CIVIL MONEY PENALTY (CMP) FUNDED PROJECT

FINAL REPORT

Grantee

Alzheimer's Association

Southeastern Wisconsin and Greater Wisconsin Chapter

620 South 76th Street

Milwaukee, WI 53214

Project Title

Intimacy and Sexuality in Dementia Care

Award Amount

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Additional Information and Resources

Department of Health Services / Division of Quality Assurance
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F-01593 (08/2015)

Final Report

Project: Sexuality and Intimacy in Dementia Care – Train the Trainer Program
Submitted by: Krista Scheel, Program Director
Date: January 5, 2015

Summary of program success and outcomes

Program Development

The Intimacy and Sexuality (I&S) Train the Trainer Program was developed in conjunction with a content expert consultant along with feedback and input from our advisory committee. The first initial months were spent on content development and coordination of materials, including the approval for the multimedia training clips to be provided to attendees on one edited DVD. Additionally, a pre/post survey was developed to measure attendees' knowledge about dementia (10 question item) and attitudes about intimacy and sexuality in dementia care (10 question item).

The training product consisted of six modules, each about one hour in length. The training outline and modules were as follows:

Caring for People with Dementia: Focus on Intimacy and Sexuality

A. Introduction to a six-part training program for nursing home staff
B. Pre-training survey: Knowledge about dementia and attitudes about sexuality and intimacy in dementia

I. Dementia and Dementia Care

A. Facts about dementia including types, stages, diagnosis, treatment
B. Principles of Person Centered Care
C. Methods: Completion of 10-item quiz, video, group discussion.

II. Creative Responses to Challenging Behaviors

A. Meaning underlying behaviors
B. Triggers
    1. Physical
    2. Environmental
    3. Emotional
    4. Caregiver approaches
C. The "Soft Approach" to minimize and prevent behaviors
D. Methods: Group exercise about personal and private space, lecture, video, group discussion

III. Intimacy and Sexuality in Older Adults with Dementia

A. Our attitudes shape our behaviors
B. Rights of nursing home residents

IV. Intimacy and Sexuality between Residents

A. Levels of behavior
    1. Consensual intimacy without sex
    2. Consensual sex
    3. Non-consensual intimacy or sex
B. Abilities required for consent
    1. Ability to voluntarily participate
    2. Ability to say no
    3. Ability to be free from harm
    4. Ability to be free from abuse or exploitation
C. Levels of capacity for consent
    1. Low understanding required for low risk behaviors
    2. High understanding required for high risk behaviors
    3. No understanding - in need of protection
    4. Who determines capacity?
D. Case example of level one intimacy and level one capacity for consent
E. Methods: lecture, video, group discussion

V. Non-Consensual Intimacy and Sexuality between Residents

A. Review of levels of behavior and levels of capacity for consent
B. Review of rights: freedom from abuse
C. Case examples
D. Reporting and documenting

VI. Consensual Intimacy and Sexuality between Residents

A. Review of levels of behavior and levels of capacity for consent
B. Review of rights: dignity and self-determination, privacy
C. Case examples
D. Reporting and documenting

The training concluded with a post-training survey: Knowledge about dementia and attitudes about intimacy and sexuality in dementia. Each individual was matched by their birth date indicated on the pre and post surveys.

Train-the-trainer training sites and locations were coordinated and confirmed along with the development of marketing materials and a registration process. For the earliest training date, nursing homes were mailed information about the train-the-trainer sessions. Additionally, we utilized the list-serv from Department of Quality Assurance (DQA) to get the word out about the train-the-trainer sessions. We also asked our advisory group members to share the train-the trainer marketing materials with their membership through Leading Age and the Wisconsin Health Care Association.

Program Implementation

The first train-the-trainer session took place on January 24, 2014 in Milwaukee. There were 11 nursing homes in attendance along with staff from the Alzheimer's Association and members of the advisory committee for a total attendance of 47 attendees. This initial training session was provided by our curriculum developer and consultant, Dan Kuhn, LCSW.

Subsequent to the initial training date, the following train-the-trainer sessions took place:

- Wausau, February 19, 2014 – Northcentral Technical College; 12 nursing homes in attendance; 34 total attendees
- Racine, February 25, 2014 – Racine Marriott; 8 nursing homes in attendance; 24 total attendees
- Seymour, March 20, 2014 – Good Shepherd Services; 12 nursing homes in attendance; 36 total attendees
- Sheboygan, March 20, 2014 – Campus Life; 10 nursing homes in attendance; 35 total attendees
- LaCrosse, April 8, 2014 – Western Technical College; 12 nursing homes in attendance; 29 attendees total
- Madison, April 16, 2014 – Radisson Hotel; 17 nursing homes in attendance; 58 attendees total
- Eau Claire, April 17, 2014 – The Florian Gardens; 24 nursing homes in attendance; 58 attendees total

The ownership breakdown of the 106 nursing homes in attendance of the train-the-trainer program was as follows: 41 (39%) nonprofit church/corporations, (38%) 40 for-profit corporations or Limited Liability Companies and 25 (23%) Government – City/County/Federal.

Overall, **231 staff from 106 nursing homes participated in the train-the-trainer program** and completed the pre/post test. Due to the nature and complexity of the training program, we requested from each nursing home that at least one attendee is a member of the management team. Each nursing home was asked to send at least two staff members and up to three staff members under the fee of $50 per nursing home. The **demographic breakdowns of the trained trainers** were as follows:

Primary role

Social Work = 93	40%
RN = 65	28%
Administrator = 17	7%
Adm Support = 12	5%
Life Enrich/Activities = 14	6%
Other = 12	5%
CNA = 10	4%
LPN = 7	3%

Service at organization:

37= less than one year	16%
75 = 1-5 years	33%
45 = 6-10 years	20%
72 = 11 or more years	31%

Experience working with individuals with dementia:

9 = Less than one year	4%
46 = 1-5 years	20%
43 = 6-10 years	19%
131 = 11 or more years	57%

Each nursing home that attended an I&S train-the-trainer session was asked to return to their nursing home and implement the six-module training program with their staff. Due to timeline and data collection constraints we asked each nursing home to implement the training within 90 days of their train-the-trainer session and to provide the training to a minimum of 20 staff at their nursing home.

Through September 2014 we received pre/post surveys from **39 Nursing Homes** (38% completion rate) representing **642 nursing home staff**. Staff from the Alzheimer's Association did two to three follow-up calls with attendees to see how implementation was coming along and if there was assistance we could provide or help answering any questions. Some nursing homes required staff to attend while others kept attendance optional. Some of the reasons we were given as to why implementation had not occurred or would not occur are as follows:

- Low interest from staff
- Could not devote 6 hours to one topic of training as it does not fit with their training schedule
- Staff coverage an issue when staff are pulled off the floor for training
- Wanted to condense six modules into one hour
- Low census and cutting of staff and cuts in budget to pay for staff time to be at training
- Preparation for state survey
- Other training needed to be implemented first; EMR and med admin
- Staff resistance to training and content
- Undergoing building renovations
- Heavy pressure to train on AED first
- Finding the time to implement the training
- Scheduling issues, stretched on CNA hours
- Other person-centered things have taken priority
- Finding time to coordinate larger groups of people to have the training sessions.

The **demographic breakdowns of the nursing home staff** that were trained are as follows:

Service at organization:

122 = less than one year	19%
249 = 1-5 years	39%
119 = 6-10 years	18%
154 = 11 or more years	24%

Experience working with individuals with dementia:

48 = Less than one year	8%
187= 1-5 years	30%
128 = 6-10 years	20%
269 = 11 or more years	42%

Primary Role:

CNA = 265	41%
RN = 102	16%
LPN = 63	10%
RA/PCW = 3	.5%
OT/PT/ST = 6	1%
Social Work = 35	5%
Administrator = 11	2%
Adm Support = 18	3%
Operations support = 66	10%
Student = 4	.5%
Volunteer = 1	
Life Enrich/Activities = 49	8%
Other = 19	3%

Pre/Post Survey Results and Data Analysis

The 10-item attitude inventory and the 10-item dementia knowledge inventory were administered immediately before each training session (pre-survey) and immediately following the last module (post-survey). The pre/post surveys were administered to attendees at the train-the-trainer sessions (231 total) and to the staff from each nursing home (642 total) where the training was delivered by the trained trainers.

Data analysis support for this project was provided by Matthew Scheel, PhD, Associate Professor of Psychology at Carroll University. Data were analyzed within the trained trainers group and within the nursing home staff group. This was done to better compare the different groups since many from the trained trainers group were more skilled staff with extensive dementia experience. Participants were instructed to respond to each attitude statement with a response from a four-item likert scale: “strongly agree (1)”, I agree somewhat (2)”, “I disagree somewhat (3)”, and “I strongly disagree (4)”.

For example, attitude statement #4, *A spouse living in the community is entitled to become intimately involved with someone else if his or her spouse has dementia and resides in a care facility*. The trained trainers had a mean score of 2.721 on the pre-survey (close to "I disagree somewhat") and on the post-survey the mean score was 1.725 (beyond "I agree somewhat"). The nursing home staff had a mean score of 2.999 on the pre-suvey ("I disagree somewhat") and a post-survey score of 2.135 (close to "I agree somewhat").

For all of the 10 attitude statements, participants from both the trained trainers group and the nursing home staff group were significantly more likely to give a lower or higher score on the post-survey. **The two-tailed P value for each attitude statement was primarily <0.0001 which is considered extremely significant.**

For the 10 question knowledge inventory, participants were instructed to select the answer they thought was correct for each question. They received one point if their answer was correct and 0 points if their answer was incorrect. The trained trainers had a mean score of 7.126 points on the pre-survey and on the post-survey a mean score of 8.173 points. The nursing home staff had a mean score of 6.092 points on the pre-survey and on the post-survey a mean score of 6.868 points.

Overall, for the 10 question knowledge inventory, participants from both the trained trainers group and the nursing home staff group significantly achieved more correct points on the post-survey. **The two-tailed P value analyzing differences between pre and post is <0.0001 which is considered extremely significant.**

From the 10 question knowledge inventory, **the top 3 <u>incorrectly</u> answered questions** on the pre-test scores for each group and compared to the post-test scores were the following:

<u>Trained Trainers:</u>

Q8: **Alzheimer's disease is the ____ leading cause of death across all ages in the United States.** The correct answer is "6th". On average, this question was indicated as correct by **15.6%** of train-the-trainer attendees on the pre-test. On the post-test the average percentage correct increased to **49.4%.**

Q5 **Which of the following is the most overlooked source of distress among people with dementia?** The correct answer is "Pain". On average, this question was indicated as correct by **60.2%** of train-the-trainer attendees on the pre-test. On the post-test the average percentage correct increased to **81.4%**

Q1 **Which of the following is the most common cause of memory loss in people over age 65?** The correct answer is "Alzheimer's disease". On average, this question was indicated as correct by **62.8%** of train-the-trainer attendees on the pre-test. On the post-test the average percentage correct increased to **86.1%.**

Nursing Home:

Q8 **Alzheimer's disease is the ____ leading cause of death across all ages in the United States.** The correct answer is "6th". On average, this question was indicated as correct by **23.9%** of nursing home staff attendees on the pre-test. On the post-test the average percentage correct increased to **40%.**

Q5 **Which of the following is the most overlooked source of distress among people with dementia?** The correct answer is "Pain". On average, this question was indicated as correct by **45.1%** of nursing home staff attendees on the pre-test. On the post-test the average percentage correct increased to **57.1%**

Q2 **A potentially reversible cause of dementia is?** The correct answer is "Depression". On average, this question was indicated as correct by **52.8%** of nursing home staff attendees on the pre-test. On the post-test the average percentage correct increased to **66.7%**

See below for the pre/post survey that was administered along with data analysis for each attitude statement and the data analysis across all of the dementia knowledge questions:

Survey Respondent Data

Enter today's date _____ **/** _____ **/** _____

Month Day Year

Enter <u>your birth-date (month/date/year)</u>: ___ ___ **/** ___ ___ **/ 19** ___ ___

Month Day Year

Circle your length of service at this organization:

1. Less than one year 2. 1-5 years 3. 6-10 years 4. 11 or more years

Circle your length of experience in working with individuals with dementia:

1. Less than one year 2. 1-5 years 3. 6-10 years 4. 11 or more years

Circle your primary role:

1. CNA 2. RN 3. LPN 4. RA/PCW 5. OT/PT/ST 6. Social Work/Admissions

7. Administrator 8. Administrative/Support 9. Operations Support (maintenance, laundry, housekeeping, dietary, etc.) 10. Student 11. Volunteer 12. Life Enrichment/Activities 13. Other

Circle the highest level of education that you completed:

1. Grade school 2. High school 3. Two year college 4. Four year college

5. Advanced degree (master's/doctorate)

Survey Instructions: *Please rate each statement according to how much you agree or disagree with it. Circle the number according to how you feel or think about each statement.*

1. **Competent and consenting residents are entitled to be sexually intimate with their spouses in a private place within a care facility.**

1	2	3	4
I Strongly Agree	I Agree Somewhat	I Disagree Somewhat	I Strongly Disagree

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	1.126	1.017	.1082	Mean:	1.326	1.139	.1865
# of points:	231	231	231	# of points:	638	638	638
Std deviation:	.4030	.1307	.3861	Std deviation:	.6248	.4458	.6866

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 231. Sum of positive ranks (T+) = 231. Sum of negative ranks (T-) = 0. Number of pairs = 21. Note: 210 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 7824. Sum of positive ranks (T+) = 10272. Sum of negative ranks (T-) = -2448. Number of pairs = 159. Note: 479 pairs were excluded from calculations because both values were equal.

2. **Competent and consenting residents who are single are entitled to be sexually intimate with each other in a care facility.**

1	2	3	4
I Strongly Agree	I Agree Somewhat	I Disagree Somewhat	I Strongly Disagree

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	1.381	1.035	.3463	Mean:	1.867	1.263	.6033
# of points:	231	231	231	# of points:	634	634	634
Std deviation:	.6132	.1832	.5909	Std deviation:	.8976	.05635	.9137

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 2415. Sum of positive ranks (T+) = 2415. Sum of negative ranks (T-) = 0. Number of pairs = 69. Note: 162 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 43230. Sum of positive ranks (T+) = 46500. Sum of negative ranks (T-) = -3270. Number of pairs = 315. Note: 319 pairs were excluded from calculations because both values were equal.

3. Residents who have dementia are not capable of making sound decisions regarding participation in sexual relationships.

1	2	3	4
I Strongly Agree	I Agree Somewhat	I Disagree Somewhat	I Strongly Disagree

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	2.567	3.392	-.8247	Mean:	2.190	2.723	-.5331
# of points:	231	231	231	# of points:	634	634	634
Std deviation:	.8307	.7049	1.008	Std deviation:	.9054	1.007	1.179

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = -10507. Sum of positive ranks (T+) = 948. Sum of negative ranks (T-) = 11455. Number of pairs = 157. Note: 74 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = -48470. Sum of positive ranks (T+) = 16670. Sum of negative ranks (T-) = -65140. Number of pairs = 404. Note: 230 pairs were excluded from calculations because both values were equal.

4. A spouse living in the community is entitled to become intimately involved with someone else if his or her spouse has dementia and resides in a care facility.

1	2	3	4
I Strongly Agree	I Agree Somewhat	I Disagree Somewhat	I Strongly Disagree

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	2.721	1.725	.9957	Mean:	2.999	2.135	.8645
# of points:	231	231	231	# of points:	631	631	631
Std deviation:	1.003	.8335	1.124	Std deviation:	.9781	.9591	1.136

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 13273. Sum of positive ranks (T+) = 14602. Sum of negative ranks (T-) = -1329. Number of pairs = 178. Note: 53 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 72537. Sum of positive ranks (T+) = 81107. Sum of negative ranks (T-) = -8569.5. Number of pairs = 423. Note: 208 pairs were excluded from calculations because both values were equal.

5. Two residents, both of whom have dementia, are entitled to an exclusive and consensual relationship but should not be sexually intimate if one of them is married to another person.

1	2	3	4
I Strongly Agree	I Agree Somewhat	I Disagree Somewhat	I Strongly Disagree

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	2.216	3.004	-.7879	Mean:	2.322	2.657	-.3352
# of points:	231	231	231	# of points:	631	631	631
Std deviation:	.9117	1.507	1.735	Std deviation:	1.074	.9816	1.360

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = -10765. Sum of positive ranks (T+) = 2944. Sum of negative ranks (T-) = -13709. Number of pairs = 182. Note: 49 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = -31668. Sum of positive ranks (T+) = 34454. Sum of negative ranks (T-) = -66122. Number of pairs = 448. Note: 183 pairs were excluded from calculations because both values were equal.

6. Two residents, one with Alzheimer's disease and the other who is cognitively intact, are entitled to be sexually intimate as long as they are both single and their relationship appears consensual.

1	2	3	4
I Strongly Agree	I Agree Somewhat	I Disagree Somewhat	I Strongly Disagree

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	2.567	1.684	.8831	Mean:	2.770	1.955	.8152
# of points:	231	231	231	# of points:	633	633	633
Std deviation:	.8949	.9393	1.219	Std deviation:	.9951	.9555	1.239

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 11866. Sum of positive ranks (T+) = 13899. Sum of negative ranks (T-) = -2032.5. Number of pairs = 178. Note: 53 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 71758. Sum of positive ranks (T+) = 85052. Sum of negative ranks (T-) = -13294. Number of pairs = 443. Note: 190 pairs were excluded from calculations because both values were equal.

7. Two residents both of whom are single and have dementia, are entitled to be sexually intimate if their relationship appears consensual and their family members do not object.

1	2	3	4
I Strongly Agree	I Agree Somewhat	I Disagree Somewhat	I Strongly Disagree

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	1.861	1.448	.4134	Mean:	2.214	1.618	.5957
# of points:	231	231	231	# of points:	632	632	632
Std deviation:	.7549	.7279	.9412	Std deviation:	.9338	.8307	1.060

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 5185. Sum of positive ranks (T+) = 6850. Sum of negative ranks (T-) = -1665. Number of pairs = 130. Note: 101 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 51865. Sum of positive ranks (T+) = 63085. Sum of negative ranks (T-) = -11220. Number of pairs = 385. Note: 247 pairs were excluded from calculations because both values were equal.

8. A resident is entitled to masturbate in private as long as his or her personal safety is ensured.

1	2	3	4
I Strongly Agree	I Agree Somewhat	I Disagree Somewhat	I Strongly Disagree

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	1.104	1.048	.05628	Mean:	1.421	1.159	.2618
# of points:	231	231	231	# of points:	634	634	634
Std deviation:	.3330	.3126	.4079	Std deviation:	.6775	.4548	.6465

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is = 0.0112, **considered extremely significant**. Sum of all signed ranks (W) = 164. Sum of positive ranks (T+) = 220. Sum of negative ranks (T-) = -56. Number of pairs = 23. Note: 208 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 11795. Sum of positive ranks (T+) = 13165. Sum of negative ranks (T-) = -1370. Number of pairs = 170. Note: 464 pairs were excluded from calculations because both values were equal.

9. Two residents who are of the same sex are entitled to be sexually intimate with one another as long as their relationship appears consensual.

1	2	3	4
I Strongly Agree	I Agree Somewhat	I Disagree Somewhat	I Strongly Disagree

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	1.543	1.091	.4524	Mean:	1.873	1.254	.6186
# of points:	231	231	231	# of points:	628	628	628
Std deviation:	.7418	.3432	.7267	Std deviation:	.9227	.5601	.9185

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 4309. Sum of positive ranks (T+) = 4531. Sum of negative ranks (T-) = -222. Number of pairs = 97. Note: 134 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 43977. Sum of positive ranks (T+) = 46874. Sum of negative ranks (T-) = -2896.5. Number of pairs = 315. Note: 313 pairs were excluded from calculations because both values were equal.

10. No one should interfere in the sexual lives of residents as long as no civil or criminal laws are broken.

1	2	3	4
I Strongly Agree	I Agree Somewhat	I Disagree Somewhat	I Strongly Disagree

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	2.195	1.680	.5152	Mean:	2.156	1.818	.3373
# of points:	231	231	231	# of points:	630	630	630
Std deviation:	.9319	.9413	1.030	Std deviation:	.9302	.9639	1.093

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 5684. Sum of positive ranks (T+) = 7231. Sum of negative ranks (T-) = -1547. Number of pairs = 132. Note: 99 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = 28006. Sum of positive ranks (T+) = 46134. Sum of negative ranks (T-) = -18128. Number of pairs = 358. Note: 272 pairs were excluded from calculations because both values were equal.

Knowledge About Memory Loss and Dementia

1. Which of the following is the most common cause of memory loss in people over age 65

_____ 1. Normal aging

_____ 2. Senility

_____ 3. Alzheimer's disease

_____ 4. Hardening of the arteries

_____ 5. Benign senescent forgetfulness

2. A potentially reversible cause of dementia is

_____ 1. Alzheimer's disease

_____ 2. Depression

_____ 3. Strokes

_____ 4. Lewy Body Dementia

_____ 5. Frontal Temporal Dementia

3. Which of the following is <u>incorrect</u> about Alzheimer's disease

_____ 1. It is a progressive disease

_____ 2. It is a mental illness

_____ 3. It has no cure

_____ 4. It affects over 5 million Americans

_____ 5. It has short-term memory loss as one of the first symptoms

4. Giving reminders such as the date and place to persons with memory loss disease will

_____ 1. Improve memory for a time

_____ 2. Improve orientation for a time

_____ 3. Not change memory or orientation

_____ 4. Increase confusion

_____ 5. Be useful temporarily, but will have no lasting effect on memory or orientation

5. Which of the following is the most overlooked source of distress among people with dementia?

_____ 1. Pain

_____ 2. Noise

_____ 3. Loneliness

_____ 4. Unfamiliar people

_____ 5. Fatigue

6. A person with moderate dementia

_____ 1. Is safe to drive independently

_____ 2. Cannot participate in normal activities

_____ 3. Is confined to a bed

_____ 4. Can handle finances on their own

_____ 5. Needs 24 hour supervision

7. Which of the following approaches is NOT HELPFUL for persons with memory loss in completing tasks

_____ 1. Breaking tasks down into smaller steps

_____ 2. Encouragement to try harder

_____ 3. Repeating old, familiar tasks

_____ 4. Having other assist them as needed

_____ 5. Companionship

8. Alzheimer's disease is the ____ leading cause of death across all ages in the United States

_____ 1. 5th

_____ 2. 6th

_____ 3. 7th

_____ 4. 8th

_____ 5. 9th

9. Alzheimer's disease affects the following functions

_____ 1. Concentration

_____ 2. Movement

_____ 3. Memory

_____ 4. Emotions

_____ 5. All of the above

10. Person Centered Care for people with memory loss does NOT include which of the following principles

_____ 1. Valuing them

_____ 2. Prescribing appropriate medications

_____ 3. Individualizing care

_____ 4. Seeing the world through their eyes

_____ 5. Providing a social environment

Knowledge Questions Overall Results:

Trained trainers				**Nursing Home Staff**			
Parameter:	Pre-test	Post-test	Difference	Parameter:	Pre-test	Post-test	Difference
Mean:	7.126	8.173	-1.048	Mean:	6.092	6.868	-.7757
# of points:	231	231	231	# of points:	642	642	642
Std deviation:	1.456	1.592	1.715	Std deviation:	1.871	1.915	2.030

Trained Trainers: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = -12091. Sum of positive ranks (T+) = 1742.5. Sum of negative ranks (T-) = -13834. Number of pairs = 176. Note: 55 pairs were excluded from calculations because both values were equal.

Nursing Home Staff: An analysis with a nonparametric Wilcoxon matched-pairs signed-ranks test of whether median of the differences between pre and post differ significantly from zero. The two-tailed P value is < 0.0001, **considered extremely significant**. Sum of all signed ranks (W) = -61277. Sum of positive ranks (T+) = 31737. Sum of negative ranks (T-) = -93014. Number of pairs = 499. Note: 143 pairs were excluded from calculations because both values were equal.

Feedback From Trained Trainers

An electronic survey was emailed to the trained trainers approximately 120 days after their training session. The electronic survey had focused questions on the implementation of the training program, policy practice change, and benefits within care and practice. The survey was completed by 25 nursing homes (64% response rate; 25/39 nursing homes that implemented the training and completed onsite pre/post surveys) and the survey asked the following questions:

1. **Please indicate how you implemented the training program within your nursing home.**
    - 92% indicated they implemented the training program as it was provided to them via the train-the trainer program.
    - 4% indicated they adapted the training by removing one of the modules.
    - 4% indicated they changed the order of the modules but did provide all of the content.

2. **Did you implement the training program as optional (those who wanted to come) or as required (selected staff to attend) the training program?**
    - 68% indicated attendance at the training was required.
    - 32% indicated attendance at the training was optional.

    Comments:
    - Many indicated they required RN staff and senior leadership/department heads to attend.
    - Others indicated they assigned the training on the staff's work schedule.
    - Some focused their training efforts on their dementia unit staff.

3. **As part of this project, did your facility change or develop policies around intimacy and sexuality in dementia care? If yes, please explain what you changed or developed.**
    - 80% indicated “No”
    - 20% indicated “Yes”

    Comments:
    - Not at this time (3).
    - We are in the process of changing policies at the moment to implement knowledge gained from the training and some of the resource materials provided as reference (2).
    - We are working on updating our current policies (4).
    - We have not yet but hope to start working on a policy.

4. **As part of the project, did your facility develop new practices or new protocol for staff as to how your facility would respond to instances of intimacy and sexuality in residents with dementia?**
    - 64% indicated “No”
    - 36% indicated “Yes”

    Comments:
    - Following the guidelines we will be using that.
    - Not at this time, will be reviewing/developing.
    - ***Staff are more aware of what can happen and staff were able to share experiences and have questions answered. Overall, this training brought awareness.***
    - Yes, after those notified that are necessary, guardians, etc – will allow more privacy for those that can say “no” and that can leave a situation if they so desire.
    - We do not have this completely accomplished at this time. We continue to work on this. (4)
    - Already in place.
    - We highlighted that if both parties have the ability to say no, but want to be intimate, we need to find a way to let that happen. But the staff should inform social services and nursing management.
    - ***We are in the process of having all facility staff go through the intimacy and sexuality training. They need a much broader scope of practice and sensitivity regarding this vital aspect of being human.***

5. **If applicable, do you intend to use the curriculum in other care settings within your organization? e.g., assisted living?**
    - 48% indicated “Yes”
    - 44% indicated “Not applicable”
    - 8% indicated “No”

    Comments:
    - Assisted living (2)

- At our group homes

6. **For those staff who went through the training program did the program increase the awareness of their own personal, religious and cultural biases toward intimacy and sexuality in persons with dementia?**
   - 56% indicated “Agree”
   - 28% indicated “Strongly Agree”
   - 12% indicated “Neutral”
   - 4% indicated “Strongly Disagree”
   - 0% indicated “Disagree”

   Comments:
   - ***Personal awareness and introspection in my opinion was the most eye-opening challenge to this training.***

7. **Did you experience benefits in care and practice with the implementation of the training program? Please describe your benefits of the training program to your facility and if you have a success story, please share.**
   - Yes, staff is more aware of sexuality for dementia.
   - Staff appeared to have a better understanding of what was acceptable in terms of sexuality with dementia residents.
   - Increased awareness and resident’s rights related to topic understanding of responsibility related to interventions.
   - Too early to tell.
   - ***We raised awareness of the sexual and intimate needs of residents. Staff are now less judgmental and more understanding and are starting to think outside of the box.***
   - Basically made staff aware of resident’s rights regarding sexuality and intimacy; also that overall it is a resident’s decision, not staff or family.
   - Awareness. Foundation of resources to utilize for review and further development of policies and procedures.
   - It helped raise staff awareness and gave them tools on how to handle situations as they arise.
   - ***During the training; it was amazing to listen and have the staff come together to share stories about their loved ones and residents. Staff from all shifts were able to communicate challenges and ask questions. I did see many staff members become emotional about how this can be very hard on all parties.***
   - Greater staff awareness of residents rights with sexuality and dementia.
   - ***Benefits include more awareness of person-directed care approach.***
   - I think it was helpful to open up minds of staff on the awareness of this topic and how to handle events as they take place in this setting.
   - The program helped to train people that the Alzheimer’s patients still do have rights to be in a relationship even though they have guardians. Some staff do

have a hard time with this but I believe with the education from this training that they are more open minded and aware of what they need to do with situations now.

- ***Staff are more aware that residents with dementia can consent to intimacy. They know now that our own values and thought process on this subject may need to be tailored. The other benefit is that we know how families may react and this training will help us work with families who are very oppositional with their loved one being intimate with another in our facility.***
- Provided an increased awareness for the staff on residents with dementia.
- Not yet.
- No.
- Biggest change was awareness.
- ***I think it was very beneficial for staff to realize that they had their own biases in certain areas and that they should keep an eye on their own biases when caring for other individuals.***
- ***I witnessed a wife lying in bed with her husband, who is our patient. I'm not sure how I would have reacted prior to the program, but it occurred after, and it was very touching. Increased all our sensitivity to such issues, I think.***
- Yes, greater empathy and understanding in working with our elderly population and respect of their feelings toward others.
- ***Benefitted us to talk with staff to make sure everyone is on the same page about how to work with this topic, who to go to if you have questions, and how your own attitude shapes how you react to situations.***
- Primary benefit was an enhanced ability to utilize the information in the program to teach staff and support families – the teaching material was clear and accessible.
- ***We received only positive feedback from staff. It opened their eyes and minds to situations that were happening in the facility that they were overlooking. It also prepared them to know how to handle a future situation. This training raised a lot of questions for staff and helped them to begin a new thinking process for our residents including very personalized care planning.***
- At this time we do not have any residents expressing the need for or engaged in any sexual activity.

8. **Do you intend to continue to use the curriculum as an ongoing training program for facility staff? Beyond the 20 trained under the pilot?**
    - 100% indicated "Yes".

    Comments:
    - I will use the training for the CNA's if they are in need for more training.
    - We will use it as situations arise, as well as when there is more staff turnover. We would condense it into a one day program vs breaking it up into modules.

- Excellent resource. Will utilize as policies and procedures are reviewed/developed.
- ***We will continue to hand out information and train 1:1 with staff. The material is a great learning tool for all staff.***
- Yes, we actually have yet to reach the 20.
- Yes but modified reach to all staff.
- We have to complete the training in the short increments to ensure that we can get it all completed. This is the only change that was really made.
- Use a much abbreviated form for all of our orientations.
- ***We'll need to parse it down, but the content is good, so we'll find a way. I have shown the Alzheimer's Association video to families who have loved ones with dementia and it has been received well.***
- Use as part of new employee orientation and future employee training sessions.
- Add it to our Stop Starting It Training, mostly the last few modules as the first few were review for most of our staff and we do cover similar topics in our own training. We also added many more examples of situations we have encountered with our residents to share with the staff.
- We may offer the different modules apart from each other, depending on the needs of the staff being trained, both to address the specific subject areas individually and to help with staff's availability for attending them.
- ***No adaptations other then choosing different staff members each time. We received all positive feedback from the ones that did attend.***

Lessons Learned

The overall experience from this project from both the Alzheimer's Association perspective and the nursing home staff perspective was very positive. Implementing a train-the-trainer program with expectations that attendees take this training back to where they work was daunting. It became apparent that there were many barriers to implementation of the training within the nursing home, ranging from staff turnover to other training demands. The three-month timeline to implementation may not have been realistic enough for nursing homes to follow.

Utilization of video clips is a great addition to learning aspects for this type of material and content and feedback from the attendees indicated they made a difference for the nursing home staff that were trained. The process of putting the video clips on to a DVD for each nursing home was quite costly and something we would reconsider in the development of further train-the-trainer programs.

Very few calls or emails were received by the Alzheimer's Association at the implementation stage of the trainings at the nursing home facilities. Having more contact at this stage initiated by the nursing home facilities to ask questions or seek guidance about the actual training could possibly have increased overall participation or more thorough training.

Additionally, there were some frustrations on behalf of Alzheimer's Association staff in not receiving return phone calls or emails as we were doing our follow-up calls/messages to check in and see how training implementation was coming along or if there were any questions. About 20% of nursing homes did not respond to repeated attempts to reach them in the months following their train-the-trainer session.

The topic itself brought unforeseen challenges due to its controversial nature. Raising awareness and creating an environment to allow for shifts in perspective during the train-the-trainer sessions were as important and difficult as the topic itself.

Recommendations for Replication

For replication purposes, we would recommend this be transitioned to a training/workshop program for anyone within long-term care to attend vs. a more regimented train-the-trainer program. We had an overwhelming response from assisted living communities (that we turned away) and recommend this program be offered for that level of care. This program could be adapted for adult day and independent living as well. Acute care providers and first responders could also benefit from the basics. We also suggest this training program be offered in webinar format and could be viewed by each module.