



The Savvy Caregiver in Indian Country

TRAINER'S MANUAL

PART ONE Introduction for Indian Country

A Product of

National Minority Aging Organization Technical Assistance Center for
the Development of Dementia Care Resources for American Indians and Alaska Natives

at the

National Indian Council on Aging Albuquerque,
New Mexico

ADMINISTRATION ON AGING
NATIONAL INDIAN COUNCIL ON AGING
UNIVERSITY OF OKLAHOMA HEALTH SCIENCES CENTER

REV: 7/23/21 by the International Association for Indigenous Aging
www.iasquared.org



AMERICAN INDIAN
and ALASKA NATIVE
RESOURCE CENTER FOR BRAIN HEALTH

For further information about the revised version of *The Savvy Caregiver in Indian Country*, contact:

International Association for Indigenous Aging
11101 Georgia Ave. #320
Silver Spring, MD 20902
(301) 861-0632
admin@iasquared.org

Revisions were supported by the Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$348,711 with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

The original project was supported in part by grant number 90HD0004 from the U.S. Administration on Aging, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

©2021 National Indian Council on Aging, Inc. & International Association for Indigenous Aging

Based on the original Savvy Caregiver program tested and implemented by the University of Minnesota:

Kenneth Hepburn, PhD
Marsha Lewis, PhD, RN
Jane Tornatore, PhD
Carey Wexler Sherman, MA
Judy Dolloff, MSW

Original program development supported by grants from:

The Alzheimer's Association
UCare Minnesota Foundation

For further information about the original Savvy Caregiver Program, contact:

Kenneth Hepburn, PhD
Emory University, Atlanta, GA
404-712-9286

Principal Author

J. Neil Henderson, PhD (Oklahoma Choctaw), Professor Emeritus

Organizations

International Association for Indigenous Aging (Revisions 2021)

National Indian Council on Aging, Albuquerque, NM

University of Oklahoma Health Sciences Center, Oklahoma City, OK

Alzheimer's Association, New Mexico Chapter, Albuquerque, NM

Banner Alzheimer's Institute, Phoenix, AZ

Caddo Nation of Oklahoma, Binger, OK

Inter Tribal Council of Arizona, Phoenix, AZ

Laguna Rainbow Corporation, Laguna, NM

Zuni Senior Center /Adult Day Care, Zuni, NM

Individuals

Angus Abeita, MSW (Laguna), National Indian Council on Aging,
Albuquerque, NM

Cecelia D. Aldridge, Administration for Community Living /Administration
on Aging, Washington, DC

Thelma J. Atsye (Laguna), Senior Community Service Employment Program,
Laguna, NM

Dave Baldrige (Cherokee), International Association for Indigenous
Aging, Silver Spring, MD

Lee Begay (Navajo), Inter Tribal Council of Arizona, Phoenix, AZ

Randella Bluehouse, BSW (Navajo), National Indian Council on Aging,
Albuquerque, NM

Myles Copeland, Alzheimer's Association, New Mexico Chapter, Albuquerque, NM

Ellen T. Costilla, LISW, New Mexico Human Services Department, Santa Fe, NM

Prudencia Denetclaw (Laguna), Senior Community Service Employment Program,
Laguna, NM

Emily Freede, MA, MEd, National Indian Council on Aging, Albuquerque, NM

L. Carson Henderson, BSN, RN, MPH, PhD, University of Oklahoma
Sciences Center, Oklahoma City, OK

Kenneth Hepburn, PhD, Emory University, Atlanta, GA

Filmer Lalio, BSW, MEd (Zuni), Banner Alzheimer's Institute, Phoenix, AZ

Karen Leekity (Zuni), Zuni Elderly Services, Zuni, NM

Archie Mariano (Navajo), Inter Tribal Council of Arizona, Phoenix, AZ

Chris McCaffrey, Alzheimer's Association, New Mexico Chapter, Albuquerque, NM

Linda L. Morales (Laguna), Laguna Rainbow Corporation, Casa Blanca, NM

Carol Swindell (Oklahoma Caddo), Senior Community Service Employment
Program, Binger, OK

Agnes Vallejos, Alzheimer's Association, New Mexico Chapter



CONTENTS

PART ONE Introduction for Indian Country

Section A	Orientation and Using the Manual	9
Section B	Savvy Program Overview	13
Section C	Culture and Caregiving: <i>Adapting the Savvy Program to Any AI/AN Culture</i>	23
Section D	Structure and Format of the Savvy Classes	35
Section E	Family First in Indian Country	45
Supplement	Benefits of Taking the Savvy Training	49

PART TWO Class Sessions

Session 1	Caregiving and Dementia Basics
Session 2	Self-Care and Caregiving Strategies
Session 3	Contented Involvement and Dementia Stages
Session 4	Structuring Support and Understanding Behavior
Session 5	Applying Skills and Managing Day-to-Day
Session 6	Strengthening Families as Resources of Care



PART ONE

Introduction for Indian Country



Page intentionally left blank.

Section A

ORIENTATION AND USING THE MANUAL

Orientation

The *Savvy Caregiver in Indian Country Trainer's Manual* is designed for use by all American Indian and Alaskan Native people caring for an elder with memory loss and thinking problems, referred to as dementia. "Dementia" is a general term for brain diseases or injuries that lead to increasing memory loss and thinking problems. Alzheimer's disease is one of the types of dementia. This manual will use the word "dementia" because it applies to many brain diseases that cause memory and thinking problems.

The original Savvy caregiver program was developed and tested in urban areas with members of the majority population. Testing showed that it was a very good way to teach caregivers the best skills for achieving "Contented Involvement" for the elder with dementia. "Contented Involvement" occurs when elders with dementia participate with the family *at their level of ability*. The course will teach caregivers how to know at what level of ability the elder is functioning and what types of activities are best at that time.

Of course, caregiving is a "two-way street." The Savvy concept helps caregivers have less stress because the elder with dementia is involved in daily life in ways that fit their changing abilities. One of the main themes of the *Savvy Caregiver in Indian Country Trainer's Manual* is to teach caregivers to know the stage of dementia corresponding to their loved one's functioning. The stage of dementia changes over time. Knowing how to determine the stage allows the caregiver to use activities and tasks that fit the elder's changing abilities. This results in more hours of "Contented Involvement" for the elder and much less upset. Also, caregivers have a better quality of life because they are not as heavily stressed.

Since caregiving is a difficult and time-consuming role, caregivers may need encouragement to set aside the time for this valuable class. It is a good idea for Savvy Trainers to explain why and how the course will help caregivers. To help you do this, a Supplement is included at the end of this Part One entitled “Benefits of Taking the Savvy Course.”

Using the Manual

You will notice pages with a border and solid white pages throughout the *Savvy Caregiver In Indian Country Trainer’s Manual*. **WHITE PAGES** show you the original *Savvy* training program information. **PAGES WITH A BORDER** are new additions that give you specific thoughts about teaching the *Savvy* classes in Indian Country. Read the white pages first to understand the general class structure, then read the blue pages to learn how to adapt the program for your own tribal community.

Occasionally you will find a special note for Indian Country, indicated by a picture of three eagle feathers:



When you see the icon, read the note carefully because it is written especially for you.

The manual is divided into two parts. PART ONE gives an overview of how the *Savvy Caregiver* program works (**Section B**). It is printed on white pages because this is the original program information. It is followed by a very important “mini-course” on Culture and Caregiving (**Section C**), printed on blue pages because it is written especially for Indian Country.

Section C on Culture and Caregiving shows you how to adapt the Savvy Caregiver program for any American Indian/Alaska Native (AI/AN) culture. The section is only for you and *will not be taught to the caregivers*. This “mini-course” will help you 1) recognize cultural factors occurring in family caregiving that may help or detract from quality care, 2) help caregivers to strengthen their use of cultural factors, and 3) adapt the manual and teaching style to best fit your locale.

Section C teaches you about the importance of culture in caregiving and how to identify parts of culture. AI/AN people have very different cultures and life settings from coast-to-coast so that one, single “way of caregiving” will not fit well everywhere. Examples include how important culture can be to the way people think about their problems and how they problem- solve. There are also pointers on the factors that comprise culture.

Section D describes how the classes are structured, including an overview of your role as a Trainer (Program Leader). **Section E** “Family First

in Indian Country” highlights the importance of family and community in Indian Country. This can help you decide how to modify the class structure or change the sequence of the classes that you teach in your tribal community.

PART TWO of the manual gives an outline for each of the six *Savvy* classes, including references to the PowerPoint slides that you may use when teaching your class sessions. The original *Savvy Caregiver* session outline is highlighted in a white box with a “Session Agenda” clipboard icon at the right. But most importantly: each of the six sessions begins with a set of thoughts and information about AI/AN life and caregiving that are relevant to the lessons in that session. These pages are printed on a blue background, titled, “American Indian/Alaskan Native Savvy Caregiver Trainer Essentials.” You should also modify, delete, or add cultural factors that best fit your area.

AI/AN caregivers have very diverse cultures compared to non-Natives in the United States. For that reason, “Culture and Caregiving” has been added to Part One of the *Savvy Caregiver Trainers’ Manual for Indian Country*. Part Two provides the trainer with thoughts about AI/AN life and ways that are tied to the content of each session. *Parts One and Two, together, provide Indian country with one of the most important weapons against dementia found anywhere: informed and capable caregivers!*

Before You Go . . .

1. You make all the difference!
2. All caregivers need help!
3. Really digging into this material will help you become a *lifeline to caregivers!*

Best wishes as you, the trainer, take up the fight! *And, thank you!*

J. Neil Henderson, PhD (Oklahoma Choctaw)

Page intentionally left blank.

Section B

SAVVY PROGRAM OVERVIEW

What the Savvy Caregiver Program Seeks to Accomplish

Family caregivers serve a critical role in the health care system for persons with Alzheimer's and other dementing diseases. In fact, they are the center of the system—or, in most cases, the non-system. The care that they provide, in all its dimensions, that keeps the person in the community for as long as possible. At the same time, they often remain invisible in the larger system.

Depending on the awareness and sensitivity of clinicians, caregivers may or may not be present when the person with the disease is being examined or questioned. They may or may not be brought into deliberations that result in effective care plans. They may or may not be given information about what is happening to the person or about how to provide care. Not only do family caregivers go through their “unexpected career” with mixed amounts of help and support, but the overall experience also tends to be very harmful to their physical and emotional health. So, family caregivers are in the paradoxical situation of providing great help—help that benefits society (by keeping costs down) as well as the person—and of paying a high personal price to do so.

Savvy Caregiver is a training program for caregivers. It is based on the notion that family members who become caregivers assume a role—caregiving—for which they are unprepared and untrained. The role is usually built on their relationship with the person for whom they care, but the role is different from the relationship. The role is a way of describing the work that they will undertake to care for the person, and that role can be understood in terms of knowledge, skills, and attitude that it takes to be able to do the work, to be successful at it, and to go through the experience with as much reward and as little distress as possible.

You are the leader of this training program. The program is modeled on programs that have been proven in field-tests to successfully increase

caregiver confidence and reduce the adverse effects of caregiving. Savvy, itself, has undergone extensive field-testing to help instill or increase a caregiver's sense that s/he understands that caregiving is a new role that s/he has assumed and that s/he is effective in this role. The terms mastery, competence, self-efficacy, and confidence are all used, both in the Savvy program and in the larger field, to express this sense of self-appreciated effectiveness. The diagram on the next page outlines the theoretical basis of the Savvy program.

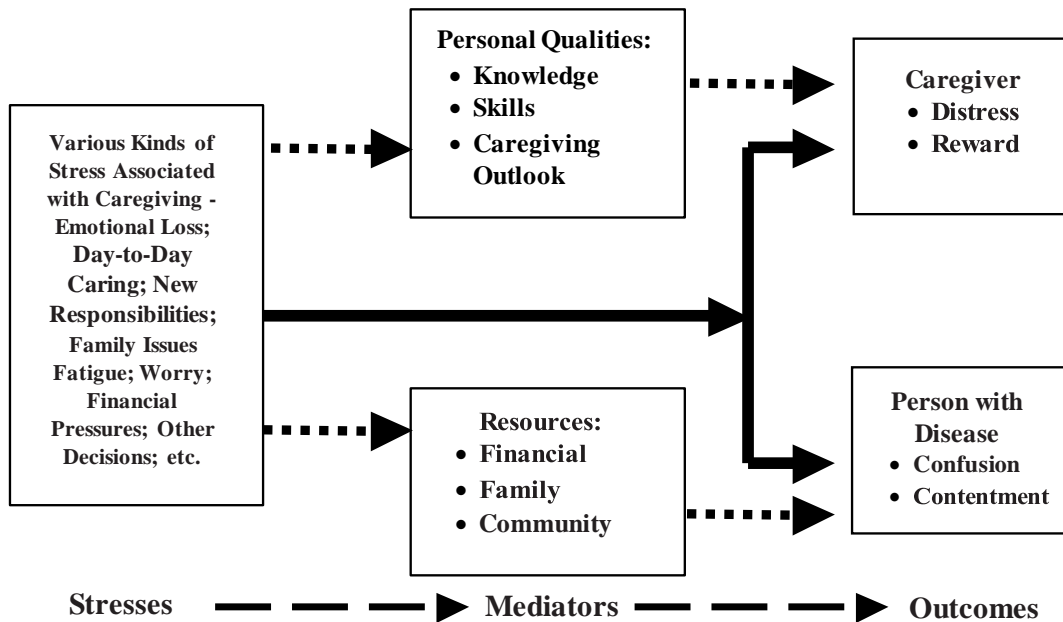
Savvy brings a unique angle to caregiving and caregiver education. The many clinicians and educators who have contributed to the development of the program agree that caregiving is a form of clinical work, and so caregivers need a form of clinical training. Throughout the program—and laced through the various program materials like the Caregiver's Manual—the central concept that is emphasized is the notion of strategy. Over and over in the program, caregivers will be urged to learn, develop, and modify strategies that they will use to accomplish their goal of caregiving—the “contented involvement” of the person with the disease in their daily life.

In order to help caregivers develop such strategies, the program presents ideas from many disciplines and points participants to information from many sources. We don't claim these ideas or this information as our own; we provide citations and web addresses that both acknowledge the sources of these ideas and encourage caregivers to explore further in the work and disciplines cited.** The program offers distillations of these ideas—a particular teaching technique (termed, by some, “psychoeducation”) This approach emphasizes active involvement in learning, independent practice of the ideas presented in group sessions, and very interactive debriefing and coaching that reflects on the practice and experiments that caregivers conduct at home with their care recipients.

*Although the majority of dementia family caregivers are women, a fair number of men also occupy the role. We have tried to acknowledge this—both in the Trainer's Manual and in the Caregiver's Manual—by using masculine and feminine pronouns (like the s/he) throughout.

**Thus, for example, the theory we use as the basis for Savvy and similar programs relies on the work of a number of psychologists. See, for example: Lazarus, R. S., & Folkman, S. (1984), “Coping and Adaptation,” in W. D. Gentry (ed.), *The Handbook of Behavioral Medicine* (pp. 282–325), New York: Guilford.

The Theoretical Basis of the Savvy Caregiver Program



Family caregivers are under a tremendous amount of stress. Not only do they have to deal with the day-to-day reality of the situation—making sure the person gets safely and securely (and, hopefully, pleasantly) through the day—they also must deal with their own feelings of sadness, loss, disappointment, etc. Caregivers typically take on added responsibilities--both within the family (becoming the chief financial officer as well as the full-time laundry and housekeeping staff) and outside of it (managing all the boundaries between the person and the various institutions with which they interact (physicians, nurses, bankers, social workers, lawyers, etc.). They are often faced with added financial pressures (having now to consider spending their own or their loved one's assets on care services). Often, they are also at the center of the cyclone of a family system trying to deal with a situation they don't want and don't understand.

Following the model diagrammed above, these stresses would—if nothing happened to dampen their impact—lead to a series of bad outcomes for both the caregiver and the person with the disease. If the situation were to proceed without anything to moderate it—the condition represented by the solid arrows in the diagram—the caregiver would surely be overwhelmed by the distress of the situation and the person with the dementia would struggle in a situation in which little or none of the confusion of the disease would be moderated by any effective caregiving. The person's quality of life would suffer for this.

Notice that the diagram has a middle portion—the mediators. The theory suggests that mediators are strengthened in a stress situation, and outcomes become more positive. This is the situation represented by the bold dashed arrows. In it, two kinds of mediators—the personal qualities of the caregiver and the number and amount of resources available to help the caregiver—can create more balanced outcomes. In this case, the caregiver still experiences distress, but it is reduced, and s/he also experiences—again, to a greater degree than in the unmediated situation—rewards for caregiving. Similarly, the outcome for the person with dementia is also improved. In the mediated situation, one in which there is more effective caregiving, the person with the disease is likely to have a higher quality of life, one in which they will feel greater comfort and less confusion.

The Savvy Caregiver Training Program

The Savvy program attempts to strengthen the mediators in the stress model presented above. The program's principal focus is on strengthening mediators' personal qualities. The program focuses on helping caregivers acquire and strengthen the knowledge, skills, and attitudes that are appropriate for the role they have undertaken. How caregivers understand and interpret the situation they're in, the kind of knowledge they have about what the disease is doing to their care recipients, the strategies (skills and techniques that are informed by knowledge and improved through practice) they can bring to bear on the situation, and how competent or masterful they feel in the situation (their ability to manage the situation)—all play big parts in determining how much the stress of the situation will result in negative or positive outcomes for caregivers and their family members. The program places less emphasis on strengthening the resource mediators. Sections of the training focus on strategies for strengthening the family as a caregiving resource (involving multiple family members in the Savvy training is recommended), and caregivers are directed to websites (such as those maintained by the Alzheimer's Association and the Administration on Aging) where they might find help identifying community-based resources for caregiving. But the major program emphasis is on the acquisition of knowledge, skills, and attitude for caregiving.

Areas of knowledge, skill, and outlook (attitude) that are taught or developed in the program include:

Information and Knowledge

Many caregivers simply do not have the facts straight about what they are dealing with.

- They don't understand—or believe—they are dealing with a disease that will not improve.
- They don't have a very clear understanding about the course of the disease or it's usually progressive impact on the person with the disease.
- They don't realize, in any specific way, that Alzheimer's and most other dementing diseases progress in stages and that the stage of the disease has great relevance for caregiving strategies.
- They usually don't have any information on the impact of caregiving on caregivers.

Skills

Caregiving is a complex job and entails many tasks. A basic premise of the Savvy Caregiver program is that few caregivers have received any training for the work they do as caregivers. Since the principal task of the caregiver is to manage day-to-day life with the care recipient, the program focuses on these skills. In particular, the program is designed to develop several key skills:

- How to take into account, in their interactions with the care recipient, the person's disease-produced losses.
- How to take the person's disease stage into account in caregiving.
- How to help the person become and remain involved in daily tasks and activities that allow them to be contented throughout the day.

The program also provides instruction in:

- Important self-care skills—especially those related to understanding and managing a caregiver's own feelings.
- Skills for making decisions as they continue their caregiving career.
- Skills for navigating family issues that come up while providing care.

Outlook or Attitude

The program aims to foster an increased sense of mastery in caregiving by affecting at least three areas of attitude:

Objectivity. Caregivers have to learn to become less emotionally involved—at least when they are trying to figure out a caregiving problem—and more “clinically detached.”

- We want caregivers to become more analytic and experimental in their caregiving.
- We want them to be able to step back from the person and the situation and to examine—objectively and dispassionately—just what they are seeing.
- Then we want them to be able to put that observation together with other knowledge they gain from the program to be able to create a plan for what they want to happen and how they will get it to happen.

Self Confidence. Caregivers have to believe they can do the work they have chosen to do. The program fosters growth in self-confidence through the home exercises and in-group coaching that constitute most of the latter part of the program. Caregivers learn new skills through trying them. They become surer of their abilities through the successes they experience in trying them.

Self-Valuing. We want caregivers to appreciate their own work and worth.

- They should be clear about why they have undertaken this role (motives), be able to state the objectives they have in mind for it (what they hope to accomplish), and be able to say what it is they want to get out of it (rewards and satisfactions).
- They should also recognize the need for self-care—that they have an obligation to themselves and the people for whom they are providing care to preserve their own physical and mental health.

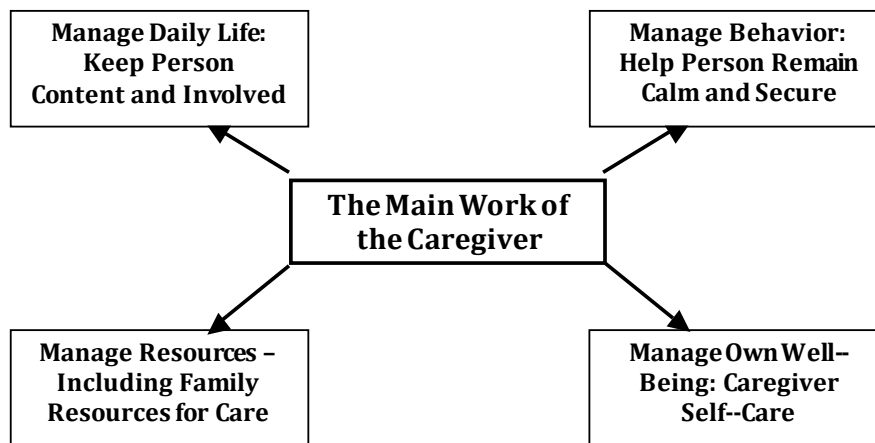
What is the Savvy Caregiver Program About?

The diagram following portrays what the Savvy Caregiver program is about. At the center of the program is the assertion that caregiving is work, a task or role, and that (for almost all who fill the role) it is work for which most caregivers are unprepared and untrained. The Savvy Caregiver program provides training for the caregiving role.

The four boxes surrounding the central focus of the program represent the main content of the program. Each area of content is described briefly below.

Managing Daily Life

This area of content makes up the majority of the program. The first four sessions deal, in sequence, with the impact of Alzheimer's and similar progressive dementias on the person with the disease.



The idea is to take caregivers through the ways in which these diseases affect thinking, feeling, behavior, and the ability to do things in life. Each of these four topics is presented in the same way and with the same objective in mind:

- First, the content of instruction—and this material is typically provided both in the form of a talk that you can give and in written information in the Caregiver’s Manual—concentrates on how the disease affects one of four areas. Basically, the instruction unpacks for the caregivers the ways in which these diseases gradually erode the person’s abilities to: (1) use normal thinking powers, (2) maintain emotional balance, (3) direct his/her own actions, and (4) do everyday things.
- Next, each of the losses presented is looked at from the perspective of the caregiver. The basic question that is addressed is, “if the person loses this capacity, what should you expect? How should you prepare yourself for what you are likely to see happening?”
- Finally, each section on losses ends with a focus on the development of caregiving strategies: if this is what’s happening to the person, and if this is what you can expect, what should you do to make this situation as positive as possible?

The concept is that caregivers are responsible for getting themselves and their persons through each day as successfully and effortlessly as possible. The program teaches that the caregiver is responsible for managing the day and that as the disease progresses, s/he becomes more responsible. In order to succeed in this task, the caregiver has to develop a caregiving repertoire—a set of strategies s/he can call on both to structure the day’s activities and to respond when things don’t go as planned (and to protect him/herself from the possible emotional damage that can occur). In all of this, it is useful to have a general caregiving goal in mind. The program suggests that an appropriate and feasible caregiving goal is to help the person become and remain content and involved in everyday tasks and activities.

The program teaches a number of techniques for enabling the caregiver to help his/her person become and remain contentedly involved in things throughout the day. In addition to clarifying the cognitive losses that occur with dementia and their implications for caregiving, the program teaches a staging system that helps caregivers understand how a dementing disease like Alzheimer's affects the person's ability to do things. The system is one that combines a traditional Early-Middle-Late structure with an occupational therapy-based numerical staging system, the Allen Levels of Thinking. As part of the program, participants may arrive at a working estimate of their person's disease stage. The program then links this estimate to strategies of Structure (the design of and environment for tasks and activities) and Support (methods for communicating with the person to help him/her begin and stay with a task) that help caregivers design tasks, activities and events appropriate to their person's strengths and likely to help them become involved. The program encourages the development and/or strengthening of daily routines to promote comfort and familiarity.

Managing Behavior

Difficult behaviors expressed by persons with dementia are strongly linked to caregiver distress and burden. The program attempts to give caregivers a basis for understanding behaviors they might consider difficult or troubling. Moreover, it provides strategies for quelling and/or responding to the behaviors—so that they reduce in intensity, stop, or so that the caregiver finds them less troubling. The program encourages caregivers to develop strategies—stock or routine responses to frequently occurring situations that they find troubling—for example, developing one or two standard answers to their person's repetitive questions.

Managing Own Well-Being

The feelings associated with caregiving can be overpowering and even incapacitating. The program examines the impact of caregiving on caregivers and provides tools for caregivers to examine their own feelings and to do something about them—especially those that are negative and reinforce the sense that they are powerless in the situation. The program also urges caregivers to examine their own interests and to have a repertoire of things that they will do when they can free time to do them.

The focus on having caregivers be conscious of managing their own well-being ties in with the program's emphasis on this being a form of clinical training. Becoming aware of the impact of the work on one's own self is a part of the training of every kind of clinician. We train nurses, physical therapists, doctors, and social workers that the people and the conditions they're dealing with can affect them; can get to them. We train them both to recognize that this can happen and what to do to avoid it and to deal with this if and when it

does happen. If we acknowledge that caregivers are playing a role similar to clinicians, we must help them deal with the emotional impact of the role, just as we do with clinicians.

Managing Resources

Content about this topic is presented in two parts. The first centers on the family as a resource for caregiving. The program provides a description of family caregiving types and encourages caregivers to figure out in which type s/he finds him/herself—and which type s/he would like to have. The program provides a structure for strengthening family involvement in caregiving. The second area of content regards decision-making. Regardless of their previous role in the family, the caregiver is now thrust into a more prominent decision-making role. Whether it involves deciding what to do with the day or whether and when to sell the family home, the caregiver must make decisions. The program provides a technique for processing information and making decisions.

Mantras for the Program

Three themes recur throughout the program--three messages that you will find yourself repeating across all the sessions in one form or other.

You're in Control

Taking charge, giving directions, making decisions for another person are all actions that make us uncomfortable—perhaps even find repugnant—because of the profound sense of respect for personal autonomy that we hold as a fundamental cultural value. To be successful in the role, a caregiver has to take control of the situation and the person. This is a progressive process, one propelled by the progress of the disease in the person. But to meet the modest caregiving goal this program proposes (keeping the person content and involved) and to retain his/her own sense of well-being, the caregiver must recognize that the disease at work forces him/her to cross this line and to be in control.

Don't Just Stand There, Do Something: All Behavior Has Meaning

Every part of the Savvy Caregiver program content—relating to the impact of Alzheimer's and other progressive dementing diseases on the person's thinking, feeling, behavior, and ability to do daily tasks and activities—has a core message: Watch carefully and methodically before giving a name to a behavior or trying to do something about it. Watch the behavior and try to figure out what the person is trying to “say” by the behavior, because it does mean something. Deciphering the behavior isn't always easy, and the caregiver, as often as not, won't get at the meaning on the first try.

But forming a response based on the best sense of what the person is expressing by whatever it is that s/he is doing gives the caregiver the best chance of restoring order to the world.

So What? (Curb Expectations)

Alzheimer's and similar progressive dementias, as well as more static dementias, change everything. They change how people with the diseases look at and make sense of what's in front of them. It changes their ability to do things in the world, including how long it takes them to do things and how well they do them. They will never again be as good at doing things as they once were. They will never again do things well that they used to excel at. Caregivers must recognize this, and they have to accept the fact that, as these diseases progress, the pace of the day will slow, and the quality of performance will diminish. To avoid frustration—their own and the frustration they will transmit to (and therefore provoke in) their persons--caregivers must let go of expectations based on who their persons used to be and what they used to be able to do. The caregiving goal—"content and involved"—only means that the person has times during the day when s/he is doing something that keeps him/her occupied and that s/he is deriving some kind of enjoyment from doing that. The goal has nothing to do with speed, accuracy, or excellence of performance. Caregivers will be happier and more relaxed if they can let go of those expectations.

Section C

CULTURE AND CAREGIVING

Adapting the Savvy Program to Any AI/AN Culture

First, there are some required insights about culture that Savvy Caregiver Trainers must understand to customize the Savvy caregiver program to any given American Indian / Alaska Native group. After learning the cultural insights, you will be shown the action-steps to apply them and achieve a culturally specific Savvy program.

Why are Cultural Insights Needed?

Savvy caregiving trainers will be helped by understanding AI/AN caregiving experiences *as a part of tribal ways of life*. You will have the ability to provide training that really fits into your trainees' ways of life. That makes the Savvy training more understandable, acceptable, and useful.

Tribal cultural variations are huge among AI/AN people. One person may not know the tribal ways of another Native Nation. This would be particularly true for aspects of tribal culture that are not very obvious to outsiders.

Examples of tribal cultural variation include language differences. Even across tribes that have similar cultural histories, such as the Pueblo people, there can be important language differences. Tribal languages may not have words for "dementia." However, there may be words for people who have unusual behavior due to schizophrenia or other severe mental disorders. These conditions have been present in all cultures over all time. Yet, dementia that develops in older adults may not show symptoms until late life. AI/AN people as a group have only started living into the (older) ages of greatest risk for dementia in the last few decades. Shorter lifespans in the past meant that

fewer people would experience the late-life dementias seen today. Specific terms for dementia simply weren't developed because that experience in life was very uncommon.

Even if all the trainer's participants in the Savvy course are from the same tribe, "family culture" within the larger tribal culture can be assessed as potentially helpful with the training and use of the Savvy approach.

American Indian/Alaska Native elder caregivers are more likely than others to get inadequate support and suffer more stress as caregivers because many aspects of tribal life are not part of mainstream programs. The challenge to caregiving trainers is to develop a self-aware cultural sensitivity which will help them identify what aspects of their client's behavior are influenced by their cultural background. This is important because culture is so quietly powerful.

Knowing some of the basic principles of culture can help the Savvy caregiver trainer find the cultural ways that make a difference to how caregiving takes place in a certain family in a tribal community. Customizing the Savvy training to any AI/AN cultural system can be done by understanding a few cultural principles and action-steps. These are described immediately below under the heading, "The Power of Culture."

The Power of Culture

The power of culture is incredible.

Culture is the foundation of conscious and unconscious beliefs, values and behaviors that embody "proper" ways to live. Culture strongly influences our thinking, problem-solving skills, and meanings attached to life events.

CASE EXAMPLE: A father and son were in a car wreck. They were transported to a hospital. The father was dead on arrival. The son was alive but needed emergency surgery to survive his injuries. At the hospital, the doctor who was on call to do the surgery said, "I cannot do this surgery. This boy is my son."

How could this be?

Answer: The doctor is his mother.

Cultural reason: Most people don't get this riddle because our culture accepts that men will become doctors and women will become nurses. We learn this so strongly that we could not come up with the simplest answer, that the surgeon is the boy's mom. This is a sexist thought to hold. But culture is so powerful, it can defeat even our best efforts to answer the riddle because, UNKNOWN TO US, a culturally derived belief was influencing our thinking.

CASE EXAMPLE: In the 1970's, a television show called "All in the Family" featured a bigoted man named Archie Bunker. One episode was about a temporary beef shortage in the United States. As a result, horse meat was sold at some meat markets. Archie's family played a trick on him by serving a roast of horse meat without telling him what it was. He ate several bites and kept talking about his day as if nothing was wrong. But finally, the family tells him that he was eating horse meat. Upon learning this, Archie jumps up from his chair and runs to the bathroom, where he vomits.

Why would this be?

Answer: American culture has values against eating horse meat.

Cultural reason: The cultural insight to learn is not whether eating horse meat is bad or good. The cultural insight to learn is that the cultural rule against eating horse meat (which will NOT hurt a person) was so powerful, that the cultural rule produced vomiting. Vomiting is a complex physiological event that by itself is strictly biological. But, a cultural belief was able to trigger it. UNKNOWN TO ARCHIE, his cultural belief that it was bad to eat horse meat was so strong that it made his body vomit.

CASE EXAMPLE: A class of urban, non-Indian students was told of an event that their teacher saw. At a meeting on AI/AN health, two AI men went walking outside the meeting. Across the street, they saw a group of people huddled together--all looking down at the sidewalk. Wondering what was going on and if someone was hurt, the two men went to see what was causing the commotion. Upon being able to see through the crowd, they saw that people were admiring a very cute puppy that was rolling and bouncing and yapping. One of the two AI men made the comment, "Oh, soup dog." His friend, although thinking he knew, asked for clarification. The man said, "Yes, you thought right! *Small* dogs are best for eating." The classroom broke into loud "Ewwwws" and "Gross!!"

Why would this be?

Answer: Most people have learned a cultural rule that dogs are not for eating.

Cultural Reason: Some AI/AN tribes have had, in the past or present, cultural rules that "allow" for eating dogs. Today, it is certainly not a common thing, and may not have been common in the past because dogs often helped with hunting, pulling burdens, and keeping other dangerous animals away. Still, the cultural rules "allowed" for eating dogs. By the way, this cultural rule is found worldwide. However, the non-Indian students had not imagined such an end to the story and reacted in a disgusted way. Their teacher gave cross-cultural examples of such rules and suggested that one way to understand eating dogs could relate to conditions of low food supplies and need to survive.

Note to Savvy Trainers: Consider creating an example of culture influence from your own life experience as a member of your Native family and community.



Professionals who know how to detect cultural aspects of caregiving behavior will be able to:

1. Develop services which work with, and not against, caregivers' culture.
2. Communicate with caregivers in more effective ways.
3. Obtain better outcomes for caregivers.

People all over the world are more alike than different.

For example, all AI/AN caregivers must respond to patients who wander, don't sleep much, or must be cleaned due to incontinence. So, what are the differences between diverse AI/AN caregivers and other caregivers? Nothing and everything.

Nothing is different, in the sense that wandering away is just that, no matter the tribal culture of the caregiver.

But there are different levels of anxiety, community and neighborhood patterns, and tolerance of symptoms that make a significant cultural difference in caregiving strategies. These cultural differences must be understood to effectively increase the use of services among AI/AN caregivers and to better respond to elderly needs in general.

Some Basic Concepts About Culture

Concept #1: What is Culture?

Culture consists of the many things, including beliefs, values, and attitudes learned as a member of a certain society.

Cultural beliefs, values, and attitude serve as a mental map to guide behavior.

In a complex society like the United States, some parts of culture are shared by all, yet some parts of culture are found only in certain segments of society.

Family caregiving can be affected by cultural "rules" that define who is a family member and "how close" a family member they are.

Cultural traits can be very obvious or very subtle.

AI/AN children learn to treat the elderly with respect in the process of being taught manners. However, more subtle learning leads to the many

negative stereotypes about old people. People simply absorb these beliefs by living around behavior that reinforces such biases.

Cultural beliefs are strong!

Savvy trainers must understand not only their trainee's culture but their own as well, since their background and way of life determines what "feels right" to them.

People *absorb* their own cultural map for living so that certain ways of behaving appear to be the only reasonable way to act. Of course, most ways of thinking and acting are cultural in origin. That is, they were learned by individuals as members of a certain society, religious affiliation, political affiliation, economic group, or age.

Caregiving for an elder with dementia is often done in AI/AN homes due to a strong value placed on taking care of elders, whether with dementia or not. Sometimes caregivers may over-do caregiving in ways that exhaust themselves and leave the elder with dementia without an effective caregiver.

Culture is sometimes not conscious.

People are not always aware of the cultural roots of their behavior. For example, research has shown that the distance between people when they talk varies due to cultural background. Overall, Latinos prefer a short, "cozy" distance, and, overall, Anglos favor more distance from each other. The study even gave the average distance in inches for each group. However, imagine if you were asked, "How many inches apart does your culture prefer when having a conversation?" You could not give the answer, but your behavior does!


For caregivers, "unconscious culture" may show in ways that assume (*due to cultural "rules"*) that women will be the "hands-on" caregivers and men will be the "managers" of how the resources for caregiving are arranged.

Concept #2: Cultural Relativism

Understand cultural matters of another person or group by "seeing" THEIR way of life "through THEIR eyes."

For example, think about a person who refuses buffalo meat offered at someone's house they are visiting. Is this a clear act of rudeness? Refusing the buffalo may be due to that person's belonging to the Buffalo Clan in their tribe and consequently not being allowed to eat it because buffaloes are like family. Their refusal was not rude. The person was honoring their traditions and ways of life.

For example, imagine that a grandson of an elder with dementia is part of the caregiving group. The grandson wants to get married and knows that it will cause a problem with the caregiving coverage for his grandfather. At the time



of a family discussion about the marriage plans, another person from a very different tribal culture is visiting in the home. The visitor sees the grandson leave the house by walking past his father to talk with his mother's brother. At first, the visitor considers this very rude to the father. Later, it is explained that in this culture, the mother's brother is expected to play a large role in important decisions for his sister's children.

IMPORTANT: The concept of cultural relativism should not be used to excuse behaviors that are clearly harmful to others. The point is that just *understanding* a person's behavior does not necessarily mean that you think it's acceptable.

Savvy trainers may often observe that caregivers do not use community resources as much as they could.

Find out why community resources are under-used. Reasons may include things that relate to certain agencies, clinics, or people working there. Each agency, clinic, and staff can have meanings associated with them that could be negative and keep that caregiver from using them. One agency may have been unhelpful in some past experience and has come to be seen as always unhelpful. Staffing of community resources may have people that are not as friendly and understanding as they could be. Such people come to be seen as barriers to getting services. Work with the caregivers to get past such meanings so they can get the resources needed.

Concept #3: Cultural Pluralism

Cultural pluralism means that many cultures may live in one place and still have distinctive life ways.

Many tribal Nations with distinctive cultures and life experiences live across the U.S.

Savvy trainers should be sensitive to caregivers' cultural backgrounds as they do the Savvy course. Caregivers may silently wonder how much of their own personal culture it is safe to reveal. Make specific statements that all AI/AN cultures will be honored and respected.

Tribal cultures differ by language, dialect, physical traits, food preferences, religious preferences, and specific living locations.

Why the Special Concern About AI/AN Culture and Services?

Savvy trainers need to be aware of how cultural factors affect health behaviors. This is important when it comes to dealing with AI/AN elders affected by dementia.

Among AI/ANs, whole families may be involved in providing care. That can include multiple generations of cultural beliefs and practices. Age differences between service providers and service recipients may also play a role in communications. Generational differences between Savvy trainers and

participants can mean that each grew up in a different time when life and culture was not like it is now. Savvy trainers and caregivers may also differ due to tribal membership, gender, region, language, religion, etc.

Elder caregivers may be less likely to challenge service providers than are younger patients. Savvy trainers may be effective advocates for them.

Concept #4: Cultural Flexibility

Cultural “Rules”

Culture is highly complex and filled with rules and exceptions to the rules. Caregiver trainers can better organize their thoughts about a given culture or caregiving family by recognizing a few basic sources of cultural variation.

Intra-cultural Variation

Cultural variation *within* AI/AN groups should be expected. There is no one tribal culture that will practice the beliefs of all AI/ANs, for instance. For example, even in the same tribe, it would not be surprising to find one family observing a certain cultural value and another not using it. This may be due to individuals having differing degrees of attachment to their original culture. An example intra-cultural variation is found among the Choctaw people. The tribal name “Choctaw”, for instance, is an artificial one which incorporates numerous specific Choctaw groups (e.g., Oklahoma Choctaw, Mississippi Choctaw, and other Choctaws). Each has variations in history, language, and beliefs. The point is that while you may be able to think of all Choctaws as one tribe, there are many differences across all Choctaws.

Degrees of Attachment

Individuals from the same tribe may vary in how much they cling to certain cultural values. Or they may live according to some but not all these values. For example, the value placed on having extended family nearby may be reduced, but there is still a strong value of respecting all your kin.


Masked Culture

AI/AN people who have adopted large portions of American culture have not necessarily lost their AI/AN heritage. They have simply shown a great ability to adapt to the cultural system of the majority population. That can be very helpful when living in two cultures.

However, it is important to recognize that AI/AN people who seem to mainly participate in American culture, may keep many traditional values-- values that still connect them to their elders. Savvy trainers should be aware of these cultural roots even in families who appear to be culturally mainstream American.

Culturally Traditional AI/AN Elders

What is now considered “traditional” was at one time new and different. Culture change often results from adapting to new situations, such as invasion



from outsiders, new laws, and more people from other cultures. The process takes place at variable rates, or it may not happen at all. Some tribes have experienced more encroachment from the majority culture and others less. Either way, older generations are more likely to have traditional cultural orientations than younger tribal members.

Caregivers may be helped by a reminder that although an elder with dementia is living today, their memories may be of much earlier times. Earlier times may have had certain cultural expectations that today's generation does not. Understanding elders' ways as a valuable window into the past may help to make the elder's expectations important and not obsolete.

Culture is Always Changing

Because the world is always changing, culture is always changing, too. For example, climate, economics, and technology are always changing and often very quickly. Even disease patterns can change, such as less TB today but more dementia. As the world changes, people change, too, to adjust to new things in the world. People change their view of the world as they adjust to new aspects of life.

Health care providers may explain dementia in today's medical terms, such as a brain disease in which cells are being lost. However, caregivers may wonder *why* their loved one was affected, *why now*, *why in this way*, and other questions. These types of questions may be answered—at least in part—with cultural beliefs.

Expect caregivers to have many of their own explanations and questions about dementia. That is very normal. Caregiving is not a school test about medical facts, it is a journey of the heart filled with love and compassion for their elder. Life experiences such as supporting an elder with dementia always cause questions.

Culture is Expressed in Different "Amounts"

The level of participation or involvement in the majority culture by AI/ANs can vary from very little to total immersion. For example, some people may be viewed as culturally traditional, multi-cultural, or assimilated. Other casual ways to communicate this range of cultural expression include the terms "White Indian" (not very traditional), "Indian" (standard expression of Indian identity), or "*Indian* Indian" (very traditional).

Culture is Expressed Differently in Different Situations

AI/AN people adapt to life in a multicultural society by “using” their Native culture in certain situations and “keeping it to themselves” in others. For example, around non-AI/ANs, Native language may not be used, or references to religious matters may be kept silent. However, around other AI/ANs, there may be more comfort in using Native language or mentioning something about Native religion. The choice to conceal one’s cultural identity is determined by many things, including negative experience of being perceived as “different.”

Action-Steps to Customize the Savvy Caregiver Program to Tribal Culture

There are two main ways can help customize the Savvy caregiver training to the cultural ways of any tribe.

1. A list of questions is given below that help to bring-out cultural beliefs about dementia.
2. Listen very closely for terms used to talk about caregiving, dementia, family, and the ways caregivers have found to adapt to caregiving.

The 2-step approach above is simple in a way. Even so, listening closely to the caregivers’ answers takes some practice and time. Always listen for how caregivers describe their situation. Pick out words they use and encourage discussion of how they deliver care.

Savvy Caregiver Trainers can address the problem of discovering cultural beliefs about dementia and caregiving by using a set of questions to bring out trainees’ health beliefs. Trainers often learn about their own beliefs in the process of understanding those of others.

The answers to the questions are used to get a clear understanding of problems and their solutions *from the caregivers’ viewpoints*. The questions help the caregiver “*tell their story*” about how dementia is affecting their lives.

Stories of Caregiving: S-O-Cs

Questions that bring-out AI/AN health beliefs about dementia produce a “story or picture” of the caregivers’ ways of explaining what is happening to them. Their SOC is the explanation of their caregiving situation as they see it.

Through the questions below, the Savvy Caregiver Trainer can quickly obtain some sense of caregivers’ SOC. *The questions do not have to be asked in the order in which they appear.*

Caution: The questions included are fairly brief, which helps make them usable. However, this brevity also means that one-time use with a given caregiver trainee will yield a superficial and potentially misleading profile of the SOC.

These questions are most effective when you use them over and over during the course of the training sessions. You can change the wording a bit so that you still “get at” their SOC without sounding repetitive.

STEP ONE

Ask some or all the questions* below to help the caregiver give their SOC of how they experience caregiving for an elder with dementia.

1. What would be words, phrases or descriptions of dementia that are used in your language?
2. What do you think caused the dementia?
3. When do you think the dementia started?
4. What does dementia do to the elder?
5. What do you fear most about dementia?
6. What are the main problems caused by dementia?
7. What should be done about the dementia?
8. Who in the community and family helps you care for the elder with dementia?
9. What are good things that your tribal community has or does that helps you adapt?
10. What are problems that your tribal community has that hinders your adapting to caring for the elder with dementia?
11. What services and supports do you have access to, and have you used, like senior nutrition, Community Health Representative, or respite care?
12. Has anyone talked with you about the importance of taking care of yourself, reducing your stress, and ways to reduce your risk of illness?

STEP TWO

Listen closely to the answers to each question:

1. Are there certain words or phrases used that will help you communicate with the caregiver?

EXAMPLE: If the phrase “crazy behavior” is used, it may indicate that the caregiver is feeling that the elder’s behavior is stigmatizing. If so, emphasize the organic brain damage that is causing the memory loss and behavioral

*These questions are based on Arthur Kleinman’s (1980) concept of Explanatory Models. Kleinman, A. 1980 *Patients and Healers in the Context of Culture*. University of California Press: Berkeley.

problems. Also, it may be that the caregiver could benefit from being made aware that other terms can be used that more accurately describe the behavioral symptoms of dementia without resorting to the offensive term, “crazy.” For example, the elder is not crazy, the elder suffers from a brain disease that makes normal memory and thinking “come out wrong.”

2. Do the answers reveal belief that dementia is caused by both biological and/or spiritual forces related to religion?

EXAMPLE: Some families or tribes may believe that when the elder talks to people we don’t see that the elder is communicating with the “other side.” The medical term of such talk could be “hallucinations.” However, the family may stick with the belief that the elder is actually talking to people on the “other side.” If so, ask the family if it’s disturbing. If it isn’t, honor it by accepting their “way.” Take it as an opportunity to learn part of another cultural way of life, or let it reinforce your way if it happens to be the same. Such an interpretation may be less negative and stigmatizing than “hallucinations.”


3. Are there indications that the caregiver has a set of helpers in place, either from family only or from family and community?

EXAMPLE: As caregivers “tell their story” in response to the questions above, they may naturally speak about their caregiving in ways that reveals the presence and help from other family members. If not, that could be information for you that this particular caregiver should be encouraged to pay close attention to the topic of “family” mentioned throughout the course.

4. Do any of the answers suggest that the caregiver will have trouble adapting to caregiving?

EXAMPLE: As the caregiver responds to your questions, notice if there are signs in their voicetones, facial expressions, or actual statements that suggest that they are feeling depressed, “down,” or burned-out. Compassionate responses from you could include an empathetic response, such as, “It seems that you might not be feeling very good. I’m sorry to learn that. The training that we will do together can help the caregiving tasks become a more positive experience.”

NOTE: The Savvy program is NOT a support group or counseling program! It is a class on caregiving techniques that can make caregiving more beneficial to the “patient” and assist the caregiver in coping due to learning more about the disease and how to manage it. BUT, it is always appropriate for you to be empathetic and compassionate to caregivers who talk about emotional problems. If a caregiver appears to have difficulties adapting to



caregiving that are persistent and interfere with daily life, then that caregiver should be made aware of professional resources in the community.

STEP THREE

Help the caregiver understand the disease and how to adapt to caregiving in a compassionate way that honors their beliefs and yours.

EXAMPLE: You are not expected to “correct” cultural beliefs that are different currently accepted medical notions about dementia. As caregivers tell their story in response to your questions, you may hear cultural beliefs about what causes dementia or how to treat it. You may realize that their belief would be considered wrong by current medical views. Rather than tell the caregiver that they are “wrong,” you can respectfully learn the fullness of what the caregiver believes. Then, you can offer the medical viewpoint *as an additional* way to understand what causes dementia. In this way, NO ONE must give up their cherished beliefs, but can still have their understanding expanded.

Section D

STRUCTURE AND FORMAT OF THE SAVVY CLASSES

How the Savvy Caregiver Program is Structured

The program generally entails six two-hour meetings, held weekly. *The chart on the next page provides an overview of the material covered in each of the sessions. You will note that, beginning with the second session, each week begins with a review of the previous week's materials and with the home assignments that were given. This time is key in the program. It gives participants a chance to ask questions about material you covered in the previous week(s) or in the readings and to take credit for their accomplishments. It also makes it clear that they know a great deal about caregiving—they are experts and are getting even more expert at their role. The home assignments are not meant to be oppressive, and there is no expectation that you, as program leader, will “enforce” the completion of homework (no grades are given). But practice is an important component of the workshop's success—as well as getting feedback (coaching) on the experiences they had when trying out the ideas presented in the workshop. Having caregivers try to apply their learning at home is, again, a strategy that is used in clinical training: it isn't enough to read about a skill. The learner only acquires both the skill and the outlook that goes with the skill

*This is not written in stone, but it is a pattern that has worked, historically. Meeting every week and covering a lot of material creates intensity and underscores the importance of the program and caregivers' need to acquire this knowledge and skill. So, we generally recommend staying with the pattern unless there is compelling reason to change it. At the same time, we believe each leader and group should feel free to create variants on this pattern based on time demands of all involved. As you'll come to see, there are a lot of homework assignments. It may be that a group will choose to meet every other week because the members feel that they want to do the homework but will need extra time to do so.

by putting it into use over and over and having someone—in this case you and the group—with whom they can debrief and be coached.

WEEK ONE

Introduction to the program and program material
Introduction of participants
Exploring dementia—facts about dementing disorders
The impact of Alzheimer’s and other progressive dementias on thinking and the implications of these losses for Savvy Caregiving
Introduction to the resource materials for the program

WEEK TWO

Review of last week’s materials, readings, and homework
Caregiver self-care: Recognizing and dealing with feelings
Confusion: the central problem in dementing diseases
The implication of Confusion for Savvy Caregiving
A simple Model of Behavior
Communicating with confusion: Dealing in emotional truth
Taking Control

WEEK THREE

Review of last week’s materials, readings, and homework
Contented Involvement: A reasonable goal for caregiving
The concept of Fit: Matching tasks and activities to abilities
Performance—the Important elements
Introducing a Staging System

WEEK FOUR

Review of last week’s materials, readings, and homework
Anchors of Contented Involvement—Structure and support
Linking disease stages to structure and support
Basic communication techniques
Developing strategies for common behavioral problems

WEEK FIVE

Review of last week’s materials, readings, and homework
Applying Savvy Caregiver principles to day-to-day life:
 using the Anchors to design daily tasks
 Introducing a Model for Decision-Making

WEEK SIX

Review of last week’s materials, readings, and homework
Types of caregiving families
Strengthening families as resources of care
Review of Savvy Caregiver Program

The first four weeks of the program are very content-laden. The sessions—through exercises, handouts, and talks—will give participants a great deal of information and a great deal to try out and think about. This information will be reinforced by—and added to—other resource material, particularly the Caregiver’s Manual (also the optional media-based (CD-ROM/ Internet) resource, Alzheimer’s Caregiving Strategies (explained later in the introduction). The design of the program includes the expectation for caregiver performance—for the demonstration that they are taking all this information in and are “getting it” in such a way that they can put it into use in their caregiving—is deferred. While you will want to urge and prod them to do their homework, the real payoff doesn’t usually come until the fifth and sixth weeks. By then, most caregivers begin to show that they have integrated at least the main ideas of the workshop.

This can be challenging, from your perspective as a leader. In our experience, there are times when the group seems to be floundering during its early weeks. Participants might seem confused or unconvinced. Some will tell you that they “get it,” but, when you hear them talking, it is clear that they don’t yet understand the main idea. You’ve got to rely on the material and be patient. Don’t be concerned if the group seems flat, even in the middle weeks. Just keep at it. They will get it and will show you they get it—even if it’s only in the sixth week that they do so.

The Role of the Program Leader

The program proceeds through a series of exercises you will lead and brief talks you will provide. It has been designed to take advantage of your experience with caregivers, caregiver support groups, and/or other group and teaching situations. The major skills you need to lead the program are those of group facilitation. If you bring expertise in Alzheimer’s and dementia, that is a plus. The program materials supply the information participants need about the disease. The amount that you will be called upon to “lecture” about these things will be minimal. When a talk is called for, the outline is provided in this guide and the content is fully provided in the Caregiver’s Manual. The Trainer’s Manual material may help you provide additional information and guidance or from which you can draw questions to use to help the sessions be more interactive. Exercises are structured and outlined in this guide. Any handout materials you might need are provided. Slides for the talks and exercises are included in the text of this Trainer’s Manual. Program participants are given a hard copy set of the slides, so they can follow along and make notes as you use them in the sessions.

A great deal of the learning we expect caregivers to accomplish will happen through the assigned work you will expect each participant to do outside of the group. It is important that caregivers not feel this as a performance pressure, but you should emphasize that the “homework” will add greatly to their learning. Caregivers will have several resources for the work outside of class:

- The Caregiver’s Manual is the “textbook” for the program, and most of what happens in the program is covered in the manual. The order of the Caregiver’s Manual is roughly the same as the order of the materials presented in the sessions—at least as far as the core information on the impact of Alzheimer’s and managing daily life. The content is covered in the live sessions and in the manual, so you can direct caregivers to appropriate sections to review material and to read ahead. You, as leader, will have a copy of this manual and should read it carefully, use the ideas in it, and refer to it. The Trainer’s Manual will provide specific page references to the Caregiver’s Manual when these are relevant for exercises or tasks. As mentioned, each participant receives a copy of all the slides used in the sessions. These slides—with room for notes—may be all the participants need to bring to the sessions. A number of worksheets and handouts are also provided.

- Video Materials. A series of videos are available to accompany the Trainer’s Manual. The video has three segments. The first captures persons at various stages of Alzheimer’s, being directed by an occupational therapy aide to perform two common tasks: making a sandwich and folding towels. This segment is used in Session 3 when teaching the staging system used in the program. You may want to use portions of the segment in Session 4 when discussing the Anchors of Contented Involvement. The second segment of the video portrays a group of persons at various stages of Alzheimer’s, led by an occupational therapist, engaged in a common activity. The video can be an effective tool for illustrating the way in which a skilled clinician works to involve persons at varying stages in an activity. The third segment of the tape presents a talk by Dr. Marsha Lewis on the decision-making model that is taught in Savvy in Session 5. You can use this to replace a brief talk that you would provide on the decision-making model.

“Savvy Caregiver Materials.” This interactive educational program is available for purchase online. This program can be obtained from the distributor, Healthcare Interactive, found at www.hcinteractive.com. The program contains additional information relevant to the Savvy Caregiver program. The program includes additional video material, including a video of other persons with dementia completing the

sandwich-making and towel-folding tasks. The Savvy Caregiver DVD was developed in conjunction with researchers from the University of Minnesota, Emory University in Georgia, Duke University in North Carolina, and Michigan State University as well as a national team of experts.

The curriculum of the DVD and the Savvy Caregiver program derives from research conducted at the University of Minnesota on family caregiver education programs--the Minnesota Family Workshop and Partners in Caregiving. Further information on that program and the results of that research can be found in the following articles:

Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: a randomized psychoeducational intervention for caregivers of persons with dementia. *The Gerontologist*, 39(3), 299-309, and Hepburn, K, Lewis M, Narayan, S, Tornatore, J, Center, B, Lindstrom- Bremer, K. Partners in Caregiving: A psychoeducation program to reduce caregiver distress. *Clinical Gerontologist*, Sept., 2005.

HOMEWORK ASSIGNMENTS. Caregivers are given assignments—homework—after every program session. They will be asked to read sections of the Caregiver Manual (and optional assignments are given for viewing relevant sections of the Alzheimer’s Caregiving Strategies program). More importantly, they will be asked to apply what they have learned in the session in their work with the person at home. For example, they will be asked after Sessions 4 and 5 to design and structure tasks and activities the person might find involving and contenting and to apply behavior management principles to guide the person away from troubling behaviors. Participants will not achieve a sense of mastery about their new skills and knowledge unless they try them and experience comfort and success in their use. So, it is important that they practice. The other important thing that practice accomplishes is to provide caregivers with a sense of comfort in experimentation, a skill, and a sense that they need to carry forward after the program ends. Many caregivers are extremely cautious about trying anything new or different with their person. The program gives them direction and permission to do so. One of the big lessons from the program should be that caregivers will develop a

bigger repertoire if they try new things—and that even a failed experiment provides information that eventually leads to something that works and that can be added to the bag of tricks.

Home assignments may pose problems for some caregivers. For some, making time to come to the sessions may use up all the free time they have. For others, it may prove difficult to find time and place at home where they can be away from the person they care for. They may have a hard time being able to do the homework. This is a reality of caregiving. You can offer some suggestions that might help:

- Encourage family participation. Have other family members help out while caregivers do their homework. Alternatively, have the homework be a group activity with the other family members.
- Encourage them to follow along carefully in class and to keep the homework material handy—someplace where they can get to it quickly and easily. Then do it when they get the time.
- Encourage them to remember the assignments. Even if they can't do the reading or fill out the forms right now, they should keep them in mind. Remember they are available and meant to be a resource. They should make a deal with themselves to get these materials out when they feel the need for them.

INTERACTION WITH FAMILY. A number of exercises specifically expect caregivers to interact with other family members. However, there is no intent to limit interaction to these specified times. Caregivers should be encouraged to bring family members to the program and/or to share the readings (and the Alzheimer's Caregiving Strategies program) with them.

The Savvy Caregiver program is often the first opportunity caregivers must see that there is a great deal they can learn and that they can access resources to help them. As the program progresses, and as caregivers become more comfortable and confident in it, more and more questions will arise. The material itself will stimulate questions. For example, the material on staging in Session 3 (and in the optional interactive program) will likely involve a method of staging that most people have not heard of before. Similarly, the linkage between stages and strategies for designing tasks and activities (Session 4) is probably something they have not heard before.

You as Leader

Because you are the group leader, questions will be addressed to you. Group leaders will be expected to follow four guidelines in addressing questions from caregivers.

- **Validate (and Clarify) the Question.** Process the question. Be sure the person (as well as you) understands what s/he is asking. Recognize the importance of the question—encourage questions and the search for information. That is an important caregiving strategy and is one mark of a savvy caregiver.
- **Stay within Your Own Expertise.** Give the best answer you can from your own knowledge—but, if there are limits to that knowledge, make them known. (For instance, if asked about the effectiveness of Alzheimer’s drugs, you might respond, “Well I’m not a physician, but I do know that a lot of physicians are prescribing these, and a lot of caregivers are satisfied with the results.”) Don’t guess and don’t try to wing it. If you are trying to reason through to something, based on your knowledge, let the group know this.
- **Try to Find Answers.** Recognize and acknowledge when you don’t know an answer and—if you think it feasible—take it on yourself to search out the answer outside of the group. If you do say you’ll look for information, make note of this so that you can hold yourself accountable for seeking the answer and then reporting back on it.
- **Refer to Appropriate Disciplines.** Make it clear that some answers might best come from experts in various fields. Physicians, nurse practitioners, and pharmacists can be sources of information about Alzheimer’s medications and medications that can be useful with some of the behaviors that can manifest themselves in Alzheimer’s and other diseases. The occupational therapy-based staging system presented in the Savvy Caregiver program allows caregivers to estimate their person’s approximate stage. If they want a professional assessment that can provide an exact staging, they should be referred to an occupational therapist who knows the Allen Stages. The strategy material presented in Session 4 relies heavily on Occupational Therapy and nursing.

Preparing to Lead the Program

We have learned from feedback from other program leaders, it is essential to prepare a “lesson plan” for each session. The Trainer’s Manual gives you the structure of each session and, together with the Caregiver’s Manual, provides content material. However, it doesn’t work well to try to use the Trainer’s Manual as a sort of cookbook for leading the class. The best preparation—especially for the first time through the program—is to thoroughly digest each session’s intent and structure and to read all the material, and then to use whatever teaching/leading strategy works best for you (note cards, an outline,

etc.). This should become *your* program. The manuals give you the structure and content, but the way you lead is your own.

Icons as Guideposts

Information

The Trainer's manual uses several icons to provide you with guideposts through the text. This icon is used when the manual is providing you with information about your task. Typically, sections marked with this icon are intended to let you know what's coming in the program and what the intention of the next section is. These sections give background information on the section ahead and often suggest what you as the leader should be aiming at and looking for by way of response from the participants. Exercises and talks typically use slides and/or handouts. As noted above, hard copies of the forms, handouts, slides, and "talking point" notes for each slide are incorporated into the Trainer's Manual.



INFORMATION

Session Agenda

At the beginning of each session, you will see this icon. It will provide you with an overview of the session. The overview will include the main topics to be covered in the session and guidelines for time to be spent covering each topic.



SESSION
AGENDA

Exercise

This icon signals an exercise. Exercises are used extensively in the training program, so you'll be seeing it frequently. Before each exercise, the manual explains the purpose of the exercise—what learning objectives it is meant to accomplish—and gives you a sense of how to conduct the exercise. It provides a sense of how long the exercise should take and gives an idea of what kind of response you should expect to see from the participants. When there are slides or overheads with the exercise, these are also provided.



EXERCISE

The specific directions for each exercise are enclosed in an area highlighted like this. Typically, you are provided with specific directions for the exercise. Often, suggestions are provided for ways to start the exercise and/or prompt participants through it.

Brief Talk

This icon signals a brief talk by the group leader. Every effort has been made to keep these parts of the program to a minimum. The material for each lecture is provided in the text of the Caregiver's Manual and in slides. The manual is meant to support you in the talks, but you should feel free to



BRIEF TALK

search beyond the manual for additional information. Whenever you feel confident that you can provide the group with additional information, you should do so.

The limiting factor is the length of the sessions and of the program. On the other hand, if your strength for leading the program is in process rather than content, we want you to feel comfortable that all that you need to give the talks has been provided.

Transition to Next Point

The icon to the right will alert you to shift gears—it's like a form of punctuation in talks. Typically, it will appear in sections of the Trainer's manual in which material for the brief talks is being presented, using slides. Once you get the hang of using the slides for talks, this icon will seem unnecessary. However, it is meant to be helpful for leaders who may have less experience with using slides in talks.



Media

This icon alerts you to the use of teaching media—the video materials and the CD-ROM/Internet-based program. When the teaching video is called for in the program, you are given guidance about its use and the learning objectives that are sought.



Homework

This icon refers to the homework assignments. This manual provides instructions for the homework, and if any handouts are used, they are provided as well.



Indian country

This icon is for Trainers working in Indian country. Comments and guidance are provided to help the Trainer adapt the training program for their specific tribal community.



A Final Word

Participation is a key to success in the program. Another key is covering all the material. *You may sometimes find these two at odds with each other. There is no easy or fixed answer to this problem: cover as much as possible.* Many caregivers will enter the program either passively or reluctantly. Others will enter it thinking that it is another kind of support group. One of your big jobs will be to clarify the nature and purpose of the program and to draw the participants into it. Another big job will be to defer questions that are outside the scope of the training until after the session—to keep it from turning into a support group.

Thus, your group skills will be paramount to the success of the program.

Keep in mind that much of this material is new to participants, and that most of them are learning a great deal in the program. When you see opportunities to do so, remind participants of things they learned. Also, if you see that something from an earlier session was incompletely understood, circle back to it and review it to be sure participants understand.”

Savvy is just one piece of instruction and support from which caregivers can benefit, and completing the program does not, in itself, prepare the caregiver for all that is to follow. From your experience, you will know of other programs that would be of benefit. We encourage you to refer caregivers into those. At the same time, we urge you to recognize the enormous power you have as a program leader, power that would enable you to use Savvy as a platform for other ideas you may deeply believe. Keep the Savvy program intact; teach it as it is presented; alter it only in small ways that are consistent with what the program is setting out to accomplish. But don’t hesitate to point caregivers in other directions after the program is over.

We’ve found it is helpful if the clinicians with whom caregivers are dealing know something about the Savvy program. It is helpful for clinicians to understand what caregivers are learning and to see that they, the caregivers, are strengthening their competence, based on a certain way of thinking about strategies for management. If clinicians and caregivers can share a common language and frame of reference about the disease and how the caregivers are handling it, those clinicians can provide invaluable on-going assistance. So, share the program with clinicians.

Finally, the schedule (six two-hour sessions) isn’t set in stone. We know of one organization that runs two six-hour sessions to accommodate rural caregivers. Do what works.

Section E

FAMILY FIRST IN INDIAN COUNTRY

“Family and Community” is of great importance among AI/AN people. The original Savvy training document included family issues as part of Class Session 6. We include a section about family here, BEFORE Class Session 1, because family issues are inseparable when it comes to caregiving in Indian Country.

Use the following “Headlines” about family as important points to consider as a Savvy trainer to put caregiving in the context of the AI/AN family. You may 1) become familiar with these points so that you can put them into your discussions and teachings to caregivers, and 2) you may also share these points directly with them.

Role of the AI/AN Family in Caregiving to Elders with Memory and Thinking Loss

People are the Best Medicine

Elders with memory and thinking loss do not have a pill that will cure their problems. But, experienced and well-trained caregivers know that *people are the best medicine!* Caregivers dispense love, concern, security, a familiar place, familiar people, and constantly wrap the elder in a blanket of assurance that they will be given the honor and care they deserve.

Shared Caregiving

Caregiving at home is long, hard work for a long-term disease. Families can be very helpful in spreading out the hard work so that one person does not get burned-out. Families who help each other with caregiving for an

elder may often find that it strengthens bonds that hold the family together. Caregiving is another way of honoring elders.

Family Stresses

The family approach to caregiving can have stresses, too. Sometimes a family member may think that they are doing most of the hard work. That may be true. One thing to do if this happens is to say that more help is needed. That is, *communicate* in a compassionate way so that others will respond well. Families often have young adults and teenagers that can help with caregiving and learn important life lessons.

Generations of Caregivers

AI/AN families often have life practices that cut across age groups and tie the generations together. The example of grandparents serving as parents to their grandchildren is frequent in Indian Country. This type of caregiving is “intergenerational.”

Youth Honor Elders by Caregiving

Intergenerational caregiving can also apply when grandchildren provide care to their elder grandparents. This is a type of “role reversal” that can be very appropriate and helpful. The family today is more likely to have several generations alive at one time than ever before because people are living longer now. Younger people can experience caregiving as a way to honor their elder loved one.

Family Nearby

AI/AN families often have family members living nearby. Reservation communities, trust land patterns, and sharing land and housing space contributes to this pattern. This way of life helps make family caregiving more likely than if family members were far away. Some families can share caregiving so completely that the elder has “24-7” caregiving coverage.

Small Communities as Caregiver Partners

AI/AN people often live in small communities. One benefit is that many people know each other. Families coping with an elder with memory loss and thinking problems are often well-known in the community. If the elder is seen outside the home and is distressed, most people will know exactly who they are and where they live. Assisting the elder to return to a safe place can be done by taking them there if the elder is accepting, getting in touch with the elder’s family members, or calling for qualified first responders and advising them of the situation to allow them to help correct the problem. In this way, community members can be caregivers, too.

Spiritual Element Present

Spirituality can be a source of strength for caregivers. All across Indian country, many ways of spiritual belief and practice exist. If caregivers are comfortable with discussing spirituality, let it be an important part of nurturing caregivers and elders with dementia.

There may also be AI/AN families that keep to older beliefs of their tribe. They may believe the elder's changed way of being is a sign that they are communicating with the "other side" or "preparing to go to the other side." Such beliefs can be a more positive way of understanding the changes that are taking place with the elder. Caregivers may see themselves as involved in a much larger life experience than the ordinary tasks of caregiving alone.

Teach Family, Friends, and Other Community Members

No one is born knowing about the facts of dementia. Tell your caregivers that they will learn many things in this Savvy caregiving course. Tell them to *share their new knowledge with others*. They will be glad to understand what is happening to the elder and feel more motivated to be helpful in the caregiving process, even if it is just to teach their family and friends the facts of memory and thinking losses.

To help your caregivers to get started discussing and answering questions about dementia for your family and friends, the next page can be removed and given to caregivers as an informational "handout."


For Our Family, Friends, and Community

Some Facts about Memory and Thinking Loss for American Indians / Alaska Natives

American Indians and Alaska Natives (AI/AN) have always respected their elders. This is more important now than ever before. More and more AI/AN people are living into old age. This means many good things for families. It also means living into older ages in which some elders appear or may be confused and forgetful. Recent research has shown that AI/AN people are most likely at higher risk for dementia and Alzheimer's than the rest of the population. Yet, they are more likely to never be diagnosed or mis-diagnosed.

Some people believe that odd behavior is simply due to the elder preparing for another world. Medical doctors may miss troubling signs of confusion and forgetfulness the are bad enough to cause problems with a person's daily life. Even without a diagnosis, family and friends want to be sure that their elders are feeling comfortable, secure, and have time to plan for their future care needs.

Many Native people combine expert advice of traditional healers and medical doctors to find out if their elder's confusion and forgetfulness is caused by problems that can be cured or treated from both ways of healing.



To provide the best possible care for the elder, you as a friend and community member should:

- Keep a calm spirit yourself and among your family and friends.
- Listen to the elder talk of days gone by, their history, and recollections.
- Keep the elder safe from harm while still assisting them to do as much for themselves as possible.
- Make sure the elder eats properly and regularly and uses Title III and VI nutrition programs of the Older Americans Act.
- Make sure the elder is healthy in all ways--mind, body and spirit.
- Try to understand if the elder's odd talk may simply be a different way of telling you that he or she is hungry, in pain, or lonely.
- Determine if a pet would work as an additional source of comfort to the elder, even if others had to help with the pet's feeding and health.
- Show respect for yourself by keeping yourself healthy. That way you will be able to provide help for your elder loved-one or friend as long as possible.
- As the circle of life continues its march, show respect for your elders in the community by caring for them when they are dependent.
- Above all, show them that you love them. This can never be overdone, especially when the elder is forgetful and confused.

Supplement

BENEFITS OF TAKING THE SAVVY TRAINING**What is the Purpose of This Section?**

This section will give you basic information that you can use to inform people about the benefits of the Savvy Caregiver Training Program. Detailed information for you about dementia and its symptoms will be found elsewhere in the Trainer's Manual.

What is the Savvy Caregiver Training Program?

- The Savvy caregiver training program helps people who give care to elders who have dementia.
- "Elders" may mean those that are over age 65, but it can also refer to people of any adult age that are given high status and prestige in the community.
- Caregivers need information about how to adapt to the hard things that dementia caregiving requires.
- Caregivers will learn skills that result in less stress for them, family members, and the elder with dementia.
- Savvy caregiver training results in higher quality of life for the whole family, particularly the elder with dementia.

Who are Caregivers?

Anyone who helps to care for elders is a "Caregiver." Caregivers can also be younger family members--grandchildren as well as family friends.

If someone has an elder in their home or family and they help the elders with things from advice to bathing to going to the clinic to keeping them safe, then they are a caregiver. Many times, caregivers do more and more as time goes on and do not realize that they are doing so many important things for the elder.

What if Someone is a Caregiver?

- Caregivers are the best medicine possible for the elder!
- Caregivers need to keep their strength.
- Caregivers are the critical link to manage the elder's well-being.
- Caregivers show the elder they are cared for and loved, even if the elder cannot always remember the verbal "I love you's, they can feel a sense of security and calm.
- Caregivers are always GIVING their care and love to the elder, regardless of the elder's ability to directly respond.
- Elders with confusion, memory loss, and thinking problems NEED the caregiver's loving, skillful presence.
- The Savvy Caregiver Training Course will help the caregiver get the skills to give the best care to the elder AND to cope with the situation so that they too can have a good quality of life.

How Will the Savvy Caregiver Training Help Me?

- Savvy training will give caregivers:
- Knowledge about the elder's condition and how it changes
- Ways to cope with the stresses of caregiving
- Ways to understand what is happening to the elder
- Things to do so that the elder and caregiver are happier
- New ways to show their love, respect, and patience for the elder by learning how to give high quality at-home care.

Why Take the Savvy Course?

- Receiving the Savvy training will help caregivers remain able to provide care over the course of the elder's time of memory and thinking loss.
- Savvy training may also make the elder happier and more secure because the caregiver has learned new skills.
- Caregivers' new skills will be put into practice daily.
- By using the new skills, caregivers will be able to provide the best care for their loved one.

Is There Only One Caregiver?

- American Indian and Alaskan Native (AI/AN) people place great importance on family and community.
- The caregiver that has learned Savvy caregiving skills will be able to pass on those new skills to other family members, so that the whole family can be better able to help the elder.

- Taking a family approach can also help to give everyone a purpose in the life of the elder whose memory and thinking abilities are changing.

What Do I Have to Do?

- Take the Savvy course.
- You will be given a guidebook for caregivers that has information for you to keep.
- Your trainer will help you through the guidebook.
- There are also visual aids to watch and discuss.

Page intentionally left blank.