Translating Evidence-Based Dementia Interventions to the Community

A Report on Administration on Aging Grants

Elizabeth Gould, MSW
Learning Objectives:

By the end of the presentation, attendees will be able to:

• List three key factors for selecting an intervention
• Describe different participant recruitment tactics
• Understand successful strategies for hiring, training and retaining interventionists
• Define effective approaches for fidelity monitoring
• Identify barriers to community translation of evidence-based dementia interventions
• Since the late 1990s, randomized controlled trials (RCTs) conducted in the U.S. and other countries have found positive results for 100+ non-pharmacological (non-drug) interventions (care practices and services) for persons with dementia and their family caregivers.

• RCTs are the ‘Gold Standard’ for evaluation of these kind of care practices and services.

• Positive results from RCTs indicate that there is “Something To Do” for people with dementia and their family caregivers.
Research to Sustained Implementation

• **Research**: one or more RCTs show statistically significant positive outcomes for particular care practices and services, which are then said to be “evidence-based” (E-B)

• **Translation**: one or more translation studies are conducted to test whether E-B care practices and services also work outside the research setting in “real world” settings

• **Sustained implementation**: tested care practices and services are provided in the community with non-grant funding; e.g. paid for by Medicare, Medicaid, VA, a private health plan or clinic, a community agency, a consumer, or embedded in an existing program, such as NFCSP or another Administration on Aging program
Translation Studies

- **Critical** in moving from research to sustained implementation

- Test feasibility and effectiveness outside the research setting:
  - in larger, more diverse groups of persons with dementia and family caregivers, and
  - delivered by different kinds of agencies and service providers
Six Factors that Influence Contextual Fit

1. General availability of resources in the community targeted for the translation project

2. Characteristics of the lead agency for the translation project

3. Characteristics of the intervention

4. Characteristics of the target population

5. Availability of trained staff to deliver the program

6. Availability of staff training, supervision, and performance assessment
Between 2008-2010, the Administration on Aging/Administration for Community Living (ACL) funded 27 grants to states for translation studies to test evidence-based care practices and services for people with dementia and their family caregivers.

- Grants were made from the Alzheimer’s Disease Supportive Services Program (ADSSP)
- States used the grant funding to test 9 E-B care practices and services

Other funders including the Department of Veterans Affairs, Rosalynn Carter Institute, the National Institute on Aging, and other government agencies and foundations also fund translation studies.
ACL Criteria for Evidence-Based Interventions

• Tested through randomized controlled trials.
• Demonstrated to be effective at improving, maintaining, or slowing the decline in the health or functional status of older people or family caregivers.
• Demonstrated to be suitable for deployment through community-based human services organizations and involve nonclinical workers or volunteers in the delivery of the intervention.
• The research results have been published in a peer-reviewed scientific journal.
• Translated into practice and ready for distribution through community-based human services organizations.
Evidence-Based Dementia Interventions

- BRI Care Consultation™
- Coping with Caregiving
- New York University Caregiver Intervention (NYUCI)*
- Reducing Disability in Alzheimer’s Disease (RDAD)*
- Resources for Enhancing Alzheimer's Caregiver Health (REACH II)*
- Savvy Caregiver
- Skills2Care™
- STAR Community Consultants (STAR-C)
- Tailored Activity Program (TAP)

©2018 National Association of Social Workers. All Rights Reserved.
Methodology Used

• Review of general translation literature on dementia care as well as health related and community care interventions
  – RTI team identified 8 important issues and challenges that agencies, individuals, and funders are likely to confront

• Review of published articles and reports about the ADSSP translation projects and published articles about projects not funded by ADSSP grants using the 8 identified issues and challenges

• Interviews and focus groups with ADSSP grantees and their community partners using questions about the 8 identified issues and challenges
Eight Identified Issues and Challenges

- Selecting an intervention
- Working with community partners
- Recruiting and retaining program participants
- Hiring, training, and retaining staff to deliver the program
- Monitoring for fidelity
- Making modifications to the original intervention
- Evaluating the translated program
- Sustaining the translated program
Selecting an Intervention

Grantees were most interested in interventions that:

- Met specific needs of desired target population
- Were developed by a researcher they knew
- Complemented existing programming and used existing staff
- Had existing materials to ease planning and implementation process
- Required less staff time and cost less
Grantees worked with community partner organizations who could:

- Provide outreach and referrals to the program
- Deliver the intervention
- Train others to deliver the intervention
- Develop evaluation plans and collect and analyze program data
Types of Community Partners

Number of Grants Partnering with Each Type of Organization

- AAAs: 21
- Universities: 19
- Alzheimer's Association chapter(s): 15
- Hospital/clinic: 10
- Community organization(s): 9
- County agencies: 3
Grantees recruited and retained participants by:

- Promoting the program as skill building to caregivers
- Recruiting through existing programs or other organizations
- Encouraging word of mouth by those who went through the intervention
- Establishing eligibility criteria and describing participation requirements clearly
Grantees hired, trained, and retained staff by:

- Recruiting professionals from more varied disciplines than the original intervention.
- Using role play during interview to determine ability to deliver intervention as intended.
- Training staff to deliver the intervention along with providing ongoing supervision and refresher trainings.
- Offering online training for new staff hired after start of project and for reaching staff in broader geographic areas.
- Providing opportunities for professional development and ability to interact with other interventionists.
- Sharing the positive changes that participants made because of the intervention.
Monitoring for Fidelity

Grantees monitored for fidelity by:

- Using intervention manuals, referral forms, screening criteria, and other materials from the original implementation
- Training staff specifically on how to maintain fidelity to the intervention
- Developing a replication manual that contains detailed protocols, data collection procedures, program flyers, screening forms, and letter templates to ensure consistent implementation across sites
- Following a checklist that covered the key components for each session
- Listening to recorded sessions to identify any areas that may have been missed
Making Modifications to the Original Intervention

Grantees made modifications to the original intervention to:

- Manage budget constraints and expand the potential reach of the program
- Maximize recruitment and make services available to a broad segment of the community by broadening participant eligibility requirements
- Accommodate participant needs by meeting via teleconference or Skype when meeting in person was too difficult
- Decrease travel time, harsh winter weather, or caregiver reluctance to participate by reducing the number of in-person sessions
Evaluating the Translated Program

Grantees tested whether the translations yielded the same results of the original intervention by:

• Using the same set of measures as the original researchers

• Using pre/post testing to collect data at baseline and immediately post-program with additional follow-up assessments

• Examining changes in caregiver knowledge, competence, and use of community resources and social supports
<table>
<thead>
<tr>
<th>Outcome</th>
<th>Reports</th>
<th>Statistically significant improvement</th>
<th>No significant change or significance not reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved caregiver stress/burden/coping</td>
<td>15</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Decreased caregiver depression*</td>
<td>14</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Improved caregiver knowledge/competence</td>
<td>10</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Increased knowledge, use and satisfaction with services and social supports</td>
<td>8</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Improved caregiver health</td>
<td>6</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Reduced frequency/severity of behavioral symptoms</td>
<td>6</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Delayed/decreased placement in facility</td>
<td>5</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>
Sustaining the Translated Program

Grantees described factors for successful sustainability such as:

- Identifying sources of ongoing funding
- Determining a proper fit between the agency and the specific intervention
- Getting staff buy-in
- Planning early and managing expectations
- Establishing the logistical details of how the program would function after grant end
Practice Knowledge and Tools from Translation Studies

• Vast amounts of new knowledge and insights from real-world implementation of E-B care practices and services
  – what works and does not work (for whom)
  – who will use which interventions / what modifications are needed
  – which agencies and service providers can deliver particular interventions effectively / what modifications are needed
  – what training, mentoring, supervision, and fidelity monitoring is needed

• New tools and materials that support sustained implementation
  – manuals, position descriptions, and training materials and procedures
  – new delivery methods to reduce costs and increase the number of persons with dementia and family caregivers that can be reached and served
QUESTIONS?

Elizabeth Gould, MSW
RTI International
230 W. Monroe St. Suite 2100
Chicago, IL 60606
egould@rti.org

Access to full report available at
https://nadrc.acl.gov/node/102