Alzheimer's State Plan Task Force
Work group – Impact on the State, Safety and Independence
Ruth Gay, M.S.; Liaison
Overview of Topics and Abbreviated Goals:

Family Guardianship Oversight
- Courts should be required and funded to monitor the family guardians of adults and enforce and review the annual reporting requirements.
- The State should consider a "Friends of the Court" volunteer program to safeguard the rights of the wards.
- Incorporate mandatory administrative or judicial reviews of all persons placed out of state or simply out of their home, involuntarily, at least every 6 months to review appropriateness of placement, reasonableness of care and efforts to return the person to his or her home or to the most homelike, least restrictive setting.

Crisis Care in Hospital and Emergency Rooms
- Mandatory training and education about Alzheimer's disease and dementia for emergency room personnel
- Improve communication from hospital to family
- To have someone with the patient at all times, either a family member or hospital volunteer
- Require dementia specific training for all medical levels of hospital personnel as part of the hospital's licensing requirement
- Investigate federal funding through Medicare Innovations or CMS as opportunities to develop a transitions planning and or to avoid the hospital setting altogether ie: mobile dementia team approach
- Hospitals will address Care Coordination/Care Management specifically focuses on aspects of dementia care for patients to ensure a more successful discharge process
- Establish transition care programs that include information on community resources for caregivers and persons with dementia
- Require social work involvement in discharge planning when dementia is present
- Examine federal waiver's currently available that fund innovative transition programs at the hospital level, that include Alzheimer's/dementia as a special need population

Education and Training for related Emergency Personnel:
- First responders, sheriff, police, and fire department personnel will have a specified number of hours of training to help them assess and learn how to handle/respond to people with dementia and Alzheimer's disease.
- Families in crisis will be referred to organizations like the Alzheimer's Association, Nevada Caregiver Support Center for services, support, and education.
- Nursing schools will require specific training about dementia and AD in their curriculum.
- Develop a crisis intervention team that includes a Social Worker specializing in dementia care to travel with police when a call related to dementia care goes out. (This model has made a big difference in how people with mental health issues are handled).
- Examine funding streams to help develop teams that can assess, manage, and train staff in urban areas and provide video conferencing to rural communities.

EXHIBIT F – Alzheimer's
Document consists of 12 pages.
Entire document provided.
Meeting Date 09-12-12

Financing and Cost of Care:

- Adult day programs and respite funding can be a tremendous asset to families who are trying to work, are frail themselves or need a break, and are willing to keep their loved one at home. These programs are economically, socially and medically cost effective models and make the services available and affordable to more people
- Enable adult day care programs to provide care for people with skilled needs, for example, people with diabetes who have an insulin shot
- Create a sliding fee scale for those above Medicaid eligibility levels to help sustain their income, rather than being forced to use Medicaid
- Increase number and amounts of respite grants available to families. Broaden the eligibility requirements for use of respite grants
- Create mandatory number of Medicaid beds within private memory care facilities

Research

- Investigate more research opportunities throughout Nevada

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Younger Onset Issues

- Remove age barriers that keep people with younger onset and other cognitive impairment from receiving services that seniors can receive (meals, legal services, and respite). Adopt language of the Older Americans Act at the federal levels
- Explore “continuum of life” programs that do not discriminate based on age, but serve people based on need.
- Develop a “navigator” who might be a social worker, or other professional of some sort to guide families through the complex web of available services
- Explore innovative programs that would specifically serve people with young onset dementia

Early Detection

- Create a an Alzheimer’s awareness campaign and public service announcements with specialized marketing around the need for and importance of early detection and identification, and when and why people should get diagnosed.
- Develop private/public partnerships to help educate the public about warning signs, and importance of seeking medical diagnosis for Alzheimer’s in adults of all ages.
- Engage nonprofits and other private organizations to provide education to businesses about early recognition and detection of Alzheimer’s disease and related dementias.
- Primary care physicians will engage in ongoing education about recent developments, research and treatments of Alzheimer’s disease and related dementias.
- Primary care physicians will refer families for specialized cognitive testing when appropriate
- Primary care physicians will refer families to Alzheimer’s and dementia resources

Employer/ Caregiver Education

- Train businesses about Alzheimer’s and related dementias and the challenges family caregivers face. This may include establishing benefits such as flexible work schedules and working from home
- Help business to create employee assistance programs that include education and training for caregivers

- Develop partnerships with other organizations that also have co-morbidity with Alzheimer's disease to help get the word out about services and the added element of needed care, when dementia is present as well.

Out of State Placement

- Investigate whether an increased rate, on top of the existing reimbursement rate, is still provided in regulations; provide incentives for memory care facilities to receive persons with Alzheimer's or related dementias
- The State of Nevada will invest in a pilot program to engage a medical specialist who can serve as a mobile medical coordinator to assess a client, determine needs, help advise and train staff or family, and possibly treat the client to reduce his/her agitation and aggression
- Investigate regulatory measures that may serve as a barrier to present facilities retaining more behaviorally challenged clients
- Investigate the possibility of having one unit in a skilled nursing facility in Nevada that specializes in dementia care for individuals with challenging behavioral issues. Use a higher reimbursement rate as an incentive. Develop the idea of a mobile individual or team that could evaluate and respond to persons residing in this unit. The idea is of a multidisciplinary team or individual that could come out and evaluate the person with dementia in place, provide assessment and give training to staff/family members before the person with dementia ends up in a catastrophic situation that forces the out of state placement. Investigate private and public grant streams to fund this type of project. Innovation grants through CMS (Centers for Medicare and Medicaid Services) may be available to help avoid hospitalization.

Summary: Goals and Objectives:

Family Guardianship Oversight:

The courts in Nevada, due to lack of personnel, are unable to follow up regularly on wards under family guardianship. Because family members are less restricted than court appointed guardians, they report infrequently about the condition of the ward. As a result, cases of neglect, mismanagement of funds, placement of wards in facilities that do not meet their needs, and abuse are more likely to occur with family guardians than with public or private guardians. The only legal oversight is the court. There are few requirements to qualify as a family guardian other than the absence of a felony on their record.

Goals:

- **Courts should be required and funded to monitor the family guardians of adults and enforce and review the annual reporting requirements.**
- **The State should consider a "Friends of the Court" volunteer program to safeguard the rights of the wards.**
- **Incorporate mandatory administrative or judicial reviews of all persons placed out of state or simply out of their home, involuntarily, at least every 6 months to review appropriateness of placement, reasonableness of care and efforts to return the person to his or her home or to the most homelike, least restrictive setting.**
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Objective:

- To protect and enhance the lives of adult wards under family guardianship

Crisis Care in Hospital and Emergency Rooms:

Hospital settings often drive a decline in overall cognitive functioning for persons with dementia. The unfamiliar setting, routines and requirements that staff operate under, and 24 hour schedule can result in people with dementia being more confused, delirious, or increasingly agitated. Staff may be doing their best to provide assessment for medical needs and provision appropriate care, but are not adequately trained in the complexities of dementia or AD. Training of all levels of hospital staff is needed to provide more appropriate care in this challenging setting.

Challenges for hospitals and emergency rooms include lack of reimbursement for certain services. In addition, there is a reluctance to treat the individual who has dementia because he or she may have a complex array of health challenges even unknown to the patient because of their dementia. Caregivers have been known to drop off their loved one at the emergency room because they are exasperated and don't know what else to do. This problem is intensified when the patient is living alone or is homeless.

Goals

- **Mandatory training and education about Alzheimer's disease and dementia for emergency room personnel**
- **Improve communication from hospital to family**
- **There is a definite need to have someone with the patient at all times, either a family member or hospital volunteer**
- **Require dementia specific training for all medical levels of hospital personnel as part of the hospital's licensing requirement**
- **Investigate the federal funding through Medicare Innovations or CMS as opportunities to develop a transitions planning and or to avoid the hospital setting altogether ie: mobile dementia team approach**
- **Hospitals will address Care Coordination/Care Management with a specific focus on aspects of dementia care for patients to ensure a more successful discharge process**
- **Establish transition care programs that include information on community resources for caregivers and persons with dementia**
- **Require social work involvement in discharge planning when dementia is present**
- **Examine federal waiver programs currently available that would fund innovative transition programs at the hospital level, that include Alzheimer's/dementia as a special need population**

Objective

- To readily assess, identify and implement procedures when they find someone has dementia or Alzheimer's. This should be similar to urgent treatment modalities that are implemented when someone has a heart attack, stroke or other urgent and critical care need.

Education and Training for related Emergency Personnel:

There are key professionals who often have no training in how to manage a person with dementia or Alzheimer's disease. For example, a person with dementia or AD may not recognize a loved one as their spouse or adult child and may strike out fearfully or aggressively to protect him/herself. In response, the caregiver calls first responders or 911 for help. Instead of providing needed medical intervention, perhaps pain or infection control, the first responders provide restraints or even call the police for help. The need for the first responders to intervene appropriately is imperative; education and training are the keys to helping these professionals feel they have tools and resources to aid in these difficult situations.

Goals

- **First responders, sheriff, police, and fire department personnel will have a specified number of hours of training to help them assess and learn how to handle/respond to people with dementia and Alzheimer's disease.**

- **Families in crisis will be referred to organizations like the Alzheimer's Association, Nevada Caregiver Support Center for services, support, and education**.

- **Nursing schools will require specific training about dementia and AD in their curriculum.**

- **Develop a crisis intervention team that includes a Social Worker specializing in dementia care to travel with police when a call related to dementia care goes out. (This model has made a big difference in how people with mental health issues are handled).**

- **Examine funding streams to help develop teams that can assess, manage, and train staff in urban areas and provide video conferencing to rural communities.**

Objectives

- To assure that all emergency personnel are trained to assess and respond appropriately to persons with dementia and Alzheimer's disease.
- To reduce repeated visits and the high cost of care for persons with dementia or AD in emergency rooms.
- To assure that family caregivers in crisis are referred to appropriate resources for the ongoing care of their loved ones with dementia or AD.

Financing and Cost of Care:

Families caring for loved ones with AD or dementia lack affordable and adequate options for care. Memory care facilities in Nevada cost upwards of $5,000 monthly depending on level of care. For those on Medicaid, a family in Reno wishing to move their loved one to a Medicaid facility specializing in memory care has only the choice of moving their loved one to Fallon or Carson City. There are skilled nursing facilities in Reno, but none that can provide the specialized care found in memory care facilities. In home care is another option, but costs on average $22.00 an hour, making it unaffordable for many families.

Respite grants, presently funded by diminishing tobacco settlement funds administered through the State of Nevada aid families, but are limited in amount. At the average cost of in home care, these grants provide 10-15 hours of respite care per quarter. Families greatly appreciate this help, but 5 hours of respite care a month is not adequate for the health of the caregiver. Therefore, caregivers are often faced with the difficult decision to have to quit their jobs, reduce hours, to help care for someone. In this way we impoverish the caregiver in that they NOT only lose their job, but also their health insurance forcing them onto Medicaid themselves and Welfare programs.

Goals

- **Adult day programs and respite funding can be a tremendous asset to families who are trying to work, are frail themselves or need a break, and are willing to keep their loved one at home. These programs are economically, socially and medically cost effective models and make the services available and affordable to more people.**

- **Enable adult day care programs to provide care for people with skilled needs, for example, people with diabetes who have an insulin shot.**

- **Create a sliding fee scale for those above Medicaid eligibility levels to help sustain their income, rather than being forced to use Medicaid.**

- **Increase number and amounts of respite grants available to families. Broaden the eligibility requirements for use of respite grants.**

- **Create mandatory number of Medicaid beds within private memory care facilities**

Objective

- To create quality affordable respite day care, in home, and memory care facilities to accommodate families caring for persons with AD and dementia

Research:

Research efforts are limited in the State of Nevada. We may need to wait for the research community to have some significant advances before we begin to weigh in on this type of legislation. To our knowledge there currently is no law that keeps people who are not under guardianship from participating in research. The need to protect individuals is key when they are losing the ability to provide informed consent or there is no durable power of attorney.

Goals

- Investigate more research opportunities throughout Nevada

Objectives

- To come to a consensus around current law as it applies to the Alzheimer's and dementia populations

- To educate about the need for and ability to perform Alzheimer's and AD research safely with appropriate precautions

Younger Onset Issues:

People who are under age 65 with Alzheimer's or other dementias have unique and amplified needs. Often caregivers and family have been compromised by the loss of the patient's job or the threat of the primary caregiver's need to balance caregiving with continuing income and health coverage. Sometimes there are children at home who need education and support to live with the many changing needs of a loved one who may soon no longer recognize them, understand their needs, or be able to help them grow up. Some families are faced with an older child having to give up schooling to help care for an ill and unsafe parent. These are only a small part of the challenges, but we do believe that a prepared State can help these families remain intact and keep their homes and their family together.

For example, Senior Law project cannot serve people who are under age 65 with younger onset dementia who could benefit from their services. In addition, social workers are unable or unwilling to be part of the legal process with the family. In addition there are currently no specialized programs for younger people, and people in their 40's and 50's don't fit well into assisted living facilities or adult day care programs that serve people in their 70's – 90's – even if the program is legally able to provide care for them.

Goals

- **Remove age barriers that keep people with younger onset and other cognitive impairment from receiving services that seniors can receive (meals, legal services, and respite). Adopt language of the Older Americans Act at the federal level.**

- **Explore "continuum of life" programs that do not discriminate based on age, but serve people based on need.**

- **Develop a "navigator" who might be a social worker, or other professional of some sort to guide families through the complex web of available services**

- **Explore innovative programs that would specifically serve people with young onset dementia**

Objectives

- To remove age barriers so that individuals with younger onset Alzheimer's or other dementia can at the very least benefit from the services that would be offered to them if their age was over 60.

- Educate the public younger onset and early detection

- To reduce the stress young onset families who face who face unique and amplified needs

Early Detection:

People do not recognize the signs of dementia, nor do people seek support or diagnostic work up early enough in this disease process.

Goals

- **Create a an Alzheimer's awareness campaign and public service announcements with specialized marketing around the need for and importance of early detection and identification, and when and why people should get diagnosed.**

- **Develop private/public partnerships to help educate the public about warning signs, and importance of seeking medical diagnosis for Alzheimer's in adults of all ages.**
- **Engage nonprofits and other private organizations to provide education to businesses about early recognition and detection of Alzheimer's disease and related dementias.**

- **Primary care physicians will engage in ongoing education about recent developments, research and treatments of Alzheimer's disease and related dementias.**

- **Primary care physicians will refer families for specialized cognitive testing when appropriate**

- **Primary care physicians will refer families to Alzheimer's and dementia resources.**

Objectives

- To educate public and businesses about the benefits of early detection

- To encourage doctors to refer patients with possible cognitive impairment to specialists

- To encourage doctors to engage ongoing education about Alzheimer's and related dementia

- To encourage doctors family caregivers to relevant community resources

Employer/ Caregiver Education:
Employers do not understand the implications when they have an employee who is caring for a loved one with dementia, and that the caregiver can't just "tell mom to take a chill pill and quit calling you" when dementia is involved.

Goals

- **Train businesses about Alzheimer's and related dementias and the challenges family caregivers face. This may include establishing benefits such as flexible work schedules and working from home**

- **Help business to create employee assistance programs that include education and training for caregivers**

- **Develop partnerships with other organizations that also have co-morbidity with Alzheimer's disease to help get the word out about services and the added element of needed care, when dementia is present as well.**

Objectives:

- To allow families to keep working while caring for a loved one

Out of State Placement:
To begin changing the culture of the practice of moving behaviorally challenged individuals with Alzheimer's disease and related dementias out of state, we see that it will be important to gather support from key leadership individuals in the system of care. There is good evidence that individuals who are placed far from home and away from family are at high risk of other morbidity and even mortality. While the recommendations we have made have potential, there are various additional measures that might also influence the longer term success of this endeavor. In preparation for this discussion, Sally Ramm, Esq. provided a summary report of the work of the Out of State Placement Task Force that was operating for approximately 4 years and led by Judge Frances Doherty. This active and focused task force was able to address several questions and identify the multiple facets of this situation.

Recommendations for Out of State Placement

Goals

- **Investigate whether an increased rate, on top of the existing reimbursement rate, is still provided in regulations; provide incentives for memory care facilities to receive persons with Alzheimer's or related dementias**

- **The State of Nevada will invest in a pilot program to engage a medical specialist who can serve as a mobile medical coordinator to assess a client, determine needs, help advise and train staff or family, and possibly treat the client to reduce his/her agitation and aggression**

- **Investigate regulatory measures that may serve as a barrier to present facilities retaining more behaviorally challenged clients**

- **Investigate the possibility of having one unit in a skilled nursing facility in Nevada that specializes in dementia care for individuals with challenging behavioral issues. Use a higher reimbursement rate as an incentive. Develop the idea of a mobile individual or team that could evaluate and respond to persons residing in this unit. The idea is of a multidisciplinary team or individual that could come out and evaluate the person with dementia in place, provide assessment and give training to staff/family members before the person with dementia ends up in a catastrophic situation that forces the out of state placement. Investigate private and public grant streams to fund this type of project. Innovation grants through CMS (Centers for Medicare and Medicaid Services) may be available to help avoid hospitalization.**

Objective

- To keep families intact and close to their loved ones with dementia within the State of Nevada

ALZHEIMER'S STATE PLAN TASK FORCE
Workgroup Report on Out of State Placement
Sally Ramm, Aging & Disability Services

The purpose of this report is to give workgroup members a history of how this subject has been discussed in the past. In March, 2006, Judge Frances Doherty formed a Northern Nevada Task Force on out-of-state placement. The task force began with 14 members and at the most had 25 members. Many people were at some of the meetings to discuss a specific issue, so the overall contribution of people from around the state cannot be accurately described in numbers.

Two incidents prompted the formation of this task force. The first, which happened in 2004, was an older man suffering from dementia who threatened his wife with a knife. The police were called. They could not find a suitable place to take him, so he ended up in jail, charged with a crime. He was in jail for at least two months, when the judge said that he could not be kept in jail for one more day. He was released back to his home, where the knife incident was an anomaly, and his wife felt that she could care for him. A task force on mental health for the elderly was formed, and their work informed some of the work done by this subsequent task force. The second was an older man who lived in the same house for 35 years, was nearly blind, was suffering from dementia, and had serious health problems. He was taken to the hospital, against his will, where he used is cane to keep people away from him. He was released to rehab, and was actually in four different facilities in two months before being sent to Utah. He died two weeks later.

I am attaching two papers that will give subcommittee members a good idea of the work that was done in the nearly two years and one legislative session during which this task force worked. Following is some chronological background information, taken from my files:

2003 Legislative Committee on Health Care report to legislature:

- No nursing facilities in Nevada accept residents with severe behavior problems.

- 72 residents in out of state nursing facilities, all with "severe behavioral problems."
- Approximately one or two new out of state placements per month.
- Nevada facilities refused a higher reimbursement rate to care for people with behavioral issues.
- It costs an average of $97 per day to place 60 of the 72 persons out of state, and an average of $121 per day to keep them in Nevada. The other 12 out of state placements require a high level of care and average cost is $250 per day.

Methods to address this problem:

- Convince an out of state facility to open a facility in Nevada.
- Develop a team to identify behavioral interventions necessary to address the needs of an individual and enhance patient safety. The team would be readily available to assist nursing facilities when a resident exhibits behavioral problems.
- Use state-owned mental health facilities for serving individuals with severe behavior problems.

2006: Everyone is talking about out of state placement in conjunction with mental health. Alzheimer's disease and other forms of dementia are not considered a mental health issue, but the conversation continued to be centered on mental health as though "behavioral issue" is synonymous with "mental health issue" and includes persons with any form of dementia causing behavior problems as a mental health issue.

2006, 2007, 2008: Task force meeting topics:

- Meeting with Mike Willden, Director Health & Human Services, and Mary Liveratti, Deputy Director, Programming.
  - ➢ What is state doing to entice a behavioral unit provider?
  - ➢ Possibly 20 beds in Dini-Townsend facility available to be used for population with behavior issues. (Mike Willden)
  - ➢ Industry does not want to use existing funds (federal and facility taxes) to pay for increased behavioral rate.
- Meeting with Dr. Carlos Brandenburg, Administrator, Mental Health and Developmental Services and then with Senator Randolph Townsend.
  - ➢ Statutory change to allow greater access to mental health services for mentally ill seniors who also suffer from dementia. Suggested including dementia in definition of mental illness to allow for emergency treatment. Dr. Brandenburg said he would have to put a $5 million fiscal note on this to build necessary capacity.
  - ➢ One-shot funding ($800,000) for a behavioral health provider public/private venture to open a new facility in Nevada.
  - ➢ Increasing the $121 regular daily rate to long-term care facilities by $261 per day for residents with behavioral issues.
  - ➢ Increasing waiver services under the group home waiver.
  - ➢ Create a Program for Assertive Community Treatment (PACT using mental health professionals to assist in providing assessment and case management in jails, emergency rooms, and long-term care facilities. This would be an incentive for long-term care facilities to accept these residents, as it would give them assistance and training in dealing with aggressive behaviors.

- Attached is a proposal to establish a multi-disciplinary Community Team as a short-term stopgap measure. Proposal from Washoe County Public Guardian's office.

2009: Legislative Health Committee work session document for the 2009 Legislature.

Among other issues, this Committee drafted a letter to Division for Aging Services requesting they work with the Bureau of Licensing and Certification and Medicaid to support and encourage on-going training for existing care staff to transition and stabilize residents diagnosed with dementia, and to create industry incentives and remediation of potential misperception of licensing challenges encountered by facilities housing individuals diagnosed with dementia, as requested by Judge Frances Doherty.

The Committee also decided to amend the definition of mental illness pursuant to NRS 433A. to include Alzheimer's disease. They did not act on this, as it would be too expensive.

This is a brief overview of the work of many people over more than two years to try to find solutions to the problem of sending Nevada residents out of state for care and treatment. Unfortunately, the only thing that happened was to provide skilled nursing facilities with $261 per day plus the regular daily fee for accepting residents with behavioral issues. They do not take advantage of this.