

Exhale Overview and Individual Project Summaries June 5, 2023

Program Overview

Recognizing the critical role family caregivers play in the lives of older adults, and the need for caregiver respite, the Ralph C. Wilson, Jr. Foundation, Health Foundation for Western and Central New York, and Ann Arbor Area Community Foundation partnered with The Philanthropic Initiative to create and implement *Exhale, The Family Caregiver Initiative* (Exhale). The goal of Exhale is to increase respite opportunities for family caregivers of older adults. Exhale works toward this goal by supporting the development and implementation of innovative respite activities in communities.

Caregiving, though commonly emotionally rewarding, is associated with physical, emotional, and financial hardship, as well as higher rates of depression, anxiety, emotional difficulties, and chronic disease. Respite can reduce the negative consequences of caregiving. In Exhale, organizations learn and apply Creative Problem-Solving techniques and work together to increase local access to respite services that are caregiver informed, partnership and community based. A description of each of the 16 Exhale respite projects is summarized below.

Exhale Cohort #1 Project Summaries: Three western New York programs launched in 2020

Ardent Solutions - Forever Young

Forever Young is a collaboration between Ardent Solutions, Inc., the Genesee Valley Central School District (GVCS), the Wellsville School District, and the Allegany County Office for the Aging. Forever Young utilizes school system resources to provide educational and social programming with the goal of establishing connections between community youth and older adults to benefit both age groups and to offer respite to family caregivers of older adults. Caregivers may choose to participate in school activities or drop their loved one off for time away to take a break. Feedback from caregivers and older adult participants in Forever Young has been highly positive. Data also suggests that once participants join Forever Young, they return again and again. For more information, contact Carrie Whitwood at whitwoodc@ardentnetwork.org.

Healthy Community Alliance – Caregiver Tech Solutions

Caregiver Tech Solutions, a collaboration between Health Community Alliance, Total Senior Care PACE, three local Offices for the Aging (Cattaraugus, Wyoming, Chautauqua), and other local partners, uses individualized coaching and technology resources to provide respite to caregivers using a model that emphasizes flexibility to address what matters most to participants. The program focuses on how digital and physical technology can be used to help caregivers remotely achieve a sense of relief (respite), learn self-care techniques, and solve new problems in caregiving. The program includes distributing and setting-up free technology solutions to caregivers to achieve respite.

In its first year, Caregiver Tech Solutions showed positive outcomes when comparing pre- and post-caregiver assessments and results of the Caregiver Intensity Index (CII), including reduced mean CII scores, an increased sense of support, and more frequent respite experiences. Findings included statistically significant decreases in overall caregiver burden, stress, family disagreement, and statistically significant increase in reported "more time for me" among participants. HCA is exploring broader WNY and statewide partnerships for expansion and long-term sustainability of Caregiver Tech Solutions. For more information, contact Ann Battaglia at abattaglia@hcanetwork.org.

West Falls Center for the Arts - Musical Memories Cafe

Musical Memories Café (MMC) uses music, meal service, and supportive services to engage individuals with dementia and their caregivers in activities that offer entertainment, social support, and respite. Grant funding and other services provided through Exhale are facilitating expansion and replication of the model in other western New York communities, as well as the development of infrastructure (e.g., website and tools) to support that expansion and sustainability through a potential mix of funding sources. West Falls Center for the Arts provides technical support and online training with videos and tutorials on how to implement and sustain the program (https://www.musicalmemoriescafe.org/). West Falls reports very high levels of engagement at both the original and replication MMC sites, as well as positive caregiver outcomes, including stress reduction and a sense of emotional support. For example:

- 88% of participating caregivers said MMC helped reduce stress associated with caregiving
- 95% felt emotionally supported
- 84% said that MMC helped them to be a better caregiver
- 96% said that MMC is beneficial to the wellbeing of their caree
- 74% said they are better informed because of MMC
- 61% said MMC helped them find community resources to help with caregiving

For more information, contact Carolyn Panzica at carolynpanzica@icloud.com.

In the past 18 months, these three Exhale projects provided over 1,200 respite sessions to 1,500 caregivers, offering more than 4,500 hours of caregiver respite while also (at the same time) serving nearly 1,500 older adults. All three work with partner organizations (including Offices for the Aging) to obtain referrals. Geographic expansion is also underway: HCA added Chautauqua County to its target market in 2022; Forever Young now operates in two Allegany County school systems; and West Falls Center for the Arts has successfully attracted replication partners (licensees) that are adopting the MMC model, including Amherst Senior Center, the Dale Association, and Canopy of Neighbors/Temple Beth Zion. All four MMC sites report growing enrollment, and most are operating at capacity.

Exhale's impact on caregivers:

- "With the cameras installed, it was the first time I didn't feel anxious and worried about leaving my mom while I went to Roswell Park for my own treatment, as I was able to check-in on her."

 (Caregiver Tech Solutions)
- "My husband has a lot of bad days with his pain, but the iPad keeps him busy with different games and reading the news. I'm also grateful that I can go grocery shopping for an hour and keep an eye on my husband with the indoor camera installed now." (Caregiver Tech Solutions)
- "[My husband and I] started going to Musical Memories Café...And it was just the best thing that ever happened to us, because the musicians were just fabulous. They played feel-good music. Everybody joined in when there was singing, and especially the people with Alzheimer's that were really inclined –you know, they couldn't sit still in their seats they would get up, they would be

clapping, and they would be encouraged to get up and dance... I can't say enough about how they touch your soul. And the caregivers just – that hour seems like a three-day weekend."

Exhale Cohort 2 Project Summaries: 10 programs in western New York and 3 in Washtenaw County, Michigan (launched in 2022)

Exhale Programs in Western New York

Alzheimer's Association of Western New York – Virtual Inclusive Technology for Alzheimer's Disease Caregivers (VITAIZWNY)

This project aims to improve caregiver well-being by formalizing and consolidating the delivery of virtual respite, engagement, support, and education free of charge and from any location using iN2L tablets and content. iN2L is the leading provider of person-centered content to the senior living market. Their tablets are designed with a simple, streamlined interface and are pre-loaded and automatically updated with applications, so users can access tailored content ranging from music, worship, and games to virtual support groups, 24/7 helpline, and educational programs provided through the Alzheimer's Association's existing program infrastructure. The iN2L tablets have many features, but the primary purpose is to provide users with a means of connection to the people and services they need, when they need it. During this project, the Association will distribute Wi-Fi and cellular enabled tablets (60 total) to caregivers located in each of the eight counties of western New York. Caregivers will be identified through county Office for the Aging case managers currently working with caregivers of people living with Alzheimer's Disease and dementia. Participating caregivers will receive a tablet and a one-year subscription for iN2L's services. Project partners include iN2L and western New York's eight county Offices for the Aging. For more information, contact Natalie Weil at nweil@alz.org.

American Cancer Society – Caring for Caregivers

This project is creating a central hub of information and resources to guide cancer patient caregivers to respite and support opportunities, while also promoting greater collaboration among local caregiver support organizations and cancer treatment centers throughout greater Rochester, New York. Through creation of a program website and Caregiving 101 curriculum, this project will address one of cancer caregivers' primary concerns: giving caregivers more time for themselves without requiring them to do additional work to find and plan activities. Project partners include the Breast Cancer Coalition of Rochester, Cancer Support Community of Rochester, the James P. Wilmot Cancer Institute, the Lipson Cancer Institute, Pluta Cancer Center, and Jewish Senior Living. Once demonstrated, this model has potential to spread throughout upstate New York and beyond through the American Cancer Society. For more information, contact Kim McMahon at kim.mcmahon@cancer.org.

Buffalo Federation of Neighborhood Centers – *Erie County Neighborhoods*Dual Caregiver/ Receiver Respite and Mystery Trips

This project for offers caregivers and receivers a variety of sites to access caregiver respite and life enrichment programs to assist caregivers in prioritizing their well-being, increase stability, and strengthen their use of support service networks in Buffalo and Erie County. Caregivers will be able to drop their loved ones off at collaborating senior centers and churches to engage in social activities. Caregivers will have up to four hours of free time to take a break from caregiving and spend time taking care of personal needs or business. Seasonal Mystery Trips will offer caregivers the opportunity to participate in full- or half-day outings to area attractions while their loved one is cared

for at our trusted locations. Project partners include Buffalo Federation of Neighborhood Centers – Westminster Community House, Seneca Babcock Community Association, Inc. at Schiller Park Senior Center, Compeer at Sanders Road Community Center, Erie County Department of Senior Services, and Hearts and Hands. For more information, contact Daysi Ball at dball@bfnc.org.

Catholic Health Continuing & Home Care Foundation – Weekend Respite Program for Family Caregivers of Older Adults

This program provides respite care on Saturdays from 10am to 2pm at LIFE/PACE Day Center at Villa Maria in Cheektowaga, New York. Having respite available during weekend hours allows caregivers time to complete tasks they may not be able to complete during workday business hours, such as errands, house cleaning, self-care, or relaxation activities. Older adults who are not independently mobile or need help with toileting are welcome to attend. Participants may utilize transportation available through Catholic Health to attend the Weekend Respite Program. During the respite service hours, caregivers will have the opportunity to meet with Catholic Health LIFE/PACE staff on-site, attend a caregiver education session, or leave the facility to have time to themselves. A program coordinator will interface with caregivers to support their loved one's participation in the program and assist with needs the caregiver may have. Saturday respite will initially be offered once a month during year one of the program, increasing to twice a month in year two. Project partners include Catholic Health LIFE/PACE, Villa Maria College, several local Catholic Health health centers, Hamburg Adult Day Center, Hamburg United Methodist Church, Open Door at Orchard Park Presbyterian Church, and C&V Senior Care Specialists (offering on-site education sessions and support for caregivers). For more information, contact Kate Heidinger at kheidinger@chsbuffalo.org.

Cradle Beach, Inc. - Pathways for Caregivers Program

This program offers a four-hour, day respite program for caregivers and their loved ones at Cradle Beach's campus — a beautiful 66-acre camp-like setting on the shores of Lake Erie in Angola, Erie County, New York. Family caregivers can choose to remain at Cradle Beach's relaxing campus during respite hours or leave Cradle Beach to have time to themselves. During respite program hours, a caregiver support group will be offered, along with caregiver education and support services. Formal and informal transportation resources will be explored to increase caregiver access to the Cradle Beach campus. Project partners include Harmonia Collaborative Care and Lisa Rood, Consultant. For more information, contact Ann-Marie Orlowski at aorlowski@cradlebeach.org.

Healthy Alternatives through Healing Arts - Mobile Respite Care Program

This program offers healing arts mobile respite services to caregivers at a wide range of community settings throughout Buffalo and Erie County, New York. Healing arts services will include opportunities for caregivers to participate in classes or sessions offering yoga, QiGong, acupressure, meditation and mindfulness, Reiki, aromatherapy, and more — all stress reduction strategies designed to help caregivers relax, take a break, and learn how to reduce stress on their own, at any time. Practitioners affiliated with Healthy Alternatives through Healing Arts will bring their services and expertise to community settings, including other Exhale sites providing respite services so that caregivers can easily access the program and participate. Project partners include YMCA Buffalo Niagara, Cradle Beach, Inc., People Inc., and Clinical Healthcare Management Services. In addition, informal partnerships exist with many community centers and other settings where healing arts services can be made available to family caregivers and the public. For more information, contact Jill Ohara at healthyalternativeshaha@gmail.com

Lifespan of Greater Rochester, Inc. - Drop In Respite Program

A partnership of Lifespan, St. John Fisher University, and community organizations in a diverse, underserved inner-city neighborhood of southwest Rochester, this program aims to develop trained student respite service volunteers combined with community volunteers who will provide adult day drop-in respite care to older adults with staff from Lifespan. Through this collaborative model, caregivers can drop off their loved one at one of several community centers while they take a break, address personal needs or business. The project goal is to develop an incubator drop-in respite program for college students and community-based volunteers to engage in all activities related to respite intervention. Additionally, caregiver families will be able to access additional programming through community centers and connect with a plethora of caregiver services from Lifespan. A replicable toolkit will be developed for other colleges and universities to utilize in building their own respite drop-in programming. Project partners include Lifespan of Greater Rochester, St. John Fisher University, and multiple community organizations in southwest Rochester. For more information, contact Doris Green at DGreen@lifespan-roch.org.

St. John's Dementia Resource Center

This program will offer caregivers relief and support in several ways, including opportunities for adult day care drop off respite services, a spa and fitness facility, a pool, beauty salon services, and a resource library. At the Resource Center, caregivers will have access to a care manager and resource center coordinator who can help schedule activities, training programs for caregivers on caring for persons with dementia, opportunities to engage a loved one in an activity that both may be missing, such as concerts, games, spiritual services, and other supportive programming and events for caregivers. St. John's will partner with Lifespan of Greater Rochester for program and staffing support, as well as caregiver recruitment and outreach. The Dementia Resource Center will open in a new facility on the St. John's Home campus in 2024. A part-time Dementia Respite Program will be offered beginning July 2023. Caregivers and their older adult loved ones from throughout greater Rochester will be invited/welcome to visit St. John's Home and Dementia Resource Center on a drop-in basis. Project partners include St. John's Home and Lifespan of Greater Rochester, Inc. For more information, contact Anne McKenna at amckenna@stjohnsliving.org.

United Way of Orleans County – Caregivers Revitalize – Orleans and Genesee Counties

This program provides caregiver respite services initially at two locations at either end of Orleans County. In year one, three-hour drop off adult day care respite services will be available at Community Action of Orleans & Genesee (at Main Street Thrift Store in Albion, New York) and at Orleans County YMCA in Medina, New York. In year two, the program will expand into Genesee County. In year three, respite services will also be offered at Eastern Orleans Community Center in Holley, New York. Through this program, caregivers in Orleans County (and later in Genesee County) will be offered a place where they can safely drop off their loved one and utilize a period of three hours for personal time to take a break, relax, work out at the YMCA, conduct errands or personal business. Participating caregivers will be offered respite time/opportunities, community interaction, and wellness opportunities. Transportation vouchers will be available to caregivers and their loved ones to expand access to respite in these two rural counties. Project partners include United Way of Orleans County, Community Action of Orleans & Genesee, and Orleans County YMCA. For more information, contact Matt Holland at grants@orleansunitedway.org

YMCA Buffalo Niagara - enCOURAGE, Benefit for Both Program

This program is a companion-based, non-medical adult day respite program for older adults with earlymoderate dementia and their caregivers. The Y's Care Recipient Respite program is currently offered once a month, from 10:30am to 2:30pm at the Southtowns Family YMCA. In years two and three, a second day per month will be added. Caregivers who's loved ones participate in the Care Recipient Respite program will be able to stay onsite and use the YMCA fitness facilities or participate in caregiverfocused programming at the Y during the hours that their loved one is busy with the program. During this time, opportunities for caregivers will include access to the YMCA Wellness Center, indoor track, group exercise classes, indoor aquatics center, open gymnasium, as well as social activities such as card games, board games, and facilitated caregiver support conversations. Educational activities and caregiver support will also be available, such as case management consultations with staff from Erie County Dept. of Senior Services and Alzheimer's Association of Western New York. If caregivers prefer, they can leave the Y during respite hours to have time to do errands, take care of personal business, or relax on their own. Transportation support will be available (arranged by partner agency, Hearts and Hands). Childcare is also available at the Y for caregivers who might need it. YMCA's partners include Elder Transition Consulting, Hearts and Hands, 716 Fresh LLC, Lisa Rood (Consultant), Erie County Dept. of Senior Services, Alzheimer's Association of Western New York, and Harmonia Collaborative. For more information, contact Jilyana Baumgarden at jbaumgarden@ymcabn.org.

Exhale Programs in Michigan

Chelsea Senior Center - Ease the Day: Caregiver Respite Support

Chelsea Senior Center's Ease the Day: Caregiver Respite Support initiative serves as a hub for caregivers and their older adult loved ones in Western Washtenaw County. Local needs are great and varied in scope. Together with our partners, we are working to meet these needs and bridge the gap in respite care opportunities in our rural area. The Chelsea Senior Center hosts Ease the Day, an onsite social model of respite care, which includes meaningful and purposeful physical, cognitive, and social engagement. In-home volunteer-based companion care and in-home skilled respite services are provided by our partners Catholic Social Services of Washtenaw County and Jewish Family Services. Additional support is provided by Silver Maples and the Chelsea Hospital Ministerial Association, local organizations serving seniors. Together we are creating an inclusive, community-based service to support caregivers and Ease the Day Friends to enhance caregiving options available. For more information, contact Lisa Klinkman or Katie Garvey at caregiversupport@chelseaseniors.org.

Regents of the University of Michigan – Silver Club – Respite Alternatives (Washtenaw Support Network for Caregivers)

This program will provide caregivers with a variety of respite opportunities:

- Silver Club Group Respite Caregivers of individuals with dementia can sign their loved one up for a group activity at University of Michigan's Silver Club. Activities include art, music, fitness, and games in a lively social environment led by Silver Club staff trained in dementia care.
- In-Home Professional Respite Care Jewish Family Services has a relationship with HomeWatch Caregivers to provide in-home care for older adults while family caregivers spend time taking a break or attending to errands or personal business.
- Volunteer Respite Program Catholic Social Services of Washtenaw County offers a volunteer respite program that pairs families with respite visits at home.

In addition to these respite offerings, partnering agencies will design and offer 8-10 events per year for family caregivers. These will include free caregiver outings to local museums, sporting events, and nature settings (transportation will be provided); educational programs; caregiver resource fairs; and social and networking opportunities such as luncheons and happy hours for caregivers. Other services available to support caregiver respite will include in-home chore support (a handyman service), a volunteer caregiver program (to provide care and coverage while the caregiver takes a break), and care consultations for caregivers to support caring for older adults or lining up caregiving support from other sources in the community. Project partners include the University of Michigan Silver Club, Jewish Family Services, and Catholic Social Services of Washtenaw County. For more information, contact Shannon Etcheverry at smguida@med.umich.edu.

Ypsilanti Meals on Wheels - Care on Wheels Program

This program provides in-home caregiver respite, chore support, home modifications, and clinical occupational therapy (for older adult care recipients) through partnership with Seniors Helping Seniors, Catholic Social Services of Washtenaw County, and Disability Made Easy. Seniors Helping Seniors is a paid in-home care provider offering in-home respite care services, chore support, meal preparation, shopping support, personal care assistance, light housekeeping, pet care, medical appointment assistance, medication reminders and safety checks. Seniors Helping Seniors provides family support services for dementia and Alzheimer's care, respite care, and overnight visits. Catholic Social Services of Washtenaw County and Disability Made Easy both offer chore support to older adults/their families in greater Ypsilanti. Meals on Wheels has an Occupational Therapist and Community Health worker on staff to support this program. Meals on Wheels is reaching out to its large database of meal recipients to market Care on Wheels. Caregiver participation and tracking occurs through an intake program for caregivers and older adults that includes a Quality Aging Matrix assessment to determine program eligibility and impact on participating family caregivers and older adults. Project partners are Seniors Helping Seniors, Catholic Social Services of Washtenaw County, and Disability Made Easy. For more information, contact Alison Foreman at alison@ymow.org.