

Summary Report

The Forgetting: A Portrait of Alzheimer's

A Project on
Impact Assessment
of Outreach Activities

A study initiated by the National Center for Outreach
and funded by the Corporation for Public Broadcasting





The National Center for Outreach (NCO) was founded in 1999 with the vision of helping Public Television stations become better connected to their communities through community outreach.

The overall mission is to extend the impact of public broadcasting and to engage and foster community participation through public broadcasting. NCO's goals are to provide resources, training and funding for PBS stations, promote meaningful outreach at the local level and expand the impact of public broadcasting efforts through assessment and effective partnerships.

Fall 2004

Introduction & Project Overview

The Need for Impact Assessment

PBS stations are increasingly facing the challenge to measure the impact of programming and outreach services being provided to local communities. The National Center for Outreach (NCO) is working to make the task of impact assessment realistic for public television stations. This report is one of the first steps the NCO has taken toward developing the necessary tools for impact assessment.

The NCO is currently working with Transition Assistance Programs, Inc. (TAP) to develop a variety of outreach impact assessment tools. These tools will help stations measure the impact of outreach services being provided to their communities.

One of the first tasks was to conduct an impact assessment of outreach activities organized around *The Forgetting: A Portrait of Alzheimer's*. With the help from Twin Cities Public Television (TPT), three stations were recruited to work with TAP to first define obtainable goals with intended impact, and then create templates for outcome measurement.

The summary report that follows explores how the assessment for *The Forgetting* outreach was conducted, provides major findings obtained from the data collection, lessons learned from the assessment as well as outlines next steps for developing impact assessment tools. The National Center for Outreach convened a committee of outreach professionals in June 2003 to comment on the state of outreach impact assessment in public television. This committee concluded that authentic outreach assessment would benefit public television stations by:

- Enhancing public perception of the station as a convener of social change;
- Leveraging time and resources through better design and implementation of outreach activities;
- Gaining greater clarity of outreach goals; and
- Developing the station's capacity to communicate outreach impact to their stakeholders.

Just to know that we're not alone and that there are other people who are struggling too. The workshop helped me to get a sense of that and that there are other people and help out there.

In addition, this committee concluded that the field would benefit from:

- The creation of a set of outreach impact tools that can be adapted for use in a variety of outreach contexts;
- The identification of a set of standardized outreach impact goals and indicators; and
- The provision of a model for conducting, reporting and disseminating outreach impact. Transition Assistance Programs (TAP), Inc. was contracted by The National Center for Outreach to conduct an Impact Assessment of outreach activities organized around *The Forgetting: A Portrait of Alzheimer's*. This assessment was focused around the following objectives:

To provide an examination of outreach activities organized around *The Forgetting: A Portrait of Alzheimer's* for the following sites:

- **KCPT** – Kansas City's outreach efforts included two caregiver's workshops, a children's caregiver workshop and phone bank.
- **MPTV** – Montana focused their outreach efforts on sixteen viewing and community organizing sessions, a phone call center and web site.
- **PBS.Org** – *The Forgetting* Web site was the national site for *The Forgetting* broadcast and included information about Alzheimer's, resource links and "The Living Center" a place where caregivers, family members and care recipients could participate in activities together.
- **WHYY** – Philadelphia's work around *The Forgetting* was supplemental to their local health initiative. Their efforts included a resource guide and phone bank.

The purpose of this outreach assessment is three fold:

Provide an analysis of outreach impact that is supported by both quantitative and qualitative data; This includes testing assumptions

of audience composition, audience needs, outreach materials and methods associated with anticipated impact. Examining limitations in outreach impact assessment and the ability to address impact. To then provide prescriptions for pursuing successful outreach in the future.

- Test assumptions of audience composition, audience needs, and outreach materials and methods associated with anticipated impact;
- Examine limitations in outreach impact and the ability to address impact; and
- Provide prescriptions for pursuing successful outreach in the future.

Understand the dynamics of conducting outreach impact assessment in Public Television to develop an assessment strategy that would produce the following:

- A set of common methods that can be used across a variety of outreach programs;
- A set of common impact indicators that can be utilized across a variety of outreach programs and sites;
- The creation of an outreach assessment model that will enable outreach managers to engage in assessment design early in the outreach project design process; and
- Facilitate a greater degree of dialogue between outreach sites and projects.

Development of Outreach Impact Assessment Tools and Templates:

- *The Forgetting* assessment is designed to produce a set of tools that can be adapted for use in a variety of outreach projects in public television. These tools will assist outreach managers in collecting both “real time” data from outreach participants as well as provide a set of procedures to conduct longitudinal investigations of outreach impact.

*[Through networking]
we had a woman step
forward and said that
she would be a support
group contact person.
Our nursing home
was there and she said
that she had paper
work on her desk about
joining the Alzheimer's
association and now
she will join.*

Impact Goals

This outreach assessment is based on data collected through surveys and interviews with outreach participants and interviews of stakeholders in each of the four sites. Data was collected in “real time” as participants interacted directly with the outreach activity and as part of a follow-up phase occurring one to two months after the outreach activity to examine long-term impact. Although each site had distinct goals for the project, there was considerable overlap in both short and long-term outreach goals. In general, the impact measures around *The Forgetting* were based on the following three themes:

1. Learning/Awareness Raising

- Enhanced knowledge about Alzheimer’s Disease.
- Enhanced knowledge about the resources available to Alzheimer’s caregivers.
- Enhanced access to caregiver resources.
- Enhanced ability to navigate through available resources.
- Enhanced knowledge of caregiver tools and techniques.

2. Attitude Change

- Enhanced perception of the station as a convener of social change.
- Reduction in feelings of isolation.
- Enhanced awareness and openness to sharing the burdens of the caregiver role.
- Enhanced empathy towards care recipients and other caregivers.
- Enhanced perspective in regard to the caregiver experience.

3. Behavioral Change

- Implement new techniques into practice.
- Improve ability to communicate with care recipients.
- Decrease stress, anxiety and workload associated with caregiver demands.
- Seek out new resources via web sites, support groups and user guides.
- Enhance ability to form relationships with care recipients
- Formulate community response plans.
- Improve quality of care provided.

The data obtained in the surveys, interviews and Web-surveys provided both quantitative and qualitative indicators. The following conclusions are based on an analysis of the survey, interview and Web-survey data:

A. Learning/Awareness Raising

There was significant evidence to suggest that participation in outreach resulted in enhanced learning and awareness raising about Alzheimer's Disease and the resources available to caregivers. In addition, outreach participants reported an enhanced ability to acquire and process available information thereby increasing their ability to be effective consumers of information.

Specifically, participation in *The Forgetting Outreach*:

- Enhanced learning about Alzheimer's Disease.
- Increased awareness of Alzheimer's Disease caregiver resources.
- Enhanced awareness of the resources available to caregivers.
- Enhanced the ability to navigate through the vast amount of available resources.

B. Attitude Change

There was considerable evidence to suggest that outreach participation facilitated attitude change, most notably in the areas of enhanced empathy and patience in their role as caregivers. Participants also reported that outreach caused them to feel a greater sense of predictability, control and validation in their role as caregivers

Specifically, participation in *The Forgetting Outreach*:

- Reduced caregiver feelings of isolation.
- Increased the likelihood of sharing the burden of the caregiving role.
- Enhanced empathy towards Alzheimer's Disease care recipients.
- Motivated the desire to learn more about Alzheimer's Disease.

Major Findings

It helped “mobilize” me and enabled me to realize that it was OK for my Dad to reside in an assisted living facility where he had care 24 hours per day, and that making this decision did not mean that I had failed him as a daughter.



C. Behavioral Change

Although evidence of behavioral change was less frequently observed in this assessment, outreach participants reported changes in their behaviors relating to relationship formation and communication with care recipients.

Specifically, participation in *The Forgetting Outreach*:

- Enhanced the ability to form mutually beneficial caregiving relationships with care recipients.
- Enhanced the ability to communicate with care recipients with greater patience, understanding and tolerance.

The success of *The Forgetting Outreach* appears to be primarily in the areas of learning/awareness raising and attitude change. Although all four sites identified behavioral goals for *The Forgetting Outreach*, behavioral change was less frequently observed.

Specifically, participation in *The Forgetting Outreach* was not able to:

- Reduce caregiver fatigue.
- Result in an ability to balance the caregiver role with other demands.
- Lead to community action or coalition building.
- Cause individuals to utilize the resources presented in Community Resource Guides.

The findings obtained and reported in this assessment were used to formulate a set of recommendations for enhancing outreach efforts in the future. Although each recommendation presented here applies to specific attributes of *The Forgetting* Outreach, they are intended to be applicable to any outreach activity pursued in public television.

Awareness raising is a precursor to behavioral change.

The outreach activities were most successful in informing participants about Alzheimer's Disease, raising awareness of the vast amount of resources available to caregivers and enhancing the ability to navigate through the vast amount of available resources. Sustained behavioral change was less frequent.

Sustained behavioral change requires ongoing contact with outreach participants, beyond that pursued in these outreach activities. In some cases, the outreach goals identified by some sites were not realistic given the limited resources, meeting times, and training provided as part of the outreach.

Outreach designed to produce sustained behavioral change would require:

- Significant outreach participant role clarification;
- A structured guide to direct action;
- Multiple and frequent meeting times to clarify and reinforce desired behavior;
- Clearly identified behavioral outcomes;
- Consistency between the goals of outreach participants and targeted behavioral change; and
- A commitment of outreach participants to engage in behavioral change.

People request resource guides for general knowledge.

Contrary to expectation, the resource guides compiled and distributed by station affiliates were not utilized to address the

Lessons Learned

specific immediate needs of primary caregivers. Instead, most reported requesting caregiver guides for future reference.

The typical user acquired the caregiver's guide for general knowledge of caregiver resources rather than to address a specific problem or concern. In addition, few users contacted agencies, Web sites or any other resources within the first two months after receiving the caregiver's resource guide.

Outreach succeeds in making people feel less isolated in their experience.

Outreach participants reported benefiting greatly from hearing about the experiences of other caregivers, sharing advice and participating in outreach in an effort to gain peer support. Outreach participants reported a greater likelihood of sharing caregiver tasks with others, specifically other family members. Interaction with individuals in similar situations allowed caregivers to feel validated in their experience and to feel they have some added predictability and control in their role.

Outreach succeeds in providing the ability to be better consumers of information.

Many outreach participants reported being discouraged by information overload and the resultant confusion about finding the resources that are best for their specific needs. One of the big successes in this project is that outreach participants reported greater efficacy in searching, accessing, and assessing caregiver resources.

To be more effective, outreach efforts need to better target audiences.

The outreach audience examined in this assessment was diverse in terms of caregiver role and relationship to Alzheimer's Disease. Outreach participants consisted of primary caregivers (individuals providing care directly to a care recipient), secondary caregivers (individuals providing supplemental care to a primary caregiver),

We already knew and understood that she didn't do things on purpose, but we thought she did. The workshop made us definitely understand that these things were not done on purpose.

health care professionals (individuals who are involved in the care of Alzheimer's patients not as a friend/family member, but in their employment role), and researchers/students (individuals who have an interest in Alzheimer's Disease from a scholarly point of view).

Each of these individuals were stratified across the activities offered at the four sites. These groups participate in outreach with different goals and benefited from different types of resources. Public Television stations had assumed that most participants in outreach would be primary caregivers. However, this was found to be the case only one third of the time. The majority of participants in real time activities (e.g. workshops, phone banks) were secondary caregivers. Web survey respondents were mostly caregivers in either a primary or secondary capacity, while a minority were healthcare professionals or researcher/students.

The outreach activities pursued in this project would have benefited from a greater degree of customization to meet the needs of each of these stakeholder groups. Primary caregivers would have benefited the most from user guides, peer sharing groups, and instruction on specific caregiving techniques. In addition, this group would have benefited greatly from follow-up sessions designed to reinforce desired behaviors.

Secondary caregivers would have benefited from a greater understanding of their role, the degree to which they can support the efforts and provide relief to the primary caregiver. Healthcare professionals would have benefited from insight on how they can work more effectively in collaboration with primary caregivers and friends/family members of care recipients. Researchers/students were most interested in information about the disease, specifically on the biological aspects of disease progression and the latest breakthroughs in pharmacological and behavioral treatment methods.

My brother is the primary caregiver for his sister and we went to the workshop together. But the workshop was very good for him. He was able to meet people and talk to them and support each other. It was important that one of these people is another man and another caregiver in his shoes.

Impact Assessment Tools & Templates

The National Center for Outreach convened a group of outreach professionals in 2003 to comment on the state of outreach impact assessment in public television and provide a set of recommendations for enhancing this practice. This group concluded that a need exists to provide a set of common outreach impact assessment indicators, a set of impact assessment tools that can be modified to address a wide range of outreach activities and sites, and training and development in the data collection and analytical methods involved in outreach impact assessment. The tools presented in this section represent a first step in this process. These tools are designed to be a resource for the field that will facilitate the collection of assessment data in an efficient manner, provide a standardized set of impact indicators, and facilitate comparisons between sites and outreach projects.

Transition Assistance Programs, Inc. worked in collaboration with each of the four assessment sites to generate a set of impact assessment tools customized to meet the needs of each individual site. Each tool was comprised of multiple indicators designed to provide quantitative and qualitative evidence of goal attainment.

Each tool was created through an iterative process of item generation, refinement and pilot testing to ensure reliability and validity. In this process, the station managers provided most of the wording for survey and interview items. There was a high degree of convergence between the sites in terms of the content and structure of these measurement instruments. Each instrument contains a section asking participants for permission to be contacted for follow-up feedback. This will enable outreach managers to compile a database of volunteers for longitudinal impact feedback.

The data collection instruments formulated for this project yielded the following eight generic tools that can be easily adapted for a variety of outreach programs and sites:

- **Viewer Survey:** This instrument is designed to assess viewer reactions to any type of PBS programming. It provides indicators of program perceptions, learning, attitude change, and perceived likelihood of behavioral change.

- **Workshop/Event/Educational Survey:** This instrument is designed to assess reactions to any type of classroom based outreach activity. It provides indicators of program perceptions, learning, attitude change, and perceived likelihood of behavioral change.
- **Workshop/Event Follow-up Protocol:** This instrument is designed to assess long term impact of any classroom/ workshop based outreach activity. It provides a mechanism to quantify data obtained through interviews or open ended survey items. In addition, it provides for the collection of testimonials focused on impact.
- **Web Interface Survey:** This instrument is designed to assess real time Web site user reactions. It provides indicators of Web site usability, perceptions of the usefulness of Web site resources as well as estimates of impact.
- **Web Impact Survey:** This instrument is designed to measure how Web site users were impacted by Web site content.
- **Phone Bank Profile:** This instrument is designed to profile phone bank callers and document their requests and preferences.
- **Phone Bank Follow-up Interview Protocol:** This instrument is designed to assess the impact of resources distributed through a phone bank by providing a structured set of questions and response coding options for follow-up interviews.
- **Community Response Survey:** This instrument serves as a planning guide and assessment tool for any community planning activity. It will allow for community response plans to be panel assessed in a systematic and standardized fashion.

I am certainly more educated in the role of caregiver, thanks to both the program and Web site. I find myself regularly checking the Web site for any new added information in all aspects of Alzheimer's.

Measuring Impact

One of the major objectives for the project is to provide insight into the process of conducting outreach impact assessment in public television to aid in the design and implementation of future outreach impact assessment efforts. Our experience in this project leads us to make the following conclusions:

- **Participants are willing to give contact information:** Approximately 70% of all outreach participants agreed to be contacted in the future for follow-up feedback on program impact. This is an unusually high response rate for this request. We found this rate to be consistent for all of the sites and data collection instruments employed in this study. This provided us with a list of willing participants for follow-up interviews. Since most impact occurs after the outreach experience, the ability to study impact longitudinally is essential to determining outreach impact.
- **Participants are willing to fill out Web surveys:** This project utilized two Web surveys. In each case, approximately 10% of the population filled out these surveys and supplied detailed qualitative responses to open ended questions. This provides optimism for using Web-based data collection instruments in the future. In addition, this allows for the collection of both real time user interface feedback as well as data that requires reflection and time.
- **People want a forum to exchange personal stories:** Outreach participants seem to benefit from the ability to compare experiences and exchange caregiving methods with their peers. Contrary to expectations, individuals used the Web-surveys as a forum to tell their story, request resources and make contact with relevant individuals and agencies. This suggests that the Internet may provide a powerful tool to establish online dialogues, list-servs, and informational bulletin boards as a formal part of the outreach process.
- **Authentic outreach impact assessment requires follow-up:** In most cases, outreach assessment is based on data collected as people interact with the outreach activity.

At best, impact is measured by self reports of what people expect to do. There is often a disconnect between this and what people actually do to apply the content/experiences presented in outreach activities. This project relied on interviews with outreach participants one to two months after participation to document how outreach actually affected learning/awareness raising, attitudes, and behaviors.

- **Outreach impact assessment should examine changes in learning/awareness raising, attitudes and behaviors:**

One of the goals of this project is to begin the process of establishing a set of common indicators that can be used to measure outreach impact across a variety of sites and projects. This project utilized impact measures based on the following model:

1. Learning/awareness-raising

- Changes in knowledge about the outreach topic.
- Changes in knowledge about how to find out more about the outreach topic.
- Changes in knowledge about applying the topic to your or other's context.
- Changes in awareness about the importance and pervasiveness of the outreach topic.

2. Attitude Change

- Changes in beliefs or feelings relating to the outreach topic.
- Changes in efficacy relating to the outreach topic.
- Changes in perceptions of relevance of the topic to you or others.

3. Behavioral Change

- What are you or others doing differently as a result of participating in outreach?

I am better able to take care of myself physically, emotionally and spiritually. I now also know that what I am experiencing is normal for Alzheimer's patients and their caregivers.



This model can be readily adapted to fit any outreach activity and it gives outreach managers the ability to engage in a common dialogue regarding impact along these three themes. However, it gets progressively more difficult to move from learning to behavioral change.

In sum, effective impact assessment requires:

- The assessment process needs to be designed at the beginning of an outreach initiative;
- All key stakeholders – partners and Public Television stations should be involved in the process of assessment design and given a voice in reporting impact;
- The employment of strategies designed to obtain follow-up feedback; and
- Station personnel need to understand the benefits of providing authentic impact data.

Outreach helps people in the community who have these problems and don't know who to talk to. It's a real help to them.

This assessment suggests that it is both practical and viable for outreach managers to collect, analyze and report authentic outreach impact assessment data. We were able to collaborate with station managers and other relevant stakeholders to design and implement a variety of assessment tools, collect quantitative and qualitative “real time” and “longitudinal” indicators of impact, and provide meaningful results and recommendations for each of the four project sites.

This outreach impact assessment provided compelling evidence that participation in *The Forgetting* Outreach facilitated greater learning and awareness raising. Specifically, participants learned about Alzheimer’s Disease, became more aware of available resources and learned how to navigate through the vast amount of available information and resources relevant to Alzheimer’s caregivers.

In addition, this assessment provided compelling evidence that outreach participation facilitated attitude change. Specifically, participants reported acquiring greater empathy and patience as well as increased openness to sharing the demands of the caregiver role with other care providers. Participants also reported that outreach caused them to feel a greater sense of predictability, control and validation in their role as caregivers.

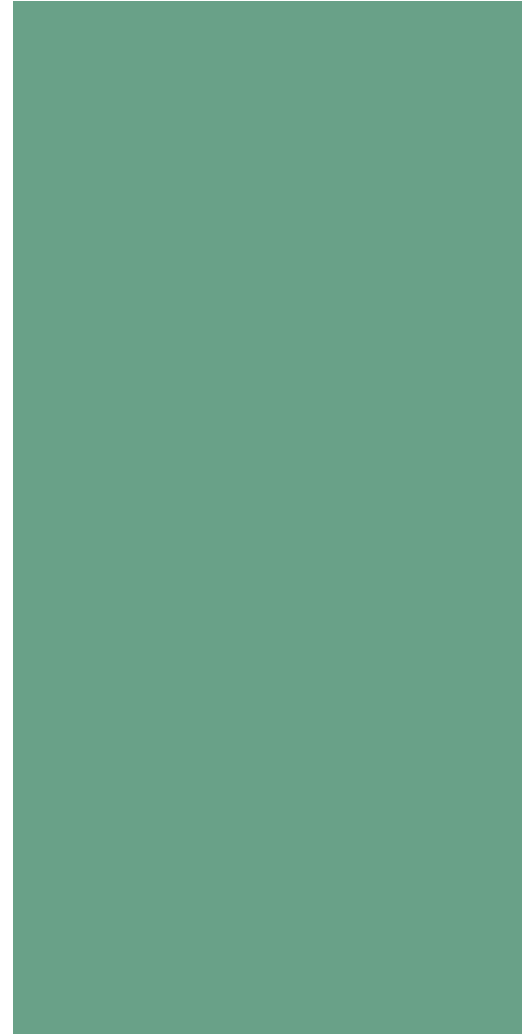
Finally, although behavioral change was less frequently observed, outreach participants reported an increase in effective communication and relationship building methods. In addition, a small minority of outreach participants reported seeking out the support of others or connecting with resource groups in their local community.

This assessment provides the first step in the provision of a set of methods, tools and reporting models to the field. However, success in future assessment efforts depends on creating a sense of efficacy and ownership in the assessment process by outreach managers.

Overall Summary & Conclusions

Future effort in this area should be directed towards the provision of the following:

- The development of an online Outreach Impact Assessment Primer that is field endorsed, searchable by term and customizable to meet the diverse needs of the Public Television Outreach community. This primer will contain an overview of the major concepts involved in impact assessment, examples of effective assessment practices, instructional guides to the most commonly used assessment methods, and a list of relevant resources to assist in assessment practice.
- The development and implementation of an online Assessment Toolbox designed to address the diverse assessment needs of this community through the provision of a set of interactive templates for building and implementing the most commonly used assessment tools. The eight tools designed for this assessment represents a first step in this process. The resources contained in the toolbox will focus on assessment planning and management, data collection and analysis, assessment reporting and dissemination and strategies for financing the assessment component of outreach projects.
- The design and implementation of a comprehensive training and development program that addresses the fundamentals of Outreach Impact Assessment and provides hands on experience in the implementation of these methods in the field. It is critical that outreach managers receive instruction on the effective use of the primer and toolbox as well as access to mentors to assist them through the process. With these steps, the vision of authentic outreach impact assessment in public television is not only possible, but practical.



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