregiver-directed respite model.

Caregiver Focus Groups

Methodology

NYSOFA developed a comprehensive workgroup that met from January 2021 to August 2021 and included representatives from AAAs, State Respite Programs, NYSCRC, and NYSOFA to discuss what other states are doing regarding the caregiver-directed model, and to gather new ideas. During one of these meetings, it was proposed to involve caregivers in the planning process to ensure their needs and preferences were being considered. The intent of the caregiver focus groups was to identify what would be helpful for caregivers, so that the expanded model will meet their unique needs and preferences.

A flyer (see Appendix A) was created by NYSOFA to distribute throughout New York State to recruit caregivers to participate in the focus group. The flyer was shared statewide via social media and e-mail.

The focus group meetings were facilitated by Colette Phipps, Director of Program Development at Westchester County Department of Senior Programs and Services. Ms. Phipps was chosen to facilitate the focus groups as she holds credentials for facilitation and has expertise in working with caregivers. The focus groups were held via Zoom on June 29 and June 30, 2021. At the start of the meetings, a script (Appendix B) was read

to the caregivers thanking them for their time and emphasizing the importance of their opinions. Caregivers were provided a glossary of terms and acronyms (Appendix C) to reference. The caregivers were asked seven questions to elicit their opinions (Appendix D).

Data Collection

Data was collected verbally during the Zoom meetings. The focus groups had eighteen participants in total. Participants were asked a question and they verbally responded while a scribe recorded their answer. The focus groups were also recorded.

Participant Demographics

Caregiver demographic data was collected directly from participants. Participants were from the following counties in New York State; Chautauqua (1); Madison (2); Onondaga (1); Orange (1); Rockland (1); and Westchester (12).

The following demographic information represents the 18 focus group participants.



GENDER
83% are female



RACE
89% are white
6% are asian
5% are black



EDUCATION
78% are college educated
High school 11%
Some college 5%
PhD 6%



EMPLOYMENT
44% are not employed
Employed 17%
Retired 11%
Full-time 11%
Part-time 11%
Consumer Directed Participant 6%



DIAGNOSIS
42% of care receivers have Alzheimer's disease or other dementia (the most common diagnosis)

Table 1. Who the Caregivers Care For

Relationship	N	(%)
Mother	10	(53)
Father	2	(11)
Sibling	2	(11)
Husband	1	(5)
Uncle	1	(5)
Wife	1	(5)
Unknown	1	(5)
Total	18	(100)

Table 2. Main Diagnosis Cared For

Disease	N	(%)
Alzheimer's Disease/ Other Dementia	8	(42)
Parkinson's Disease	1	(5)
Stroke	1	(5)
Uncommon Neuropathy & Cognitive Decline	1	(5)
Unknown	8	(42)
Total	19*	(100)

*One individual has two diagnoses



Interview Questions & Key Findings

1. Which of the following respite types do you prefer? In Home Respite, Out of Home Respite (day), Out of Home Respite (overnight), Other Respite, Voucher System.

- Caregivers indicated different preferences for the different types of respite, and said they are all great options.
- Caregivers also indicated they would favor a respite voucher model.
- Many caregivers noted that they would like to be able to switch among the different options to meet their needs.

2. Once services are rendered, should the family caregiver be responsible for paying the respite provider and then be reimbursed, or should the respite provider be paid directly?

- None of the caregivers want to be responsible for payment and then be reimbursed. Caregivers do not want an additional responsibility of payment up front in addition to their caregiving responsibilities.
- Caregivers prefer the care provider be paid directly, but they want confirmation the payment has been received by the provider.

3. Based on your answer to the previous question, do you feel that a formal agreement with individual respite providers (family, friends, etc.) is necessary?

- All caregivers agreed a formal agreement is necessary.
- Caregivers want the respite care provider to understand the needs and expectations for care. There is no one-size-fits-all approach to caregiving and respite care.
- An agreement on paper is a good starting point, to then be reinforced with a verbal conversation.

4. Would you like training provided for the respite providers that you intend to use?

- Caregivers responded training is necessary. Some would like to provide their own training, as they stated they know what is best for their loved one. Some stated an online training option would be beneficial.
- Concerns were raised regarding who would do the training, what kind of platform it would be delivered through, and if the information would be specific enough based on diagnosis.

5. New York is considering creating a standardized name for its caregiver directed respite program. Do any of these program names resonate with you? (A list of the proposed program names can be found in Appendix B).

- Many caregivers preferred the name “Care for the Caregiver.” Some liked “Caregiver Relief Program” or “Caregiver Relief.”
- Participants favor a short name and names with “caregiver” and “respite” in them as it is descriptive of the program intent and easy to remember.

6. How were you first made aware of caregiver supports?

- Each caregiver described a different path for how they came to find caregiver supports. Some caregivers responded they did not know about the AAA and their resources.
- Multiple caregivers responded they learned about caregiver supports through an AAA caregiver class, or the Alzheimer’s Association.
- Others stated independent research on the internet, through family experience, a caregiver support group, senior center, a newsletter, or from an email through a local municipality.
- Some caregivers shared frustrations that they were not aware of caregiver supports and did not think the AAA was a resource for them since they are not an older adult. One stated, “There needs to be more information in general because for younger people, we just don’t know about it. We don’t know that these resources are available.”

7. Do you think if New York State had a different infrastructure with regionally named caregiver centers, information and resources would be more accessible? Would this be better?

- Caregivers agreed that a physical center would be extremely helpful. Caregivers described challenges they faced not knowing that services and supports for caregivers exist and having trouble navigating the complex systems to find supports.
- Some mentioned that over-the-phone resources or online resources would be good options in addition.
- Some caregivers stated they think it would be great if doctors could refer their patients and caregivers to a caregiver center for additional information and resources.

Issues and Concerns Raised by Caregivers

- Respite is very expensive and there is a lack of facilities and staff available to provide respite. Even with grants, it is expensive. If caregivers want to take a vacation they need to pay for their vacation as well as respite, and it can be quite expensive.
- Finding information about respite is not user friendly.
- Day programs that caregivers used prior to the COVID-19 public health emergency have been closed and not reopened.
- Care providers might be hesitant to sign a formal contract, but it is important because sometimes care providers might not have the necessary skills needed, or they are not prepared for the situation they are walking into.
- Some caregivers do not have faith in formal training, partly due to some specialized need (dementia/Alzheimer's disease).
- Some informal care providers (other family, friends) may be resistant to mandatory training.
- Some caregivers fear being judged by doctors and being told they are an inadequate support for their loved one.
- One caregiver stated they feel the current system is based on finances and makes some caregivers feel like a "dollar figure."

Other Recommendations Raised by Caregivers

- Alzheimer's Disease and dementia material should be part of the respite provider training, with a positive approach.
- Resources for caregivers should be given by doctors when a diagnosis is made.
- Discharge planners at hospitals should have information to provide upon discharge.

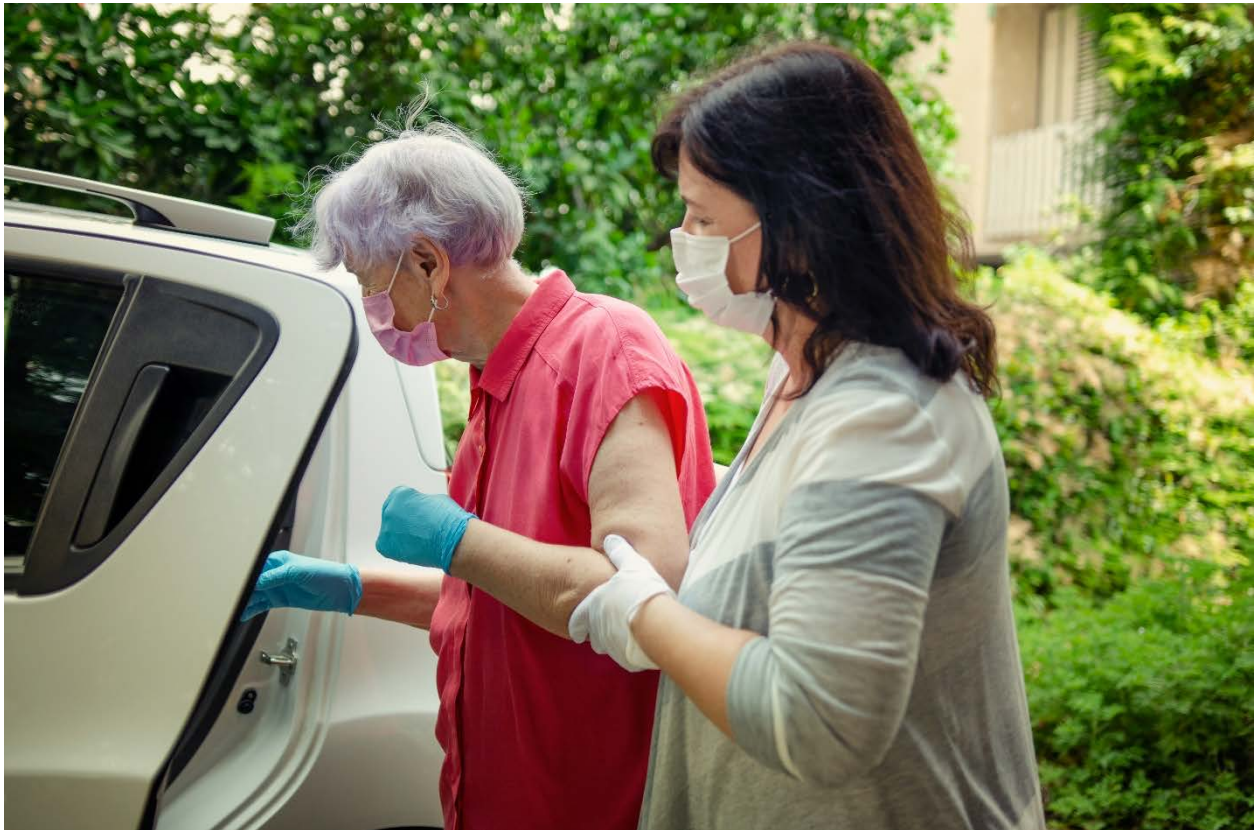
- Respite and caregiver resources need to be more widespread because younger caregivers are unaware of resources available.
- If regional caregiver centers were to exist, doctors and other health care professionals should be trained to refer caregivers to these centers.

Caregiver-Directed Respite Program Recommendations

1. Allow freedom of choice regarding when (day/night) to use **respite services** and where respite will be provided. Caregivers have different preferences and needs for when they would use respite services. It is beneficial to provide the freedom to choose, so more caregivers can use the services.
2. The care provider should be **paid** directly by the agency, bypassing the family caregiver. The family caregiver should receive a confirmation that payment was received by the provider. Caregivers already have a lot of responsibilities and stress from their caregiving duties. They should not have to worry about paying the provider up front for the care. Some caregivers might not have the funds to be able to do this. By not having to provide payment up front, this will allow more caregivers to access the services.
3. Create a **formal agreement** for the respite provider to be responsible for and sign. Respite providers should know exactly what is expected of them. Caregivers would feel better knowing that the provider understands and agrees to the caregivers' expectations.
4. **Training** should be mandatory for respite care providers. If caregivers are going to take a break and truly relax, they need to feel confident that the person caring for their loved one has the skillset to do so. Caregivers would be able to take a break and better their own health if they know the provider is properly trained.
5. The **program name** should include the words "caregiver" and/or "respite" and be short. Caregivers are often unaware that there are resources specifically for them. The program name should make this clear.
6. Disseminate information regarding **caregiver supports** to as many outlets as possible to reach a range of caregivers. Caregivers are typically unaware there are supports specifically for them. The more widespread this information is disseminated, the more caregivers the information will reach, and thus more caregivers will partake in the services.
7. Create a physical regional caregiver information and **resource center**. Caregiving is already overwhelming for many caregivers. Many do not know what services are available or know what to look for when trying to find services. Having a physical location to visit or call will help the caregivers find resources.

Conclusion

Informal caregivers provide 80 percent of LTSS, allowing their loved ones to stay at home, which decreases health care costs systematically. In New York State alone, informal caregivers provide 2.1 billion hours of unpaid care, valued at \$31 billion (Reinhard et al., 2019). Caregivers need to be supported in their care for themselves and be healthy in order to provide care for their loved ones. There is no one-size-fits-all approach to caregiving and the respite services to support the caregiver. To meet the needs of caregivers and care receivers, caregiver supports must be flexible and include a variety of locations for respite service delivery.



Resources

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APPENDIX A

Caregiver Focus Group Flyer

CAREGIVER FOCUS GROUPS



Are you a caregiver who needs a break (respite)? Would you like to choose who provides care for your loved one?

If the answer is YES, we would like to speak with you!

The New York State Office for the Aging (NYSOFA), New York State Caregiving and Respite Coalition (NYSCRC) and the Westchester County Department of Senior Programs and Services will be hosting caregiver focus groups to gain a better understanding of your wants and needs as a caregiver to be able to self-direct the respite care provided to you and your loved one. This will be a great opportunity to provide us with your thoughts on how we can best expand our self-directed respite program to better serve you, the caregiver!

DATES: Tuesday, June 29th (virtual via Zoom),
Wednesday, June 30th (virtual via Zoom), **and**
Thursday, July 1st (telephonic)

TIME: All focus groups will be held from
10:00AM—11:30AM

Self-directed care, or caregiver-directed care, means that the caregiver can choose the type of respite care provided, the provider of the respite care, and when the respite care takes place.

If you are interested in attending a focus group, please contact Colette Phipps at (914) 813-6441 or cap2@westchestergov.com

All participants will receive a \$25 Visa gift card!

APPENDIX B

Caregiver Focus Group Script

“Thank you for your participation in this focus group discussion on respite care. Your input is important to us. We will be asking you 6 questions about how you feel about respite care as it relates to caregiving.

The National Institute on Aging defines respite care as a provision of short-term relief for primary caregivers. It can be arranged for just an afternoon or for several days or weeks. Care can be provided at home, in a healthcare facility, or at an adult day center.

We will be discussing various types of respite programs and the proposed protocols that are associated with them. To clarify some of the terms that will be used please refer to the list of terms sheet previously provided to you.

We want you to feel comfortable during this experience. Do not be concerned about right or wrong answers, it is your opinion that matters most to us. As caregivers you know first-hand the significant impact caregiving has had on your life. We are seeking to support you on your journey by developing a user-friendly respite program. Thank you for helping us to do that.”

APPENDIX C

2021 Caregiver Focus Groups

Glossary of Relevant Terms & Acronyms

Acronyms

AAA – Area Agency on Aging

CD – Caregiver (Consumer) Directed

NFCSP – National Family Caregiver Support Program (also referred to as Title III-E)

NYSCRC – New York State Caregiving and Respite Coalition

NYSOFA – New York State Office for the Aging

OAA – Older Americans Act

Definitions

- ❖ **Caregiver:** An adult family member, or another individual, who is an informal provider of in-home and community care to an older individual or to an individual with Alzheimer’s disease or a related disorder with neurological and organic brain dysfunction. (Source: OAA)

- ❖ **Caregiver (Consumer)-Directed Care:** An approach to providing services (including programs, benefits, supports, and technology) intended to assist a caregiver and their care receiver with activities of daily living, in which such services (including the amount, duration, scope, provider, and location of such services) are planned, budgeted, and purchased under the direction and control of such individual. Also referred to as “participant-directed” or “self-directed.”

- ❖ **Respite Care:** Services that offer temporary, substitute supports or living arrangements for care recipients in the home or outside of the home, in order to provide a brief period of relief or rest for caregivers.

- ❖ **Respite Voucher:** A monetary amount that is awarded to families/caregivers that can be redeemed to receive respite services during a specified time period. The family/caregiver is either reimbursed the awarded amount after they have received respite services, or their chosen respite provider is paid directly by the awarding agency for services rendered.
 - “Vouchers offer families greater flexibility to use respite when they really need it and allow them to hire friends and family members who are familiar with the individual with the disability or special need.” – Access to Respite Care and Help (ARCH) National Respite Network & Resource Center, 2011

APPENDIX D

Caregiver Focus Group Questions

1. Which of the following respite types do you prefer? In Home Respite, Out of Home Respite (day), Out of Home Respite (overnight), Other Respite, Voucher System.
2. Once services are rendered, should the family caregiver be responsible for paying the respite provider and then be reimbursed, or should the respite provider be paid directly?
3. Based on your answer to the previous question, do you feel that a formal agreement with individual respite providers (family, friends, etc.) is necessary?
4. Would you like training provided for the respite providers that you intend to use?
5. New York is considering creating a standardized name for its caregiver-directed respite program. Do any of these program names/ideas resonate with you? And/or do you have any other name ideas for consideration?
 - Brief Relief for Caregivers
 - Timeout for Caregivers
 - Select-It Respite
 - Request-It Respite
 - Break for Caregivers
 - Respite Refresh
 - Respite R & R
 - Caregiver Relief Program
 - Care for the Caregiver
6. How were you first made aware of caregiver supports?
7. Do you think if New York State had a different infrastructure with regionally named caregiver centers, information and resources be more accessible? Would this be better?

Notes



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