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Healthy IDEAS for Caregivers of People with Dementia in Maine: Evaluation Report

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Evaluation Report

Healthy IDEAS
for Caregivers of People with Dementia
in Maine

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Background and Context

Maine has a long history of providing services and supports for people with Alzheimer's or related dementia and their families. Since 1993, Maine has continuously received federal funding to develop programs for the diagnosis and treatment of people with dementia, to create and expand the capacity of local agencies to provide services for caregivers, to conduct statewide provider trainings, and to link people with dementia and their families with support services provided in the home and community-based care system, such as respite, mental health services and end-of-life care.

In April 2007, Maine policymakers held an Alzheimer's/Dementia Planning Summit with forty-two leaders in the aging services and policy community. The consensus of this group was that future services and supports needed to focus on the stress and burden of caring for people with dementia. Data from previous Alzheimer's demonstration programs showed that 20% of caregivers frequently or always felt depressed or lonely and another 30% sometimes felt depressed or lonely.¹ National studies have also focused on the impact of caregiving on the physical and mental health of caregivers. Some of the most common health consequences of caregiving include decreased energy and sleep, stress and/or panic attacks, pain/aching, depression, headaches, and weight gain or loss.² While mental health services had been available as a service under previous grant programs, the referral and use of such services had been uneven.

The ADDGS grant announcement in the spring of 2007 provided the opportunity to meet the unmet emotional and mental health needs of caregivers by proposing the use of a depression intervention that could be delivered by community-based case managers. Specifically, in spring 2007, Maine received a grant from the Administration on Aging to implement Healthy IDEAS (Identifying Depression, Empowering Activities for Seniors), a program "designed to detect and reduce the severity of depressive symptoms in older adults with chronic conditions and functional limitations".³ Under the grant, the original Healthy IDEAS program was modified and implemented for use with caregivers of people with Alzheimer's disease or dementia.

The overall goal of the Maine Healthy IDEAS program was to improve and expand the care and support provided to people with Alzheimer's disease and their caregivers. The objectives of the program were:

- To improve the health and wellness of caregivers
- To improve access to services
- To enhance the knowledge of care coordinators about caring for people with dementia

The desired outcomes were improved health and mental health status of caregivers; increased rate of referral to services; high participation and completion rates for the evidence-based programs; and greater consumer choice and control.

Overview of Healthy IDEAS

Healthy IDEAS includes four components: (1) screening and assessment, (2) education, (3) referral and linkage to health and mental health professionals, and (4) behavioral activation. These components were identified and adopted for use in the original program based on research and literature from a number of other evidence-based interventions.^{3 (p.141)}

During the *screening* process, case managers use a standard two-question screening instrument to determine potential symptoms of depression. Regardless of the response to the two screening questions, caregivers are provided with written *education* materials on depression. Those who answered yes to one or both of the screening questions are assessed further using a nine-question instrument. They receive further instruction on the link between mood and the role of meaningful activities and other self-care strategies. Those scoring 5 or higher on the assessment are offered assistance with *referral and linkage* to a health or mental health professional, if appropriate. Finally, during the *behavioral activation* phase, case managers work with clients to select goals that will add pleasurable or satisfactory activities into their life.^{3 (p. 141)}

The original Healthy IDEAS model included testing the utility of administering the program by nonprofessionals serving frail elders in the community in three case management agencies in Texas^{3 (p. 141)} Based on the results of the program, the Administration on Aging identified this program as one of its recommended model programs of health promotion.

For a number of reasons, the Healthy IDEAS model provided a good fit within Maine's long term care system. First, prior funding from Alzheimer's demonstration grants had been used to support the role of Alzheimer's coordinators within Maine's five area agencies on aging. These coordinators had been providing assistance to caregivers of individuals with Alzheimer's or related dementia in identifying, accessing, and coordinating services for a number of years. The Alzheimer's coordinator is the primary resource person within each agency when people call or need help caring for people with dementia. They also administer the respite funds for caregivers through Maine's state-funded Partners in Caring Respite Program and coordinate with the National Family Caregiver programs at the area agencies on aging. The qualifications of the Alzheimer's coordinators in Maine also vary from bachelor-prepared case managers to professionally licensed social workers.

This grant provided an opportunity to test the feasibility and effectiveness of modifying the original Healthy IDEAS model for use by caregivers of people with dementia. Many of the caregivers are younger adults (e.g. children of people with dementia) and may or may not have other chronic conditions or functional limitations but who are often experiencing the stress and emotional demands of caring for a loved one with dementia.

Implementation of Healthy IDEAS for Caregivers in Maine

The Healthy IDEAS program was funded as of July 1, 2007. Because Maine already had an infrastructure of Alzheimer's coordinators within each of its five area agencies on aging, it was possible to begin implementation planning for Healthy IDEAS in Maine almost immediately. Representatives from state project staff and Alzheimer coordinators from one of the area agencies on aging traveled in August of 2007 to participate in a training program for Vermont's implementation Healthy IDEAS. These representatives were able to provide an initial overview of the program to the other Alzheimer's coordinators and became early advocates for the program.

All of the Alzheimer's coordinators participated in a two-day training on Motivational Interviewing in September, 2007 and a two-day training on Healthy IDEAS, provided by the original developers, in October, 2007. Dr. Elizabeth Hart, a physician consultant on the project, participated in Maine's Healthy IDEAS training program and was available throughout the project to answer questions, provide support and special training during monthly project meetings. Topics covered in those trainings included: depression and suicidality; grief and complicated grief; depression, medical conditions, and treatment; and other mental health conditions and their impact on caregiving.

The Alzheimer's coordinators also received training on the use of a data entry and database system developed by the Muskie School of Public Service for recording answers to intake, screening and other

questions for the evaluation. The database captured all the demographic, service use, screening and follow-up questions. It also produced a copy of the results of the depression screening instrument (PHQ-9) to share with the individual and the physician. Hard copy versions of the questionnaire were also made available to those who did not choose to use the computer database.

At the same time that the Healthy IDEAS program was being implemented for caregivers of people with dementia, it was also being implemented for another grant initiative funded by the Administration on Aging⁴ for clients in Maine's home and community-based waiver program. In order to learn from and coordinate activities of the two programs, a Healthy IDEAS Advisory Group was formed. The members of the group included: representatives from both Healthy IDEAS projects, a geriatric psychiatrist, geriatric social worker, case managers, nurse consultant and staff from the evaluation team. This group provided input, support and advice on both programs.

The Alzheimer's coordinators were trained on the Healthy IDEAS program in early October. Meetings were held in November and December to review the protocols, practice the elements of the program, and review the use of the Healthy IDEAS database. Many of the Alzheimer's coordinators started screening, intake and behavior activation in earnest in early 2008. The process of screening, assessment and goal setting was initiated in each agency.

The intake components of the Healthy IDEAS program could take up to three weeks to complete – from intake to final goal setting. Follow-ups were generally scheduled for three months after goal setting. This limited the number of follow-ups completed.

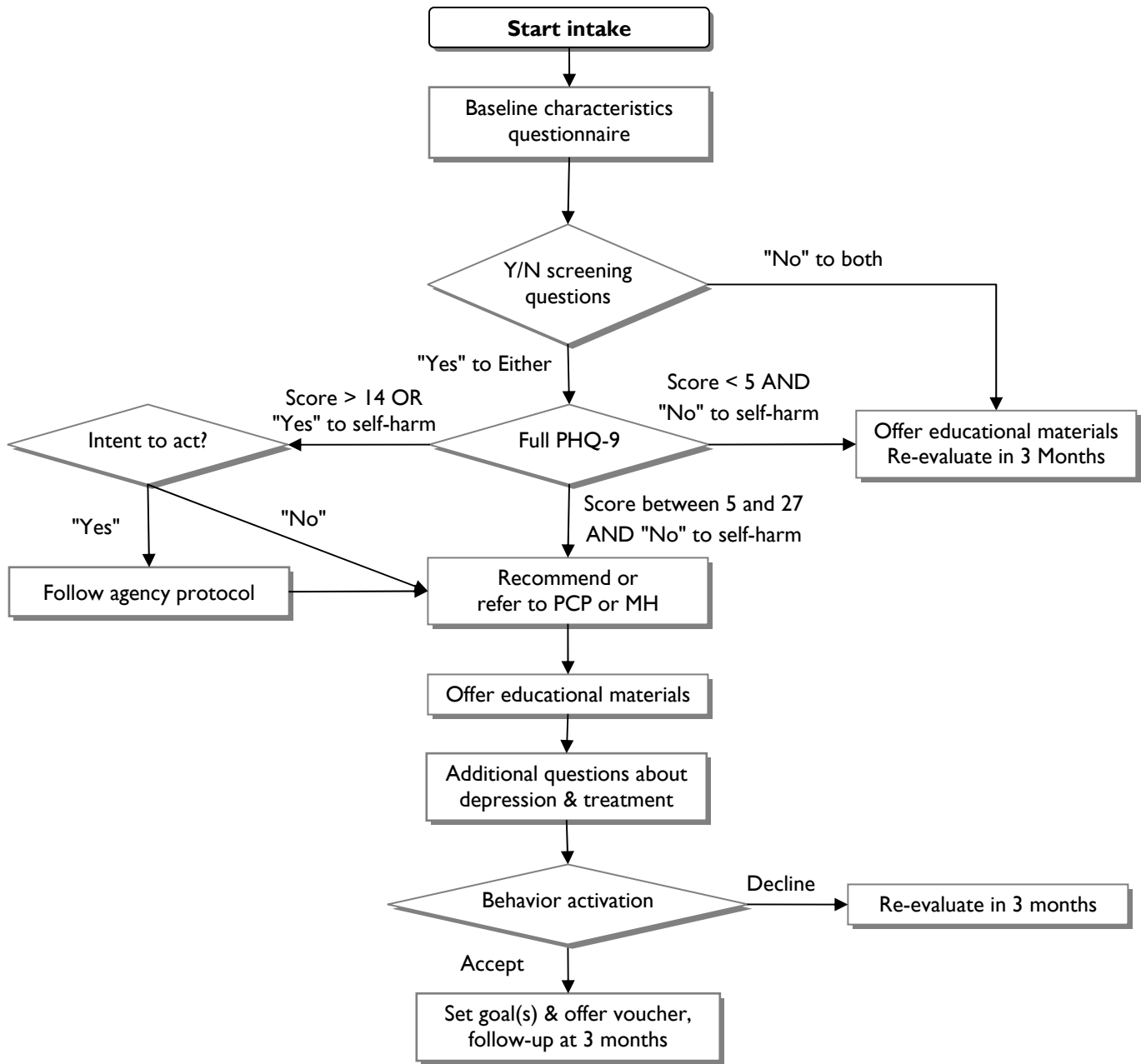
Throughout the project year, project staff were hopeful that the grant would be extended beyond the one-year funding period, thus allowing more time to complete all the components of the Healthy IDEAS program and to continue to offer the services on an ongoing basis.

Because program funding was not continued, the number of people who completed all the components of the program was limited. The following provides an overview of the initial results of the program implementation and evaluation.

Program Components

Figure 1 provides a flowchart of the Healthy IDEAS model as it was implemented in Maine.

Figure 1: Maine Healthy IDEAS Model



Potential Participants

Each of Maine’s five area agencies on aging had one or more Alzheimer’s coordinators who had an existing case load of caregivers of people with dementia for whom they were facilitating ongoing care planning and providing supportive services. In order to focus the size of the program during the initial implementation, participation was targeted at caregivers who were also receiving services through Maine’s state-funded respite program. The Alzheimer’s coordinators used the protocols of the Healthy IDEAS program to screen potential participants.

All potential participants completed an enhanced intake, developed for the program, that included a number of demographic questions (e.g., age, sex, education level, relationship to person with dementia,

length of time caregiving, self-rated health status) and questions about the person with dementia (e.g., amount of help needed with activities of daily living (ADLs)⁵ and instrumental activities of daily living (IADLs)⁶; and number of days in the past week that the person with dementia exhibited certain behaviors. Caregivers were also asked about their use of services and the use of services by the person with dementia in the last three months.

Screening

In the original Healthy IDEAS program designed for older adults, people were screened using the 15-item Geriatric Depression Scale (GDS). In the Maine program implemented for caregivers of people with dementia, the Patient Health Questionnaire-9 (PHQ-9) was used instead (see Attachment A). The PHQ-9 is a nine-question survey with five possible response categories related to the number of days in the past two weeks that a person felt bothered by certain feelings. The scores on the PHQ-9 range from 0 to 27.

The PHQ-9 was chosen for a number of reasons. First, it has been used and tested as a depression screening tool for all ages, including those over and under 65.⁷ This was important since almost 45% of the caregivers in the respite program were known to be under 65. Second, it is more widely used by primary care physicians in Maine than the GDS and thus would be more readily understood by the physicians and compatible with current practice. Finally, the Healthy IDEAS Advisory Committee, which included medical, mental health and other aging professionals in the state, recommended the use of this instrument and felt that it could be easily administered by the Alzheimer's coordinators conducting the screening.

As part of the intake process, people were first asked two screening questions:

Over the past two weeks, have you been bothered by either of the following problems:

- (a) little interest or pleasure in doing things?
- (b) feeling down, depressed, or hopeless?

This two-question screen was generally asked over the phone. If a caregiver answered yes to either of the above questions, he or she was offered the full PHQ-9 assessment which was usually completed during a face-to-face interview at home. People who scored 5 (suggesting minimal symptoms of depression) or higher on the PHQ-9 (possible scores can range from 0 to 27), were eligible for the additional components of the program. All people who were screened were offered educational materials on depression, regardless of whether they screened into the program or not.

Those who scored 5 or higher were offered help linking to health and mental health professionals. If the caregiver agreed, a copy of the results of the PHQ-9 was sent to his or her designated health care provider. Additional protocols were included for people who indicated they had had thoughts about death or hurting themselves. Because of the program, each agency had to review and in some cases more formally articulate its policies and procedures for responding to people who were potentially suicidal.

Those who screened into the program (i.e., scored 5 or higher on the PHQ-9) were asked a number of questions related to referral and linkage with health and mental health professionals, education and self-efficacy; and quality of life. These questions are the same as those used in the original Healthy IDEAS program and were selected from other tested questionnaires or surveys.^{3 (p.145-6)}

The Alzheimer's coordinators worked with caregivers who screened into the program to set goals and select some activities that would make them feel better.

Evaluation

The goal of the evaluation was to assess the extent to which the project fulfilled its objectives:

Objective 1. To improve the health and wellness of caregivers

Objective 2. To improve access to services

Objective 3. To enhance the knowledge of case managers about caring for people with dementia

Objective 1 was measured by the caregivers' rates of participation and completion of the program; by caregivers' acceptance of educational materials; by improvement in their health and mental health status and by increased knowledge of depression and understanding of the link between mood and activity.

Objective 2 was measured by rates of referral of the caregivers to services. Objective 3 was measured by the responses the care coordinators gave to a survey instrument that addressed the Alzheimer's coordinators satisfaction with and comfort in conducting the Healthy IDEAS program.

In addition, based on the evaluation, the project staff have drawn conclusions about the feasibility of delivering the Health IDEAS program by Maine's five area agencies on aging and adopting the original model for use with caregivers of people with dementia.

The evaluation of the program results were compiled by the Muskie School of Public Service at the University of Southern Maine. The proposed evaluation plan was submitted to and approved by the University of Southern Maine's Institutional Review Board. All data submitted to the University as part of the project were de-identified and did not contain any individually identifying information. Informed consent was not required and the protocols for the program were embedded within the ongoing operations and practice of the Alzheimer's coordinators.

Results

Objective 1. To improve the health and wellness of caregivers

This objective was measured by the caregivers' rates of participation and completion of the program. Descriptive statistics on recent use of mental health professionals, knowledge of depressive symptoms and self-efficacy, and quality of life were available for those who were screened into the program. We describe here the baseline situation of the caregivers, based on assessments and screenings conducted from November, 2007 to June, 2008. However, the low number of people who completed a three-month follow-up due to the short implementation period prevents any analysis of change in these activities or scores.

Rates of participation and referral

During the Maine Healthy IDEAS initiative, 136 potential participants were screened. Of those, 127 provided complete demographic and health/mental health status information. The rest of the evaluation report will focus on the 127 caregivers.

The number of caregivers receiving services: Of the 127 caregivers who were screened, 50 caregivers (39%) answered yes to either of the two preliminary screening questions and were eligible for further screening. Of those eligible for further screening, 36 (72%) scored 5 or higher on the PHQ-9 and thus were eligible for the behavior activation component of the program. Thus, 36 out of 127 people screened, or 28% of potential participants, were eligible for the program. About one-fifth of those screened (28 out of 127) completed the step of choosing a behavior activation goal (See Table 1 and Figure 2).

TABLE 1: HealthyIDEAS Screening Process

Caregivers who	Number	Percent of previous step	Percent of all 127
Answered all the demographic questions	127	n/a	100%
Answered "yes" to at least one screening question	50	39% (of 127)	39%
Were eligible for the intervention (scored 5 or higher on the PHQ-9 or answered "yes" to self-harm)	36	72% (of 50)	28%
Chose a behavioral activation goal	28	78% (of 36)	22%
Completed a 90-day follow-up interview	11	39% (of 29)	9%

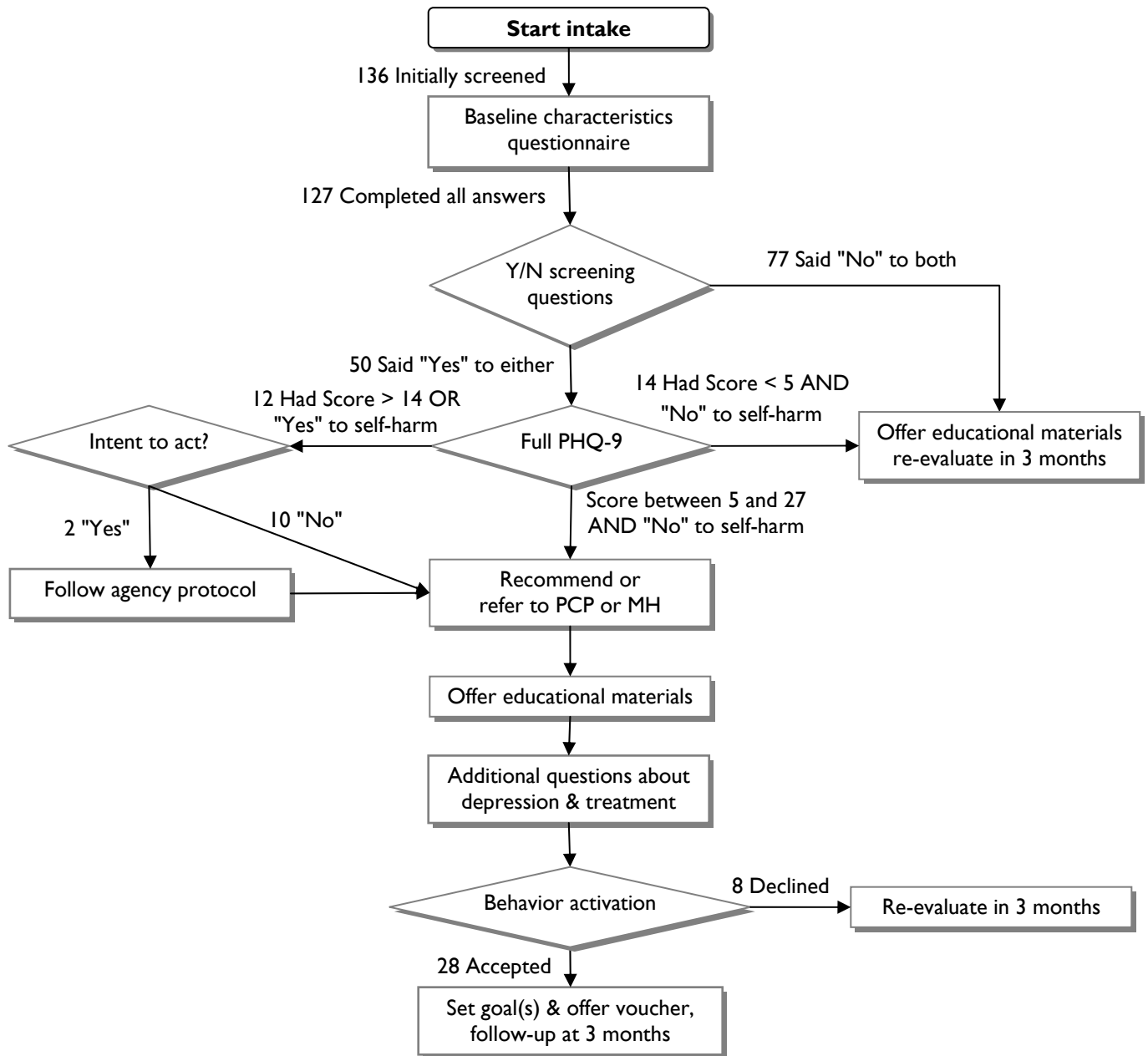
The following is a list of the number of assessments completed by each agency as of May, 2008.

TABLE 2: Number of Caregivers Screened, by Agency

Area Agency on Aging	Number of caregivers answering all questions
Aroostook Area Agency on Aging	46
Eastern Agency on Aging	36
SeniorsPlus	7
Southern Maine Agency on Aging	19
Spectrum Generations	19
Total	127

The following figure summarizes the number of caregivers at each stage of screening: those who participated, received educational materials, and completed the goal setting and the three-month follow-up.

Figure 2: Maine Healthy IDEAS Model (with Numbers of Caregivers)



As indicated in the Figure 2, 12 people had a score of greater than 14 and/or expressed thoughts of hurting themselves. Of those, two indicated that the thoughts were a problem or something they might act on. They were immediately referred to a supervisor to follow the agency’s protocols for high risk or suicide.

Among the 77 people who screened out of the program were a number of caregivers who the Alzheimer’s coordinators actually thought were under a lot of stress even if they did not score five or

above on the PHQ-9. Some of the Alzheimer's coordinators thought these individuals could still benefit from the components of behavior activation. They continued to work with the caregivers on understanding the relationship between mood and activities and then helped seven of these caregivers set goals and identify activities. We did not conduct any further analysis of these seven individuals, since they were not part of the Healthy IDEAS model program. However, there was interest among the program staff in the potential benefits of the behavior activation and goal setting activities for those caregivers who seemed stressed but did not pass the threshold screening questions for depressive symptoms.

Of the 36 caregivers who screened into the program, 28 (or 78%) chose a behavior activation goal. The goals and activities listed by the caregivers can be divided into six general categories. The categories and the number of goals chosen within each category are: Excursions and Community Activities (3); Health and Wellness Activities (17); Spiritual and Religious Activities (1); Social Activities (4); Physical Activities (7) and Recreational Activities (6). Some of the goals chosen included enrolling in an exercise class, taking a vacation in another state, walking, swimming, going to the hair salon, doing crafts, and getting more help in the house. Twenty-two of the caregivers identified one goal each; three caregivers had two goals; and three caregivers had three different goals. Participants also rated themselves on a "readiness" scale about their likelihood of following through with these steps in the next two weeks. The scale ranged from 1 (not likely) to 10 (very likely). Of the 38 goals set by the 29 caregivers, 33 of the goals (87%) had a readiness score of 7 or greater.

While some agencies were able to conduct a few assessments in the fall of 2007, most agencies got started in January 2008. Of those that set behavior activation goals, the Alzheimer's coordinators were only able to follow-up with 11 individuals.

As part of the project, a voucher was available to help offset some of the costs that might be associated with the activities listed as part of the participant's goals. Approximately \$1,325 in funding was used as "vouchers" by 15 caregivers who completed behavioral activation. Purchases included walking shoes, swimsuit, gym and exercise activities, hair styling, massage, embroidery materials/class and medical services. (As indicated, many of the activities could be done at little or no cost.) The coordinators did not actively promote the voucher option but used their discretion if a situation arose where they thought a caregiver could benefit from the voucher.

Characteristics of the caregivers screened. These are described in Table 3. Most of the caregivers (61%) were under 65. Those eligible were significantly more likely to be under age 65 (78%) than those who were not eligible (55%).

Over three-fourths (78%) of eligible participants were females and 97% were white. Thirty-six percent (36%) of eligible participants were spouses and fifty-eight percent (58%) were children or children-in-law.

Almost six in ten (58%) had some college education. The average number of years of caregiving was 6.6 for those who were eligible and 4.7 for those who were not. Sixty-two percent (62%) of those eligible described their health status as poor or fair; compared with 26% of those who were ineligible. This difference was significant at the $p = 0.0003$ level.

TABLE 3: Baseline Demographic Characteristics of All Caregivers by Eligibility for Healthy IDEAS[†]

Characteristic	Eligible [†]		Ineligible		Total		p Value
	(n = 36)	%	(n = 91)	%	(n = 127)	%	
Age in years, mean (SD)	57.7	12.9	63.7	13.0	62.0	13.2	t-test
≤ 64	28	78%	50	55%	78	61%	p = 0.029
65 to 74	4	11%	13	14%	17	13%	
75 to 84	3	8%	25	27%	28	22%	
85-plus	1	3%	3	3%	4	3%	
Gender							χ^2 test
Male	8	22%	29	32%	37	29%	P = 0.281
Female	28	78%	62	68%	90	71%	
Race							N/A
White (Alone) non-Hispanic	35	97%	89	98%	124	98%	
Other	1	3%	2	2%	3	2%	
Caregiver relation to Person with Dementia							χ^2 test
Husband	3	8%	13	14%	16	13%	P = 0.305
Wife	10	28%	25	27%	35	28%	(husband vs. wife vs. other)
Son or son-in-law	4	11%	13	14%	17	13%	
Daughter or daughter-in-law	17	47%	28	31%	45	35%	
Other [‡]	2	6%	12	13%	14	11%	
Caregiver's educational attainment							χ^2 test
High school grad or less	15	42%	52	57%	67	53%	P = 0.115
Some college or higher	21	58%	39	43%	60	47%	
Estimated years of caregiving (SD)	6.6	8.2	4.7	4.4	5.3	5.8	t-test
							p = 0.202
Caregiver's self-rated health							χ^2 test
Poor	11	31%	5	5%	16	13%	P = 0.0003
Fair	11	31%	19	21%	30	24%	
Good	7	19%	37	41%	44	35%	
Very good or excellent	7	19%	30	33%	37	29%	
Educational materials on depression							χ^2 test
Accepted materials	30	83%	80	88%	110	87%	P = 0.495
Did not accept	6	17%	11	12%	17	13%	

[†] Caregivers became eligible by scoring 5-or-higher on the PHQ-9 depression scale (range: 0 to 27).

[‡] Other includes significant other, sibling, parent, other relative and not related.

Note: All tests of significance were two-tailed tests

TABLE 3: Baseline demographic characteristics (Continued)

Characteristic	Eligible		Ineligible		Total		p Value	
	(n = 36)	%	(n = 91)	%	(n = 127)	%		
Person w/ Dementia 's functional status (ADLs)								
No limitations	3	8%	17	19%	20	16%	χ^2 test P = 0.005	
1 or 2 limitations	7	19%	40	44%	47	37%		
3 or 4 limitations	19	53%	23	25%	42	33%		
5 or 6 limitations	7	19%	11	12%	18	14%		
Ave. number of ADL limitations (SD)	3.1	1.7	2.2	1.7	2.5	1.8	t-test p = 0.009	
Person w/ Dementia 's functional status (IADLs)								
0 to 6 limitations	5	14%	7	8%	12	9%	χ^2 test P = 0.011	
7 to 8 limitations	4	11%	13	14%	17	13%		
9 to 10 limitations	27	75%	71	78%	98	77%		
Ave. number of IADL limitations (SD)	8.7	2.3	9.0	1.9	8.9	2.0	t-test p = 0.398	
Problem behaviors								
Ave. number of problem behaviors 3 or more times a week (SD)***	5.0	3.1	3.2	2.6	3.7	2.9	t-test p = 0.003	
Services for Persons with Dementia								
Paid supervision	8	22%	26	29%	34	27%	t-test p = 0.204	
Personal care services	12	33%	14	15%	26	20%		
Homemaker services	6	17%	14	15%	20	16%		
Home health services	4	11%	12	13%	16	13%		
Adult daycare/day health	4	11%	10	11%	14	11%		
Group/home delivered meals	2	6%	12	13%	14	11%		
Other services	4	11%	7	8%	11	9%		
Transportation	3	8%	7	8%	10	8%		
Companion Services	3	8%	5	5%	8	6%		
Mental health support	5	14%	2	2%	7	6%		
Average number of services used (SD)	1.7	1.4	1.3	1.1	1.5	1.3		
Services for caregivers								
Home health	3	7%	1	1%	4	3%		t-test p = 0.193
Personal care services	2	5%	1	1%	3	3%		
Mental health support	10	24%	11	14%	21	18%		
Support groups	6	15%	14	18%	20	17%		
Transportation	2	5%	3	4%	5	4%		
Caregiver training program	4	10%	14	18%	18	15%		
Institutional caregiver respite care	2	5%	1	1%	3	3%		
Non-institutional caregiver respite	9	22%	23	29%	32	27%		
Other services	3	7%	10	13%	13	11%		
Average number of services used (SD)	1.3	1.1	1.0	1.1	1.1	1.1		

† Caregivers became eligible by scoring 5-or-higher on thePHQ-9 depression scale (range: 0 to 27) or answered “yes” to the self-harm question.

Note: All tests of significance were two-tailed tests

Of the persons with dementia who were cared for by the eligible caregivers, 72% had 3 or more limitations in activities of daily living (ADLs), and 19% had 5 or 6 limitations. The average number of ADL limitations was 3.1. These differences were statistically significantly different at $p = 0.005$ and $p = 0.009$. People with dementia also had a high level of need for assistance with instrumental activities of daily living (IADLs), since 75% needed help with 9 or 10 IADLs.

Eligible participants were caring for people with very challenging behaviors. Eligible participants were caring for people who exhibited an average of 5 challenging behaviors at least three times a week. The difference in number of challenging behaviors was significant at the $p = 0.003$ level for those eligible versus those not eligible. Table 4 provides details about the behaviors exhibited by people with dementia.

TABLE 4: Challenging behaviors displayed by persons with dementia three or more times a week

Problem behaviors	Eligible (n=36)		Ineligible (n=91)		Total (n=127)	
Repeats questions/stories	23	64%	66	73%	89	70%
Clings to or follows you around	18	50%	35	38%	53	42%
Becomes restless or agitated	19	53%	25	27%	44	35%
Hides belongings and forgets about them	13	36%	30	33%	43	34%
Keeps you up at night	18	50%	20	22%	38	30%
Acts depressed or downhearted	18	50%	18	20%	36	28%
Becomes irritable or angry	15	42%	19	21%	34	27%
Has a bowel or bladder "accident"	13	36%	20	22%	33	26%
Tries to dress wrong way	6	17%	19	21%	25	20%
Becomes suspicious or believes someone is going to harm him/her	13	36%	12	13%	25	20%
Cries easily	8	22%	8	9%	16	13%
Swears or uses foul language	7	19%	8	9%	15	12%
Wanders	5	14%	9	10%	14	11%
Shows sexual behavior or interest at wrong time or place	3	8%	0	0%	3	2%

The services that persons with Alzheimer's most frequently used at baseline were personal care services (used by 33% of those whose caregiver was eligible), and paid supervision (22%) (Table 3). The services most frequently used by eligible caregivers were mental health support (24%) and non-institutional respite (22%).

In Maine, people who want to access long term care services -- either home-based services or nursing home services-- must be assessed for need by Goold Health Systems, the statewide assessing agency. A referral to Goold would indicate a potential need for additional services, either through state-funded or MaineCare-funded services. Of the 36 persons with dementia who had an eligible caregiver, 9 (25%) had a Goold assessment, and of the 91 persons with dementia whose caregiver was ineligible, 13 (14%) also had a Goold assessment. In addition, 2 of the ineligible caregivers had their own Goold assessments.

All of the 127 caregivers were offered educational materials about depression, regardless of whether or not they were eligible for Healthy IDEAS. Eighty-seven percent of the caregivers accepted those materials. There were no significant differences in the characteristics of those who did or did not accept educational materials. (These tests were limited by the small number (n=17) who did not accept materials). We conclude that materials should be offered to all caregivers who are screened, regardless of the results of the screening.

Use of mental health services, knowledge of depression and role of activities, and quality of life.

Participants were asked a series of questions about their health and activity levels. Approximately two-thirds of participants had contact with a medical provider in the last three months; 16 out of thirty-six (44%) had received a prescription to help with emotional difficulties; 31(86%) said they knew how to make an appointment to get help and said they knew how to identify symptoms of depression; 26 (72%) participants understood that increasing activities could make them feel better; 15 (42%) indicated that their physical health or emotional problems had interfered with their normal social activities; and 21(58%) indicated that they had experienced moderate to severe bodily pain in the past 4 weeks. Only three caregivers had been physically active in the past 4 weeks.

TABLE 5: Referrals, Education and Quality of Life

	Eligible Caregivers (n = 36)	
		%
During the past 3 months did the caregiver:		
Have contact with a medical provider?	24	67%
Discuss personal or emotional problems with a medical provider?	15	42%
Received a prescription to help with emotional difficulties or depression?	16	44%
Had contact with a mental health provider for counseling or treatment?	8	22%
Did the caregiver agree or strongly agree with:		
If you had a personal or emotional problem, you would know how to make an appointment to get help.	31	86%
You can identify symptoms of depression.	31	86%
You know what to do if you experience an increase in depression symptoms.	28	78%
I can make myself feel better by increasing my activities.	26	72%
During the past 4 weeks:		
To what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups? (<i>caregivers answering "moderately" or more</i>)	15	42%
How much bodily pain have you had during the past 4 weeks? (<i>caregivers answering "moderate" or "severe"</i>)	21	58%
How active you have been? That is, did you have hobbies, work, social activities or other activities that kept you busy? (<i>caregivers answering "fairly active" or "quite active"</i>)	11	31%
How physically active you have been during the past 4 weeks? That is, have you done activities such as brisk walking, swimming, dancing, general conditioning, or recreational sports? (<i>caregivers answering "fairly active" or "quite active"</i>)	3	8%

As was noted above, due to the shortness of the program, it was difficult for the agencies to conduct the planned three-month follow up interviews after the baseline interview. As a result, at close out of the evaluation data collection period, we had received follow-up data on only 24 caregivers, 11 of whom had been determined eligible at intake. The other 13 follow-ups were for caregivers who been determined to be ineligible at intake because they had answered “no” to both screening questions or scored less than 5 on the PHQ-9. In all, we received data on 19 caregiver follow-ups performed by the Aroostook Area Agency on Aging and 5 follow-ups performed by the Southern Maine Area Agency on Aging.

Because of the small number of follow up interviews, we are not able to make statistical comparisons or to draw conclusions about how the project might have contributed to changes in their outcomes. Neither did we have a control group with whom we could compare changes over time. We give the following results but caution the reader not to put too much weight on them.

Eight of the 11 eligible caregivers (73%) showed improvement in the PHQ-9 scores, a key outcome measure; while only 3 (27%) saw their depression score increase. However, at the follow-up interview, four of the eligible caregivers reported less agreement with the statement “I can make myself feel better by increasing my activities,” than they had at intake, while only one caregiver agreed more strongly.

Four of the 11 eligible caregivers (36%) reported small improvements in their general health, while one (9%) reported a small decline.

Three of the eligible caregivers found at follow-up that their physical health and emotional problems interfered less with normal social activities while an equal number of caregivers found that their health and emotions interfered more.

Three eligible caregivers reported a decrease in their bodily pain between intake and follow-up while one caregiver reported an increase from “not at all” in the past four weeks to “very mild”.

Two eligible caregivers reported that they had become more active with “hobbies, work, social activities or other activities” while two caregivers reported a decrease in their activity.

Two eligible caregivers reported that they had increased their level of physical activity between intake and follow-up, while none reported a decline in their physical activity.

Objective 2: To Improve access to services. This objective was measured by the rate at which caregivers were referred to mental health services.

One of the goals of the program was to increase linkages and referrals to mental health and other health professionals. Of the 36 eligible participants, 12 (33%) were referred for treatment, 17 (47%) were already in treatment and 7 (19%) were undecided or declined to seek treatment. Thus, 12 of 19 who were not in treatment (63%) sought treatment from mental health or other health professionals. The types of referrals included at least 4 (33%) that were to primary care physicians and at least 4 (33%) that were to mental health professionals. The type of provider was not identified for the other 4 referrals. At least four of the referrals were made by telephone and two by mail or email. The contact method for the other six referrals was not identified.

Objective 3: Enhance the knowledge of care coordinators about caring for people with dementia

The Alzheimer’s coordinators were surveyed in the spring of 2008. They were asked questions about their comfort level with administering the PHQ-9; asking about their agency’s suicide protocols; how to connect caregivers with mental health and other resources; and initiating behavior activation. The results of the survey are included as Attachment B. For the most part, the 10 Alzheimer’s coordinators indicated

they were comfortable or very comfortable with the components of the Healthy IDEAS project. The open-ended questions prompted more qualitative responses from the coordinators regarding barriers, challenges and rewards of the programs.

Discussion and Lessons Learned

Although the number of people who participated in this program was limited by the short funding duration, we were able to learn a number of things about the characteristics of people who participated in the program and the challenges and opportunities for continuing the program as part of the ongoing operations of the area agencies on aging and the activities of the Alzheimer's coordinators.

This report confirms what has been reported by others: that caregivers of people with dementia are under a great deal of stress, often have fair to poor self-rated health, and care for people with high ADL needs, and multiple challenging behaviors. A number of the caregivers' goals related to getting more help to care for the person with dementia during the day or taking the person with dementia to adult day care so the caregiver could get some rest. Because the persons with dementia tended to have high numbers of ADL needs, it may be appropriate to work with the Alzheimer's coordinators and others on ways to improve caregivers' links to the home and community-based services available in Maine.

The two-question screen appears to be an efficient, low-cost way of identifying people who are likely to be eligible for the Healthy IDEAS program. The two questions screened in almost four out of ten potential participants and almost three-quarters of those people became eligible for the program with the administration of the full PHQ-9. Of the total of 127 people who were assessed, almost one-third (28%) scored five or higher on the PHQ-9.

A combined examination of this program's results and the results of the Healthy IDEAS program for Maine's HCBS waiver clients, could suggest beneficial changes in the intake and assessment process for Maine's long term care system. Policy makers may want to consider adding the two-question depression screen to the standard Gould assessment process. Protocols for follow-up by case managers could then be developed for clients and/or caregivers who answer yes to either question. Varying the schedule and frequency of case management visits to target people who are at risk of depression could improve the efficiency and effectiveness of limited resources. Educational materials could also be offered at the time of the assessment to those who answer yes to either question.

While almost three-quarters of the participants understood that they could make themselves feel better by becoming more active, less than 10% had been physically active in the past month. The Alzheimer's coordinators helped caregivers understand how increased activity can improve mood and emotional health, and the coordinators worked with them to set simple yet doable goals for activities to help improve their sense of well-being. Ten out of the 33 goals they set involved increased physical activity.

Implementation of the program

Healthy IDEAS was successfully implemented by Alzheimer's coordinators in the five area agencies on aging. For many of the Alzheimer's coordinators, this involved incorporating new or enhanced skills within their usual case management functions. Alzheimer's coordinators learned how to apply the principles of Motivational Interviewing to help caregivers set new behavioral goals and help caregivers overcome barriers to the goal implementation. Alzheimer's coordinators also learned new ways of talking with people about mood, depression, and the relationship between those feelings and physical and social activities. The Alzheimer's coordinators were supported throughout the project by a physician consultant who participated in monthly meetings, held trainings on specific subjects, and responded to questions about individual cases. As the project progressed, the confidence and experience of the Alzheimer's coordinators grew as they changed from tentative supporters to advocates of the program. Alzheimer's

coordinators gained confidence and experience as the project progressed and while they changed from tentative supporters to program advocates. This change became apparent when some of the Alzheimer's coordinators began requesting permission to expand the application of behavioral activation to some caregivers who did not meet the eligibility threshold, but who they thought would benefit from behavioral activation. Many of the coordinators continued to screen and work with caregivers after the end of the project. For them, the protocols and procedures had become part of usual practice rather than an external set of functions required by a grant.

As indicated by the original grant application, funding for mental health services had been made available through prior grants but those services had been underused and unevenly accessed by the Alzheimer's coordinators across the different regions. While this approach allowed each agency on aging to find local solutions and alliances, there had been no standard approach to screening, no way to identify those most in need, and no standard approach for coordinating with physicians or other mental health professionals. The structured approach offered by Healthy IDEAS provided Alzheimer's coordinators with tools to efficiently screen by phone for potential signs of depression. It also provided a way to communicate concise and useful information to physicians via the use of the sample letter and PHQ-9, the instrument most likely to be familiar to the medical and mental health community. Alzheimer's coordinators also indicated that the caregivers appreciated learning about and seeing the results of the PHQ-9.

Agencies also realized early in the program the need to have agency-wide policies and protocols for persons at very high risk or expressing suicidal thoughts. Involvement of mental health representatives from the Maine DHHS in ongoing Healthy IDEAS group meetings facilitated identification and updating of resource lists and websites that were mutually beneficial to the mental health system and the older adults service system.

Caregivers were very receptive to receiving educational materials about depression, regardless of whether they screened into the program or not. This would suggest making such materials more widely available to caregivers who are experiencing the burden and stress of caregiving.

Future work

The short duration of the program was a frustration to the project staff, Alzheimer's coordinators and evaluators. It is difficult to develop a relationship with a caregiver, offer support and services, and then have to discontinue components of that service.

With low numbers of participation, it is impossible to fully evaluate the effectiveness of the program and thus hard to build support for its sustainability among policy makers or legislators without evidence of its utility or effectiveness in meeting its objectives. While Healthy IDEAS is considered an evidence-based program for home-based care clients, its applicability has not been tested for caregivers. Initial results from this evaluation suggest that it provides an efficient way to screen for depressive symptoms, that it is effective in linking people to health and mental health providers, and that it has potential for improving the health and mental health status of caregivers who are experiencing depressive symptoms. An evaluation that provided an opportunity to examine these outcomes by incorporating a randomized control group into study design could offer the opportunity to examine additional outcomes related to cost effectiveness, use of health services and diversion from nursing home admission. Answers to these questions would be of great use to policy makers who must decide how to allocate limited resources and purchase value-based services.

Recommendations

Based on the results of this evaluation, we recommend the following:

Screening: Consider adding the two-question screen to the Goold assessment process for both clients and caregivers of people with dementia. Develop protocols for follow-up by the case managers and Alzheimer’s coordinators. Alzheimer’s coordinators who are providing services to caregivers through the state respite program could continue to use the two-question screen to identify people at greater risk of depressive symptoms. Program staff will need to assess whether to continue the in-home visits and other aspects of behavior activation.

Educational Materials: Offer educational materials to all who answer yes to either or both screening questions. The materials could be offered by the Goold assessors and by the Alzheimer’s coordinators for people accessing respite services.

Respite versus personal care services. A number of caregivers were caring for people with high levels of ADL need. While respite funds can be used, at the discretion of the caregiver, for personal care services, it may be beneficial to conduct “root cause” analysis or a focused study of how people who have both dementia and high ADL needs could get services; of the trade-off between respite and services; and of protocols for referral to a Goold assessment when the person with dementia may have needs that exceed what can be managed with respite funds.

Further research: It would be beneficial to design a longer-term study with a randomized control group that would provide the opportunity to test the effectiveness of the Healthy IDEAS with caregivers and examine outcomes related to potential for cost savings, health service utilization, and nursing home diversion. Such a study would contribute to the literature on this subject and provide evidence of value to policymakers for sustaining or expanding the program.

Attachment A: Patient Health Questionnaire-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at All	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling/staying asleep, sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite– being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way.	0	1	2	3

Add columns: _____ + _____ + _____

TOTAL: _____

10. If you checked off <i>any</i> problems, how <i>difficult</i> have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	_____
	Somewhat difficult	_____
	Very difficult	_____
	Extremely difficult	_____

Attachment B: Coordinator Survey

The Maine Alzheimer's Project
Healthy IDEAS

Coordinator Survey

N = 10

In order to help determine if the Healthy IDEAS training provided to-date has been sufficient or if there is a need for additional training/refreshers, we would like to ask you about your level of comfort around specific aspects of implementing Healthy IDEAS.

Please let us know about your level of comfort:

1. Asking caregivers the two screening questions.

5 = Very Comfortable
5 = Somewhat Comfortable
0 = Somewhat Uncomfortable
0 = Very uncomfortable
0 = Not applicable/haven't done it yet

2. Asking caregivers the questions on the PHQ9.

5 = Very Comfortable
4 = Somewhat Comfortable
1 = Somewhat Uncomfortable
0 = Very uncomfortable
0 = Not applicable/haven't done it yet

3. Interacting with the caregivers while you do the PHQ9.

6 = Very Comfortable
4 = Somewhat Comfortable
0 = Somewhat Uncomfortable
0 = Very uncomfortable
0 = Not applicable/haven't done it yet

4. Entering the information into the database while asking the questions.

1 = Very Comfortable

3 = Somewhat Comfortable

2 = Somewhat Uncomfortable

0 = Very uncomfortable

4 = I don't enter while asking questions/enter the data later

0 = Not applicable/haven't done it yet

Please let us know about your level of comfort:

5. Asking the questions about the risk of suicide.

4 = Very Comfortable

4 = Somewhat Comfortable

2 = Somewhat Uncomfortable

0 = Very uncomfortable

0 = Not applicable/haven't done it yet

6. With your agency's protocols for people at risk of suicide.

4 = Very Comfortable

6 = Somewhat Comfortable

0 = Somewhat Uncomfortable

0 = Very uncomfortable

0 = Not applicable/haven't done it yet

Please let us know about your level of comfort with:

7. **How** to connect caregivers with mental health or other resources.

6 = Very Comfortable

4 = Somewhat Comfortable

0 = Somewhat Uncomfortable

0 = Very uncomfortable

0 = Not applicable/haven't done it yet

8. **When** to connect caregivers with mental health or other resources.

4 = Very Comfortable

6 = Somewhat Comfortable

0 = Somewhat Uncomfortable

0 = Very uncomfortable

0 = Not applicable/haven't done it yet

9. Initiating behavior activation and goal setting.

4 = Very Comfortable

5 = Somewhat Comfortable

1 = Somewhat Uncomfortable

0 = Very uncomfortable

0 = Not applicable/haven't done it yet

10. Using the Healthy IDEAS database as part of the intake/assessment process.

1 = Very Comfortable

8 = Somewhat Comfortable

1 = Somewhat Uncomfortable

0 = Very uncomfortable

0 = Not applicable/haven't done it yet

11. Thinking back, what was most helpful to you in preparation for implementing Healthy IDEAS?

Please explain:

- Working with the program at the office. Working with staff as we have questions. Staff meetings. Initial training that helped gain perspective on where others were at, within State and outside of State.
- Training with people from Texas.
- The implementation meetings with the folks from Texas. These were very practical.
- Reading the booklet and placing the goals worksheets right in the Healthy IDEAS booklet. This allows me to have the goal information clearly presented and able to review back to.
- Actual implementation and practice with the tool in the real life setting.
- Making sure I had plenty of time to spend with the client and caregiver. Very time consuming.
- Having the workshops I guess. Might have needed a little more time to digest and think about the program. Sensed an urgency to implement without enough time to know and understand the program.

12. Have you made any changes in how you conduct an intake since you started the screening process?

8 = Yes

Please explain:

- We use a lap top computer now and we allow additional time for our visits.
- We now use a laptop for all our PIC intakes. Longer visits.
- I was not formally screening for caregiver depression before.
- I have had to adjust to PIC intakes. Our approach to clients is less formal in the Family Caregiver program.
- The PHQ-9 score sheet I have photocopied in bold colored paper to use as a guide/tool to have when scoring.
- I am more comfortable explaining the goal of the intake and more at ease with the database.
- Again, making sure I have a couple of hours to spend with the client and caregiver.
- I am not quite sure what. I guess we become more aware and confident with each intake.

2 = No

13. Have you made any changes in how you interact with the caregivers since you started doing the screening process?

2 = Yes

Please explain:

- More relaxed as comfort is gained with the process.
- I'm more aware to look for depressive symptoms.

8 = No

Please explain:

- Just spending more time with them.
- Other than trying to keep the 2 questions in the back of my mind for use when appropriate, my interactions are pretty much the same.
- Not really. A caregiver is a caregiver and needs are important to look at whether it is Healthy IDEAS or a pat on the back.
- Still handle as we did prior to Healthy IDEAS.

14. Have you made any changes in how you enter the information since you started doing the screening process?

4 = Yes

Please explain:

- I slowed down and double checked for completion at the end of each intake.
- I wasn't using a laptop before.
- We are completing manual intakes and then entering later into a lap top.
- Again, even the PIC database is new for me.

6 = No

Please explain:

- Don't dare to.

15. Do you have any suggestions that will make the intake process, interactions with caregivers, or data entry easier or quicker?

8 = Yes

Please explain:

- Everyone having the ability to enter independently would be helpful.
- Simply tweaking suggestions previously made.
- Still need to work out some kinks in the software. I have encountered glitches which have made the process less smooth and interrupted the natural flow that might otherwise happen.
- The three goals of psychology are to understand, predict, and control human behavior. I think that it is what the goals are. We just need to remember that each individual is unique so the goals may be attend not all the same way. We do the best we can though we try to make a piece of paper universal in addressing human behavior. We do the best we can with what we know, therefore, we relax, multitask a little less and carpe diem.
- Having the goal worksheets photocopied and to the back of the Healthy IDEAS packet is a visual reminder to complete setting those goals with the caregiver. I also have the worksheet on various activities that I have the caregiver review and check off the activities that they participate in or would like to participate in if time/money allowed.
- Having the laptop helps so we do not have to do things twice is helpful.
- Split up and done in steps.
- Number of questions could be reduced.

2 = No

16. Is there anything related to the Healthy IDEAS initiative you would like more training or clarification on?

3 = Yes

Please explain:

- All.
- How it could be used to screen ALL caregivers, not just caregivers of PIC clients.
- Technical training on use of the database (entering & quirks of the system). Documenting Behavior Activation in a way that is easier for staff to remember and track progress. Maybe a form would help.

7 = No

17. Have you contacted any project staff (Jan, Linda, Betsy, Stuart) for help or with questions?

5 = Yes

Please explain:

- Stuart has helped with computer issues.
- I have asked for clarification around use of funds (Jan), I have asked for specific advice from Betsy around a difficult caregiving scenario, and I have contacted Stuart with questions, comments and suggestions.
- Stuart has been great about addressing database issues as they arise. Jan and Romaine have also been quick to respond to procedural questions.

5 = No

- Supervisor does.
- Our procedure is to go thru our supervisor and he/she will decide if a contact is needed and then she confirms with us she will take care of it.

18. Do you have any comments on the Intake Form or the Healthy IDEAS screening process that could make it better for Alzheimer's Coordinators or the caregivers?

4 = Yes

Please explain:

- Despite being comfortable with technology, having a comparable paper form to use with some people would make the process more comfortable. The laptop, although more efficient, can be cumbersome.
- Corrections are being made per Stuart and Mark.
- It would be helpful to know what each agency should be using for forms when implementing the program to make it more standardized between the agencies (referring to actual forms we give to the caregivers or complete outside of the computerized assessment). Maybe having a standardized packet between the agencies.
- Even with all the training we have all had we never really went through and were told here are the forms we would like you to use and this is how we would like them completed.

6 = No

19. Please describe any barriers you have encountered during the implementation of Healthy IDEAS.

- Having to complete the PHQ-9 face to face has slowed down the process due to the rural nature of my area. I also have had difficulty with passwords, and the database, but Stuart is always available to help.
- Caregivers show lack of interest. State it's just one more thing to do and if they are depressed, that's truth.
- Most caregivers are willing to share what their struggles are. On a rare occasion I have wondered if the caregiver was being truthful when they answered the questions.
- A learning in progress.
- Some caregivers are reluctant to open up about emotional issues (especially older caregivers).
- Time to implement the program and the time that it takes to do the screening and behavioral activation. It can easily add 45 minutes to several hours to a visit. It has also been a busy year

within the program as we also had the LD-519 program that we were managing along with our usual program activities.

- Technical difficulties with the programming.
- Despite being comfortable with technology, having a comparable paper form to use with some people would make the process more comfortable. The laptop, although more efficient, can be cumbersome. Also, it has been frustrating to feel compelled to administer this to all people in one group and no one else. Some of the people within the PIC program are not appropriate for this, while other caregivers who are caring for someone who has issues other than dementia need it desperately. This has been the nature of the short term trial run but it felt like a barrier nonetheless.

Do you have any other comments or suggestions you would like to add?

- I think that it is valuable to offer this program to caregivers, even if only a small percentage take advantage of the behavioral activation. I think just getting them information on depressive symptoms and starting the conversation is important.
- I have found the tool to be a wonderful way for caregivers to feel less isolated. They seem very pleased that the state as a whole is recognizing all the hard work that they complete. Some caregiver's have found that the tool has allowed them to "step back" and recognize all that they do on a daily basis.
- I think sometimes the talking with the client weekly for a month or so has helped them realize I really do have an interest in them and their situation and they become more willing to at least start very small steps towards a bigger goal.
- Overall, I think it is going well- it is a good tool to start a conversation about caregiver emotional health.
- Mental Health Funds that we had were a big resource in helping with this too.
- Great program but we needed more time to get through the bugs. Tough to do in such a short time period. Would love to see this rolled out to all caregivers in some form.

ENDNOTES

¹ Maine Department of Health and Human Services. *2007 Alzheimer's Disease Demonstration Grants to States (ADDGS)*. Augusta, ME: Maine DHHS; 2007.

² Evercare and the National Alliance for Caregiving. *Evercare® study of caregivers in decline: A close-up look at the health risks of caring for a loved one. Findings from a national survey*. Minnetonka, MN: Evercare in collaboration with the National Alliance for Caregiving; 2006.

³ Quijano LM, Stanley MA, Petersen NJ, et al. Healthy IDEAS: A depression intervention delivered by community-based case managers serving older adults. *J Appl Gerontol*. 2007;26:139-156.

⁴ This grant is a three year grant from AOA, entitled Empowering Older People to Take More Control of Their Health Through Evidence-based Prevention Programs: A Public/Private Collaboration. Healthy IDEAS is one of five evidence based programs being implemented in Maine. The others include the Chronic Disease Self-Management Program, A Matter of Balance Lay Leader program, Enhance Wellness, and Enhance Fitness.

⁵ Activities of daily living include: eating, getting in and out of bed, getting around inside, dressing, bathing, using the toilet.

⁶ Instrumental activities of daily living include: doing heavy housework, doing light housework, doing laundry, cooking/preparing meals, buying/getting food/clothes, getting around outside, going places that require transportation, managing money, taking medicine, using the telephone.

⁷ Lowe B., Unutzer J., Callanhan C, et al. Monitoring depression treatment outcomes with the patient health questionnaire-9. *Med Care*. 2004;42:1194-201.