



NEVADA LEGISLATURE
LEGISLATIVE COMMITTEE ON HEALTH CARE'S
TASK FORCE TO DEVELOP A STATE PLAN
TO ADDRESS ALZHEIMER'S DISEASE
(Assembly Concurrent Resolution No. 10 [File No. 42, *Statutes of Nevada 2011*])

SUMMARY MINUTES AND ACTION REPORT

The fourth meeting of the Nevada Legislature's Legislative Committee on Health Care's Task Force to Develop a State Plan to Address Alzheimer's Disease was held on September 12, 2012, at 9 a.m. in Room 4401 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. The meeting was videoconferenced to Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, Nevada. A copy of this set of "Summary Minutes and Action Report," including the "Meeting Notice and Agenda" ([Exhibit A](#)) and other substantive exhibits, is available on the Nevada Legislature's website at <http://www.leg.state.nv.us/interim/76th2011/committee/>. In addition, copies of the audio record may be purchased through the Legislative Counsel Bureau's Publications Office (e-mail: publications@lcb.state.nv.us; telephone: 775/684-6835).

TASK FORCE MEMBERS PRESENT IN CARSON CITY:

Virginia "Gini" Cunningham
Ruth Gay
Wendy Simons

TASK FORCE MEMBERS PRESENT IN LAS VEGAS:

Senator Valerie Wiener, Chair
Charles Bernick, M.D.
Albert Chavez
Sandra Owens, Ph.D.

LEGISLATIVE COUNSEL BUREAU STAFF PRESENT:

Roger McClellan, Health Care Policy Specialist, Research Division
Marshailah D. Lyons, Supervising Principal Research Analyst, Research Division
Lisa Gardner, Senior Research Secretary, Research Division

OTHER STAFF PRESENT:

Casey Catlin, Doctoral Student, University of Nevada, Reno, State Plan Drafter

OPENING REMARKS AND TASK FORCE SCHEDULE

- Senator Valerie Wiener, Chair, welcomed members, presenters, and the public to the fourth meeting of the Nevada Legislature's Legislative Committee on Health Care's Task Force to Develop a State Plan to Address Alzheimer's Disease (Task Force).

PUBLIC COMMENT

- Chair Wiener called for public comment; however, no testimony was presented.

DISCUSSION ABOUT DEVELOPING A RESEARCH AND RESOURCES CLEARINGHOUSE FOR ALZHEIMER'S AND DEMENTIA-RELATED CONDITIONS

- Roger McClellan, Health Care Policy Specialist, Research Division, Legislative Counsel Bureau, reported that the Task Force has requested and received information regarding the Nevada 2-1-1 system and how it might be used to inform people of available options for care, current resources, and space in different facility types. (Please see [Exhibit B.](#)) He further stated that information was also requested and received from the Health Division, Department of Health and Human Services, regarding the Public Health Preparedness Program's bed tracking system (HavBED) on possible ways of using the HavBED system to monitor placement for persons with Alzheimer's disease and related disorders. (Please see [Exhibit C.](#)) Mr. McClellan said that both systems have the capacity to address the targeted population, identify potential health needs, and work together to provide essential information on the services and available bed space. He noted there are some considerations; for instance, in the HavBED tracking system, the information is manually input at each facility, and it is a voluntary system, which may impact staff resources.

In response to Chair Wiener's inquiry regarding whether funding would be required if the HavBED system were used to track bed availability, Mr. McClellan stated that the Health Division would incur costs to upgrade its program, and there would also be a fiscal impact on the facilities to set up the system, train staff, and provide refresher training.

- Dr. Bernick commented that, based on his experience, the Nevada 2-1-1 system is not widely known.
- Mary Liveratti, Administrator, Aging and Disability Services Division, Department of Health and Human Services, stated that she is the Chair of Nevada 2-1-1 and outreach has been a problem because there is no marketing budget for the program. She noted that the three recent major disasters in northern Nevada provided visibility for Nevada 2-1-1 as the emergency call center. Ms. Liveratti said that Nevada 2-1-1 is a

portal for people to obtain information about a variety of services. She noted that Nevada 2-1-1 receives between 70,000 and 80,000 telephone calls annually.

- Ms. Liveratti gave a Microsoft PowerPoint presentation regarding the Aging and Disability Resource Center (ADRC). (Please see [Exhibit D](#).) Her presentation included information on: (1) the mission of the ADRC; (2) the goal of the ADRC Program; (3) ADRC partnerships; (4) key concepts of the ADRC; (5) target audience of the ADRC; (6) required levels of service; (7) ADRC staffing; (8) the ADRC website; and (9) the five current walk-in ADRC sites.

In response to Chair Wiener's inquiry regarding the number of links to other resources in the ADRC's website, Ms. Liveratti stated there are approximately 7,500 items in its online library, which includes website links and links to articles.

Responding further to Chair Wiener regarding outreach for the ADRC, Ms. Liveratti said that the ADRC is an initiative under the Older Americans Act, which is a major source of federal funding for the Division's senior programs, and the ADRC is listed on the Division's website. She stated that the program is constantly promoted among the senior and disability network of service providers and at health fairs, town hall meetings, and other events to which they are invited, such as television and radio shows.

Chair Wiener asked if there is monitoring of the people who access the Nevada 2-1-1 resources. Ms. Liveratti responded that the Division is required to report to the federal government and does have those statistics. She said she will provide them for the Task Force.

Discussion ensued between Chair Wiener and Ms. Liveratti regarding the need to educate young people about the importance of long-term care insurance.

In response to a question from Dr. Bernick regarding how someone could get their name on the Nevada 2-1-1 list, Ms. Liveratti said there is a vetting process for organizations that apply to be included on the list. She noted that once an organization is included, the main concern of the Division is to make sure the information provided remains accurate and up to date. Ms. Liveratti pointed out that a difference between Nevada 2-1-1 and the ADRC is that the ADRC includes for-profit entities that offer services to seniors and people with disabilities.

Dr. Bernick questioned if the current social worker system could handle the increasing demand for services for individuals with Alzheimer's disease and related disorders. Ms. Liveratti confirmed that is a concern. She informed the Task Force that a \$199,000 grant was recently received through the Division's federal partner at the Administration on Aging, United States Department of Health and Human Services.

- Dr. Bernick commented that placing informational brochures in physician's offices would be helpful in getting information out about the available services.

In response to Ms. Cunningham's inquiry about how an ADRC walk-in site could be added in rural Nevada, Ms. Liveratti said any group could apply as long as it meets the requirements. She described the process to apply for funds to set up an ADRC, which begins with a request for proposal put out by the Division when money is available.

Discussion ensued between Ms. Gay and Ms. Liveratti regarding the resources that are included on the ADRC's website.

- Ms. Simons suggested that information regarding the ADRC be included in newsletters the medical boards send to their members.
- Ms. Liveratti informed the Task Force that a stakeholder survey was recently completed to get input on how to improve the Nevada 2-1-1 system and the comments they received will be used in an attempt to improve the website.

REPORTS ON WORKING GROUPS

Access to Services

- Ms. Cunningham reported that the Access to Services Work Group arrived at 13 objectives. She identified the goals, strategies, indicators, and funding for each objective. (Please see [Exhibit E](#).) Ms. Cunningham stated that one of the Work Group's first concerns is the caregiver bill of rights as well as the Alzheimer's victims' bill of rights to understand what can and cannot be done. She noted that a large focus is on the needs of caregivers. The second major concern is younger-onset versus older-onset Alzheimer's disease, and the need for legislation that would change the determination of benefits to the diagnosis rather than being tied to the age of 65.

Impact on the State and Safety and Independence

- Ms. Gay discussed the report submitted by the Impact on the State and Safety and Independence Work Group ([Exhibit F](#)), which included goals for the following topics: (1) family guardianship oversight; (2) crisis care in hospital and emergency rooms; (3) education and training for related emergency personnel; (4) financing and cost of care; (5) research; (6) younger-onset issues; (7) early detection; (8) employer/caregiver education; and (9) out-of-state placement.

Quality of Care and Regulation

- Ms. Simons reported that the Quality of Care and Regulation Work Group established two primary goals: (1) to develop, enhance, and improve the variety and supply of informal and formal supports for persons with Alzheimer's disease and related dementias and their caregivers and (2) to develop partnerships and initiatives to provide

for systems to enrich quality of life for persons with Alzheimer's disease and related dementias. Ms. Simons reviewed the objectives for each goal. (Please see [Exhibit G.](#))

- Chair Wiener thanked the Task Force members, who served as the liaisons between the working groups and the Task Force, for their passion and the commitment of leadership they have devoted to this step of the process in developing a State Plan.

UPDATE ON THE DEVELOPMENT OF THE STATE PLAN TO ADDRESS ALZHEIMER'S DISEASE

- Casey Catlin, Doctoral Student, University of Nevada, Reno, State Plan Drafter, provided an overview of the current draft of the State Plan to Address Alzheimer's Disease ([Exhibit H](#)).

Chapter 1 of the State Plan Draft, "Introduction," was discussed. Chair Wiener suggested that information about younger-onset Alzheimer's and the prevalence of the disease be included in the Plan's Introduction.

- Ms. Gay reported that the *World Alzheimer Report 2012* will be released on September 21, 2012, and suggested the report could be used as a resource during the development of the State Plan.

Task Force members and Ms. Catlin discussed the value of identifying and addressing Alzheimer's disease properly, the stigma and fear associated with the diagnosis of the disease, public awareness, and the economic impact of the disease.

- Continuing, Ms. Catlin next discussed Chapter 2: "Access to Services."

Discussion ensued regarding the sequence in which the information regarding services is presented, the statistics regarding out-of-state placement, the definition of each level of care, and the inclusion of adult day care services and community respite programs.

- Marsheilah D. Lyons, Supervising Principal Research Analyst, advised the Task Force that in the draft plan they will see areas that need expansion. She noted that was not an oversight but staff was waiting for guidance from the Task Force regarding the areas on which the Task Force wanted to focus.
- Ms. Gay commented that the term "behavioral services" might be interpreted to mean psychiatric services, as opposed to nonmedical services, and suggested the term be changed to "support services."

Discussion ensued regarding the terms used by professionals, which may be confusing to members of the public who read the State Plan. Ms. Lyons suggested that in order to meet the expectations of the policy makers who will need to know the citations used in the

Nevada Revised Statutes (NRS) and for the public's understanding, the common names for the facilities and services be used in addition to the terms used in the NRS.

- Chair Wiener agreed that this is an opportunity to create a plan that can be easily understood and used as a meaningful educational tool by both the public and the policy makers.
- Ms. Catlin continued reviewing Chapter 2, including the subsections titled "Rural Services," "Early-Stage," and "Younger/Early-Onset."
- Dr. Bernick commented that, in the future, there will be changes in the field of Alzheimer's disease because techniques will be developed that will enable earlier diagnosis of the disease, and this will raise other concerns and needs.

The structure of the State Plan was discussed, and Ms. Catlin explained that the document will begin with an Executive Summary that summarizes each of the recommendations of the Task Force. She stated that the chapters following the Executive Summary will include additional information and more detailed recommendations.

- Ms. Catlin next reviewed Chapter 3: "Quality of Care," including the subsections titled "Measuring Quality of Care," "Education and Training," "Cultural Competency," and "Communication Gaps Between Physicians and Patients."
- Chair Wiener commented that if there is data and sourcing for the survey referenced under "Communication Gaps Between Physicians and Patients," it would be important that it be included. She also suggested that information provided by Touro University Nevada at the July 11, 2012, meeting of the Task Force be included under "Education and Training."
- Dr. Bernick noted that the Cleveland Clinic Lou Ruvo Center for Brain Health is also providing training.

Discussion ensued regarding the title "Communication Gaps Between Physicians and Patients." It was noted by the Task Force members that there is a lack of communication success at all levels of care.

Responding to Ms. Cunningham's comment regarding the available programs and resources and how to ensure that all the schools that have programs and services available are included, Ms. Lyons suggested that the State Plan Draft be revised to reference the Nevada System of Higher Education and include examples, to ensure that a program or resource is not inadvertently missed. She noted that the State Plan will include a resource list that more specifically references the programs.

- Ms. Catlin continued her review of the State Plan Draft with Chapter 4: “Quality of Life.”

Discussion ensued regarding the inclusion of information about the challenges of treating people with dementia, who have other conditions, and how difficult it is to diagnose those conditions.

- Ms. Catlin next presented Chapter 5: “Public Safety and Public Awareness.”
- Ms. Lyons suggested that, instead of listing various programs in this chapter, it include some of the specific safety issues that people with Alzheimer’s or dementia face.

Task Force members discussed the challenges for people with Alzheimer’s disease with regard to driving and wandering, as well as the need to educate the public and professionals about the challenges of these safety issues.

- In response to Chair Wiener’s inquiry if the Policy Recommendations in Chapter 6 should be addressed at this time, Ms. Lyons noted that the recommendations in that chapter are described as “Identified Gaps in Services.” She suggested that the Task Force first address the policy recommendations in Agenda Item VI, and if any of the identified gaps in services are not included in the recommendations, they could be addressed at that time.
- Ms. Gay commented that retirees aged 55 to 64 have been identified as falling into a gap of insurance coverage in No. 11 of the “Identified Gaps in Services.” She noted that this is true; however, people under the age of 65 who develop Alzheimer’s disease can receive Medicare within two years if they are considered disabled.

The Task Force suggested that the State Plan include quotes from caregivers in the community, who have testified regarding their experiences with Alzheimer’s disease.

DISCUSSION REGARDING POSSIBLE POLICY RECOMMENDATIONS FOR INCLUSION IN THE STATE PLAN

- Chair Wiener stated that some of the policy recommendations in the “Legislative Committee on Health Care’s Task Force to Develop a State Plan to Address Alzheimer’s Disease Recommendations” ([Exhibit I](#)) will require legislation to change the statutes. She noted that Assemblywoman April Mastroluca, who chairs the Legislative Committee on Health Care, has committed to reserving one bill draft request in the next legislative session for the Task Force.

- Chair Wiener advised that the Task Force has the following options to consider:
 1. Use the bill draft offered by Assemblywoman Mastroluca to create an ongoing body to refine and follow up on the State Plan and the implementation of the recommendations. This approach would create a body that would continue with the work of the Task Force.
 2. Use the bill draft request to advance a policy recommendation the Task Force feels is important, immediate, and necessary.
 3. The Task Force has the ability and the creative opportunity to reach out to individual legislators to carry or sponsor a bill.

Discussion ensued regarding the recommendations to be included in the State Plan, the number of recommendations that should be included, whether some of the recommendations could be combined, prioritization, and the number of categories.

Access to Services

- Roger McClellan, previously identified, read Recommendation Nos. 1 through 26 under “Access to Services,” with the subcategories of “Out-of-State Placements and Facilities” and “Medicaid, Health Insurance, and Financing Care.” (Please see [Exhibit I.](#))
- Chair Wiener noted that Recommendation No. 2, which pertains to a statewide information and referral system, may have a fiscal impact and require legislation.
- Marsheilah D. Lyons, previously identified, said the Task Force, as a policy recommendation, may request the removal of age barriers so the younger people can have access to State services and, as a policy statement, say they would also prefer that the barriers are removed from the federal programs.
- Chair Wiener reminded the Task Force that, although some of the recommendations may require legislation, the Task Force is not excluded from addressing them as policy recommendations of the Task Force. She noted it is up to the Task Force to determine whether or not the recommendations should be included in the State Plan. Chair Wiener pointed out which of the first 26 recommendations would be mandates, involving regulation, and those that would require increased funding.

Discussion ensued regarding the 26 recommendations under “Access to Services,” including how to categorize and group the recommendations.

- Chair Wiener commented on the extensive work that remains to be done to prepare a State Plan for approval by the Task Force, and noted it would be difficult to have it completed by the next scheduled meeting of the Task Force on October 10, 2012.

She suggested that the date of the next Task Force meeting be rescheduled to October 24, 2012. The Task Force members concurred with this change.

The Task Force continued discussing Recommendation Nos. 1 through 26 under the category “Access to Services.”

- Chair Wiener noted that the first 26 recommendations have been read by Mr. McClellan and discussed, and asked that the Task Force members indicate by raising their hands if they support the recommendation as she calls the number. There was majority support by the Task Force members for Recommendation Nos. 1, 2, 3, 6, 7(a) through 7(e), 14, 15, 16, 17, and 21.

Quality of Care

- Chair Wiener next read Recommendation Nos. 27 through 32 under the category “Quality of Care.” A majority of the Task Force members indicated their support for Recommendations No. 27 and No. 31.
- Chair Wiener read Recommendation Nos. 33 through 44 under the subcategory “Education, Training, and Professional Development.”
- Dr. Bernick stated that the word “require” in Recommendation Nos. 33 through 38 is not realistic; however, he endorses the spirit of the recommendations.
- Ms. Simons stated she agrees with Dr. Bernick that the recommendations have value and suggested that they be combined and reworded.

Following discussion, Chair Wiener summarized that it is the decision of the Task Force to combine Recommendation Nos. 33 through 38 and to revise the wording. Ms. Lyons stated it is her understanding that the Task Force wants to encourage the various boards and entities that license the professionals to develop a program to educate their professionals in the areas mentioned in the recommendations and to develop collaboratives.

Chair Wiener asked the Task Force if they supported combining Recommendation Nos. 33 through 38, as indicated, and a majority of the Task Force members supported this suggestion. A majority of the Task Force members also supported Recommendations No. 40 and No. 43.

Quality of Life

Chair Wiener next read Recommendation Nos. 45 through 48 under the category “Quality of Life.” A majority of the Task Force members supported Recommendations No. 47 and No. 48.

Public Safety and Awareness

Chair Wiener read Recommendation Nos. 49 through 55 under “Safety, Independence, and Awareness.” A majority of the Task Force members indicated their support for Recommendation Nos. 49, 50, 53, and 54.

- Chair Wiener read Recommendation Nos. 56 through 65 under the subcategory “Public Awareness and Education.” The following recommendations were supported by a majority of the Task Force members: 56, 58, 59, 60, and 61.

Other Related Topics

- Chair Wiener next addressed “Other Related Topics” and its subcategory “Guardianship.” She read Recommendation Nos. 66 through 71. None of the recommendations were supported by a majority of the Task Force members.
- Chair Wiener stated the majority of the Task Force supported Recommendation Nos. 1, 2, 3, 6, 7(a) through 7(e), 14, 15, 16, 17, 21, 27, 31, 33 through 38 (with amended language, removing the word “require” and substituting “encourage” and “collaboration”), 40, 43, 47, 48, 49, 50, 53, 54, 56, 58, 59, 60, and 61.
- Chair Wiener suggested if members of the Task Force have a strong interest in any of the recommendations that were not selected to be included in the State Plan that they work with Legislators who may be looking for legislation to sponsor in the next session. She stated that, if the Task Force members agree, she will work closely with Ms. Catlin in the preparation process for the State Plan. Chair Wiener noted that the document will be provided to the members for their review before the next meeting of the Task Force.

PUBLIC COMMENT

- Marsheilah D. Lyons, previously identified, called the Task Force’s attention to the following documents included in their binders under “Public Comment.” She noted that the documents were submitted by Mary Liveratti, Administrator, Aging and Disability Services Division, DHHS, in response to requests for information made at previous meetings of the Task Force:
 1. A document titled “Alzheimer’s-Specific Benefits to Businesses, September 5, 2012.” ([Exhibit J](#));
 2. A document containing information on Medicaid waivers ([Exhibit K](#)); and
 3. A document titled “Alzheimer’s State Plan Task Force, Subcommittee Report on Out of State Placement, Sally Ramm, Aging & Disability Services” ([Exhibit L](#)).

- Subsequent to the meeting, Lane Simonian, private citizen, Carson City, provided an electronic mail message and information regarding clinical trials using essential oils to treat Alzheimer's disease ([Exhibit M](#)).
- Chair Wiener thanked the Task Force members, work groups, and staff for their extraordinary efforts in preparing the recommendations. She noted that she voted on the recommendations only when it was necessary to break a tie vote.
- Ms. Simons commended all of her partners who have participated in the process and Chair Wiener for her leadership.
- Chair Wiener noted that in her years of service at the Legislature she has chaired seven committees and this Task Force and is gratified at the extraordinary level of engagement that each of the members has exhibited with their participation, energy, and intelligence. She also recognized Ms. Catlin and staff for their contributions. Chair Wiener reminded the Task Force members that the date of their next meeting is October 24, 2012. She encouraged them to read the next draft document they receive before the meeting and to bring any concerns, questions, or other considerations to the meeting.

ADJOURNMENT

There being no further business to come before the Task Force, the meeting was adjourned at 1:20 p.m.

Respectfully submitted,

Anne Vorderbruggen
Senior Research Secretary

Roger McClellan
Health Care Policy Specialist

APPROVED BY:

Senator Valerie Wiener, Chair

Date: _____

LIST OF EXHIBITS

[Exhibit A](#) is the “Meeting Notice and Agenda,” provided by Roger McClellan, Health Care Policy Specialist, Legislative Counsel Bureau (LCB).

[Exhibit B](#) is a document titled “Program Description of Nevada 2-1-1,” submitted by Kathy Jacobs, Crisis Call Center, Reno.

[Exhibit C](#) is a letter dated September 6, 2012, to The Honorable Valerie Wiener, Chairwoman, Task Force to Develop a State Plan, from Marla McDade Williams, Deputy Administrator, Health Division, Department of Health and Human Services (DHHS), containing an enclosure titled “Nevada State Health Division, Public Health Preparedness Program, Bed Tracking System (HaVBED).”

[Exhibit D](#) is a Microsoft PowerPoint presentation titled “Aging and Disability Resource Centers,” submitted by Mary Liveratti, Administrator, Aging and Disability Services Division, DHHS.

[Exhibit E](#) is a document titled “Nevada Alzheimer’s Plan Task Force, Access to Services – Item #2, Overview,” provided by Virginia (Gini) L. Cunningham, M.Ed., Volunteer and Support Group Facilitator, Humboldt Volunteer Hospice and Alzheimer’s Association in Northern Nevada.

[Exhibit F](#) is a document titled “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,” submitted by Ruth Gay, Director, Public Policy and Advocacy, East Bay Office Site Director, Northern California and Northern Nevada Chapter, Alzheimer’s Association.

[Exhibit G](#) is a document titled “Quality of Care and Regulations Workgroup, Summary and Goals, September 5, 2012,” provided by Wendy Simons, Chief, Bureau of Health Care Quality and Compliance, Health Division, DHHS.

[Exhibit H](#) is a document titled “State Plan Draft, *Draft for Discussion*, September 12, 2012,” presented by Casey Catlin, Doctoral Student, University of Nevada, Reno, State Plan Drafter.

[Exhibit I](#) is a document titled “Legislative Committee on Health Care’s Task Force to Develop a State Plan to Address Alzheimer’s Disease Recommendations, September 12, 2012,” provided by Roger McClellan, Health Care Policy Specialist, LCB.

[Exhibit J](#) is a document titled “Alzheimer’s-Specific Benefits to Businesses, September 5, 2012,” provided by Mary Liveratti, Administrator, Aging and Disability Services Division, DHHS.

[Exhibit K](#) is a document containing information on Medicaid waivers submitted by Mary Liveratti, Administrator, Aging and Disability Services Division, DHHS.

Exhibit L is a document titled “Alzheimer’s State Plan Task Force, Subcommittee Report on Out of State Placement, Sally Ramm, Aging & Disability Services,” submitted by Mary Liveratti, Administrator, Aging and Disability Services Division, DHHS.

Exhibit M is an electronic message and attachments submitted by Lane Simonian, Carson City.

This set of “Summary Minutes and Action Report” is supplied as an informational service. Exhibits in electronic format may not be complete. Copies of the complete exhibits, other materials distributed at the meeting, and the audio record are on file in the Research Library of the Legislative Counsel Bureau, Carson City, Nevada. You may contact the Library online at www.leg.state.nv.us/lcb/research/library/feedbackmail.cfm or telephone: 775/684-6827.