



Translating Evidence-Based Practices to Community Settings for People Aging with Disabilities and their Caregivers: Gaps and Opportunities

**Administration for Community Living
Webinar**

February 4, 2016, 1:00pm - 2:30pm (ET)

Agenda

- **Introductory Remarks**, Margaret Campbell, NIDILRR Office of Research Sciences and Elena Fazio, Office of Performance and Evaluation
- **Context: ACL/AoA Priority and NIDILRR Perspective on Evidence-Based Interventions**, Ruth Brannon, NIDILRR Office of Research Sciences
- **Translating a Wellness Promotion Intervention for Individuals with Aging with Physical Disabilities: State of the Science and Next Steps**, Ivan Molton, PhD, Associate Professor, Department of Rehabilitation Medicine, University of Washington
- **Translating Evidence-Based Dementia Caregiving Interventions into Practice: State-of-the-Science and Next Steps**, Laura Gitlin, PhD, Professor and Director, Center for Innovative Care in Aging, Johns Hopkins University
- **Q&A and Discussion**

Overall Webinar Objectives

- This webinar is designed as a “bridging” event to increase awareness among the fields of both gerontology and disability regarding recent efforts to use translational research strategies to increase the availability of evidence-based programs for individuals aging with disabilities and caregivers for older adults with dementia.
- While the pace of progress differs between gerontology and disability, researchers, administrators, practitioners, and funding agencies from both fields face similar challenges in meeting the growing demand for EB programing for older adults and people with disabilities in community settings.

ACL/AoA Context:

Priority for EB Programming

- Investment in evidence-based programming to promote the health and well-being of older adults and adults with disabilities is a priority throughout ACL/AoA's grant programs. For example:
 - AoA awards competitive grants to states, tribes, universities, and various community-based organizations to implement evidence based chronic disease self-management education and falls prevention programs.
 - The Older Americans Act also invests in evidence-based programs through disease prevention/health promotion funding under Title IIID.

NIDILRR Context:

- NIDILRR's research focuses on generating new knowledge and promoting its use to change policy, practice, and programs to improve short and long-term outcomes of individuals with disabilities of all ages.
- To reach this goal, NIDILRR funds discretionary research projects and programs in major life domains of employment, health and function, and community living and participation.

NIDILRR Context (cont.)

- For many years, NIDILRR focused on knowledge creation because rehabilitation and disability research was in its infancy.
- For the last decade, knowledge translation (defined in the NIDILRR context as a multidimensional, active process of ensuring that new knowledge and products gained via research and development are relevant to the users' needs, reach intended users, are understood by these users, and are used to improve participation of individuals with disabilities in society) has been a core requirement of our grants.

NIDILRR Context (cont.)

- NIDILRR has adopted a field-initiated approach for grants portfolio in recent years, and several grantees have been successful in adding translational research projects to our portfolio. We have learned a lot from these grantees.
- We are actively seeking to learn more from ACL's experience to formally incorporate translational research into a continuum of interventions development targeted at real-world environments. The ecological framework of translational research makes it a powerful tool that blends well with NIDILRR's commitment to community living and participation.

Introduction Keynote Presenters

- Ivan Molton, PhD, Associate Professor, Department of Rehabilitation Medicine, University of Washington
- Laura Gitlin, PhD, Professor and Director, Center for Innovative Care in Aging, Johns Hopkins University

Translating a Wellness Promotion Intervention for Individuals Aging with Physical Disabilities: State of the Science and Next Steps

ACL Webinar

February 4th, 2016

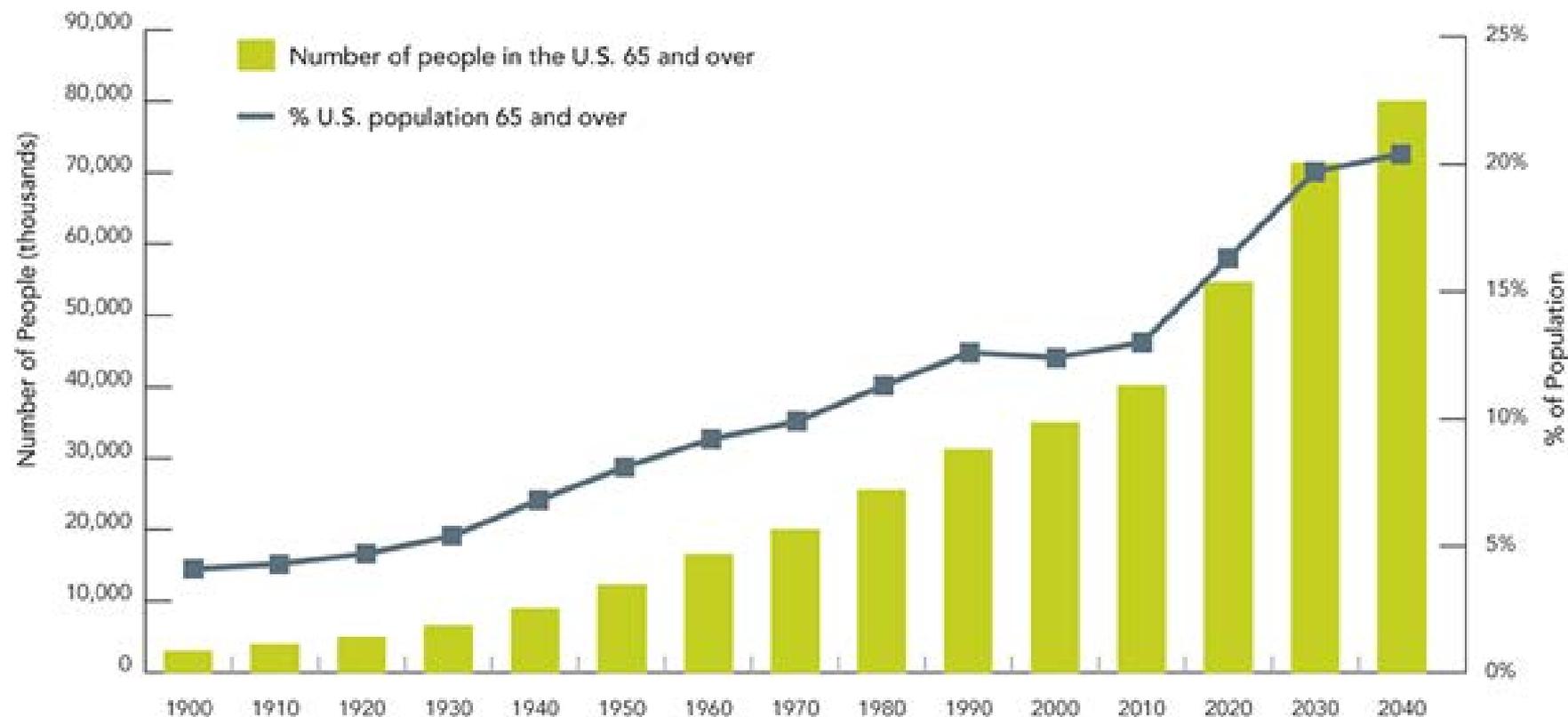
Ivan R. Molton, PhD

Dept. of Rehabilitation Medicine

University of Washington

Aging *into* Disability

Aging U.S. Population



- Currently 12.4% of US Population are >65 (37.3 million)
- By 2030, expected to be 20.4% (71.5 million)

Aging *with* disability



Aging “*with*” disability

- In 2010, 29.5 million Americans aged 21-64 (16.6% of the working age population) reported physical disabilities
- 260,000 individuals with SCI
- 350,000 individuals with MS
- 100,000+ individuals with CMT
- 177,000 individuals with post-polio syndrome
- Each year, 1.7 million TBI’s

Aging *with* disability

- Spinal Cord Injury
 - Average age now ~ 40 years
 - 40% are over age 45
 - Average age at onset increased from 28.7 to 38.0 from 1973
- Multiple Sclerosis
 - Mean age 49-53 years
 - 42% over the age of 65
- Post-polio syndrome
 - 90% are over the age of 55
- Cerebral Palsy
 - Death in childhood is now rare (about 2%)
 - 86% of those who survive childhood will live past age 50

Many diagnoses

Aging “*into*” disabilities

- Osteoarthritis
- COPD
- Vascular dementia
- Coronary artery disease
- Osteoporosis
- Diabetes (complications)
 - limb loss
 - peripheral neuropathies

Aging “*with*” disabilities

- Spinal cord injury
- Traumatic brain injury
- Neuromuscular disease
- Multiple sclerosis
- Developmental disabilities
- Post-polio syndrome

Shared needs

Problems with balance

Risk of falls

Chronic pain

Risk for infections

Risk for fractures

Need for caregiver
support

Cognitive impairment

Depression/withdrawal

Changes in
vision/hearing

Mobility limitations

Different philosophies

“for the disabilities system, aging is a success; for the aging network, disability is a failure.”

-Ansello, 2004

There is an increased awareness of mutual opportunity

- 2009 federal expansion of the Aging and Disability Resource Center model
- Inclusion of the National Institute on Disability and Rehabilitation Research *and* the Administration on Aging into the ACL
- Increasing pressure for community agencies to serve both older adults and those with disabilities

There is a need for *translation research* to promote evidence based health promotion programming for this population

- Individuals with disability describe a need for community-based programs for exercise and wellness
- There is a perception of barriers to participation

Two roads to translation

1. Take existing “rehab” interventions and disseminate them, adapting as needed to include older adults

AND/OR

2. Take existing “older adult” interventions and adapt to include younger people with disability

Rehab-based Interventions: A promising evidence base...

- In spinal cord injury
 - 28 unique exercise trials
 - Peer navigator programs for health
- In multiple sclerosis
 - Falls reduction trials
 - Trials to increase exercise
 - Group-based health educational programs
 - Collaborative care trials to manage pain and fatigue

But we lack translation...

- Most interventions are based in hospitals or clinics
- Most are diagnosis specific
 - Low prevalence (relative to other disabilities)
- Most are research trials
 - Unsustainable funding, no model for translation
 - National societies are unable to maintain interventions
- Many tend to emphasize recently diagnosed

Community interventions for older adults: Promising translation

The screenshot displays the NCOA website interface. At the top, the NCOA logo is visible, along with a search bar and a 'GO' button. A navigation menu includes 'Enhance Economic Security', 'Improve Health', 'Public Policy', 'Get Involved', 'News', and 'Events'. The current page is 'About Evidence-Based Programs' under the 'Center for Healthy Aging' section. A sidebar on the left lists categories like 'Chronic Disease', 'Falls Prevention', 'Physical Activity', 'Behavioral Health', and 'Self-Management Alliance'. The main content area features a 'Getting Started' section with a link to 'Evidence-Based Health Promotion 101' and a 'Sign Up' button for a newsletter. An 'Online Training' section is also visible at the bottom right.

Title III-D Highest Tier Evidence-Based Health Promotion/Disease Prevention Programs

PROGRAM	WEBSITE/ CONTACT	PROGRAM GOALS & TARGET AUDIENCE	PROGRAM DESCRIPTION	DELIVERED BY	TRAINING REQUIREMENTS	PROGRAM COSTS	KEY WORDS
A Matter of Balance (MOB)	www.mainehealth.org/mob	<ul style="list-style-type: none"> Reduce fall risk and fear of falling Improve falls self-management Improve falls self-efficacy and promote physical activity Target Audience: Adults 60+ who are ambulatory, able to problem solve, concerned about falling, interested in improving flexibility, balance and strength and have restricted their activities because of concerns about falling 	<ul style="list-style-type: none"> 8 weekly or twice weekly sessions 2 hours per session 8-12 group participants Emphasizes practical coping strategies to reduce fear of falling and teach fall prevention strategies Structured group intervention activities include group discussion, problem-solving, skill building, assertiveness training, videos, sharing practical solutions and exercise training 	<ul style="list-style-type: none"> 2 coaches (volunteer lay leaders) teach the class to participants Guest therapist visit (1 session for 1 hour) 	<ul style="list-style-type: none"> Master Trainers: 2-day training and on-going updates Coach/Lay leader training: 8 hours and attend annual 2.5 hour training update 	<ul style="list-style-type: none"> Licensing Cost: None. Everything is included in the training fee Training Cost: <ul style="list-style-type: none"> Master Trainer session open to anyone (includes all materials): \$1,500 per Master Trainer plus travel Group training available at an agency's location upon request: <ul style="list-style-type: none"> a) 11-15 attendees: \$16,000* plus \$220/person for materials b) 16-20 attendees: \$18,500* plus \$220/person for materials * plus travel, meals and lodging for 2 Lead Trainers Post-training Materials Cost: <ul style="list-style-type: none"> Coach Handbook: \$20 Participant Workbook: \$13 Guest Therapist Handbook: \$6 DVD (Fear of Falling and Exercise: It's Never Too Late): \$164.76/set A Matter of Balance DVD: \$11.00 A Matter of Balance Lay Leader Model CD-ROM for Coaches: \$2.00 	<ul style="list-style-type: none"> fall prevention group setting self-management health promotion
Active Choices	Contact person: Cynthia M. Castro, Ph.D., Program Developer and Trainer, cync@stanford.edu , (650) 498-7281	<ul style="list-style-type: none"> Physical activity program that helps individuals incorporate preferred physical activities in their daily lives 	<ul style="list-style-type: none"> 6-month telephone-based individualized program that provides remote guidance and support and 	<ul style="list-style-type: none"> Trained activity coach/peer counselor/facilitator who monitors progress, modifies exercise strategies 	<ul style="list-style-type: none"> Facilitator training and certification (recommended, but not required): <ul style="list-style-type: none"> 8-hour minimum workshop Assigned reading and written test 	<ul style="list-style-type: none"> Licensing Cost: None. One time purchase of Active Choices Manual. Training Cost: <ul style="list-style-type: none"> Minimum \$1200. Costs vary depending on organization, 	<ul style="list-style-type: none"> telephone-based physical activity self-management health promotion

REVISED 04/17/2015

But (when it comes to disabilities) a limited evidence base...

- In a scoping review of the NCOA list...
- 49 unique interventions
- More than 150 randomized controlled trials
- *Only two trials specifically included people with early-acquired disability conditions*

Were adults with disabilities incidentally included?

- Example exclusion criteria:
 - Those with “disabilities that required higher levels of supervision”
 - Those with “disabilities primarily related to neurological impairments”
 - Those who were “wheelchair bound, or experienced loss of balance while standing”
 - Use of “any assistive walking device”
 - Those “too disabled” per study staff

Other areas of exclusion

- The intervention itself is not appropriate to those with disabilities
 - Sustained walking, balancing, standing aerobic exercise
- Key outcome measures are not suitable
 - Timed “sit and stand” tests, timed up and go test, gait speed, self-report measures of physical activity requiring ambulation

A Translational Research Challenge

- We need greater reach of community interventions to those with disabilities
- The most efficient method is adaptation:
 - Capitalize on existing structure; build evidence-base for interventions already disseminated in community settings
- One structured approach for adaptation is called *Intervention Mapping*

Intervention Mapping Approach

- Step 1: Perform needs Assessment
 - How does the new population compare in terms of demographics, context, needs, etc to the development population?
- Step 2: Define a logic model of change
 - What changes in behavior and environment should be sought by the new program? What are target outcomes?
- Step 3: Match practical methods to desired outcomes
 - What are the essential active ingredients in the original program? How can these be maintained?

Intervention Mapping (2)

- Step 4: Consider existing treatment components and delivery channels
 - What changes in treatment materials or delivery are necessary to meet needs of target population?
- Step 5: Implement the program
 - What changes are necessary to maintain fidelity across the adaptation?
- Step 6: Evaluate the program
 - Was the program effective and feasible in the new population?

Study goals

- Identify an existing, evidence-based health promotion intervention designed for older adults
- Partner with a community agency already delivering this intervention
- Engage in a structured adaptation process
- Test efficacy in a quasi-experimental design
- If efficacious, design materials for use by existing dissemination partners

A case study

Chronic Disease Self-Management Program (CDSMP)	<i>Refer to Stanford Suite of Self-Management Programs below for community-based, Spanish and online versions</i>						<ul style="list-style-type: none"> • physical activity • chronic condition • group setting • self-management • health promotion
Chronic Pain Self-Management Program (CPSMP)	<i>Refer to Stanford Suite of Self-Management Programs below for community-based program details</i>						<ul style="list-style-type: none"> • physical activity • chronic pain • chronic condition • group setting • self-management • health promotion
Diabetes Self-Management Program (DSMP)	<i>Refer to Stanford Suite of Self-Management Programs below for community-based, Spanish and online versions</i>						<ul style="list-style-type: none"> • diabetes • chronic condition • group setting • medication management • self-management • health promotion
EnhanceFitness	www.projectenhance.org/EnhanceFitness.aspx	<ul style="list-style-type: none"> • Improve the overall functional fitness and well-being of older adults • Target Audience: Sedentary older adults wishing to maintain and/or improve their physical functioning and stay socially connected 	<ul style="list-style-type: none"> • Ongoing 1 hour, 3 times/week group physical activity • Focused on 4 areas: <ul style="list-style-type: none"> - Stretching and flexibility - Low impact aerobics - Strength training - Balance 	<ul style="list-style-type: none"> • Certified fitness instructor 	<ul style="list-style-type: none"> • Attend a 1.5 day EnhanceFitness New Instructor training • Be a certified fitness instructor by a nationally recognized organization 	<ul style="list-style-type: none"> • Licensing Cost: <ul style="list-style-type: none"> - Basic package fee, including licensing fee: \$3,000 - \$500 per new site for the first year - Renewal fee: \$50 per site • Training Cost: <ul style="list-style-type: none"> - Master Trainer training: \$2,000 • Online Data System Fee (optional): Data Entry System for data management and report creation is \$200/year for each data entry user 	<ul style="list-style-type: none"> • physical activity • chronic condition • self-management • health promotion
EnhanceWellness	www.projectenhance.org/EnhanceWellness.aspx	<ul style="list-style-type: none"> • Maintain or increase the health and functional status of community-based older adults with chronic conditions • Target Audience: Older adults with one or more chronic conditions, excluding dementia 	<ul style="list-style-type: none"> • 6 month individualized program, along with regularly scheduled optional support group meetings and evidence-based workshops such as Chronic Disease Self-Management Program (CDSMP) and Matter of Balance (MOB) 	<ul style="list-style-type: none"> • A nurse practitioner and/or social worker work with the participant to develop a health action plan and provide support and encouragement to the participant in achieving the goals of that plan 	<ul style="list-style-type: none"> • Provider training in EnhanceWellness training 	<ul style="list-style-type: none"> • Full Program Cost (program licenses, SS Services, with training limited to Licensee employees, access to web-based data management program (WellWare) and one copy of the Program Materials): <ul style="list-style-type: none"> - Complete package fee: \$6,000 for one site; \$1,000 for each additional site, same licensee 	<ul style="list-style-type: none"> • chronic conditions • physical activity • self-management • health promotion

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Poll: Has your doctor ever told you to do something you know would be good for you, but you didn't do it?



Features of ENHANCE WELLNESS



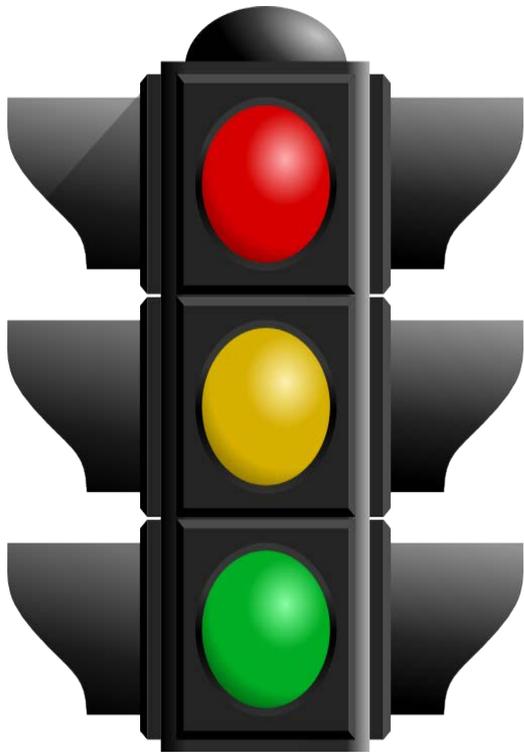
- Offered at 22 sites in 8 states
- Individualized and participant-driven
- Interventionist is a Social Worker and/or Registered Nurse
- Motivational interviewing intervention to identify personal, health or participation related goals
- Action planning to build on strengths and meet personal goals
- Active participation with physician involvement
- Computerized outcomes monitoring

Our Adaptation Process

- “Phase 1”, Pre-implementation adaptations
 - Includes IM steps 1-4: pre-implementation adaptations based in consultation with stakeholders
- “Phase 2”, ongoing adaptations
 - Includes IM steps 5-6, iterative adaptations made during the intervention trial
- “Phase 3”, post-implementation dissemination
 - Includes documentation of final changes and dissemination to treatment sites

Select a structured method for
considering proposed adaptations

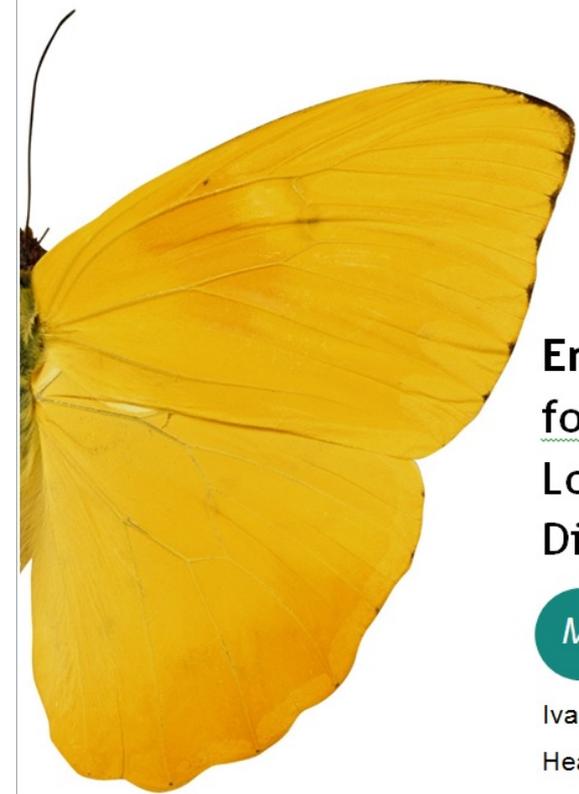
“Adaptation traffic light” for evidence-based programs (CDC)



- *Red light:* Adaptation removes or alters key aspects of the program that will weaken the EBP’s effectiveness.
- *Yellow light:* Adaptions should be made with caution so that the core components are adhered to and adaption does not cause other issues. Consult with model developer.
- *Green light:* Adaptations are appropriate and encouraged so that the program better fit the age, culture, and context of the population.

Maintain a manual of procedures,
and an adaptation log

Manual of procedures



EnhanceWellness for Adults with Long-Term Physical Disability

Manual of Procedures

Ivan R. Molton, PhD

Healthy Aging RRTC Project II

Table of Contents

1: Important Contacts	Page 3
2: Institutional Review Board Summary of Modifications	Page 4
3: Study Flowchart	Page 5
4: Protocol Summary	Page 6
5: Study Procedures	Page 7
5.1 Recruitment	Page 7
5.2 Screening	Page 9
5.3 Eligibility Criteria	Page 10
5.4 Consent	Page 11
5.5 Outcome Assessments	Page 12
5.6 Intervention	Page 13
5.7 Thank you Payments	Page 14
6: Withdrawals	Page 16
7: Adverse Events	Page 17
8: Protocol Deviations	Page 18
9: Using the Access Tracking Database	Page 19
10: Suicide Ideation Protocol	Page 20
11: Adaptation Process	Page 24
12: Unresponsive Participants	
Appendix 1: Measures	Page

Adaptation Log

Date	Challenge	Adaptation
February 2014	EnhanceWellness does not have any specific exclusion criteria regarding mobility limitations or suicidal ideation.	In order to ensure safety of our study, we decided to exclude participants who endorse active suicidal ideation with intent or plan. We will also exclude those who require the use of a mechanical ventilator to breathe or speak, as this would limit the participant's ability to communicate with the Wellness Coach.
May 2014	EnhanceWellness does not typically employ a physical therapist to be available for consult. Due to the special considerations for individuals exercising with a physical disability, we felt this was a safety issue.	We have a physical therapist who is available to consult with the Wellness Coach at any time regarding concerns about physical activity or mobility for study participants.
May 2014	For study tracking purposes, we need to know if participants experience any adverse events related to their participation in the study.	The Wellness Coach asks participants if they have experienced any negative effects related to their participation in the program at the beginning of each visit. Any adverse events endorsed are examined by the study PI and tracked closely according to University IRB requirements.
June 2014	EnhanceWellness is currently offered through a community senior center. In order to reach an adequate sample size of adults with physical disability, we need to broaden our reach.	Wellness coach travels out in the community rather than being based at a senior center or community center. This requires more funding for transportation but also allows us to reach individuals in more rural settings.
June 2014	EnhanceWellness typically offers participants to continue the program after their 6-month visit, either with a brand new goal or a modification of an existing goal. For the purposes of this study, we do not have the funding or time to allow for continuation of the program, past the 6-month mark.	Participants complete program after 6 months and do have the option of continuing with a new or modified goal, but not through our study. Participants would be required to continue the EnhanceWellness program through a community center that currently offers it. This challenge has also required our Wellness Coach to prepare for an adjusted "graduation" process at the 6-month mark.
August 2014	The current EnhanceWellness outcome questionnaire does not address issues regarding fatigue. We know from our research that fatigue can be a significant problem for adults living with physical disability.	A measure of fatigue impact was added to the EnhanceWellness questionnaire as well as a question on fatigue severity. Participants who endorse problems with fatigue in their EnhanceWellness questionnaire will prompt a flag in the EnhanceWellness system to tell the Wellness Coach to address issues around fatigue. It will also direct the Wellness Coach to possibly connect the participant with the Chronic Disease Self-Management Program (CDSMP).
November 2014	The current EnhanceWellness outcome questionnaire includes questions regarding physical activity, but the examples given for light, moderate and vigorous activities do not always apply to participants with assistive devices. Feedback from study participants	Alternate examples of light, moderate and vigorous exercise were added to the EnhanceWellness questionnaire, that would pertain to individuals who use assistive devices such as a wheelchair, crutches or braces.

Phase 1: Pre-Implementation

- Stakeholder engagement
- Initial conversations with community partners
- Establish ongoing advisory board meetings with researchers, consumers, community providers
- Focus groups with consumers
 - Focusing on needs for health promotion, acceptability of the existing EnhanceWellness approach
- Plan for follow-up interviews with individuals who have completed the program

Examples of phase 1 adaptations

- Challenge: Community providers requested additional training to better serve the new population

Solution: Provided 2 day training to our Wellness Coach and other community providers on:

Medical Aspects of Disability | Secondary Conditions
| Employment & Benefits | Sexuality and Disability |
Legal Issues | Ableism | Cognition | Assistive
Technology | Physical Activity and Falling Concerns

Additional phase 1 adaptations

- Eligibility criteria
 - Age (≥ 45)
 - “Mobile” coach (all of King County, WA)
- More flexible meeting locations (home visits)
- Physical therapist consult as needed for exercise
- Use of outcome measures validated for adults with disabilities
 - Quality of Life
 - Fatigue
 - Physical Activity

Phase 2: Ongoing adaptations

- Based on clinician experience, participant feedback, or outcomes data
- Establish a formal system for making ongoing, iterative program adaptations
 - Committee of 5 stakeholders who discuss each proposed adaptation, using the CDC’s “Traffic Light” model; in our case this committee contains the primary clinician, intervention developer, PI and others

Example phase 2 adaptations

- High levels of participant fatigue now generate a “flag” for the interventionist
- “psychotropic medication use” no longer flagged as problem area
- Some participants found wording of self-efficacy questions objectionable (“control” your chronic condition); corrected wording with stakeholder feedback

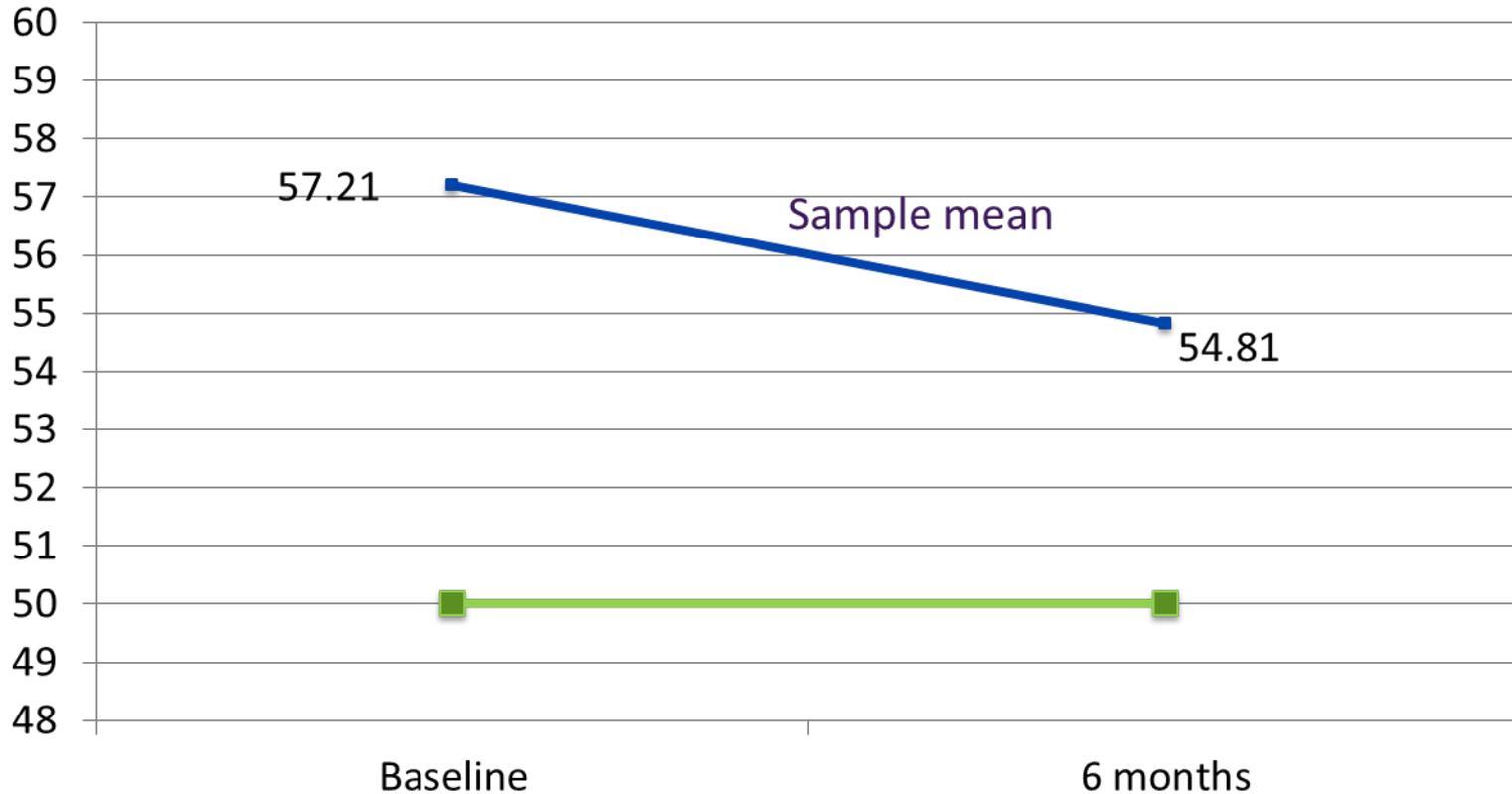
Enrollment To Date

- Adaptation trial target: n=120 individuals with SCI, MS, PPS, NMD from King County, WA
- 108 Enrolled
- 54 Complete
- Waitlist in place since the beginning; significant interest in the program

Preliminary Results

- Mean age: 64 (range 57 – 79)
- 26 with MS, 4 with SCI, 5 with PPS
- Primarily female (67%), with at least a college degree (60%) and identified as White/Caucasian (100%)
- Treatment Satisfaction
 - Helpfulness: mean 7.67 (0 – 10 NRS)
 - Benefits outweighed the effort: 15 (42%)
 - Equaled the effort: 15 (42%)
 - Efforts outweighed benefit: 1

Preliminary Results – Pain Interference

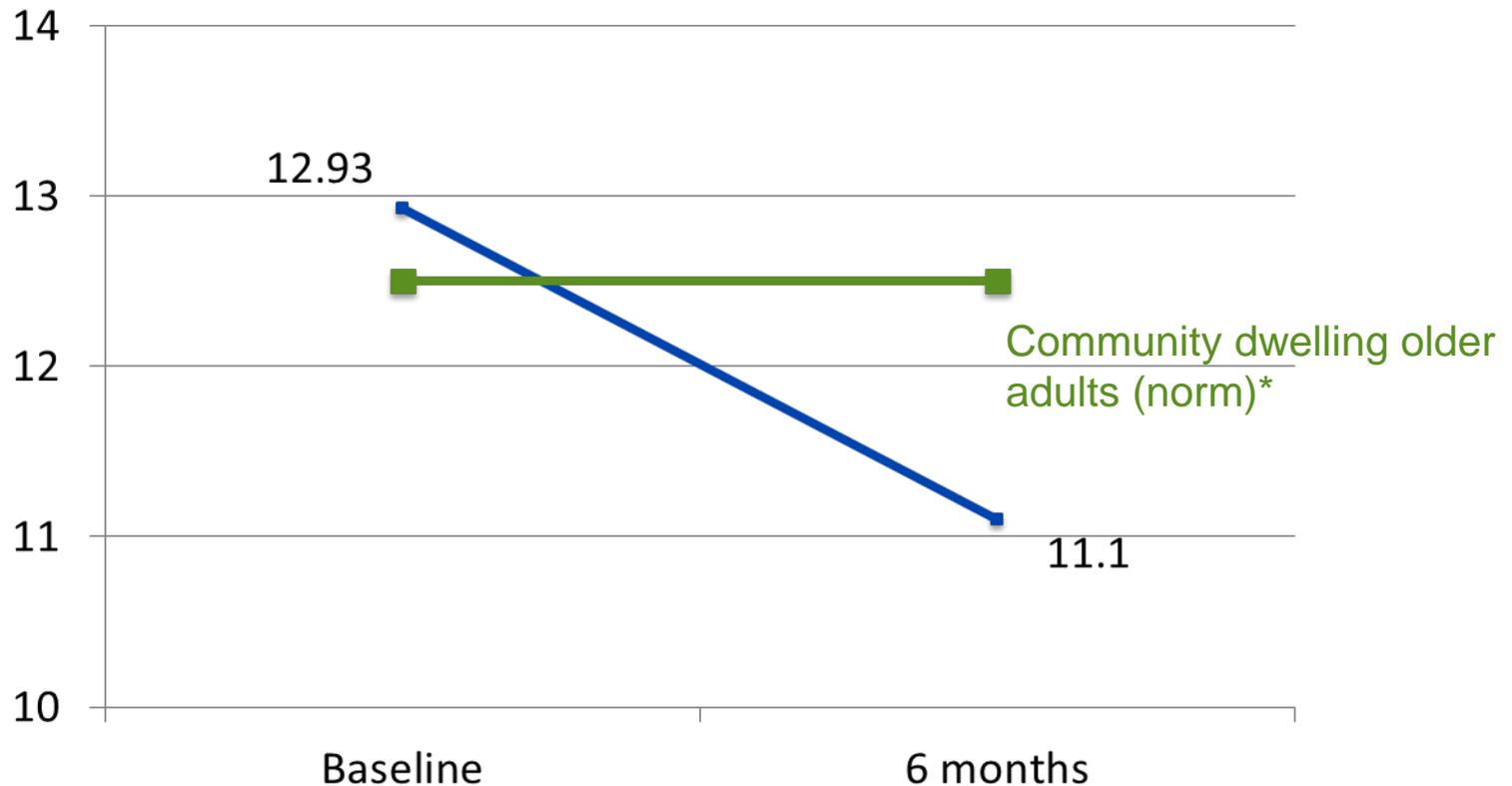


PROMIS Pain Interference T Score:

$N = 33, t(32) = 1.98; p = .06$

Amtmann, D. A., Cook, K. F., Jensen, M. P., Chen, W-H., Choi, S. W., Revicki, D., Cella, D., Rothrock, N., Keefe, F., Callahan, L., Lai, J-S. (2010). Development of a PROMIS item bank to measure pain interference. *Pain*, 150(1), 173-82.

Preliminary Results – Fear of Falling



FES- I;

$N = 30, t(29) = 2.63, p = .01;$

*Gertrudis IJM, Kempen JM, Yardley L, et al. (2007) "The Short FES-I: a shortened version of the falls efficacy scale-international to assess fear of falling. Age Ageing: 37(1): 45-50.

Additional positive findings

- Increase in leisure physical activity:
 - 23.46 to 33.43, $n=35$; $p = .03$
- Increase in satisfaction with social roles:
 - 45.12 to 48.43, $n=34$; $p = .01$
- Decrease in fatigue:
 - Fatigue 10.88 to 9.68, $n=34$; $p = .02$
- Decrease in anxiety ($n=19$):
 - Anxiety 9.0 to 8.0, $n=19$; $p = .05$

Phase 3: Dissemination of adapted intervention materials

- After demonstrating efficacy of the adapted intervention
 - Design of a new module for the Treatment Manual
 - Dissemination to sites currently offering the program
 - Remote training as needed for existing interventionists, maintained by program designer
 - Test for feasibility and acceptability in existing sites

Thank You
Ivan Molton, PhD
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<http://agerrtc.washington.edu/>

The EnhanceWellness program is owned and administered by *Sound Generations*
<http://www.seniorservices.org/>



Key References

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Translating Evidence-Based Dementia Caregiving Interventions into Practice:

State-of-the-Science and Next Steps

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Setting the Stage

Mr. Smith cares for his wife at home in West Virginia who was diagnosed with dementia 4 years ago. He learned of the Alzheimer's Association by chance from a neighbor and received some helpful information.

Mr. Smith had to stop working to care for his wife. He feels isolated and depressed and is financially strained. He has difficulties managing Mrs. Smith's increasing physical dependence and behavioral symptoms. He has no help.

Mrs. Smith's physician provided anticholinesterase medications that are ineffective.



GOOD NEWS!

☐ We know how to help Mr. and Mrs. Smith

☐ Strong Evidence :

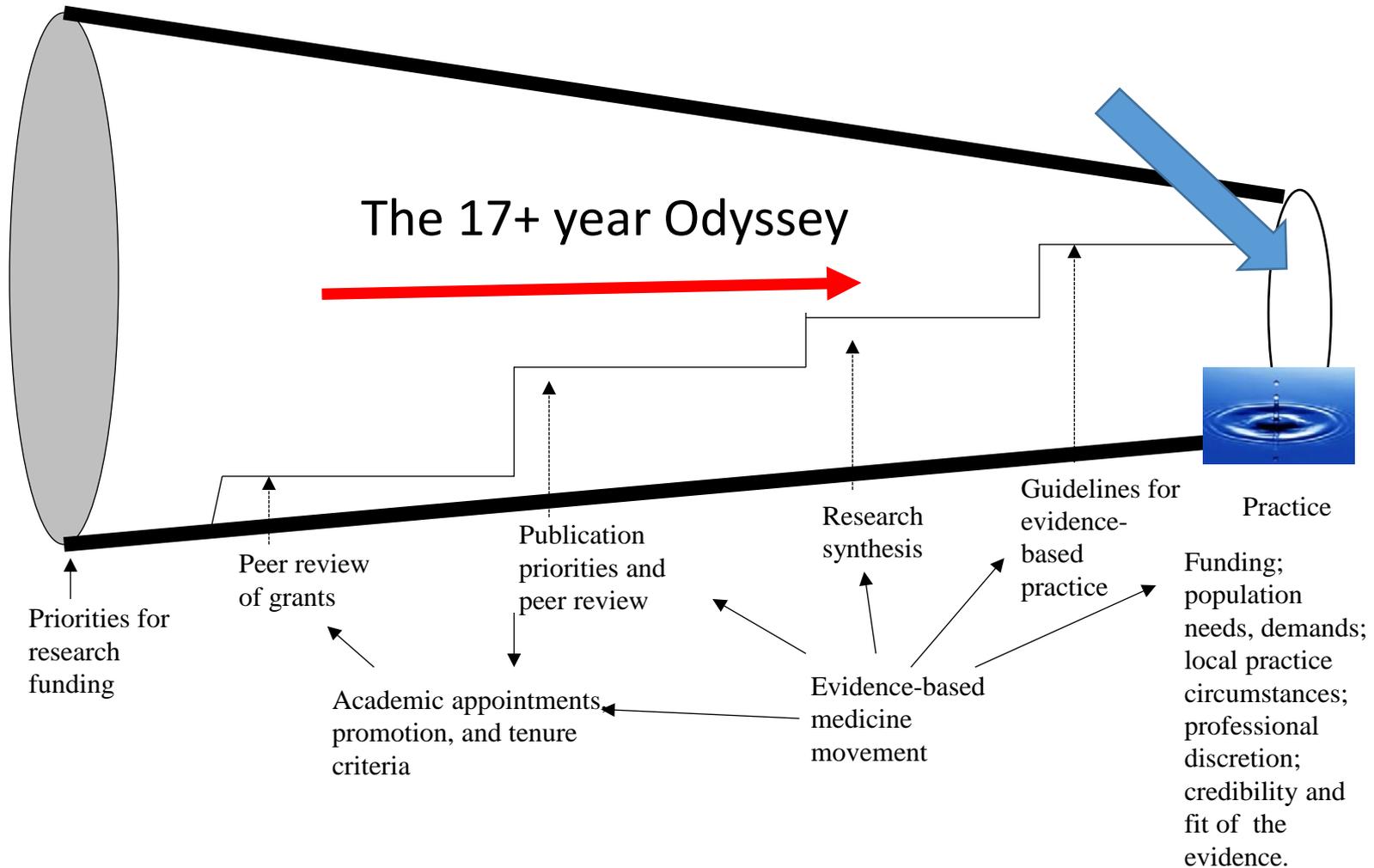
- 6 meta-analyses and 14 systematic reviews of >200 RCTs published between 1966 and 2010 (>8,000 caregivers)
- More caregiver interventions reported yearly
- 59 RCTs of home-based interventions for persons with dementia

☐ Positive Outcomes

- Caregiver – improvements in knowledge, burden, self-efficacy, psychological morbidity, health behaviors, skills
- Person with dementia – improvements in quality of life, function, behavioral symptoms, time to institutionalization, engagement

Gitlin & Hodgson, 2015; Gitlin, Hodgson & Choi, 2016

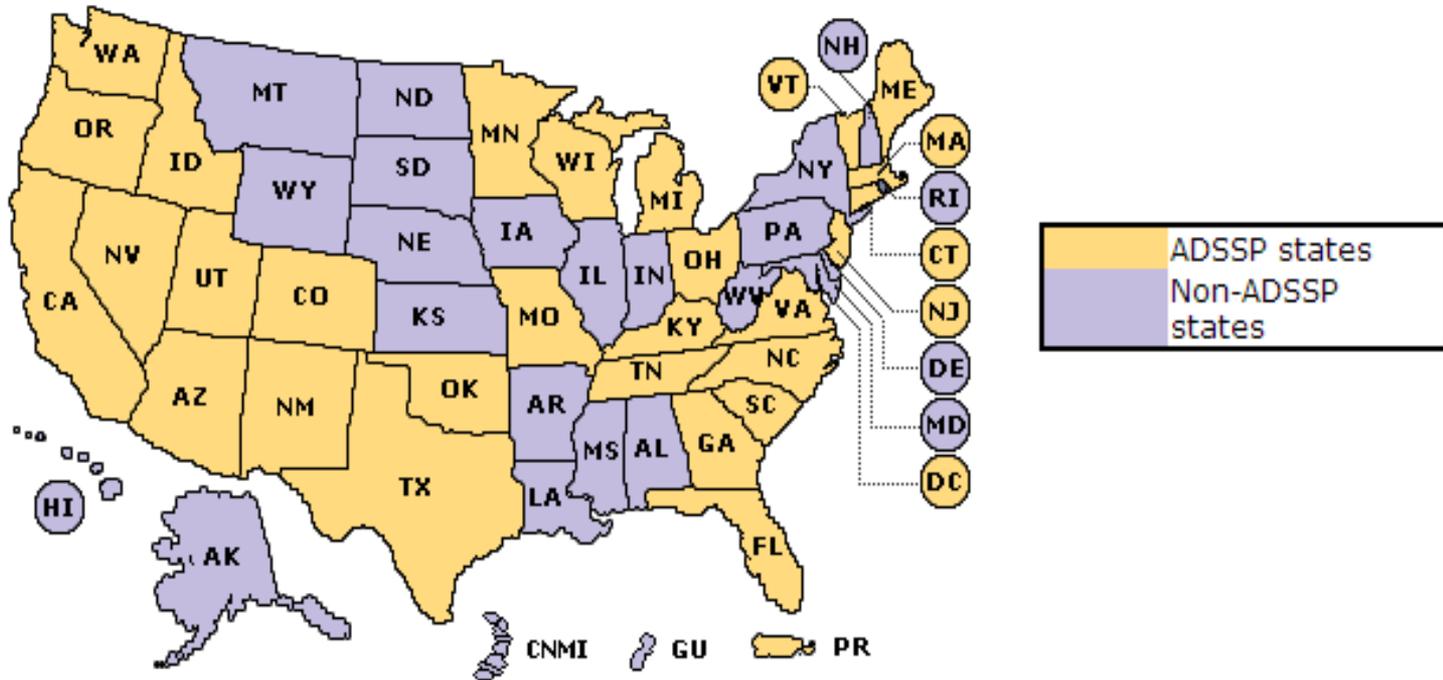
The Long Road from Research to the Community



Brownson, Colditz, Proctor, *Dissemination and Implementation Research in Health*, Oxford, 2012;
Balas, Boren (2000). *Managing clinical knowledge for health care improvement: Yearbook of medical informatics.*

Translation and Implementation Progress in Dementia Caregiving

US States/Territories Receiving ADSSP Grant Funding



36 states and territories have received AoA ADSSP grant funding since 2007.

**Total People Served by Alzheimer's Disease Supportive Services Program (ADSSP):
National Total = 37,783**

Great Progress with Translating REACH-VA from 2012 to Present

- REACH VA Dementia = 238 sites trained
- REACH VA Indian Country = 35 sites trained
- REACH Community Indian Country = 9 sites trained
- Estimated number of caregivers = >800

Nichols et al, The Gerontologist, online 2014; in print, 2015

NIH REACH I Philadelphia Site

Skills₂Care™

- 20 agencies trained:
 - Area Agencies on Aging = 4
 - Home health agencies (Medicare A) = 8
 - Home based agencies (Medicare B) = 3
- Consultants (individual OTs) = 5
- Total number of OTs trained = 85
- Number of caregivers receiving program
 - Jefferson Elder Care Clinical Practice (Med B) = 292
 - Jefferson Elder Care Grant = 62
 - Other agencies/OTs > 800

Rosalynn Carter Caregiver Institute and Johnson and Johnson Initiative

- From 2007 to 2009, 9 translational efforts of 4 interventions:
 - Skills₂Care™
 - REACH Out/REACH adapted for Hospital/REACH II
 - NYC caregiver support program
 - Benjamin Rose Care Consultation
- Continuation with implementation of REACH intervention
- Unclear number of caregivers served
- Most efforts discontinued or elements of program have become embedded in individual practices

Select Other Interventions in Varying Stages of Testing, Translation, Implementation, Adoption

- NYU Caregiver Intervention
- Care of person in their environment (COPE) Program (Medicaid Waiver)
- New Ways, Better Days: Tailoring Activities for Persons with Dementia
- Benjamin Rose Care Coordination Program
- Savvy Caregiver
- MIND at Home Care Management Program
- WeCareAdvisor™

Some Progress But More is Needed

- 16 published studies on translational efforts in USA
- 6 (<3%) translated programs (REACH II, Skills2CareR, NYUCI, Savvy Caregiver Program, RDAD, & STAR-C)
- 15 million caregivers in US yet few have access to evidence-based program
 - $37,783/15 \text{ million} = .00025\%$ received an evidence-based caregiver program

Why Is It Challenging to Integrate Evidence into Practice?

Limitations of Existing Evidence

- Programs tested outside of existing care/payment systems
- Interventions address family needs at one time point
- Poor link to person with dementia (etiology, disease stage)
- Limited outcomes on cost, cost savings, health care utilization and health care savings, financial distress, physical disease burden
- Limited evidence for certain subgroups (e.g., men, minority populations, rural, long-distance carers, multiple carers, minority populations)
- Unclear which intervention to use and when

Limited funds for Translation

- U.S. Administration on Aging (AoA)
 - Primarily through the Alzheimer's Disease Supportive Services Program (ADSSP)
 - Separate category for translational studies developed in 2008
- Joint NIA/AoA research grant program (*Translational Research to Help Older Adults Maintain Health and Independence in the Community*)
 - 1st published 2012
 - Only one to date (limited NIH funds devoted to D & I)
- U.S. Department of Veterans Affairs
- New programs mandated by the 2010 health reform law
- Rosalynn Carter Institute for Caregiving (Johnson & Johnson)

What's a Community-based Agency or Clinic To Do?

- What intervention should be adopted?
 - What interventions exist and are ready for implementation
 - How to choose a particular intervention to adopt
 - How to access the intervention/program
 - What are costs and cost savings of an intervention
 - What training is required (time, expense and who can be trained)
 - How can fidelity be maintained
 - How to staff and budget and what are administrative requirements
- Accessing families:
 - Many families do not self-identify as caregiver
 - What is volume of service delivery needed in order to invest in adoption of an intervention

Gitlin, 2012 Editorial

Other Significant Barriers

- **Funding/reimbursement in current care systems MAJOR limitation**
- Time commitment of investigators, providers extensive
- **Training/ preparation needs of workforce is needed**
- Lack of guidelines (when to use which intervention and why)
- Needs of families are complex (no one program or silver bullet)
- Lack of comprehensive dementia care to embed caregiver interventions
- Different drivers move interventions forward
 - Which programs get translated and why?
 - Overreliance on individual investigators
- What about Intellectual Property?
 - Who owns programs? Who owns training program? Where do or should programs reside?

Strategies for Accelerating Translation, Implementation and Sustainability

□ Develop classification system to describe existing interventions

- Hartford ChangeAGENTS initiative developing a web-based database
 - Intervention components, cost
 - Where to obtain training and staffing
 - Translational lessons to date

□ Publish results of efforts that “succeed” and “fail”

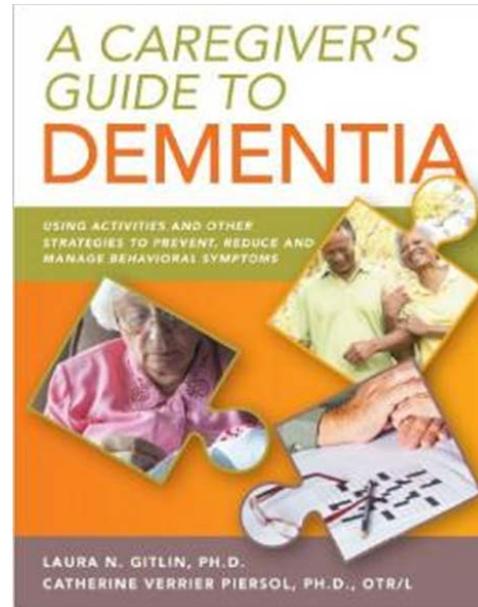
- Need to identify drivers of success and failure
- When do payment models and contexts support adoption and when not
- Need more rigorous study designs at translation/implementation/sustainability evaluative phases

Strategies for Accelerating Translation, Implementation and Sustainability (con't)

❑ Disaggregate common elements of interventions and disseminate those to agencies and professionals

- Motivation interviewing
- Stress reduction techniques
- Problem solving
- Taking care of self
- Coordinating care
- Situational counseling
- Environmental modifications
- Strategies for managing behavioral symptoms

❑ Integrate training on basic elements in health and human service professional education



WeCareAdvisor Web-based Program



Other Strategies

- **New ways of conducting research to develop/test novel programs**
 - Involve stakeholders early on
 - Test interventions using hybrid approaches (combine efficacy, effectiveness and/or implementation questions and methodologies)

- **Create a Dissemination & Implementation Collaboratory**
 - Link agencies to existing training programs
 - Create a virtual pipeline from efficacy to implementation to sustainability by linking funders, sites, users

SUMMARY

Good News

- Robust body of evidence ready for knowledge translation
- Health care and aging services knowledgeable about need to use evidence-based programs
- Scaling up slowly occurring in existing healthcare systems (VA, Homecare, Medicaid Waiver, State programs)

Challenges Ahead

- Payment models
- Retraining/retooling of health and human service professionals
- No industry or centralized mechanism for learning about evidence-based program
- Overreliance on individual developers
- Sustaining practices after grant funding
- Still not reaching enough caregivers
- Most caregivers have never had access to a caregiver program

BEHAVIORAL INTERVENTION RESEARCH

DESIGNING, EVALUATING, AND IMPLEMENTING

LAURA N. GITLIN · SARA J. CZAJA

WITH CONTRIBUTORS

HAVE YOU CONSIDERED?...



SUMMER RESEARCH INSTITUTE (SRI)

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GETTING STARTED - JUNE 6-8, 2016

ADVANCING INTERVENTIONS - JUNE 9-10, 2016

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WHAT IS THE SOCIETAL COMMITMENT?

"Caregiver multi-component interventions (comprising education, training, support and respite) maintain caregiver mood and morale, and reduce caregiver strain.

.....

Nevertheless, we are aware of no governments that have invested in this intervention to scale-up provision throughout the dementia care system, and hence coverage is minimal.“



Q&A and Discussion



Comments/Questions?

Please contact:

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