

STATE OF IOWA ALZHEIMER'S TASK FORCE
Official Minutes of the
September 24, 2007 Meeting
Iowa State Historical Building
Des Moines

September 24, 2007

Call to Order

John McCalley, Director of the Iowa Department of Elder Affairs, called the business meeting of the Alzheimer's Task Force to order at 12:40 P.M. on Monday, September 24, 2007.

Roll Call

Member	Present	Absent	Member	Present	Absent
Barbara Barker	X		Sandra Koll		X
Dr. Robert L. Bender II		X	Linda Larkin	X	
J Bennett Proxy: Steven Mandernach	X		Linda Lunderbaum	X	
Don Chensvold	X		John McCalley	X	
Tony Dietsch		X	Julie McMahan Proxy: Carol Peterson	X	
Representative Ro Foege		X	Senator Amanda Ragan	X	
Pat Gill	X		Dr. Mehrdad Razavi	X	
Becky Groff	X		JoAnn Simpson	X	
Renee Grummer-Miller, MSW, LISW	X		Representative Mark Smith		X
Senator Jack Hatch	X				

Others Present: DEA Staff: Greg Anliker, Terry Hornbuckle, Debi Meyers, Katie Mulford, Joel Wulf, Jeanne Yordi, Others: See attached sign-in sheet (Hard copy only).

Director McCalley welcomed participants and conveyed his vision on how he sees the following meetings of the Task Force proceeding with an overview of the agenda and presentations. Director McCalley had an opportunity to look at the past executive summary of final report (white copy). Some of the recommendations are carried forward but now there is a lot of new knowledge with time passing to incorporate.

Agenda

Brief Overview SF 489

Director McCalley reviewed the Alzheimer's Task Force directives set in Senate File 489, Section 1. 3. through 6.

Introductions of Task Force Members

Director McCalley had the members introduce themselves and how their experiences with Alzheimer's disease relate to the Task Force directives.

Logistical Considerations

Decision-Making Proposal: Director McCalley had an opportunity to speak with past task force chair, Betty Grandquist, regarding their decision-making and process-inclusion of recommendations. The previous task force decided for the final report recommendations were considered by consensus. Director McCalley asked if this task force would proceed in this matter. All present members were in agreement. Members also agreed that items in which the task force spends sufficient amount of energy discussing, but not appearing in the final report will be included in an appendix for benefit of the public.

Available/Additional Resource Material: Director McCalley stated as the task force moves through the materials presented that we will be looking to outside resources and counting on friends in the industry to help provide background information such as department staff and the Alzheimer's Association. There will be more materials and speakers than what the task force's time will allow and Director McCally asked for any additional materials or speakers at this time.

Becky Groff stated Iowa Department of Public Health direct care workers in one of the accountability measures perhaps the task force could ask contact the Department of Humans Services to receive a summary of what is already out there and not re-invent the wheel. Director McCalley replied we could make requests of the department heads. Carol Peterson interjected that the task force could look at www.idph.state.ia.us and look under the search column.

There is a report that might have some bearing on this discussion: Saunders report developing Adult Day Services. Director McCalley shared that the next meeting will be held on October 29th concurrently with the Elder Rights Conference at the Sheraton in West Des Moines. At this meeting the research of Professor Saunders will be released.

Dr. Razavi pointed out that his scope of work as well as Dr. Bender II's lie in early Alzheimer's detection. They do not work with patients in nursing facilities. Dr. Razavi pointed out that possibly adding a member to help fulfill the goals and directives of the task force such as a psychiatrist. Dr. Steenblock might be a possible candidate. Dr. Razavi added Arizona and Florida have advanced in their knowledge therefore the task force could learn from those states' experiences.

If any task force members have additional items they would like to see on the agenda feel free to contact Director McCalley at 515-725-3301.

Overview of Alzheimer's Disease

Ms. Sipfle stated this disease and the condition of our state leaves special challenges. People with Alzheimer's disease under 65 years of age have to retire too early for services by the Area Agencies on Aging, Medicare does not necessarily work for these folks, and retirement plans are not available to draw upon such as 401K's. Rural areas in Iowa are worse. There is denial this disease exists on many levels no matter what sort of background or education is available. Direct care workers are low in respect and pay-scale. They often change jobs, the training is not available or not often enough. Looking county by county in Iowa a lot of constituents do not fully understand Alzheimer's disease in Iowa. Mental health versus physical health is a big issue and often fragmented. Ms. Sipfle ended on did you know Shift Happens, "We live in exponential times."(Alzheimer's disease Facts and Figures 2007) She asks the task force to please think exponentially.

Following Carol Sipfle's presentation Ms. Groff asked where the persons under 65 would be classified as well as persons' with Downs, or head injury. These are people who are unique in their diseases and wonders would they be considered with folks who have Alzheimer's disease? Ms. Sipfle responded the lines are blurred with possibilities. Pat Gill asked if Medicare would be a possibility. Carol Peterson responded stating there some resources 6 or 7 waivers for processes.

Director McCalley responded with the key being early detection at an early age. Carol Sipfle's vision stems from the slide showing that the only cause of death shows Alzheimer's disease percentage increasing. When Doctors and the public know what the risk factors and their heredity are they do proactive remedies to stop the disease before it is prevalent. Doctors are monitoring and can prescribe treatments before diagnosis. What would happen if everyone knew the factors behind Alzheimer's disease? People would be able to be treated and find out what needs to be done in order to be stopped.

During the presentation, Ms. Sipfle had a slide stating 887 people had a cause of death of Alzheimer's disease. Senator Hatch questioned this statistic. If this is determined on the death certificate by the Iowa Department of Public Health and Doctor what was the clinical nature of the death? Dr. Razavi pointed out there are many possibilities such as aspiration or tongue swallowing people can die directly of Alzheimer's disease. Most often found is a multi-organ failure as a secondary to the Dementia or Alzheimer's disease. Unfortunately not one factor of the Alzheimer's disease can be placed on a higher priority it would be like sticking a finger in the dam.

Senator Hatch clarified the disease cannot be cured, can it be detected early how feasible is that? Dr. Razavi replied there are different technologies they can use in the research field. These easy 1 minute psychological testing screening tools can be used for detection by families and physicians. Senator Hatch asked if someone is diagnosed can there be medications available or is that an emerging treatment issue? Dr. Razavi stated medications help the symptoms, but do not cure the disease. Medications will help reduce brain shrinkage, and the earlier Alzheimer's disease is treated the better the disease will progress.

Senator Hatch pointed out the higher population over 85 years of age 1/3 over 65 years of age appears to be a growing. He stated it looks like can we help manage the disease by funding, long-term care, early screening and better care as we look at the future of our health care systems. Dr. Razavi pointed out in 10 people, 7 in the early stages of Alzheimer's disease are not usually diagnosed, and that statistic might be higher at 8 or 9 people with early onset.

Mr. Gill asked as far as the state budget goes is there an amount allocated for Alzheimer's disease research? Senator Hatch replied not as far as we know. What they would like to look at is how are the disease managed and the services going along with Alzheimer's disease as the government looks at a better quality of life for patient and family. Mr. Gill replied the task force's focus might have to be on the services and families. Looking back at the Y2K issue this was not an epidemic, but folks were prepared for it, but Alzheimer's disease is a different story. There is not a value on it, but following the deaths of the people with the disease the caregivers are worn out and the disease kills the caregiver as well. Mr. Gill asks that we look at how to assist the caregivers. Senator Ragan agreed with Mr. Gill and stated she has many stories in regards to the caregivers.

Dr. Razavi replied by stating the quality of lives improves with early detection and money is saved by keeping the people out of the nursing facilities. Director McCalley stated the task force should take a

look at overall all life to help improve all participants' lives. Perhaps during the next meeting session the task force could look at Dr. Bender's treatment program as parts of it specifically touch on memory care management. Director McCalley stated he will have copies next meeting.

Alzheimer's disease Demonstration Projects

Following Ann Bossen's presentation Director McCalley asked if the nurses received just classroom training. Ms. Bossen replied they had 2 hours at a time and had to develop a plan of action. Turnover is hard and is hard to pull the numbers for. Resources are very limited for early onset and early stages of dementia Alzheimer's disease unfortunately because they have the categorization they do not have any capacity anymore. More people with the disease than we realize need assistance.

Mr. Chensvold asked as to what the primary reason is that Adult Day Service facilities are failing in Iowa? Ms. Bossen stated the regulations changed as well as the classification. Iowa went from having 80 facilities to 30 facilities the sustainability is rated on whether or not they are in risk of closing.

Senator Ragan stated the cash flow is not there. Ms. Bossen replied Alzheimer's disease reimbursement rate is not as high as other types. Ms. Groff asked if the research such as the Saunders report regarding Adult Day Services is stagnated, in which, Mr. Wulf replied these are 2 different research projects.

Mr. Chensvold asked in future research, is it possibly to look at individual cases or are they looking at trying to get a program designed for various cultures such as rural vs. urban? Ms. Bossen replied by having people with the disease to start accessing services earlier therefore improving their quality of life. Preventative programs are a way to go due to early detection, and it would keep the people with Alzheimer's disease functioning longer. By looking at the community people can pull together a network of visitors, or support groups. Dr. Razavi stated instead of establishing new services to look at improving services such as Medicare. Ms. Bossen replied it will take everyone looking at all aspects. For example, case management is going through some new changes and they are waiting to see how that will integrate into the new system as well how they will manage through the new system.

Ms. Groff stated systemic lack of capacity as we further look at Alzheimer's disease. Mr. Chensvold added the very poor might have better access to services than what the middle class do who have the disease. Ms. Simpson added people usually take care of their own socialization. We want them to be independent, but possibly need some outside assistance to aid in detection of the disease. Ms. Bossen added rural areas do not have the trained specialist to do that kind of diagnosis.

Mr. Chensvold asked what a memory nurse's background and training consisted of. Ms. Bossen replied 2 days of training with Dr. Hall and herself. Nurses were also trained in geriatrics. Senator Ragan stated the industry might not be able to attain that goal with everyone who works. Dr. Razavi added some positive pushing, but not too much or the workers will not complete the training. He also added that educating the public might be more attainable goal.

Ms. Bossen added they looked at education for professionals at the community colleges in which they reviewed the CNA training materials, and those colleges accepted changes they offered. Mercy College is a certification program and not masters degree. As there is a lot of stigma from professionals, they did not want to use dementia as we still do not know the diagnosis.

Linda Larkin added after the workers spent so much time for training is there some kind of a certification class for these specially trained nurses other than CNA, LPn, Rn. Ms. Bossen added there are a lot of technology trainings at a lot of meal sites and senior centers that do not have the technology capability to have this training. Leadership and administration of successful programs will come from all of the facility staff working as a team it cannot only come from activities, Rn, or cook. The facility must adapt a whole unit approach.

Dr. Razavi stated early detection is the systemic approach in all communities to spread the word. Ms. Bossen stated Heritage AAA research went into the Hispanic community. They had respite worker who was Hispanic as well. They found through research not only did they take care of their own, but they enjoyed and were open to having outside folks come in and assist them in starting to use the services. They were not presenting the service in the way that was open to them.

Renee Grummer-Miller stated this is a difficult task to keep memory loss nurse specialist in community. They receive the training and then the issue is having the on-going funding to keep the nurse specialist around for the caregivers. Mr. Chensvold added MDS ignores dementia and assumes there is not any care for folks with Dementia. Ms. Peterson stated there is very little funding for mental diagnosis due to Medicare acute illness only care. They cannot serve them with the Alzheimer's disease diagnosis.

Public Comment

Geri Hall: Dementia can have a young onset. Many have children. The youngest person they encountered with dementia was 22. Ms. Hall states dementia is not an uncommon problem. The public cannot understand the safety concerns of a person who must maintain employment. Very often the person is fired and then disability kicks them out of services. Adult Day Services based on needs of older adults may not be based on the needs of the younger person and institutionalization is not very open to have younger folks in their facility due to other present neurological problems. Some persons with dementia may have behavior problems and most often facilities result in having the person discharged whether than work with the person and their disease. Ms. Hall has been involved with an on-line support group for the past 11 years and states it has not been hard to maintain. A lot of the people with dementia state "I do not want services all I want is empowerment."

Ms. Hall charges to consider having access to services and Medicare waiver abilities earlier than age 65. In addition to this, petition people who have sheltered workshops to develop programs for folks with early on-set Alzheimer's disease. Having programs focus on caregiver empowerment, and offering hands-on what we do sort of items for education.

Ann Riesenberg: Ms. Riesenber has been the Program Director for the Alzheimer's Association during the past four years. She states a big piece of the puzzle would be an education review of individuals and personnel such as caregivers, fire fighters, police force. Administrators in Adult Day Services, Assisted Living, Long-Term Care facilities should include a preparatory education along with CNA and Rn training. Employees should have best practices education. The Global Deterioration Scale is merely a tool for staging and does not address dementia. Chapter 58, 25, 4 a CCDI unit shall have training appropriate to the facility, and that training should be within 30 days 6 hours with 9 hours continued education. Is the public to leave the persons with dementia in the hands of persons who may not have the appropriate training? In Illinois their regulations state to have the training within 4 hours of the first 72 hours of hire and have continued education of 12 hours a year.

There is not State approved curriculum for the approved training in Iowa as long as they have 24 hour staffing constraints. Nowhere is there a regulation by the State. Clinical practice should be included in education of caregivers. Most people living already in the Assisted Living facilities have some form of dementia. Ms. Riesenberg charges to increase the need to have expanded education.

Connie Lucas: Program Specialist Alzheimer's Association working in an Assisted Living. Ms. Lucas's focus is early diagnosis, but does the person get the right early diagnosis? Ms. Lucas offered the following story. \$186.00 spent for the Doctor to state mom was just old versus having dementia. The family physician had the family put mom in a dementia locked unit until 2 years later a specialist found mom had a thyroid disorder.

Ms. Lucas resolves to give strengths and empowerment to folks with dementia. Communities and people with dementia need to have opportunities to get together with each other in social events. She charges not to overlook the person. There are two issues, one being driving and the other staffing. How can we give the person with dementia the services to remain independent? (Global Deterioration Scale compares the person with dementia to child development)

Six hours of training is what Iowa education asks of its future staff to work with people with Alzheimer's disease. Ms. Lucas states she can pass the written test, but then can turn around and say to Mr. Smith who states he's on to lunch that "No, it's breakfast time". With three or four staff persons in a CCDI unit for 12 people with dementia those standards only let her give average care as she runs around making sure everyone is safe. Staffing ratios are a hot topic at this time.

Projected Agenda for Meetings #2-#4

Presentation of Proposed Report Outline: There were not any initial comments regarding the plan elements at this time.

Other

Ms. Groff pointed out there is a report entitled Know Where to Go, which was made about people who are difficult to place in long term care settings due to there behavior. Geri Hall stated she can help locate the report.

Senator Ragan stated perhaps the task force or the department could perhaps find and electronic version of the Alzheimer's Caregiver's Handbook put together in Mason City Iowa and post it on the department's website. Senator Ragan interjected the manual is a very easy read. Director McCalley added it is well organized and a good knowledge of the system. Mr. Chensvold asked if the task force could receive the document by email.

Ms. Groff added under the Community Services Section in Ann Bossen's presentation where communities developed their own intervention plans perhaps the task force could receive a copy of the community response template or some of the community response programs such as the Easter Seals/Alliance on Caregiving Rural Caregiving.

Mr. Chensvold asked for future meetings the task force may want to keep in mind some Long-Term Care providers such as Good Samaritan looking at closing all dementia units in Iowa due to regulatory system right now.

Mr. Gill asked why there is not a database with demographics for Iowa. She is surprised there is not a database where the numbers for especially this task of specific Alzheimer's disease numbers are accessible. Director McCalley will speak with Director Concannon to see if there is data that is collected through the Department of Human Services local offices regarding memory loss/dementia with case management. Ms. Groff stated the Department of Human Services might have information as they are the keeper of people looking for the diagnosis with Long-Term Care people with disorders. Mr. Chensvold added IFMC might have info as well.

Director McCalley wanted to be sure that the task force meetings remain a public endeavor and wants it to be as inviting as possible.

Adjournment:

There being no further business to discuss at this time, Director McCalley adjourned the meeting at 3:45 P.M.

Chair

Date

Recording Secretary

Date