**BRIEF OVERVIEW**

**OF THE**

**LONG TERM CARE SYSTEM IN ALASKA:**

**WE NEED A PLAN**

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1. **Community Care Coalition**

The Community Care Coalition is comprised of trade associations who provide care for elderly, disabled and at-risk Alaskans. The Alaska Association on Developmental Disabilities, Alaska Behavioral Health Association, AgeNet, Assisted Living Association of Alaska and the Personal Care Assistant Provider’s Association have banded together in a united voice to bring forward our collective message on behalf of our most vulnerable citizenry. As members of the home and community-based long term care industry, we collectively represent all of Alaska with over 50,000 consumers, family members and staff.

The Community Care Coalition seeks to influence the Legislature, the Administration and Commissioners on issues common to each of our members. We will accomplish this by:

1. communicating legislative and expenditure priorities
2. fostering communication channels with administrative and legislative offices at both Juneau and other local office locations
3. providing experienced input when these offices seek information regarding our industries
4. **Purpose of the presentation**

The highest single cost in providing health and human services for the senior population is labor. As Alaska grays, we will need to be prepared on many fronts: Business, Jobs, Infrastructure, and Education. Further, we will need to be at the forefront of technological discoveries that will reduce the direct labor expenses with innovations such as telemedicine and tele-care to name a few. There will need to be a coordinated effort with the health and human service community to determine the most cost effective and efficient system for delivering long term care which will lead to the creation of new industry, jobs for our Alaskan youth and the need for education reform. There also needs to be a coordinated effort with the insurance industry, both public and large-pool private insurance groups, to make private and public paid long term care insurance realistically affordable and attractive to citizens in all sectors. Finally, Alaskans considering their retirement choice of residence need to know what Alaska has to offer them, so that fears of the unaffordability of living in Alaska, or of long term care service unavailability in Alaska do not “scare” people into choosing to move away for all or part of their retirement years.

Alaska needs a long term care plan that will ensure Alaskan communities will be prepared and can take action. There needs to be a new vision of services to older Alaskans and individuals with disabilities as a renewable, sustainable sector in our economy, and not just a social services burden. We need to plan now for what types of businesses, jobs and educational strategies we will need in preparation for the gray tidal wave that will hit Alaska. We need to ensure that Alaskan citizens are encouraged to stay in Alaska throughout their retirement and end of life, so as to enjoy their resources in our economy. We also need to encourage our citizens to take reasonable steps to provide as much as possible for their own support and care. We need to plan now what types of insurance plans or other private purchased investments could be put into place to attract private citizen investment for their own support and care.

1. **History of the Long term care industry in Alaska**

The long term care industry has come together in a piecemeal fashion over many decades. Home and community based services are one element of the long term care system. It is funded by a conglomeration of public and private payers. Long term care provider agencies include government, quasi-government, non-profit, or private business entities. The long term care industry is complex and fragmented. Further, Alaska’s current long term care industry is experiencing unsustainable growth as our population ages and we continue to experience a high proportion of individuals with lifelong disabilities.

Ideas about the best way to care for the elderly and people with disabilities have undergone dramatic changes in the past several decades. The pendulum has swung toward in-home and community-based care with greater control over services by the recipient of care. The initial step in this direction was the provision of in-home services by home care agencies that sent nurses, therapists, and aides into the home to deliver both medically related home health services and personal care assistance.

The next shift was the realization that much of the long term care needed at home was not “medical” in nature, but could be provided by paraprofessional workers who perform tasks that available family members could do, or are already doing part of the day. This is known as the “social model” of long term care - - ways to provide substitute part-time paid caregivers for the missing family members, or to support family members in providing care for a person whose advanced medical care from the health care system will keep the person alive much longer, but with disabilities.

The social model of long term care includes services such as congregate adult day centers, day habilitation, supported employment, respite, chore, care coordination to advice elders and their families on available services whether public or private, and group homes or assisted living homes as a step before or instead of nursing homes or other institutions.

Alaska made a sea change in its public policy and public funding assistance in about 1994, when Alaska joined the other 49 states that had already added Home and Community Based Care “Waivers” to their state Medicaid programs. Medicaid coverage of nursing home costs has always been mandatory (once a certificate of need for the beds has been granted), but Home Care Waivers were then, and still are, “optional” Medicaid services. Personal Care Assistance (PCA) is another optional Medicaid service, one that Alaska chose to rely on to further its policy of funding less costly, less restrictive care—in lieu of allowing significant growth in nursing home bed usage.

The result of starting the waiver program has been that Alaska has added very few nursing home beds since 1994. Nursing homes will always be a valued, needed part of the long term care system, but Alaska made policy choices in the 1990’s that have controlled the need for more nursing home beds for nearly 20 years -despite the fact that we’ve been in the top three states for fastest growing elderly population during this entire period.

The second sea change by Alaska in the 1990s was the closing of the state’s only institution for the “mentally retarded and developmentally disabled”—Harborview. As residents were transitioned out of Harborview, they often initially lived in group homes. Eventually, former residents of Harborview—and all “future” citizens needing similar assistance, are now being served in independent living settings to the full extent possible for each person.

Finally, public policy shifted to provide supports for gainful, mainstream employment by persons with disabilities. For many hundreds of adults with disabilities, waiver and PCA services are what enable them to get ready for work each day, and to maintain themselves in their own homes.

For the past several years, Alaska has had the highest per capita growth of seniors in the country. People are living longer and choosing to stay in Alaska versus migrating south. As people age they utilize a higher level of health and human services. Our current system of health and human service delivery is experiencing unsustainable cost growth. As we have more people entering the health and human service system we will be unable to simply provide more of the current array of services as the ever increasing costs will become even more prohibitive.

1. **Who makes up the current long term care system**
   1. Home and Community based grantees
      1. Senior community-based grantees (21,261 recipients)
         1. Adult Day Programs -12 providers
         2. Senior in-home grantees – 19 providers
         3. National Family Caregiver’s Support program – 14 providers
         4. Senior Rural Residential Services – 2 providers (96 residents)
         5. Senior Services grants for meals, home delivered meals, senior rides– 60 providers
      2. Developmental Disability grantees (1200 recipients)
         1. Community DD grantees – 27 providers
         2. Short term assistance and referral grantees – 12 providers
      3. Aging and Disability Resource Centers – 7 (15,682 recipients)
      4. General Relief (961 recipients)
   2. Medicaid Home and Community Based Providers (6100 recipients)
      1. Personal Care Assistant – 71 (4006 recipients)
      2. Care Coordination agencies – 133 with 337 certified care coordinators
      3. Assisted Living Homes – 253 certified providers operating 621 homes (3408 licensed beds)
      4. Waiver service providers – 274 providers
   3. Private pay provider companies – who take private pay or long term care insurance payments
   4. Veteran’s Administration – provides home health care in its medical program and limited PCA and respite in its social work programs
   5. Mental Health Providers – 40
   6. Licensed Home Health Care agencies
   7. Licensed Hospice Agencies
   8. Nursing Homes – 15
      1. Alaska State Hospital and Nursing Home Association
   9. State of Alaska
      1. Pioneer Homes – 6 homes (508 beds)
      2. Care coordinators - 2
   10. Boards and Commissions
       1. Alaska Mental Health Trust Authority
       2. Alaska Commission on Aging
       3. Governor’s Council on Disabilities and Special Education
       4. Alaska Mental Health Board
2. **Recent Studies**
   1. The Lewin Group: Long Term Forecast of Medicaid Enrollment and Spending in Alaska: 2005-2025 (2006) The Lewin Group report provided us with a summation of what our system can expect in the next 20 years. The Alaska Medicaid program will fundamentally change over the next 20 years from a program that centers on children to one that is dominated by seniors (age 65 and older). This is a result of changes in Alaska’s demographic profile, which will include many more seniors. On a per-recipient basis, spending on Medicaid services for seniors is substantially higher than spending for children. As this portion of the population grows rapidly over the next 20 years, Medicaid spending will also grow rapidly. In calendar year 2005, approximately 42% of spending on Medicaid claims was devoted to children and 22% was devoted to seniors. By 2025, we expect that approximately 45% of Medicaid spending will be devoted to seniors and approximately 30% will be devoted to children.

The long term forecast of Medicaid enrollment was updated in January, 2010. The results of this update indicate that the population forecast includes assumptions about the changing demographic profile of Alaska. The average annual growth rate in enrollment of the elderly (65 and older) is expected to be 5.1 percent, which is higher than the growth rate for other age groups. As a result, the overall focus of the Medicaid program will shift from a child-based program to a program more evenly distributed between children, working-age adults, and the elderly. This demographic change affects spending because spending on the elderly is growing at a rate almost double that of children and working-age adults, and this growth is likely to continue. The expected shift in spending towards the elderly is still likely to occur, but the timing is delayed compared to earlier forecasts.

* 1. Public Consulting Group –Alaska Long Term Care and Cost Study February 2006 reports: Individuals served by Alaska’s long term care system—people who are aging, people with dementia, people with traumatic brain injuries, people with physical disabilities, and people with developmental disabilities—currently face a system challenged by the state’s vast geographic composition, extreme climate and dramatically changing demographics, which remains fragmented and without an overarching infrastructure. DHSS also continues to struggle with Medicaid budget growth and cost effectiveness. As a result, Alaska suffers from parallel systems of care, ineffective rates, and a continuum of long term care that does not provide complete and consistent delivery of services. Moreover, the unique evolutionary nature of Alaska’s system has made it increasingly difficult to accurately measure performance and outcomes across a wide range of providers.

The PCG report listed recommendations as:

* Overarching Recommendations
* Nursing Home Recommendations
* Pioneer Homes Recommendations
* General Relief Assisted Living Facilities Recommendations
* Personal Care Assistant Services Recommendations
* Waiver Program Recommendations
* Grant Program Recommendations

The PCG long term care study provided the State of Alaska with recommended changes to the system for the next 3, 10, and 20 years. However, given that the foundation for this study was a review of the current system, it will not function as a standing, statewide strategic plan for long term care services. In their review of a myriad of documents and reports, one key document that was found missing was a statewide strategic plan for long term care. In order to ensure that Alaska’s service system continues to be responsive to its consumers’ needs, to providers, and to all other stakeholders, they recommended that a 3-5 year statewide strategic plan for long term care be developed within the state. A statewide strategic planning process will require DHSS and all other relevant state staff to collaborate with the complete array of stakeholders who receive and those who provide long term care services across the state. This plan will provide DHSS with a blueprint to set goals, strategies, and performance outcomes over a 3-5 year period that can be used to guide the service system as it continues to grow and expand. Developing a statewide plan for 3-5 years in length will also allow DHSS to respond and recalibrate its direction as the consumer’s needs and funding changes.

Two critical elements that would need to be included in this strategic planning process are an effort to plan with regard to geographic issues and a consideration of cultural/population issues. Both of these elements have an impact on the array of available services, the continuum of care in each region of the state, and the way in which care meets or overlooks the cultural needs and values of Alaska’s diverse population.

In order to ensure that thorough attention is paid to geographic needs, the plan should at a minimum:

* address urban, rural, and remote areas;
* describe services available in each region of the state;
* describe services missing in each region of the state; and,
* address the transportation challenges facing each region and how these challenges can be overcome to provide needed services in the region.
  1. HCBS Strategies: Recommendations for the Alaska Long Term Care Plan, 2008 report: Alaska is one of the leading states in establishing a balance between supporting people in the community versus in an institution. Alaska operates a wide variety of programs that provide long term care services that range from institutional care to home and community-based services. A recent AARP report stated, ―Alaska has one of the most balanced LTC systems for older people and adults with physical disabilities in the nation, and recent trends indicate that the state is continuing to make even more progress towards balancing. Alaska is one of only eight states that do not have a large state DD facility and the only state to have no ICFs-MR.

However, strong growth in long term care expenditures and recipients threaten the sustainability of the program. In addition, the debate over the quality of long term care has moved beyond simply keeping people out of institutions. Individuals and family members expect that health and safety will be maintained regardless of where the person lives. They are also requesting greater ability to direct the supports they receive. The federal government has also dramatically increased quality requirements.

The HCBS Strategies report listed a series of recommendations aimed at making Alaska’s long term care programs more cost effective. Their recommendations included:

* **Restructure the process for matching people with funding sources**: To manage the long term care system, the State must understand who they are serving and be able to channel individuals to the most cost effective service options. Thus, this is an important first step that the State must take to have a sustainable system.
* **Restructure the process for setting budgets for the waiver and PCA** **services**: The State must adopt an approach that allows it to manage budgets in the aggregate and permits the maximum amount of flexibility at the service level. This will provide the State with more predictability and control over the budget and will allow individuals, Care Coordinators, and providers to have greater ability to tailor supports to an individual‘s needs, strengths and preferences.
* **Shift consumer directed funds to a Medicaid authority that provides the State with greater control while providing consumers with greater flexibility**: The State has limited ability to control the use of thecurrent CDPCA program. CDPCA also offers individuals less control thanthe approach used by the Cash and Counseling Demonstration, whichextensive research has shown to be very effective. To develop a moreeffective consumer directed program, we recommend the State fold thecurrent spending for CDPCA under a 1915(j) State Plan Self-DirectedPersonal Care option, a new Medicaid authority created by the DRA.
* **Support populations not meeting the Nursing Facility Level of Care (NF-LOC) eligibility criteria**: The NF-LOC creates a significant barrier toobtaining Medicaid FFP for people with ADRD and brain injury.Unfortunately, a lack of data and uncertain federal rules would make itirresponsible to offer a specific recommendation regarding how to addressthis issue. Thus, we recommend the State engage in parallel efforts tocollect necessary data to analyze the implications of changing the NFLOCand to determine the feasibility of using the 1936 Benchmark Planauthority for providing supports to these individuals.
* **Draw down more Medicaid FFP for CAMA and Pioneer Homes:** We propose pursuing an 1115 Demonstration for drawing down FFP for CAMA. To draw down more FFP for PHs, the State must first alter the asset criteria so that it matches Medicaid. We also propose several additional steps that could substantially increase FFP.
* **Improve Quality Management Process**: We recommend a process that is consistent with CMS‘ HCBS Quality Framework, which itself is based upon Continuous Quality Improvement (CQI) principles. We also propose major changes to the licensing and certification processes for ALFs.
* **Restructure Care Coordination**: We recommend that, where feasible, Care Coordinators be independent of service providers. We have a series of recommendations that should allow Care Coordinators to play a more central role in the quality management system. We also recommend restructuring how the State reimburses care coordination.
* **Expand Information Technology (IT) efforts**: DSDS should expand its promising Division for Senior and Disabilities Services Data System (DS3) effort to provide support to more core business functions. This effort will be essential to supporting the earlier recommendations.

While the HCBS Strategies report was a comprehensive overview of the existing long term care system and involved input from many stakeholders, it did not provide a vision for the long term care system beyond that of cost containment.

1. **Current considerations in the long term care industry**
   1. Department of Labor and Workforce Development Alaska Economic Trends, September 2010, Industry and Occupational Forecasts: 2008 -2018 report: Health care and social assistance is expected to experience the largest amount of growth of any industry over the projection period, up 9,400 jobs or 26.5 percent. This sector alone will be responsible for about 28 percent of the state’s total projected employment gains.

Many health care related industries are strongly influenced by changes in the population of older Alaskans. The population of Alaskans age 65 and above is expected to rise by at least 50 percent during the projection period. Consequently, there will be exceptional job growth in doctors’ and health care providers’ offices, hospitals, nursing and residential care facilities, and among providers of social services for the elderly.

b. Department of Commerce, Community and Economic Development – Alaska Forward: Phase I Situational Analysis: The situational analysis report described and analyzed the current economic development system in Alaska and the state’s unique set of economic and business climate factors. The report identified several dynamic clusters which they titled “stars”. Star clusters represent the key areas of focus for Alaska. These clusters represent businesses in which Alaska has some capability, but also ones that will experience above-average growth over the next decade. Clusters in this quadrant have been competitive in markets that continue to hold good future prospects. There should continue to be emphasis on clusters as key sectors for development. One of the clusters that has been identified as a star in Alaska includes Community and Social Services which includes civic and social organizations as well as social advocacy organizations. They are considered a cluster because these organizations are a common platform to connect various industries and groups in the state. Civic and social organizations is quite large, the industry employed 1,878 people in 2008 and had an employment concentration of 2.2 times the national average. Employment with social advocacy organizations more than doubled from 426 in 2003 to 980 in 2008.

1. Alaska Health Workforce Development Plan, Health Workforce Coalition, May 2010 reports the following: Health care is one of the largest and most dynamic industries in Alaska, accounting for eight percent of total employment and around 16 percent of the value produced by the state’s economy. Between 2000 and 2009, health care employment increased 46 percent, about five times as fast as the state’s population and three times as fast as all other sectors of the economy.

Health care positions are found in all regions of the state, offering close-to-home employment for many Alaskans. Although some positions require advanced training, many jobs are entry-level, requiring limited preparation. Often, these entry-level positions are the start of a career ladder or lattice that can—with additional experience and education— lead to life-long, meaningful careers. With a payroll of more than $1.4 billion in 2008, this industry employed more people than state government, oil industry or most other industries.

1. **What’s Next**

The Community Care Coalition would challenge the Governor and his Commissioners to appoint representatives from the Departments of Health and Social Services, Commerce and Economic Development, Labor and Workforce Development, Education and Administration to work in concert with the long term care industry in the development of a statewide Long Term Care Plan to address the vision, quality, accessibility, availability and sustainability of long term care for all citizens of the state. Short term funding for staffing and consulting should be made available to ensure completion of the plan.

Resources

Long Term Forecast of Medicaid Enrollment and Spending in Alaska: 2005-2025

<http://dhss.alaska.gov/fms/Documents/AK_Long_Term_Medicaid_Forecast_2005-2025Report.pdf>

Long Term Forecast of Medicaid Enrollment and Spending in Alaska: Supplement 2009-2029

<http://dhss.alaska.gov/fms/Documents/MESA_2029.pdf>

Alaska Long Term Care and Cost Study

<http://hss.state.ak.us/dsds/docs/alaskaLongTermCareCostStudy.pdf>

HCBS Strategies: Long Term Care Plan for Alaska

<http://www.hcbsstrategies.com/project_page_Alaska_LTC.html>

Alaska Economic Trends, September, 2010 Industry and Occupational Forecasts

<http://labor.alaska.gov/trends/sep10.pdf>

Alaska Forward: Phase I Situational Analysis

<http://alaskapartnership.net/wp-content/uploads/2011/01/Alaska-Forward-Project-Situational-Analysis.pdf>

Alaska Health Workforce Development Plan

<http://www.ashnha.org/content/images/stories/20100427-workforceplan-v4.pdf>