

Evaluation of our Practices: How Do We Measure "Success"

**Laura N. Gitlin, Ph.D.
Director,**

**Jefferson Center for Applied Research on Aging and Health,
Thomas Jefferson University, Philadelphia, PA**

**Prepared for NIA ADC Education Core
October 6, 2009**

Outline

I. Evaluation Frameworks

II. Assessing Professional Education

III. Evaluating Recruitment Efforts

IV. Cross-site Considerations

I. Evaluation Frameworks

Why Evaluate?

Understand-Improve-Continue Improving

- ◆ **Continually infuse practices with evidence-based approaches**
 - What works/what doesn't
 - Engage in evidence-informed activities to continue to improve
- ◆ **Inform/improve outreach, recruitment, education programs:**
 - Develop targeted approaches
 - Shape programming
- ◆ **Inform stakeholders**
 - Funders
 - Community partners (giving back to communities)
 - Participants of our programs
 - Internal program staff
- ◆ **Generate knowledge that is:**
 - For a clear, articulated purpose
 - Useful
 - Applied to field activities

"Evaluation Practice"

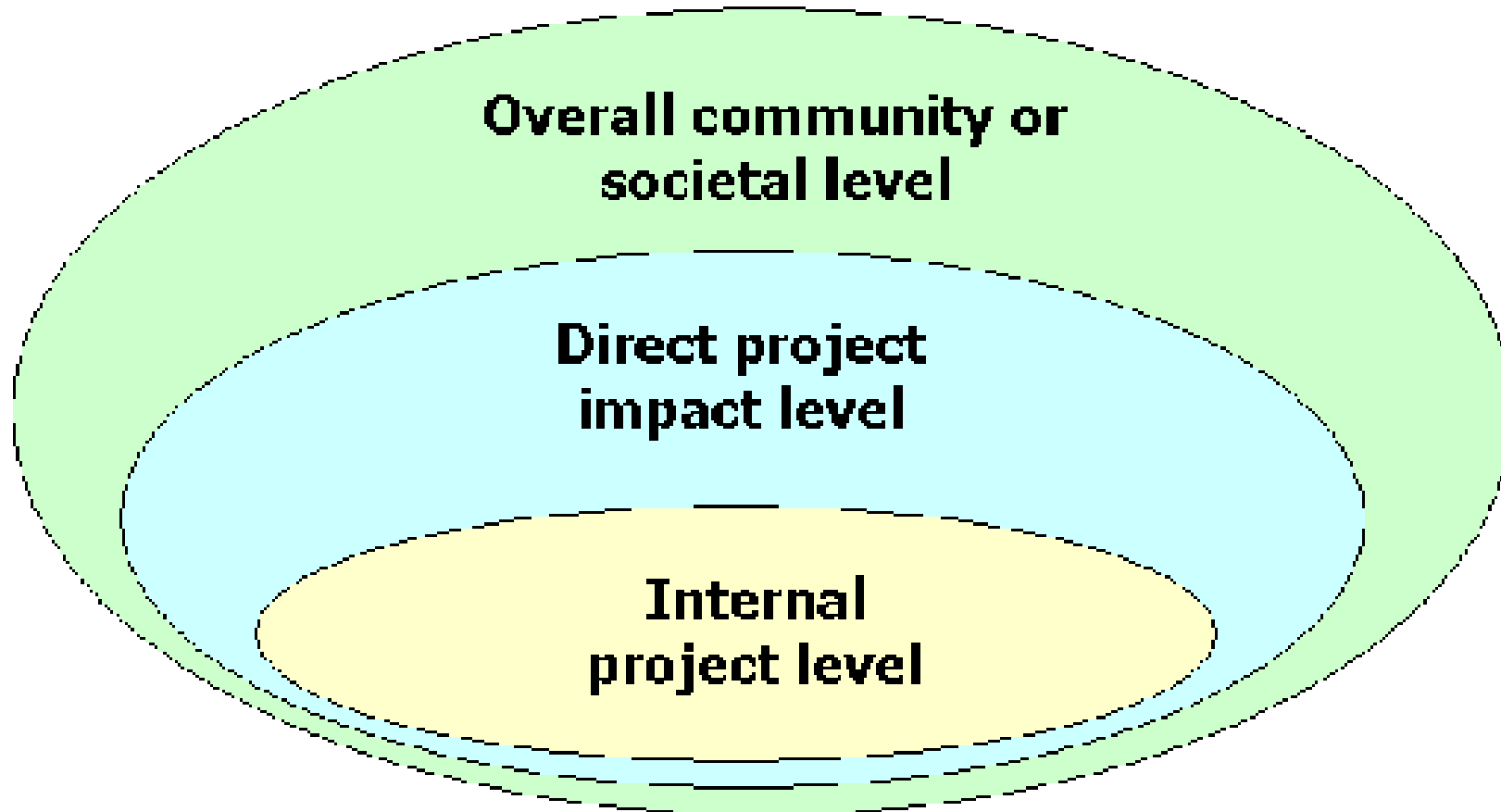
- ◆ **Infuse everyday practices with an evaluative and systematic knowledge-generating framework**
 - Problem and need clarification
 - Reflective intervention
 - Outcome assessment
- ◆ **Systematic approaches to evaluating practice**
- ◆ **Systematic approaches to integrating research into practice**
- ◆ **Iterative processes of planning – reflection-action**

DePoy and Gibson, *Evaluation Practice*, 2003. Wadsworth

DePoy and Gitlin, *Introduction to Research: Understanding and Applying Multiple Strategies*, 2005 3rd edition, Elsevier

Ecological Evaluative Framework

3 Ring Approach



RE-AIM Framework

- ◆ Provides set of standard criteria to evaluate application of intervention programs or policies
- ◆ Five elements:
 - R = REACH
 - E = Efficacy or effectiveness
 - A = Adoption by target settings or institutions
 - Implementation = consistency of delivery of intervention
 - Maintenance = sustaining intervention effects in individuals and populations over time/and continued agency and interventionist use of intervention

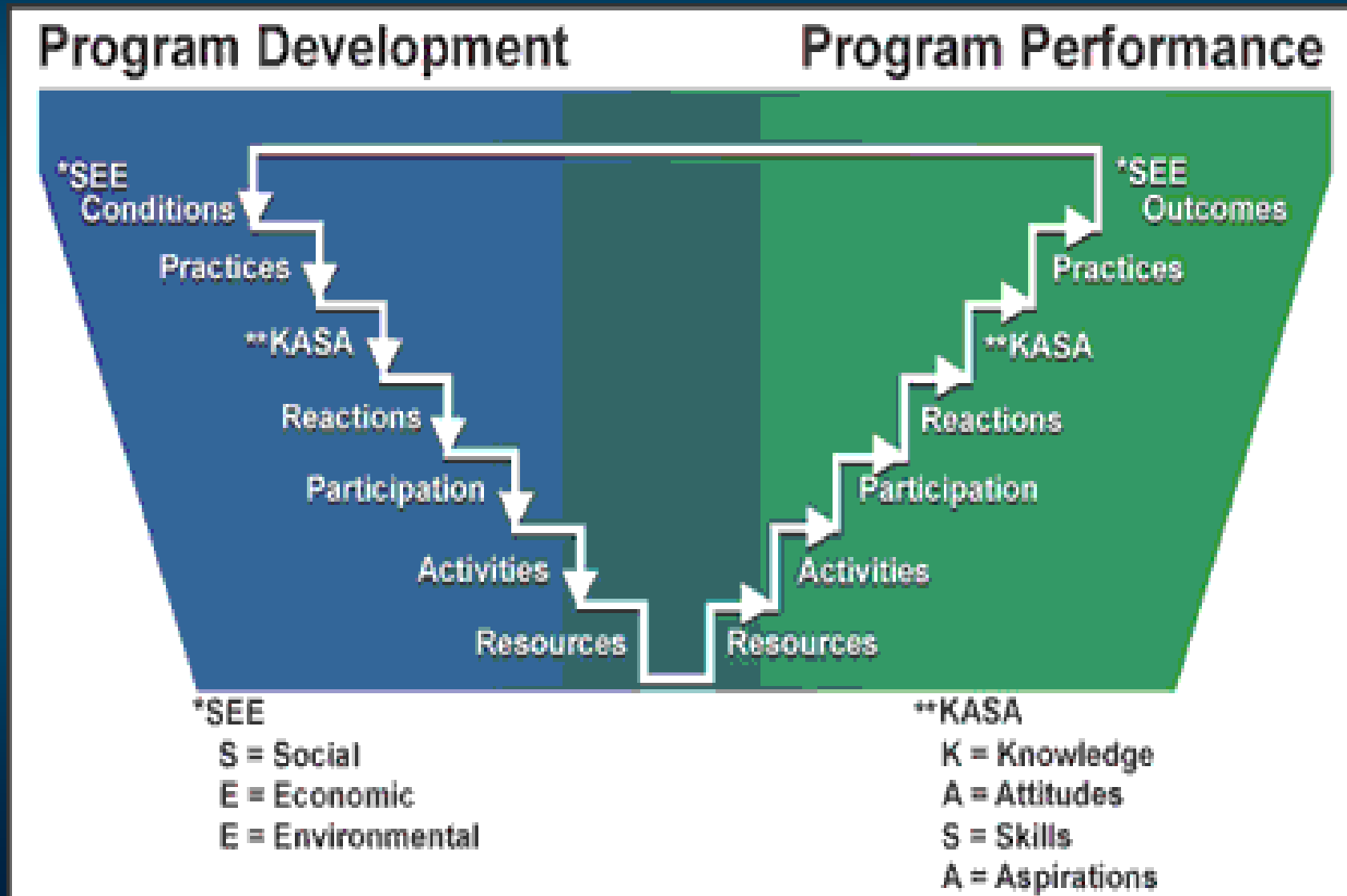
<http://www.re-aim.org/>

Targeting Outcomes of Programs (TOP)

- ◆ Hierarchy for program development, objective writing and evaluation widely used in Extension work to identify and categorize program objectives and outcomes.
- ◆ Focuses on outcomes in planning, implementing, and evaluating programs
- ◆ Based on hierarchy that integrates program evaluation within the program development process.
- ◆ Uses simple framework to target specific outcomes in program development and then to assess degree to which the outcome targets are reached

<http://citnews.unl.edu/TOP/index.html>; Bennett, C. F., & Rockwell, K. (1996). Targeting Outcomes of Programs (TOP): An Integrated Approach to Planning and Evaluation. Washington, DC: CSREES, USDA

Bennett/Rockwell Targeting Outcomes of Programs (TOP) Model

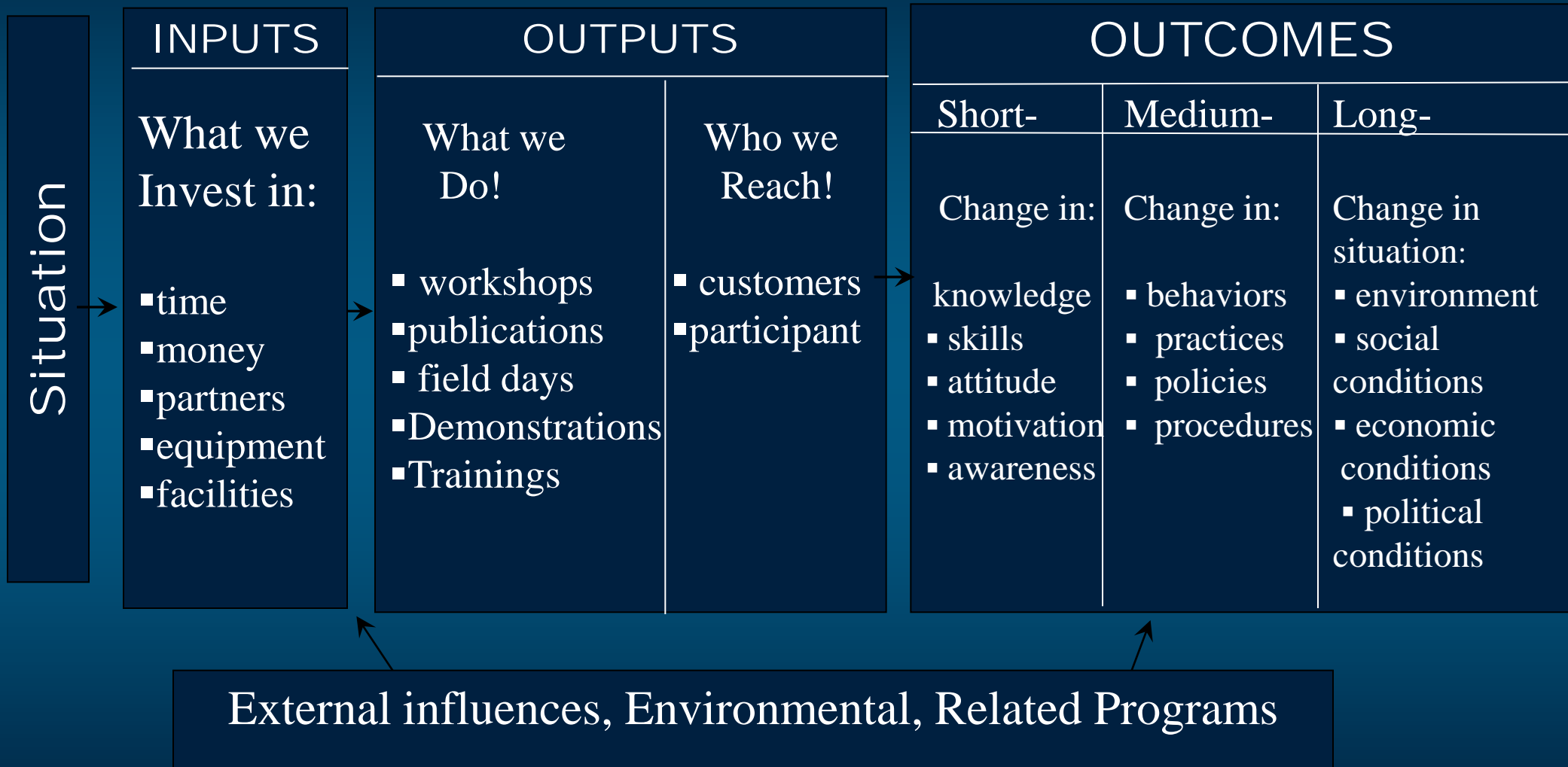


Logic Model

- ◆ Widely used
- ◆ Provide graphic, visual representation
- ◆ Systematic approach to:
 - Establishing goals, inputs and expected outcomes
 - Assuring integration and linkage of situation with inputs, outcomes
- ◆ Mechanism for enabling team discussions and decisions
- ◆ Helpful to broadly outline a program
- ◆ Consider for Cross-site Model definition

<http://www.wkkf.org/Pubs/Tools/Evaluation/Pub3669.pdf>

Elements of the Logic Model



Bennett's Hierarchy of Evidence



7. Impact – Social, economic, environmental public benefits - End results

6. Actions – Behavioral change (Practice)

5. Learning (Knowledge, attitudes, skills, aspirations)

4. Participant reactions (Positive/negative to material presented)

3. Participation – who participated and how many

2. Activities – events, educational methods used

1. Resources (Input)– staff and volunteer time: salaries

II. Evaluating Professional Education Programs

- ◆ **What to measure and why:**
 - Determine "success"
 - Identify how each measure/evaluation data point will be used
- ◆ **What level of evaluation is important and for whom?**
 - Outreach
 - Knowledge
 - Behavioral change
 - Impact on study recruitment/enrollment

Bennett's Hierarchy of Evidence



7. Impact – Social, economic, public benefits

End result

6. Actions – Behavioral change (Practice)

5. Learning (Knowledge, attitudes, skills)

4. Participant reactions

3. Participation – who participated and how many

2. Activities – events, educational methods used

1. Resources (Input)– staff and volunteer time: salaries

Foundational Knowledge Across ADC Sites

1. Basic description of inputs and activities:

- Fits Logic Model inputs
- Cost factors for internal project evaluation

2. Descriptive

3. Immediate quantitative outcome of activity

3. Participation – who participated and how many

2. Activities – events, educational methods used

1. Resources (Input)– staff and volunteer time: salaries

Knowledge Gains and Behavioral Change

7. Impact – Social, economic, public benefits

End result

6. Actions – Behavioral change (Practice)

5. Learning (Knowledge, attitudes, skills)

4. Participant reactions

3. Participation – who participated and how many

2. Activities – events, educational methods used

1. Resources (Input)– staff and volunteer time: salaries

Guiding Evaluative Questions

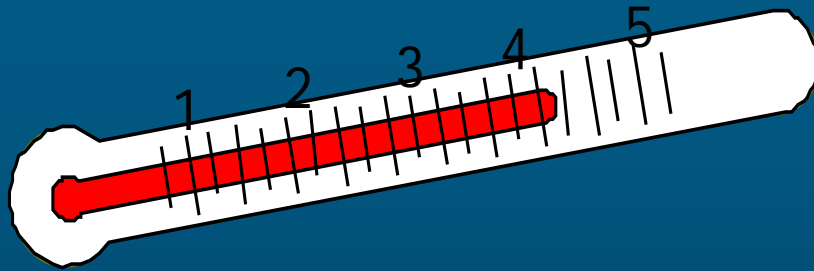
- ◆ **Reaction** - What is the participants' response to the program?
- ◆ **Learning** - What did participants learn?
- ◆ **Behavior** - Did participants' learning affect their behaviors?
- ◆ **Results/impact**- Did participants' behavior change affect the organization, society at-large?

Level 4- Participant Reactions

DOMAIN	Assessment Tool	Target Audience
Caregiver Stress reduction	Stress thermometer http://www.edc.pitt.edu/reach2/public/	Family caregivers
Risk appraisal	REACH II 16 items Czaja et al., JAGS 2009	Family caregivers
Social validity of program	Investigator developed to evaluate: A) Content, B) Acceptability C) Training delivery, D) Usability of information	Professionals Family caregivers
Marketing	Investigator developed to evaluate: A) Ease of attending; B) How participants learned of program	Any participants

Pre-post Caregiver Stress Reduction

- ◆ Use This Scale to Rate Your Level of Tension



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

Level 5 - Knowledge Gains

DOMAIN	Assessment Tool	Target Audience
Knowledge of dementia and caregiving	Carpenter et al., TG, 2009	Professionals Family caregivers
Communication	6-item negative Communication Items from various instruments including REACH frustrations of caregiving	Professionals Family caregivers
Risk appraisal	REACH II 16 items Czaja et al., JAGS 2009	Family caregivers
Dementia management strategies	19-item task simplification strategies (Gitlin et al., 2002) Hinrichsen et al, 1994	Professionals Family caregivers

Level 6 - Behavioral Change

DOMAIN	Assessment Tool	Target Audience
Readiness or intention to change behavior	Based on Transtheoretical Model of Change Gitlin under development	Professionals Caregivers
Appraisal of Change in relevant areas	Perceived Change 13-item index (Gitlin et al, 2006)	Professionals Caregivers
Attitudes and intention to change e.g., refer to Alzheimer's Association	Impact European Study	Professional
Efficacy Confidence in specified areas	How confident are you that you can manage ____? Based on Bandura's theory	Professionals Caregivers

Categorizing Behavioral Change: 4 Areas of Clinical Significance

- ◆ **Symptom reduction**
 - Reduced caregiver stress
 - Reduced behavioral symptoms
- ◆ **Quality of life**
 - Improved well-being
 - Enhanced activity engagement
- ◆ **Social Significance**
 - Reduced nursing home placement
 - Reduced risk of falls
 - Reduced mortality
- ◆ **Social validity**
 - Acceptability of approach
 - Perceived benefit

III. Recruitment

- How to assess success of strategies developed to overcome barriers to recruitment?
- How to evaluate activities that may have a delayed effect (i.e. doing community talks now may lead to improve recruitment several years later)

Evaluating Recruitment Efforts

◆ 3 Potential Levels of Evaluation

- Individual/Family Level
 - Focus group; key informant feedback
 - Market research
 - Willingness to participate in clinical trial research
- Agency Level
 - Administrative feedback
 - Willingness to continue to recruit
- Community Level
 - Saturation of a community

Evaluation at Individual Level

- ◆ **Identify individual perspective - key to effective recruitment:**
 - Key informant interviews
 - Focus groups
- ◆ **Tailor message and delivery to different target populations**
 - Naming and framing
 - Does target group refer to selves as "caregivers"
 - What is important to target group?

Different Perspectives on Participating in Clinical Research

◆ Family caregivers

- In search of a cure
- Improve relative's health
- Learn new information

◆ Individual with dementia

- Engage in a meaningful activity
- Fill up time
- Feel productive
- Help others

Why African American Elders Participate in Clinical Research

◆ **"Giving Back" (Generativity)**

- Leaving behind lessons learned
- Desire for voices to be heard, have a meaning, make a difference
- Chasm between young and old and responsibility of elder

◆ **"Get it straight"**


- Aging plus gender plus misunderstanding/lack of knowledge of African American experience
- Need to have voice heard in a meaningful way

◆ **"Mistrust"**

- Distrust of medicine/pills, experimentation as solution
- Historical events and experiences profoundly influence continued mistrust.


Implications for Recruitment

- ◆ Confidentiality – what happens if I tell you my story; who hears my story and what is done with it
- ◆ Desire for full disclosure – straight talk
- ◆ How will I learn of results?
- ◆ How will study benefit me personally?
- ◆ How does my participation help my community at large?



Boredom, depression, agitation, and
problem behavior (resisting care, etc.)
are common in persons with Alzheimer's
disease or related disorders

Project COPE



Project COPE is a study designed to help caregivers learn
new ways to manage challenging behaviors common in
persons with Alzheimer's Disease or related disorders.

Participants receive information and training on:

- Caregiving and memory loss
- Ways to manage behavior problems of dementia
- Coping strategies and ways to handle stress
- Learning ways to engage your family member
in meaningful activities

All participants receive payment for interviews.

There is no cost for any part of the program. Participation
does not affect services received through the Philadelphia
Corporation for Aging, Jefferson, or any other agency.

Please call for more information

215-503-2897

Conducted by Thomas Jefferson University, Jefferson
College of Health Professions in collaboration with the
Philadelphia Corporation for Aging.

Funded by the Pennsylvania State Department of Health as
part of the Pennsylvania Center of Excellence in Alzheimer's
Disease at the Farber Institute for Neurosciences.

JG 08.1629

Example of What Not to Do:

- Not gender neutral
- Uses technical terms
- Title of study is vague
- Confused with breast cancer
Research because of pink print

OUTCOME

Study enrollment reflected
smallest #of male caregivers



Thomas
Jefferson
University

Jefferson
College of
Health Professions

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL

FIRST CLASS PERMIT NO. 21973 PHILADELPHIA, PA

POSTAGE WILL BE PAID BY ADDRESSEE:

CENTER IN THE PARK
BEAT THE BLUES
5816 GERMANTOWN AVE
PHILADELPHIA, PA 19143-0007

Beat the Blues Partners

Beat the Blues is a collaborative
research program funded by the
National Institute of Mental Health.

Center for Applied Research



Beat the Blues

A Research Program in your Community

What will I do if I participate in Beat the Blues?

Are you:

- Sad or blue?
- Experiencing a loss of interest in activities you used to enjoy?
- Feeling anxious, down in the dumps or you can't get moving?
- Having problems sleeping?
- Experiencing a loss of appetite or overeating?
- Distressed, fatigued or having other problems?

These may be depressive symptoms. Depressive symptoms are NOT a natural part of growing old, a sign of personal weakness, or something you have to go through alone.

If you are experiencing these symptoms, consider participating in **Beat the Blues** if you are:

- African American
- 60 years of age or older



Beat the Blues is a study to determine whether a program to learn ways to stay active and manage sadness or distress is helpful to you. The program occurs in the privacy of your own home and includes up to 10 visits with a trained social worker who will:

- Help you develop a personal plan to manage your sadness or distress
- Link you to important social services
- Provide helpful information
- Help you feel more in control of your daily life

First you will be visited in your home by a trained interviewer who will ask you questions about your health, daily activities and how you are feeling. These questions help us understand how you are doing.

After the interview, you will be assigned by chance to one of two groups. Both groups receive the same home program.

Group A receives the home visits immediately.

Group B receives the home visits four months later.



Regardless of which group you are in, you will be interviewed again by telephone at 4 and 8 months from the time you began the study. The questions will be similar to the first interview and will help us understand whether the program was helpful.

Both groups A and B receive payment for completing three interviews.

There is no cost to you for participating in the program. Beat the Blues does not involve taking medications for depression.

Participation in Beat the Blues does not affect your eligibility for other services provided by Center in the Park, Jefferson, or any other agency. All information is kept strictly confidential.



I would like to know more about Beat the Blues

Please complete and return this pre-paid reply card or call Center in the Park at 215-848-0463 to find out if Beat the Blues is right for you.

Name

Address

City

State Zip

Home Phone

Other Phone

Best Time to Call

E-mail address



For More Information Contact Center in the Park 215-848-0463

JC 08.0045



Why Participate In Research

What is Research?

Research is a way of systematically answering important questions concerning the health and well-being of individuals and communities. Research is conducted by scientists alone or in partnership with communities and individuals. Research is funded by government agencies, private foundations or health care organizations.

Why Do People Participate in Research?

- To play an active role in one's own health and well-being
- To participate in new services before they become available
- To receive potentially beneficial information
- To share personal experiences so that others may benefit

Why should you participate in research?

Most approaches to helping people cope with feelings of sadness or distress have been developed for and tested with Whites or college students. It is unclear whether services developed for and tested on these groups are acceptable to and effective for older African Americans. The participation of African Americans in research is critical to help develop and offer the most effective ways of enhancing their health and well-being.

What about the risks of participating in a study? How am I protected?

Before agreeing to participate in a study, the procedures, benefits and risks must be fully explained to you. If the study is right for you and you are willing to

Why Participate In Research (continued)

participate, you will be asked to read and sign an "Informed Consent" form that states:

- The purpose, length, required procedures and key contacts for the study
- The funding agency and sponsor of the study
- What researchers hope to learn from the study
- The risks (if any) to participants
- The potential benefits (if any) of participating
- What you will receive for participation (test results, payment)

Signing an Informed Consent is not a contract. Your participation in a study is completely voluntary. You can decide to leave a study at any time. Participating in a study, does not prevent you from receiving services or participating in other activities.

What is an Institutional Review Board?

All research studies must be approved and monitored by an Institutional Review Board (IRB), a legal entity of the institution conducting the study. The IRB ensures that you are protected from risks that may be too great, that your privacy is protected and that you are fully informed about the study and have chosen freely to participate. For more information about informed consent and your protection go to: <http://clinicaltrials.gov> or contact the Thomas Jefferson University IRB at 215-503-8966.

Beat the Blues is a collaborative research program between Thomas Jefferson University and Center in the Park funded by the National Institute of Mental Health. The purpose of this study is to evaluate the effectiveness of a home-based program to reduce feelings of sadness and distress in older African Americans.

We need your help to evaluate whether this program is beneficial to older African Americans.

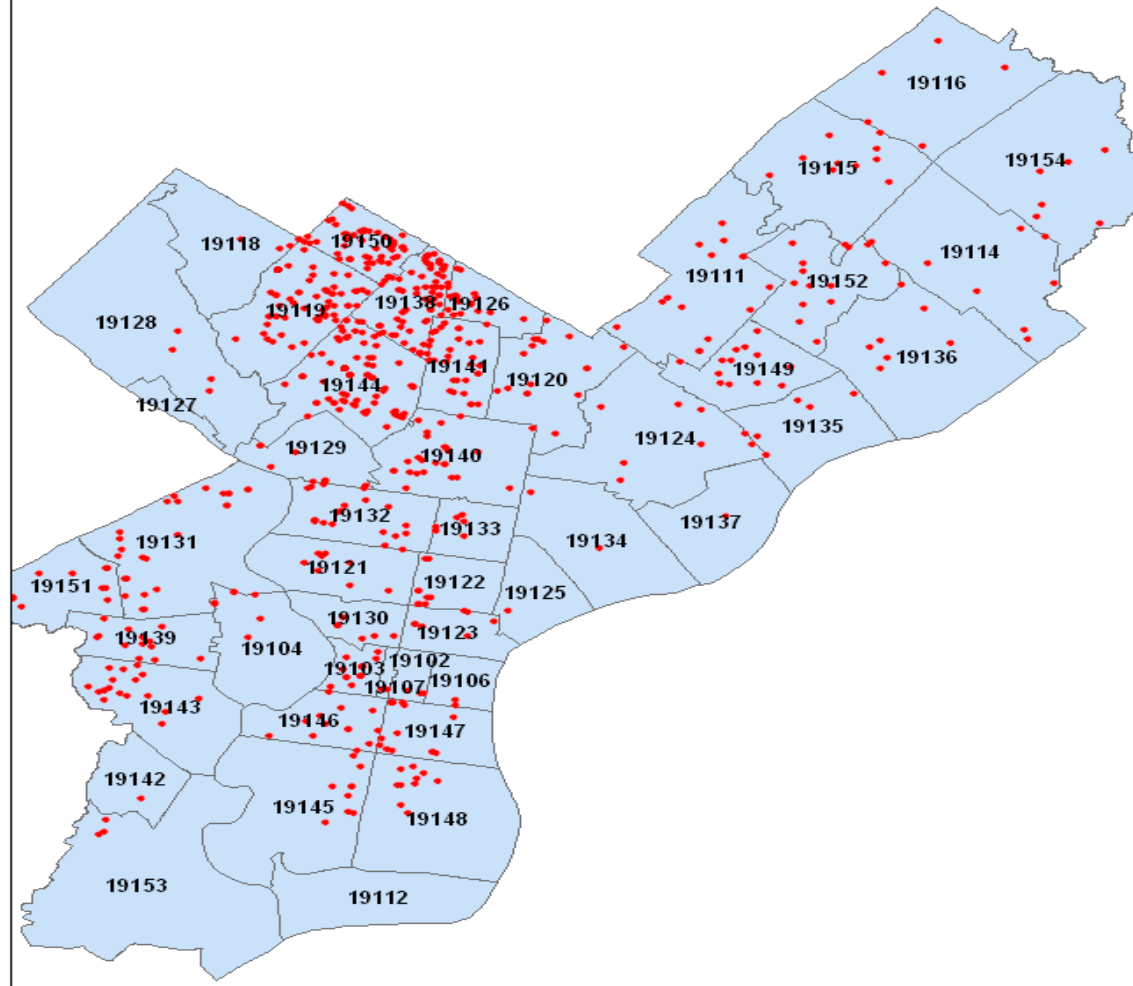
Agency Level:

- ◆ **Partnering with agencies/community groups is key to enhance:**
 - Outreach and building community trust
 - Name and frame study and recruitment materials
 - Brochure development
 - Effective recruitment strategies
- ◆ **Evaluation of partnership:**
 - Strength of partnership (use collaborative questionnaires)
 - # of study referrals and enrollees
 - Agency feedback of their member's experience
 - Agency willingness to continue participation in recruitment efforts
 - Key informant interviews with administrators
 - Agency satisfaction with partnership:
 - What does agency need?
 - Did they get the return on investment they were looking for?

Embedding Evaluation in Outreach Activities

- ◆ **3 approaches varying in resource intensity:**
 - Letter to Adult Day Centers asking to schedule a no-cost in-service about dementia and our studies
 - Same letter to Adult Day Centers followed by telephone call 2 weeks later
 - Same letter, telephone call, followed by either e-mail and check-in call one month later or face-to-face visit
- ◆ **Evaluation of yield of each approach as to:**
 - # of in-services scheduled
 - # of mailings implemented

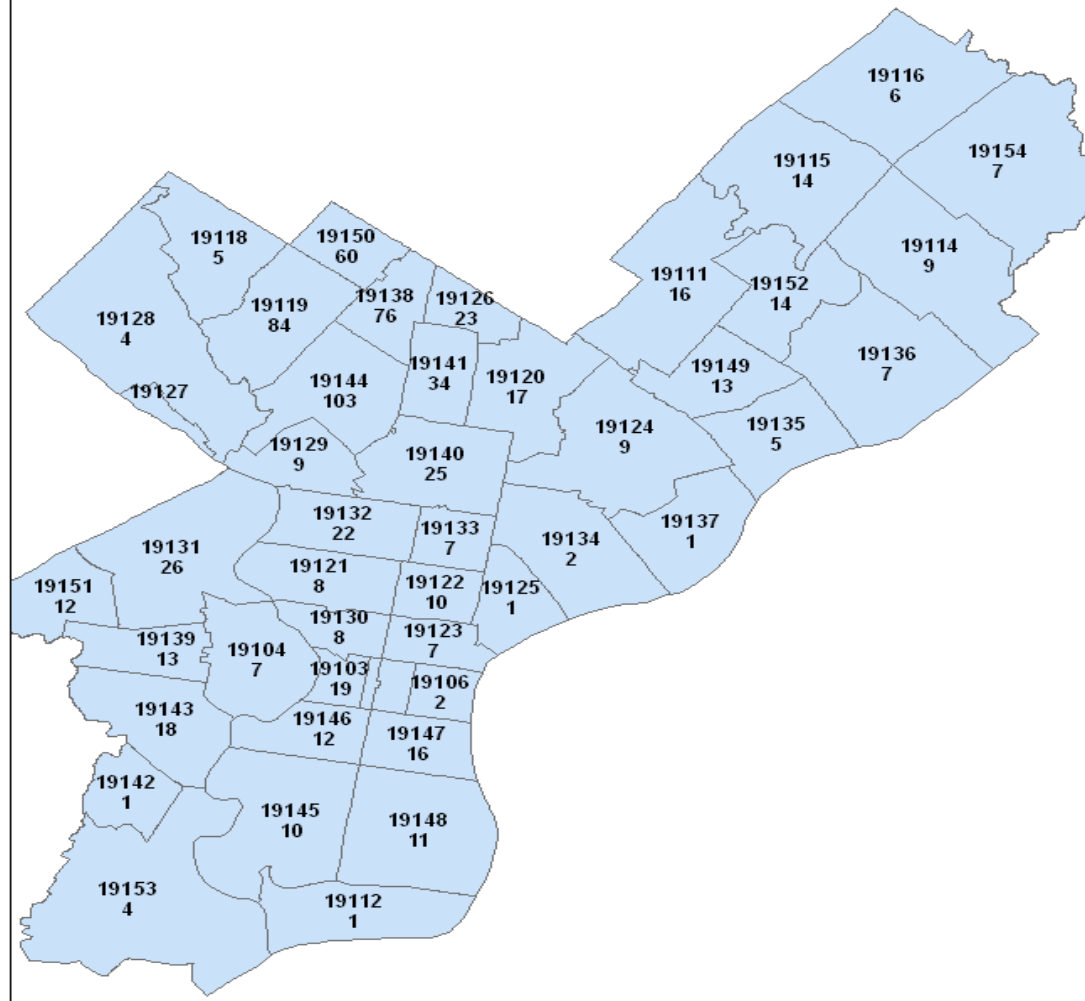
Location of CARAH Patients
By Philadelphia County Zip Code



**Community
Level:**

**Geographic
Information
System**

Number of CARAH Patients By Philadelphia County Zip Code



0 1.25 2.5 5 7.5 10
Kilometers



**Evaluation of
community
penetration
using
GIS overlay
With:**

- ◆ Census Tract
- ◆ Agency partnerships

Tracking Recruitment Activity

Recruitment Source	Referrals and Inquiries	Enrolled Participants	Yield (%)
Direct Mailings	158	138	.87
Media announcements	72	62	.86
Conferences/Fairs	5	4	.8
Presentations	5	3	.33
Miscellaneous	43	35	.81
Total	283	242	.86

Details of Direct Mailings

Recruitment Source	Referrals/ Inquiries	Enrolled Participants	Yield (%)
Adult day centers	62	58	.93
Alzheimer's Association support groups	4	4	1
Family caregiver support programs	19	15	.79
Geriatric medical practices	31	24	.77
Home health care	4	4	1
Paratransit (CCT)	3	2	.67
CARAH subject registry	34	30	.88
Senior center	1	1	1
Totals	158	138	.87

Tracking Considerations

- ◆ **Breakdown each recruitment method:**
 - Characteristics of enrollees of interest (e.g., race, gender, SES)
 - Ratio of inquiry/eligibility/enrollment
 - Inputs (personnel, materials)
- ◆ **Track Cost:**
 - Personnel involved
 - Time spent
 - Materials

The Long View

- ◆ **On-going evaluative framework critical:**
 - Infrastructure for documenting and tracking recruitment across studies/activities
 - Dedicated personnel, tracking data base
 - Activity embedded in the conduct of science
- ◆ **Following each recruitment activity conducted document:**
 - What worked
 - What did not work
 - What was implemented
 - Lessons learned
 - Future modifications to messaging

IV. Cross-site Considerations

- ◆ **Identify a broad working model for cross-site analyses and which allows for site-specific variations**
 - Logic model
 - Bennett's hierarchy
- ◆ **Identify site-specific needs, measures and cross-site needs, measures**
- ◆ **Establish templates for cross-site use at every level of evidence**
- ◆ **Use standardized scales, agreed upon items**

Take Home Points

- ◆ **Evaluation is strategic and on-going:**
 - Identify clear purpose of evaluation
 - Identify criteria for success
 - Target evaluation and collect targeted useful information
- ◆ **Limited funds to formally test different strategies:**
 - Leverage opportunities:
 - Workshop with caregivers can also be used to evaluate caregiver willingness to pay for such services
 - Build on existing literature
 - Continuous evaluation of all major activities
- ◆ **Cross-site evaluation strongest to show overall societal impact**

References

- ◆ Bandura, A. (1997). Self-efficacy: The exercise of control. W.H.Freeman & Co., N.Y.
- ◆ **Bennett, C.F. (1976). *Analyzing impacts of Extension programs*. Washington D.C., U.S. Department of Agriculture Extension Service, No. ESC 575.**
- ◆ Czaja, S. J., Gitlin, L. N., Schulz, R., Zhang, S., Burgio, L. D., Stevens, A. B., Nichols, L. O., & Gallagher-Thompson, D., (2009). Development of the risk appraisal measure (RAM): A brief screen to identify risk areas and guide interventions for dementia caregivers. *Journal of American Geriatrics Society*, 57, 1064-1072.
- ◆ DePoy and Gibson, *Evaluation Practice*, XX
- ◆ DePoy and Gitlin, *Introduction to Research: Understanding and Applying Multiple Strategies*
- ◆ Gitlin, L. N., Winter, L., Dennis, M. P. & Hauck, W. (2006). Assessing perceived change in well-being of family caregivers: Psychometric properties of the perceived change index (PCI) and responses patterns. *American Journal of Alzheimer's Disease and Other Dementias*, 21(5), 304-311.
- ◆ Gitlin, L. N. Winter, L., Dennis, M., Corcoran, M, Schinfeld, S. & Hauck, W. (2002). Strategies used by families to simplify tasks for individuals with Alzheimer's disease and related disorders: Psychometric analysis of the task management strategy index (TMSI). *The Gerontologist*, 42, 61-69.

References con't

- ◆ Glasgow, RE. Evaluation Models for Theory-Based Interventions: The RE-AIM model. In Glanz K, Rimer BK, & Lewis FM, eds. *Health Behavior and Health Education: Theory, Research, and Practice*. 3rd ed. New York, NY: Jossey-Bass; 2002:531-544.
- ◆ Hinrichsen, G. A., & Niederehe, G. (1994). Dementia management strategies and adjustment of family members of older patients. *The Gerontologist*, 34, 95-102.
- ◆ **W. K. Kellogg Foundation, Logic Model Development Guide**
- ◆ **Schulz et al., In Search of Clinical Significant, TG 2002**

Helpful Evaluation Web Sites

- ◆ Harvard Family Research Project - describes 8 different models:
http://www.hfrp.org/evaluation/the-evaluation-exchange/issue-archive/evaluation-methodology/eight-outcome-models#_ftn3
- ◆ University of Wisconsin Program Development and Evaluation Unit - provides training and technical assistance to plan, implement and evaluate high quality educational programs
<http://www.uwex.edu/ces/pdande/>
- ◆ Bennett, C. F., & Rockwell, K. (1996). Targeting Outcomes of Programs (TOP): An Integrated Approach to Planning and Evaluation. Washington, DC: CSREES, USDA
<http://citnews.unl.edu/TOP/index.html>;
- ◆ Clinical research brochure for African Americans
<http://www.ciscrp.org/e-store/brochure-aa.asp>
- ◆ Dick, B. (2006) *The Snyder evaluation process* [On line]. Available at
<http://www.scu.edu.au/schools/gcm/ar/arp/snyder.html>