Leah Eskenazi, MSW  Katie Maslow, MSW

Presented at the HCBS Conference
Baltimore, Maryland

August 27, 2019
COLLABORATING ORGANIZATIONS

Benjamin Rose Institute on Aging, Center for Research and Education — A Cleveland-based nonprofit, founded in 1908, whose mission is to advance support for older adults and caregivers. (Bass, Ciancibello, Rentsch, and Schaffer)

Family Caregiver Alliance / National Center on Caregiving — A San Francisco-based non-profit celebrating 40+ years dedicated to the health and well-being of family caregivers through information, education, support, and research. (Kelly and Eskenazi)

GSA Visiting Scholar — (Maslow)
PROJECT FUNDERS

The John A. Hartford Foundation
Dedicated to Improving the Care of Older Adults

Jane Carmody and Mary Jane Koran, Program Officers

The Retirement Research Foundation

Nancy Zweibel, Program Officer

Laura Rath, Program Officer
FAMILY AND FRIEND CAREGIVERS

✓ 8.5 million U.S. family/friend caregivers
✓ Dementia caregivers more adverse effects
✓ Assist with more and more difficult tasks
✓ Deal with stressful symptoms
✓ Person’s ability for self-care is limited and worsens over time
PROGRAMS THAT SUPPORT FAMILY AND FRIEND CAREGIVERS

A major advance has been the development and testing of programs that support family/friend caregivers and, in some cases, the person living with dementia.

The Challenge:

✓ Few programs are available in most communities
✓ Most programs are not being delivered by health and social organizations
✓ Most programs are not accessible to families
ONE REASON PROGRAMS ARE NOT AVAILABLE

No comprehensive source with detailed information about proven programs

✓ Limited information in published articles — Particularly about implementation experiences and delivery tools

✓ Lack of easy-to-find, detailed program descriptions to know:
  • The best match for an organization or community
  • Which ones are available and ready for community delivery
  • Which ones have worked well in other communities
Goal: Increase program availability for families by giving organizations and professionals easy access to:

- Comprehensive program profiles
- Basics about research findings
- Detailed information about implementation features
- Information about experiences of existing delivery sites
- Designed for healthcare and social service organizations, providers, and funders
GUIDING PRINCIPLES

✓ Inclusive definition of “Evidence-Based”
✓ Detailed information; not subjective ratings
✓ All the information needed to take the next step toward implementation of a new program
✓ Identify gaps in existing programs; inform new program development
✓ Provide sustained, updated information
PROGRAM ELIGIBILITY

1. At least 1 completed, U.S.-based, study that:
   – was a randomized controlled trial, non-randomized controlled trial, or pre-test post-test without a control group
   – had at least 50% of the sample comprised of family/friend caregivers assisting a person living with dementia in the community.
   – at least one statistically significant, published, beneficial outcome for caregivers.

2. At least 1 other implementation where the program was:
   – delivered by a health or social service organization or provider as a regular service.
   – used by at least some family/friend caregivers assisting a person living with dementia living in the community.

3. Permission and/or license to deliver the program is available, along with manuals, training, and any other delivery tools.
CURRENT PROGRAM LIST

1. Acquiring New Skills While Enhancing Remaining Strengths
2. Active Caregiving: Empowering Skills
3. Adult Day Services Plus
5. Aging Brain Center
6. Alzheimer’s Disease Coordinated Care for San Diego Seniors
7. At the Crossroads
8. Behavioral Treatment of Insomnia for Caregivers
9. BRI Care Consultation
10. Building Better Caregivers
11. Building Better Caregivers Online Mode
12. CALMA: Reach to Caregivers
13. Care of Persons with Dementia in their Environments
14. Care Partners Reaching Out
15. Early-Stage Partners in Care
16. Inner Resources for Stress
17. Memory Club
18. Mindfulness Training for Patients with Progressive Cognitive Decline and their Caregivers Program
19. Mindfulness-Based Alzheimer’s Caregiving Program
20. Mindfulness-Based Dementia Care
21. Mindfulness-Based Stress Reduction
22. Minds in Motion
23. New York University Caregiver Intervention
24. Powerful Tools for Caregivers
25. REACH Community
26. REACH VA
27. Reducing Disability in Alzheimer’s Disease
28. Rosalyn Carter Institute REACH
29. Savvy Caregiver
30. Scott & White Family Caregiver Program
31. Skills2Care
32. STAR Caregiver
33. Stress-Busting
34. Support Health Activities Resources Education
35. Tailored Activity Program
36. Tailored Caregiver Assessment and Referral
37. Telehealth Education Program for Caregivers of Veterans with Dementia
38. Telenovela Mirela
39. The Unforgettable
40. Together We Can!
41. UCLA Alzheimer’s and Dementia Care
42. Yogic Meditation
PROGRAM PROFILING METHODOLOGY

1. Developer and Distributor Survey
2. Manuals Review
3. Delivery Site Survey
4. Studies Review
<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program description and conceptual framework</td>
</tr>
<tr>
<td>Languages program is available</td>
</tr>
<tr>
<td>Applicability to other chronic conditions</td>
</tr>
<tr>
<td>Types of organization that delivers program</td>
</tr>
<tr>
<td>Discipline and experience of qualified delivery persons</td>
</tr>
<tr>
<td>Strategies for financial support of program</td>
</tr>
<tr>
<td>Program delivery costs: training, licensing, recordkeeping systems, manuals, marketing</td>
</tr>
<tr>
<td>Changes made from original program</td>
</tr>
<tr>
<td>Training for delivery staff: length, method, frequency</td>
</tr>
<tr>
<td>Assistance program provides</td>
</tr>
<tr>
<td>How assistance is provided: direct assistance, skills training, providing information, referring</td>
</tr>
<tr>
<td>Expected outcomes</td>
</tr>
<tr>
<td>Who to contact for more information</td>
</tr>
<tr>
<td>MANUALS REVIEW</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Assistance program provides</td>
</tr>
<tr>
<td>Description of sessions and contacts</td>
</tr>
<tr>
<td>Languages program is available</td>
</tr>
<tr>
<td>Applicability to other chronic conditions</td>
</tr>
<tr>
<td>Discipline &amp; experience of qualified delivery persons</td>
</tr>
<tr>
<td>Target populations to receive program</td>
</tr>
<tr>
<td>Characteristics of manuals</td>
</tr>
<tr>
<td>Characteristics of recordkeeping systems</td>
</tr>
<tr>
<td>Licensing agreements</td>
</tr>
<tr>
<td>Required organizational resources: staffing, supplies, space, equipment, marketing</td>
</tr>
<tr>
<td>#</td>
</tr>
<tr>
<td>-----</td>
</tr>
<tr>
<td>23</td>
</tr>
<tr>
<td>19</td>
</tr>
<tr>
<td>17</td>
</tr>
<tr>
<td>16</td>
</tr>
<tr>
<td>16</td>
</tr>
<tr>
<td>13</td>
</tr>
<tr>
<td>8</td>
</tr>
<tr>
<td>8</td>
</tr>
<tr>
<td>7</td>
</tr>
<tr>
<td>6</td>
</tr>
<tr>
<td>6</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>
15 TYPES OF ASSISTANCE

✓ Assessing Symptoms and Care
✓ Coordinate/Monitor Services
✓ Coping with Illness/Caregiving
✓ Daily Tasks
✓ Diagnosis or Prognosis
✓ Effective Communication
✓ End-of-Life Care
✓ Finances

✓ Health and Wellness
✓ Involving Family/Friends
✓ Managing/Understanding Symptoms
✓ Medical Care
✓ Planning for Care
✓ Relationship of Dyad
✓ Transitions in Care
### MOST AND LEAST COMMON TYPES OF ASSISTANCE PROVIDED

<table>
<thead>
<tr>
<th>MOST COMMON:</th>
<th>LEAST COMMON:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing and Understanding Symptoms</td>
<td>Finances</td>
</tr>
<tr>
<td>Health and Wellness</td>
<td>End-of Life Care</td>
</tr>
<tr>
<td>Coping with Illness/Caregiving</td>
<td>Coordinate/Monitor Services</td>
</tr>
<tr>
<td>Relationship of Dyad</td>
<td></td>
</tr>
</tbody>
</table>

www.benrose.org  @BenRoseResearch
## DELIVERY SITE TYPE

<table>
<thead>
<tr>
<th>#</th>
<th>%</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>68</td>
<td>29%</td>
<td>Area Agency on Aging</td>
</tr>
<tr>
<td>58</td>
<td>26%</td>
<td>Health System</td>
</tr>
<tr>
<td>56</td>
<td>25%</td>
<td>Alzheimer’s Association Chapter or Dementia Support Organization</td>
</tr>
<tr>
<td>39</td>
<td>18%</td>
<td>Senior Center or Meals Program</td>
</tr>
<tr>
<td>31</td>
<td>13%</td>
<td>Family Caregiving Organization</td>
</tr>
<tr>
<td>27</td>
<td>12%</td>
<td>Adult Day Program</td>
</tr>
<tr>
<td>24</td>
<td>11%</td>
<td>Long-Term Care Facility</td>
</tr>
<tr>
<td>19</td>
<td>9%</td>
<td>Therapy Organization</td>
</tr>
<tr>
<td>17</td>
<td>8%</td>
<td>Recreational Organization</td>
</tr>
<tr>
<td>16</td>
<td>7%</td>
<td>Senior Housing Facility</td>
</tr>
<tr>
<td>9</td>
<td>4%</td>
<td>Home Health Organization</td>
</tr>
<tr>
<td>9</td>
<td>4%</td>
<td>Independent Service Provider</td>
</tr>
<tr>
<td>9</td>
<td>4%</td>
<td>Faith-Based Organization</td>
</tr>
<tr>
<td>2</td>
<td>1%</td>
<td>Developmental/Intellectual Disabilities Organization</td>
</tr>
<tr>
<td>21</td>
<td>10%</td>
<td>Other</td>
</tr>
</tbody>
</table>

**NUMBER OF DELIVERY SITES = 221**
THANK YOU!

Please feel free to email me if you have or know of a program we should consider for the *Best Practice Caregiving* database.

Kmaslow@aol.com
DATABASE DESIGN

Leah Eskenazi
Family Caregiver Alliance
PATHWAYS TO DATABASE ENGAGEMENT

Leah Eskenazi
Family Caregiver Alliance
WHO WILL USE?

PRIMARY:
Hospital and Healthcare Systems
Health Care Associations
State Departments on Aging and Health
Large Community Based Social Service Organizations
Alzheimer’s and Dementia Specific Organizations

SECONDARY:
Federal Agencies
Policy Associations
Foundations and Interested Private Donors
Researchers and Academic Professionals and Organizations
Learning Collaboratives
Advocates for Caregivers and Individuals living with Dementia
USE THIS DATABASE AND YOU WILL BE EVEN SMARTER ...

✓ Are vetted with documented outcomes — evidence and practice-based

✓ Offer direct experience as a service delivered to a family/friend/partner caring for an individual living with dementia

✓ Are published and included in a comprehensive literature review covering all programs in this database

✓ Offer implementation materials for program adoption and delivery
WHAT CAN YOU DO?

best practice caregiving

A comprehensive and interactive online resource for Best Practice Dementia Caregiving Programs

Join us to **Beta Test**.

**Send Contact Info:** yours — and any others who need to know — to receive the official *Best Practice Caregiving* launch announcement!
THANK YOU! & QUESTIONS?
CONTACT US

Benjamin Rose Institute on Aging
David Bass, PhD
dbass@benrose.org
Alyssa Ciancibello, MPH
aciancibello@benrose.org
Julie Rentsch, MA
jreentsch@benrose.org
Rachel Schaffer, MPH
rschaffer@benrose.org

Family Caregiver Alliance
Leah Eskenazi, MSW
leskenazi@caregiver.org
Kathleen Kelly, MPA
kkelly@caregiver.org

The Gerontological Society of America
Katie Maslow, MSW
kmaslow@aol.com