

2009 HOUSE HUMAN SERVICES

HB 1043

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. 1043

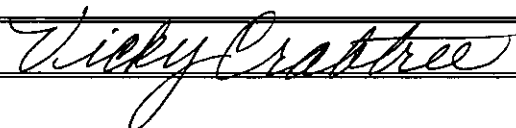
House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: January 12, 2009

Recorder Job Number: 6831 70 min. 47 sec.

Committee Clerk Signature



Minutes:

Chairman Weisz: We will open the hearing on HB 1043.

Sheila Sandness, Fiscal Analyst for the Legislative Council presented information on the bill. **See attached testimony #1.**

Chairman Weisz: Any questions from the committee? Thank you.

Gretchen Dobervich, the Eastern ND Regional Center Director for Alzheimer's Association, testified in support of the bill. **See attached Testimony #2.**

Chairman Weisz: You indicated you did some (inaudible) consultant services. As you envision this bill, let the committee know how this would transpire (inaudible) continuing of care for someone with dementia.

Gretchen Dobervich: If this bill passes there will be a dementia care consultant in each region of ND which would be eight. The person could travel to the community and meet them in their homes or anywhere to help them develop a plan of care. The care givers can contact the Alzheimer's Association for assistance with home safety, wandering, and behavior management. Care consultants can work with that agency to help them move that (inudible) care into that level of care. When person is required to have skilled nursing care or nursing home placement, the care consultants would be available for that facility to consult with. And

they can make sure the staff has developed a plan of care that meets those specific needs.

Most people with dementia don't recognize a change going on until they are in the middle stage of the disease. With education component, care consultants will be going into communities whether rural or urban and doing education about the early warning signs of the disease.

Representative Nathe: What percentage of population in ND suffers from dementia?

Gretchen Dobervich: Rough estimate of 18,000. Can't give a percentage.

Representative Nathe: How many care consultants per region are you thinking?

Gretchen Dobervich: One full time person per region or a total of eight

Representative Nathe: Is that enough to service a region?

Gretchen Dobervich: It's a start.

Chairman Weisz: Do you have a number of the total of dementia in this state?

Gretchen Dobervich: Will get that to you as currently don't have that information with me.

Representative Porter: Who is eligible for contract made available?

Gretchen Dobervich: It's my understanding it will be an open contract. Anyone who feel they can provide that service.

Representative Porter: Currently is there anybody doing these functions in the state right now?

Gretchen Dobervich: Currently, doing specific dementia care consultation is the Alzheimer's Association and two employees for the state of ND that in addition to their other job functions provide care consultation.

Representative Porter: In relationship to the Governor's (inaudible) entry point program and coordination of all the different program across the state, how does this fit into that or compute with it or how will it work in the scheme of things as we move towards as a single point of entry

for all the various programs that are available, so that someone is referred to private or public group who takes of that situation?

Gretchen Dobervich: Single point of entry, the dementia care consultation would be like any other service.

Representative Porter: If someone calls local public health unit and states spouse has dementia or Alzheimer's, they have no training or education in place right now to help them deal with any of the issues related to being at home and taking care of an Alzheimer's or dementia patient?

Gretchen Dobervich: It is my understanding that Public Health does not have any programs in place that would provide for those.

Representative Holman: There some data looking at how we spend money in one place and save money in another. (Inaudible)

Gretchen Dobervich: We've done some research on saving dollars. Don't have that information with me today, but would be happy to provide it for you.

Representative Conrad: Are the costs per month (inaudible) in ND?

Gretchen Dobervich: Varies by levels of care. On average it is about \$60,000 a year.

Representative Hofstad: Explain what your organization is and how it is structured, amount of employees and what's your history?

Gretchen Dobervich: The Alzheimer's Association is a non-profit organization and is completely funded by private donations. Two offices which are in Eastern and Western North Dakota. Bismarck and Fargo and both offices serve one half of the state. Each office has one employee and Fargo has a one quarter time assistant. We do care consultation the best we can with limited staffing. We do community education services. We have 24 hour seven days a week help line which is answered by a live person. We are part of a national organization

and the Alzheimer's Association has been working in North Dakota on a volunteer base. We have evolved quite a bit since the late 80's. The association on the whole has been in existence for over 25 years.

Representative Damschen: Who do you see reaps greatest benefits from this bill?

Gretchen Dobervich: I envision that people with dementia will receive the most benefit. Because the care givers will be given the tools to provide them with the best care they can possibly receive.

Chairman Weisz: Further questions? If not, thank you.

Rodger Wetzel, Director of Northland PACE (Program of All-inclusive Care for the Elderly), testified in support of bill. **See attached Testimony #3.**

Chairman Weisz: How many total dementia cases in North Dakota?

Rodger Wetzel: Can only estimate at 25,000.

Chairman Weisz: Why are we seeing an increase in dementia? Is it because we are living longer?

Rodger Wetzel: That's a common question that we receive. It is age related. We live longer.

Representative Conrad: (Inaudible). Can you elaborate on that?

Rodger Wetzel: Have Alzheimer's Association answer that.

Gretchen Dobervich: Minnesota program is a model that ND is moving towards. (Inaudible) placement in 18 months. Have a copy of that and is available for you.

Representative Porter: Looking at the program, why are we going to a private provider when we have infrastructure in human service centers and county social services in part with the public health units?

Rodger Wetzel: Human Services Centers doing a great job, but this is an overwhelming problem. Because of challenges, it would be a major challenge to keep on top of all of this plus everything else on their plate.

Representative Porter: We don't have state funded programs for heart disease for specific people or cancer. Why should we just pick one disease and not have something that encompasses the things that will affect certain population?

Rodger Wetzel: Within the Health Dept. they do have some specific programs like cancer (inaudible). This is at epidemic. If we look at over half the people in nursing homes have dementia or will have dementia and that will rapidly increase, I think it is epidemic and need to get our arms around it. Doctors are specialists to work with heart disease and cancer. There is no one with specialty to work with these families.

Chairman Weisz: Any other questions from the committee? If not, thank you very much. Senator Dever would you like to.

Senator Dever: Senator Dever is from District 32 and served as Chairman of the Long Term Care Committee who generated this bill. He spoke in support of the bill. He stated the issue for him was public policy and personal experience. He talked about his father-in-law who was diagnosed with Alzheimer's in 2007. His wife went to live with her parents in the summer of 2007 and found her mother was not dealing with the Alzheimer's issue very well. He contacted the Alzheimer's Association and they visited with his wife and mother-in-law and they helped them understand some things. As a family they decided to have father-in-law live with Senator Dever and wife for seven months and now is in the Newport Community Center in Bismarck. He described the experiences of his father-in-laws behavior and the things he could and couldn't do anymore. He stated the bill enables families across the state to treat loved ones

with respect. The Alzheimer's Association helps people understand the disease and how to deal with it and with loved ones.

Chairman Weisz: Any questions from the committee? Did you come up with any data that might indicate any dollar savings?

Representative Dever: One of the criteria in creating the bill is to report to the legislative council on actual savings. Discussed adding FTEs to the Dept. of Human Services. One per region and it was my suggestion that we (inudible) the Alzheimer's organization is really the only organization that provides the kind of services that they do. Want to make ND a dementia friendly state.

Representative Hofstad: Several dementia centers are going to be or are being built across the state. Are there are collaborative arrangements between what you are trying to accomplish here and those centers. Seems to me that those centers are two of the well qualified and equipped to have some sort of early intervention to families.

Representative Dever: You need to consider that the Alzheimer's Association has special expertise, focused just on dementia. There are 17,000 to 18,000 people in ND that have dementia and I don't know how the two people in the association do what they do.

Chairman Weisz: Any questions? Thank you Senator. Anyone else here in support of HB 1043?

Marcia Buringrud: testified in favor of the bill. She explained of her mother's Alzheimer's disease and how this bill would unite the medical and healthcare facilities to provide the support that is much needed. **See attached Testimony #4.**

Chairman Weisz: Any questions from the committee? If not, thank you very much. Anyone else in support of 1043?

Pamela Offerdahl from Casselton, ND: had no written testimony, but testified in support of the bill. She is a care giver for her husband who has dementia. When doctor gave diagnosis, he told them to come back in six months. They felt lost and alone when they left the doctor's office and felt that way for about a year. Then they met Gretchen Dobervich from the Alzheimer's Association and she gave them hope and help.

Chairman Weisz: Any questions from the committee? Thank you very much. Any other support for 1043?

Carol Portermacher, representing Farmers Union: she brought in a letter of support from the President of Farmer's Union. **See attached letter of support #5.**

Chairman Weisz: Any questions? If not, thank you very much. Anyone else in support?

Krista Headland, Western ND Director of the Alzheimer's Association: testified in support of the bill. **See attached Testimony #6. She also handed in a letter sent to her from National Active and Retired Federal Employees Association in support of HB 1073. See attached letter #7.**

Chairman Weisz: I have a question. Roughly how many families do you helped personally in a year?

Krista Headland: Care consultation is just one of the parts of my job and time intensive. I do advocacy and education for professionals and communities. Been with association for five months and worked with 10 new families on top of other duties. You can follow a family for years, from diagnosis until end of life.

Chairman Weisz: Any further questions?

Representative Porter: What is your educational background?

Krista Headland: Education is in Public Administration and worked with elderly in an internship at a (inaudible) Memorial Homes in Grand Forks. Got a Health Administration

through my masters degree program and worked in long term facilities for a couple of years before coming the Alzheimer's Association.

Representative Porter: For the care consultations positions that are would be funded in this particular bill. Do you see that background as the one that would be carried forward or a social worker background or nursing? What background do you see as the background necessary for these eight positions?

Krista Headland: We budgeted for bachelor level social workers.

Representative Porter: This fiscal note for the eight would come out to be about \$75,000 a year?

Krista Headland: That would be everything for the whole program. It would be their salary and benefits package, recruiting, training process, set them up with supplies for their office, most likely in their home. It includes everything the program would need in the two years.

Chairman Weisz: Further questions? Thank you very much. Anymore support?

Beth Hughes: No written testimony, but spoke in support of bill. Talked of her father having Alzheimer's and how hard it is on her mom. Mother has contacts through Alzheimer's Association and they help her mother.

Linda Johnson Wurtz, representing AARP: did not speak, but handed in a written testimony in support of the bill. **See attached Testimony #8.**

Lois Knoll, RN and President of ND Hospice Organization: did not speak, but submitted hand written testimony in support of the bill. **See attached Testimony #9.**

Bruce Murry, lawyer with ND Protection and Advocacy Project: did not speak, but handed in a written testimony. **See attached Testimony #10.**

Chairman Weisz: Any questions? Thank you. Anyone else here in support of 1043? Any opposition to HB 1043? If not, we will close the hearing on HB 1043?

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. 1043

House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: February 3, 2009

Recorder Job Number: 8523 9 min. 04 sec.

Committee Clerk Signature



Minutes:

Chairman Weisz: Let's take up HB 1043. Discussion?

Rep. Potter: Is the appropriation of 1.2, I have a note that says the point of entry is in the Governor's budget and what's the difference?

Chairman Weisz: AGRC that's in the Governor's budget is (inaudible) referral system and this bill specifically deals with issue of Alzheimer's dementia. (Inaudible) assessment the AGRC doesn't provide that per say, just a resource to get you in the right place. Whereas a FN focuses (inaudible) that.

(Discussion back and forth between Rep. Weisz, Rep. Potter and Rep. Pietsch.)

Rep. Nathe: Motion for a DO PASS with a referral to Appropriations.

Rep. Holman: Second

Rep. Conrad: We make investment in system, but saving money in the long run.

Roll Call Vote: 13 , yes, 0 , 0 absent

DO PASS carried and re-referred to Appropriations

Bill Carrier: Rep. Damschen

Date: 2-3-09

Roll Call Vote #:

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 1043

House HUMAN SERVICES Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken ☒ Do Pass ☐ Do Not Pass ☐ Amended

Motion Made By Rep Nathe Seconded By Rep. Holman

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN ROBIN WEISZ	✓		REP. TOM CONKLIN	✓	
VICE-CHAIR VONNIE PIETSCH	✓		REP. KARI L CONRAD	✓	
REP. CHUCK DAMSCHEN	✓		REP. RICHARD HOLMAN	✓	
REP. ROBERT FRANTSVOG	✓		REP. ROBERT KILICHOWSKI	✓	
REP. CURT HOFSTAD	✓		REP. LOUISE POTTER	✓	
REP. MICHAEL R. NATHE	✓				
REP. TODD PORTER	✓				
REP. GERRY UGLEM	✓				

Total (Yes) 13 No 0

Absent 0

Bill Carrier Rep. Damschen

If the vote is on an amendment, briefly indicate intent:

re-refer to Appropriations

REPORT OF STANDING COMMITTEE

HB 1043: Human Services Committee (Rep. Welsz, Chairman) recommends DO PASS and BE REREFERRED to the Appropriations Committee (13 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). HB 1043 was rereferred to the Appropriations Committee.

2009 HOUSE APPROPRIATIONS

HB 1043

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. **HB 1043**

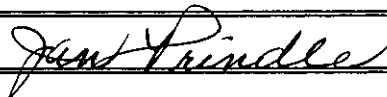
House Appropriations Committee

☐ Check here for Conference Committee

Hearing Date: **February 12, 2009**

Recorder Job Number: 9333

Committee Clerk Signature



Minutes:

Rep. Weisz introduced HB 1043. This establishes a dementia care services program in the state. Dementia is a complicated and complex issue. This sets up a process of working with people with Alzheimer's and with their families to come up with the best care and the best services. Minnesota found that when they instituted this program it shortens nursing home stay by 18 months. There is \$1.2 million appropriation. It could save the state over \$4 million based on the experience MN has had with this type of program. The Human Services Committee thought this program has merit and is a positive investment for the state of ND.

Chm. Svedjan: It looks like most of the money is required for is more of an administrative nature rather than care giving. The piece that get's the closest is the training piece.

Rep. Weisz: This helps train and helps families address issues that arise as a result of family members having dementia so they can take care of that person in their home for a longer time before they have to end up in a skilled nursing facility. It makes the family more capable to handle the problems that are there. It doesn't cure the disease.

Chm. Svedjan: You used Minnesota as a reference to come up with the \$1.2 million. Did you get a breakdown as well?

Rep. Weisz: No. The Department will do a RFP for providers.

Chm. Svedjan: Did you analyze the facilities that provide services? Did you ascertain the number of facilities in the state who provide dementia care?

Rep. Weisz: No we did not.

Rep. Hawken: We had a bill for one point of access for our senior citizens and Rep. Porter said this is a bill that could at some point be expanded to deal with other senior issues and it would be handled by private entities. This bill has a lot of parts that would impact the early catching of Alzheimer's. Aside from the compassionate part, this deals with a problem that is much larger than we want it to be. I hope we will pass this.

Rep. Delzer: Did you ask about timing? How quick will it come in to place?

Rep. Weisz: No we did not. We assumed the department would put together and RFP.

Rep. Delzer: This would reside in the Grants line under economic assistance. Is there anything that if there was no RFP this money would be reserved in the future or would it be used elsewhere in the department?

Rep. Weisz: Section 3. I don't know if they didn't get enough RFP, would it make it go away?

Chm. Svedjan: This bill came out of the LTC Interim Committee; this came in as a separate bill and not a part of their budget. Did you discuss this? Was it not a priority for the department since they didn't put it in their budget?

Rep. Weisz: The department thought that their ADRC was a higher priority than this was and your policy committee decided the opposite.

Rep. Pollert: Because they have to issue and RFP, if the RFP is not granted to anyone, this \$1.2 million wouldn't happen. We have so many programs in the DHS budget that we struggle funding fully every session. We are going to have another program that we will struggle with every session. I'm not saying this is not important but it is a constant struggle and we can't keep everything funded.

Rep. Weisz: I can't disagree. We don't necessarily see everything that you do. The reason we sent this forward is the information provided to the policy committee showed that this would save the state money in the future.

Rep. Nelson: It's difficult in HR Subsection because what Rep. Pollert said is true. Our population is aging and dementia is becoming a bigger part of it. Nursing Homes can take care of it and that budget will explode in coming years. We are going to have to find alternatives to nursing home care in the future. This state cannot afford the explosion that is going to take place in future years. The direct offset in expenditures you probably won't see because of the increase in the number of people (elderly). We're going to have to tackle this soon.

Rep. Kaldor: Are these types of services being provided by the State of ND in other ways already?

Rep. Weisz: The Alzheimer's Association does try to work with a limited number of people to help them. There is nothing organized as a statewide.

Rep. Kaldor: Would they possibility for one of the agents to fulfill and RFP? I do have experience with a relative that was helped by the Alzheimer's Association. It was an unbelievable aid to them and he did not go to the nursing home right away.

Rep. Weisz: I would assume they would respond to an RFP.

Rep. Wald: I move a Do Not Pass

Rep. Pollert: Second

A roll call vote was taken: Yes: 10, No: 13 Absent: 2 (Kerzman and Wieland)

The motioned failed.

Rep. Nelson: I move Do Pass.

Rep. Kroeber: Second.

A roll call vote was taken. Yes: 13, No: 10, Absent: 2 (Kerzman and Wieland)

Representative Damschen will carry the bill.

Date: 2/12/09
Roll Call Vote #: 1 of 2

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 1043

Full House Appropriations Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken

Failed
No Not Pass

Motion Made By

Wald

Seconded By

Pollert

Representatives	Yes	No	Representatives	Yes	No
Chairman Svedjan	✓				
Vice Chairman Kempenich	✓				
Rep. Skarphol	✓		Rep. Kroeber		✓
Rep. Wald	✓		Rep. Onstad		✓
Rep. Hawken		✓	Rep. Williams		✓
Rep. Klein	✓				
Rep. Martinson		✓			
Rep. Delzer	✓		Rep. Glassheim		✓
Rep. Thoreson		✓	Rep. Kaldor		✓
Rep. Berg	✓		Rep. Meyer		✓
Rep. Dosch		✓			
Rep. Pollert	✓		Rep. Ekstrom		✓
Rep. Bellew	✓		Rep. Kerzman		✓
Rep. Kreidt	✓		Rep. Metcalf		✓
Rep. Nelson		✓			
Rep. Wieland		✓			

Total (Yes) 10 No 13

Absent 2

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

Date: 2/12/09
Roll Call Vote #: 2 of 2

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 1043

Full House Appropriations Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken

No Pass

Motion Made By

Nelson

Seconded By

Kroeber

Representatives	Yes	No	Representatives	Yes	No
Chairman Svedjan		✓			
Vice Chairman Kempenich		✓			
Rep. Skarphol		✓	Rep. Kroeber	✓	
Rep. Wald		✓	Rep. Onstad	✓	
Rep. Hawken	✓		Rep. Williams	✓	
Rep. Klein		✓			
Rep. Martinson	✓				
Rep. Delzer		✓	Rep. Glassheim	✓	
Rep. Thoreson	✓		Rep. Kaldor	✓	
Rep. Berg		✓	Rep. Meyer	✓	
Rep. Dosch	✓				
Rep. Pollert		✓	Rep. Ekstrom	✓	
Rep. Bellew		✓	Rep. Kerzman	✓	
Rep. Kreidt		✓	Rep. Metcalf	✓	
Rep. Nelson	✓				
Rep. Wieland					

Total (Yes) 13 No 10

Absent

2

Floor Assignment

Rep. Damacher

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE (410)
February 13, 2009 6:30 p.m.

Module No: HR-28-2806
Carrier: Damschen
Insert LC: . Title: .

REPORT OF STANDING COMMITTEE

HB 1043: Appropriations Committee (Rep. Svedjan, Chairman) recommends **DO PASS**
(13 YEAS, 10 NAYS, 2 ABSENT AND NOT VOTING). HB 1043 was placed on the
Eleventh order on the calendar.

2009 SENATE HUMAN SERVICES

HB 1043

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. HB 1043

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 03/03/2009

Recorder Job Number: 10069, 10095

Committee Clerk Signature

Mary K Monson

Minutes:

Senator Lee Opened the hearing on HB 1043.

Sheila Sandess Fiscal analyst for Legislative Council. Provided information on HB 1043.

Spoke about the purpose of and appropriation in the bill. Made herself available for questions.

Senator Dever Did the house include the funding?

Sandress It was already in the bill. This is not an amended bill.

Senator Dever District #32. Served as chair of the interim chair of the long term care committee. I wanted to comment that we asked ourselves what we could do to make ND a dementia friendly state. This bill is a result of that discussion. Outlined some possible solutions and provided some personal stories about individuals living with dementia related illnesses. He urged the passage of 1043.

Rodger Wetzel Director of the Northland PACE program in ND. Spoke in support of 1043. See attachment #1.

Krista Headland Director of the Western ND Alzheimer's Association. Spoke in support of 1043. See attachment #2.

Senator Dever Would you mind if we shared a copy of the budget to the committee?

Headland I would be happy to e-mail that out to the committee.

Senator Dever There is no waste in the budget; it is a very responsible budget.

Gretchen Dobervich Eastern ND Regional Center Director for the Alzheimer's Association.

Spoke in support of 1043. See attachment #3.

Pamela Offerdahl Gave personal testimony. Spoke in support of 1043. Talked about her husband's dementia and the help she has received from Gretchen Dobervich. The education provided but the personal care counsel sessions and support systems were very helpful to them.

Susanne Olson Works for the Red River Valley hospice care facilities. Gave personal testimony about her mother's struggle with Alzheimer's Disease. The best services they received were from a county homemaker; otherwise they were the primary care givers. Urged a Do Pass on 1043 as there are not many families that have the ability to support family members nor do they have the education necessary to understand the disease.

Senator Lee I am glad to hear the RR Valley hospice is collaborating with other facilities.

Marcia Buringrud Gave personal testimony. Spoke in support of 1043. See attachment #4. Also briefly discussed some available medications for dementia.

Jim Jacobson Director of the Protective Services Unit for the ND Protection and Advocacy Project.

Senator Lee Who should someone call first if you see a neighbor might need help?

Jacobson Hopefully wherever you would go would work collaboratively with the people who do work with vulnerable adults. We are doing what we can right now to implement that approach.

There was no opposition testimony given.

Senator Lee Closed the public hearing on HB 1043.

Job # 10095

Senator Lee Opened the discussion on HB 1043.

Senator Dever I move **Do Pass and Rerefer to Appropriations**.

Senator Heckaman Second.

Discussed how this bill was good for families all over ND.

The Clerk called the role on the motion to **Do Pass and Rerefer to Appropriations**. **Yes: 4,**

No: 0, Absent: 2 (Senator Erbele and Senator Marcellais).

Senator Dever will carry the bill.

Date: 3/3/09

Roll Call Vote #: _____

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. HB 1043

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken ☒ Do Pass ☐ Do Not Pass ☐ Amended ☐ Rerefer to Appropriations
☐ Adopt Amendment ☐ Reconsider

Motion Made By Sen. Dever Seconded By Sen. Heckaman

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee, Chairman	✓		Senator Joan Heckaman	✓	
Senator Robert Erbele, V.Chair			Senator Richard Marcellais		
Senator Dick Dever	✓		Senator Jim Pomeroy	✓	

Total (Yes) 4 No 0

Absent 2

Floor Assignment Senator Dever

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

HB 1043: Human Services Committee (Sen. J. Lee, Chairman) recommends DO PASS and BE REREFERRED to the Appropriations Committee (4 YEAS, 0 NAYS, 2 ABSENT AND NOT VOTING). HB 1043 was rereferred to the Appropriations Committee.

2009 SENATE APPROPRIATIONS

HB 1043

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. 1043

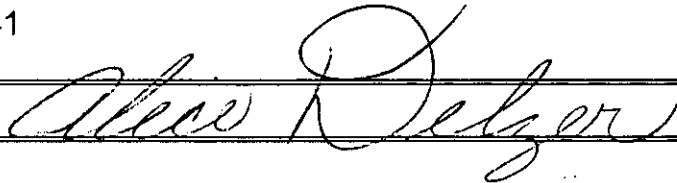
Senate Appropriations Committee

☐ Check here for Conference Committee

Hearing Date: 03-12-09

Recorder Job Number: 10841

Committee Clerk Signature



Minutes:

Chairman Holmberg called the committee hearing to order at 2:30 pm in reference to HB 1043 relating to a dementia care services program; to provide for a report to the legislative council; and to provide an appropriation.

Senator Dick Dever, District 32, Bismarck testified in favor of HB 1043 and shared information regarding the bill. I served as chairman in long term committee during the interim. This bill is a result of the efforts of that committee. We had a meeting and we asked ourselves what would a dementia friendly state look like and North Dakota wanted to take that approach and from that we developed this bill. We put out a RFP to an independent organization. We had considered the possibility of hiring FTE's in each region of the state through the department of human services to provide resources to people who are dealing with Alzheimer's. We decided that a better approach because there is a better Association to do that would be to put out a RFP for that Association to hire an employee in each of the regions in the state. You might be familiar what the bill does is provide for that program section 2 of the bill that they would provide a report to the legislative council. The care giver is usually a close family member. One of the real complications is what it does to the care giver. Section 3, these will be dollars that will be well spent. People will be able to stay in their homes longer. He talked about a couple of examples. Early detection allows people to be on medication earlier.

Like a lot of others, we are dealing with Alzheimer's in my own family, my father in law, who has good days and bad days, more bad days than good. A couple of weeks ago my wife went to visit him at the care center. She called she would be there longer because he was having a good day and he knew her. He then gave examples about people he knows and how they are affected by this disease. This bill will provide resources to the care givers in order to enable them to take care of their loved ones at home for a longer time.(9.15)

V. Chair Grindberg congratulated Senator Dever for his work on this bill. I always find it challenging with the size of the Human Service budget, and the volume of email we get because we have the budget now. Just a side note, I am amazed by the number of councils, commissions, associations and private groups that have grown over the years involving care for people. I am amazed by the growth in a state that is relatively flat in population. (10.08) My question is I would assume there are services available, if there is a gap here, it seems like we already have this service provided now.

Senator Dever, stated that is one of the questions I ask myself when are we helping or when are we enabling people. I think this is one where we are truly helping people to help themselves. I wish there was a way we could quantify the savings that I expect to see in this bill because you could make adjustments elsewhere in the budget to take that into consideration. This bill was not considered in the executive budget. (11.42) we visited Krista Headland of the Alzheimer's Association. She and I visited with the county social service directors and most of the social workers and they thought this was an excellent program. It serves as a resource for them to do their job better. It is a matter of providing people that have a special expertise in a certain area that represents an impact on a large segment of our population. (12.46)

V. Chair Bowman stated I was just reading part of this, training, aren't the ones that take care of Alzheimer patients trained already and won't you learn from those that are already working in this field. Or is this something totally different?

Senator Dever said this goes beyond that. There are special needs for different ones with dementia. He gave an example from a home experience with his father in law. (17.01)

Gretchen Dobervich, Alzheimer's Association, Eastern Division stated she is one of the two people who works in this state that provides this specialized service for the Alzheimer's Association. If we took every person that had Alzheimer's Disease and every person that had their primary caregiver every single day, the person who helps them eat, reminds them to take their medicine, drives them around our towns, that's a family member it would be equivalent to the population of Minot. Last week we got an updated statistic that estimates there are 20,000 people with Alzheimer's Disease that live in North Dakota. That doesn't include all the forms of Dementia of which there are 200 different kinds of Dementia. 70% of people with this disease live at home. They don't live in nursing homes and it is their family members that provide that care because there is no service. Half of all people with this disease don't get a diagnosis, so they don't get the patient education that my family got when my dad was diagnosed with Alzheimer's Disease. On a personal standpoint, 25 years ago my grandmother, who had the early stages of Alzheimer's Disease came to live with us on our farm and ranch in Slope County and there was no help. She described the hardship that was to her family at that time and at that time we knew even less about this disease than we do now. (19.05) She gave further information regarding her personal life dealing with her loved ones with this disease. The nursing homes in our state do a great job. This bill is not designed to be an alternative. What we know that the leading cause of long-term care placement for people with Dementia is not that their physical health has changed. Their caregivers have worn out. This is a long

disease. Most people have the symptoms 5 years before they get a diagnosis and they live for 8 to 10 years after the time of diagnosis. Imagine being a care giver for 15 years of someone that can't tell you when they are hungry or hits you because they don't want to take a bath. This is what causes a lot of premature placing into care facilities and we know through a study nursing home is delayed by about a year and half. One of the advantages of this bill is that not only does it help people who are caring for someone in their home, when they move into a care facility care consultation doesn't stop. We have care facilities that call us all the time. We have this resident, they have dementia, we don't know what is going on. Can you give us some ideas? This bill would literally follow people prior to the diagnosis to when they move into the care facility. And there was mentioned earlier of bills where money follows the person to help them stay in their homes and when that program started I was so excited about the implications for people with Alzheimer's Disease and when I called and talked to Mr. Berger who administers that program he said actually people with Dementia are not eligible for this program and so we could not find any programs. One of the other questions that come up why would you need 8 people. There are not a whole lot of people who live in region 1 and region 2. For my experience in 9 years it is much more difficult for me to help a family that lives in rural North Dakota than lives in Fargo or Bismarck because there are a lot more resources that are available to them. So if I am working with a family in the rural places, they don't have as much access to other services and so we are spending more time training those people.

Senator Krebsbach asked can you tell me what the difference is between Alzheimer and other forms of Dementia

Gretchen stated Dementia is not a diagnosis, it is a symptom. If you just have problems with your memory you have amnesia. If you had problems with your memory, cognitive abilities, the ability to problem solve, the ability to put tasks in order, the ability to use attention,

perception, along with memory you have what is called Dementia. There are over 200 kinds of Dementia. The most commonly occurring form is Alzheimer's Disease or Alzheimer's Dementia. It accounts for about 75% of Dementia diagnosis.

Senator Krauter stated as I read the bill I believe there is a need out there. Are you the only provider in the state? Could this be divided between the 8 regions?

Gretchen said we are the only 2 providers in the state. I don't know why the Alzheimer's Association is not named as the recipient of the bill. No one else in the state provides this service. It will be our hope that this bill fully funded, so we can hire a consultant for each region. Much of what we do is over the phone. It sounds like a tremendous amount of money. How this would play out, part of their role would be to ? to encourage people to ask their doctors. One on one services. Care techniques, manage behaviors. One full time employee providing these services in each region.

Senator Robinson asked if there are people out there that can step into this training.

Gretchen stated as far as the training, no one else provides this service. ND does not have Dementia training laws like other states do, anyone can open the building to house these people. There are no regulations . to have training and be an expert, that will be a big piece of the first year of this program. ? we can help foster that. There are facilities that area fabulous. Most people will need long term care as it progresses. 17,000 to 20,000 people have this disease. (29.24)

Rodger Wetzel, Director of the Northland Program of All-inclusive Care for the Elderly (PACE) Program in North Dakota testified in favor of HB 1043 and provided written testimony # 1. (34.15)

V. Chair Bowman asked how many families go through this where the support comes from the family themselves. Is this for those who do not have access to these resources?

Rodger Wetzel stated that is an excellent question. The care giving is 24/7 and what works this morning might not work this afternoon. It is not predictable. You are trying to cope with that, the stress, the unpredictability and more. Would you learn through the training how to deal with these people? I volunteered to help people and I have learned a lot through that.

Chairman Holmberg asked him to talk about the money.

Krista Headland, Alzheimer's Association, Western Division said the main focus on the money on this bill is to be able to pay 8 providers. That would cover the costs to hire these people, their salary and benefits, their equipment, and all the over materials that would go into training the care givers.

Chairman Holmberg stated the subcommittee for Human Services, which are Senator Fischer, Senator Kilzer, Senator Krebsbach, Senator Warner, and Senator Mathern will take a look at this bill. He then closed the hearing on HB 1043.

Bruce Murry, ND Protection and Advocacy Project provided written testimony # 2 in support of HB 1043.

Department of Human Services provided Dementia Care Budget written testimony # 3.

Robert L. Carlson, President ND Farmers Union provided written testimony # 4 in support of HB 1043.

On 03-13-09 Gretchen Dobervich provided by Email a summary of her testimony in support of HB 1043.

Testimony of Gretchen Dobervich(#34)

3-12-09 Senate Appropriations

Chairman Holmberg, Members of the Committee, my name is Gretchen Dobervich. I am the Eastern North Dakota Regional Center Director. I am here today in support of House Bill 1043.

This bill which would create and support a statewide dementia care consultation program would not only serve as a direct investment to the people of North Dakota with dementia, but also their families and communities.

A statewide dementia care consultation program would not replicate any existing services.

The Alzheimer's Association a private, non-profit offers dementia care consultation on a limited basis. I am not aware of any other such service in the State.

A statewide dementia care consultation program would not replace any services in existence. As many of the most common forms of dementia are progressive most persons with dementia will require medical and custodial care services, utilize both home and community- based services and skilled nursing services.

The goal of care consultation is to assist families in creating an "action plan" that promotes quality of life throughout the disease process for individuals and their families. Care consultation provides ongoing education and support. It is not counseling, therapy or a referral only service.

Dementia care consultation services affects quality of life through improved disease management not only for the person with the dementia, but also for their families. Seventy percent of people with dementia live at home with a family member as their primary caregiver. The long-term physical and emotional stressors of caregiving as dementia progresses and care needs increase often results in the caregiver's health being compromised as well. A recent study showed that with caregiver intervention, such as care consultation, premature skilled care placement for people with dementia was delayed by 18 months.

House Bill 1043 also provides for professional care consultation services. Assisted livings, skilled nursing facilities, home care services; etc would be able to utilize this service to help in creating care plans that improve disease management and consultation for non-medical

symptom management. The final benefit to North Dakotans is the community education component of House Bill 1043. Care consultants would provide community education on the warning signs of dementia in an effort to increase the number of North Dakotans diagnosed in the early stage of dementia, when diagnosis, treatment and care consultations can positively influence disease management outcomes.

House Bill 1043 serves to provide substantial savings to the North Dakota Medicaid program and would help North Dakotans caring for a loved one with dementia to preserve finances for future long-term care costs, ultimately decreasing the number of North Dakota nursing home residents using Medicaid as their payer source.

Currently 55% of North Dakota nursing home residents use State Medicaid as the payer source for their care. The estimated cost of a year in a nursing home is \$60,000.

Dementia care consultation (utilizing the Mittelman Caregiver intervention model) has been proven to delay nursing home placement by 18 months. This calculates to a \$90,000 per person with dementia cost savings to the ND Medicaid program; through a delay in utilizing Medicaid for long-term care expenses. The Alzheimer's Association projects estimated minimum cost savings of a statewide dementia care consultation program to be \$2,000,000-4,000,000 in Medicaid savings to the State of ND per biennium.*

As the number of North Dakotans with dementias continues to rise sharply, the passing of House Bill 1043 would not only set a national precedent in addressing what has been called the "Health Care Epidemic of the 21st Century", it would directly improve the quality of life for tens of thousands of North Dakotans.

Thank you for the opportunity to speak before you today. I am happy to answer any questions you may have.

The savings will vary by the total number of individuals served in the intervention. This estimate is based on projected service delivery to 160 families with a fully funded contract providing eight dementia care consultants, one for each Human Services Dept. region of the State.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. HB 1043

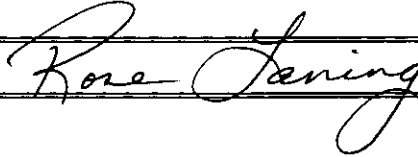
Senate Appropriations Committee

☐ Check here for Conference Committee

Hearing Date: April 2, 2009

Recorder Job Number: 11703

Committee Clerk Signature



Minutes:

Chairman Holmberg opened discussion on HB 1043.

Senator Fischer showed an amendment to HB 1012. (amendments .0205) The committee thought there should be some legislative intent. In section 10, it says, "that the department of Human Services integrate the dementia care services program established in HB 1043 with home and community based care services programs of the department". That is that these services get to the people and there will be education involved too, but the thing is that they get to the people out there that have people at home that they can get some education from and training in how to take care of their loved ones. The one amendment goes into the bill, but then it doesn't go back clean. It will go to conference committee. You put it in the budget, the other one is HB 1012, and if this committee would like to is to put the intent in the budget and leave the dementia bill alone and pass it out. That way we're certain this will be a double edged sword. The bill will be in place but this piece will have the intent of getting it into the people's homes and helping people rather than just another layer. Maybe Senator Kilzer has some comments.

Senator Kilzer: Alzheimer's disease is a continuum type of process and we want to keep it integrated and slowly as the disease progresses. These people will have home and community based care. Their families will be involved to a greater extent, and often times, this

is the weakest link in the chain. Later on as the patient becomes more dependent, more severely affected by the disease, it may even require institutionalization. By the time you get to that stage, you have professional service, professional social workers. You have a hospital, usually, or a long term care facility that has these services. We don't want the people that will be hired by this bill to be divorced from all the other services. We want it to be integrated, and especially in the early stages, and that's why we're talking about integrating with the home and community based services rather than creating another isolated monstrosity as one of our committee members said.

Chairman Holmberg: If your strategy was to place this in HB 1012, then we don't do anything with this but pass it?

Senator Fischer: Pass the bill and we'll bring the amendment back to the committee when HB 1012 is ready to come here.

Senator Warner moved Do Pass on HB 1043.

Senator Fischer seconded.

A Roll Call vote was taken. Yea: 14 Nay: 0 Absent: 0

The bill goes back to the Human Services committee and will be carried by Senator Dever.

Date: 4-2-09
Roll Call Vote #: 1

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 1043

Senate Senate Appropriations Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken ☒ Do Pass ☐ Do Not Pass ☐ Amended

Motion Made By Warner Seconded By _____

Representatives	Yes	No	Representatives	Yes	No
Senator Krebsbach	✓		Senator Seymour	✓	
Senator Fischer	✓		Senator Lindaas	✓	
Senator Wardner	✓		Senator Robinson	✓	
Senator Kilzer	✓		Senator Warner	✓	
V. Chair Bowman	✓		Senator Krauter	✓	
Senator Christmann	✓		Senator Mathern	✓	
V. Chair Grindberg	✓				
Chairman Holmberg	✓				

Total Yes 14 No 0

Absent 0

Floor Assignment Human Services Dev

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE (410)
April 2, 2009 4:05 p.m.

Module No: SR-56-6054
Carrier: Dever
Insert LC: . Title: .

REPORT OF STANDING COMMITTEE

HB 1043: Appropriations Committee (Sen. Holmberg, Chairman) recommends **DO PASS**
(14 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). HB 1043 was placed on the
Fourteenth order on the calendar.

2009 TESTIMONY

HB 1043

Mr. Chairman, members of the committee:

For the record, my name is Sheila Sandness and I am a Fiscal Analyst for the Legislative Council. I am here to present information on House Bill 1043 relating to a dementia care services program in each area of the state served by a regional human services center. I appear neither for nor against the bill, but just to provide information and answer any questions you may have.

The 2007 Legislative Assembly, in House Concurrent Resolution No. 3022, directed a study of the availability and future need for dementia-related services, as well as funding for programs for individuals with dementias. The Long Term Care Committee was assigned this study. The Long Term Care Committee's findings and recommendation can be found on pages 275-277 of the "Report of the North Dakota Legislative Council".

The committee recommends House Bill No. 1043 that:

- Directs the Department of Human Services to contract for a dementia care services program in each area of the state served by a regional human service center to provide personalized care consultation services, training, and education regarding dementia;
- Provides for a \$1.2 million general fund appropriation for the program; and
- Provides for a report to the Legislative Council regarding the outcomes of the program.

- House Human Services - Fort Union
Chairman Rep. Weisz

Testimony of Gretchen Dobervich(#34) 1-12-09

Representative Weisz, Members of the Committee, my name is Gretchen Dobervich. I am the Eastern North Dakota Regional Center Director. I am here today in support of House Bill 1043.

This bill which would create and support a statewide dementia care consultation program would not only serve as a direct investment to the people of North Dakota with dementia, but also their families and communities.

A statewide dementia care consultation program would not replicate any existing services. The Alzheimer's Association a private, non-profit offers dementia care consultation on a limited basis. I am not aware of any other such service in the State.

A statewide dementia care consultation program would not replace any services in existence. As many of the most common forms of dementia are progressive most persons with dementia will require medical and custodial care services, utilize both home and community- based services and skilled nursing services.

The goal of care consultation is to assist families in creating an "action plan" that promotes quality of life throughout the disease process for individuals and their families. Care consultation provides ongoing education and support. It is not counseling, therapy or a referral only service.

Dementia care consultation services affects quality of life through improved disease management not only for the person with the dementia, but also for their families. Seventy percent of people with dementia live at home with a family member as their primary caregiver. The long-term physical and emotional stressors of caregiving as dementia progresses and care needs increase often results in the caregiver's health being compromised as well. A recent study showed that with caregiver intervention, such as care consultation, premature skilled care placement for people with dementia was delayed by 18 months.

House Bill 1043 also provides for professional care consultation services. Assisted livings, skilled nursing facilities, home care services; etc would be able to utilize this service to help in creating care plans that improve disease management and consultation for non-medical symptom management. The final benefit to North Dakotans is the community education component of House Bill 1043. Care consultants would provide community education on the warning signs of dementia in an effort to increase the number of North Dakotans diagnosed in the early stage of dementia, when diagnosis, treatment and care consultations can positively influence disease management outcomes.

As the number of North Dakotans with dementias continues to rise sharply, the passing of House Bill 1043 would not only set a national precedent in tackling the

Health Care Epidemic of the 21st Century, it would directly improve the quality of live for tens of thousands of North Dakotans.

Thank you for the opportunity to speak before you today. I am happy to answer any questions you may have.

House Human Services Committee
Testimony on HB1043 - January 12, 2009
By Rodger Wetzel

Mr. Chair and members of the committee:

Thank you for this opportunity to appear before you and testify in support of HB1043.

I have worked in the field of aging in North Dakota since I was 26, and I am now 64...almost 40 years. I currently am director of the Northland PACE (Program of All-inclusive Care for the Elderly) program in North Dakota. Previously I served as Director of Eldercare at St. Alexius for 23 years; and prior to that I was the Assistant Administrator of the Aging Services Division of the NDDHS.

I appear before you today from a 40 year perspective in aging and various work with the Alzheimer's Association. I currently serve as the Vice Chair of the Minnesota-North Dakota Alzheimer's Association Board. I am co-chair of the Public Policy Committee for Minnesota-North Dakota as well. I also serve on the Western North Dakota Leadership Council for the Alzheimer's Association. I facilitated two family support groups for 23 years, working with hundreds of family caregivers. But very importantly, my mother has beginning Alzheimer's; two of my aunts, now with advanced Alzheimer's, are living in nursing homes. Four other relatives had Alzheimer's and other dementias, but are now deceased.

Alzheimer's disease and other memory loss illnesses (dementias) are some of the most challenging diseases for families to manage. We don't know the cause/s; we can't predict how long family members must cope with the disease...3-20 years can be the range...and unfortunately there is no cure, or no medications to guarantee slowing the disease process.

In addition, the person with the disease often doesn't realize he/she has the disease, doesn't appreciate the intense family caregiving needed, may exhibit strange and challenging behaviors day and night, and often expresses anger, accusations, and resistance toward the very family members providing the most care for them. Burnout, depression, guilt and anxiety become the norm for family caregivers. It often becomes easier just to give up and place their family member in a nursing home. It is now estimated that over half of residents of nursing homes have Alzheimer's and other dementias. An increasing per cent of those entering assisted living and basic care facilities also have memory loss illnesses (dementias) such as Alzheimer's.

Alzheimer's and related dementias do not fit into the medical model of care that we have for other major diseases, such as heart disease, cancer or diabetes. Doctors also often know little about managing these diseases, especially the daily challenging behaviors. Families often first come to them for help with managing the family member. Nursing home placement often is suggested. But much of the behaviors and caregiving can be managed by family members with professional assistance. But the burden of learning about the disease and the tremendous burden of caregiving falls on family caregivers, who often feel overwhelmed. They would come to support group meetings for months, sometimes years, hoping to learn how to manage the newest crisis.

What these family caregivers need is support from, assistance from, and availability of knowledgeable professional staff, such as the two Alzheimer's Association regional directors in North Dakota, who already are stretched far too thin. They need help when their family member accuses them of stealing their money or having an affair. They need help when their family member keeps trying to get out of the house in the middle of the night, or insists on milking the cows at 4 am. Or when they refuse to take a bath for two weeks, refuse to take medications or to change clothes for 4 days. Or when they keep asking their spouse of 50 years who he is, and why he doesn't get out of his house. Or when they refuse to give up driving, keep asking the same questions 10 times in a row, pay the same bills several times, or now have bowel and bladder accidents on a regular basis.

But these are only two professional Alzheimer's staff persons for thousands of family caregivers. To support these usually uncompensated, dedicated, and quickly burning out family caregivers, we need the services and staff that would be made available through this legislation. It also would delay institutionalization significantly, based on the Minnesota program experience.

I ask for your support for HB1043...on behalf of the Alzheimer's Association; on behalf of thousands of family caregivers, on behalf of my aunts, uncles and cousins who are caregivers; and on behalf of my family, who are caring for my mom.

I would be happy to answer any questions. Thank you.

marsha B

#4

I would like to thank everyone for giving me this opportunity to testify before you on behalf of Bill #1043 for Alzheimer's.

As you are all aware my mother was diagnosed with Alzheimer's the summer of 2003. Unfortunately, she passed away November 24, 2006. During the three and a half year battle we were on our own for supporting Mom with her Alzheimer's. Dad became Mom's primary caregiver and because I live in the lower level of the twin home I assisted Dad after work and on weekends so that Mom could continue to live at home. Most families are not in this situation, but nonetheless support is still needed.

My mother had the high anxiety and anxiousness and through medication it controlled it some, but not 100%. She was always wanting to be outside and walking and several times she would quietly leave the house without our knowing and go out for walks. When we noticed she wasn't in the house we would have to go outside and look for her. My mother enjoyed flowers and several times we would find her in the yards on the block picking their flowers. We would try to explain to her that she shouldn't do that, but an Alzheimer's person doesn't understand that and in Mom's mind she told us that they said it was okay for her to pick their flowers.

In 2004 when my dad went to look at various nursing homes so if and when the time came he would have a fairly good idea of which one would be best he was made aware of the Adult Day Care program at Rosewood Nursing Home through the staff that was showing him around. As a result Mom started going there one day a week and eventually twice a week. This program not only gave Dad a break and opportunity to do things he needed to do, but also gave Mom the chance to be with other people and be involved in various activities two days a week. If we could have had someone to turn to offer assistance and support, what Rosewood offered would have been something we could have done sooner for Mom. Not only would this have been something we could have done sooner, but it also would have given Dad more of a direction as to what health care facilities are more advanced to treating Alzheimer's patients.

Mom's primary doctor and specialist were very uninformative and never passed on information for support or help. It is important for the proposed dementia care consultants and the doctors to network so the patients and their families are aware of the services available. As a result, since we as a family were not provided this service we did what we felt was right at the time and hoping that we were handling things correctly. Because of the lack of support we had this is why it is so important for this bill to be passed.

This bill will "unite" the medical and healthcare facilities to provide the proper support that is much needed. It will also make services available at an earlier time of the disease and provide assistance to the caregivers. It is so important to the caregivers to have support so if things come up that they are not sure of how to handle they have a program such as this bill will provide to advise them or give them the necessary contacts for assistance.

The replies I have received back from you from my initial email, along with personal acquaintances that I associate with, has made me aware of the number of people that are dealing or have dealt with this disease. Because of this awareness I feel it is so important to support and have this bill passed to provide essential care and support for the State of North Dakota and the families and patients now dealing with Alzheimer's.

Again, thank you for this opportunity and the replies I received back sharing your messages of how Alzheimer's has also touched a lot of you. Let us be the State to show other states how successful a program such as Bill #1043 can be for providing assistance for Alzheimer's families and patients.



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#5

January 7, 2009

Representative Robin Weisz, Chairman
House Human Services Committee

Dear Chairman Weisz,

This letter is to express North Dakota Farmers Union's support for House Bill 1043, a bill that creates an innovative program to assist in the care of individuals who suffer from Alzheimer's disease in North Dakota.

North Dakota Farmers Union has long been an advocate for accessibility of healthcare in rural North Dakota. NDFU, a general farm organization of 40,000 member families, has worked along with other organizations to advocate for healthcare that promotes good health and wellness for all North Dakotans. We are excited to be joining The North Dakota Alzheimer's Association in advocating for the creation, implementation and funding of a dementia care consultation program.

Alzheimer's disease is a serious concern in North Dakota. The most common form of dementia, it affects 18,000 North Dakotans. For every person that is affected by this form of dementia, many family members also are directly affected by the amount of care that they provide for that individual. I know firsthand the amount of care that is needed and the emotional toll Alzheimer's disease has on family, as my mother was diagnosed later in her life. Having a network of healthcare professionals who have the expertise to not only educate, but also provide support to families is priceless.

Rural North Dakota has great opportunities to provide its citizens the care they need, while allowing them to stay in their communities. Although our state's small towns may not have the same economic advantages as the larger urban areas, one thing is certain; our rural areas have a sense of cohesiveness that other areas lack. As we look to the future of healthcare in our state, creating networks of professionals and communities will be a crucial catalyst for improving everyone's quality of life. The adoption of HB 1043 will send the message to the rest of the nation that North Dakota is serious about care for its citizens.

Sincerely,

North Dakota Farmers Union

Robert L. Carlson
President

*Same given
to Senate
approps-*



#6

Chairman Weisz and Representatives of the House Human Services Committee, my name is Krista Headland and I am the Western ND Director for the Alzheimer's Association. Thank you for listening to my testimony in support of HB 1043.

One of the most common reasons families make the decision to move their loved one with dementia into a long-term care facility is caregiver burnout and stress? What if you, as lawmakers, could change that by passing a law that would give family caregivers access to the support services they need to keep their loved one at home as long as possible and learn ways to care for themselves as caregivers? What if this also included providing community education on dementia, the benefits of early detection and treatment and care options? What if you also knew that providing these services would save the state of North Dakota a great deal of money?

HB 1043 provides a proven plan for North Dakota to address its exponentially growing population of people with dementia—an expected increase of over 30% between 2005 and 2020¹. The Interim Long-Term Care Committee spent a significant amount of time studying this issue and coming to the conclusion that increasing the number of dementia care consultants in the state will provide the most help to the largest number of people in the most cost-efficient way possible.

The proposed services are unique and different from any other services currently available in that they would be provided by people with advanced training in dementia care to train and assist family caregivers in every stage of the disease process. This would include education on the disease itself, the stages and what to expect. It would also include practical, hands-on tips for behavior management, communication and how to plan ahead for the future. The proposed care consultants would also network with community health care professionals and the public to provide education and resource referrals. The Alzheimer's Association provides these services, but with only two staff members in the entire state, thousands of people with dementia and their families are falling through the cracks. This must be changed and you have the power to make it happen.

Not only will HB 1043 ensure that families dealing with dementia have access to support services proven to reduce caregiver depression levels and feelings of isolation², similar support services have been shown to boost the physical health of caregivers which allows them to care for their loved one with dementia at home for an average of 18 months longer than if they did not have access to the services³. Given that the average cost of a nursing home stay per year in North Dakota is \$58,000⁴, we only have to keep 21 people

¹ ND Data Center Statistics.

² Mary Sherman Mittelman, Dr. P.H., Henry Brodaty, M.D., D.Sc., Aaron Seth Wallen, Ph.D., Alistair Burns, M.D.: "A Three-Country Randomized Controlled Trial of a Psychosocial Intervention for Caregivers Combined with Pharmacological Treatment for Patients with Alzheimer's Disease: Effects on Caregiver Depression," *American Journal of Geriatric Psychiatry*, Volume 16, November 2008, pages 893-904.

³ Mittelman, MS; Haley, WE; Clay, OJ; Roth, DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*. 2006; 67:1592-1599.

⁴ North Dakota Long Term Care Association

with dementia in their homes 18 months longer than without services to completely pay for this program. We know that it would do much more than that.

I am blessed with a position that gives me the opportunity to work with people with dementia and their caregivers. When I provide care consultation services and families tell me that they are so thankful for the education, practical tips and resources, I feel two things: relieved that care consultations give them the tools they need to care for their loved one at home for as long as possible; and heartbreak that I cannot help more families that desperately need it because I am only one person.

There are not many programs funded by state dollars that provide services that are a direct investment in its citizens and also save money. HB 1043 is a rare exception. It makes good common sense from both social and fiscal perspectives. Please give HB 1043 a do pass recommendation—the need, purpose and positive outcomes are clear.

Thank you for your time.



NARFE

National Active and Retired Federal Employees Association

#7

CHAPTER 0195

January 9, 2009

Arden E. Mathison, President
Bismarck-Mandan NARFE Chapter
1815 Harmon Ave.
Bismarck, ND 58501

Ms Krista Headland
Western ND Regional Center Director
Alzheimer's Association Minnesota-North Dakota
1223 S 12th St, Suite 7
Bismarck, ND 58504

Subject: NARFE Support for Dementia Care Services Program Legislation, HB1043

Dear Ms Headland:

The Bismarck-Mandan Chapter of NARFE express our strong support for the subject Legislation, and strongly encourage the ND Legislators to vote in favor of HB1043.

We are one of eight NARFE Chapters in North Dakota with a total combined membership of 1720 members. NARFE recognizes the urgent need to provide more care and services for ND citizens suffering from Dementia, and especially Alzheimer's. Nationally, and in North Dakota, NARFE is fully committed to help seek a cure and prevention for Alzheimer's through Research. During the past eight years, members of NARFE have contributed nearly \$8 million dollars to help support 42 Alzheimer's research projects. Five new Alzheimer's research projects were selected for funding in 2008 in partnership with the American Alzheimer's Association.

The Dementia Care Services Program legislation, HB1043, is a great opportunity for ND to provide greater care for those citizens suffering from Alzheimer's. It will also help prevent, or reduce, the affects of Alzheimer's based upon the results from the Research Projects NARFE has helped support. On behalf of the 275 NARFE members in the Bismarck-Mandan area, I thank you for this opportunity to express our support of this vital legislation.

Sincerely,

Arden E. Mathison, Chapter President

HB
January 12, 2009

Representative Weisz and Members of the House Human Services Committee:

I am writing in support of HB 1043, which will greatly expand the dementia care services in North Dakota.

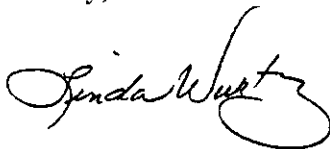
The occurrence of some forms of cognitive disorders—Alzheimer's disease and other kinds of dementia—increases with age. One in ten people over 65, and nearly half of those over 85, have Alzheimer's disease.

Because of these startling statistics, AARP has developed policy recommendations for states to address dementia and Alzheimer's related issues.

- ✓ AARP supports training direct care workers in dementia care practices that focus on maximizing quality of care while supporting the independence, autonomy, dignity, and privacy of individuals with cognitive disorders.
- ✓ AARP supports coordination of mental health services and all appropriate health and long term support services to meet the needs of older people in the community. This strengthens the ability to monitor quality through performance-based outcome measures and client satisfaction.
- ✓ AARP encourages mechanisms to ensure the long term supports and mental health needs of older people with cognitive disorders are met.
- ✓ AARP supports policies that provide adequate capacity and infrastructure to provide necessary care, including dementia and other specialty care, in reasonable and appropriate care settings for all eligible individuals.

I have listened to much of the discussion that has resulted in a proposal to advance a dementia care services program. That information and the language of HB 1043 are aligned with our policy in this area and we support your favorable recommendation.

Sincerely,



Linda Johnson Wurtz
Associate State Director for Advocacy
AARP North Dakota

Same
given to
Senators



ND Projections for Increase in Population with Alzheimer's Disease and other Dementias:

- 2020—19,000 North Dakotans with Alzheimer's disease. Since Alzheimer's disease accounts for roughly 70% of all forms of dementia, we can estimate that there will be 27,143 people with all forms of dementia in 2020.
- 2025—20,000 North Dakotans with Alzheimer's disease. 28,571 people with all forms of dementia.

Reference:

State-specific projections through 2025 of Alzheimer disease prevalence. Hebert et al. *Neurology*. 2004; 62: 1645



#9

January 9, 2009

Dear Members of the ND Legislature,

It is my pleasure to write this letter on behalf of the ND Hospice Organization to voice our support of House Bill # 1043.

Dementia has become the fastest growing Hospice admission diagnosis signifying more people being diagnosed with very challenging condition.

This bill would provide education and support for patients and caregivers, enabling dementia sufferers to remain at home as long as possible. In addition, this would certainly result in cost savings for out state with the decrease in long term care admissions.

Currently the Alzheimer's Association is the only organization providing care consultation specifically for people with dementia. With only two staff members, many of our North Dakota citizens that have dementia or are caring for a loved one with this are "falling through the cracks."

In conclusion, the North Dakota Hospice Organization (NDHO) fully supports this bill to provide funding for added resources and staff to assess the needs of individuals with dementia and their caregivers.

Sincerely,

Lori Knoll, RN
President, NDHO

TESTIMONY – PROTECTION AND ADVOCACY PROJECT

HOUSE BILL 1043 (2009)

HOUSE HUMAN SERVICES COMMITTEE

Honorable Robin Weisz, Chairman

January 12, 2009

Chairman Weisz, and members of the House Human Services Committee, I am Bruce Murry, a lawyer with the North Dakota Protection and Advocacy Project (P&A).

P&A strongly supports the services proposed in HB 1043. Information presented in the interim showed these services have been successful where offered. P&A has ongoing experience helping people with dementia and related conditions. People often come to P&A when their family and informal caregivers are burned out or make caregiving mistakes. It appears to us that supporting family and informal caregivers is a very effective way to improve people's quality of life.

Training to treatment professionals and community officials also tends to be very effective in helping these "generic" systems respond the needs of individuals with various needs.

Thank you very much for your consideration.

Senate Human Services Committee
HB1043 Testimony – March 3, 2009 - By Rodger Wetzel

Madame Chair and members of the Senate Human Services Committee:

Thank you for this opportunity to appear before you and testify in support of HB1043. First of all I wish to thank Senators Lee, Dever, and Heckaman for your work during the interim addressing this issue, and for the Interim LTC Committee sponsoring this legislation.

I have worked in the field of aging in North Dakota since I was 26, and this year I will turn 65...almost 40 years of professional, and now my own personal, aging experience in our wonderful state. I currently am director of the Northland PACE (Program of All-inclusive Care for the Elderly) program in North Dakota. Previously I served as Director of Eldercare at St. Alexius for 23 years; and prior to that I was the Assistant Director of the Aging Services Division of the NDDHS.

I appear before you today from a 40-year perspective in aging in North Dakota. At St. Alexius I facilitated two Alzheimer's/dementias family support groups for 23 years, working with hundreds of family caregivers. But very importantly, my mother has early Alzheimer's; two of my aunts, now with advanced Alzheimer's, are living in nursing homes. In one case two elderly sisters tried to care for one aunt; and in the other case an uncle in his 80's tried to care for his wife at home for as long as possible. Four other relatives have had Alzheimer's and other dementias, but are now deceased.

Alzheimer's disease and other memory loss illnesses (dementias) are some of the most challenging diseases for families to manage. We don't know the cause/s; we can't predict how long family members must cope with the disease (3-20 years can be the range); unfortunately there is no cure; and there are no medications to guarantee slowing the disease process.

In addition, the person with the disease often doesn't realize he/she has the disease, doesn't appreciate the intense family caregiving needed, may exhibit strange and challenging behaviors day and night, and often expresses anger, accusations, and resistance toward the very family members providing the most care for them. Burnout, depression, guilt and anxiety become the norm for family caregivers. It often becomes easier just to give up and place their family member in a nursing home. And when they consult their doctor for answers and advice, often the easiest medical answer is "It's probably time to put him/her in a nursing home." It is now estimated that over half of residents of nursing homes have Alzheimer's and other dementias. An increasing per cent of those entering assisted living and basic care facilities also have memory loss illnesses (dementias) such as Alzheimer's.

Alzheimer's and related dementias do not fit into the medical model of care that we have for managing other major diseases, such as heart disease, cancer or diabetes. With those diseases we know we have them, we accept the diagnosis, we call our doctor and go to our appointments; The doctor tells us what may have caused it, how to prevent further problems, what medications can affect the disease process, and how exercise and diet can help. We continue to work with our doctor to manage our diseases.

But doctors often know little about managing Alzheimer's and dementias, especially managing the daily challenging behaviors, which often lead to nursing home placements. The burden of learning about the disease, daily behaviors, and the tremendous burden of caregiving, falls on family caregivers, who often feel overwhelmed. They would come to support group meetings for months, sometimes years, hoping to learn how to manage the latest crisis they were experiencing.

Many of the challenging behaviors and most healthcare needs can be managed by family members with regularly available professional assistance. They need personal support when their family member accuses them of stealing their money or having an affair. They need help when their family member keeps trying to get out of the house in the middle of the night, or refuses to take meds, refuses to take a bath, or refuses to go the doctor. Or when they keep asking their spouse of 50 years who he or she is, and why he or she doesn't get out of his house. Or ask when their mom and dad are coming to get them to take them home. And when they refuse to give up driving, keep asking the same questions 10 times in a row, pay the same bills several times, or have bowel and bladder "accidents" on a regular basis.

What these family caregivers need is personal support from, assistance from, and ongoing availability of knowledgeable professional staff, such as the two Alzheimer's Association regional directors in North Dakota, who already are stretched far too thin. And it is especially challenging to serve caregivers in our many rural areas. But these are only two professional Alzheimer's staff persons for thousands of family caregivers. To support the many overburdened, uncompensated, dedicated family caregivers we need the services and staff that would be made available through this legislation. It would make essential services directly available to family caregivers and others.

This program also could significantly delay institutionalization for some, based on a similar Minnesota program experience. It would be funded for two years, and requires ongoing outcomes/benefits reports to the Legislature.

I ask for your support for HB1043...on behalf of the Alzheimer's Association; on behalf of us professionals in aging; on behalf of thousands of North Dakota family caregivers; on behalf of my aunts, uncles and cousins who are caregivers; ...and especially on behalf of my family members, who are caring for my mom.

I would be happy to answer any questions. Thank you!

Madam Chair and members of the Senate Human Services Committee, my name is Krista Headland and I am the Western ND Director for the Alzheimer's Association. Thank you for listening to my testimony in support of HB 1043.

One of the most common reasons families make the decision to move their loved one with dementia into a long-term care facility is caregiver burnout and stress? What if you, as lawmakers, could change that by passing a law that would give family caregivers access to the support services they need to keep their loved one at home as long as possible and learn ways to care for themselves as caregivers? What if this also included providing community education on dementia, the benefits of early detection and treatment and care options? What if you also knew that providing these services could save the state of North Dakota a great deal of money?

HB 1043 provides a proven plan for North Dakota to address its exponentially growing population of people with dementia—an expected increase of over 30% between 2005 and 2020¹. The Interim Long-Term Care Committee spent a significant amount of time studying this issue and coming to the conclusion that increasing the number of dementia care consultants in the state will provide the most help to the largest number of people in the most cost-efficient way possible.

The proposed services are unique and different from any other services currently available in that they would be provided by people with advanced training in dementia care to train and assist family caregivers in every stage of the disease process. This would include education on the disease itself, the stages and what to expect. It would also include practical, hands-on tips for behavior management, communication and how to plan ahead for the future. The proposed care consultants would also network with community health care professionals and the public to provide education and resource referrals. The Alzheimer's Association provides these services, but with only two staff members in the entire state, thousands of people with dementia and their families are falling through the cracks. This must be changed and you have the power to make it happen.

Not only will HB 1043 ensure that families dealing with dementia have access to support services proven to reduce caregiver depression levels and feelings of isolation², similar support services have been shown to boost the physical health of caregivers which allows them to care for their loved one with dementia at home for an average of 18 months longer than if they did not have access to the services³. Given that the average cost of a nursing home stay per year in North Dakota is \$58,000⁴, the program has the potential to save the state millions of Medicaid dollars. We know it would do much more than that.

¹ ND Data Center Statistics.

² Mary Sherman Mittelman, Dr. P.H., Henry Brodaty, M.D., D.Sc., Aaron Seth Wallen, Ph.D., Alistair Burns, M.D.: "A Three-Country Randomized Controlled Trial of a Psychosocial Intervention for Caregivers Combined with Pharmacological Treatment for Patients with Alzheimer's Disease: Effects on Caregiver Depression," *American Journal of Geriatric Psychiatry*, Volume 16, November 2008, pages 893-904.

³ Mittelman, MS; Haley, WE; Clay, OJ; Roth, DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*. 2006; 67:1592-1599.

⁴ North Dakota Long Term Care Association

March 3, 2009

Dear Members of the Senate Human Services Committee,

It is my pleasure to write this letter on behalf of the ND Hospice Organization to voice our support of House Bill # 1043.

Dementia has become the fastest growing Hospice admission diagnosis signifying more people being diagnosed with very challenging condition.

This bill would provide education and support for patients and caregivers, enabling dementia sufferers to remain at home as long as possible. In addition, this would certainly result in cost savings for out state with the decrease in long term care admissions.

Currently the Alzheimer's Association is the only organization providing care consultation specifically for people with dementia. With only two staff members, many of our North Dakota citizens that have dementia or are caring for a loved one with this are "falling through the cracks."

In conclusion, the North Dakota Hospice Organization (NDHO) fully supports this bill to provide funding for added resources and staff to assess the needs of individuals with dementia and their caregivers.

Sincerely,

Lori Knoll, RN
President, NDHO

Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease

Mary S. Mittelman, DrPH; William E. Haley, PhD; Olivio J. Clay, MA; and David L. Roth, PhD

Abstract—Objective: To determine the effectiveness of a counseling and support intervention for spouse caregivers in delaying time to nursing home placement of patients with Alzheimer disease (AD), and identify the mechanisms through which the intervention accomplished this goal. **Methods:** We conducted a randomized controlled trial of an enhanced counseling and support intervention compared to usual care. Participants were a referred volunteer sample of 406 spouse caregivers of community-dwelling patients who had enrolled in the study over a 9.5-year period. The intervention consisted of six sessions of individual and family counseling, support group participation, and continuous availability of ad hoc telephone counseling. Structured questionnaires were administered at baseline and at regular follow-up intervals, every 4 months for the first year and every 6 months thereafter. Cox proportional hazard models were used to test the effects of the intervention on the time to nursing home placement for the patients after controlling for multiple time-invariant and time-dependent predictors of placement. **Results:** Patients whose spouses received the intervention experienced a 28.3% reduction in the rate of nursing home placement compared with usual care controls (hazard ratio = 0.717 after covariate adjustment, $p = 0.025$). The difference in model-predicted median time to placement was 557 days. Improvements in caregivers' satisfaction with social support, response to patient behavior problems, and symptoms of depression collectively accounted for 61.2% of the intervention's beneficial impact on placement. **Conclusion:** Greater access to effective programs of counseling and support could yield considerable benefits for caregivers, patients with Alzheimer disease, and society.

NEUROLOGY 2006;67:1592–1599

Dementia increases the risk of nursing home placement (NHP) among the elderly more than fivefold.¹ Family caregivers help people with dementia remain at home, although they vary considerably in their ability to do so.^{2–4} NHP reduces direct care obligations, but does not necessarily reduce caregivers' distress,⁵ and is very costly to society.^{6,7}

A randomized controlled trial of a counseling and support intervention for spouse caregivers of patients with Alzheimer disease (AD) began in 1987 at New York University (NYU). The median time from baseline to NHP of patients was 329 days longer in the treatment group than in the control group among the 206 subjects who enrolled between 1987 and 1991.⁸

An additional 200 spouse caregivers enrolled between 1991 and 1997, resulting in a final sample of 406 subjects. Caregivers have been followed longitudinally for up to 17 years, with documentation of the dates of NHP, death, and study termination. The NYU study, with its large sample size and extended length of follow-up, provides a unique opportunity to

gauge the potential long-term impact of psychosocial intervention.

Over the past two decades, efforts at cost containment have led to substantial decreases in utilization of nursing homes in the United States.⁹ We hypothesized that despite this trend, the NYU counseling and support intervention would continue to demonstrate a significant effect on time to NHP over the entire time period examined (1987–2005), mediated by previously demonstrated improvements in spouse caregivers' social support, depressive symptoms, and tolerance of problem patient behaviors.^{10–12}

Methods. Overview. Caregivers were assigned a family counselor when they enrolled in the study. Participants completed a comprehensive baseline assessment, consisting of structured self-report questionnaires, and then were randomized by lottery to an enhanced counseling and support intervention ($n = 203$) or to usual care ($n = 203$). Allocation was concealed from participants and counselors until after the baseline assessment, and was then revealed by the counselors opening a sealed envelope in the caregivers' presence showing randomization to treatment or usual care conditions. The assessment was repeated 4, 8, and 12 months after baseline, and every 6 months thereafter. Participation con-

From the Department of Psychiatry (M.S.M.), New York University School of Medicine, NY; School of Aging Studies (W.E.H.), University of South Florida; and Department of Biostatistics (O.J.C., D.L.R.), University of Alabama at Birmingham.

Funded by the NIMH (R01 MH 42216) and the NIA (R01 AG14634). Additional funding was provided through the NYU Alzheimer's Disease Center (P30-AG08051). W.E.H. was supported by the Florida AD Research Center (P50-AG025711).

Disclosure: The authors report no conflicts of interest.

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tinued until the caregiver became too ill to participate, died, or refused to continue in the study, or until 2 years after the death of the patient with AD. No adverse events were reported during the study.

Participants. Approximately half the caregivers who were recruited were spouses of subjects of our AD Center ($n = 214$, 53%); these patients had received a diagnosis of AD according to National Institute of Neurologic and Communicative Diseases and Stroke-AD and Related Disorders Association (NINCDS-ADRDA) criteria.¹³ The rest of the sample of caregivers ($n = 192$, 47%) were spouses of patients who had received a diagnosis of AD and were recruited through referrals from the New York City chapter of the Alzheimer's Association, other community organizations, private physicians, or other study participants. To be eligible, caregivers were required to be living with the patient at baseline and they or the patient had to have at least one relative living in the metropolitan area. This study was approved by the Institutional Board of Review of the NYU School of Medicine. Informed consent was obtained from all participants.

Treatment. The intervention consisted of two individual and four family counseling sessions tailored to each caregiver's specific situation, encouragement of weekly support group participation, and availability of ad hoc telephone counseling. Individual and family counseling sessions occurred within 4 months of enrollment. The content of the counseling sessions depended on the needs of each spouse caregiver and family (e.g., learning techniques for managing troublesome behaviors, promoting better communication between concerned family members). The family counseling sessions included relatives suggested by the caregiver; the person with AD was not included. Caregivers in the intervention group agreed at baseline that they would join a support group that met weekly after the 4-month follow-up for ongoing emotional support and education. There are many support groups in the New York metropolitan area, and caregivers were encouraged to join groups in their own neighborhoods. Ad hoc telephone counseling was available to caregivers and their families, making it possible for them to determine the amount of contact they had with counselors beyond the scheduled individual and family counseling sessions and helping them deal with crises and with the changing nature of the patient's symptoms over the course of the disease. Counselors also provided resource information and referrals for auxiliary help, financial planning, and management of patient behavior problems. Each caregiver in the intervention group had access to all the interventions, and was provided with support for an unlimited time. A published counseling manual describes the intervention in detail.¹⁴

Caregivers assigned to the usual care group received services routinely provided to patients and their families in the NYU-ADRC, such as resource information and help upon request, but they did not participate in formal counseling sessions, and these caregivers' family members did not generally have any contact with the counselors. Although the nature of the study made it impossible for caregivers or counselors to remain blind to group assignment, caregivers in the usual care group were free to join support groups and could call the same counselors as those in the intervention group. Thus usual care participants undoubtedly received more information and support than is generally provided in typical medical or community treatment settings.

While agreement to participate in a support group was a criterion for inclusion, and no one refused at the outset to do so, not all participants in the treatment condition ultimately joined support groups, and many subjects in the usual care condition joined support groups on their own; 42% of the caregivers in the control condition joined support groups within 12 months of enrollment, compared to 58% of those in the treatment condition ($\chi^2 = 10.13$, $p = 0.0015$). All caregivers were permitted to continue in the study, and remained in the condition to which they were originally assigned regardless of whether they joined support groups.

Measures. Demographic information, including patient and caregiver age, caregiver gender, and caregiver reports of patient income, was obtained at the baseline assessment. A number of self-report instruments were completed by caregivers at baseline and at each follow-up assessment to determine the extent of patient impairment, the psychological status of the caregiver, and the physical health of the patient and caregiver. Dates of permanent nursing home placement and of death were monitored throughout the project during regular follow-up interviews and

telephone contacts with caregivers and family members. Dates of death were subsequently confirmed by use of the Social Security Death Index.¹⁶

Patient functioning was assessed by the counselor, using the Global Deterioration Scale (GDS; Cronbach's $\alpha = 0.83$),¹⁶ a semi-structured rating based on an interview with the caregiver. Patients with dementia have scores ranging from 4 to 7 on this scale. Caregivers also reported on the frequency of 30 memory and behavior problems using the Memory and Behavior Problems Checklist (MBPC, $\alpha = 0.80$).¹⁷

We included several self-report scales to assess the psychological status of the caregiver. The Geriatric Depression Scale ($\alpha = 0.94$)¹⁸ is a 30-item, yes/no depression scale specifically designed for older adults. Caregivers reported on the degree to which they found each of the memory and behavior problems in the MBPC upsetting; this has been used in previous research as an indicator of caregiver appraisal or burden.^{11,12,19} The Burden Scale ($\alpha = 0.88$)¹⁷ consists of 22 questions to measure the perceived burden experienced by caregivers of patients with dementia.

Caregiver satisfaction with social support was assessed by averaging three questions from the Stokes Social Network Questionnaire ($\alpha = 0.92$)²⁰ about the caregiver's satisfaction with general support, assistance, and emotional support from family and friends, each ranging from 1 (very dissatisfied) to 6 (very satisfied). Caregiver and patient physical health were estimated for these analyses with the subjective rating of overall health (excellent/good/fair/poor) from the OARS Physical Health Form (ICC = 0.83).²¹ Caregivers provided ratings for themselves and their spouses with AD.

Data analysis. The predictors of nursing home placement were primarily examined using Cox proportional hazards models.^{22,23} The time, measured in days, from date of enrollment and randomization into the project until date of nursing home placement, served as the primary outcome variable. Two patients entered Alzheimer's units in assisted living facilities and were included in the analyses as nursing home placements. For patients who died without ever being placed, date of death was used as a right-censoring event (except in supplemental cumulative incidence analyses described below, in which date of death was considered a competing risk event). For patients who dropped out of the study, the date of the last follow-up interview was used as the censoring date. Caregivers who were continually active in the study and were still caring for their family member in the community were censored at the date August 30, 2005, for these analyses.

Treatment group and gender were included as indicator variables (enhanced counseling = 1, usual care = 0 and female = 1, male = 0). Information on patient income, which was obtained in seven categories and coded at the midpoint of each category interval, was transformed by taking $\log_{10}(1 + \text{income})$, to reduce the effects of extreme values. The Global Deterioration Scale was recoded into a set of three dichotomous (0,1) variables representing moderate dementia (GDS 5), severe dementia (GDS 6), and very severe dementia (GDS 7), with the mild stage of dementia (GDS 4) serving as the reference group for the other GDS levels. Other variables were entered without transformation.

Predictors were categorized as either time-invariant (do not change over time) or time-dependent (variation assessed over time). The primary time-invariant predictor was treatment group, but we also examined other potentially important time-invariant predictors including caregiver and patient age, caregiver gender, patient income, and year of study entry. Time-dependent predictors were classified as to whether they were likely to be influenced by the enhanced support intervention. Time-dependent risk factors for placement that were likely to be affected by psychosocial intervention included caregiver burden,^{24,25} caregiver depression,^{27,28} caregiver social support,⁴ and appraisal of patient behaviors as stressful.^{11,29} While unlikely to respond to our intervention, we also considered other time-dependent risk factors, GDS stage, caregiver and patient physical health, and frequency of memory and behavior problems.

In the Cox proportional hazards models, we first examined the predictive effects of each variable individually. Next, in a multivariable model, we examined the effect of the intervention after taking into account the effects of time-invariant predictors and the baseline (pre-intervention) observations of the time-dependent predictors. Baseline covariates were included primarily to esti-

mate their own effects on time to placement, and also to account for these effects before estimating the incremental effect due to the intervention. Including baseline variables as covariates to adjust for small and random baseline imbalances is a common and well-accepted strategy that yields an estimate of the intervention effect that is both adjusted for and stratified by the covariate influences.³⁰⁻³²

Mediation analysis is increasingly being used in intervention research to identify the likely underlying mechanisms of successful psychosocial interventions and the factors that should be targeted to maximize intervention effectiveness.³³ Changes in the time-dependent covariates, including caregiver satisfaction with social support, reaction to patient memory and behavior problems, burden, and number of depressive symptoms, were subsequently added to the multivariable model to test our hypotheses that these changes would mediate or explain a significant portion of the intervention's effect on nursing home placement rates.

In order to demonstrate statistical mediation according to accepted guidelines,³³⁻³⁵ the intervention must lead to significant change in the potential mediator (e.g., caregiver depression), and this intervention-induced change must also explain a significant proportion of variance in the primary outcome, time to nursing home placement. The structure of our mediation analysis models is summarized below:

$$\log h(t) = a(t) + b_1X_1 + b_2X_2 + \dots + b_jX_j \text{ (time-invariant and baseline covariates)} \\ + b_{j+1}(M(t) - M(0)) \text{ (change from baseline in hypothesized mediator)} \\ + b_{j+2}(\text{group}) \text{ (direct (unmediated) intervention effect)}$$

In these models, t represents the time, in days, of each observation up to placement (or censoring), j indicates the number of individual time-invariant and baseline covariates, and M represents the hypothesized mediating variable. Consequently, $M(t) - M(0)$ is a time-dependent predictor that quantifies the change observed on the mediator over time from baseline.

By examining the predictive influence of time-dependent changes in each potential mediator separately, we were able to determine that mediator's total mediation effect. The proportion of the intervention effect that can be attributed to the mediator is the difference in magnitude between the intervention effect in the baseline covariate-adjusted model and the intervention effect in the mediation model that also includes the change score for that time-dependent predictor. We determined the percentage of the intervention effect that could be attributed to changes in the mediator as follows:

$$\% \text{ mediated} = 100 \times ((\ln(HR_B) - \ln(HR_M)) / \ln(HR_B))$$

where HR_B = the hazard ratio for the intervention effect from the baseline covariate-adjusted model and HR_M = the hazard ratio for the intervention effect from the mediation model.

The total mediation effect for each mediator includes the unique contribution of that mediator as well as the effect it might share with other mediators, since intervention-induced changes in these mediators are not necessarily independent from each other. Indeed, we have previously shown that intervention-induced changes in depression and reaction to patient behavior problems after 1 year of intervention were correlated both with each other and with changes in satisfaction with the social support network.³⁶ This suggests that these mediators would share explanatory power in the present analyses, accounting for a significant portion of the intervention's impact on nursing home placement. Therefore, additional multivariate mediation models were estimated in which multiple time-dependent changes were entered simultaneously. These models allowed us to quantify the proportion of the total intervention effect on nursing home placement rates that could be attributed to changes on the potential mediators collectively.

Because patient death was a common right-censoring event, we conducted a supplemental analysis to estimate the effect of treatment, using Kaplan-Meier cumulative incidence analysis methods,^{37,38} in which patient death was an informative competing risk event rather than a non-informative right-censoring event. The magnitude of the treatment effect was compared to similar findings from the right-censored proportional hazards models to examine whether simple treatment group differences might be an artifact of an informative censoring process. There is little information available on the use of cumulative incidence for competing

risks analyses in multivariate models, particularly those with time-dependent predictors, so these methods were not used for the multivariate and mediation model analyses that were central to our primary research questions.

Results. Baseline characteristics of subjects, subject accrual, and follow-up. Salient baseline characteristics of caregivers and patients are presented in table 1. We used t-tests to compare the treatment and control groups on continuous variables, and χ^2 tests for caregiver gender and GDS. In spite of randomization, imbalances ($p < 0.05$) were found between the treatment groups on four of the baseline variables—gender, GDS, MBPC, and depressive symptoms. These variables were included, along with the other baseline variables, in our analytic models as potential prognostic predictors of nursing home placement. Effects for intervention and for other variables are also adjusted for these imbalances between treatment groups by including the relevant baseline variables in the models as covariates.

At least one follow-up interview was obtained from 396 of the 406 caregivers, and information on the primary endpoint for this analysis was available for all 406 subjects. There were 210 nursing home placements and 196 censored cases as of August 30, 2005 (figure 1).

Univariate effects on nursing home placement. The results of the univariate proportional hazard models, including hazard ratios and 95% CIs, are presented in table 2. This analysis, unadjusted for covariates, showed that caregivers in the intervention group were able to keep their spouses at home longer than caregivers in the usual care control group (hazard ratio = 0.714, $\chi^2 = 5.88$, $p = 0.015$). The difference in the model-predicted median time from baseline to nursing home placement for the two groups in this univariate analysis was 585 days; the estimated median time for the usual care group was 1,181 days compared to 1,766 days for the enhanced counseling and support group.

Slightly stronger group differences were found in supplemental analyses using Kaplan-Meier cumulative incidence methods that treated patient death as a competing risk event. Cumulative incidence rates in analyses that account for competing events are generally lower than those that treat such events as censoring events.³⁷ In this context, a median (i.e., 0.50) cumulative incidence rate from the censored analysis corresponded to a cumulative incidence adjusted for competing risk (CICR) of 0.40 for the intervention group, and the two groups differed by 697 days at this CICR point (intervention = 1,766 days, usual care = 1,069 days). Thus, the right-censored proportional hazards estimate of the intervention effect was lower than the similar estimate from the CICR approach, suggesting that the censored approach was not leading to a spuriously inflated estimate of the intervention effect.

Among the demographic variables we considered, the proportional hazards models summarized in table 2 indicated that neither caregiver gender nor age were significant predictors of placement. An effect that approached conventional levels of statistical significance was found for patient age. Patient income was a significant predictor, with people of higher income being less likely to place. Year of study entry also had a significant impact, with those who entered more recently being less likely to place their relatives than those who entered in the earlier years.

Table 1 Key demographic and predictive characteristics at baseline by treatment

	Treatment, n = 203	Control, n = 203	Total, n = 406
Female caregiver, n (%)	111 (54.68)	133 (65.52)	244 (60.10)
Caregiver age, y, mean (SD)	71.52 (8.61)	71.15 (9.31)	71.33 (8.96)
Patient age, y, mean (SD)	73.80 (8.46)	74.81 (8.30)	74.31 (8.38)
Patient income,* mean (SD)	3.54 (1.45)	3.70 (1.26)	3.62 (1.36)
Global Deterioration Scale (GDS), n (%)†			
4	72 (35.47)	64 (31.53)	136 (33.50)
5	91 (44.83)	77 (37.93)	168 (41.38)
6 or 7	40 (19.70)	62 (30.54)	102 (25.12)
Caregiver physical health, mean (SD)	2.15 (0.64)	2.07 (0.63)	2.11 (0.64)
Patient physical health, mean (SD)	2.20 (0.72)	2.17 (0.73)	2.18 (0.72)
Satisfaction with social support, mean (SD)	4.52 (1.32)	4.41 (1.41)	4.47 (1.37)
Frequency of memory and behavioral problems, mean (SD)	41.15 (18.29)	46.55 (19.49)	43.85 (19.07)
Reaction to memory and behavioral problems, mean (SD)	22.31 (13.77)	24.77 (16.99)	23.54 (15.50)
Depressive symptoms, mean (SD)	8.92 (5.74)	10.58 (7.21)	9.75 (6.56)
Caregiver burden, mean (SD)	34.46 (14.01)	37.13 (16.25)	35.80 (15.21)

* Patient income was log transformed.

† Only one patient had a GDS of 7 at baseline, so this case was combined with those who had a GDS = 6 for the baseline covariate analyses only.

Among the time-dependent predictors, increased severity of dementia, poorer caregiver physical health, poorer patient physical health, lower satisfaction with social support, greater frequency of memory and behavior problems, greater reaction to memory and behavior problems, more symptoms of depression, and higher caregiver burden were all significant predictors of higher nursing home placement rates ($p < 0.020$, see table 2).

Effect of the intervention on time to nursing home placement after adjusting for the effects of baseline covariates.

The time-invariant covariates and the baseline (pretreatment) values of the time-dependent predictors were entered simultaneously along with treatment group in our baseline covariate-adjusted model of the effect of the intervention condition. The hazard ratios and 95% CIs from this model are displayed in table 3. The primary effect of interest from this table is the one for treatment group (hazard ratio = 0.717, $\chi^2 = 5.05$, $p = 0.025$), indicating that, after considering the influence of all other covariates in table 3, including those with significant imbalances at baseline between the intervention and usual care groups, the patients who were cared for by spouses in the enhanced counseling and support group were placed at slightly less than 72% of the rate observed for those whose spouses were in the usual care group. The difference in the model-predicted median time from baseline to nursing home placement for the two groups from this model was 557 days (usual care = 1,209 days, enhanced counseling and support group = 1,766 days). The intervention effect, adjusted for baseline covariates, is displayed graphically in figure 2, where 11-year survival curves show the significant difference between the two groups. In addition, significant covariate effects were found for patient income, year of study entry, GDS, and depressive symptoms.

Mediators of the intervention effect on nursing home placement. The results of the mediation analyses are presented in table 4. The hazard ratio of 0.717 for treatment group from the baseline covariate-adjusted model (table 3) represents the intervention effect before considering the impact of any time-dependent changes in potential intervention mediators. Each row of table 4 reports the results when changes on that time-dependent predictor only are added to the model summarized in table 3. The hazard ratio for the intervention effect will move closer to the null value of 1.00 if the change in the mediator under consider-

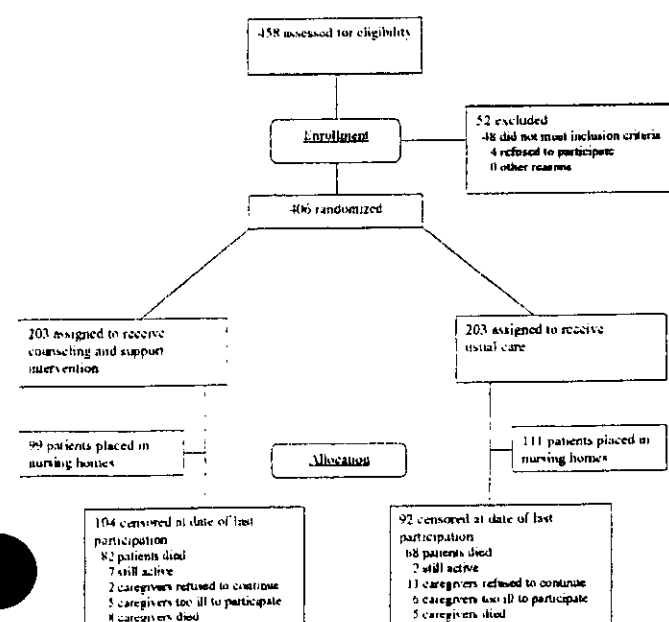


Figure 1. Trial profile. Information about the nursing home placement status (placed, deceased, still at home) and date of placement was known for all patients.

Table 2 Univariate Cox proportional hazard ratios for the effect of each time-invariant and time-dependent variable on time to nursing home placement

	Hazard ratio (95% CI)	p Value*
Time-invariant predictors		
Group (intervention vs usual care)†	0.714 (0.544–0.937)	0.0153
Caregiver gender (female vs male)†	1.237 (0.939–1.629)	0.1310
Caregiver age	1.005 (0.990–1.020)	0.5163
Patient age	1.013 (0.996–1.030)	0.1285
Patient income‡	0.840 (0.769–0.918)	0.0001
Year of study entry§	0.908 (0.863–0.955)	0.0002
Time-dependent predictors		
Global Deterioration Scale at baseline		
5 vs 4	14.529 (1.994–105.838)	0.0083
6 vs 4	46.154 (6.434–331.098)	0.0001
7 vs 4	33.049 (4.420–247.081)	0.0007
Caregiver physical health	1.287 (1.059–1.565)	0.0113
Patient physical health	1.228 (1.042–1.447)	0.0141
Average satisfaction with support network	0.830 (0.757–0.910)	<0.0001
Frequency of memory and behavior problems	1.042 (1.033–1.052)	<0.0001
Reaction to memory and behavior problems	1.032 (1.026–1.039)	<0.0001
Depressive symptoms	1.049 (1.029–1.070)	<0.0001
Caregiver burden	1.038 (1.028–1.048)	<0.0001

* χ^2 test.

† Treatment group was coded as a dichotomous variable (intervention = 1; usual care = 0) as was caregiver gender (female caregivers = 1; male caregivers = 0).

‡ Patient income was log transformed.

§ Year of study entry was coded as 1987 = 0 to 1997 = 10.

ation is both predictive of placement rate and an effect of the intervention. The proportion of the intervention effect that could be attributed to each mediator was determined from the natural logarithms of the hazard ratios for the intervention condition from models with and without the mediator in question. For example, we determined that 22.6% of the baseline-adjusted intervention effect on nursing home placement rates could be attributed to treatment-induced changes in depression from the natural logarithms of the relevant hazard ratios $[(\ln [0.717] - \ln [0.773]) / \ln (0.717) = 0.226, \text{ or } 22.6\%]$.

Neither change in caregiver nor patient physical health mediated the intervention effect on nursing home placement. This can be inferred from the fact that the change scores did not predict nursing home placement rates and the intervention effect was still significant with nearly the same hazard ratio after including changes on these time-dependent variables in the model. Although changes in dementia severity did predict nursing home placement rates, these changes did not mediate the intervention effect, as indicated by the fact that change in dementia severity did not alter the size of the hazard ratio associated with the intervention.

There was evidence for partial mediation effects for the remaining time-dependent variables listed in table 4. The largest effects were observed for changes in caregiver reaction to patient memory and behavior problems, satisfaction with social support, and caregiver burden. Each of these mediators was significantly affected by the intervention,

and these intervention-induced changes accounted for at least 30% of the intervention's effect on nursing home placement rates when examined individually. Most striking was the effect of the intervention through decreasing caregiver reaction to patient behavior, which accounted for 48.7% of the impact of the intervention on nursing home placement. Depressive symptoms and frequency of memory and behavior problems were significant, but weaker, individual mediators of the intervention effect.

The proportional hazards models that included all the time-invariant covariates and multiple time-dependent changes from baseline simultaneously indicated that the model with changes in caregiver reaction to patient memory and behavior problems, satisfaction with social support, and depression included together reduced the hazard ratio for the intervention condition to 0.879 ($\chi^2 = 0.689, p = 0.406$). The comparison of this hazard ratio and the reference value of 0.717 indicated that, collectively, these three mediators accounted for 61.2% of the intervention effect on nursing home placement rates $[(\ln [0.717] - \ln [0.879]) / \ln (0.717) = 0.612]$.

Discussion. The current analyses of data collected over an 18-year period indicate that, both before and after comprehensive covariate adjustment, the enhanced caregiver support intervention developed for spouse caregivers at NYU led to significant delays in nursing home placement. The covariate-adjusted

Table 3 Covariate-adjusted Cox proportional hazard ratios of nursing home placement from a multivariable predictor model with time-invariant and baseline covariates

	Hazard ratio (95% CI)	p Value*
Time-invariant predictors		
Group (intervention vs usual care)	0.717 (0.537–0.958)	0.0247
Caregiver gender (female vs male)	1.249 (0.883–1.767)	0.2081
Caregiver age	1.004 (0.979–1.029)	0.7642
Patient age	1.015 (0.989–1.043)	0.2655
Patient income	0.839 (0.760–0.925)	0.0005
Year of study entry (0 = 1987 – 10 = 1997)	0.907 (0.859–0.957)	0.0004
Baseline values of time-dependent predictors		
Global Deterioration Scale		
5 vs 4	1.939 (1.332–2.824)	0.0006
6 vs 4	2.505 (1.578–3.977)	<0.0001
Caregiver physical health	1.079 (0.835–1.394)	0.5628
Patient physical health	0.982 (0.786–1.227)	0.8742
Satisfaction with support network	1.129 (0.997–1.279)	0.0552
Frequency of memory and behavior problems	0.987 (0.975–1.000)	0.0499
Reaction to memory and behavior problems	1.013 (0.999–1.027)	0.0743
Depressive symptoms	1.016 (0.988–1.044)	0.2791
Caregiver burden	1.009 (0.996–1.021)	0.1759

* χ^2 test.

model indicated a median delay in placement of 557 days, or approximately 1.5 years. This is substantially larger than the median delay of 329 days that was reported in 1996 over a more limited time period for the first 206 participants.⁸

Delaying placement was not accomplished at the expense of caregiver well-being. Caregivers in the treatment group were not only able to keep their spouses at home with them longer, but, as the results of our mediation analysis indicate, the effects of the intervention on nursing home placement were largely achieved through improvements in caregiver well-being that we have reported previously.^{10,11,36}

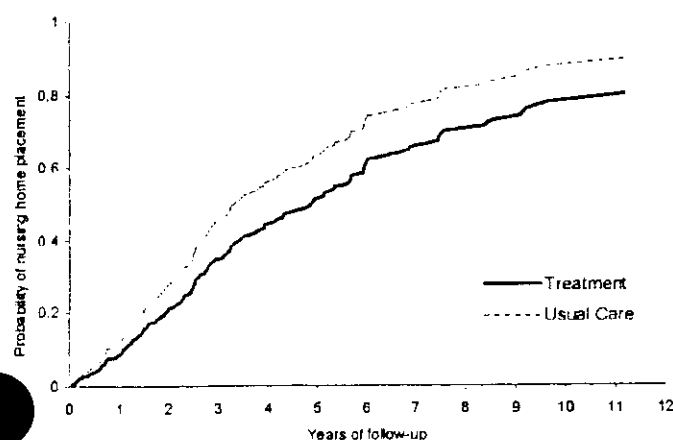


Figure 2. Probability of nursing home placement (1 – survival probability) as estimated from a Cox proportional hazards model. Curves are depicted for each intervention group at the mean value of the covariates.

greater tolerance for patient memory and behavior problems, improved satisfaction with the support provided by family and friends, and fewer symptoms of depression.

Our results suggest that with sufficient counseling and support, it is possible to achieve outcomes that are beneficial to most family caregivers, older patients, and society. While nursing home placement may be necessary when caregivers are unable or unwilling to manage the care of their relatives at home, it typically does not reduce caregiver distress.^{5,39} With placement, caregivers may encounter new stressors such as coping with guilt, feeling their relatives are not receiving adequate care, and conflicts with nursing home staff. Remaining at home longer is generally also to the advantage of patients with dementia, for whom nursing home placement can lead to increased confusion due to the strain of adapting to an unfamiliar environment⁴⁰ and increased risk of mortality.⁴¹ Nevertheless, we recognize that nursing home placement may be the best option for some individuals. Caregivers should be supported in decisions to seek placement, and clinicians should be alert to circumstances where placement should be recommended to protect the caregiver's health and well-being.

This study had several limitations that should be addressed in future research. Despite utilization of random assignment, we found imbalances at baseline between treatment and control participants on several key measures. We entered these variables, along with other covariates, in our analyses to ad-

Table 4 Covariate-adjusted Cox proportional hazard ratios of nursing home placement for change in each time-dependent predictor and for the treatment group*

Time-dependent predictor added to the model†	Change from baseline ($b_{j,1}$)			Treatment group (b_e)			% of Group effect mediated‡
	HR (95% CI)	χ^2	<i>p</i>	HR (95% CI)	χ^2	<i>p</i>	
Global Deterioration Scale				0.742 (0.56–0.99)	4.04	0.0443	10.31
5 vs 4	12.059 (1.63–89.18)	5.95	0.0147				
6 vs 4	35.705 (4.81–265.30)	12.21	0.0005				
7 vs 4	25.405 (3.20–201.73)	9.36	0.0022				
Caregiver physical health	1.053 (0.82–1.35)	0.16	0.6851	0.734 (0.55–0.98)	4.27	0.0388	7.06
Patient physical health	1.139 (0.93–1.40)	1.55	0.2134	0.726 (0.54–0.97)	4.66	0.0309	3.76
Average satisfaction with support	0.853 (0.75–0.97)	5.68	0.0171	0.803 (0.59–1.09)	1.98	0.1597	34.05
Frequency of memory and behavior problems	1.048 (1.04–1.06)	72.64	<0.0001	0.770 (0.58–1.03)	3.09	0.0788	21.43
Reaction to memory and behavior problems	1.030 (1.02–1.04)	44.21	<0.0001	0.843 (0.63–1.13)	1.29	0.2565	48.66
Depressive symptoms	1.036 (1.01–1.07)	5.87	0.0154	0.773 (0.58–1.04)	2.94	0.0864	22.60
Caregiver burden	1.038 (1.03–1.05)	42.66	<0.0001	0.800 (0.60–1.07)	2.21	0.1367	32.94

* Each row reports the results for a model that includes the change scores associated with one time-dependent predictor.

† The rightmost column in each row shows the reduction in the size of the intervention effect after accounting for the changes in the potential mediator in the model represented by that row.

‡ Added to the time-invariant and baseline covariates from table 3.

just our test of the intervention effect for baseline imbalances, but future studies might use stratified randomization techniques to ensure baseline equivalence on major covariates such as gender and disease severity. In addition, this project was conducted in a university hospital setting, and focused on spouse caregivers, few of whom were of minority ethnic backgrounds. More recent caregiver intervention projects have shown that culturally diverse family caregivers can respond well to appropriate psychosocial interventions offered in community settings.⁴²

Interventions that help reduce nursing home utilization without overburdening family members will be essential for our society, which is confronted with a projected tripling of cases of AD in the decades ahead.⁴³ Given the average annual cost of \$60,000 for nursing home care in the United States in 2004,⁶ a delay in placement of 1.5 years represents about a \$90,000 savings per patient. While our study did not collect sufficient information to conduct a careful cost-benefit analysis, the average nursing home cost savings for a single participant in the treatment group is far greater than the annual salary of a full-time counselor. Future research should include detailed cost-benefit analyses, but the results of this study suggest that wider dissemination of this intervention would be cost-effective health care policy.

The value of social support for family caregivers is not restricted to AD. For example, family support has been found to have positive effects on quality of life of caregivers for patients recovering from stroke.⁴⁴ Despite the fact that results from this project and others demonstrate the effectiveness of

evidence-based interventions for family caregivers, such specialized and individualized caregiver intervention programs are not widely available. Most caregivers in the United States do not receive individual or family counseling services from trained professionals. Typically, those who seek services are only provided referrals to support groups, even though recent research suggests that unstructured support groups may be far less effective at achieving desirable outcomes than individualized caregiver interventions.⁴⁵

In community settings, caregivers frequently have even greater need for resources and patients more commonly have multiple etiologies underlying their dementia. Studies to determine the feasibility and effectiveness of counseling and support interventions in typical community settings are necessary. One promising recent study showed that community service providers can be trained to deliver effective, evidence-based caregiver intervention in caregivers' homes, and intervention improved caregiver depression, burden, and stress appraisal, while also improving patient quality of life and behavioral problems.⁴⁶ Further efforts to extend evidence-based caregiver interventions beyond research settings should be a high priority, given their potential benefit to caregivers, patients with dementia, and society.

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Semi Annual Progress Report

April 1, 2008 to September 30, 2008

ADDGS New York University Caregiver Intervention (NYUCI)

Introduction

The Minnesota Board on Aging has completed its first twelve months of translating the evidence-based New York University Caregiver Intervention (NYUCI) in 4 sites across the state including a local chapter of the Alzheimer's Association, a rural county public health agency, a medical clinic and a memory disorders clinic. At each of these sites a caregiver coach is using a chronic care framework to identify and assess 10 to 15 spousal caregivers, provide one individual counseling session, followed by four family sessions and an another family session in a four to 6 month period. Each caregiver receives ad hoc telephone or in person support for 12 months and is encouraged to attend dementia support groups at least twice a month.

The goal of our intervention is to improve the ability of spousal caregivers to withstand the difficulties of caregiving by improving social support and minimizing family conflict. We intend to demonstrate that this caregiver intervention delays or prevents nursing facility placements, as the original research did.

The outcomes to be achieved include: delay or prevention of institutionalization, reduced negative impact of caregiving behaviors; decreased level of depression; enhanced support network composition and effectiveness, fidelity to the original research, and cost effectiveness. Products will include: intervention guidelines/forms/protocols, promotional materials, 'how to' manual, evaluation, and cost analysis reports.

The primary challenge in the last six months has been to move the spousal caregivers from the individual sessions to the family sessions including scheduling family members to participate in the 4 month time period allotted for this intervention. Given the difficulties of scheduling far-flung family members, these sessions have not been completed within the 4 month time period.

This semi-annual report discusses the questions, challenges and difficulties experienced during the six month reporting period. We remain mindful that our program translation process will evolve, adapting to caregiver needs. This will benefit future implementation sites. We are pleased with the accomplishments of our caregiver coaches and optimistic about enrolling 51 caregivers before March 31.

Minnesota has made significant progress during the period April 1 – September 30, 2008. The five coaches to date have recruited 42 spousal caregivers, most have completed the counseling portion of the Intervention (2 individual and 4 family sessions) and have been reassessed. Some of the reassessment data will be discussed in this report. All sites have resumed recruitment; an additional 9 spousal caregivers will be recruited for this intervention in the next two months.

Outcomes

The first five outcomes will be measured using the Montgomery TCare assessment with additional assessment tools from the NYUCI intervention. This assessment is administered at intake, at 4 months/upon completion of the counseling intervention and at 8 and 12 months. Initial results for those caregivers who have completed the counseling sessions are included below.

Expected outcomes and the tools to measure them:

1. 75% of spousal caregivers participating in the research-to-practice application demonstrate a reduction in depression as a result of this intervention;

Caregiver depression is measured with the Center for Epidemiological Studies Depression Scale (CES-D) in the Montgomery TCare assessment. In the attached RE-AIM report caregiver coaches report a reduction in depression for most of the caregivers.

2. 75% of spousal caregivers participating in this research to practice application demonstrate reduced negative impacts of caregiving behaviors.

Impact of caregiver behaviors is measured using the Revised Memory and Behaviors Problem checklist as in the original NYUCI study which has been added to the Montgomery TCare assessment--with permission--replacing the problem behaviors tool used in the regular TCare assessment. In the attached RE-AIM report caregiver coaches report a reduction in burden for most of the caregivers.

3. 75% of spousal caregivers participating in this research to practice application demonstrate enhanced support network effectiveness and composition;

Support network effectiveness is measured with the Stokes Social Network List and additional questions, as in the NYUCI study, and has also been added--with permission--to the Montgomery TCare assessment. In the attached RE-AIM report caregiver coaches report an enhanced support network effectiveness and composition for most of the caregivers. They site many cases of change in family behavior and relationships as a result of the intervention.

4. 75% of spousal caregivers participating in this research to practice application demonstrate reduced burden and increased caregiver self-efficacy. (Will be compared to the results in the current Minnesota ADDGS grant).

Caregiver burden and caregiver self-efficacy are measured using the Montgomery TCare assessment, and because the current ADDGS projects are also using this caregiver assessment, these results will be compared to the results from all Minnesota TCare assessments to get a comparison of the impact of the NYUCI and those receiving "usual care". This will be completed at the end of the 18 months using all caregiver 12 month reassessments that are complete at that time.

5. 60% of the spousal caregivers participating in this research to practice application report being able to avoid or delay institutionalization as a result of this intervention and display a combined reduction in depression, reduced negative impacts of caregiving behaviors and enhance support network composition and effectiveness.

A self report on delay in institutionalization is included in the Montgomery TCare assessment. Dr Mary Mittelman will be receiving aggregated results of the caregiver assessments and will provide an analysis of this data to determine the overall caregiver results. Dr Mittelman will also determine whether these results are consistent with the original study. This will be completed with all 12-month reassessments that are complete by the end of the 18 month grant period.

6. 100% of participating caregiver coaches are trained and apply the NYUCI with fidelity to the original study.

Caregiver coach training is documented and curriculum materials will be included in the project dissemination handbook. Training that has occurred this period is documented in the narrative below. Dr Mittelman along with our evaluation consultant, Deborah Paone, will determine fidelity to the original NYUCI study. Deborah Paone is completing a process evaluation. The RE-AIM report is included as an attachment and defines the training received by the coaches this quarter. Cynthia Epstein is also very involved in working with the coaches to ensure that the intervention counseling sessions are conducted with fidelity.

7. A cost analysis conducted by an outside evaluator determines that the NYUCI can be cost effectively applied in Minnesota and other states.

Deborah Paone in conjunction with the AoA ADDGS staff developed cost analysis materials for state and site cost tracking. Cost analysis data has been provided quarterly by each site. The cost analysis report is included as an attachment to this report. The costs per quarter have varied as the coaches have completed the bulk of their individual and family sessions and have returned to recruiting new participants.

Major Work Objectives and Accomplishments

1. 3 Rural and 1 Metro Site are trained and apply the NYUCI with fidelity to the original study

Minnesota is developing a statewide network of caregiver coaches who are social workers, nurses and others with similar backgrounds who provide one on one education and support to caregivers. Caregiver coaching sites are hosted by a wide variety of organizations including medical clinics, volunteer service agencies and other nonprofit local service agencies. These sites are often incorporated within Aging and Disability Resource Centers (in Minnesota known as MinnesotaHelp™ sites). The four Intervention sites were selected from among these sites before the grant itself started, allowing the sites to get up and running quickly. The three rural and one metro site have been trained and are applying the NYUCI with fidelity to the original study. Below is a description of the four Minnesota sites:

- Carlton County Public Health and Human Services is located in Cloquet, a rural community in northern Minnesota. Kristine Dwyer, a licensed social worker certified in Gerontology, caregiver coaching, and research interviewing for the Alzheimer's Association. Kristine is completing her Masters in Gerontology
- Central Minnesota Memory Disorders Clinic is based in St. Cloud, a community 65 miles northwest of Minneapolis. Denis McGuinness (licensed independent clinical social worker) and Dora Haugen (occupational therapist) lead the caregiver support program.
- Waseca Medical Center Mayo Health System (Waseca) is located in southern Minnesota. Caregiver coach Kristin Shirley is a certified life coach and is trained as a caregiver coach and dementia/Alzheimer's disease Kristin works closely with Bonnie Betts, PsyD who provides support and guidance in working with both the spousal caregivers and their families.
- Alzheimer's Association Minnesota/North Dakota chapter Metro Area office is located in Edina, a suburb of Minneapolis. Heidi Haley-Franklin is a licensed graduate social worker with specialized training in caregiver coaching and dementia/Alzheimer's disease.

During the first three months of the project, the sites, Area Agencies on Aging and other partners worked with Dr Mittelman and Cynthia Epstein to develop an implementation timeline and translation guidelines. These guidelines include:

- Caregiver Selection Process/Intervention Recruitment Protocol and Timeline
- Spousal Caregiver Assessment and Care Plan Protocol
- TCare Plus Assessment

The implementation timeline, guidelines, TCare Plus Assessment and IRB consent form were included in a draft handbook that was developed for the translation. It was provided to AoA in our last semi annual report. We are in the process of rewriting the handbook to develop the "How To" manual with an entirely different structure and format focused on adult learning strategies and using the RE-AIM format.

Implementation Meetings

During this semi annual period, monthly day long meetings of the coaches were held during April, May, June, July and September. The August meeting was combined with the Age and Disabilities Odyssey conference held in Duluth (the Minnesota Board on Aging and the Minnesota Department of Human Services annual statewide conference). Cynthia Epstein joined these meetings by phone and the Age Odyssey in person. During these meetings the coaches provided a monthly update of their work with caregivers and their families and discussed challenges with the translation of the intervention and approaches to addressing them. The greatest challenges discussed related to issues presented by caregivers in the individual sessions, moving the caregivers from the individual to the family sessions, inviting family members,

scheduling family members and challenging situations presented by families in the family sessions.

Most recent discussions have focused on providing closure to families as they complete the family sessions and closure with the individual as they conclude the final individual sessions. Another area of discussion is the number of family sessions and including the person with dementia in at least one family session. A protocol was developed with approval from AoA and reviewed and approved by Dr Mittelman. Issues surrounding the number of sessions included the need for two individual sessions at the beginning of the intervention, one where the person with dementia is met. In discussions the coaches discovered that some of the coaches routinely met the person with dementia at the onset of the intervention and felt that this added value. Meeting the person with dementia prior to or early in the intervention has now been incorporated into the protocol as well.

Some families have completed their work by the end of the third session and do not wish to engage in a fourth session. Dr Mittelman agreed that 6 sessions of either combination of three and three (3 individual and 3 family) or two and four (two individual and four family) would maintain fidelity with the original study. There is no way to force a family to go through a fourth session if they have decided that they are done.

Meeting minutes are attached as an appendix.

In addition to the monthly in person meetings, a monthly conference call with Cynthia was also initiated for discussion of family sessions, approaches and issues. Coaches also provided an update on progress in working with the family and on other issues related to translation.

Training to Engage In the Intervention

Four different types of training for the caregiver coaches who are applying the intervention were determined to be needed: training as a caregiver coach, training in the TCare and the additional NYUCI tools, training in counseling strategies for the individual and family sessions and advanced dementia training.

As previously reported the Minnesota Board on Aging provides a 12 hour, two day, coach training. The curriculum includes: coaching theory, assessment, care planning, individual coaching strategies and family meetings. The Montgomery TCare Assessment is being piloted in Minnesota both in a controlled trial and at development sites. Dr Montgomery provides an initial 12-hour onsite training, followed one month later by an additional 7 hour onsite training in addition to two to three webinaires, as well as individual telephone support. Each caregiver professional using the TCare is required to submit completed assessments, care plans and pass an online exam to be certified to use TCare. All NYUCI coaches are certified TCare assessors and care planners.

We are contracting with Cynthia Epstein of the original NYUCI study to provide the training in counseling strategies for the individual and family sessions. Cynthia Epstein provided six hours of in-person training on April 11, 2008. This training focused on moving from the assessment to

the individual session, the content of the individual sessions, moving from the individual session to the family sessions and what the family sessions would be like and finally transitioning from the family sessions back to the final individual session. The training included a combination of informal presentation, case discussions and scenario problem solving. The coaches developed a strengthened working relationship with each other and Cynthia and now call and email each other as well as Cynthia for insight on individual cases. This "coaching the coach" approach is intended to develop our current coaches who have been trained by Cynthia to themselves coach the next generation of NYUCI coaches.

We also provided a dementia track at the Age and Disabilities Odyssey that featured Cynthia and the coaches in both a three-hour "intensive" session and back-to-back workshops as well as additional informal working sessions with the coaches. The purpose of these sessions was to introduce the next wave of coaches to the NYUCI and prepare them for implementing the intervention. A synopsis of the sessions is included as an appendix. The NYUCI coaches presented with Cynthia and by working in small groups as well as in work shop presentations they expanded their own knowledge base as much as those that they were training.

An additional tool was added to the data collection protocol: the Global Deterioration Scale. The coaches use the family version of the scale to assign a stage to the person with Alzheimer's disease. Dr Joe Gaugler provided a one hour training on the use of the Global Deterioration Scale with the family to determine the stage of the disease that the care receiver is in.

Advanced training in dementia was provided by Dr Stan Smith, a noted Twin Cities Geriatrician who served as the Medical Director for the Minnesota site of the Chronic Care Networks for Alzheimer's Disease project and currently provides physician training in diagnosing and treating dementia as well as staffing a Memory Care Clinic in Stillwater, Minnesota. Dr Smith, provided 6 hours of training to the NYUCI coaches at the end of May regarding medical assessment/screening tools and treatments for Alzheimer's Disease, dementia care coordination, management of the person with Alzheimer's disease, managing behavior problems and late stage dementia. A copy of the course outline is included as an appendix. Individual consultation on Alzheimer's is also being provided by the Alzheimer's Association.

The coaches are currently developing a three session training series for the new NYUCI coaches. These all day training sessions are scheduled for November 6th, December 4th and January 16th. Information on these sessions will be provided in the next semi annual report.

A family systems training is also being planned for the next semi annual period. This training will be jointly provided by the masters level coaches and an expert in the field of family systems and geriatric therapy.

2. Marketing and outreach activities will be conducted to recruit 51 spousal caregivers for participation in the complete NYCUI at the intervention sites

Marketing and outreach activities were a major project focus in the initial six months of the project and were described in our last semi annual report. In the attached RE-AIM report marketing and outreach strategies are examined under Reach. To summarize, each coach used

different strategies to recruit the caregivers that are currently participating in the study. No one strategy was more successful than others. People were recruited through caregiver support groups, pharmacists, physicians, a variety of newsletters, presentations to groups and newspaper articles.

While all the strategies yielded some referrals, no one strategy produced all the desired referrals. Initially we thought that the coaches would be able to draw all of their participants from their current client base, but for a variety of reasons this proved only partially successful. We also thought that coaches that had close ties to medical clinics would have an easier time with recruitment than those that did not. This proved also not to be the case. Some referrals did come from these sources but not the numbers that were anticipated. What we did learn is that recruitment is time consuming and requires an opportunity to tell the story. The brochure (included with our last semi annual report) that includes pictures of each of the coaches is the most useful marketing material that has been developed. We will be revising this brochure to tailor the contents more to families and include an insert with pictures of the new coaches.

Active recruitment was suspended in April. Coaches were overwhelmed with providing individual and family sessions to so many families at once. Now that the coaches have completed the individual and family sessions they resumed recruitment in September. We expect to be at the full complement of 51 in the next two months.

3. NYU caregiver intervention provided to 51 spousal caregivers.

We are currently working with 42 spousal caregivers, and expect that we will be at 51 by the end of November or early December. Most of the family sessions are nearing completion. All coaches have been through at least one final family session and one final individual session, some coaches have been through many. Nearly all of the 4 month reassessments have been completed, most were completed at 6 months. Most families were not far enough into the family sessions at 4 months for a reassessment to be appropriate. Both Mary and Cynthia were consulted. In the NYUCI study reassessments occurred between 4 and 6 months, we remain consistent with the original study. The content of the sessions including the caregiver experience is reported in the attached RE-AIM report. To summarize, by the time the family reached the third session they had begun to work together at a much deeper level and real movement was seen in the family to change behaviors and relationships to address the issues at hand.

During the individual and family sessions all coaches experienced infrequent ad hoc calls, more may come now that the active phase of the intervention is over for many of the caregivers. Support group participation is as expected with over half of the caregivers participating in support groups.

The RE-AIM report includes issues that have arisen including: the difficulty or ease of family participation in the family sessions; the length of sessions and types of issues that are identified; and strategies families have identified to address these issues. At this time we are getting an avalanche of data and need time to review it. Each coach has submitted copy of caregiver logs detailing the time and content of all contacts with the caregiver and the family, as well as additional services that they have assisted in arranging for the family. Unlike the coaches past

work with caregivers, this intervention focuses on empowering the caregiver and the family to carry out their own plan and identify and arrange the services that they need. The coach helps when the family needs help but supports their efforts to do as much as possible on their own. While nearly all of the reassessments have been completed, half are currently entered into our Snap software (24). We have completed our first data run and are now refining the data for analysis.

4. A project wide evaluation will be conducted to determine fidelity, impact and cost of this intervention.

The evaluation has two major components: the first will use published tools (identified below) to assess and track the outcomes for participating caregivers' well-being during the 12-month data collection period. These caregiver outcomes focus on four areas: (1) depression, (2) social support, (3) stress due to problem behaviors, and (4) delay in nursing home placement. The likelihood of a nursing facility admission delay--over time--will be determined based on comparisons with the NYUCI experience. The results of Dr Mittelman's research demonstrated that reduced depression, reduced negative impacts of problem behaviors and enhanced support networks, when combined, accounted for over 60% of delays in nursing home placement.

This project has worked with Dr Mittelman to identify and select the four measurable outcomes that formed the key results of the NYU Caregiver Intervention. Dr Mittelman selected the following outcome domains to be measured at baseline, 4, 8 and 12 months: 1) Depression. The CES-D tool is being used; 2) Social Support. The Stokes Social Network List is being used to measure the social support and to track changes in support as a result of the caregiver and family interventions; 3) Appraisal of problem behaviors. The revised memory and behavior checklist (RMBPC; Teri et al., 1992) is being used to measure the stress impact of problem behaviors; 4) Nursing home placement. Caregiver/receiver self-reports will indicate date of nursing home placement.

A very rough look at the comparison of total depression scores from the initial assessment to the reassessment shows an overall decrease in caregiver depression. The participant average score at initial assessment was 19.39 and was reduced to 17.87 at the time of reassessment. Many participant depression scores decreased significantly, a few stayed the same and a few increased. This is consistent with caregiver coach reports that are included in the attached RE-AIM report.

The RMBC (Revised Memory and Behaviors Problem Checklist) data is less conclusive. The average frequency of memory problems increases from 18.86 at initial assessment to 21.75 at reassessment as one would expect with a progressive disease such as Alzheimer's. The average frequency of disruptive behaviors decreases slightly from 5.48 to 5.20. The frequency of depressive behaviors increases from 11.39 to 11.87. The caregiver reaction to memory behaviors for the 24 caregivers that are entered increases from 7.65 to 8.9, the average reaction to disruptive behaviors decreases from 5 to 3.83 and the average reaction to depressive behaviors increases slightly from 8.2 to 8.7. These results would indicate that coaches have been successful in reducing the impacts of disruptive behaviors. The ways in which the coaches can assist caregivers in working through issues with behaviors related to deteriorating memory and care receivers depression need to be examined and implemented.

The Stokes data show a consistent increase in the numbers of relatives, close relatives, friends, and close friends in the caregiver's social network. The average number of friends increased from 1.18 to 1.58 and relatives from 1.48 to 4.45, close friends increased from an average of 1.25 to an average of 1.48 and close relatives increased from an average of 3.79 to an average of 4.458. The average increase of friends and relatives at the initial to the first reassessment was from 7.72 to 8.375. This data would seem to indicate that the individual and family sessions have been successful in increasing both the size and complexity of the caregiver's social network.

Intention to place is addressed by the question in the assessment "Given the care receivers current condition, would you consider placing him/her in a different type of care setting such as a nursing home or another care facility for long-term placement?" At the initial assessment 90% of the caregivers responded they either definitely or probably would not, at the time of reassessment even though the average care receivers behaviors and condition had worsened 95% said they definitely or probably would not.

Service utilization and contact logs are kept for each caregiver to document participation in formal individual and family counseling sessions, the number and content of ad hoc phone calls by the spousal and other family caregivers, support group participation and frequency and the use of support services. This information is submitted quarterly along with cost analysis reports.

Our evaluator, Deborah Paone, continues to work closely with our project. She is creating a composite report of the cost analysis data, reviewing the RE-AIM report and receives copies of meeting notes and other project materials. She has attended meetings and did attend Age Odyssey sessions on the NYUCI presented by Cynthia and the coaches to observe coach progress.

The cost analysis report is included as an appendix.

Quarterly reports are prepared and submitted by sites using the RE-AIM framework; those reports were submitted in July and October and the results aggregated in the attached RE-AIM report.

The MN work group meets on a regular basis. Our five caregiver coaches and consultants (Joe Gaugler of The University of Minnesota, Deborah Paone, Michelle Barclay (Vice President – MN/ND Alzheimer's Association, three MBA staff and five coaches from the four sites) have convened each month since October for a comprehensive meeting at the Alzheimer's Association. The project staff meets bi-weekly with each caregiver coach keeping detailed notes on successes and barriers which are reviewed by the evaluator.

5. Develop project dissemination materials by March 31, 2009

A replication handbook was developed for intervention site use and provided to AoA in the last semi annual report. This handbook will be completely restructured using the RE-AIM format. A draft outline of the new manual is included as an appendix. Coaches have developed initial components of the manual and a professional curriculum developer is being contracted to both develop this handbook and the final curriculum for coach training. The first draft of this

handbook will be used in the training of the new NYUCI coaches that will begin this month. We will be working with Dr Mittelman and the two Rosalynn Carter Institute funded sites in Vermont and New York to develop the final "How To" manual. The recent RCI caregiver conference provided an opportunity for all sites to meet and discuss the content and structure of this manual. Counseling the Alzheimer's Caregiver (Mittelman, Epstein and Pierzchala, 2003) has provided a useful resource for coaches as they have engaged in the intervention and will be included as part of the "How To" manual. Copies of this book are being purchased through a related state Community Service/Service Development (CS/SD) grant for inclusion in the "How To" manual.

Outreach materials, protocols and copies of this draft manual have been provided to other states and projects interested in the NYUCI intervention including the Vermont NYUCI site, the Washington ADDGS project and others. Materials have also been provided to a number of Minnesota organizations that are pursuing replication through other funding sources.

This translation of the NYUCI was honored to have been awarded the Rosalyn Carter Leadership in Caregiving Award.

Problems and Strategies to Address Problems

There is inherent challenge in translating research to practice. As Dr. Mittelman and Cynthia Epstein have stated, our work in Minnesota will smooth the path for other sites.

In the first six months the biggest challenges were the development and implementation of the TCare Plus assessment tool and its corresponding data collection mechanisms. Those have largely been addressed. We will continue to streamline the data collection strategies to make them less time consuming. The time of reassessment averages less than an hour.

The time to recruit and enroll new caregivers will not decrease, although we have learned which recruitment strategies are less effective and are focusing our efforts on those that produce the most consistent results. Given the intense nature of this intervention, it takes more time for the caregiver and the family to embrace it, but once they do the results are worth it.

The coaches have shortened the time to complete the initial caregiver assessment, largely through increased familiarity with the tool itself. Most of the coaches complete the assessment online but pay attention to the comfort level of the caregiver and use a paper tool when appropriate. Completing the assessment online has saved considerable time in reentering data, but with practice, time to enter data has decreased as well.

The funding of the AE grant has addressed the second principal challenge for this intervention. We can now spread enrollment across a more reasonable time period. Initial results of caregiver sessions may have been negatively effected by the level of stress the coaches were experiencing as a result of having so many caregivers participating in individual and family sessions at the same time. Coaches no longer feel overwhelmed by recruitment, assessment, data entry or the individual and family sessions.

A current challenge experienced by the coaches is closure at the end of the fourth family session and the last individual session. The coaches are working with Cynthia Epstein and each other to address this issue. Another challenge is the depth of issues and dynamics of family sessions. Coaches who are masters level social workers have a stronger educational and experience base that does make a difference in working with families in these sessions. Coaches who are not masters level professionals are being matched with coaches who are to provide ongoing support and guidance that is close at hand. Additional training in family systems is also being planned.

Another area that has been challenging is scheduling and bringing the family together for the four family sessions. This has required a significant amount of work by all of the sites. We are using several strategies to address this. More education and outreach will occur at the time of recruitment focusing on the importance of the participation of the family in the intervention and getting agreement and even scheduling family sessions up front. Coaches that have been able to do this have more success with scheduling and participation by family members. This is addressed more fully in the RE-AIM report attached.

Modifications to Accommodate Translation

Not surprisingly there have been fewer modifications needed this period to accommodate translation. The number and order of sessions and the length of time to complete the sessions have been the largest modifications. Everyone agrees that despite the best intentions life happens, sometimes a family member shows up during the individual session and the individual session becomes a family session, or the caregiver needs an individual session to address a timely important issue. Both Cynthia and Dr Mittelman agreed that it is more important to address the needs of the caregiver than rigidly apply a protocol. It is the six sessions that are important, not their order or even their time frame. Some families need less family sessions and more caregiver individual sessions so three of each is allowed. An additional individual session is also acceptable. Agreement was reached that two individual sessions, one including the caregiver for part of the session, is optimal. Also given the busy schedules of families completing all 6 sessions in more than 4 months is ok. Many are taking up to 8 months to complete all six sessions.

Another modification was the inclusion of the person with dementia if appropriate in a family counseling session and meeting the person with dementia during the assessment. While the focus of this intervention is the caregiver, given that we are targeting people with Alzheimer's in the earliest stages there were strong feelings that it was respectful to include them and inappropriate not to. The Vermont and New York sites had included them from the outset. It was agreed that they would be included if the caregiver wished them to be. The approved protocol is included as an appendix.

Activities Planned For the Next Period

The final 9 caregivers will be recruited and provided the intervention. 4 new sites will be launched and 5 new caregiver coaches trained.

The "How To" manual draft will be completed in the next three months for use by the five new NYUCI coaches. A training curriculum will be developed and the new coaches trained in three full- day monthly sessions.

The outreach materials will be revised to place a stronger emphasis on the importance of family involvement.

The RCI award provides an opportunity to do a major media blitz that will support the recruitment of new caregivers for the expansion sites. We are working with the Governor's office to have the award presented to the governor.

The cost analysis of this 18 month translation will be completed as well as the evaluation.

We will work with Dr Mittelman to develop an article for publication in a peer reviewed journal that will focus on the translation of the intervention

Dissemination Activities

Reported under *Accomplishments* above

Appendices

- A. RE-AIM Report
- B. Cost Analysis
- C. Minutes
- D. Curriculum Outline for Advanced Training in Dementia
- E. Age Odyssey NYUCI sessions
- F. Curriculum and "How To" manual outlines
- G. Including the Person with Alzheimer's Disease Protocol

Testimony of Gretchen Dobervich(#34)
Senate Human Services Committee
3-3-09

Senator Lee, Members of the Committee, my name is Gretchen Dobervich. I am the Eastern North Dakota Regional Center Director. I am here today in support of House Bill 1043.

for the Alzheimers Assn

This bill which would create and support a statewide dementia care consultation program would not only serve as a direct investment to the people of North Dakota with dementia, but also their families and communities.

A statewide dementia care consultation program would not replicate any existing services. The Alzheimer's Association a private, non-profit offers dementia care consultation on a limited basis. I am not aware of any other such service in the State.

A statewide dementia care consultation program would not replace any services in existence. As many of the most common forms of dementia are progressive most persons with dementia will require medical and custodial care services, utilize both home and community-based services and skilled nursing services.

The goal of care consultation is to assist families in creating an "action plan" that promotes quality of life throughout the disease process for individuals and their families. Care consultation provides ongoing education and support. It is not counseling, therapy or a referral only service.

Dementia care consultation services affects quality of life through improved disease management not only for the person with the dementia, but also for their families. Seventy percent of people with dementia live at home with a family member as their primary caregiver. The long-term physical and emotional stressors of caregiving as dementia progresses and care needs increase often results in the caregiver's health being compromised as well. A recent study showed that with caregiver intervention, such as care consultation, premature skilled care placement for people with dementia was delayed by 18 months.

House Bill 1043 also provides for professional care consultation services. Assisted livings, skilled nursing facilities, home care services; etc would be able to utilize this service to help in creating care plans that improve disease management and consultation for non-medical symptom management. The final benefit to North Dakotans is the community education component of House Bill 1043. Care consultants would provide community education on the warning signs of dementia in an effort to increase the number of North Dakotans diagnosed in the early stage of dementia, when diagnosis, treatment and care consultations can positively influence disease management outcomes.

As the number of North Dakotans with dementias continues to rise sharply, the passing of House Bill 1043 would not only set a national precedent in addressing the Health Care Epidemic of the 21st Century, it would directly improve the quality of live for tens of thousands of North Dakotans.

Thank you for the opportunity to speak before you today. I am happy to answer any questions you may have.

My name is Marcia Buringrud and I would like to thank everyone for giving me this opportunity to testify before you on behalf of HB 1043 for dementia.

Every 71 seconds a person is diagnosed with Alzheimer's. 5.2 million Americans are living with Alzheimer's. In 2009 an estimated 121,875 people in ND and MN will have Alzheimer's. These numbers are from the ND - MN Alzheimer's newsletter recently sent out. The newsletter goes on to say quote unquote "Alzheimer's disease is a prevalent and growing issue and is being called a certain healthcare epidemic". Based on this information can we afford NOT to pass this bill?

My mother was diagnosed with Alzheimer's in 2003. Unfortunately, she passed away November 24, 2006. During the three and a half year battle we were on our own for supporting Mom with her Alzheimer's. Dad became Mom's primary caregiver and because I live in the lower level of the twin home I assisted Dad after work and on weekends so that Mom could continue to live at home. Most families are not in this situation, but nonetheless support is still needed.

My mother had the high anxiety and anxiousness and through medication it controlled it some, but not 100%. She always wanted to be outside and walking and at times she would quietly leave the house and go out for walks or wander. My mother enjoyed flowers and at times she would pick the neighbors flowers. We would try to explain to her that she shouldn't do that, but an Alzheimer's person doesn't understand that, and in Mom's mind she told us that the neighbors said it was okay for her to pick their flowers. On a couple of occasions she did get lost and luckily residents on the block helped us look for her. At the time we were not aware that we could have given the law enforcement a profile of her and if she became lost they would have assisted us in looking for her. House Bill 1043 will provide information as this to families.

In 2004 when my dad went to look at various nursing homes so if and when the time came he would have a fairly good idea of which one would be best. He was made aware of the Adult Day Care program at Rosewood Nursing Home during this time. As a result Mom started going there one day a week and eventually twice a week and we discovered that being with these people also helped her situation and the personnel at Rosewood were very informative and understanding of Alzheimer's. This program not only gave Dad a break and opportunity to do things he needed to do, but also gave Mom the chance to be with other people and be involved in various activities. What Rosewood offered is something we would have done sooner for Mom if we had been made aware of this program earlier. With support and assistance it also would have given Dad more of a direction as to what health care facilities are more advanced to treating Alzheimer's patients. This is what HB 1043 will do and provide to families for help and support.

Mom's primary doctor and specialist were very uninformative and never passed on information for support or help. It is important for the proposed dementia care consultants and the doctors to network so the patients and their families are aware of the services available. We felt at the time of my mother's doctoring the medical staff lacked knowledge and information on Alzheimer's, so as a result we as a family were not provided the best service and medical information and we did what we felt was right at

the time and hoping that we were handling things correctly. Because of the lack of support we had this is why it is so important for this bill to be passed.

When my sister had cancer the last month and a half of her life she was put into a nursing home. As a result the very first day my sister was there I met a lady and she was having problems opening up a door. I went to the lady to see if I could assist her and through the few minutes I was with her I realized she had Alzheimer's. Through my visits to my sister I made a point to visit Edna and even though she never remembered my name she would always smile, say hello and call me the "Pretty Lady". On one occasion she asked me if she could wheel herself down to the reception area and visit with me as I was on my way out so I told her absolutely. However, two young CNA's came over to us and told her they needed to take her back to her room and that she shouldn't bother the visitors. I told them she wasn't bothering me; however they still proceeded to take her back to her room. The sadness and look in her face will never leave my memory. Is this what we want our healthcare facilities to continue doing? With the passing of this bill, hopefully the healthcare facilities will be provided proper training and issues like this can be avoided.

This bill will "unite" the medical and healthcare facilities to provide the proper support that is much needed. It will also make services available at an earlier time of the disease and provide assistance to the caregivers. It is so important to the caregivers to have support so if things come up that they are not sure of how to handle they have a program such as this bill will provide to advise them or give them the necessary contacts for assistance.

Again, thank you for this opportunity and the replies I received back sharing your messages of how Alzheimer's has also touched a lot of you. Let us be the State to show other states how successful a program such as HB 1043 can be for providing assistance for Alzheimer's families and patients.

TESTIMONY – PROTECTION AND ADVOCACY PROJECT

HOUSE BILL 1043 (2009)

SENATE HUMAN SERVICES COMMITTEE

Senator Judy Lee, Chair

March 3, 2009

Senator Lee, and members of the House Human Services Committee, for the record my name is Jim Jacobson, Director of the Protective Services Unit for the North Dakota Protection and Advocacy Project (P&A).

P&A strongly supports the services proposed in HB 1043. In P&A's protective services role we have seen a significant increase in reports that do not involve a licensed mental health or developmental disabilities provider. Most of these reports present concerns that would best be defined as self neglect and anecdotal information indicates that dementia is often a factor. In attempting to find resolution to the issues central to these reports, it is often a coordination of formal and informal supports that is successful. This coordinated effort of formal and informal supports often effectively addresses health and safety issues while allowing a person to remain in their home.

P&A believes that supporting family and informal caregivers is an efficient and sensitive way to improve people's quality of life. Training to treatment professionals and community officials also tends to be very effective in helping these "generic" systems respond to the increasing needs of individuals as they began to realize the negative effects of dementia. House Bill 1043 establishes a plan and process to improve the effectiveness of this coordination of generic efforts. Therefore, P&A strongly supports House Bill 1043.

Thank you for the opportunity to testify.

**Senate Appropriations Committee
HB1043 Testimony – March 12, 2009
- By Rodger Wetzel**

Mr. Chair and members of the Committee:

Thank you for this opportunity to appear before you and testify in support of HB1043. I have worked in the field of aging in North Dakota since I was 26, and this year I will turn age 65...almost 40 years of professional...and now personal... "aging experiences" in our wonderful state. I currently am director of the Northland PACE (Program of All-inclusive Care for the Elderly) program in North Dakota. Previously I served as Director of Eldercare at St. Alexius for 23 years; and prior to that I was the Assistant Director of the Aging Services Division of the NDDHS.

At St. Alexius I facilitated two Alzheimer's/dementias family support groups for 23 years, working with hundreds of family caregivers. They would come to support group meetings for months, sometimes years, hoping to learn how to manage the latest crisis they were experiencing. What they often needed was much more regular support for their caregiving.

And very importantly, my mother has early Alzheimer's; two of my aunts, now with advanced Alzheimer's, are living in nursing homes. In one case two elderly sisters tried to care for one aunt, causing concerns with their children. In the other case an uncle in his 80's tried to care for his wife at home for as long as possible, with support from his adult children living elsewhere. Four other relatives of mine have had Alzheimer's and other dementias, but are now deceased. All lived at home with relatives for various periods of time.

Alzheimer's disease and other memory loss illnesses (dementias) are some of the most challenging diseases for families to manage. We don't know the cause/s; we can't predict how long family members must cope with the disease (3-20 years can be the range); unfortunately there is no cure; and there are no medications to guarantee slowing the disease process.

In addition, the person with the disease often doesn't realize he/she has the disease, doesn't appreciate the intense family caregiving needed, may not even recognize their spouse or family members, may exhibit strange and challenging behaviors day and night, and often expresses anger, accusations, and resistance toward the very family members providing the most care for them. Burnout, depression, guilt and anxiety become the norm for family caregivers. It often becomes easier just to give up and place their family member in a nursing home. And when they consult their doctor for answers and advice, often the easiest medical answer is "It's probably time to put him/her in a nursing home." It is now estimated that over half of residents of nursing homes have Alzheimer's and other dementias. An increasing per cent of those entering assisted living and basic care facilities also have memory loss illnesses (dementias) such as Alzheimer's.

This is not a typical "medical" disease, and doctors don't know how to manage these patients at home. Alzheimer's and related dementias do not fit into the medical model of care that we have for managing other major diseases, such as heart disease, cancer or diabetes. With those diseases we ourselves know we have them, we accept the diagnosis, we call our doctor and go to our appointments. The doctor tells us what may have caused it, how to prevent further problems, what medications can affect the disease process, and how exercise and diet (over)

may help. We continue to work with our doctor to manage our diseases. Those with Alzheimer's behave just the opposite...not understanding, not complying, not changing.

Many of the challenging behaviors and most healthcare needs can be managed by family members with regularly available professional assistance. What these family caregivers need is personal support from, assistance from, and ongoing availability of knowledgeable professional staff, such as the two Alzheimer's Association regional directors in North Dakota, who already are stretched far too thin. And it is especially challenging to serve caregivers in our many rural areas. But these are only two professional Alzheimer's staff persons for thousands of family caregivers. To support the many overburdened, uncompensated, dedicated family caregivers we need the services and staff that would be made available through this legislation. It would make essential services directly available to family caregivers, professional staff, and others interacting with people with dementias.

This program also could significantly delay institutionalization for some, based on a similar Minnesota program experience. The Minnesota results indicated that family caregiver support could delay NH placement by an average of 18 months. That could equate to about \$120,000 in Medicaid or private funds. The \$1.2 million cost of this program would equate to delaying NH placement by 18 months for only 10 elderly, but hopefully many more. Plus many other direct services would be provided. The program would be funded for two years, and requires ongoing outcomes/ benefits reports to the Legislature. In addition, it would be developed through an RFP process, not requiring that new, possibly permanent, state employees be added to the NDDHS.

The past interim LTC Committee was assigned a study resolution on this need, and developed the draft legislation, with unanimous support from its members. Both the House and Senate Human Services Committees have given it very solid support. The entire House voted overwhelmingly to support this much-needed program.

I ask for your support for HB1043...on behalf of the Alzheimer's Association; on behalf of us professionals in the field of aging in ND; on behalf of thousands of ND family caregivers; on behalf of relatives who are caregivers; ...and especially on behalf of my own family members, who are caring for my mom.

I would be happy to answer any questions. Thank you!

TESTIMONY – PROTECTION AND ADVOCACY PROJECT

HOUSE BILL 1043 (2009)

SENATE APPROPRIATIONS COMMITTEE

Honorable R Holmberg, Chairman

March 12, 2009

Chairman Holmberg, and members of the Senate Appropriations Committee, I am Bruce Murry, a lawyer with the North Dakota Protection and Advocacy Project (P&A).

P&A strongly supports the informal services proposed in HB 1043. Information presented in the interim showed these services have been successful where offered. P&A has ongoing experience helping people with dementia and related conditions. We receive referrals when it appears someone violated the person's legal rights. People often come to P&A after their family and informal caregivers burn out or make care-giving mistakes. Unfortunately, some of these mistakes lead to serious neglect, self-neglect, or even abuse. When they come to P&A, it is too late for some of the simplest solutions.

It appears to us that supporting family and informal caregivers is a very effective way to improve people's quality of life and reduce abuse & neglect.

The bill also offers training to treatment professionals and community officials. We see training from an organization like the Alzheimer's Association as very effective in helping these existing community systems respond to the needs of individuals with dementia.

Thank you very much for your consideration.

Dementia Care Center Operator Budget

Expenses Salary/Benefits

	Year 1 Individual	Year 1 Total Cost	Year 2 Individual	Year 2 Total Cost	Year 3 Individual	Year 3 Total Cost	Year 4 Individual	Year 4 Total Cost	Year 5 Individual	Year 5 Total Cost	Year 6 Individual	Year 6 Total Cost
Salary	\$35,000	\$280,000	\$35,200	\$289,600	\$37,500	\$300,000	\$39,000	\$312,000	\$40,500	\$324,000	\$42,000	\$336,000
Benefits (25% of salary)	\$8,750	\$70,000	\$9,050	\$72,400	\$9,375	\$75,000	\$9,750	\$78,000	\$10,125	\$81,000	\$10,500	\$84,000

Supplies

Office supplies	\$3,000	\$24,000	\$3,100	\$24,800	\$3,200	\$25,600	\$3,300	\$26,400	\$3,400	\$27,200	\$3,500	\$28,000
Laptop Computer	\$1,500	\$12,000	\$0	\$0	\$0	\$0	\$1,500	\$12,000	\$0	\$0	\$0	\$0
Printer	\$300	\$2,400	\$0	\$0	\$0	\$0	\$400	\$3,200	\$0	\$0	\$0	\$0
LCD Projector	\$600	\$4,800	\$0	\$0	\$0	\$0	\$600	\$4,800	\$0	\$0	\$0	\$0

Telecommunications

Blackberry Cellphone	\$1,200	\$9,600	\$1,250	\$10,000	\$1,300	\$10,400	\$1,350	\$10,800	\$1,400	\$11,200	\$1,450	\$11,600
Office phone line/Internet	\$1,000	\$8,000	\$1,035	\$8,280	\$1,070	\$8,560	\$1,110	\$8,880	\$1,150	\$9,200	\$1,200	\$9,600

Postage/Shipping

	\$300	\$2,400	\$310	\$2,480	\$320	\$2,560	\$330	\$2,640	\$340	\$2,720	\$360	\$2,880
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Printing/Advertising

Flyers, brochures, fact sheets, etc.	\$1,000	\$8,000	\$1,100	\$8,800	\$1,200	\$9,600	\$1,300	\$10,400	\$1,450	\$11,600	\$1,600	\$12,800
Advertising	\$3,000	\$24,000	\$3,105	\$24,840	\$3,214	\$25,709	\$3,326	\$26,609	\$3,443	\$27,541	\$3,563	\$28,504

Staff Development Miscellaneous Costs

	\$1,500	\$12,000	\$1,550	\$12,400	\$1,600	\$12,800	\$1,660	\$13,280	\$1,720	\$13,760	\$1,780	\$14,240
	\$500	\$4,000	\$520	\$4,160	\$540	\$4,320	\$560	\$4,480	\$580	\$4,640	\$600	\$4,800

In-state Travel

Automobile Expense (Mileage reimbursement, rental cars, and other)	\$7,000	\$56,000	\$7,250	\$58,000	\$7,500	\$60,000	\$7,750	\$62,000	\$8,000	\$64,000	\$8,300	\$66,400
Lodging	\$1,500	\$12,000	\$1,550	\$12,400	\$1,600	\$12,800	\$1,650	\$13,200	\$1,700	\$13,600	\$1,750	\$14,000
Meals	\$2,500	\$20,000	\$2,600	\$20,800	\$2,700	\$21,600	\$2,800	\$22,400	\$2,900	\$23,200	\$3,000	\$24,000

	\$68,650	\$549,200	\$68,620	\$548,960	\$71,119	\$568,949	\$76,386	\$611,089	\$76,707	\$613,341	\$79,603	\$636,824
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Other Expenses

Management / Supervision	\$2,500	\$20,000		\$20,700		\$21,500		\$22,000		\$23,000		\$24,000
Administrative Costs	\$3,500	\$28,000		\$29,000		\$30,000		\$31,000		\$32,000		\$33,000
Program Development Cost		\$4,500										

Total Other Expenses

		\$52,500		\$49,700		\$51,500		\$53,000		\$55,000		\$57,000
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Total Expenses

		\$601,700		\$598,660		\$620,449		\$664,089		\$668,341		\$693,824
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NDLA, S APP ASST

From: NDLA, S APP
Sent: Wednesday, March 18, 2009 8:21 AM
To: NDLA, S APP ASST
Subject: FW: HB 1043
Attachments: Copy of Dementia Care Coordinator Budget.xls; ND Dementia Care Services Bill cost assumptions.doc; Mittelman Caregiver intervention postpones nursing home placement.pdf; Caregiver Intervention Semi Annual Report 10-26-08.doc

From: Krista Headland [mailto:krista.headland@alzmdak.org]
Sent: Monday, March 16, 2009 12:53 PM
To: Holmberg, Ray E.; Bowman, Bill L.; Grindberg, Tony S.; Christmann, Randel D.; Fischer, Tom L.; Kilzer, Ralph L.; Krauter, Aaron J.; Krebsbach, Karen K.; Lindaas, Elroy N.; Mathern, Tim; Robinson, Larry J.; Seymour, Tom J.; Wardner, Rich P.; Warner, John M.
Cc: Gretchen Dobervich; NDLA, S APP
Subject: HB 1043

Good afternoon Chairman Holmberg and Members of the Senate Appropriations Committee—

Thank you for the opportunity to provide testimony last Thursday on HB 1043 for dementia services.

HB 1043 requires the Department of Human Services to initiate a Request for Proposals (RFP) for Dementia Care Services in the eight DHS regions of North Dakota. The Alzheimer's Association would have interest in responding to such an RFP, and provides the attached budget (first attachment) as a preliminary representation of costs associated with performing the services described in HB 1043.

The second attachment (ND Dementia Care Services Bill cost assumptions) outlines the cost savings projections for the state in Medicaid dollars if this bill were passed into law. Minimum cost savings for the state are estimated at \$2 – 4 million dollars as well as significant cost savings for families paying privately for long-term care facilities.

The third attachment (Mittelman Caregiver intervention) is a study done by New York University on the effects of providing caregiver intervention and support services very similar to those proposed in HB 1043. The study found that caregivers were able to delay nursing home placement for their loved one by an average of 18 months when participating in the program (p. 3).

The fourth attachment (Caregiver Intervention Semi Annual) is a report on the replication of the NYU study that is currently underway in Minnesota. This study finds that 60% of participants have been able to delay nursing home placement for their loved one as a result of the support services provided to them (p.3).

Please let me know if you have any questions. Thank you for your time!

Krista Headland

Western ND Regional Center Director | Alzheimer's Association Minnesota-North Dakota

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Dementia Care Coordinator Budget

Expenses

	Year 1 Per Region	Year 1 Total Cost	Year 2 Per Region	Year 2 Total Cost
Salary	\$35,000	\$280,000	\$36,200	\$289,600
Benefits	\$8,750	\$70,000	\$9,050	\$72,400
Supplies	\$5,400	\$43,200	\$3,100	\$24,800
Telecommunications	\$2,200	\$17,600	\$2,285	\$18,280
Postage/Shipping	\$300	\$2,400	\$310	\$2,480
Printing/Program Marketing	\$4,000	\$32,000	\$4,205	\$33,640
Staff Development	\$1,500	\$12,000	\$1,550	\$12,400
Miscellaneous Costs	\$500	\$4,000	\$520	\$4,160
In-State Travel	\$11,000	\$88,000	\$11,400	\$91,200
Staff Supervision		\$52,500		\$49,700
Total Expenses		\$601,700		\$598,660

HB 1043 cost assumptions

Biennium cost savings calculation as follows:

- \$60,000 is the rounded cost of one year in skilled nursing care in ND;
- MN replication of the Mittelman intervention resulted in a delay into nursing homes of 18 months (p. 3 of Mittelman Caregiver intervention attachment);
- \$90,000 is the rounded figure for 18 months of skilled nursing care;
- Our projected estimate is 160 families could be served in the biennium;
- MN replication of the Mittelman intervention concluded 60% of those served would experience delayed placement into the nursing home (p. 3 of Semi-Annual Report attachment);
- 60% of 160=96 individuals;
- 96 individuals X a savings of \$90,000=an overall savings of \$8,640,000;
- \$1,200,000 is the cost of providing the service;
- \$7,440,000 (\$8,640,000 minus \$1,200,000) would be the net savings;
- 55% is the percentage of ND nursing home residents utilizing ND Medicaid funding;
- 55% of \$8,160,000=\$4,092,000 savings to ND Medicaid funding;
- 45% of \$8,160,000=\$3,348,000 savings to private pay ND families.

The Alzheimer's Association projects estimated minimum cost savings of \$2,000,000-4,000,000 in Medicaid savings to the State of ND. The savings will vary by the total number of individuals served in the intervention. This estimate is based on projected service delivery to 160 families with a fully funded contract providing eight dementia care consultants, one for each Human Services Dept. region of the State.

This service delivery has achieved delayed entry into skilled nursing homes for 60% of families served. Using \$60,000 as the base figure of one year of skilled nursing home care, we suggest there will be substantial cost savings to ND in the form of Medicaid savings as well as significant savings to families who are private pay patients.

In addition, ND families will experience an increase in quality of life, as well as access to education and supportive services. HB 1043 is a win-win for the state budget and for the thousands of people in the state affected by dementia.