

# **EVALUATION OF EXHALE –THE FAMILY CAREGIVER’S INITIATIVE**

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# EXHALE – THE FAMILY CAREGIVER INITIATIVE

- Exhale funds and supports collaborative projects in Western New York (WNY) and Southeast Michigan that offer respite and other programming for caregivers of older adults
- Launched in WNY in 2019, the initiative has provided support to 27 respite projects across 3 cohorts
- Support includes:
  - Grants + resources for effective implementation, sustainability, and expansion
- Exhale is managed by TPI



## EXHALE (CONTINUED)

- Requires collaboration and caregiver input in the design of respite programs
- Encourages innovation; innovations have included:
  - Caregiver and care recipient engaging in respite opportunities together
  - Individualized technology-based respite that is not bound by time or place
  - A broad range of programs and services that may include music, household chores, wellness activities
  - Brief periods of respite

# EVALUATION FOCUS

1. Assessing changes in access to, and use of, respite among caregivers of older adults
2. Building the evidence base to better support respite needs and innovative respite models
3. Documenting the development, implementation and significance of new collaborative partnerships
4. Examining the Exhale model and component parts

# EVALUATION METHODS: SELECTED DATA SOURCES

- Caregiver surveys: baseline, 3-month, 6-month, “single activity”
  - ARCHANGELS Caregiver Intensity Index (CII)
- Interviews
  - Caregivers
  - Grantees & grantee collaborators
  - Exhale Leadership Team
- Grantee proposals and reports

# EVALUATION METHODS: CAREGIVER SURVEYS – DATA ELEMENTS

- Caregiver and care recipient basic demographics
- Caregiver and care recipient health and wellness (at baseline and follow-up)
  - General health
  - Mental health: stress, anxiety and depression
  - Emergency department and hospital use
  - Caregiver intensity (optional)
- Respite experience
  - Prior respite experience and motivation for participation
  - Frequency of respite
  - Satisfaction with and impact of respite programs (at follow-up)

# EVALUATION METHODS: CAREGIVER INTERVIEWS – DATA ELEMENTS

- Caregiving responsibilities
- Participation in respite programs (primarily Exhale programs)
  - Motivation, experience, perceptions of the program
  - Impacts (e.g., reduced stress, access to additional resources, connections to other caregivers)

# FINDINGS



# CAREGIVER TECH SOLUTIONS (COHORT 1)

- Led by Healthy Community Alliance, a rural health network serving WNY
- Key components of the program:
  - **Assessment** – Identify needs and values through the *What Matters Most* caregiver assessment
  - **Coaching** – E-Respite Coaching Sessions to design and support the respite solution with the caregiver
  - **Solutions** – Deploy and train caregivers on technology solutions
  - **Follow-up** – Measure impact, understand ongoing utilization of technology, and provide referrals to meet additional needs



# PROGRAM IMPACT: CAREGIVER TECH SOLUTIONS

## Selected Program Impacts at 3 Month Follow-up (N= 121)

Because of this program ...		
I know about new opportunities for taking a break from caregiving	120	(99%)
I have new resources that support me as a caregiver	119	(98%)
I feel supported knowing that I have ready access to supports that allow me to take a break from caregiving when needed	119	(98%)
I have new opportunities for taking a break from caregiving	115	(95%)
The person I care for has new recreational or social opportunities	79	(65%)
I have connected to other caregivers	72	(60%)

# PROGRAM IMPACT: CAREGIVER TECH SOLUTIONS

Frequency of Rest or Relief in the Past Month at Baseline and 3-Month Follow-up (N= 121)		
	Baseline	3 Month Follow-up
At least once a week	61 (50%)	88 (73%)
Less than once a week, including no rest or relief	55 (45%)	33 (27%)
Missing	5 (4%)	0 (0%)

<sup>a</sup>  $p < .05$  in paired Wilcoxon signed-rank test

# PROGRAM IMPACT: CAREGIVER TECH SOLUTIONS

Caregiver Intensity Index (CII) Score at Baseline and 3-month Follow-up (N=102)				
Overall CII score	Baseline		Follow-up	
High caregiver intensity	35	34%	14	14%
Moderate caregiver intensity	64	63%	80	78%
Low caregiver intensity	3	3%	8	8%
<b>Mean CII score (SD) <sup>a</sup></b>	47.83 (12.70)		39.67 (12.86)	
<b>Range of CII scores</b>	14 to 74		5 to 71	

<sup>a</sup>  $p < 0.01$  in paired t-test

# CAREGIVER ASSESSMENTS AND INTERVIEWS (COHORT 2)

- Programs collecting assessment data from caregivers at multiple points in time, linked with a unique ID (n=9 programs)
  - Baselines: 214
  - 3-month follow-up: 117
  - 6-month follow-up: 88
- Programs collecting data at each activity (n=3 programs)
  - Single activity survey: 151
- Caregiver interviews: 16

# SELECTED CHARACTERISTICS AT BASELINE: COHORT 2 (N=214)

- Caregivers
  - 56% age 65 or older, 27% age 75+
  - 72% women
  - 39% feel “worried, nervous, or anxious” daily
  - 66% had never participated in a respite program before
- Care recipients
  - 68% age 75 or older, 28% age 85+
  - 56% women

*Some of the hurdles are convincing the population that they truly are caregivers and that it's okay to be vulnerable, which are two things that this population struggles with. “I’m the rock. I don’t have an option but be the rock.” – Grantee*

# REASONS FOR PARTICIPATION: COHORT 2

Reasons for Participating in this Program at Baseline (N = 214)		
Want to offer new opportunities to the person I care for	144	(67%)
Looking for opportunities to take a break from caregiving	143	(67%)
Want resources that support my caregiving responsibilities	137	(64%)
To help cope with the stresses of caregiving	128	(60%)
Want to learn about opportunities to take a break from caregiving	106	(50%)
Want to connect to other caregivers	66	(31%)
Socialization for me or the person I care for	11	(5%)
Other	4	(2%)

# IMPACT AT 3-MONTH FOLLOW-UP: COHORT 2

Selected Program Impacts at 3-Month Follow-up (N= 117)		
Because of this program ...		
I am better able to cope with the stresses of caregiving	103	(88%)
I feel supported knowing that I have ready access to supports that allow me to take a break from caregiving when needed	100	(85%)
I have new resources that support me as a caregiver	99	(85%)
I have new opportunities for taking a break from caregiving	98	(84%)
I know about new opportunities for taking a break from caregiving	93	(79%)
The person I care for has new recreational or social opportunities	91	(78%)
I have connected to other caregivers	56	(48%)



# CHANGES IN ACCESS TO RESPITE: COHORT 2

Frequency of Rest or Relief in the Past Month at Baseline and Follow-up <sup>a</sup>			
	All Baselines (N = 214)	All 3-month Follow-ups (N = 117)	All 6-month Follow-ups (N = 88)
At least once a week	122 (57%)	78 (67%)	58 (78%)
Less than once a week, including no rest or relief	78 (36%)	33 (28%)	25 (34%)
Missing	14 (7%)	6 (5%)	5 (7%)

<sup>a</sup> matched pairs analysis (Wilcoxon signed ranks test) showed a statistically significant increase in frequency of having a period of rest/relief from baseline to follow-up

# CAREGIVER DESCRIPTIONS OF IMPACT

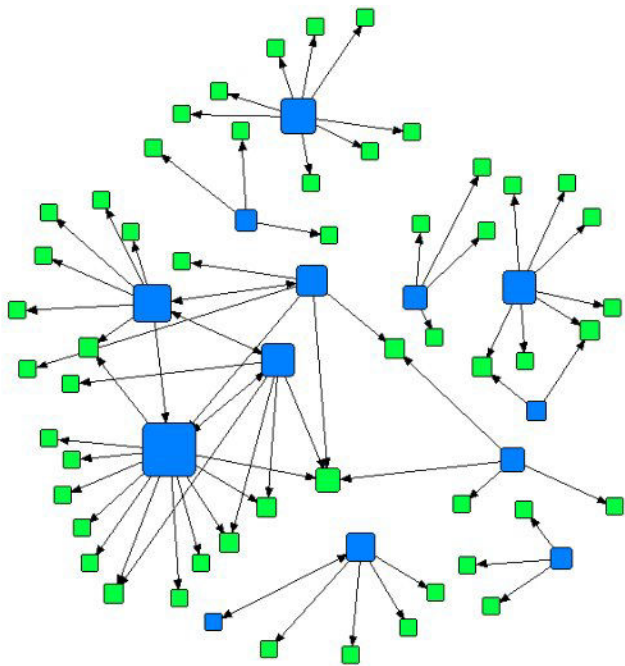
*If I can see [my wife] having a good time, and singing, and smiling...yeah, that's even better than a couple of hours off. – Caregiver*

*In the beginning, I was really hesitant to say it was for me, a break from family. "Oh, no, I'm taking my mom since she loves this. It's great for her." But yeah, it's just when I leave there, I just know I don't have to worry about her, just taking—like the program's called, Exhale.... I feel like the break makes me a little bit more patient with my mom when we do spend time together, so then, that helps my wellbeing, because if you lose your patience or—then you have that whole quilt.... So, I feel like it helps with that, and then, just stress level. – Caregiver*

# DEVELOPMENT, IMPLEMENTATION & SIGNIFICANCE OF COLLABORATIONS

- Project collaborators
  - Cohort 1 grantees: total 35 collaborators, average of 12 (range 3-22)
  - Cohort 2 grantees: total 62 collaborators, average of 5 (range 1-8)
- Approximately half of collaborators receive funding through Exhale grants
- Roles and responsibilities of collaborators vary and include:
  - Outreach/advertising
  - Referrals
  - Resources, including volunteers, transportation, training, space
  - Programming
  - Advisory

# COHORT 2 NETWORK MAP



Key:

Node color:

blue = Exhale grantees

green = collaborators

Node size: Degree centrality (a measure of the number of connections an individual node has)

Arrows: Indicate reported direction of collaboration. In this map, all arrows indicate grantees' connections to their collaborators

# THE DEVELOPMENT, IMPLEMENTATION, & SIGNIFICANCE OF COLLABORATION

- Benefits: greater knowledge of community services, more extensive programming, support for sustainability
- Challenges: inadequate commitment and control, additional time required

*To have access to more professionals to come in and offer programming for our people. I mean, we've had drum therapy, art therapy, the dog therapy, getting the referral, the word of mouth. I, for sure, think that the partnership aspect to this is essential. – Grantee*

*People get kind of fatigued with a project that they're not as intimately involved in necessarily, as the grant lead. I think we saw that. And then, as those organizations' priorities change or they get new grants, their resources shift to their mission and their priorities. – Grantee*

# SUMMARY

- Preliminary findings point to:
  - Growth in access to and uptake in respite
  - Multiple models with positive impact
  - Expanded networks of organizations supporting caregiver respite

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# FOR MORE INFORMATION

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- Information on Exhale

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