HCBS STRATEGIES INC.

Recommendations for the Alaska Long Term Care Plan

Final Report

HCBS Strategies, Inc.

STATE of ALASKA
Department of Health and Social Services

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RECOMMENDATIONS FOR THE ALASKA LONG TERM CARE PLAN

Final Report

EXECUTIVE SUMMARY

The State of Alaska issued a Request for Proposals (RFP) to analyze the Alaska Medicaid program's long term care services and make recommendations for the development of a Long Term Care Plan (LTCP). This report presents the following:

- A summary of the input received from stakeholders via focus groups, interviews and surveys;
- Our analyses of strengths and vulnerabilities of the operational infrastructure the State uses to deliver and monitor long term care services;
- Our analyses of expenditure trends;
- Recommended actions to be included in the LTCP;
- A summary of stakeholder reactions to these recommendations and modifications we made based upon this input;
- A three year action plan (3YAP) that translates the recommendations to be implemented within the first three years into discrete and interrelated tasks; and
- The framework for an Ongoing Planning Process to oversee the implementation of these changes.

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 (HCBS). 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."[1] Alaska is one of only eight states that do not have a large state facility for persons with developmental disabilities (DD) and the only state to have no Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR).[2]

However, strong growth in long term care expenditures and recipients threaten the sustainability of the program. 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. In addition, the federal government has also dramatically increased quality requirements.

We have crafted a series of recommendations aimed at making Alaska's long term care programs more cost-effective. We did not make recommendations regarding service reimbursement methodologies or amounts because the State has already engaged Myers & Stauffer to conduct this work. Our recommendations primarily focus on HCBS rather than institutional services because there are not ICFs-MR in the State. In addition, nursing facilities are subject to quality management processes established by the federal government that are relatively rigorous and well financed. In contrast, the size and complexity of HCBS in general and the Medicaid PCA program and HCBS waivers in particular have grown dramatically.

Our major recommendations fall into the following categories:

1. **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.
2. **Restructure the process for setting budgets for waiver and Personal Care Attendant (PCA) services**: The State must adopt an approach that

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[1] Enid Kassner, Susan Reinhard, Wendy Fox-Grage, Ari Houser, & Jean Accius (July 2008). ***A Balancing Act: State Long-Term Care Reform***, AARP.

[2] Research and Training Center on Community Living Institute on Community Integration/UCEDD at the University of Minnesota (August 2008). ***Residential Services for Persons with Developmental Disabilities:Status and Trends through 2007.***

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.

3. **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 the current Consumer Directed Personal Care Attendant (CDPCA) program. CDPCA also offers individuals less control than the approach used by the Cash and Counseling Demonstration, which extensive research has shown to be very effective. To develop a more effective consumer directed program, we recommend the State fold the current spending for CDPCA under a 1915(j) State Plan Self Directed Personal Care option, a new Medicaid authority created by the Deficit Reduction Act of 2005 (DRA).
4. **Support populations not meeting the Nursing Facility Level of Care (NF-LOC) eligibility criteria**: The NF-LOC creates a significant barrier to obtaining Medicaid Federal Financial Participation (FFP) for people with Alzheimer's Disease and Related Disorders (ADRD) and Brain Injury. Unfortunately, a lack of data and uncertain federal rules would make it irresponsible to offer a specific recommendation regarding how to address this issue. Thus, we recommend the State engage in parallel efforts to collect necessary data to analyze the implications of changing the NF-LOC and to determine the feasibility of using the 1937 Benchmark authority for providing supports to these individuals.
5. **Drawing down more Medicaid Federal Financial Participation (FFP) for the Chronic and Acute Medical Assistance (CAMA) Program and Pioneer Homes (PH):** 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.
6. **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 Assisted Living Facilities (ALFs).

7. **Restructure Care Coordination**: We recommend that, where feasible, Care Coordinators be independent of services 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.
8. **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.

We also include several other miscellaneous recommendations that we discuss in the body of the report.

Implementing these reforms will require a substantial investment in resources and staff time over several years. The level of resources the State and Legislature are willing to allocate to these efforts will affect the speed at which these recommendations can be implemented. In deciding what resources to allocate, we would encourage the State to ensure that State staff have sufficient time to play a central role in the development and implementation of the initiatives and not rely solely upon the work of outside contractors. The State should also make provisions to ensure that external stakeholders have active input in the process. We also encourage the State to recognize that reforms of this magnitude take time and external circumstances will likely require course corrections.

BACKGROUND AND INTRODUCTION

The State of Alaska issued a Request for Proposals to analyze the Alaska Medicaid program's long-term care services and make recommendations for the development of a Long Term Care Plan (LTCP). This project is a result of the 2007 Alaska Legislative session during which the Alaska Legislature passed Senate Bill 61 (Chapter 10, SLA 2007), an appropriations bill that included funding for the Department of Health and Social Services to develop a "comprehensive program associated with designing, planning, and implementing the Legislative Medicaid Program Review Report." Among the projects identified by the Department as part of this effort was the development of a LTCP that would provide a detailed, coherent, comprehensive strategy for addressing the future needs for long term care in the most cost effective way and assessments of whether and how to draw down federal Medicaid funds (called FFP or Federal Financial Participation) for Alaska Pioneer Homes and the Chronic and Acute Medical Assistance (CAMA) program.

The growing cost of providing long term care services is a critical issue facing Alaska's Medicaid program. Long term forecast projections from the Department of Health and Social Services (DHSS) predict that the cost of Medicaid will at least quadruple from 2006 to 2026. This report stated:

> *"The main factors responsible for growth in spending on Medicaid services are population growth, aging of the population, increasing utilization of Medicaid services by enrollees, and growth in the prices of medical services."*[3]

Clearly, future strategies will need to focus on finding the most appropriate, cost effective approach to providing long term care services. This long term care system must include a range of options with the capacity to adapt the system over time to fit with the needs of the State and new federal opportunities.

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[3] The Lewin Group and ECONorthwest (February 2006). Long Term Forecast of Medicaid Enrollment and Spending in Alaska: 2005-2025.

The RFP included three primary deliverables, including:

- The Long Term Care Plan;
- A Three Year Action Plan (3YAP); and,
- The framework for an ongoing strategic planning process.

The vision of the RFP was that the 3YAP would translate the LTCP into clear action steps that would lead to implementation. The ongoing strategic planning process would then pick up the work developed by the consultants and oversee the implementation of the 3YAP.

The effort examines services that are used by older adults and individuals with physical or developmental disabilities. This includes individuals who are receiving services from nursing facilities, Pioneer Homes, Home and Community-Based Services (HCBS) Waivers, and Medicaid State Plan Personal Care Services. The RFP also requested that this effort explore options for potentially underserved populations, such as individuals with Brain injuries, Alzheimer's Disease or Related Disorders (ADRD), HIV/AIDS, or individuals with a mental illness in conjunction with a disability (or being an older adult).

The RFP included several specific areas that the LTCP must address, including:

- Exploring the feasibility of and developing plans to increase the amount of Medicaid FFP drawn down for Pioneer Homes and the CAMA program;
- Examining whether the changes made to the management of the Medicaid Personal Care program are appropriate, and whether the Personal Care program should be folded into a waiver; and,
- Reviewing DSDS' progress toward reducing the waiting list for the Developmental Disability Waiver and making recommendations as appropriate.

The RFP included several organizing principles that the effort was to use to provide the context for recommendations and the LTCP:

- **Sustainability**: The LTCP must improve the State's ability to manage and control the cost of services for a growing caseload and inflation. Building a sustainable system requires two major categories of strategies. One, there are strategies for controlling cost including maximizing FFP, the redesign and redefinition of the benefit structure, preventing fraud and abuse, and efficiencies created through changes in the authorization and administration of services. Two, there are strategies to build the administrative capacity to quickly identify and address cost pressures. These strategies include building management reports and processes.

- **Support in the home**: The LTCP should assist the State in its effort to allow people to live in a home that they or a family member owns or controls to the extent practicable. To incorporate this principle, the LTCP must identify and propose plans for remediating policies or operational infrastructure that create a bias that favors support in institutions or Assisted Living Facilities (ALFs) over support in the home.
- **Support for families**: The LTCP should recognize the central role that families and other informal supports play in allowing people to remain in the community. Recommendations should help build a system that supports rather than supplants families.
- **Integration with Tribal Care**: Effectively supporting Alaska Natives is a key component of an efficient system. They account for a large and growing portion of Medicaid eligible individuals. A service system that does not consider their unique cultures and the logistical challenges will face the following negative outcomes:
    - Costs may increase because people will deteriorate to the point where they require much more expensive services or be permanently moved to an out-of-home placement in a metropolitan area.
    - Tribal Health Organizations (THOs) may be unable or unwilling to provide services resulting in less culturally appropriate support, thus preventing the State from receiving 100% FFP that it can potentially receive when services are provided from a THO.
    - The quality of life for individuals and the integrity of the Native community may be damaged by preventing the THO from fulfilling the cultural preference to support elders within traditional communities.
- **Transparent and accountable system**: We interpret transparency as meaning that external stakeholders, such as the individuals who use services, their family members and advocates, and the organizations that provide services must be able to understand how the long term care system works. This means that rules and reimbursement methodologies must be publically available and understandable. We interpret

accountability as meaning that there are clear and measureable goals and outcomes for long term care services and that the State has processes for examining performance using these outcomes and remediating where performance is lacking.

- **Services must be culturally appropriate**: This organizing principle is interrelated to the integration with the Tribal Care principle. However, it is important to recognize that Alaska faces cultural diversity issues beyond supporting Alaska Natives. As the State grows, populations from other cultures have become more prominent and the State must identify appropriate methods of supporting them.

Membership and Role of the Advisory Committee

The State selected an Advisory Committee that included representation from the relevant State agencies and external stakeholders (see ***Table 1)***.

Table 1: Long Term Care Plan Advisory Committee Membership

	Name/Title	Organization
State Agency Representatives		
1.	Dave Cote, Pioneer & Veterans Homes Acting Director	Pioneer Homes
2.	Jerry Fuller, Medicaid Director	DHSS
3.	Bill Hogan, Commissioner	DHSS
4.	Rod Moline, Director of DSDS (through early August) Rebecca Hilgendorf, Acting Director of DSDS (after 8/08)	DHSS-DSDS
5.	Jon Sherwood, Medical Assistant Administrator	DHSS
Stakeholders		
6.	Rod Betit, President-CEO Linda Fink, Vice President	Alaska State Hospital and Nursing Home Association
7.	Kay Branch, Elder/Rural Health Program Coordinator	Alaska Native Tribal Health Consortium
8.	Nancy Burke, Program Officer	Alaska Mental Health Trust
9.	Denise Daniello, Executive Director	Alaska Commission on Aging
10.	Pat Luby	AARP
11.	Joel Niemeyer, Program Officer	Rasmuson Foundation
12.	Millie Ryan, Executive Director	Alaska Governor's Council on Disabilities and Special Education

Jon Sherwood served as the Project Director. The Advisory Committee provided guidance regarding the role of the project as well as input and reactions to the recommendations. They received briefings on the findings of each component of the project and were instrumental in revising and prioritizing the LTCP.

Approach

The work on this report started on May 7, 2008. Our approach built upon previous analyses of the Alaska long term care system, such as those done by the Public Consulting Group and the Pacific Health Policy Group. We have filled in the gaps that remain, notably, the lack of a business process analysis of the long term care delivery systems. We briefly summarize our work plan below:

Background Research: We researched background material pertinent to the issues and challenges presented in this project. In addition to researching the studies already completed for Alaska and monitoring the contracts operating under SB 61, we collected information from federal, state, and national sources. This included research and interviews with early adopters of options under the DRA, states with optional eligibility groups, states with personal care services, federal/state/local initiatives to improve cultural competency, prevention and early intervention initiatives, select states using mental health rehabilitative optional services, and states with consumer directed options. We also interviewed national experts to obtain their feedback about draft recommendations.

Business Process Review and Funding Stream Crosswalk: Concurrent to the research phase of the project, we conducted a structured overview of the key business processes that comprise the Alaska long term care system. During this task, we examined key systems infrastructure, such as standardized assessments, Information Technology (IT) systems, quality management protocols, reimbursement structures, and mechanisms for enrolling providers. We also developed a matrix that cross walks key requirements for programs that are funded with Alaska-only dollars with potential federal funding streams, such as the new 1915(i) and (j) options created under the DRA. We include a summary of these findings this report.

Obtaining Stakeholder Input: We used a five-pronged approach to obtaining input from stakeholders, including consumers and their representatives and providers:

1. We obtained input from an Advisory Committee that included external stakeholders;
2. We conducted in-person and telephone interviews with key stakeholders;
3. We conducted a series of consumer focus groups across the State;
4. We sent out surveys to consumers, providers, and other stakeholders; and
5. We held Community Forums in Anchorage, Juneau, and Fairbanks. Individuals unable to attend in person were able to participate via webinar and telephone at any or all of the forums. We presented an overview of the draft plan and obtained input during each of the sessions.

Developing the LTCP: The LTCP provides specific direction and steps to be taken to improve the outcomes and cost effectiveness of Alaska’s long term care services. We first developed an outline of the draft recommendations and obtained input from the Advisory Committee. We also incorporated input from Community Forums and guidance from the Advisory Committee into the Final Plan.

Three Year Action Plan (3YAP): The 3YAP is intended to provide the State with specific implementation plans for each of the activities scheduled to begin within the first three years. The recommendations are an outgrowth of the larger LTCP. Thus, we provided a timeline overlay for this subset of recommendations in order to put them into context with longer term changes that will be recommended.

CMS Concept Paper: The final deliverable was a concept paper to Alaska that can be used in discussions with Centers for Medicaid and Medicare Services (CMS). We believe that early talks with CMS regarding LTCP can be of great benefit. This deliverable is a useful tool for establishing the context within which changes will be sought. We believe that it can be used to ease the way as amendments and waiver plans are forwarded to the regional and central offices of CMS. This paper is not included as part of this report.

FUNDING AUTHORITY CROSSWALK

Appendix 1 provides a matrix of various CMS authorities, such as the traditional HCBS waivers (1915(c)), Demonstration waivers (1115), state plan HCBS (1915(i)), state plan consumer directed personal care (1915(j)), and targeted case management. The matrix served as the basis of discussion during the development of the LTCP. It allowed us to weigh the benefits and limitations of each of the Medicaid funding authorities.

Medicaid funding for HCBS has evolved dramatically. Much of this evolution can be attributed to the creation of new authorities by Congress, such as the provisions created by the Deficit Reduction Act (DRA) of 2005. In some cases, changes are driven by the publication of new federal regulations. In addition, in some cases, differing interpretations of existing legislation or regulation can also have a major impact on what is allowed.

1915(a): States may use this authority to set up a managed care arrangement. However, enrollment in these plans must be voluntary.

1915(b) - Freedom of Choice Waivers: Section 1915(b) provides for the authority to grant waivers that allow states to implement managed care delivery systems, or otherwise limit individuals' choice of provider under Medicaid.

1915(c) - HCBS Waivers: States use this authority to waive Medicaid provisions to provide community-based alternatives to institutions. In order to qualify for these services, individuals must meet the level of care criteria that the state uses for a qualifying institution, such as a nursing facility, Intermediate Care Facility for Individuals with Mental Retardation (ICF-MR), or hospital. Alaska currently operates four of these waivers.

1915(i) - State Plan HCBS: This option was created under the DRA. It allows states to provide many of the services that would otherwise require a 1915(c) waiver. While states could potentially use this option to serve individuals who do not meet the institutional level of care, there are limitations on financial eligibility and operational requirements that may impair the ability of states to use it to broaden coverage.

1915(j) - State Plan Self-Directed Personal Care: This option was also created by the DRA. It allows states to create programs that offer individuals control over a budget that can be used to pay for personal care or items that substitute for personal care. This model is often referred to as Cash and Counseling.

1937 - Benchmark Plans: Originally conceived to limit Medicaid benefits by allowing states to benchmark plans to HMOs, etc., the statute also allows states to provide additional benefits as “wraparound” coverage.

State Plan PCA/HH: This gives states the authority to provide personal care or home health under the Medicaid State Plan.

Targeted Case Management: States can use this authority to pay for case management.

EPSDT: Early Periodic Screening, Diagnosis, and Treatment (EPSDT) requires that states provide services that a child may need that could be covered under Medicaid whether or not it is the Medicaid State Plan. States often use this authority to provide HCBS to children.

1115 Demonstrations: This section provides the Secretary of Health and Human Services broad authority to approve projects that test policy innovations likely to further the objectives of the Medicaid program. The demonstrations must be budget neutral to the federal government.

PROGRAM DESCRIPTION

Alaska operates a wide variety of programs that provide long term care services that range from institutional care to home and community-based services (HCBS). 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."[4] Alaska is one of only eight states that does not have a large state DD facility and the only state to have no Intermediate Care Facilities for Individuals with Mental Retardation (ICFs-MR). The State has the third highest average spending per DD recipient in the country.[5]

The four programs highlighted in yellow in ***Table 2*** accounted for approximately 91% of the State's long term care spending in State Fiscal Year (FY) 2006, which ran from July 2005 to June 2006. The most notable statistic is that Alaska spends nearly four times as much on HCBS than it does on nursing facilities.

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[4] Enid Kassner, Susan Reinhard, Wendy Fox-Grage, Ari Houser, & Jean Accius (July 2008). ***A Balancing Act: State Long-Term Care Reform***. AARP.

[5] Research and Training Center on Community Living Institute on Community Integration/UCEDD at the University of Minnesota (August 2008). ***Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007.***

Table 2: DHSS Long Term Care Expenditures and Recipients in 2005 and 2006

	Expenditures (in millions)				Recipients			
	FY05	%	FY06	%	FY05	% *	FY06	% *
Medicaid Long Term Care								
Institutions								
Nursing Facilities	$68.6	21%	$72.0	21%	1,075	15%	1,179	16%
ICF-MR	$0.0	0%	$0.0	0%	-	0%	-	0%
Total Institutions	$68.6	21%	$72.0	21%	1,075	15%	1,179	16%
Waivers								
CCMC	$8.4	3%	$8.7	2%	219	3%	217	3%
MRDD	$65.0	20%	$67.5	19%	1,014	14%	1,013	14%
APD	$15.1	5%	$16.0	5%	948	13%	999	14%
OA	$27.9	8%	$30.7	9%	1,420	20%	1,500	20%
All Waivers	$116.3	35%	$122.9	35%	3,601	50%	3,729	51%
PCA	$80.5	24%	$83.8	24%	3,943	55%	3,954	54%
Medicaid Long Term Care Total**	**$265.4**		**$278.8**		**7,131**		**7,338**	**100%**
Non-Medicaid Long Term Care								
General Relief	$2.9	1%	$4.1	1%	246		337	
CAMA	$1.5	0%	$1.5	0%	1,176		1,336	
Pioneer Homes (avg. monthly census)	$36.9	11%	$43.0	12%	423		448	
Multi-Program Grants to Regional Native Health Organizations	$1.9	1%	$2.2	1%				
Community Developmental Disabilities Grants	$11.1	3%	$11.1	3%				
STAR and DD Mini-Grants	$1.2	0%	$1.1	0%				
Resource and Development	$0.6	0%	$0.2	0%				
Protection of Rights & Investigation of Abuse	$0.2	0%	$0.2	0%				
Nutrition, Transportation and Support Services	$5.3	2%	$5.5	2%				
Adult Day Services	$1.3	0%	$1.4	0%				
National Family Caregiver Support Program	$0.9	0%	$0.9	0%				
Senior Residential Services	$0.2	0%	$0.2	0%				
Senior In-Home Services	$1.8	1%	$2.1	1%				
ADRD - Education Support and Mini-Grants	$0.0	0%	$0.4	0%				
Geriatric Education & Training	$0.3	0%	$0.3	0%				
Nutrition Supplemental Incentive Program	$0.4	0%	$0.0	0%				
Non-Medicaid Long Term Care Total**	**$65.3**	**20%**	**$71.1**	**20%**				
Total***	**$330.8**	**100%**	**$349.9**	**100%**				

* of Medicaid

** Unduplicated (some on waiver & PCA)

***Pioneer Homes include Medicaid revenue. This amount was excluded from the total to prevent duplication

Appendix 2 provides a summary of the key characteristics of all of the long term care programs funded through DHSS. Below we provide a brief description of each of the HCBS funding sources. These descriptions were adapted from the Alaska State Plan for Senior Services from May of 2007 with the generous permission of the Alaska Commission on Aging. Descriptions for services that do not target older adults were adapted from the DSDS website.

HCBS provide needed care to seniors and individuals with disabilities in their own homes or communities, thus allowing them to remain with their families or in familiar communities, and vastly reducing the cost of care compared to the care they would receive in a skilled nursing facility or other institution.

For individuals who meet income and asset requirements as well as “level of care” requirements (that is, the need for an institutional level of care), the Medicaid Waiver program provides an array of home and community-based services. For those with somewhat higher incomes or who do not meet the waiver’s level of care requirements, grant services are available through organizations statewide to help pay the cost of HCBS. In some cases, grant funds are also used to pay for services that an individual cannot get through a waiver. The grants are provided through a combination of federal (Older Americans Act) funding, State general funds, and Mental Health Trust Authority funds. Unfortunately, the components of the grant fund sources have not increased in recent years to keep pace with the needs of Alaska’s rapidly growing senior population.

The State offers the following HCBS programs:

Medicaid

- **Medicaid Personal Care Assistance (PCA) Program.** The Personal Care Assistant (PCA) program provides home care services to Medicaid-eligible seniors and others. These services enable low-income frail elderly Alaskans and functionally disabled, physically disabled, and frail Alaskans to live in their own homes and communities, instead of being placed in a more costly and restrictive long term care institution. The program provides services that help individuals accomplish activities of daily living such as bathing, dressing and grooming, shopping, cleaning, and other activities that require semi-skilled or skilled care. Services are provided through two different Personal Care Assistant models. The agency-based PCA program (ABPCA) allows consumers to receive services through an agency in which a registered nurse oversees, manages, and supervises their care. This model has been operational for over 10 years. The consumer directed PCA program (CDPCA) allows the consumer to manage his or her own care by selecting, hiring, training, and supervising his or her own

Personal Care Attendant. The agency provides administrative support to the consumer and the PCA. This model became operational in 2001. Unlike programs using the popular “cash and counseling” model where the consumer is the employer and receives a specific amount of money to cover a given time period, the CDPCA program in Alaska utilizes a PCA agency as the employer; while the consumer makes the decisions about who to hire and how to train that person, the worker turns in the timesheets to the agency that then bills Medicaid. About half of the consumers in each of the personal care assistance programs are seniors.

- **Medicaid Waiver Programs.** This program was designed to provide an alternative to institutional placement for low-income individuals certified to need the services of an institution. They are called “waivers” because they allow the State to waive certain Medicaid requirements, including allowing states to provide many types of HCBS that could not be covered under the regular Medicaid program. HCBS waivers are also known as 1915(c) waivers because they are authorized under section 1915(c) of the Social Security Act. Under these waivers, the State can cap the number of people that are served and the amount of services any person will receive. Alaska has also taken advantage of the ability to have more liberal income criteria. DSDS, which is part of the single State Medicaid agency, operates four waivers that target the following populations:
    - Children with Complex Medical Conditions (CCMC),
    - Individuals with Developmental Disabilities (DD),
    - Adults with Physical Disabilities (APD), and
    - Older Alaskans (OA).

  Alaska is somewhat different from most states in that one agency, DSDS, operates all of the waivers and they are all structured in a similar fashion. In most other states, one or more of the waivers is operated by an agency outside of the Medicaid agency (e.g., a Department of Aging or a Developmental Disabilities Administration).

  All of the waivers offer a core set of services (respite, environmental modifications, specialized medical equipment, chore services, transportation, and meals). Each of the waivers also has a mechanism to pay for Assisted Living Facility (ALF) care, though the actual Medicaid service is called either Residential Habilitation or Residential Supported Living services (RSL), depending upon the waiver and the needs of the individual. Residential Habilitation also includes services in the person's own home under the DD waiver and the CCMC waiver. Nursing is available in all waivers except the CCMC waiver (children get nursing through EPSDT), and Intensive Active Treatment services are available in all waivers except the OA waiver.

All of the waivers also pay for and require care coordination services. Care coordination, which has traditionally been called case management, is designed to coordinate services and help ensure that the person is receiving appropriate supports and that there are no health or safety concerns. Alaska allows providers of direct services to also serve as Care Coordinators with the exception of ALFs that serve people on the OA and APD waivers.

None of the waivers pay for personal care (defined as assistance with activities of daily living (ADLs), such as bathing, dressing or eating) for someone who does not live in an ALF. These services would be paid for through the PCA program described above. People using waiver services can also access PCA services through regular Medicaid.

State and Federal Grants

- **Home and Community-Based Services Grants.** For those seniors who do not qualify for the Medicaid waiver because of their income or their assessed level of care needed, the home and community-based care grants help pay for services to help these seniors continue living in their homes. Grant services mirror the services provided under the Older Alaskans waiver. Providers must be Medicaid-certified. Services are provided under the Senior In-Home Services, Adult Day Services, National Family Caregiver Support, ADRD Education, Support and Mini-grants, Nutrition, Transportation, and Support Services (NTS), and Geriatric Education programs. The State of Alaska has received federal Title III (E) funds from the National Family Caregiver Program under the reauthorization of the Older Americans Act since FY 2001.

  The home and community-based care grants operate through non-profit grantee agencies. Funding is distributed through a competitive grant process, which is jointly administered by DSDS and the Grants and Contracts Support team unit of DHSS' Division of Finance and Management Services. The program provides services to physically frail individuals 60 years of age and over, individuals of any age with Alzheimer's disease or related disorders (ADRD), and caregivers. The grant programs have no income requirements, but a sliding fee scale is used for client contributions toward the cost of services in the case of Adult Day and Senior In Home Grants. The program goal is to help these Alaskans maintain as much independence as possible, and to improve their quality of life at home or in a community-based setting. The HCB senior grants are partially funded by Title III Older Americans Act funds, with additional funding from State general funds and Mental Health Trust Authority Authorized Receipts (MHTAAR).

- **Senior In-Home Services:** Historically, the service components of this program were offered through separate grants for Care Coordination, Respite Care, and Innovative Respite/ ADRD Support Services. Originally, the Innovative Respite project was funded by the Alaska Mental Health Trust Authority and focused on services to best meet the needs of individuals with ADRD and their families by increasing the flexibility in the delivery of respite services. Upon completion of the federal Alzheimer's Demonstration Project, it was determined that the provision of case management was a key component for supporting individuals with ADRD and their caregivers. As a result, the Innovative Respite project was expanded to include wraparound services for the individual and renamed "ADRD Support Services." In July, 2006, thanks to the successful outcomes of the project, DSDS restructured and combined the previous components to create one project called Senior In-Home Services and made it available to a broader population throughout the State. Consolidation also allowed for a more streamlined grant application process for providers.

  Services under the Senior In-Home Services project include Care Coordination (Case Management), Chore, Respite and Extended Respite.

  To be eligible for services, individuals cannot qualify for services under the Choice Medicaid Waiver program and must meet criteria of the intended target population and priority of service. Services target persons of any age with Alzheimer's disease or related dementia and persons 60 years of age and older with physical disabilities (which includes frail elders) or mental health issues who are at risk of institutional placement. Priority of service is given to eligible individuals who are at risk for institutionalization, have the greatest social and economic need, are Alaska Natives, or are residing in a rural area.

- **Adult Day Services:** There are grant funded adult day services located in eleven communities throughout Alaska. These programs provide structured, therapeutic activity programs for at least five hours per day, three days a week. Some programs provide extended hours on weekdays and occasional Saturday service. Adult day program participants undergo assessments to determine their social, physical, emotional, and cognitive strengths and needs, in order to develop an individualized plan of activities. For maximum benefit, most clients attend an adult day program on a regular basis. Adult day services often help stabilize individuals after a health crisis, and provide assistance in daily living activities that help individuals remain at home and in the community. For persons with ADRD, adult day programs provide an environment that helps individuals maintain function even while the disease progresses. Adult day programs also provide respite, education, and support to caregivers. The funding source is 100% State general funds.

- **Nutrition, Transportation and Support Services (NTS):** NTS Services are funded through the Older Americans Act (OAA) under Title III and State general funds, and are provided to seniors in a variety of settings and through varied delivery methods across the State. These services contribute the seniors' health, safety, welfare, and ability to remain independent as long as possible. NTS services often become the point of entry for seniors who may need access to other services in the continuum of long term care. The Division of Senior and Disabilities Services (DSDS) solicits for grant proposals every three years, and awards grants to non-profit organizations, tribal governments, school districts, and local governments. NTS services are available to seniors age 60 and older. In accordance with the OAA, NTS services are to target seniors whose health and welfare is at highest risk. Grant recipients target their outreach toward seniors who are frail, over 80, disabled, minority, and low-income. Special emphasis is also given to seniors in rural areas, in response to geographic and economic impacts associated with rural living. NTS grant funds are distributed statewide based on the State Plan funding guidelines and criteria detailed in the Request for Proposals. Services funded by the NTS grant program include: congregate and home delivered meals, nutrition education and counseling; health education and services; assisted (escorted) and unassisted transportation; homemaker; outreach and information and assistance; health promotion and disease prevention; statewide legal and media services; and, supportive community services such as Senior Companion, Retired Senior Volunteers, and Foster Grandparent/Elder Mentor Programs.
- **National Family Caregiver Support Program:** Caregivers often make it possible for disabled adults to remain in their home setting rather than moving into a long term care facility. Although providing care to a family member can be a positive and rewarding experience, family caregiving can be stressful. The National Family Caregiver Support Act, part of the reauthorized Older Americans

Act, authorized a variety of services implemented through partnerships between state, tribal, and local governments, both public and private organizations and community service providers to develop programs whose sole purpose is to provide relief from the emotional, physical, and financial stress experienced by family caregivers. Family caregiver programs in Alaska offer information and assistance, counseling, respite, and some other supplemental services.

Currently, there are eight National Family Caregiver Support programs throughout the State of Alaska. Three of these programs offer services on a Statewide basis: (1) services to caregivers serving elderly individuals with no program in their area; (2) services focusing on the legal needs of caregivers; and (3) services to grandparents raising grandchildren. Some of the highlights of the Grandparents Raising Grandchildren program include a Statewide “warm-line” or support line for grandparents, a website with resources, a monthly statewide newsletter focusing on topics for grand-families, monthly breakfasts, a Kinship Caregiver’s Resource Guide, voucher-type respite services, and a summer camp that includes respite, support and training for grandparents, and many activities for the children.

- **ADRD Education, Support and Mini-Grants.** The ADRD Education, Support and Mini-grants program provides funding for statewide education and support services to people with ADRD and their caregivers as well as providing education about ADRD to the general public, health care professionals, professional caregivers, agencies and organizations. These ADRD education and support services include:
    - support to families that assists them to maintain the ADRD consumer at home;
    - forestalling or preventing institutionalization;
    - dissemination of information to families and the general public regarding the process, prevalence and research findings of ADRD;
    - promotion of general awareness statewide of ADRD and the impact on families and communities; and
    - advocacy for services for persons with ADRD.

  This program is also responsible for the statewide distribution of Mini-grants to individuals who experience ADRD. These Mini-grants can include, but are not limited to, therapeutic devices, access to medical, vision and dental, special health-care, and other supplies or services that might remove or reduce barriers to an individual’s ability to function in the community and become as self-sufficient as possible. The funding source is 100% Alaska Mental Health Trust Authority funds.

- **Community Developmental Disabilities (DD) Grant Program[6]**: The Community DD Grant Program (CDDG) addresses the needs of individuals with developmental disabilities for habilitation, which is the acquisition or maintenance of skills to live with independence and improved capacity, and reduces the need for long term residential care. Services that a person with a developmental disability may receive from the program vary depending upon the person's age and unique needs. Services include supported employment, respite care, care coordination, day habilitation, case management, specialized equipment and Core Services. In some situations, the program may provide residential care in a group living or independent living arrangement. For those who meet the diagnostic and income limits, the HCBS Waiver Program may provide similar services. However, not everyone having a developmental disability qualifies for the Waiver Program. Additionally, everyone does not need the long term residential care that the MRDD Waiver is designed to provide. CDDGs allow cost effective service to be provided that is tailored to meet the needs of individuals, particularly for those whose families are their primary caregivers.

  This program also funds Core Services. Core Services are limited to $3,000 per person and offered to individuals on the waitlist for Waiver services who receive no other services from the Division. Early availability of Core Services may alleviate crisis until individuals are in need of long-term care and are selected off the waiting list.

- **Short-Term Assistance & Referral Programs (STAR)/Mini-Grants:** The STAR program assists people with developmental disabilities and their families in addressing short-term needs before a crisis occurs and to defer the need for more expensive residential services or long term care. Many people who are on the Developmental Disabilities (DD) Waiting List access STAR services. Allowable costs under the STAR Program include, but are not limited to, environmental modifications, adaptive equipment, and services that assist the family such as behavioral training, personal care, or medical appointments. Assistance with basic living needs necessary to avert a crisis that is not covered

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[6] This language was adapted from the DSDS website.

by another public or private program, such as emergency transportation and clothing, may be approved on a limited basis.

Mini-Grants are one-time awards made to individuals not to exceed $2,500 per recipient for health and safety needs not covered by grants or other programs and are to help beneficiaries attain and maintain healthy and productive lifestyles. The kinds of supplies or services the Mental Health Trust considers appropriate for Mini-Grants include, but are not limited to, therapeutic devices, access to medical, dental and vision care, or special healthcare needs. Adult dental care is the most frequently requested service by those who receive Mini-grants.

- **Nursing Facility Transition Program**: The funds from the Nursing Facility Transition Program can be used to help an elderly person or individual with a disability transition from a nursing facility back into the community. One-time funds can be used for:
  - Home or environmental modifications;
  - Travel/room/board to bring caregivers in from a rural community to receive training;
  - Trial trips to home or an assisted living home;
  - Payment for an appropriate worker for skill level needed;
  - Security deposits;
  - One-time initial cleaning of home;
  - Basic furnishings necessary to set up a livable home;
  - Transportation to the new home; and,
  - Other needed items or services may be approved by Program Coordinators.

  An eligible person is one who qualifies both medically and financially for the Medicaid HCBS Waiver program. The grant is used only for one-time costs associated with the transition; thereafter, the Medicaid program will pay for all services when the HCBS waiver is approved.

EXPENDITURES ANALYSES

We requested and received information on expenditures and recipients for many of the programs that Alaska operates and used these data to better understand trends and patterns within the program. Once we analyzed the data, we held a conference call with State staff to assist us in interpreting the meaning of some of the anomalies.

These analyses did not repeat the analyses that were included in the Public Consulting Group, Pacific Health Policy Group, and the Lewin/EcoNorthwest reports. Instead, our analyses focused on trying to identify anomalies in expenditure patterns. These analyses were helpful in understanding how the programs have been working and how providers and consumers have reacted and adjusted to policy changes the State made. These are the types of data driven program analyses that could be incorporated into our proposed restructuring of the State's Quality Management Strategy.

Table 3 shows that there has been a substantial increase in nursing facility expenditures and recipients from 2001 to 2007. The growth in the number of nursing facility residents fairly closely parallels the growth in the population which is at greatest risk of going into a nursing facility, individuals 85 years of age and older. This population grew 55.9% during this timeframe according to census bureau estimates for an annualized growth rate of 7.7%.

Table 3: Nursing Facility Expenditures and Residents from FY 2001 to FY 2007

	FY01	**FY02**	**FY03**	**FY04**	**FY05**	**FY06**	**FY07**[7]	**% Change 01-07**	**Avg. Annual Increase**
Residents	883	905	950	1,150	1,075	1,179	1,360	54.0%	7.5%
Expenditures (in millions)	$51.2	$59.9	$61.3	$57.3	$68.6	$72.0	$68.9	34.7%	5.1%

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[7] The increase in residents and decrease in expenditures from 2006 to 2007 makes it appear as though the average cost per resident decreased. We examined data on actual bed days and found that, in fact, the average daily cost of a nursing facility actually increased slightly over that time period (as it has throughout the 2001-2007 period).

There appeared to have been substantial increases in the number of nursing facility residents in 2006 and 2007. The annualized growth rate in residents from 2001 to 2005 is only 5% per year.

Table 4 presents summary characteristics for Alaska's four 1915(c) waivers from 2001 to 2004. We highlighted the rows for the CCMC and APD waivers to point out that these waivers grew at a substantially faster rate than the other waivers. DSDS staff attributed the growth in the CCMC waiver to the following policy changes:

- Improved outreach efforts that started in 2001;
- Increased coordination with and referrals from infant learning programs; and
- An increase in the number of DD nurses that resulted in greater outreach.

Table 4: Alaska Waiver Spending and Recipients

	FY01	FY02	FY03	FY04	FY05	FY06	% Change 01-06	Avg. Annual Increase
	Recipients							
CCMC	147	191	204	219	219	217	48%	8%
MRDD	814	866	935	976	1,014	1,013	24%	4%
APD	664	815	859	806	948	999	50%	9%
OA	1,128	1,269	1,339	1,290	1,420	1,500	33%	6%
Total	2,753	3,141	3,337	3,291	3,601	3,729	35%	6%
	Expenditures (in millions)							
CCMC	$6.3	$8.1	$8.5	$8.4	$8.4	$8.7	39%	7%
MRDD	$43.0	$54.8	$57.6	$62.7	$65.0	$67.5	57%	9%
APD	$8.8	$11.6	$14.2	$15.0	$15.1	$16.0	82%	13%
OA	$15.2	$19.8	$25.2	$27.3	$27.9	$30.7	101%	15%
Total	$73.3	$94.3	$105.5	$113.4	$116.3	$122.9	68%	11%
	Average cost per day							
CCMC	$129	$138	$126	$119	$118	$123	-4%	-1%
MRDD	$155	$176	$173	$178	$181	$183	18%	3%
APD	$45	$48	$53	$59	$53	$52	16%	3%
OA	$49	$53	$63	$67	$67	$69	41%	7%
	Spending per recipient on Care Coordination per day							
CCMC	$6.56	$6.74	$6.33	$6.17	$6.65	$6.65	1%	0%
MRDD	$6.59	$6.47	$6.45	$6.57	$6.67	$6.68	1%	0%
APD	$6.31	$6.32	$6.31	$6.32	$6.40	$6.48	3%	1%
OA	$6.31	$6.30	$6.37	$5.98	$6.28	$6.41	2%	0%
	% of spending on Care Coordination							
CCMC	5.1%	4.9%	5.0%	5.2%	5.6%	5.4%	6%	1%
MRDD	4.2%	3.7%	3.7%	3.7%	3.7%	3.6%	-14%	-3%
APD	14.1%	13.2%	12.0%	10.7%	12.0%	12.5%	-12%	-2%
OA	12.9%	11.8%	10.1%	8.9%	9.4%	9.3%	-28%	-6%

DSDS staff attributed the increase in the APD waiver to the following:

- Changes to the eligibility process that removed some barriers to entry;
- A limited ability to remove individuals who no longer met the NF-LOC because of a lawsuit;
- Spillover from CDPCA growth (people who were recruited for CDPCA were enrolled in the waiver);
- The nursing facility transition project; and

- People who were on the waitlist for the DD waiver with mental health needs were enrolling in the APD waiver because it was the sole mechanism for funding services.

We highlighted per recipient spending for the OA waiver because it was increasing at a rate that was more than double that for the other waivers. DSDS staff attributed this to a shift to cost-based rates in ALF care under this waiver in 2001. This resulted in an 86% increase in the costs for ALF care from 2001 to the 2008.[8] The Myers & Stauffer report should shed more light on this development and make relevant recommendations.

Lastly, we highlighted the percentage of waiver dollars spent on care coordination in ***Table 4****.* Because the rate for these services has been a flat monthly per diem and the average overall per recipient spending for the waiver has increased, this percentage has been dropping. It is reasonable to assume that the cost for paying for a Care Coordinator's time has increased during this time. Thus, providers have had to respond by either curtailing the amount of care coordination that they do or by reducing profits or incurring losses.

Tables 5 and 6 provide summary data on changes for individual waiver services between 2001 and 2006. We highlighted areas where spending was increasing quickly in yellow and areas where spending had decreased in blue.

The following services have decreased use across all waivers in which the service was included:

- **Environmental modifications**: DSDS staff attributed much of this drop to a decision to not approve modifications for ALFs and other efforts to reduce fraud and abuse. Some of the external stakeholders and Care Coordinators we met with argued that the approval process for environmental modifications was so difficult to navigate that the service was under-utilized. Some State staff also indicated that there is a lack of available providers.
- **Specialized Equipment and Supplies**: DSDS staff noted that they shifted most of the spending for these items to Durable Medical Equipment under the Medicaid State Plan (as mandated by federal regulations). One of the advocates argued that access to assisted technology should be increased under the waiver.

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[8] Analyses done by Pat Sidmore at DSDS.

Table 5: Summary Data on CCMC and MRDD Waiver Changes and Individual Services 2001-2006

	CCMC				MRDD			
	FY01	**FY 06**	**% Increase**	**Annual %**	**FY01**	**FY 06**	**% Increase**	**Annual %**
Recipients	147	217	48%	8%	814	1,013	24%	4%
Expenditures	$6,262,835	$8,719,379	39%	7%	$43,012,273	$67,533,185	57%	9%
Average cost per day	$129.09	$123.38	-4%	-1%	$155.27	$183.40	18%	3%
Individual Services								
Care Coordination	$318,350	$476,235	50%	8%	$1,824,316	$2,488,628	36%	6%
Respite Care	$740,006	$909,775	23%	4%	$1,794,455	$2,767,090	54%	9%
Residential habilitation	$4,132,129	$5,813,652	41%	7%	$31,878,620	$50,031,930	57%	9%
Day habilitation	$162,461	$594,318	266%	30%	$3,512,230	$8,981,604	156%	21%
Supported employment	$64,424	$13,218	-79%	-27%	$2,995,372	$3,860,833	29%	5%
Intensive active treatment/therapy	$109,542	$1,038,006	848%	57%	$93,066	$639,328	587%	47%
Environmental modifications	$156,344	$47,386	-70%	-21%	$197,605	$47,958	-76%	-25%
Transportation	$3,389	$3,253	-4%	-1%	$56,436	$62,455	11%	2%
Specialized equipment & supplies	$517,778	$63,937	-88%	-34%	$549,005	$20,346	-96%	-48%
Chore services	$58,412	$12,744	-78%	-26%	$89,957	$20,679	-77%	-25%
Meals	$0	$0			$4,440	$12,141	173%	22%
Specialized private duty nursing					$3,530	$0	-100%	-100%

Table 6: Summary Data on APD and OA Waiver Changes and Individual Services 2001-2006

	APD				OA			
	FY01	**FY 06**	**%Increase**	**Annual%**	**FY01**	**FY 06**	**%Increase**	**Annual%**
Recipients	664	999	50%	9%	1,128	1,500	33%	6%
Expenditures	$8,779,340	$15,978,460	82%	13%	$15,249,364	$30,703,844	101%	15%
Average cost per day	$44.73	$52.01	16%	3%	$48.80	$68.72	41%	7%
Individual Services								
Care Coordination	$1,238,159	$2,006,970	62%		$1,972,786	$2,904,889	47%	8%
Respite Care	$1,642,461	$1,127,241	-31%	-7%	$3,145,315	$1,615,668	-49%	-12%
Adult Day Care	$236,822	$531,735	125%	18%	$1,112,084	$2,004,223	80%	13%
Residential habilitation	$957,039	$1,528,386	60%	10%				
Day habilitation	$48,659	$182,163	274%	30%				
Supported employment	$42,798	$94,363	120%	17%				
Intensive active treatment/therapy	$6,379	$34,056	434%	40%				
Environmental modifications	$343,448	$241,189	-30%	-7%	$463,560	$308,809	-33%	-8%
Transportation	$312,947	$1,006,487	222%	26%	$404,109	$1,069,062	165%	21%
Specialized equipment & supplies	$482,014	$281,688	-42%	-10%	$552,936	$279,902	-49%	-13%
Chore services	$944,763	$1,170,370	24%	4%	$876,857	$1,206,753	38%	7%
Meals	$281,389	$724,615	158%	21%	$543,331	$900,804	66%	11%
RSLA	$2,168,167	$7,270,906	235%	27%	$6,043,292	$20,621,109	241%	28%
Specialized private duty nursing	$74,295	$58,022	-22%	-5%	$135,094	$62,093	-54%	-14%

- **Specialized Private Duty Nursing**: DSDS attributed much of the decreased use of this service to a change with one provider.

Costs for Intensive Active Treatment increase substantially across the three waivers in which it is offered. DSDS staff see this service becoming a "catch-all" for nursing and other needs that cannot be addressed using another service. The need for this catch-all may have increased as children with chronic medical conditions aged into the APD waiver and more people with DD were being enrolled in other waivers because of the waitlist on the MRDD waiver.

Respite care costs decreased substantially for the OA and APD waivers, while it increased moderately for the CCMC waiver and substantially for the MRDD waiver.

Day Habilitation costs skyrocketed for the three waivers in which it is offered. DSDS staff attributed this increase to greater awareness among Care Coordinators, more provider capacity, and a shift in services due to the caps that were placed on respite. Thus, the effort to crack down on respite costs may have inadvertently resulted in some people being moved to day habilitation programs. This may also explain the 80% increase for adult day care costs under the OA waiver.

Residential Supported Living (RSL), the funding source for ALFs under the APD and OA waivers, grew dramatically during this period and was the primary factor driving increased costs for these waivers. RSL expenditures as a percentage of all waiver expenditures increased from 25% in 2001 to 46% in 2006 for the APD waiver and from 40% to 67% for the APD waiver. The percentage of APD recipients receiving RSL services increased slightly over this period while the percentage of OA waiver recipients receiving RSL services increased from 32% to 44%. This marks a fundamental shift in these waivers from services in the home to services in ALFs, especially for older Alaskans. This supports a point that many of the external stakeholders made to us; State-imposed restrictions on in home services, such as personal care and respite, may have caused some people to move into ALFs rather than remain in their own homes.

Table 7 presents data on the use of PCA and waivers. These data capture the increase in PCA costs that peaked in FY06 and decreased after the State took steps to halt the growth. The main points to be gleaned from this table are as follows:

- Per recipient PCA spending was increasing dramatically until the State intervened.
- There was a large increase in PCA spending for the OA and APD waivers that corresponds to the placement of the caps on respite in 2004. This suggests a shifting of billing that is similar to that seen for day habilitation and adult day care.

- PCA makes up a large portion of long term care expenditures for Medicaid recipients. OA waiver spending through the waiver is roughly equivalent for PCA spending for OA waiver recipients. This demonstrates that PCA is a central service for waiver recipients.
- This point is even more dramatic when examining per recipient expenditures for only those waiver recipients who receive PCA (effectively leaving out people who are in ALFs). The average expenditure is $21,617 per year across all waivers and over $30,000 for the CCMC and MRDD waivers.

Table 7: Use of PCA and Waivers 2003-2007

	FY03	**FY04**	**FY05**	**FY06**	**FY07**	**% Change**	**Annual %**
Clients							
PCA & CCMC	48	89	80	58	51	6%	2%
PCA & MRDD	69	91	84	61	52	-25%	-7%
PCA & OA	720	685	721	764	781	8%	2%
PCA & APD	539	515	603	641	670	24%	6%
PCA & All Waivers	1,376	1,380	1,488	1,524	1,554	13%	3%
PCA Total	2,802	3,537	3,943	3,954	3,822	36%	8%
PCA & No Waiver	1,426	2,157	2,455	2,430	2,268	59%	12%
Expenditures (in millions)							
PCA & CCMC	$ 1.0	$ 1.8	$ 2.1	$ 1.8	$ 1.6	63%	13%
PCA & MRDD	$ 1.3	$ 2.2	$ 2.3	$ 1.8	$ 1.6	21%	5%
PCA & OA	$ 9.8	$ 12.1	$ 13.5	$ 14.8	$ 15.2	55%	12%
PCA & APD	$ 9.4	$ 11.7	$ 13.1	$ 14.9	$ 15.2	61%	13%
PCA & All Waivers	$ 21.5	$ 27.8	$ 31.0	$ 33.3	$ 33.6	56%	12%
PCA Total	$ 39.4	$ 65.6	$ 80.5	$ 83.8	$ 77.9	98%	19%
PCA & No Waiver	$ 17.9	$ 37.8	$ 49.6	$ 50.5	$ 44.3	148%	25%
PCA per recipient costs							
PCA & CCMC	$ 20,551	$ 20,525	$ 26,420	$ 31,298	$ 31,484	53%	11%
PCA & MRDD	$ 18,807	$ 24,619	$ 26,873	$ 29,838	$ 30,130	60%	13%
PCA & OA	$ 13,633	$ 17,678	$ 18,754	$ 19,308	$ 19,521	43%	9%
PCA & APD	$ 17,498	$ 22,631	$ 21,660	$ 23,229	$ 22,648	29%	7%
PCA & All Waivers	$ 15,648	$ 20,168	$ 20,802	$ 21,835	$ 21,617	38%	8%
PCA Total	$ 14,073	$ 18,547	$ 20,420	$ 21,200	$ 20,385	45%	10%
PCA & No Waiver	$ 12,553	$ 17,510	$ 20,188	$ 20,801	$ 19,540	56%	12%

Avg. hours per week per recipient							
PCA & CCMC	18.8	18.8	24.2	28.7	28.8	53%	11%
PCA & MRDD	17.2	22.5	24.6	27.3	27.6	60%	13%
PCA & OA	12.5	16.2	17.2	17.7	17.9	43%	9%
PCA & APD	16.0	20.7	19.8	21.3	20.7	29%	7%
PCA & All Waivers	14.3	18.5	19.0	20.0	19.8	38%	8%
PCA Total	12.9	17.0	18.7	19.4	18.7	45%	10%
PCA & No Waiver	11.5	16.0	18.5	19.0	17.9	56%	12%
PCA spending per all Waiver Recipients							
CCMC	$ 4,836	$ 8,341	$ 9,651	$ 8,365		73%	20%
MRDD	$ 1,388	$ 2,295	$ 2,226	$ 1,797		29%	9%
OA	$ 7,330	$ 9,387	$ 9,523	$ 14,766		101%	26%
APD	$ 10,980	$ 14,460	$ 13,777	$ 9,926		-10%	-3%
Spending per recipient - Waiver & PCA							
CCMC	$46,495	$46,744	$47,871	$48,547		4%	1%
MRDD	$63,001	$66,582	$66,341	$68,463		9%	3%
OA	$26,154	$30,526	$29,151	$30,303		16%	5%
APD	$27,500	$33,046	$29,673	$30,899		12%	4%

Table 8 shows that expenditures for General Relief dollars controlled by DSDS (which excludes those spent by the Division of Behavioral Health) increased at an annual rate of 14% between FY 2002 and FY 2008. Most of this increase was attributable to the growth of the number of clients, all of whom are being cared for in an ALF.

Table 8: General Relief Expenditures and Clients

	FY2002	**FY03**	**FY04**	**FY05**	**FY06**	**FY07**	**FY08***	**% Change 02-08**	**Avg. Annual Increase**
	Expenditures (in thousands)								
Total	$2,790	$1,956	$2,153	$2,981	$4,181	$5,791	$6,287	125%	14%
Recovery	($28)	($65)	($16)	($75)	($71)	($79)	($88)	212%	21%
Net	$2,762	$1,891	$2,137	$2,906	$4,110	$5,713	$6,199	124%	14%
	Average Monthly Client Count								
	218	229	210	246	337	433	411	89%	11%
	Average Cost Per Client Per Month								
	$1,056	$ 688	$ 848	$ 984	$1,016	$1,099	$1,256	19%	3%

* Estimated

OPERATIONAL REVIEW

Our business process analysis approach provides a holistic view of the service delivery system. This model captures the core business processes and views them not as separate components that can contribute to the effectiveness of a program, but as a set of interlocking complex business processes of which the interactions can be just as important as a single process itself.

Methodology

Exhibit 1 provides an overview of the business process model we used to analyze the core components of Alaska's long term care delivery system. This flowchart demonstrates the overall complexities of the basic delivery system, summarizes the overall process by which individuals access and receive supports, and incorporates the means of monitoring those supports.

The framework presented in ***Exhibit 1*** examines HCBS delivery systems from the following three perspectives: 1) individuals trying to access and receive services (consumer processes); 2) entities trying to become enrolled and act as service providers (provider processes); and individuals trying to monitor and manage the support delivery system (systems management).

The color blue is used to refer to key processes that are necessary for an individual to receive supports. The color red is used for processes whose core function is to monitor and ensure the quality of these services. The color green is used to show core functions necessary to ensure that providers are paid (i.e., claims adjudication).

The black box at the center of the diagram represents the IT systems that may be used to support each of the business processes. This box may include the following:

- Software that supports key functions, such as an automated assessment tool that informs eligibility determinations and support planning;
- Databases of raw information, such as client and/or provider characteristics; and
- Mechanisms for summarizing information so that it is more useable, such as the creation of data warehouses that match data from multiple databases and management reports that extract key pieces of data in a manner that can be acted upon (e.g., summarizing the number of critical incidents for a particular provider and if that number exceeds a set threshold, an investigation is triggered).

It is important to note that not all programs follow the sequential order included in this diagram. For example, Minnesota’s Comprehensive Assessment purposefully moves back the eligibility determination until after the assessment to try to eliminate a bias towards having funding streams, rather than assessed needs and preferences, driving the assignment of supports. Many states also set an authorization for a budget based on a more limited assessment and then require that case managers gather more detailed information and craft a service plan that fits within that authorized amount.

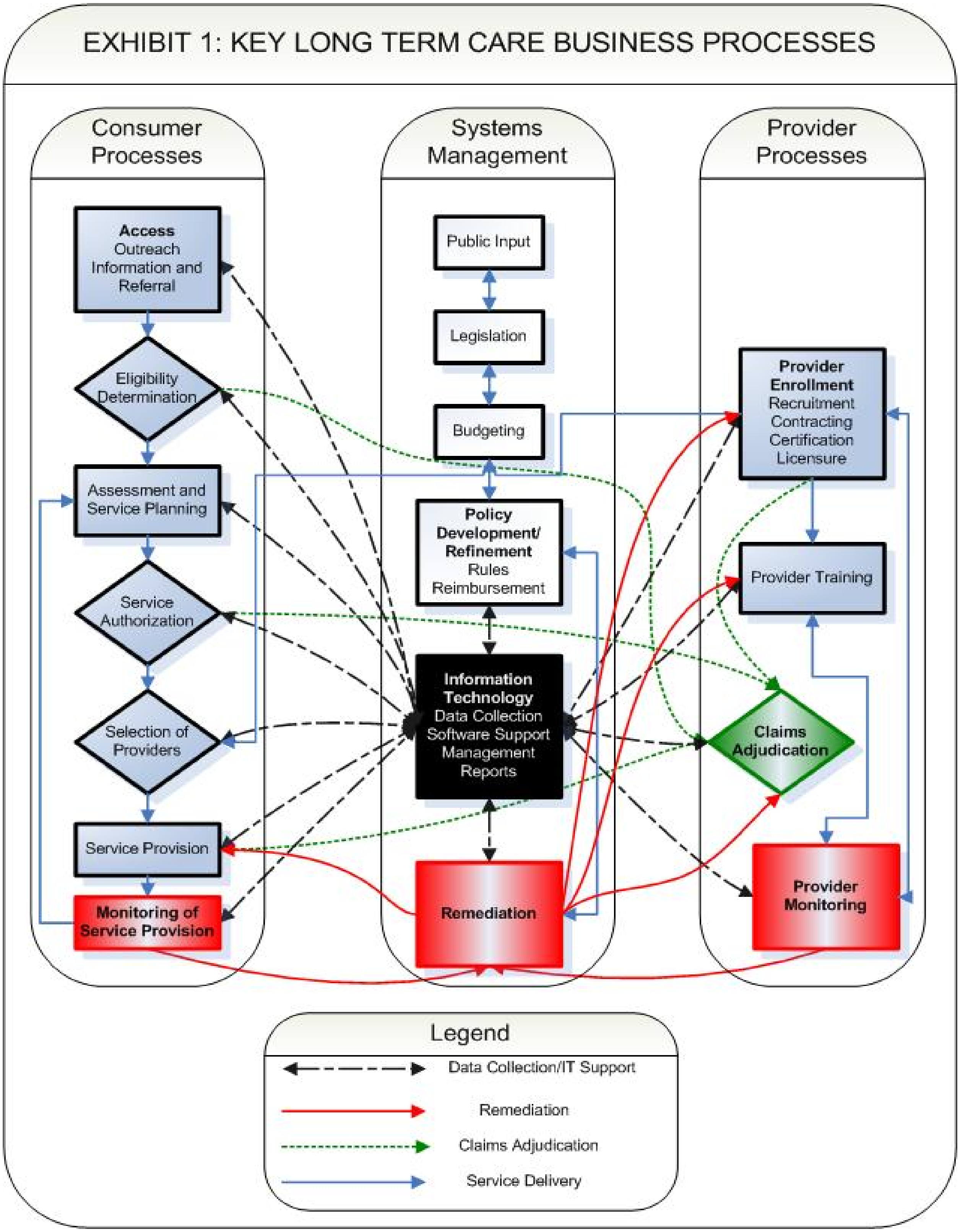

EXHIBIT 1: KEY LONG TERM CARE BUSINESS PROCESSES

CONSUMER PROCESSES

Accessing Services: Individuals in need of supports must be able to find them. State efforts can be broadly broken down into two key functions: outreach and information and referral (I & R) or assistance. For purposes of this discussion, we define outreach as efforts to inform individuals who could benefit from supports or entities that have contact with these individuals (e.g., physicians, hospitals, social service agencies, etc.) about the availability of these supports. Examples of outreach include educating hospital discharge planners about HCBS that are available or providing pamphlets at a health fair that describe a specific program. We define I & R as being the process through which individuals who express interest in receiving services are provided information about what is available and appropriate and how to access those services.

Our core areas of investigation in this area examined the extent to which systems used by consumers to find out about long term supports are successful in channeling consumers to services that are cost-effective, appropriate, and consistent with the consumer's preferences. Addressing this involved determining the following:

- To what extent is information about the range of long term supports available to individuals likely to need them? For example, in many states, it is easy to find out how to access nursing facility care, but relatively difficult to figure out how to access HCBS. States can compensate for this by working with the major pathways to long term care, such as hospital discharge planners, to ensure that they know about and refer people to HCBS options.
- Does the process for determining eligibility create distortions that may result in less than optimal service arrangements? For example, delays in processing the applications may create a barrier to individuals accessing HCBS more so than institutional care because institutional providers may have the ability to better manage cash flow, thus allowing them to start serving someone for whom eligibility has not been completed.
- Does the timeframe for starting services create distortions? For example, individuals in immediate need of personal care may be forced to move into an institution if a shortage of community-based direct care staff exists.
- Does the system include mechanisms to facilitate the ability of individuals with disabilities and their family members to make informed long term care choices? For example, the Administration on Aging's Aging and Disability Resource Center

(ADRC) effort includes efforts to create mechanisms to provide easy to understand information and counseling about long term care choices.

Sufficient and Appropriate Services: Another component of consumer access is whether preferred and appropriate services are available. States may experience a chronic shortage in certain service areas. Waiting lists for HCBS waivers or personnel shortages in State plan service areas such as home care or personal care services impair the ability of individuals to access supports in the community.

The core areas of investigation for this aspect of consumer access included the following questions:

- How does the State know what services a consumer might prefer and need? Does the system include mechanisms to identify who may be waiting for services and the urgency of need for that service? If so, how does the State routinely use that information to shape the development of services and providers to meet the needs of persons waiting?
- Does the system include mechanisms to identify gaps in service access where consumers have very specialized needs? For example, how does the State identify and address the challenges of low incidence disorders? How are culturally specific needs identified and addressed?
- Is there an approach that allows the State to anticipate, plan for, and project costs associated with future needs of consumers? What kind of information is used in this approach?

PROVIDER PROCESSES

Every state must have a mechanism by which providers are identified and selected. This effort often has two components: 1) efforts to recruit or develop new providers to ensure there is an adequate range of providers and 2) mechanisms to enroll or contract with providers.

Mechanisms for enrolling providers include the following:

- Allowing any qualified provider that meets certain criteria to enroll;
- Requests for Proposals (RFP), Quotations (RFQ), etc.; and
- Human Services Agreements.

In the case of Medicaid, these arrangements usually require that the entity be certified by the Medicaid agency to meet certain requirements. Often times, this certification includes or is replaced by licensure requirements for particular provider types. For non-Medicaid long term care services, states frequently qualify providers through an RFP or human service agreement process based the provider demonstrating an ability to meet the conditions that have been identified by the State.

The ultimate goal of this business process is to ensure that the supply of qualified providers reflects the types of long term care services that individuals demand. If this process does not fully achieve this goal, some individuals may end up in less than optimal support arrangements.

Our review addressed the process for recruiting and enrolling providers, as well as, the process by which individuals learn about and select individual provider agencies. Barriers that can distort the long term care delivery system that we looked for included:

- A lack of mechanisms for identifying when gaps in provider availability exist and/or the capability to recruit providers to fill these gaps;
- Barriers to the actual enrollment of providers, such as only allowing providers to enter the program through infrequent procurement processes (these barriers would also be identified as a compliance issue under Medicaid because they could violate any willing provider rules); and,
- Barriers to individuals selecting providers based on their preferences and the quality of the provider, such as a lack of information about what providers are available, what services they provide, and the quality of those services.

We looked for barriers to consumer-direction, such as prohibitions on agencies from hiring family members of individuals receiving personal care to allowing individual direct care staff to enroll as a personal care provider.

Analyzing System Management Capabilities Related to Access: Our review sought to determine the extent to which meaningful information about consumers' and providers' access filters up to individuals who are managing the long term care system. In our review, we applied the same framework to this area as we would to other systemic areas:

- Have performance indicators been selected and are they reasonable to assess access? For example, is there a target timeframe for eligibility determinations? Are there targets for the number of providers that should be available in particular areas?
- Are there mechanisms to gather data on these indicators?

- Are these data summarized into some sort of management report that facilitates decision making and remediation?
- Are there policies and procedures that ensure that these reports are acted upon?

We gathered information about each of these core business processes during a site visit in May 2008. Prior to the site visit, we developed and distributed a detailed protocol that identified the core areas of investigation and types of staff that we would like to interview. We then developed draft flowcharts and tables that summarized our findings. We received and incorporated input regarding these documents from the relevant State staff.

Findings

Table 9 provides a brief overview of each of the core business processes and a summary of our impression of the strengths and weaknesses of each component. Below we provide a summary discussion of the core consumer, provider, and systems management operations.

Table 9: Brief Overview of Core Operational Processes

	Brief Description of Process	Strengths	Vulnerabilities
Case Management	**Entity providing Case Management (CM)**: Case Management is referred to as Care Coordination (CC). There are 3 CC options. 1. Agencies providing direct care service can also provide CC, with the exception of Assisted Living (AL) providers that are licensed to serve older adults and individuals with physical disabilities. Prohibition for payment of residential supported living if the client is placed in ALF by a CC closely related as family or by business agreement. 2. Independent CC agencies that are not part of a provider agency or the State - can be an agency of only 1 CC. 3. The State has 2 CCs who are State employees within DSDS. **Method for Drawing Down FFP**: CC is a waiver service. Receive Medicaid administrative match for CCs who are State employees. **Qualifications**: A) BA, BS or AA degree in psychology, social work, rehabilitation, nursing or a closely related human services field, from an accredited college, and one year of full time, paid work experience with human services recipients and providers; B) 2 years of college credit, and 1 year of full time, paid work experience; C) 3 years of full-time, paid work experience with a minimum of 1 year (of the 3) of full-time, paid work experience; or D) Certification as a rural community health aide or practitioner, and 1 year of full-time, paid work experience. **Service Requirements**: CCs have standards of practice, including a description of their role in performing certain duties, including referral for assessment, development of service plans, notice of client rights, and change in client status. Practice standards also address conflicts of interest, timely submission of required information, and reporting requirements in the case of incidents or situations likely to be a detriment to the client. Most standards not promulgated rules. **IT Support**: CCs primarily fill out paper-based documentation. DSDS Assessment unit is using CAT/PCAT - entry on laptop, but does not enter into database. Print it out, scan, and is available as a pdf. Plan is to add to DS3. **Caseloads**: Case management reimbursement is probably sufficient to support caseloads around 25 to 1, however there are no caseload requirements nor tracking for non-state CCs. State CCs targeting a caseload of around 25 to 1. **Training**: Requirements are limited. Must attend CC training offered by DSDS every 2 years. Must complete online training and pass an exam.	Reimbursement rates. Caseload levels, if they indeed can be supported at 25 to 1 by the reimbursement levels, would be considered good.	Weak requirements for qualifications, training, service and caseload. Little information collected from CCs. Agencies that provide both CC and direct service may have conflicts of interest. Independent CCs may have little authority over service providers. CCs report that communication with State staff and access to important information is problematic. Reimbursement is a "flat rate" for services provided (monthly amount for ongoing CC, screening amount, etc.) This potentially creates some bias against individuals with more intense needs; however, information is not sufficient to determine that this is the case. CC standards of performance are not yet in regulation. Many CCs have caseloads that are too large. Caseload size is not regulated.

	Brief Description of Process	Strengths	Vulnerabilities
Access	**Outreach:** ADRC program and STARS expected to conduct outreach. Providers may conduct outreach. Some DSDS staff conduct limited outreach. Have a rural outreach position, which is currently unfilled. **Referrals:** Referrals come from hospitals, other social service agencies, social workers or word of mouth from other customers. Processing of referrals is complicated and differs for each program. NH Transition staff work with discharge planners. ADRC could serve to do that. **Triaging:** Only the DD waiver has a waitlist. Concerted effort to try to reduce the waitlist. Assessments triaged for crisis situations. **Tracking Ability:** DS3 has built tracking ability. Can now track when referred and timeliness for CAT/PCAT assessments. Using spreadsheets to track processing time for people being pulled off the registry. **Other Issues:** Early stages discussions about coordinating with 211 system operated by the United Way.	NF Transition effort appears to have been successful. No waitlists other than for DD waiver.	Little outreach. Lack of coordination for entry points across programs. No coordinated effort to organize and coordinate the flow of people coming into the program. Assessments may not be timely. DD waiver registry still lengthy.
Eligibility Determination	**Eligibility Criteria**: Individuals must meet NF level of care (LOC) for all waivers except DD, which applies the ICF-MR LOC. PCA criteria requires substantial need for assistance with ADL and/or medical needs that require assistance. **Determination Process**: Staff from DSDS Assessment Unit go out into the community to conduct the LOC Determinations. There are approximately 4 FTEs located in the DD Unit responsible for the ICAP. For CCMC waiver, nurses who work for provider agencies conduct the needs assessment, which is evaluated by DSDS nurses.	State took control of the process and established standardized forms ensuring greater consistency and control.	NF LOC criteria very restrictive, especially for individuals with cognitive impairments, such as BI and ADRD. CCMC still is dependent on provider assessment to determine eligibility. ADL impairment definitions do not consider environmental factors, such as the lack of running water.

	Brief Description of Process	Strengths	Vulnerabilities
Assessment, Service Planning, and Service Authorization	**Tools**: Consumer Assessment Tool (CAT) for all waivers except DD, which uses the ICAP. Use ICAP for MR/DD children. Use a different tool for other children - the NF Assessment for Children. All other programs use different assessment tools. **Process:** CCs develop a service plan that complies with the maximums set for individual services. The service plan is submitted to DSDS where it is reviewed by State staff who review the assessment information and service plan for the purpose of authorization.	State reviews all plans and has direct involvement with each case. This could allow the State to exercise greater control over quality and cost.	Inability to triage high risk individuals. Timeliness of assessments and authorizations. Tools only address a limited number of assessment domains. No direct linkage between assessment and service plan. Little incentive for CCs to ensure cost-effectiveness other than service caps. CCs not required to address PCA or acute care needs. Lack of clarity about what criteria State staff use to determine authorization amounts. CCs for DD and CCMC also reported that they are sometimes uninformed about what has been authorized. Difficulty of changing authorization amount may lead to over-authorizations.
Selection of Providers	**Mechanisms for Cataloguing Information About Providers**: Have a listing of all providers who are currently enrolled. **Process for Selecting Providers**: Individuals can select their provider, but there is limited information available about provider availability, capabilities, or quality. **Methods for Ensuring Providers are Available**: None	CDPCA gives individuals a great deal of flexibility in selecting providers.	Limited information about providers. Limited ability to determine and address where provider capacity is weak or oversaturated.

	Brief Description of Process	Strengths	Vulnerabilities
Monitoring of Service Provision	**Mechanisms for Ensuring Services in Plan were Billed**: Review of utilization done as part of annual review or amendment for some individuals in DD waiver, but not other waivers. Results are not captured in a systematic manner. **Mechanisms for Ensuring Claimed Services were Provided:** Consumers sign PCA time sheets for CDPCA. **Mechanisms for Tracking Unusual Incidents and Complaints**: DSDS has drafted an incident reporting system for waiver providers, grantees and PCA providers. In process of revising requirements to reflect stakeholder comments. Regulations must be promulgated to support requiring this reporting of agencies. Building criteria and capability to track in DS3. Have standalone database for incidents and HSS Track for complaints and incidents. **Other Mechanisms for Assessing the Quality of Services**: Conducting Participant Experience Survey (PES). Care Coordinators generally monitor services on a regular basis. CCs reported monitoring waiver services on a monthly basis, although caseload size and demands of the caseload during that month had some impact on their ability to meet this goal.	Reimbursement potentially could support relatively low caseloads.	CCs may not be in a good position to objectively monitor service quality either because they are employed by the provider or the provider does not feel obligated to be reviewed by the CC. Regulations are not clear that this is required from CCs. Little capacity to ensure care plan fulfilled. Limited capacity to verify billed services actually provided. Incident management system not implemented.

	Brief Description of Process	Strengths	Vulnerabilities
Provider Enrollment	**Mechanisms for Informing Providers about Where Services are Needed**: Informal means only. **Provider Enrollment Process**: Providers may enroll at anytime if they meet certification/licensure requirements. **Reimbursement Methodologies**: Use negotiated cost-based rates for most services, notably assisted living and habilitation services, and standard hourly rates for other services. PCA rate is defined and limited in regulations. In the past several years, DSDS has built better capacity to set negotiated rates and has centralized these functions. Rates have been frozen since 2004 until 2008 increase. Myers & Stauffer's effort should bring greater standardization to rates. **Provider Qualifications:** Providers are required to meet qualifications for each service. Qualifications generally include two components, education and experience. These components are tiered so that a higher level of education requires less experience. Experience for agencies, including supervisory experiences in the area of service enrollment, is being sought. PCA services for agencies also include requirements for RN supervision of direct care staff. Consumer directed services under PCA do not have this RN requirement. Training requirements are addressed below.	Comply with Medicaid Any Willing Provider requirements. Have started a comprehensive reform process under the Myers & Stauffer contract.	May have too many ALFs in Anchorage and undersupply of ALF and other services in other areas. Providers reported competition for staff. Provider qualifications weak especially for PCA. Lack of geographic differential in setting hourly rates problematic in frontier areas.
Provider Training	**Training Requirements**: Training requirements of 40 hours for agency PCA, but not for CDPCA. For CDPCA, the consumer is required to train the PCA. All direct service workers to have CPR/FA and universal precaution training. No mandatory training for other any waiver providers other than CC. PCA Agencies are required to take a mandatory orientation. **Training Opportunities**: APS offers training about mandated reporting requirements. DSDS has a training coordinator and offers CC, PCA Agency, and assisted living facility training. Majority of the training is related to certification requirements. **Mechanisms for Tracking Training Compliance**: Maintain a spreadsheet on CC training. CC's retest every two years when they recertify. PCA Agencies must have a certificate verifying they took the orientation training before becoming certified as a Medicaid provider. The DSDS PCA unit issues a certificate for PCAs that successfully complete the 40 hour PCA training.	Flexibility to set individual training requirements for CDPCA. Have hired a training coordinator.	Training requirements and tracking mechanisms are limited. Few training and support activities relating to hiring, training, and supervising are available for consumers participating in CDPCA. Few training opportunities for other providers.

	Brief Description of Process	Strengths	Vulnerabilities
Provider Monitoring	**Provider Qualifications**: ALFs must have an administrator who meets educational requirements, such as an advanced degree in a related area or 2 years of experience with the population, or a combination, to be licensed. Certification of Waiver Service agencies is considered and certified separately from the licensing determination. Other Waiver Services' certification requirements are all outlined in the Waiver Certification Packet. Agency Based PCA Agencies must have at least one supervisor who is a registered nurse meeting the following requirements: a) at least one year of full time experience in providing services within the human services delivery system and in supervising at least two staff in the provision of human services; and b) meeting educational requirements, which may include higher education (bachelor's degree) or other levels of education and training in combination with relevant experience. **Mechanisms for Monitoring Providers**: Licensing conducts annual onsite reviews of all ALFs and responds to complaints, incidents. SDS recertifies Waiver and PCA providers every two years. **Mechanisms for Tracking Monitoring Results**: APS and Ombudsman using Ombudsmanager. APS now transitioned to DS3. "HSS Track" tracks complaints given to QA. ALF licensing maintains 2 separate access databases for complaint and investigation tracking. Have State Circle of Care meetings every 6 weeks to coordinate. QA has piloted a record review process. **Remediation Tools**: ALF licensing appears to have a range of remediation tools that they appear to have the flexibility to apply. For other services, have Medicaid sanction tools to remediate.	ALF licensing appears to have strong remediation capability. There are tracking capabilities for all efforts. Circle of Care meetings help coordinate findings and actions. There appears to be a good informal structure for coordinating action steps.	Stronger remediation tools are needed for improving quality including: 1) ways to limit additional services or locations for problematic providers; 2) ability to freeze growth until issues are resolved; and, 3) ability to fine or otherwise negatively impact a provider. Need clearer program standards to base actions on. One size fits all approach to assisted living makes it challenging to develop more specific performance standards.

Care Coordination

Alaska has three types of Care Coordinators: Independent Care Coordinators, agency employed Care Coordinators, and State employee Care Coordinators. Agency employed Care Coordinators are employees of agencies providing a host of other services. This appears to occur most frequently in the DD and CCMC waivers. Qualifications required to be certified as a Care Coordinator are contained in the provider certification packet. Specific process requirements for Care Coordinators are contained in the regulations pertaining to each program.

Care Coordinators, whether independent or agency employed, are paid a flat monthly payment rate for each person served. For the service to be eligible for Medicaid payment, the consumer being provided care coordination must be on one of the waiver programs. The State receives FFP for the cost of this service.

Case management, the generic term often used for what Alaska calls care coordination, typically plays one or more roles in assisting individuals to obtain services in other states: 1) gate keeping; 2) advocacy; and 3) quality assurance. However, Alaska has effectively removed Care Coordinators from gate keeping; eligibility determination and authorization of services is performed by the State through the Assessment Unit within DSDS. The Care Coordinator is responsible to assist the person by completing a plan of service, identifying potential providers that are able to meet the needs of the individual, arranging services, and monitoring to ensure the service plan is implemented and continues to meet the needs of the individual. As needs change, the Care Coordinator will make changes in the service plan. Care Coordinators are required to record the nature, scope, and duration of services provided to each consumer on a monthly basis.

The State’s practice standards identify Care Coordinators’ duties. Although these practice standards contain requirements that are similar to those included in other states, Alaska’s standards lack specific and measurable indicators of performance. In addition, these practice standards do not have the force of regulation. Thus, the State is in a very weak position to enforce the quality of Care Coordinators because the performance criteria are vague (it is difficult to determine that someone is underperforming if adequate performance is not defined) and there is no legal framework to justify any corrective actions.

The provision of care coordination by agency employees creates an inherent conflict of interest. Although the gate keeping function has been taken on by the State agency, there are three remaining areas of potential conflicts of interest for agency employed Care Coordinators: 1) the ability to refer a consumer to appropriate services without pressure to use the agency employing the Care

Coordinator; 2) development of a plan of service that covers all areas that the provider is expected to address (even when that is not convenient); and, 3) the ability to identify and remediate problems with the performance of the provider. The care coordination practice standards' only requirement for addressing this issue is to require that agency employed Care Coordinators disclose this employer-employee relationship to the consumer.

A second concern is that Care Coordinators, who are in a front line position to be the eyes of ears of the State, are not systematically included in quality management processes. The State does not systematically collect any data from them. Care Coordinators also appear to be peripheral players in efforts to remediate problems, such as when an incident triggers a licensing or APS review. Care Coordinators reported that they did not have authority to require providers to respond to problems that are identified and further stated that they were, in fact, frequently ignored by the providers in their attempts to remediate a situation. Their recommendation is that improvements in the basic support infrastructure for Care Coordinators would enhance their effectiveness.

Reimbursement rates may be sufficient for supporting a caseload of 30 or lower[9], which would be consistent with best practices and lower than many other states. However, there is no caseload standard to ensure that Care Coordinators do not exceed a reasonable caseload. In addition, the flat monthly rate is problematic in two ways. First, it fails to tie the payment to the provision of services defined within the scope of care coordination. This could cause problems during a CMS audit because the State could not justify that reimbursement had any relation to the actual services that were provided. Second, the payment methodology fails to distinguish between individuals requiring very intensive levels of care coordination from those needing only minimal service, which may create a disincentive for Care Coordinators to serve people with more intense and challenging needs.

Care Coordinators also lack tools that are essential to being able to perform their core functions:

- Care Coordinators indicated that there is no formalized and ongoing line of communication with the State or among peers. Some Care Coordinators reported not receiving notice when services were approved by the State.

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[9] The monthly rate of $200 per month * 12 * 30 = $72,000. This would support a salary of $48,000 with a 17% fringe and 33% overhead rates.

- Care Coordinators identified a need for more training opportunities, peer mentoring for new Care Coordinators, and opportunities for interactive problem resolution.
- The State offers almost no IT support for Care Coordinators. Care Coordinators can fill in a Microsoft Word version of the Plan of Care. In other states, IT support improves case managers' ability to perform their job in the following ways: 1) Information can be easily retrieved and used to inform or reduce time spent on reassessments; 2) If linked to a database used for initial contact and intake, case managers will save time during the assessment process by not having to repeat requests for information already gathered during earlier stages of the consumer process; 3) Inconsistencies can be more easily identified and clarified during the assessment process, providing more accurate information for the service planning process; 4) Case managers can be given prompts about functions that need to be done ("ticklers"), such as reassessments; 5) If linked with a claims database, the case manager can potentially obtain important pieces of information such as inpatient hospital visits and diagnoses; 6) Case managers can more easily retrieve information from past assessments; 7) The automation can include guidance to train case managers about key policies or best practices; and, 8) Case files can be more easily shared and understood by other case managers who need to assume responsibility for a person.

Access

While DSDS staff conduct relatively limited amounts of outreach, the ADRC and STARS program are expected to conduct much of the outreach. In addition, providers may also conduct outreach. The State has a rural outreach position, which was just recently filled.

Referrals come from hospitals, other social service agencies, social workers or word of mouth from other consumers. Each program operates its own initial intake process creating major challenges to process a referral so that it results in the individual applying for the appropriate funding stream.

Generally, there is only limited coordination with a vital referral source, hospital discharge planners. Staff working as part of the State's Nursing Home Transition effort are working with discharge planners. However, this is not currently a major component of the ADRC effort despite AoA identifying this as a critical pathway to diverting institutionalization.

Triaging of people applying for services can be important at two different points. One, it is important to fast-track assessments and the authorization of services for people who are at immediate risk of placement in an institution or have a serious risk to health and safety. DSDS does have a process for triaging assessments, but there are concerns about the effectiveness of this process, which we discuss in the eligibility section. Two, if the State maintains a waitlist for a service, it should also have a mechanism for triaging individuals on the waitlist in order to prevent institutionalization or potential harm. Because only the DD waiver has a waitlist, this is not a concern for the other waivers. There is a mechanism for triaging people on the DD waiver waitlist in crisis situations and the State is engaged in a concerted effort to try to reduce this waitlist.

DSDS has been incorporating the ability to track referrals into the DS3. DSDS can now track when the individual was referred and timeliness for CAT/PCAT assessments. They are using spreadsheets to track processing time for people being pulled off the DD registry (when the plan comes in, when the services start, costs, and services used). The DS3 does not include any measures of the State's outreach efforts or the ability of individuals to access the eligibility process.

Eligibility Determinations

Eligibility for programs is based on a person meeting the criteria for level of care associated with a specific service as determined through the use of standardized assessment tools that have been adopted by the State. These tools measure deficiencies in a person's ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs). This would typically include measures of need for assistance in areas such as eating, bathing, grooming, and household activities.

The eligibility threshold for nursing facility level of care in Alaska is very restrictive and many people that are dependent are unable to meet the current criteria. The core of the issue is related to whether a person is physically dependent on assistance to perform activities of daily living, or whether because of cognitive disabilities (such as dementia or brain injury) they are unable to perform these activities without cuing or supervision. In the case of nursing facility eligibility, Alaska does not make allowances for the effect of cognitive disabilities, and requires that the person be medically unable or require substantial physical assistance in at least three activities of daily living. To be eligible for PCA services, a person must require significant physical assistance with at least two ADLs, and some assistance in at least one additional area.

State personnel perform all eligibility determination functions as part of an assessment unit. The biggest concern that we have about the operational performance of this unit is that consumers reported long delays in obtaining assessments, especially in remote areas.

Assessment, Service Planning, and Prior Authorization

In addition to determining eligibility for specific programs, assessment is used to inform the development of a service plan and authorize the type and amount of services that can be provided. The State uses several different assessment tools. The Consumer Assessment Tool (CAT) is used for seniors and individuals with physical disabilities for the OA and APD waivers, while the Personal Care Assessment Tool (PCAT) is used for the PCA program. The NF Assessment for Children is used with children in need of services. The Inventory for Client and Agency Planning (ICAP) is used for individuals with developmental disabilities for the DD Waiver.

The care plan is used to define what the person is entitled to receive. It is intended to match needs identified in the assessment process with a plan for delivering services. The care plan specifies the needed service, the amount of service, and what the service is expected to achieve. An approved care plan becomes the basis for legal appeals by the consumer if services are not provided, or are not delivered in accordance with the plan.

Prior authorization is the action taken by the State to approve a care plan. Prior authorization entails comparing assessment information to the care plan, and looking for consistency across the two. The State may approve services, request modifications in the care plan, or deny the request for services based on the review of assessment and care plan information and in accordance with State standards for what services can be approved. State staff conduct assessments, approve each care plan and establish prior authorizations.

Timeliness in completing assessments and prior authorizations was a major issue that was cited by multiple stakeholders. Many people seeking services from the State are in the midst of a caregiving crisis. Either the needs of the individual have suddenly increased (e.g., the person had a stroke) or the ability of the family caregiver has decreased (e.g., the caregiver strained his or her back). Without the provision of timely supports, the individual may be placed in an institution or there may be other adverse outcomes.

Table 10 shows that the average wait for an assessment was 30 days. The average wait time was substantially longer (44 days) in areas that had fewer than five assessments; these areas would typically be the most remote areas. Timeliness in completing assessments in the native villages and in frontier areas is a challenge because of the time involved in getting out to these areas. Stakeholders identified multiple circumstances in which it took longer than 90 days. The average is even longer for annual reviews. One stakeholder said it was taking longer than six months for reauthorization to occur. In a few cases, providers were experiencing gaps in payment while they waited for renewals.

Table 10: Timeframes for Assessments Conducted by Nurses Since the State Assumed Responsibility

	Initial			Reassessment		
	# of Assessments	**Longest Wait**	**Average Wait**	**# of Assessments**	**Longest Wait**	**Average Wait**
Statewide	2,260	206	30	5,758	371	33
Anchorage	1,153	206	28	2,717	371	36
Areas w/ Fewer than 5 Assessments	149	190	44	187	168	41

A number of the stakeholders claimed that these delays were adversely affecting individuals. We received several stories that provide anecdotal evidence to support this claim (see ***Appendix 3,*** Anecdotal Evidence of the Negative Impact of Delays in Providing Services).

In addition to the concern about timeliness, there are a number of other vulnerabilities in the assessment and care planning processes:

- The use of multiple tools and protocols makes it difficult to be efficient. The tools measure very similar areas, but each does so a little differently. In some cases, multiple assessments might be required prior to obtaining authorization of services from more than one program area.
- The current assessment tools and protocols are most useful for determining eligibility, but are too narrow for the development of a comprehensive plan of service. There are major domains that are not addressed, such as: need for referral to mental health treatment,

environmental or family circumstances which would influence the need for services, availability of unpaid support that might work in concert with paid supports, and individual consumer preferences (such as cultural). The current business structure fails to adequately consider these factors, all of which greatly impact the need for services.

- The current assessment process used by the State does not address a consumer's need for active treatment. The federal OBRA process requires states to screen individuals eligible for nursing home or ICF-MR levels of care for active treatment needs. If active treatment is required, this must be included in the service plan. Even if the service required is outside the scope of the program, the State is mandated to ensure that active treatment is provided in the areas needed.
- Stakeholders stated that there are cultural and language barriers between the assessors from the State and native Alaskan elders that impact the assessment process.
- The State lacks a clear process and criteria to tie together the assessment, care plan, and prior authorization.

Lastly, we heard from some stakeholders that because they cannot receive modifications to prior authorizations in a timely manner, they try to get everything that might be needed authorized in the annual plan. Thus, there appears to be a strong incentive to authorize more than is actually needed. While this practice helps avoid the need to change care plans, it also undermines the effectiveness of the prior authorization process.

Provider Selection

Consumers, assisted by Care Coordinators or others, must choose a provider of service once their eligibility and needs have been identified. In most states, this is frequently done through developing a potential provider list, interviewing or visiting the provider, viewing available quality and credentialing information, and checking with other users or former users of services. Generally, the state agency is responsible to manage the availability of providers for services. This is frequently accomplished through developing state profiles of services, doing need determinations in areas or regions, and using certification processes to track provider types and qualifications. Based on analyses of the information, the state can then determine what action steps are needed to address gaps or rebalance the array of services available.

Alaska lacks infrastructure to systematically gather and distribute information about providers and their capacity. Consumers appear to be selecting providers based on informal mechanisms (such as someone they know or local advertising by provider agencies). Care Coordinators often make referrals, but Care Coordinators often have limited information about providers.

Monitoring of Service Provision

Once supports are authorized and provided, states must verify that services have been provided and have been provided in a manner that is consistent with the support plan and the individual's preferences. Operationally, this area can be broken into ensuring that: 1) providers have filed claims for services in the support plan; 2) services for which claims were filed were actually provided; and, 3) services were provided in a manner consistent with the individual's needs, preferences and strengths.

Ensuring that Services in the Plan were Billed: A simple check on whether the support plan was fulfilled is to crosscheck that plan with filed claims. Finding that individuals were receiving substantially fewer services than they were authorized to receive could indicate that there was a shortage of appropriate providers or that a different service mix should be used.

With the exception of the annual review for the DD waiver, no one systematically compares services for which claims were filed with the original care plan.[10] Care Coordinators also have responsibility for monitoring care plans. However, they lack information on what was actually claimed and providers are under no obligation to share information with them. Thus, in most cases, ensuring that the care plan is fulfilled is left to the provider.

Ensuring Claimed Services were Provided: States have taken a variety of approaches to ensure that services were actually provided. These approaches do not necessarily need to take advantage of IT. For example, Illinois requires that parents whose children receive nursing services under the Medically Fragile Technology Dependent waiver sign each nurse's time sheet and that these timesheets be submitted with billings. However, this approach requires someone

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[10] There were some comparisons of service requests to previous utilization in the other waivers, but these reviews stopped in 2006.

to manually review these timesheets and match them up with a claim before that claim is paid.

Alaska does require that consumers sign timesheets for the CDPCA program. However, a consumer may feel pressured to sign timesheets that they know are incorrect for fear of losing the caregiver or because they are uncomfortable confronting the caregiver who may be a family member or a friend. There is no requirement for this verification or any other verification that services have actually been provided for any of the other services. Given the incentive to authorize more services than needed to avoid having to go through the authorization process again in the event that there is a change, an unscrupulous provider (or a provider facing a poor financial situation) may be tempted to bill for more services than they actually provided. Thus, there appears to be substantial opportunity for fraud and abuse.

Some providers do require a signature for other home-based services such as chore and home delivered meals. However, the State does not require this.

Tracking Unusual Incidents and Complaints: Unusual incidents are events that pose a risk to the health and welfare of the individual; actions (or inaction) that result in maltreatment or neglect; or are events that cause harm or injury to an individual. These incidents can range from slight to serious. In other states, providers are often expected to track all unusual events as a major component of their quality assurance and improvement efforts.

The State has been developing an incident management system. Although implementation of this system has been delayed to make modifications that respond to stakeholder concerns, they are making progress, notably adding capacity within the DS3 to collect and track these incidents. Successful implementation of this system will mark a major improvement in the State's capacity to identify and remediate problems.

In addition to DSDS' efforts, Alaska maintains separate Adult and Child Protection Units that are charged with investigating allegations of maltreatment and neglect. The Licensing Division may likewise have authority to investigate when the allegation relates to standards for licensure. The Provider Certification area is responsible for ensuring that qualifications, oversight, and training are complied with, and may work in cooperation with protection units and Licensing to take action. DSDS is adding the capacity to track investigations conducted by Adult Protection Services (APS), which is within DSDS, into the DS3. Eventual integration of these APS data with data from the proposed incident management system will benefit both efforts.

The current status of the department's efforts seems to be geared toward dealing with the most egregious situations. The planned enhancements will hopefully make it possible for DSDS to analyze trends or create reports that would help manage quality.

The major hole in this process is the lack of a central role for the Care Coordinator. The Care Coordinator is in the best position to monitor the health and safety of the individual, and could be the point person for assisting the individual to seek other services. In the current process, Care Coordinators are most frequently involved only when the investigators feel that they need information from the Care Coordinator. If the Care Coordinator is an employee of an agency, the Care Coordinator may be caught between acting as an advocate for the individual and assisting in defending the provider agency.

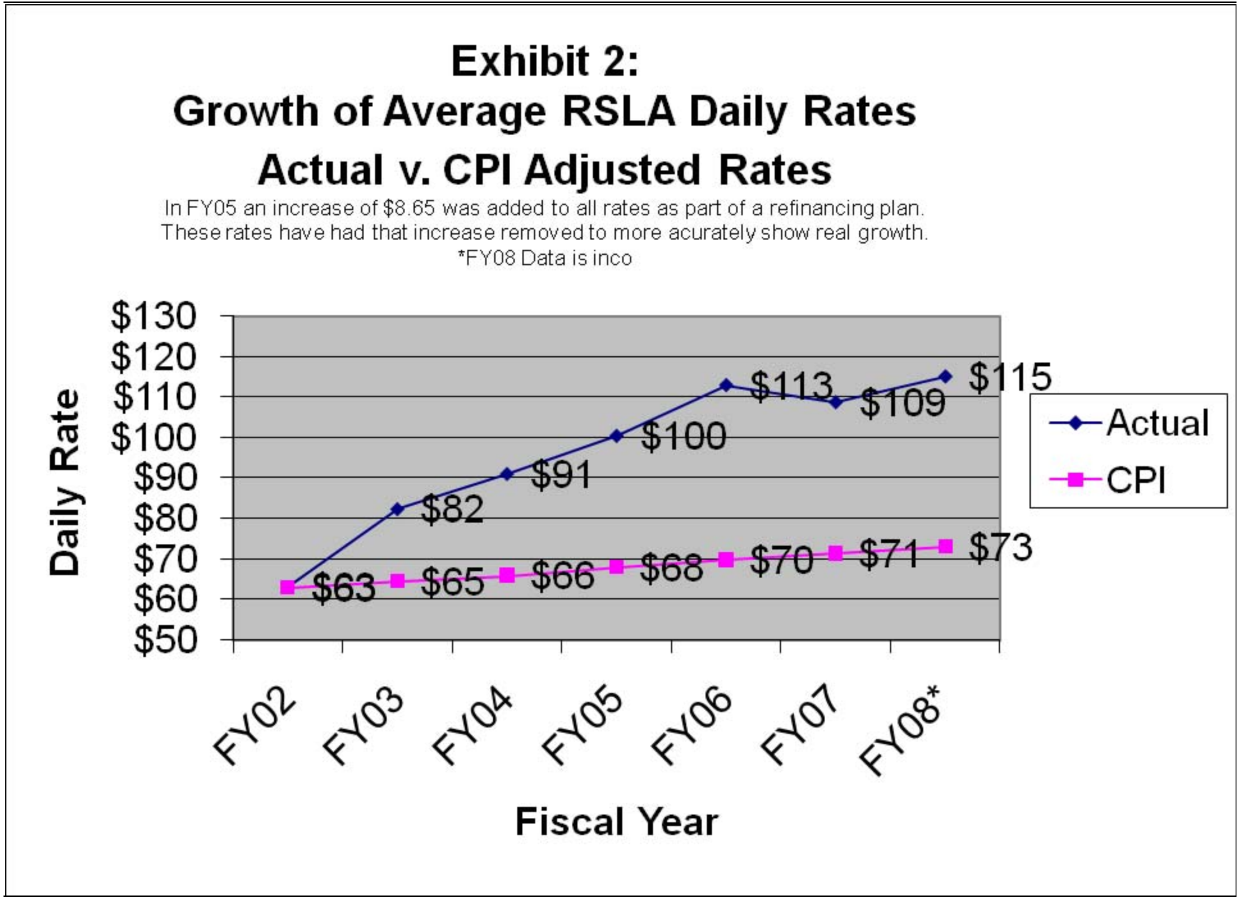
Other Mechanisms: Alaska has contracted for the completion of the Participant Experience Survey (PES), a tool developed with funding from CMS. This survey is useful for gaining a point in time picture regarding quality of life factors, consumer control over service delivery, and satisfaction with services.

Provider Enrollment

Every state must have a mechanism by which a provider becomes eligible to receive payments from the Medicaid program. This effort often has two components: 1) efforts to recruit or develop new providers to ensure there is an adequate range of providers and 2) mechanisms to enroll providers within the Medicaid program.

Federal Medicaid regulations require that states enroll any willing provider who meets the qualifications set by the state and is willing to accept the rate the state pays. Many states violate this rule by having RFP processes or other efforts that prevent some providers from participating in Medicaid. Alaska's processes appear to strongly comply with federal requirements.

Alaska uses negotiated cost-based rates for most services, notably assisted living and habilitation services, and standard hourly rates for other services. The PCA rate is a flat set rate of $21 per hour for both agency based PCA and CDPCA. These flat rates appear to be problematic for remote areas where service costs may be substantially higher. In the past, DSDS had a variety of individuals negotiate rates with different agencies resulting in inconsistencies. In the past several years, DSDS has built better capacity to set negotiated rates and has centralized these functions. Rates were frozen in 2004, but there has been an increase in 2008. The rate freeze may have had unintended consequences in that providers who had negotiated higher rates were better able to survive the freeze and may have been able to capture market share from providers with lower rates who either dropped out of the program or reduced their capacity. Thus, as ***Exhibit 2*** shows, the average cost in Residential Support Living Arrangement increased substantially faster than the Consumer Price Index (CPI) despite the rate freeze.



As the exhibit above shows, current reimbursement methodologies create distortions that impact costs and services. The State has contracted with Myers & Stauffer to reform rates. They are currently engaged in a cost survey that should serve as a basis for reformulating rate methodologies. For the most part, we have avoided making recommendations regarding rates because we recognize that Myers & Stauffer will have better information on which to base recommendations. However, we have proposed some expansions to their scope of work.

The State has no organized or systemic effort to determine availability of services, gaps in services, and overconcentration of one type of service over another. State staff, consumers, and providers claimed that in certain areas there was overconcentration of some services (like assisted living) while there were few support services for people continuing to reside in their home.

In reviewing the process for certifying that a provider is eligible to participate in the Medicaid program, we noted that many quality standards are contained in the certification requirements. Many of these requirements are only included in the certification requirements and are not included as a requirement for licensure. Because certification involves only a review of information in the application submitted and there is no other verification process for ensuring compliance with quality standards, there appears to be a gap in the State's approach to quality management.

We also found the provider standards in several areas to be very weak. Many services, such as PCA, have low certification thresholds. Little education or experience is needed to enroll as a provider, and there are few standards for describing what supervision and oversight must be done when the provider employs staff to perform services. We also found that there were few explicit standards addressing the provider's expected performance in areas such as behavioral management, monitoring for medication side effects, and consumer quality of life issues (such as access to age appropriate activities). In interviews with consumers, we heard concerns about the lack of age appropriate activities and requirements to ensure the consumer has access to community activities, family, and friends. We also heard that provider staff were not sufficiently trained to appropriately handle behavioral problems, mental health issues, or to recognize adverse reactions to medications.

Provider Training: Prior to the introduction of CMS' new application for the 1915(c) waiver, many states would have viewed training as a key provider business process, but not a key business process that the state must oversee. However, the instructions for the new waiver application include the following language:

"Conduct training and technical assistance concerning waiver requirements. *The performance of this function may include activities such as providing training to case managers concerning best practices in the development of service plans, acquainting waiver providers with waiver service documentation and billing requirements, and furnishing technical assistance to* *improve waiver operations. This function does not include training providers in order to assist them to qualify as waiver providers".*[11]

"The State implements its policies and procedures for verifying that training is provided in accordance with State requirements and the approved waiver.

The QMS [Quality Management Strategy] specifies:

- *The discovery processes that are conducted to ensure that training is provided and that the state takes action when providers do not meet the waiver's training requirements, who conducts discovery and with what frequency;*
- *Who reviews the results (data and information) from ongoing discovery activities to determine whether the performance of the system meets the assurance;*
- *Types of information used to measure performance of the system, including relevant quality indicators; and,*
- *The frequency with which system performance is measured."*[12]

Thus, DSDS has responsibility for conducting a limited amount of training and assuring that providers and their staff have met training requirements set in the service definitions.

Overall, regulations for waiver services have very limited training requirements. DSDS requires that all direct care workers have first aid and CPR training and a mandatory orientation. DSDS mandates 40 hours of training for agency based PCA. For CDPCA, the only training requirement is that the consumer is required to train direct care staff. The State provides little guidance or support to consumers in conducting this training.

DSDS currently offers limited training opportunities, but has hired a training coordinator to help rectify this situation. Currently, DSDS offers Care Coordination, PCA Agency, and assisted living facility training. APS offers training about mandated reporting requirements.

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[11] Application for a §1915(c) Home and Community-Based Waiver [Version 3.4:] Instructions, Technical Guide
and Review Criteria. Centers for Medicare and Medicaid Services. November 2006, pg. 60. Available at: http://www.cms.hhs.gov/HCBS/02_QualityToolkit.asp#TopOfPage .

[12] Ibid, pg. 232.

DSDS has some capability for tracking whether training requirements have been met. DSDS maintains a spreadsheet on Care Coordinator training. PCA Agencies must have a certificate verifying they took the orientation training before becoming certified as a Medicaid provider. The DSDS PCA unit also issues the certificates for individual PCAs that successfully complete the 40 hour PCA training.

The State expects providers and consumers to identify and direct the training of direct service personnel based on the needs of the consumer(s) served. The benefit in this approach is that it allows providers and consumers to choose training that is relevant to the people served.

DSDS has recognized that increasing training opportunities is key to improving the services. Alaska faces a daunting challenge in that it is spread over a large geography with a relatively small population that is culturally diverse. Thus, it is very difficult and cost-prohibitive to establish a rich training network that will meet the needs of all of the populations with disabilities and all the cultural groups.

Monitoring of Providers

For many community-based services, states have processes for reviewing the performance of individual providers that are separate from the monitoring typically done by case managers. States are more likely to have a formal licensure process for residential supports, such as group homes, and daytime supports that are offered in a facility specifically designed for individuals with disabilities and older adults (e.g., “brick and mortar” day treatment program, adult day care, etc.). States often have a certification process and/or annual review process for other supports.

Alaska uses provider certification, licensing, and administrative regulations to govern the practices and qualifications of providers. Alaska sets relatively limited provider qualifications for ALFs. ALFs must have an administrator who meets certain educational requirements, such as an advanced degree in a related area or two years of experience with the population or a combination to be licensed.

Waiver Service agencies are considered and certified separately from the licensing determination. PCA Agencies providing agency based care must have at least one supervisor who is a registered nurse with at least one year of full time experience in providing services within the human services delivery system and in supervising at least two staff in the provision of human services or meeting educational requirements.

Onsite monitoring of providers occurs as part of the licensing process. The Certification and Licensing unit within the Division of Public Health conducts reviews on an annual basis plus when an event or a complaint triggers an investigation. ALF licensing maintains two separate access databases for complaint and investigation tracking. There are also clear legal authorities that allow the licensing division to take action when problems are cited. However, the extent of that authority is only those standards contained within the licensing regulations and to providers who are required to be licensed.

However, many providers, such as PCA agencies and Care Coordinators, are unlicensed. Thus, the major process for monitoring these providers is the certification process. DSDS recertifies Waiver and PCA providers every two years. Provider certification standards include provider qualifications and they also incorporate administrative procedures that the provider is required to comply with. However, the function of the certification and enrollment area of the department has a more limited scope of responsibility and the authority to remediate relates to Medicaid enrollment. Although DSDS is in the process of developing a more robust provider certification process, it may be necessary to evaluate how provider requirements will be routinely monitored and remediated.

APS and the LTC Ombudsman may play a role for all long term care services by investigating complaints that they receive. Both entities use Ombudsmanager, a national system, to track investigations. APS is developing a more robust system that will be a module within the DS3. These entities also participate with ALF licensing and DSDS in an interagency group known as the State Circle of Care, which meets every six weeks to coordinate on quality issues.

Finally, because there are not performance measures to use in determining quality, it is not clear how practice standards are evaluated and what division is responsible to review performance.

STAKEHOLDER INTERVIEWS

Stakeholder interviews were conducted in order to gain a broader perspective on how well the current system functions. During these interviews, we obtained input about specific areas needing change as well as those that are working well, and tested assumptions and preliminary findings from work already underway.

The original RFP identified a list of stakeholders to interview. The Project Officer assisted us in identifying specific individuals from these organizations and expanded the list of interviewees. As potential areas of concern and recommendations emerged, we interviewed additional individuals who could help us shed light on a particular issue or provide an important perspective. The short time frame for the project limited our ability to personally interview all individuals who could have provided insight for this project. However, these individuals had the opportunity to submit input via the survey.

We conducted in person and phone interviews. All conference calls were web-enabled, which allowed participants to see and share presentation materials over an internet connection. An interview protocol guided our discussions with stakeholders. However, we tailored the questions to reflect the insights that each stakeholder could offer. The protocol covered the following areas:

- Overview of project;
- Overview of stakeholder’s role in long term care system;
- Consumer’s ability to access services;
- The role of care coordination;
- Eligibility criteria and types of services offered;
- Program rules and reimbursement policies;
- Quality management; and,
- Recommendations that stakeholder would like to see considered.

In all, we completed 12 stakeholder interviews, ranging from 1.5 hours to 3 hours each.

Interviewees

Stakeholders included a range of organizations representing different populations with disabilities, including councils, advisory groups, providers of service, and other partners of the State in the area of long term care services. We received excellent cooperation and only one organization contacted failed to follow up with our request for an interview.

Table 11 provides the names individuals and organizations that participated in this process.

Table 11: Stakeholder Interviewees

Interviewee	Organization
Denise Daniello	Alaska Council on Aging
Joel Niemeyer	Rasmuson Foundation
Kay Branch	Alaska Native Tribal Health Consortium
Linda Fink	Alaska State Hospital and Nursing Home Association
Millie Ryan	Alaska Governor's Council on Disabilities and Special Education
Patrick Reinhart	State Independent Living Centers
Connie Sipe	Center for Community
Jill Hodges	Alaska Brain Injury Network
Jim Beck	Ombudsman for Older Alaskans
Gwen Lee	ARC of Anchorage
Sandra Heffern	Job Ready Alaska
Tonja Rambow	Hope Community Resources Inc.
Emily Ennis	Fairbanks Resource Agency
Jodi Irvine	AgeNet

We also conducted two group meetings: one with Care Coordinators and another with tribal representatives involved in a work group addressing HCBS.

Common Themes

Stakeholders consistently cited the following issues with the long term care system in Alaska:

- System complexity;
- Limits on in-home services;
- Poor communication regarding changes to policies and procedures;
- Service rule inflexibility in adapting for rural and frontier needs; and,
- Failure to manage individual programs as part of an overall system.

Provider representatives also consistently told us that the reimbursement levels are having a negative impact on recruiting and retaining a skilled work force. The following summarizes the input of individual stakeholders:

Denise Daniello, Alaska Commission on Aging

Denise Daniello is the Executive Director for the Alaska Commission on Aging. She stressed that having a strategic plan for long term care services was very important and was currently missing. Ms. Daniello discussed several different studies planned or currently underway dealing with similar issues about long term care services for older Alaskans. She is hoping that these studies can be coordinated to facilitate next steps.

Ms. Daniello emphasized that the grant funding available to seniors has been very helpful in meeting needs in local areas. She was pleased to see increases appropriated for grants during recent legislative sessions and the increased rates for Medicaid waivers.

One of the important areas of concern for the Commission was the growing unmet needs of seniors. It will be important to provide outreach and information to people as they begin to plan for their older years. It also will be important to subsequently have adequate services available. She emphasized that building an Aging and Disability Resource Center would be key to assisting older adults to access appropriate services.

Ms. Daniello stated the NF-LOC should be modified so that individuals with ADRD could be eligible for waiver services. In addition, she also noted that there was a need to develop and implement behavioral health services targeting seniors to help with depression and alcohol/substance misuse. This would improve the quality of life for older Alaskans and reduce senior suicide rates.

Joel Neimeyer, the Rasmuson Foundation

Mr. Neimeyer works with the Rasmuson Foundation. He indicated that the Foundation is a partner in the public-private efforts to develop an Alaska strategy for long term care services. He views this current study of publicly financed long term care services as only one part of a broader effort that must occur. This broader effort will look at the role of individuals, public sector, and private sector resources in planning for and managing long term care needs.

He strongly supports efforts to carefully examine the specific operations of the long term care delivery system. He encouraged us to consider how this report might fit with other planning efforts that are looking at the vision for the system over a longer time horizon.

Kay Branch and the Native Alaskan HCBS Subcommittee

Kay Branch is the Elder/Rural Health Program Coordinator for the Alaska Native Tribal Health Consortium (ANTHC). She is working with a subcommittee that has drafted a proposal on how to structure HCBS to better meet the needs of Alaskan Natives.

She discussed how the State is looking at the feasibility of expanding different types of facility-based care (both nursing facility and ALF) that are tribally owned. One of the major factors was the ability to have a match in the number of people who need each type of services with capacity. Thus, there would likely only be sufficient demand for nursing facility care at regional hubs, while ALFs might work in mid-level hubs. She emphasized that there is a potential downside to any investment in facilities; once the facility is built there is a need to fill beds. Thus, these efforts could create incentives to move people out of their villages and away from their families rather than allowing them to receive supports that allow them to stay.

Ms. Branch stated that DSDS assumption of the responsibility for assessing individuals created major challenges in rural locations. She claimed that this created two issues. One, it took significantly longer to get assessments done, therefore delaying the start of services. Two, there are significant cultural barriers because the State assessors are outsiders to the individual and the tribe.

Ms. Branch thought that the nurses from the THOs who have established relationships with the tribes and frequently are onsite could perform assessments in a substantially more timely and appropriate way. We also discussed how a single point of entry under an ADRC model might work in villages. As a result of this brainstorming, we developed the recommendation for local system guides that could assist people with the first contact of the single entry point system.

Ms. Branch emphasized that care coordination is the gateway to services. She believes that no one is making sure that all the pieces fit together within the tribal health system with a few exceptions. The major barrier is maintaining a sufficient caseload.

She believes that the NF-LOC criteria is overly strict and creates an obstacle to access. She also highlighted a number of issues related to meeting the Medicaid financial eligibility criteria. She cited the example of how individuals living around the Aleutians often receive federal pensions that make them ineligible even though the cost of living in those areas, especially the cost of home heating, is very high.

She stated that reimbursement for Medicaid services is not sufficient for rural areas. The Myers & Stauffer effort should illuminate whether this is the case and propose ways of remediating this barrier.

She also cited the regulations regarding background checks as being inefficient. She recommended that the State consider altering these regulations and consider putting some of the onus on the Tribal Council for ensuring that an individual is an appropriate choice as a direct care worker.

Ms. Branch arranged for us to meet with the HCBS Subcommittee. Susan Cook, a consultant with ATHNC, facilitated the meeting. Several people participated in person, while others participated via a web-enabled conference call. During this meeting, they shared their draft proposal and we provided reactions regarding the feasibility of including components of the proposal under Medicaid. The proposal was well thought out and provided a great deal of detail. We recommended that the group further define who might be eligible under the effort. We also reviewed a draft of the Medicaid Funding Authority Crosswalk included in this report. This helped facilitate our discussion about the feasibility of using Medicaid.

The group provided us with the following observations about the current Medicaid program:

- Chore service is currently provided only to people who are eligible for a waiver. This should be an option for more individuals. They also had a concern about the prohibition of offering chore if there was someone who is able-bodied in the house.
- The definition of chore services does not address needs in rural areas, such as chopping wood, and hauling water and honey buckets.
- State employees were not familiar with rural Alaska and were, therefore, not in a position to determine what is an appropriate care plan.
- The rising cost of fuel and electricity is creating major barriers. This is a major challenge when you need to use an ATV or a snowmobile to haul water or visit with other people in the tribe.
- They recommended the adoption of a Universal Worker model that would have the same requirements for all services done by direct care staff (i.e., PCA, chore, etc.).
- Reimbursement is inadequate for rural areas.

We also reviewed the possible recommendations that arose during our discussion with Ms. Branch. The subcommittee strongly endorsed them. In addition, we discussed the possibility of altering CDPCA to a model more similar to Cash and Counseling and discussed how that model could address many of the concerns they raised. They believed this approach potentially had substantial merit.

Linda Fink, Alaska State Hospital and Nursing Home Association

Linda Fink is a Vice President with the Alaska State Hospital and Nursing Home Association. Ms. Fink indicated she was disappointed with the previous long term care reports because they did not supply recommendations that were accurate and specific enough to translate into concrete actions.

She described how out of the 15 facilities that have nursing facility beds, five are free-standing nursing homes, and only one of the free-standing nursing homes is an independent corporation. She emphasized that while she supports HCBS, the State needs to recognize that there are some individuals who require nursing facility care. She also described the recent efforts of their members to establish tele-health networks. She identified this as an initiative that is of growing importance in supporting people with chronic conditions given Alaska's geographic challenges.

Ms. Fink talked about her broad view of needing to offer consultation to individuals and families about planning ahead for long term care needs. She indicated that families should be encouraged and reinforced for such planning and for assuming responsibility to share in the care when care becomes necessary. She also recommended considering the use of mutual support networks and shared care for families and individuals as means to engage informal networks of support.

Ms. Fink emphasized that making informed choices about long term care means understanding the challenges of keeping a loved one in the home and the skills necessary to direct one's own service. We discussed the need to include this discussion as a part of a protocol for LTC Options Counseling, a function that is included as a part of one of our recommendations.

She would like to see the reimbursement system streamlined. She noted that the State has different methodologies for different providers; some facilities are rebased (the process of adjusting payment to reflect changes in actual costs) every four years based on cost reports, while others are rebased on a more irregular basis. She also felt that the State currently audits providers ad nauseam and that CMS reviews were problematic.

Because Ms. Fink represents a statewide member group, she is familiar with the special challenges of providing services in rural and frontier Alaska. She specifically expressed concern that we would not understand the needs of rural and frontier Alaska unless we viewed it personally.

Ms. Fink was positive about the efforts in Alaska to develop HCBS, but indicated grave concerns about the availability of skilled staff and the sustainability of a dispersed system of care. She stated that to be successful, the provision of HCBS would need to be more efficient. She also indicated that the lack of primary health care in many locations would make it difficult for people to remain in their homes, even if HCBS were available. She stated that lack of primary health care frequently forces people to hub areas where medical care can be provided.

Ms. Fink also expressed general support for the consumer directed options, but felt that it must be structured with more oversight than currently exists. She stated that many elders do not understand what they are getting into when selecting a consumer directed option, and that counseling would be helpful and important.

Millie Ryan

Millie Ryan is the Executive Director of the Alaska Governor's Council on Disabilities and Special Education. The Council's mission is to advocate for people with disabilities in three ways: capacity building, system change, and system advocacy.

Ms. Ryan has been very involved in the development and evaluation of the criteria for reducing the waiting list for services under the Developmental Disabilities Waiver. She indicated that changes in the criteria combined with a commitment to reduce the waiting list by 50 people per quarter was a positive change and going in the right direction.

She expressed concerns about the following areas:

- Although the STAR program is helping people with the eligibility determination process, she felt that the process is overly complex and the review and approval process at the State level is slow;
- Once a person is approved for services, the lack of skilled direct service staff complicates the process of choosing an appropriate provider. Ms. Ryan emphasized the importance of addressing the recruitment and retention of skilled staff, including looking at wage and benefit issues; and,

- The service array is inadequate for individuals with challenging behaviors. Ms. Ryan recommended the use of trained State employees or contractors to provide technical assistance on individual situations and training to caregivers about how to address challenging behaviors.

Ms. Ryan also made the following recommendations:

- Evaluating and possibly revising billing units to simplify service delivery;
- Adopting tools or systems to verify that services were provided;
- Implementation of a screening for autism and autism spectrum disorders;
- Piloting an effort to expand diagnostic capability, navigation of services, and family to family support;
- Expansion of supported employment to other disability groups; and,
- Improving quality assurance within residential and day habilitation services, including an emphasis on purposeful habilitation (i.e., make sure that the service is teaching the individual how to do the task rather than doing it for them).

Patrick Reinhart, State Independent Living Council

Patrick Reinhart was the Executive Director of the State Independent Living Council (SILC) at the time we interviewed him (he has since left the position). He emphasized that there is a need to recognize that effective solutions in meeting long term care needs must address issues holistically at the individual level. For example, to receive support in the home, the individual must have a home. Mr. Reinhart suggested that assessing basic needs is important to be effective. In addition, it is important to have related efforts between long term care and housing. Mr. Reinhart believes that housing programs frequently do not achieve results because there is no connection to the other supports that individuals with disabilities need.

Second, Mr. Reinhart discussed how they spent a lot of time and effort building cooperative agreements with senior centers. Under the ADRC initiative, they also built the Alaska Network of Care website (alaska.networkofcare.org). This website helps individuals with disabilities and seniors identify and coordinate with providers. He recommends that the State either supply additional funding for supporting this effort or folding the capacity within the DS3. He also believes that the availability of long term care options counseling is essential in allowing people to make informed choices.

Lastly, we discussed care coordination. Mr. Reinhart believes that Care Coordinators should be independent from providers of services. In areas where this is not possible, there should be advocacy networks, such as Centers for Independent Living, available to assist people.

Connie Sipe, Center for Community

Connie Sipe is the Executive Director of the Center for Community, a service provider headquartered in Sitka. She emphasized the importance of Alaska having a clearly articulated policy for long term care services that is translated into action steps that are consistent with the policy.

Ms. Sipe identified significant challenges with any approach that is too strongly centralized, and that allowing for some regional variation will be key to creating a strong, overall system. She noted that regions vary in terms of economics, geography, education and training, transportation, health care, and other primary components of community infrastructure.

Ms. Sipe observed substantial differences in service system history across populations with disabilities. These differences in background and experiences impact the choices people make and have set the standard for what people have come to expect.

Ms. Sipe stated that agencies in rural areas must address a wide range of needs. Efforts to restructure access should include using natural local points of contact, such as senior centers or other entities. Seniors, or others, would be less likely to go to special entry points for help or information.

Ms. Sipe expressed strong views that some of the decisions made on limits to less intensive services may have gone too far, and as a result people are institutionalized at a far greater cost. She acknowledged that limits had been appropriately placed on some services because of utilization that was not appropriately controlled.

Ms. Sipe also provided several examples of where service access was limited by an inability to attract workers and to maintain pay levels that are competitive with other entities. She was concerned that certain groups, especially in rural areas, were underserved.

Jill Hodges, Alaska Brain Injury Network

Jill Hodges is the director of the Alaska Brain Injury Network (ABIN). Ms. Hodges discussed the efforts her organization is currently undertaking to identify potential service options. The Network is currently working with a consultant to identify what other states are doing and what might work for Alaska’s citizens with brain injury. Much of this discussion has occurred with State staff in behavioral health, senior and disability services, injury prevention, Bring the Kids Home (BTKH), and workforce development areas of DHSS. Community providers and non-profits serving Alaskans with TBI have also been included in the discussion.

ABIN has taken the lead for developing a plan and recommendations that cover all services and supports, including prevention that may be needed for individuals with TBI to recover after TBI, transition to and return to living and working in the community as independently as possible. She noted that some individuals with TBI have co-occurring conditions, such as behavioral health or substance abuse problems, and without rehabilitation and long term services and supports, these individuals are at risk for being served out of state, in institutional or nursing home settings, correctional facilities or being homeless. She discussed how for individuals who are Medicaid eligible and need HCBS, Alaska waivers are currently restrictive both in terms of eligibility and scope of services provided. ABIN would like for waiver services to be broader to include short-term rehabilitation/therapies, behavioral supports for individuals with TBI, in-home supports, and other services that are in more keeping with TBI and other HCBS waiver services. In addition, ABIN wishes for individuals who sustained injuries after the age of 22 and are under the age of 65 to have these services.

Ms. Hodges noted that the level of care determination process, however, needs to recognize cognitive disabilities (i.e., memory) in determining the functioning level of the person. She discussed how a person with cognitive disabilities may be able to perform activities of daily living, if told or otherwise cued, but without supports, would not be able to engage in these functions placing them at risk (i.e. remembering to take medicine, to shop, remembering how to prepare food or to eat, etc.). She believes that service or care coordination is an essential service for most of these individuals. ABIN supports Alaska developing a separate waiver for TBI, but would also support expanding current waivers to serve TBI, should those waivers meet a person's needs. ABIN also supports self-directed services, but individuals with TBI may need an intermediary or other supports (person centered planning process/team of supports) to help with that.

Jim Beck, Access Alaska

Jim Beck represents Access Alaska, the largest Center for Independent Living in the State with offices in four locations. Access Alaska provides a number of services, and until recently, held the contract to run the ADRC for the State in

Anchorage and Fairbanks. Mr. Beck indicated that a growing number of people served by their agency are over the age of 62.

The CDPCA program has become a central activity for the agency. The agency is a fiscal intermediary and employer of record. They provide some individual training for consumers on what consumers need to do in using CDPCA. Access Alaska trains PCAs and also provides basic information on health and safety. The agency sets the wage level and provides paid holidays and health insurance for individuals that are working full time. Mr. Beck noted that the State reimbursement rate offers no career building opportunities for workers, and sees that as something that would help in recruitment and retention.

Mr. Beck stated that working with the ADRC had been "an adventure." He indicated that it had been quite a struggle to be seen as an agency that did serve both seniors and people with disabilities.

Mr. Beck provided a number of examples where access had been limited due to the lack of available information and assistance. His agency intends to perform all ADRC functions, but not as an ADRC contractor.

Mr. Beck also indicated that there continued to be a lot of work needed on the design of an ADRC system. The contract that Access Alaska operated under did not work well with the agency's business model.

Mr. Beck also indicated that there needed to be operational infrastructure to ensure that assessments and eligibility determinations are timely. He indicated that rural areas were being especially adversely affected by delays associated with the current structure. He also discussed related problems with service availability in rural and frontier areas, especially native villages. He felt that many people were forced to move to hub areas to receive services.

Mr. Beck gave several examples of how current regulations and limitations on services negatively impact people living in village or rural areas. He discussed cultural barriers that significantly impact access to services for Alaska natives. He recommended changing the way "the system" is presented to native people, meaning that their cultural frame of reference is not similar to how the service delivery system is described. He indicated that these types of up front barriers were substantial enough that elders walked away from needed services.

Mr. Beck gave specific examples of how the existing assessment protocols and services are not appropriately designed to meet the needs in the frontier areas. He recommended changes that would incorporate thinking about the intersection of functional need with environmental issues.

Mr. Beck spoke about a number of underserved groups, such as individuals with brain injury. His agency serves a number of people with brain injury related disabilities. The lack of services, including care coordination, available to people with brain injury, has very detrimental effects on these individuals.

Mr. Beck indicated that his agency had pared down their involvement as Care Coordinators. He is concerned about whether an independent model of care coordination is feasible without increased training and support from the State.

Gwen Lee, ARC of Anchorage

Gwen Lee is the executive director of ARC of Anchorage, an advocacy organization and a provider of services for people with disabilities. The ARC provides DD waiver services, grant services, care coordination, behavioral health services, CCMC waiver services, and services to people who are deaf and hard of hearing.

Ms. Lee indicated that ARC was pleased with the commitment for taking 50 people each quarter off the waiting list and that the new criteria being applied seem to work well. She also indicated that updating assessment information to indicate urgency in the need for waiver services is a key component.

She also indicated that STAR is working very well and that the various networks work collaboratively.

Ms. Lee indicated that the amount of paperwork prevents Care Coordinators from doing quality monitoring, which should be part of their role. Her general recommendation would be to streamline these types of requirements in order to allow more time for interaction with the consumer.

Ms. Lee indicated that Intensive Active Treatment has worked fairly well for positive behavioral plans and she indicated that the waiver eligibility criteria for the DD waiver is not problematic, though she noted that others might want it to be broader.

Ms. Lee also indicated that she feels the grant programs are very valuable for providing basic services to people who are less in need of waiver services. The grant funding is flexible and is useful in meeting smaller needs. She indicated that targeted case management would be useful for some of individuals who are not eligible for the DD waiver.

Sandra Heffern, Job Ready Alaska

Sandra Heffern is the Director of Job Ready Alaska, an organization providing waiver services, PCA, CDPCA, and care coordination.

Ms. Heffern noted that there are many points of access to the long term care systems and the ability to successfully obtain appropriate supports depends upon the individual's skill at navigating a complex system. Although her agency performs intake and provides information and assistance to people, she supports allowing people to "go shopping" for service provider(s) that will best fit their preferences.

Ms. Heffern indicated that, historically, there was not a separate organization in DD that would perform care coordination. She indicated that she could support independent care coordination; however, she is concerned about the impact on quality assurance. If the State were to take such an action, she would encourage them to ensure that they were adequately supervised. She also emphasized the need for better software support for Care Coordinators, but is concerned about the State's ability to develop an appropriate system.

Ms. Heffern would like to see eligibility changed to better serve people with ADRD.

She would like to see changes that would allow and promote companion services and respite services (additional and more flexible). She also indicated that the criteria for chore services are too restrictive. She argued that current regulations create barriers to family members providing care. In addition, the regulations do not consider the personal nature of some of the needs. For example, it could be uncomfortable for a sister with care needs to have her brother performing intimate care tasks.

She discussed changes that had been made to control costs in the PCA program, including changes to the assessment process. While she recognizes that the changes were necessary to ensure that there are qualified assessors, she is very concerned about the length of time that it takes to complete the assessment process and to obtain authorization for services. There is an expedited assessment process for individuals with more critical needs; however, Ms. Heffern said her agency's experience with this process has been uneven. While assessments have occurred quickly in some cases, in others, they have taken up to six weeks.

She noted that these delays have created a major bias that favors ALFs over in-home care. Once someone indicates that they are going into an ALF, their assessment is given priority.

Ms. Heffern also recommended the adoption of a universal worker policy. Lastly, she stated that she was thrilled that DSDS is finally looking at a process for setting rates.

Tonja Rambow, Hope Community Resources, Inc.

Tonja Rambow is the Deputy Director of Community Support Services for Hope Community Resources, Inc., a private, not for profit agency operating statewide. The agency serves approximately 975 people of which the majority are people with developmental disabilities or children with chronic health conditions. They provide a full range of service types.

Ms. Rambow indicated that receiving services was simpler and faster when the predominant funding source was State grants. She noted that the service delivery system has evolved to be more complex and requires substantially more paperwork. Although the additional money provided through Medicaid has been important for supporting people, it has made the delivery system more complex.

Ms. Rambow is supportive of allowing people to choose their Care Coordinator and believe that an independent Care Coordinator model could help eliminate potential conflicts of interest. She noted that Hope has created their own firewalls to try to prevent this from occurring when the Care Coordinator is a Hope employee.

She also believes that Hope provided Care Coordinator greatly exceed what the State required, including being more actively involved in the consumer’s life.

Hope’s experience has been that the external Care Coordinators are less involved and their skills vary substantially. While she was supportive of mandating that goals be included as part of care plans, she currently believes most goals that are written into plans are deficit based versus addressing improving quality of life and responding to the person’s interests.

If the State were to require Care Coordinators be independent of service providers, she would encourage the State to carefully orchestrate the implementation of this effort. She stated that this initiative should be done in conjunction with an additional effort to strengthen care coordination requirements so it is more explicit that the Care Coordinator be a client advocate. She also emphasized the need to have a clearly articulated value system that serves as a framework for the delivery and oversight of care coordination. She recommends that the State develop a process for evaluating the work of Care Coordinators and a grievance process for unhappy consumers.

Ms. Rambow thought that while the eligibility criteria was not a barrier for entry to the CCMC waiver, restrictions in the definitions for “related conditions” were creating barriers for the DD waiver. Additionally, the NF-LOC criteria created a major barrier to serving people on the APD or OA waivers, especially for people with TBI.

She also thought that the current service array should be expanded to add the following:

- Behavioral services;
- Services to intervene with people with high risk behaviors;
- Stronger crisis services;
- Adult dental care; and,
- Respite care for people on a wait list.

Ms. Rambow argued that communication with the State is not consistent and that different State staff provide different interpretations of program polices. She noted that announcements and information are released a variety of ways, making it difficult to keep up on all policy changes. She also was not sure how consumers were alerted to policy changes that could affect them.

She believes that the State perceives the providers as being greedy and this complicates developing a partnership. She believes that State staff should be working with providers to solve problems.

She noted that Hope has experienced gaps in payment because of reauthorizations taking more than six months.

Ms Rambo was concerned that the State's monitoring process is not focused on the experience of consumers. She believed that licensure reviews were focused on paper compliance and that consumers' input is not sought.

Finally, she recommended that the State develop guidelines around involuntary discharge by providers to protect people from being "abandoned" because providers do not want to do the work to maintain services. She noted that Hope has a policy against involuntarily discharging consumers.

Emily Ennis and Jodi Irvine, Fairbanks Resource Agency (FRA) and AgeNet

Emily Ennis is the executive director of Fairbanks Resource Agency (FRA), a provider of services for people with developmental disabilities and chronic medical conditions seniors with Alzheimer's disease and related dementia. FRA serves approximately 600 individuals of all ages and is a designated STAR program. Jodi Irvine is the Senior Services program director for FRA and is the president of AgeNet (a state-wide advocacy group comprised of 25 different provider agencies).

Because FRA is a STAR program provider, they assist people through the access process. Ms. Ennis indicated that the application and eligibility process has become very complex and includes extensive paperwork to be completed. She also explained that there were recent changes in interpretations of eligibility and particularly for seniors, there is a heightened emphasis on medical needs. Some of this may have served to narrow how eligibility criteria are applied.

Ms. Ennis stated that additional requirements and State staff changes were delaying the timeliness of assessment and access to services. Scheduling problems for State contracted assessments have caused additional delays.

Her agency usually plans for at least a 90-day turnaround period for authorizations and reauthorizations of services once documentation is submitted. There had been some instances in which payment lapsed because the reauthorization had taken longer than 90 days, and the annual renewal date had passed thus the agency is unable to bill for services rendered for duration of months.

Ms. Ennis indicated that her agency is a recipient of grant funds and that these funds are very flexible. The agency's access to grant funds allows FRA to do a better job of matching the funding stream with the service need and choice.

Ms. Irvine joined our conversation and reinforced that Senior and Family Services is also experiencing issues with the timeliness of assessment and authorization of services. She felt that the assessment process was pushing people toward more intensive levels of care, as delays were preventing people from obtaining the right amount and type of service when they need it. She had seen delays of four to six months. By that time, the situation had deteriorated and more costly and intense services were needed.

Both Ms. Ennis and Ms. Irvine discussed the need for some accommodation for people with Alzheimer's, dementia and brain injury to be able to receive HCBS waiver services. They both indicated that additional services should be developed to assist families and others to deal with behavioral issues of consumers.

Finally, Ms. Ennis and Ms. Irvine expressed that communication between the State and providers had been inconsistent and sporadic for several years. Both recommended that improving communication and making the systems for sharing information more user friendly is important to providers.

Care Coordinator Focus Group

We interviewed a group of Care Coordinators, representing all forms of care coordination. The discussion addressed the following:

- Care Coordinators currently have limited access to training, information, and other resources that would help in the performance of their job.
- Initial training is available to Care Coordinators, but little is offered on a routine basis after the initial training is completed. Training has varied in its quality over the years as well.
- Care Coordinators have developed informal networks among their peers. This is valuable, but is not statewide and many Care Coordinators are left out of these networks. Care Coordinators, especially those that are independent, see a great benefit in being able to work with a group of colleagues to do problem solving and to share information.
- Care Coordinators would like to see more interaction with State program staff to discuss issues and to obtain clarifications about expectations.
- Care Coordinators lack an efficient way to submit information about service approvals, and frequently find themselves involved in labor-intensive exchanges of paperwork. This delays service approvals.
- Care Coordinators frequently do not receive notice about authorizations.
- We noted differences in experiences with the authorization process depending upon the personal relationships that Care Coordinators had with assessment staff. It appeared to be more difficult for Care Coordinators who did not know State staff.
- Care Coordinators were not always clear about the criteria applied for approving services. There seemed to be variations from client to client and depending upon the State personnel doing the approvals.
- Agency based Care Coordinators indicated that they felt pressure to refer clients to the agency for services.
- Independent Care Coordinators indicates that they felt some pressure from providers for referrals, especially if the provider was likely to send someone to the Care Coordinator for initial steps in obtaining services.
- Independent Care Coordinators talked more often about having no authority to make changes when they saw something wrong in how services were provided.
- Care Coordinators would like to have more access to automated systems to help them with their work.

- Care Coordinators do a wide variety of activities. It was our opinion that some of these activities may not actually fall into the definition of case management. For example, Care Coordinators in some cases appeared to be providing crisis support services.
- Care Coordinators differed in their experiences with quality assurance. Agency based Care Coordinators seemed to be more involved in quality assurance on a regular basis. None of the Care Coordinators reported that any of their quality assurance activities were communicated to the State.
- Care Coordinators working for agencies were more likely to be involved in helping the agency remediate problems that were cited or being investigated by the State. In some cases, this conflicted with their advocacy role for consumers.
- Only one of the independent Care Coordinators was requiring data from providers about services and this Care Coordinator reported having problems obtaining information. Other Care Coordinators were meeting with providers, but did not routinely collect data about active treatment or other services.

CONSUMER FOCUS GROUPS

Purpose and Methodology

During the week of June 23, 2008 through June 27, 2008, we held consumer focus group sessions in Anchorage, Juneau, and Fairbanks. The focus groups scheduled at each site were for consumers (or their representatives) in the following groupings: seniors (65 and older), developmental disabilities and/or children with chronic medical conditions, and younger adults (under age 65) with physical disabilities. The Anchorage location also had a scheduled session for underserved populations, specifically Traumatic Brain Injury (TBI) and HIV/AIDS.

In addition to groups in the three cities, we made a one day trip to the Native Alaskan villages of Allakaket and Alatna. During this trip we held a focus group with elders, visited the health clinics in each village, visited the homes of two elders, and talked with home health care agency staff serving people within the two villages.

The purpose of the focus groups was to elicit input from small groups of consumers (or their family members) about how the long term care delivery system impacts them. In order to accomplish this objective, we used a process that has demonstrated success in identifying themes and trends of a diverse group. Participants were first asked to address the following questions about the long term care services that they receive:

- What is working well for you?
- What is not working well for you?
- What recommendations would you have?

Participants then wrote answers to these questions on sticky notes, which were placed on the wall. Participants talked about the responses during which time we categorized them into theme areas. This allowed us to identify areas of consensus and common experiences.

The time involved in the discussions varied with each group, depending on the size of the group and the willingness of the participants to share their experiences. With the exception of the visit to the villages, each group was originally scheduled for a two hour time period. The village visit was one day.

Summary of Participation

Obtaining adequate participants for each focus group was challenging. The timelines for the overall project only allowed for three weeks of lead-time. We requested assistance for recruiting participants from the following sources: Care Coordinators, provider agencies, senior centers, the Commission on Aging, the Governor's Council on Developmental Disabilities, the State Independent Living Council and advocacy organizations. We also followed up on multiple leads that were recommended by these primary sources. Consumers then RSVP'd to us.

We also had numerous requests from provider agencies to have staff attend the sessions. We informed providers that the sessions were open only to consumers or family members. In a couple of cases, there were provider staff that did show up for the meetings. In some cases, the staff person was also a family member or a consumer. For those staff that showed up not representing a consumer, we made adjustments to ensure that only the opinions of consumers were reflected within the information collected.

The number of actual consumer/family member participants for each location is as follows:

Anchorage (Marriott Hotel):	
Older Alaskans	5 (3 consumers/2 family)
Developmental Disabilities/Chronic Health Conditions	5 (5 family)
Adults with Physical Disabilities	1 (consumer)
Underserved Groups (e.g., TBI and HIV/AIDS)	0
Juneau (Centennial Center):	
Older Alaskans	0
Developmental Disabilities/Chronic Health Conditions	0
Adults with Physical Disabilities	1 (consumer)
Fairbanks (Westmark Hotel):	
Older Alaskans	1 (family)
Developmental Disabilities/Chronic Health Conditions	4 (family)
Adults with Physical Disabilities	2 (1 consumer/1 family)
Native Villages:	
Elder group	12 (consumers)
Individual Interviews	4 (consumers)

In addition to the consumer and family members, we received input from six provider staff. Two of these staff traveled with and assisted our efforts in Allakaket and Alatna. These two staff were of great assistance to the team in facilitating our interaction with native elders and introducing us to the customs of the village.

Themes and Overall Impressions of Information Obtained

Although participation was lower than what had been hoped, the focus groups did elicit compelling stories about personal experiences and good information about what was or was not working. There were very similar themes that emerged across the groups and the various locations. Specific notes for each group are documented and included here. However, a few of the most prominent themes include:

- Information and access to assistance in understanding options is seen as a primary need. Participants noted that frequently information is incomplete, inaccurate, and inconsistent from source to source. Participants expressed frustration in not having a definitive place to go for help.
- Navigation of the system also was cited as an area of need. Long term care options counseling, assistance with making informed choices, and helping consumers with understanding applications and forms was seen as a service that could be of great assistance to families.
- All groups expressed an appreciation that the State is funding community-based services. In general, groups felt that the need exceeds the available resources, but all agreed that existing services contribute positively to maintaining people in their communities.
- Low wages, few benefits, and poor training of direct care staff was a dominant theme in all focus groups. Consumers expressed frustration with various problems including high turnover and unqualified staff.
- Quality was a strong concern. Beyond the issue of poorly compensated and inexperienced staff was the issue of provider sustainability, given the history of rate freezes. Many consumers expressed concern about the lack of available providers and the cutbacks that existing providers are making. Consumers/families see this as both an access problem and a quality issue.
- Flexibility in services is not adequate. Some services are either so defined or limited that they fail to work within typical family structures. This was cited as something that leads to “burnout” of primary caregivers,

ultimately leading to placement into more intensive and expensive services.

A summary of each of the focus groups is presented as ***Appendix 4***

STAKEHOLDER SURVEY RESULTS

Methodology

We developed three surveys to collect information from key stakeholders, including consumers and their representatives, provider agencies, and other stakeholders, such as direct care workers. We designed the surveys to capture a limited amount of information about the respondent, a few indicators of how the long term care delivery system and State oversight functioned, and recommendations for improving the system. Our Advisory Committee and State staff reviewed the survey instruments.

The consumer and provider tools incorporated basic demographic and background questions. We created an "Other Stakeholder Survey" to allow individuals who did not fall into either group to provide input. This survey only asked for the respondent to identify their role in the long term care system and for recommendations for change. The provider survey looked at things such as regions served and services provided. The consumer survey asked about the person's area of residence, gender, whether the consumer is of Alaska Native heritage, and the person's experience with receiving services. All three surveys asked respondents to advise about what is working well and what recommendations they would make for change in the system. In addition, the surveys were constructed with controlled responses such as scales, pre-selected answers with radio buttons where respondents have to select only one option or checkboxes where multiple answers maybe selected, and open text fields for open-ended responses.

The survey was distributed via a PDF-based format to all licensed providers using the State's e-mail distribution list. We also utilized consumer advocacy groups and provider agencies for distribution using contact lists. In addition, many consumers passed on the survey to their own personal contacts.

Circulation of the surveys began on July 3, 2008 and responses were due by August 1, 2008.

Recommendations for Improving the Long Term Care Delivery System

There were a total of 179 respondents completing the three surveys; 77 providers or 43%, 79 consumers or 44% and 23 other stakeholders or 13% of respondents. Exhibit 3 summarizes how individuals filling out the "Other Stakeholder Survey" identified their role in the system.

Exhibit 3: Individuals filling out the "Other Stakeholder Survey"

The surveys included open ended items that allowed respondents to provide recommendations for improving the long term care system. We grouped these responses in ***Table 12.*** In the table, we identify which survey was used. The following summary identifies the main categories of recommendations from the surveys and whether we have included each within our final recommendations to the State.

Recommendations fell into the following categories:

- **Set equitable rates that cover costs**: Our recommendations do not address specific rate issues because this is being addressed by the Myers & Stauffer rate review effort. There were four subcategories for this area:
    - **Spend More Money on Services and Less on Administration**: We respectfully disagree with this recommendation. The uncontrolled growth of the CDPCA program demonstrated the adverse effect of under investing in program administration. Many of our recommendations require greater investment in the administration and management of programs, at least in the short term until core operational infrastructure is developed.
    - **Encourage Third Party Payment, such as Private Long Term Care Insurance**: We included this as recommendation.
    - **Change how Providers Can Bill Medicaid**: The creation of independent fiscal intermediaries under the recommendation to restructure CDPCA should address the specific concern regarding needing to bill through an agency.
    - **Provide Direct Care Staff with Better Compensation and Benefits**: We did not study the current compensation packages of direct care staff because the Myers & Stauffer project is examining staff wages and other program costs. We recommend altering consumer directed services so that the consumer could negotiate rates with workers depending on factors including scheduling and level of experience.
- **Allow More People to be Eligible for Services**: This category of responses included subcategories that called for providing services to people with Brain Injury, Alzheimer's, and dementia. Also mentioned was changing the NF-LOC, and eliminating the waitlists. We included a recommendation regarding the NF-LOC and serving people with Brain Injury and ADRD. We note that the pace for eliminating the DD waitlist should be balanced against the ability of providers to build capacity. Providers reported that the current pace is already stretching that capacity.
- **Improve Quality Management Efforts:** Survey responses included recommendations for improving licensure and certification processes, communication from the State, and training. There also were a number of specific changes to regulations mentioned. We have included extensive recommendations and a specific plan for improving quality management,

communication, and training. Many of the specific changes to regulations requested greater flexibility or more equity across waivers in the assignment of budgets. Our recommendations do include changes that would result in greater service flexibility, additional services within the waiver menu of services, and improvements to budget management that ensure costs are contained while offering more flexibility.

- **Improve the Process for Applying for Services**: These recommendations included subsets of items that requested improved assessment tools and processes for approving home modifications and mobility devices. We have recommended a major overhaul of the system for accessing services and provide a specific operational framework for this change. This effort, in combination with the new process for managing budgets should help to improve access to assistive devices and home modifications that are necessary.
- **Expand the Array of Home and Community-Based Services**: The recommendation to restructure the process for setting individual budgets in combination with a liberalization of services that can be covered should help achieve this goal. There were also several specific subcategories:
    - **Increase ALF Capacity, especially for ALFs supporting people with mental health issues**: The ALF model for populations without mental illness appears to be developing sufficient capacity in areas that have large enough populations with disabilities to sustain them. More flexible models, such as the pool of dollars approach included under the restructuring of CDPCA may be more appropriate for more rural areas. The State currently lacks a funding stream for ALFs that target people with mental health issues. The Division of Behavioral Health is developing a strategic planning effort that may address this concern.
    - **Increase Institutional Capacity:** Alaska's Nursing Facility occupancy rate in 2006 was only 83%.[13] This is below the national average of 85.2%. Adding more capacity could lower occupancy

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[13] C. Harrington, H. Carrillo, C. Crawford, and C. LaCava. Table 4, "Nursing, Facilities, Staffing, Residents, and Facility Deficiencies, 2000 Through 2006," Department of Social and Behavioral Sciences, University of California, San Francisco, accessed January 2008. Available at http://www.pascenter.org. Based on the Online Survey, Certification, and Reporting system (OSCAR), Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services.

rates even further, which would increase costs per resident and/or the financial burden on existing providers.

  - **Empower Individuals and Families**: Increased empowerment and person centered approaches are a central component to most of our recommendations.

- **Improve the State's Strategic Planning Capacity:** Many of our recommendations directly address the State's need to manage across programs, develop management reports to aid in measuring performance, and to establish processes that will help the State in forward planning. The Three Year Action Plan includes a proposal for an ongoing strategic planning process. In addition, the quality improvement recommendations include a proposal for a systemic quality management process.

Table 12: Stakeholders Recommendations for Improving the Long Term Care System

Key: P = Providers
O = Other Stakeholders
C = Consumers

Topic

Set Equitable Rates that Cover Costs

- Need more funding for senior centers. **O**
- Funding for long term care needs to be consistent with the cost of providing that care. Although generous compared to other states, it is still not keeping up with costs. **O**
- Ensure that nursing homes are at least breaking even financially. **O**
- There does not seem to be more money coming in to take care of the increase of people or prices of food and energy. We need the State to budget more of the surplus oil revenue to taking care of its seniors and senior centers. **O**
- More AHFC assistance with funding for new assisted living construction. **P**
- The State should provide equal billing rates for the care providers regardless if our clients are seniors or people with developmental disabilities. There should not be any discrimination from one sector to the other. **P**

- Fully fund service program rate. No more "frozen rates" for agencies. **P**
- Provide an add-on reimbursement for care of residents with mental health and behavior issues. **P**
- Increase reimbursements for services so that providers can pay employees a livable wage. **P**
- Reimburse agencies for actual cost of doing business. (i.e., administrative overhead, health insurance premiums, overtime pay, gas/fuel costs). This can be done by reducing the bureaucratic cost of running an inefficient Department of Health and Social Services. **P**
- Implementation of a fair rate methodology across all services. **P**
- Let the rates for caring for elders and adults with physical disabilities equal those for folks with developmental disabilities. Why are these two groups treated like second class citizens, financially? **P**
- Adequate funding for the non-profits that are performing Medicaid waiver services. **P**
- Increase Home and Community Based (HCB) grant funding in accordance with actual demonstration of provider abilities and not just automatic across the board when funds are available. The grant process does not allow for providers to demonstrate economies of services and quality of services to be eligible for additional funding. The grant process is entitled, but rarely results in a change of funding. **P**
- Need statute for automatic HSS budget increases for HCBS similar to AK hospitals and nursing homes. **P**
- Add funding that better addresses the rural village sites that respect lifestyles. Increase General Fund (GF) senior grant so that elders do not have to be Medicaid eligible to receive services. **P**
- Eliminate negative incentives in the system; for example, funding on a Fiscal Year (FY) basis with limited options to carryover funding, provides an incentive to spend the funding now even if it were better used in a few months. **P**
- Individuals receiving Medicaid waiver services should have more stringent criteria to qualify for those services. They should have to qualify for long-term care in order to be eligible for waivered services. States that have effectively controlled the cost of waiver services have made that a standard. The State does a good job of sponsoring and paying for care in long-term care facilities in Alaska. Without the cost-based reimbursement they receive many of these facilities and the acute care services connected with them would disappear. The waiver services however seem to be out of control. Once thought to the means of keeping people out of long-term care facilities, they have now taken on a life of their own. They have completely eclipsed the Medicaid payments going into institutionalized care and I see no studies that would show a corresponding decrease in the use of long-term care facilities. **P**
- Add funding that better addresses the rural village issues such as lack of

running water, lack of caregivers that respects cultural lifestyles. Increase GF senior grant so that elders do not have to be Medicaid eligible to receive services. **P**
- The challenges of hiring and retention of providers in the rural villages. The cost of living is much higher and the reimbursement rate will not cover for training costs for village-based providers. **P**
- Per Diem contracts need to be eliminated. **P**
- Nurse shortage and OT issue and Physician shortage. **P**
- Have adequate reimbursement for providers; freezes are just not acceptable. **P**
- Increase reimbursement rates to at least near private pay / insurance rates (even with the new increases they still lag between 10-15%). **P**

Spend More Money on Services and Less on Administration

- More money put towards Elder Services rather than administration. **O**
- Spend more money on services rather than QA; not every elder is out there trying to cheat the system. **O**

Encourage Third Party Payment, Such as Private Long Term Care Insurance

- Encourage third party payments for long term care services, including long term care insurance (a working benefit package for State retirees) and charges to folks who can afford to pay. The current LTC package for State retirees does not cover many of the LTC services available in Alaska. **P**
- Requirements for applying for Medicaid make it difficult for family and consumers to make plans for their future as they have to give up homes, assets, etc. **P**
- Create a self supporting industry via early age mandatory long term healthcare Insurance. **C**

Change how Providers can Bill Medicaid

- The care providers would like to bill directly to the State without going through the agencies and without having to change their business from Assisted Living Home to a full agency for the purpose of billing one topic. I would need to bill for one topic. We do not make enough monies to pay for the operation of a full agency and establishing that agency. The agencies that do the billings for us at this time take approx. 50% of the capped rate to bill for us for just the care provider. They do this on each of the billing titles. If we were able to go into the private sector, different than the agencies, they only charge 3% for billing out and paying taxes etc. In our case, there are no taxes. **O**

- Single provider number which would allow for Medicaid billings for all services delivered by a specific agency. **O**

Provide Direct Care Staff with Better Compensation and Benefits

- Treat primary care givers as the professionals they are. That includes compensation, continuing education, oversight, avenues to obtain assistance when problems arise, vacation and sick leave, promotional opportunities. Adequate staffing. Right now care givers view care giving as a temporary or fill in job until something better comes along. **O**
- Improve pay for direct care providers**.** **P O C**
- Help with affordable health insurance for employees of LTC. **P**
- Help with the workman's comp insurance that is astronomical in cost. **P**
- Incentives should be given for longevity. For example, an agency that provides benefits and increases in wages to its employees can be penalized financially if the employees stay too long. The per diem rates provide more incentive for short term, non benefit employees. **P**

Allow More People to be Eligible for Services

- Personal Care Assistance in the home that is available for broader population than just Medicaid recipients. **C**
- Chore services that are not Choice Waiver dependent. **C**
- Cover nursing home care for aliens who have been in Alaska less than 5 years**.** **O**
- Creation of two additional categories of the Home and Community-Based Waiver for 1) Alzheimer's Disease and Related Disorders and 2) Traumatic Brain Injury. I see people on a weekly basis who need home and community based services who do not qualify because their primary condition falls under one of these two categories**.** **P**
- Add waivers for ADRD and FASD**.** **P**
- Encourage and make HCBS available to more seniors**.** **P**

Provide Long Term Medical Rehabilitation Services to People with Traumatic Brain Injuries (TBI).

- Create TBI waiver so adult individuals can continue to receivedmedical treatment after leaving the hospital. **O**
- TBI waiver for children living at home to receive the needed ongoing services such as Physical therapy, speech therapy, respite for family members, counseling for the individual. **O**

- Provide a system of services for people with a TBI. Independent living services in the rural areas of Alaska that do not have access to the services offered at the Independent Living Centers in Fairbanks, Juneau, or Anchorage. **O**
- Set up a center with all resources for TBI treatment in one place. Right now doctors, labs, MRI, counseling, are all spread out. Have a center where the medical, social, psychological experts on a case may all sit down together, at one time, and review the patient's case. Most important have this in OUR state to save on Medivac to Seattle and other out of the state locations. **O**
- Funding to support TBI victims while they work to get their injury under control so they can be mainstreamed again. Right now by the time a TBI is recognized the victim has usually lost his job, dropped out of school, may be on the street as the family does not understand the problem and has given up**. O**
- Involve the individual and care providing family members in the design of a plan to fit the needs of the TBI individual. Families need to be involved in what is really needed for their loved one's recovery. **O**
- Allow plan needs to be changed easily as TBI individuals' needs rapidly change in the first few years and then as they go, some better some worse. **O**
- Remember that the family is in as much need of being treated as the individual if they keep the individual in their home. The needs are a full package. Service provider center did not care that I as a single parent was worn out with 24/ 7 care. **O**
- Remove the costly Care Coordinator into a less costly position by giving the family more direct control in the supervision, hiring and so forth of care providers. Care Coordinators / care centers should not have the expenses. **O**

Change the NF Level of Care Criteria to Serve More People

- Lobby for a system where anybody in AK who needs to have a nursing home placement will get funded through AK Medicaid**. P**
- Provide a mechanism for serving elders with a primary diagnosis of ADRD, who do not meet nursing home eligibility criteria, perhaps by implementing a new waiver and expanding State grant funding. **P**
- Experience has shown that some people who need long term care (waiver) services are not receiving them, and others who are receiving them do not really need them. Medicaid should have case workers who could help weed out the abuse and make sure those who needed services knew how to qualify. **O**
- Include Alzheimer's and CMI patients in the criteria for LTC/ALF CHOICE Medicaid. **O**

- Services - esp in ADRD - who do not fulfill for Medicaid and are not nursing home eligible fall through the cracks. BIG safety issue! **P**
- Redefine LOC for OA/AP eligibility (someone who is truly LOC for nursing home should be in a "nursing home" and other criteria should be developed for those who are in need of HCB services to keep them at home, apply waiver for them. **P**
- Improve the Choice Waiver program to include a diagnosis of just mental health issues and/or ADRD. **P**
- Allow dementia and Alzheimer's disease to be a primary diagnosis for Medicaid and Medicaid Waiver. **P**

Eliminate Waitlist

- Abolish DD wait list - ASAP! Fund all eligible clients with Permanent Fund Revenues if necessary. **O**
- Get rid of the State Medicaid/services waiver wait list for disabled children. C
- Get services (funding at current costs of living to Agencies) to people now as a preventative measure to decrease death on the "registry." With millions of dollars in Oil revenue; our rainy day is NOW, not later. **P**

Improve Quality Management Efforts

- Focus additional effort on program/service delivery quality verses compliance. **P**
- Use Agency providers as a Peer Review Tool. **P**
- Grants administrators need to be trained not to micro-manage. **P**
- Standardize P&P's so grass roots organizations can access these forms and apply to their operations. **P**
- Create technical assistance for true program quality: person centered plans, behavior modification support (PBS), meaningful day habilitation outcomes, and creative problem solving and crisis response alternatives. **P**
- Someone to check in when no family members can do it. **C**
- Make it easier to hire nurses. **O**
- One database for Title III and Medicaid providers. **P**
- Provide standards for program development open to all agencies. **P**
- Support good providers and support the effective regional providers-perhaps provide incentives etc as well. **P**
- Adopt a philosophy of technical assistance and skill building to help providers improve their quality. **P**

Recommendations for Improving Licensure and Certification

- Assisted Living Centers and other providers of long term care should have standards that they are held accountable for. Nursing homes have standards and are surveyed annually for compliance. Other providers do not have the same accountability. In our community the homemaker services have employed personnel with questionable qualifications and very suspicious ethics (many of the known drug seekers have been employed). **O**

- Decrease the amount of duplicated paperwork requirements for agencies who have DD Grants & certification requirements. **P**
- Require an accreditation system for providers to ensure quality of care is being provided and standards are being followed. **P**
- Take performance of programs into consideration for recertification. **P**
- Stream line the certification and recertification process. **P**
- Increase quality experienced personnel in the licensing office and get them out of the office and in the field more! More surprise visits. **P**
- Certification and licensing must make sense. Currently the certification process is unwieldy and cumbersome, requiring hours of paper management that, in the end, does not guarantee that the provider is equipped or capable of providing quality services to the clients in their region. **P**
- Integrate the Department of Health and Social Services and have all divisions require similar/same licensing, certification, reporting, etc. requirements. Streamline the process for provider and consumer, not the Department. **P**
- Re-evaluate the licensing system. Some requirements for larger Assisted Living Homes do not make sense nor fit in a smaller homelike environment (Family Habilitation and Group Home). **P**
- Treat providers as independent contractors. Evaluate based on performance, outcomes, track record. **P**
- Reward quality services and impose sanctions when needed; for example, I'm not sure there is a mechanism to rescind a Care Coordinator's certification if their standards of service are below par. **P**
- There should be standards of care, and monitoring of those standards, for Medicaid waiver providers. In our community there is serious concern on the part of our physicians about the training and capability of waiver service providers for the level of care that they are assuming responsibility for. **P**
- Flexibility in licensure requirements for rural students who attend school outside of Alaska. **P**
- Encourage long term contracts. Year to year contracts require tremendous administrative costs for n/p. **P**
- Integrate the Department of Health and Social Services and have all division require similar/same licensing, certification, reporting, etc. requirements. Streamline the process for provider and consumer not the Department. **P**

Improve Communication from the State

- Increase communication from the State regarding new and changed regulations or policies. **O**
- Increase communication with all stakeholders from the State regarding new and changed regulations or policies. **O**
- Informal and formal input from providers prior to process, policy and regulation changes. **P**
- Timely review and notification prior to process, policy and regulation changes. **P**
- Consistency in instructions regarding policy, regulations and process. **P**
- Clarification on regulations that apply to rural Alaska residents. **P**
- Train administrators at DSDS in supervision and leadership. The dissension at DSDS due to untrained supervisor and leadership has kept the morale low and the turnover rate high. **P**
- Establish better systemic collaboration/partnering between State agencies that are working with the same consumer -- it's very fragmented! O
- The State, SDS, has moved farther and farther away from a partnership or collaborative role each year. Their role seems to be one of oversight to the extent of micro management of agencies rather than technical assistance and problem solving for the individual client. **P**
- Have State employees understand their role in providing services. **P**
- Increase the abilities of the DSDS staff to communicate effectively with providers so that they actually know who provides what services, understand the intricacies of these services, and have a greater ability to assess consumer needs. At this time there is a disconnect between providers and those at the state level who monitor services and determine either eligibility or level of service for consumers. **P**
- Replace current LTC ombudsman with a person that has experience in LTC. Encourage working with the providers not against. **P**
- Statewide printed resource of providers/services. **P**
- When changes in policy occur, this should be communicated directly with providers and not just put on the DSDS web-site. **P**
- Be flexible and figure out a solution to the situation instead of taking the easy way out and do nothing or not respond. Not responding is the biggest factor in losing the support and services that the system provides. **P**

Specific Changes to Regulations

- We need a new way of heating many senior centers and it should be mandated by the state to be warm and economical. I believe we should use electric. Less fluctuation in price and smaller footprint. **O**
- Requirements for dietary needs should be met nutritionally - not enough

money in the budget to guarantee the healthiest meals needed to preserve the health of seniors. **O**

- Improve assisted living home standards to include 2 staff per shift requirement for each home**.** **P**
- Certification of all workers across care areas - adult day, PCA, CNA, assisted living, etc. **P**
- Too many providers allowed to open multiple homes. Causing level of care to go down. Limit how many homes a provider can open. **P**
- Ensuring care is given in a timely manner within a 2 month period of time. **P**
- Limit the number of providers in given areas (especially the Anchorage bowl) to a moderate amount. Or at least have a moratorium on new certifications. **P**
- Fewer restrictions on mental health services**.** **O**
- Fewer restrictions on adaptive equipment**.** **O**
- Review and revise the Habilitation categories of service. Some of them are very limiting and don't fit family needs, i.e. some version of an hourly service that may take place out of home but similar to "in-home supports" is needed. Hourly respite caps are insufficient to meet this need. **P**
- Change the inane way the personal care services are added up by the minute into a system that reflects the reality of caring for a disabled person whose needs and schedule may vary according to desires and medical condition of the disability person at the time the services are being provided. **C**
- Need to provide more equity between OA and MRDD waivers - including array of services caps on quantity and restrictions on family caregivers that are counterproductive! **O**
- Analyze the differences between the OA and MRDD waiver and develop a plan to make consumer options similar and equitable (for example, the array of services, caps on quantity, get rid of restrictions for family caregivers going to work)**.** **P**
- More flexibility in times for tasks**.** **C**
- Require equity in OA, APD, MRDD and CCMC waivers. There is a substantial financial and service inequity in these waivers. It takes far too long for OA and APD waivers to go through the system. Fragile elders do not have the time or supports in place to wait months for approval and services to begin when applying. Why are there no habilitations, employment services in APD waivers as there are in MRDD waivers? **P**
- For items purchased by a Choice Waiver program, more providers other than strictly rehabilitation/pharmacies should be allowed to submit estimates - including retailers, which could lead to lower costs**.** **C**

Improve Training

- Provide ongoing training to family members and providers of care. Increase training opportunities for family members who care for individuals as well as for medical staff to go into the homes to provide health care in the community. **O**
- Stop sending nurses from Anchorage to Ketchikan to supervise training for one person, perhaps allow online training in remote areas instead. **O**
- Continue to educate communities about prevention from food intake, exercise, to making good decisions to reduce opportunities for injury. **O**
- Establish a residency for geriatrics in the State similar to the teacher training fellowship available at BU, Duke, Loma Linda. It would help with medical family practice residency programs being established in the State and increase funding for training in the specialty of geriatrics. **O**
- Hire a Care Coordinator to train care coordination agency staff and DD nurses on goals, objectives and DOCUMENTATION. Have a beginner introductory training course and advanced training for more detailed experience and questions. Offer incentives for those that take the second course. **P**
- The State should provide training for the purpose of care providers doing their own billing. They would then receive a billing number for that provider and bill just like anyone else. **P**
- The State should provide training for the administrators of the Assisted Living Homes who provide care for 4 or less clients. **P**
- Offer training and support for leadership positions. **P**
- Offer technical support and consultations for program managers and directors. P
- More grant money to help people receive CNA training. Connect graduates with private employers. **P**
- Provide incentives for education of healthcare professionals. **P**
- Make sure that everyone working in long term care gets trained in Eden alternative, person centered care - including and most especially TOP MANAGEMENT. **P**
- Have training on customer service for employees. **P**
- Provide training and workshops to providers to address vicarious trauma (self-care for providers to learn how to prevent taking on the trauma of others). **P**
- Every person who owns or runs a home take a required class on how to care for Alaska Native elders, feed them their native food. **C**
- Ensure that personal care attendants are meeting the needs of people in their homes. **O**
- Assistance with workforce issues. **O**
- Quality in-home trained staff with the knowledge of providing activities for clients that give purpose to their lives. **P**

Improve the Process for Applying for Services

- Create a single point of entry for people needing services and put it on the main State website homepage. It should be a person with "front line" experience, not a bureaucrat. There should be one person who will direct inquirers to the specific area they need. For example, there should be one person who answers questions about home care. Another person will answer assisted living questions. Another person answers questions about available medical services. Also, very important, make an updated list of physicians who will accept Medicaid and Medicare!!
  Most seniors are not internet friendly. There must be phone support first and then someone who can guide them if they chose to use any other State internet site. **P**
- Have a shorter turnaround between applying for Choice Home based services and finally being approved for services. This would reduce the use of nursing or assisted living homes**.** **O**
- Adopting the "one-stop" formula for use in applying for services. **O P**
- Single point entry system to navigate app process easier. Assign a person or persons as a single point of support for providers. Give them the ability/training to answer any and all questions and give them the right to help with interpretation of laws and regulations. Provide a regularly updated list of contact information for the different departments that providers are responsible to. We need names and functions. Not a (800) number with an operator who does not understand what we need. **P**
- Have patient and knowledgeable advocates to help individuals through the processes. **O**
- Work to make referrals as seamless as possible for individuals moving through the stages of services. **O**
- More timely Medicaid certification of disabled applicants who are less than 65 years, who have disabilities. **O**
- Improve the overall customer friendless of application for care services (ease, speed, staff customer services, etc.)**.** **O**
- Need to improve Medicaid eligibility application process for nursing homes. People apply for Medicaid, it's lost by the State and retro coverage is not authorized. **O**
- Decrease the amount of duplicated paperwork requirements for agencies who have DD Grants & certification requirements. **P**
- When a Client is considered permanently developmentally disabled, we should not have to establish this over and over, year after year. Paperwork should be established, if any changes arise, then Care Coordinators can submit the changes, but initial qualification should be established once. **P O**
- Streamline the process or increase the number of staff in the area that approves authorization/reauthorization to have a person in a nursing

home. **P**

- Let the tribal medical facilities do assessments/etc for their clientele. **P**
- Assessments are still back logged in the villages, and the requirement of four face-to-face visits a year is not cost effective for traveling to the villages or for that matter safe in the winter season. **P**
- Let the tribal medical facilities do assessments/etc for their cliental. **P**
- Establish a statewide human services hot line (800#) so all Alaskans can tap into federal, State and local benefits, not just those in urban locations. **P**
- There should be someone employed by the State to explain Medicaid services to potential recipients. Right now there is a great deal of confusion out there as to what services are available and how to qualify for services. **P**
- Provide information that is easy to understand by the recipient of services. **P**
- That there are more advocates to help with families that need more support to get the help they need for the special needs and there is an effort to educate the public about the services available. **C**

Improve Assessment tools

- Re-evaluate the personal care program and Medicaid waiver LOC standards by which people become eligible. The programs are complicated; the bar is raised too high for people who actually need assistance. The paperwork is enormously cumbersome, requiring the overtaxed consumer and caregivers to fill out 2 sets of many documents when applying for both PCA and Medicaid waiver services. **P**
- Improvement of assessment tools (i.e., for Medicaid Waiver, PCA services, etc.) so that they are more culturally and elder sensitive. **O**
- Continue to improve the assessing system, perhaps automate. **P**
- State leadership in helping to develop administrative tools. For example, we use a lot of forms internally and with the State. They all use the same information, but there is no way to easily transfer information from on form to another. **P**
- Assessments must be culturally appropriate, and thorough that when the assessing nurse is in the area - (and the client is having a good day) the assessment does not preclude ALL OTHER DATA which states the client has a need not being shown on that particular day. **P**
- Standardize Forms! **P O C**

Improve the Process for Approving Home Modifications/Mobility Devices

- Allow physical building modifications based on the needs of the individual rather than the arbitrary decision of the DSHS staff (seniors wanting to have a bathtub instead of a shower is therapeutic and may be better than a roll in shower for some people). The arbitrary statement "we don't allow the use of funds to cut or add a door" for a bathroom is disgraceful. O

- Increase the information about AT and ergonomic devices to increase quality of life at home. O

Expand the Array of Home and Community-Based Services

- Have adequate regional housing and other resources so that consumers do not have to leave their community to receive services. O
- Have care available that is between independent living (in own home or apartment) and living in the Pioneer Home. In England there are sheltered accommodations where each individual has their own apartment but in the complex are people who check on you every day and who are available in an emergency. There is a way to call for help from each apartment. This would preserve people's independence but cover their need to have someone aware of how they are doing. C
- More modern up to date rooms, more availability for private rooms C
- More money towards adult day services/long term care insurance having better coverage for adult day services. O
- Direct funding to lower levels/least restrictive care (community-based or in-home) so that people can remain in their own homes and traditional communities. O
- Open categories that will encompass providers not currently certified by Medicaid categories, but whose services are positive and helpful for consumers.
- Provide standards for program development open to all agencies. P
- Hot and cold meals at all senior centers. O
- Core services to help keep our seniors in their villages. P O
- Encourage organizations in remote areas to develop integrated systems where there are choices for Assisted Living, Intermediate Care and skilled care. This might help with cost containment and cost savings. O
- Home care workers should be able to take individuals to Dr's appointments. O
- Have a place/contact dedicated for individuals to approach for support and encouragement. P O
- Provide more respite care for care givers- so that primary caregivers can work outside the home if the need/want to. P O
- Preventative care to elders and persons with disabilities.
- Alternative pain management to elders and persons with disabilities O
- Translation services for elders. O
- Provide consumer centered wrap around services. O

- Increase the options for long-term assisted care especially for the elderly (both in home and out of home). **O**
- Expand grant funded home and community-based services for elders....congregate meals, home delivered meals, adult day services, lots more respite and chore. **P**
- Life line emergency system available locally. **C**
- Flexible home care providers available in neighborhood and able to respond to calls. **C**
- To have an agency provide a person who can rotate around my MCS group to assist with additional things such navigating the process and alleviating stress involved with payments so consumers don't have to worry about the stress of bill collectors calling etc. **C**
- Free legal advice for consumers re: senior issues and care. **C**
- Someone to provide help for short periods of time i.e., if a senior has an illness that will only last a week or two. Often people are too sick to care for themselves but it is not a chronic issue they still need help and don't know how or where to get it. **C**
- Would like to be able to interview new people (DSP's) for a choice of someone that I like, or have a chance to work with them on a "trial" to see if we are a good match for each other. **C**
- Assistance for in-home care providers of elders (usually living with relatives), enabling them to remain at home. Specifically - resources for families of elderly to hire overnight help or week-long help, enabling family member to be gone for several days for work. **P**
- Encourage a greater partnership between primary care and community services. **P**
- Make service types available for individuals on all four waivers.(i.e., add supported living, supported employment, etc. to OA and APD waivers). **P**
- Medicaid Waivers for Long Term Vocational supports. **C**

Increase ALF Capacity, Especially for Mental Health Issues

- Institute care homes/ALF for the chronically Mentally Ill who need long term care and supervision. **O**
- Improve assisted living rates to increase the viability of operating homes in southeast Alaska. **P**
- Build more facilities such as the Alaska Pioneers' Homes. **P**
- More assisted living facilities which can transition into end-of-life care. **P**
- Lack of a LTC facility that has special facilities for mental health, personality disorders and behavioral issues. **P**
- More AHFC assistance with funding for new assisted living construction. **P**

Increase Institutional Capacity

- Increase the number of beds available for skilled nursing and intermediate care. **P**
- Cover nursing home care for people less than 65 without a permanent disability. **P**
- Need for more skilled beds in the State as the Pioneer Homes have moved to assisted living and our population is aging. **P**
- Alaska needs to reopen intermediate care facilities for MR/DD clients. **C**

Empower Individuals and Families

- Allow families to be more involved in the treatment and care process as well as perhaps have family activity nights instead of encouraging people to become isolated and detached from their family network. **C**
- Reorient State training to include client advocacy and sensitivity to native cultural issues. **P**
- Care Coordinators, caregivers' providers and public have to recognize what pain and trauma do to someone's ability to handle situations. More empathy. Should have training to understand how to deal with this type of consumer better. **C**
- Make sure solutions are consumer focused not provider focused. **P**
- Increase financial incentives for individuals to live with family members or other natural supports. **C**
- More money into programs that assist family caregivers. **C**
- Encourage funding and development of home and community-based services in rural communities so that elders can remain in their own homes and traditional communities. Identify what services are missing in villages that are driving elders to move where there are hospitals and nursing homes. **P**
- Continue to re-balance Medicaid spending in favor of home and community-based care. Embrace a true Money Follows the Person concept and close down nursing home beds. **P**
- Encourage consumer directed services. **P**
- Make sure solutions are consumer focused. **P**
- Provide information that is easy to understand by the recipient. **P**
- Treat all Alaskans on equal basis, especially children and elders. **P**

Improve Capacity for Community Care in Tribal Villages

- Bring Alaskan villages into the 21st century with running water and flush toilets for everyone, preventative health care, (including dental care), access to services, etc. We are more concerned with 3rd world countries than we are with rural Alaska! **P**

- Facilitate tribal/non-tribal working relationships in rural areas, so that the needs of the elders can be better served. **P**
- Work with tribal representation to create long term care in villages**.** **P**
- Need to have more Assisted Living Homes in the rural villages and in Fairbanks (Fairbanks locations should have cultural sensitivity training)**.** **P**
- There are many villages and rural communities where long-term care is not available. Many of them are too small to cost-justify having facilities or even providers in some cases. Alaska should look into those things that inhibit the family from becoming the providers of care in Alaska, and support those things that support the family.
- Churches and family counseling services should be encouraged. Community gathering places and culture centers should be encouraged, and volunteer organizations strengthened. I believe a study of who the natural helpers are and what their needs are would be well worth undertaking**.** **P**
- Make a strong commitment to developing and maintaining home and community-based services in RURAL communities. The reallocation of funds and services to the greater Anchorage area to the neglect of rural Alaska will only increase the existing population drain from small communities. This exacerbates an already difficult situation in which people move north to access services, so services are redirected north to serve the increasing population. The inevitable result of this process will be a large urban center in the Anchorage area with the rest of the State existing in a semi-colonial status, providing raw materials but lacking in any sense of community. **P**
- If a consumer, who is eligible for personal care services, is medivaced out of their village for medical reasons, they are required to notify the provider agency in order for the CDPCA to be paid - this should not have to happen. **P**
- Encourage organizations to build integrated Assisted Living to Intermediate care to skilled care system-especially in remote areas. This may help enhance cost savings and contain costs. **P**

Improve State’s Strategic Planning Capacity

- Ongoing strategic future planning with providers to identify rural and urban, local community and statewide needs and to determine capacity and support needed to meet future needs. **P**
- Define the vision for the system and get it out to stakeholders. Develop an action plan to move towards the vision. Commit funding to the vision. Evaluate the action plan on an ongoing basis to determine the need to alter the plan. Needs assessment to determine unmet needs along with action plan for meeting unmet needs. **P**
- Organize themselves for efficiency and accuracy. **P**

- Provider input should be sought before changes in the way we do business is changed. **P**
- Informal and formal input from providers prior to process, policy and regulation changes. **P**

Miscellaneous Recommendations

- Work with alternate providers: DOD, PH,VA**.** **P**
- Attract other than PAMC LTC providers so there is some specialization and competition**.** **P**
- Ability for the n/p to utilize state purchasing (ie. for vehicles and other equipment). **P**

Copies of the Survey can be found in ***Appendix 5.***

We provide a summary of the results from the specific items from each of the surveys as ***Appendix 6.***

BACKGROUND RESEARCH

This section of the report describes background research completed in three areas: 1) cultural competence initiatives; 2) early intervention efforts; and, 3) self directed service models. Within each, we describe the focus of research and methodology, general findings, and implications for recommendations to Alaska. We provide a list of the resources we identified in ***Appendix 7.***

Cultural Competence

Alaska has an increasing diverse population. As ***Table 13*** demonstrates, the most noticeable characteristic that differentiates Alaska from the rest of the country is the size of its Native population. However, Alaska also has a slightly higher percentage of Asians and a dramatically higher proportion of individuals who are Native Hawaiian or Pacific Islander or multi-racial. While Alaska has a lower proportion of individuals who are African American or Latino, these populations together make up almost 9% of the population. This diversity is reflected in the Alaska School District which is only half white and includes students who speak 84 different languages.[14]

Table 13: Race and Ethnicity in Alaska

	Number	**% in AK**	**% in US**
One race	615,544	91.9%	98.0%
White	460,170	68.7%	73.9%
Black or African American	21,476	3.2%	12.4%
American Indian and Alaska Native	88,026	13.1%	0.8%
Asian	30,151	4.5%	4.4%
Native Hawaiian and Other Pacific Islander	3,753	0.6%	0.1%
Some other race	11,968	1.8%	6.3%
Two or more races	54,509	8.1%	2.0%
Hispanic or Latino (of any race)	37,498	5.6%	14.8%

Source: U.S. Census Bureau, 2006 American Community Survey

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[14] http://www.asdk12.org/aboutasd/

Because of the limited resources and short timeline for this project, we directed our attention to Indian and Alaska Native groups. We simply did not have the time or resources to conduct an extensive literature review on all populations. Because the LTCP is intended to make state-level recommendations, we first tried to identify state or regional level systems efforts to improve service performance for minority cultures. We reviewed individual state efforts, promising practices identified by CMS and Indian Health Services (IHS), university research efforts, cooperatives among Indian nations, federal grant initiatives, and examples of state tribal agreements. We first surveyed sites specializing either in health/long term care services, or in Indian and Native service systems. Based on this initial survey, we then looked at specific state and project sites. We did not identify many documents that discussed state-level efforts in long term services; however, we identified a number of individual tribe and local agency initiatives at the direct delivery level.

Among the most promising state level practices recognized by CMS and the National Congress of American Indians (NCAI) is an effort by the State of Minnesota to develop legal agreements with Indian nations to perform certain administrative duties normally done by the state or counties. Agreements currently cover the areas of welfare administration (including child welfare) and Medicaid long term care services. The agreement covering long term care includes eligibility determinations, authorization of services, case management, and oversight of service delivery. After reviewing information on these agreements from CMS and the NCAI, we contacted officials in Minnesota to learn more about the initiative. A summary of our interview is available in ***Appendix 8.***

The Minnesota practice has been successful in identifying needs and providing earlier assistance for elders at risk of nursing home placement. Initial concerns about the tribes' abilities to appropriately perform eligibility and assessment duties have been unfounded. Based on the success of the State agreements, Medicaid contracted health plans providing managed care health and long term care services have entered into similar agreements with tribes. At the current time, Minnesota is expanding agreements to additional nations and additional service areas.

We identified the following other research that was helpful information in developing our recommendations for the State of Alaska:

- IHS has a number of useful health policy materials available on its website. One of the more interesting reports is a project that was headed by the Center for Health Policy Research in the School of Public Health at the University of California at Los Angeles (UCLA). We contacted Steven Wallace, Ph.D, the primary author of the report for more information.

The UCLA project focused on assisting tribal health organizations in becoming Medicaid providers. The findings in this project were helpful to understanding some of the barriers to possible state level arrangements with tribal entities. One of the biggest barriers identified is the willingness of tribally owned entities to serve Medicaid recipients who were not members of the tribe. This disqualified these tribal organizations from participating in Medicaid. This barrier was also identified by Minnesota officials.

- We reviewed results from a number of the IHS Elder Initiative Grant recipients and presentations from the 2002 Roundtable discussions on long term care services for Indian and Alaska Natives, sponsored by IHS and the National Indian Council on Aging. The reports identified a number of challenges at the service delivery level, including lack of adequate housing and transportation, and the inability to recruit and retain staff from within the culture. We saw evidence of these challenges during our visit with Alaska natives in village areas.
- We reviewed efforts funded by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), to develop guidelines and materials for organizations interested in improving cultural competency. "*Indicators of Cultural Competence in Health Care Delivery Organizations: An Organizational Cultural Competence Assessment Profile"* is a report prepared by The Lewin Group, Inc. in April 2002. The profile helps organizations in developing a framework for assessing their cultural competence, and applying measures of competence to their organization. This tool is applicable to all types of organizations and all cultures.

The findings fell into three categories: 1) state level practices to incorporate cultural competency into the administration of services through direct partnerships; 2) the development of service networks or collaboratives to deliver services that are culturally specific; and 3) individual organizational efforts to be culturally competent.

This research suggests that there is promise in working toward a partnership with tribal health organizations for three reasons. First, the best outcomes for Alaskan Natives are likely to occur as a result of creating access points that are culturally specific and already known to native people. Second, the State is not likely to be able to create and run an adequate infrastructure that is both culturally appropriate and able to reach villagers in rural and frontier Alaska in a timely manner. Third, there may be financial benefits to the State in having a partner that is in a better position to identify earlier and prevent conditions that lead to or exacerbate a disability.

However, we should caution that compliance with Medicaid regulations has been an issue with tribal health networks in other states. Thus, Alaska will want to work with the THOs to gradually build up their capacity and responsibility.

Early Intervention/Prevention

Our research on early intervention and prevention efforts focused on approaches that delay and/or prevent entry into intensive and more costly long term care services. We completed a brief overview of states to determine what types of state funded programs were available and how those state funded efforts relate to Medicaid services. We found that there are many targeted grant programs for individuals with disabilities, older adults, and caregivers. Many of the grant programs filled gaps by providing services for smaller defined groups (an example of this is the Alzheimer's project in Wisconsin). In other cases, the grants were distributed to local organizations for general outreach and support services.

We contacted Mr. Jim Varpness, a Regional Director for the Administration on Aging, for further guidance on finding examples of states that have aligned grant funds and Medicaid as a strategy to control the utilization of high cost services. Based on Mr. Varpness' input, the two states we focused on were Illinois and Minnesota.

Illinois and Minnesota have adopted state funded programs that are designed to delay and/or prevent entry of seniors into Medicaid and into intensive long term care services. In both states, the eligibility for the grant programs is aligned with the nursing home level of care. This is used in combination with financial eligibility for the state grant program. In both states, services were provided on a sliding scale.

The basic strategy of these programs is to help seniors use low intensity services that allow them to remain in their homes (or in homes with other family members). This results in less overall cost for services so that the individual does not spend down to Medicaid as quickly. The benefits offered under these alternative state grant programs are similar to those found under a 1915(c) waiver.

We used Minnesota's fiscal forecast information to compare the costs of elderly long term care programs.[15] The average monthly cost for nursing homes is $3540 per person. The Elderly Waiver has a monthly cost of $1423 per person. The State grant program, called the Alternative Care Grant, has a monthly cost of $795 per person. The level of care criteria is the same for each of these programs. Minnesota's experience has been that offering a more limited benefit has been a successful strategy in delaying or preventing individuals from spending down to Medicaid eligibility.

Mr. Varpness also emphasized that care coordination is an essential component to these diversion programs. He indicated that the inclusion of care coordination along with the alignment of services to the Medicaid program is what makes the Illinois and Minnesota efforts distinctive. Since many seniors find it difficult to navigate and coordinate service needs, the option to have a Care Coordinator greatly improves on service efficiency and effectiveness. By aligning services to Medicaid waivers, there is no service advantage in spending down to Medicaid more quickly. Additionally, as people get close to financial eligibility for Medicaid, a more seamless transition is able to occur.

A table summarizing the elements of the Minnesota and Illinois programs is included in ***Appendix 9.***

The implication of our research for recommendations in Alaska is that there could be a financial benefit through a strategic use of grant funds. This should be done in combination with improved long term care consultation and care coordination for non Medicaid seniors within a targeted eligibility group. Grant funds can assist with purchasing services that prevent placement into assisted living or nursing facilities and delay spend down to Medicaid. The design can also promote personal responsibility by having the consumer share in the cost of services.

A second aspect of prevention and early intervention that we researched is related to the focus on healthier lifestyle choices to prevent injury or deterioration due to chronic diseases. Prevention and early intervention activities are frequently most effective when done as a joint initiative of public health, state and

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[15] http//www.dhs.state.mn (Keyword: Reports and Forecasts)

local governments, foundations, and federal agencies. Examples of these efforts include:

- Several states have adopted Medicaid state plan amendments under benchmark authority that specifically address disease management, prenatal care, and healthy choices for high risk populations enrolled in Medicaid. Further information about these state plans is provided in the section of this report discussing the DRA activities of states.
- The National Council on Aging maintains a database of these programs at www.healthyagingprograms.org. This website lists the following evidence-based disease prevention programs:
    - Chronic Disease Self-Care
    - Physical Activity
    - Fall Prevention
    - Nutrition
    - Depression and/or Substance Abuse
- The National Center for Birth Defects and Developmental Disabilities (part of the Center for Disease Control) specializes in identifying the causes of birth defects, many of which result in developmental disabilities and chronic medical conditions requiring long term care services. Among the most prominent areas of investigation are the prenatal causes of developmental delays and disabilities. While many children are born with unpreventable conditions, a substantial number of children are affected by fetal alcohol disorders and drug related anomalies, both of which are preventable conditions. The Center also has sponsored considerable research to identify prenatal care practices that will help in minimizing the potential for birth defects. Examples of this research include the effect of maternal obesity on the development of spinal and brain related defects, the link between maternal smoking and cleft palate, and the effect of certain prescription and over the counter drugs on fetal development. The Center, along with public and private health agencies, promote healthy lifestyle choices through public campaign efforts, improved outreach, and support for good prenatal care and practices.

- A number of developmental disabilities are also caused by circumstances that occur after birth. One example of this is the effect of lead on normal child development. Exposure to lead is one of the leading causes of learning disabilities and neurological disorders. Other causes of developmental disabilities include near-drowning, falls or accidents resulting in brain injury, and uncontrolled seizure disorders.

- Early identification of developmental problems is another key strategy in helping to minimize the long term effects of impairments. Of note recently is the effort to educate the public and medical community about the need to screen for autism spectrum disorders. While there is no definitive test to determine whether or not a child has autism, physicians can screen during well baby examinations, looking for the presence of certain behaviors. These behaviors typically develop before the age of three. Current protocols for diagnosing autism spectrum disorders are considered to be valid and reliable enough that autism can be diagnosed by age two. Recent evidence has suggested that early intervention for autism spectrum disorders has positive results for some children.
- CMS has also supported earlier intervention efforts through grant funds for initiatives such as the Demonstration to Maintain Independence and Employment. These projects target individuals with specific physical or mental impairments that can lead to disability and allow states to provide benefits and assistance that help individuals manage the progression of their impairments and remain employed. Authorization for an initiative was passed in 1999. Two hundred fifty million dollars was appropriated over a six year period. The most recent solicitation for proposals was released in January of 2008.

There are many opportunities for states to participate in prevention and early intervention activities which help to reduce the likelihood that intensive and costly services are needed by individuals. Alaska may want to consider future federal grant opportunities and partnerships with public health or health care agencies.

Self-Directed Supports

Our research on self-directed supports focused on how states are changing core administrative processes to accommodate the shift in control of service delivery. According to data on the Kaiser Family Foundation website, there are 87 waivers with consumer directed options in 30 states, 12 states with home health services using a consumer directed option, and 10 of 30 states with PCA State Plan services using a consumer directed option. In addition, with the passage of new authorities under the DRA, additional states have adopted self-directed state plan options under either a 1915(j) waiver or a benchmark plan. We used information from a variety of sources including government, foundations, public policy groups, and advocacy organizations. We also interviewed national and state experts.

We first looked at what authorities states use to offer consumer directed options. Cash and Counseling states used the 1115 demonstration authority to allow consumers to purchase personal assistance services. As the demonstration authorities end for these states, most are converting to the 1915(j) authority allowed under the DRA. A growing number of states are including self-directed options under 1915(c) waivers, allowing self-direction for a broader menu of services. Kansas, for example, has a Secretary-approved benchmark plan, which allows working people with disabilities who are buying into Medicaid to self-direct personal care services.

States must have a way to manage the individual budget amount. All states offer the services of fiscal intermediaries. These fiscal intermediaries handle payroll and other payments for services on behalf of the individual. A number of states also offer a cash option in which the consumer receives a monthly amount to pay for services. In the case of the cash option, the consumer is responsible to perform payroll and payment of services. However, studies have indicated that most consumers will choose to use a fiscal intermediary to perform these duties.

State policies vary in terms of the range of services performed by the fiscal intermediary. Fiscal intermediaries always perform payroll and related functions (such as withholding and tax reporting). In some states, the fiscal intermediary may provide employer of record services, consumer counseling services, or be an agency with choice (this means that the agency may also be a service provider). However, because of problems with conflicts of interest, states and the federal government are moving to establish a clear division between service provision and fiscal intermediary functions.

The ability of individual consumers to manage a self-directed option has been addressed a number of ways. States recognize that individual capacity will vary, so consumer counseling and training is available in most states. States have also made provisions to allow consumer representatives to aide in decision-making and directing the use of supports. Many states have included a component within their long term care consultation process to screen the ability of the person to manage self-directed services. As an example of two diverse approaches, we compared New Jersey and Oregon. New Jersey allowed people to decide for themselves whether to participate after being given information about what self-direction would entail. The evaluation findings of the New Jersey program appear to suggest that this self-selection had worked well. Oregon, a state with a cash option, required the consumer/responsible party to pass an exam. Individuals unable to correctly answer 50 percent of the items correctly cannot receive and manage cash directly and must use a fiscal agent.

We also reviewed approaches states use to assign an individual budget. States tend to establish budgets by offering a dollar amount equivalent to the cost of services that the person would otherwise receive. However, early cash and counseling states established a practice of discounting the budget amount to account for better utilization of authorized levels. This practice continues to be common, and is especially important to consider in states where consumers are able to purchase other goods or services that replace caregiver assistance. Similarly, most states allow consumers to hire staff at wage levels negotiated by the consumer. While this does not increase the individual budget amount available, it does affect the proportion of the individual budget that will be spent on staff.

In evaluating self-directed services, there are similar findings across states. Some of the key findings include:

- Consumer success and satisfaction in using a self-directed option is tied to the individuals receiving up front information and having access to counseling at critical decision points;
- Self-directed services were more successful when adequate training and information is provided to the staff working with the individual. This included job descriptions and other worker information typically provided by an employer; and
- In general, satisfaction rates were consistently positive among consumers using self-directed options. Case managers, consumers, and direct care staff perceive that there are positive outcomes when using self-directed services.

The New Jersey evaluation also looked at the issue of whether consumers were able to find and employ staff. The findings suggest that success is more prevalent when the consumer hired family members. The evaluation did note, however, that spouses were not typically employed to provide direct care. This suggests that outside recruitment by consumers is not effective and that people without available friends or family willing to work, would need assistance with recruitment.

The implications of our research suggest that Alaska may want to restructure its consumer-directed option to include the following:

- An improved process for consumer counseling;
- Clearer distinctions about the roles and responsibilities of agencies providing fiscal intermediary services;

- Greater controls on expenditures;
- Increased flexibility for consumers within the individual budget amount; and,
- Processes to evaluate the use and outcomes of self-directed options.

A final area of research in the area of consumer directed services was our examination of how state administrative processes are changed by a well developed system to support consumer direction. We developed a paper that describes these approaches in a White Paper for AoA entitled, *Improving Home and Community-Based Service Delivery Systems for Older Adults and Individuals with Disabilities: Redesigning Information Technology and Business Processes to Support Participant Control, Quality and Cost Effectiveness*. This paper explores the shifts that occur in core business processes, and discusses how information technology can be used to support a more consumer directed system.

As an example of this, we looked at the core business process of assessing needs. In a fully functional consumer directed system, assessment is person centered and comprehensive. This means that the assessment not only looks at needs, but also looks at strengths, preferences, personal priorities, and the availability of unpaid/informal supports that can be used in combination with paid services. The collection of information by a state agency would incorporate data elements from each of these areas, thereby giving the state a powerful tool in making determinations for resource allocation and monitoring the outcomes of services. Additionally, because the assessment process is comprehensive, it assists the consumer in thinking about what is most critical for including in a service plan.

RESEARCH ON STATES IMPLEMENTING NEW DRA AUTHORITIES

This section of the report describes the research and interviews about state activities in adopting new Medicaid options under the Deficit Reduction Act of 2005. The relevant new authorities are the 1915(i) State Plan HCBS, 1915(j) State Plan Self-Directed Personal Care, and 1937 Benchmark plans. We discuss these authorities in the section on the Funding Authority Crosswalk.

Our work consisted of three types of activities: 1) a review of statutory language and proposed regulations; 2) a review of state plan amendments and other state information available on the internet; and 3) interviews with select state officials regarding implementation of DRA provisions. In this section we summarize information gathered during our research and discuss potential implications for recommendations to Alaska.

CMS maintains copies on its website of state plan amendments and approval letters for many of the states using the DRA provisions. We followed up on this by reviewing internet information at each state website and policy papers from groups such as Families USA and the Kaiser Family Foundation. We also reviewed information from the Kentucky Auditor of Public Accounts report to the legislature, Clearinghouse for the Community Living Exchange Collaborative, and the Association of National Medicaid Directors.

A chart containing information about each of the state plans we reviewed is contained in ***Appendix 10.*** The following is a brief summary of that information:

States Using the 1937 Benchmark Authority

Kentucky

Kentucky has adopted a 1937 benchmark plan. This allowed Kentucky to make a significant change to the benefit structure for the Medicaid program by creating new cost sharing requirements and service benefit limits, and emphasizing disease management and premium assistance. Their Medicaid plan now moves people into four targeted benefit plans: Global Choices, Family Choices, Optimum Choices, and Comprehensive Choices. People needing long term care services access Medicaid through Optimum Choices or Comprehensive Choices. **Optimum Choices** covers people with developmental disabilities (DD) and has three levels of long term care services: high intensity, targeted, and basic. **Comprehensive Choices** covers elderly and people with disabilities in need of NF level of care and covers two levels of long term care: high intensity, which includes Nursing Facilities, and basic.

West Virginia

West Virginia adopted a benchmark plan under Section 6044 of the DRA. The West Virginia program is called “Mountain Health Choices” and is targeted to healthy adults and children. The program allows individuals the opportunity to obtain optional benefits by using a partnership agreement. Individuals are assigned to a medical home and agree to participate in health and wellness programs. Participants who comply with their agreements can access enhanced service options that meet their particular need.

Idaho

Idaho adopted a 1937 benchmark plan. The **Basic Plan** is targeted to low income children and working age adults. The **Enhanced Plan** is targeted to individuals with disabilities and special medical needs. (The Elderly may also be served here if they need long term care services.) The **Coordinated Plan** is targeted to dual eligibles (Medicare and Medicaid), primarily elderly <u>not</u> in need of long term care services.

Idaho is one of the states that we interviewed. The State had originally worked to gain approval for changes under an 1115 waiver. The overall vision of the State was to better match the benefit set under Medicaid with the needs of the populations served. This was particularly focused on aged, disabled, and people with mental illness.

The State held regular monthly meetings with CMS representatives in hopes of obtaining approval of an 1115 waiver. Then as the DRA options became available, CMS and Idaho agreed to use the benchmark authority to accomplish the State’s vision. Because of the significant involvement with CMS in the earlier discussion, Idaho did not experience any issues with the approval process. State officials stated that the approved plan did not achieve everything they had wanted for each of the populations, but the approved plan allowed them to control utilization of mental health services.

These utilization controls included limiting mental health services to 26 hours per year for the general Medicaid populations, but allowing enhanced benefits for people who were classified as having serious and persistent mental illness or serious emotional disturbance.

State officials strongly advised to work in advance with CMS. Idaho officials felt that this was critical to develop a common understanding and agreement about how to achieve the State’s goals. Idaho expressed that the experience with CMS had been collaborative in nature.

Kansas

Kansas also adopted a 1937 benchmark plan. The Kansas effort was designed to provide self-directed personal assistance services to working people with disabilities who were eligible for Medicaid through a Medicaid Buy-In program. Kansas does not offer state plan personal care (though it is available through 1915(c) waivers) and the State needed a mechanism to offer personal care to individuals on the Buy-In program to quality for a CMS Medicaid Infrastructure Grant. Thus, Kansas used this provision to provide HCBS targeted to a particular population with a disability who were not eligible for a 1915(c) waiver.

The new self-directed option offers cash and counseling services for individuals meeting the following criteria: 1) must be eligible for the "Working Healthy" program (buy-in eligibility); 2) must meet the eligibility criteria for HCBS waiver; and, 3) must be able to self-direct or, if not able to self-direct, must have a representative that is able to direct their services. Services include case management, personal services, and assistive services. Case management services are not mandatory. The state allows money to be paid directly to the participant for services or the person may use a fiscal intermediary. If the cash option is selected, the individual must complete training that has been developed. The average monthly cost is approximately $1500 per person. The range of costs is from a low of $300 per month to $7000 per month.

A more extensive summary of our interview is contained in ***Appendix 11.***

Virginia

Virginia has instituted a "Healthy Returns" program under the 1937 benchmark authority. This effort provides disease management, targeting people with asthma, congestive heart failure, coronary artery disease, and/or diabetes. The Virginia program excludes: managed care enrollees, dual eligibles, individuals in institutions, and people with third party insurance. The benchmark plan provides for additional services focused on education and management of disease. It also includes access to a nurse call line, care coordination, and telephone based health care management.

Wisconsin

The Wisconsin 1937 effort provides a health plan that highlights preventative care and appropriate use of health care for pregnant women served under BadgerCare Plus. It also provides additional services including wraparound services for mental health and substance abuse, and full EPSDT benefits for pregnant women under age 19.

South Carolina

South Carolina developed a benchmark benefit package. The South Carolina program allows an option for Medicaid recipients to choose a high deductible plan that is benchmarked to the high deductible state employee health plan. The option is limited to 1000 people within Richland County.

Washington

The Washington 1937 plan offers the regular Medicaid state plan services plus disease management services to adult recipients diagnosed with certain chronic medical conditions. This effort is intended to assist people with finding a medical home or a primary care provider (PCP), and to use that PCP to improve health outcomes. The plan includes access to nurse help lines and referrals for needed services. The State intends to use these strategies to help manage the utilization of service. Those eligible include categorically needy aged, blind and disabled who are at least 21 years of age. This option does not exclude individuals using long term care services. Additional health benefits include: condition specific education, access to nurse call line, telephonic health care management and support, and care coordination.

States Using the 1915(i) State Plan HCBS Authority

Iowa

Iowa adopted the 1915(i) Home and Community Services option of the DRA. The Iowa program targets people with functional impairments typically associated with chronic mental illness. The services are designed to assist participants in acquiring, retaining, and improving the self help, socialization and adaptive skills necessary to reside in the community. Services include: case management when an individual does not qualify for targeted case management, home-based habilitation including services provided in the person’s home and community (including medication management, budgeting skills, grocery shopping, personal hygiene, etc.), day habilitation services that are provided outside the home in a day program setting, prevocational services, and supported employment.

States Using the 1915(j) State Plan Self-Directed Personal Care Authority

Alabama

Alabama was the first state to obtain approval for self-directed personal assistance services under the 1915(j) provision. Called “Personal Choices” the program is an expanded model of consumer direction targeted to participants of the state’s two HCBS waivers (elderly and disabled waivers). At the time of the review, recipients had to live in one of seven pilot counties.

Arkansas

Arkansas was one of the original Cash and Counseling Demonstration States and has converted their 1115 demonstration waiver to the 1915(j) authority. We interviewed two State officials about their program.

Because the 1115 demonstration had been in place for quite a while, the conversion and implementation went smoothly. Arkansas officials said that CMS is requiring the states with demonstration authority for cash and counseling to convert over to the 1915(j).

The Arkansas program allows individuals to choose a consumer directed option for their personal assistance services. If the person is also a waiver recipient, the consumer directed option allows them to also convert their companion services as part of their individual budget. The State additionally has a consumer directed option under their 1915(c) waiver that works in a similar fashion for a broader array of waiver services.

Individuals are assessed for PCA services by a registered nurse. This nurse provides information at the time of assessment about the consumer directed option. This discussion between the nurse and individual includes information about the responsibilities assumed by the consumer if a self-directed option is chosen. In addition, the State has developed tools to assist the consumer and offers counseling services available through the State agency.

Consumers are the employer of staff and fiscal intermediaries perform the financial functions on behalf of the consumer. The fiscal agents are given limited power of attorney to be able to sign tax and other employer forms on behalf of the consumer.

The consumer budget is based on the number of units the person would be authorized to receive under the regular PCA program. Because consumers can more easily maximize the equivalent budget, the State does apply a percentage discount to the consumer budget. This discount is 58.7% of what would be paid to an agency if all units were utilized in agency based services. Each consumer is allowed to reserve up to 10% or a maximum of $75 per month (whichever is less) in a savings account. This savings can be used for goods needed by the consumer that substitute for staff assistance. Since this is a cash option, the savings can accrue over time until enough money has been saved to make the purchase. At the present time, Arkansas has approximately 2000 people using the consumer directed option.

Summary

This research has several implications for recommendations to Alaska. First, the benchmark provisions may offer a means to address the needs of several populations for whom the State is now paying through State-only funded programs or to expand services to individuals who do not meet the NF-LOC, but are Medicaid eligible. It is important to note that this authority was not meant as a mechanism for expanding access to Medicaid funded HCBS, although several states have used the authority in that way.

Second, the 1915(j) option appears to be a promising alternative for Alaska's current consumer directed personal care program. Multiple states are using this option and have reported no serious problems with the CMS review process. This option would provide the State with more control of budgetary and caseload aspects, while also improving the option for consumer use because of increased flexibility. This option might offer a realistic alternative to people in rural and frontier areas where agency services are less likely to be available.

Third, the State may want to be cautious about the use of the 1915(i) option. We only identified one state that had moved forward with this option and it did so to target individuals with mental health conditions. Because states can only obtain approval for one 1915(i) option, most states appear to be reserving this option for services targeting people with mental illness.

EXPERT INTERVIEWS

As part of the project to develop the Long Term Care Plan (LTCP), we interviewed national experts to elicit feedback about specific recommendations being proposed in the report. These experts were selected on the basis of their knowledge and experience in services for seniors and individuals with disabilities and their understanding of promising practices and trends at the national level. Below we have indicated key points obtained during the course of each interview:

John Wren, US Administration on Aging

John Wren is the Deputy Assistant Secretary for the Administration on Aging. Our discussion confirmed that recommendations for single entry point for intake and recommendations for consumer direction are consistent with the direction that AoA is pursing with states to implement the new long-term care provisions that were included in the 2006 Amendments to the Older Americans Act.

He also thought that our recommendation for developing individualized budgets should be expanded to include Title III dollars that are used by the State to serve seniors who are at risk of nursing home placement but not eligible for Medicaid. AoA is encouraging states to take this sort of action under its Nursing Home Diversion Modernization (NHDM) effort.

He also discussed the importance of a clearly articulated philosophy and vision that will guide Alaska over time. These things, in conjunction with strong leadership and demonstrated commitment, will be necessary for success.

Changes to recommendations:

- Expanded recommendation on individualized budgets to include Title III targeted at serving high-risk individuals who do not qualify for Medicaid.

- Added a recommendation to clearly articulate the philosophy and incorporate it into program operations. Concrete action steps include adding the philosophy to any long term care reform legislation and instituting a process under which the impact of any changes to policies and regulations is considered.

Nancy Thaler, National Association of State Directors of Developmental Disabilities Services

Nancy Thaler is the Executive Director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS). Ms. Thaler was also the former Director of Developmental Disability Services for the State of Pennsylvania.

We discussed at length the experience Ms. Thaler had while in Pennsylvania with training curriculums for direct care staff, including that State's experience with online training. She stated that there are benefits to online training programs (e.g., consistency across agencies and employees; the ability to transfer training credits across agencies; ease of training for people who work for consumers directly). She emphasized that any online training program must be integrated into an agency's training and supervision structure to provide a context for the training and accountability to the employer.

Ms. Thaler also covered at length her views on case management/care coordination. It is her strong belief that Care Coordinators need to be free from the conflict of working for a service provider, and should be the eyes and ears of the State at the consumer level. Their responsibility should be to carry out the State's obligation to assure the health and welfare of each participant by assuring each has a plan, that services are delivered, that services meet the person's needs and that changes in condition will result in a modified plan. She also indicated that practice standards are not well developed and there is a need for a lot of work in this area. She believes that given the reality that the majority of people receiving services are living with their families, Care Coordinators need a better balance of clinical expertise and skills in the areas of human/family dynamics and mediation.

We also discussed the issue of alternative residential service models. Ms. Thaler pointed to models in Pennsylvania and Vermont where they have developed shared living networks that match people interested in sharing a home. These matches include non-disabled individuals and have resulted in many people with disabilities gaining an extended network of "friends and family."

Changes to recommendations: Have the State establish and pay for the online training contract. Insist that providers describe how they will incorporate this tool into their broader training program.

Susan Reinhart, AARP

Susan Reinhart is Director of the AARP Public Policy Institute.

We spent much of our interview discussing the issue of eligibility criteria for nursing home level of care. Ms. Reinhart urged caution in modifying Alaska's criteria. She advised to continue to require substantial assistance in three ADLs but to incorporate an additional option for individuals with cognitive impairments. This might enable Alaska to address its interest in coverage for people with severe dementia, Alzheimer's, and Traumatic Brain Injury. She suggested that we look at several other state approaches on eligibility.

We likewise discussed the use of respite care and caregiver support. She favors a family caregiver assessment as one potential approach to determine how much paid care would be needed to supplement unpaid care. She also advises that in-home support to cover hours that a caregiver is away would be a good addition to the waivers if the State wants to support home based models of care.

Changes to recommendations:

- Alter recommendation on changing eligibility criteria to add a separate cognitive eligibility criteria instead of altering ADLs.

- Add caregiver assessment and link to caregiver support program as part of the unified assessment.

CMS Staff

We contacted CMS for a discussion of several issues. The CMS group was headed by Suzanne Bosstick, Director of Division of Community & Institutional Services. Mary Sowers, Marguerite Schervish, Mel Schmerlerr, Donna Schmidt, and Jeannine Bell, staff representing HCBS waivers, family and children, tribal, and new DRA options were also present. This included the project officer from Alaska, Jon Sherwood, who was also on the call.

We discussed the current policies and directions within CMS for the 1915 (j) option and benchmarks. It is our understanding, based on our discussion, that a Secretary approved benchmark plan might be possible to address the long term care needs of Medicaid eligible individuals with Alzheimer's, dementia, or brain injury without changing the nursing facility level of care criteria. CMS staff noted that unlike a 1915(c) waiver, the benchmark authority does not expand eligibility. If Alaska pursues a benchmark plan that includes 1915(c)-like services, individuals would have to already qualify for Medicaid. Although individuals already enrolled in a 1915(c) waiver could be eligible for a benchmark plan with the higher income allowed under Alaska's 1915(c) waivers, people who are not eligible for a waiver would only be eligible for a benchmark plan if they met the regular Medicaid criteria.

Additionally, we briefly covered questions related to native health services that are IHS designated or compacted entities. CMS staff indicated that in a number of areas they would need to see more specific proposals in order to respond. They were supportive of submission of a concept paper, which would outline the State's interests, and would be willing to work with the State to address those interests.

CMS indicated that the timeline for regulations concerning the 1915 (j) was targeted to be prior to the end of the year.

Changes to recommendations:

- Added recommendation to pursue benchmark plans for covering ADRD, Brain Injury, and Pioneer Homes.

Pam Doty, US Department of Health and Social Services

Pam Doty is a Senior Policy Analyst in the Division of Disability, Aging, and Long-term Care Policy in the Office of the Assistant Secretary for Planning and Evaluation within the US Department of Health and Human Services.

Our interview with Dr. Doty covered primarily two issues, consumer directed services and eligibility criteria.

Dr. Doty discussed the difference between two types of self-directed supports: “fiscal/employer agent (F/EA)” versus “agency with choice”. When we described Alaska’s CDPCA program, she classified it as an “agency with choice” model. Under the F/EA model, the program participant is the common law employer. The F/EA files payroll taxes as the employer’s agent, but does not serve as “employer of record.”

In the “agency with choice” model, the agency serves as the “employer of record” for tax purposes and may be considered the legal employer for other purposes as well. She noted that this is sometimes described as a “co-employment” model in which the agency is legally the “employer” for tax and other purposes, but the consumer is characterized as the “managing employer” because the consumer retains hire/fire authority and does daily supervision.

Dr. Doty considers the “agency with choice” model unstable because the agency has employer responsibility but the consumers get the employer authority. She noted that the disequilibrium tends to make the “agencies with choice” nervous; their potential legal liability for any harm the consumer-hired worker might cause concerns them. This is exacerbated by the fact that the agency has no role in screening, training, or quality oversight. Thus, she noted that Alaska’s agencies who participate in CDPCA are in a vulnerable situation and if the State continues with the model, it should pass legislation that protects them from liability. Without such protection, she argued that these “agencies with choice” would become nervous and be inclined to take on more and more of the trappings of regular licensed home care agencies in the name of “quality” and to protect themselves from potential liability. She discussed how this could quickly degenerate to the point where consumers are left only with the freedom to select and dismiss workers whom the agency has “approved.” At this point, she argues that this is no longer consumer directed care.

Dr. Doty believes that consumer direction requires that consumers accept responsibility for a worker who turns out to be incompetent, negligent or abusive as they do under an F/EA model. Accepting this responsibility is essential to the consumers’ judgment of who is qualified to provide the care being their standard rather than a standard set by an agency. She explained how the infrastructure that an agency needs to set and enforce standards for their employees greatly increases administrative costs. She noted that because an F/EA model involves considerably less administrative overhead, the same amount of public money can be stretched further to pay for more hours of care and/or pay workers higher hourly wages.

This reasoning led her to strongly support the recommendation to move the existing CDPCA program to an F/EA model using the 1915(j) authority. She also shared that California's Public Authority is a good model to review for purposes of how direct care staff under consumer directed models are supported. She indicated that the Public Authorities offer training, although the curriculum is not mandatory. In some cases, stipends are available.

Dr. Doty does not advise mandatory curricula for consumer directed staff. She noted that most staff are friends and family members who would not likely choose caregiving as their career, except in the case that they have a relationship with the individual. In those cases, training is better when it is specific to the individual situation.

Dr. Doty also noted that information coming from cash and counseling states indicates that most caregivers under consumer direction are family and these caregivers get paid for about one hour out of three that they provide direct support.

Dr. Doty encouraged the State to consider "nurse delegation" models as a major component of the training. Nurse delegation would allow consumer directed caregivers to provide assistance with a limited range of medical tasks, such as taking medication and wound care. She indicated that family doctors and nurses are more likely to be comfortable in providing this training when the caregiver is family. The State would also need to consider potential changes to its nursing standards in developing this effort.

We also discussed the NF-LOC eligibility criteria. Similar to Ms. Reinhart, Dr. Doty advised caution in changing the current criteria. She advised consideration of separate criteria for individuals with severe cognitive impairments. However, she also said that there was not any "gold standard" for a cognitive assessment tool that would lead to clear criteria of who should and should not be eligible because of cognitive impairment.

Changes to recommendations:

- Altered recommendation on changing NF-LOC eligibility criteria to consider a separate cognitive eligibility criteria instead of altering ADLs.
- Explored addressing nurse delegation as part of infrastructure development.
- Explored using California's Public Authority effort as a model for Alaska.

RECOMMENDATIONS

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 (HCBS). 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."[16] 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.[17]

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.

We have crafted a series of recommendations aimed at making Alaska's long term care programs more cost-effective. ***Appendix 12*** summarizes our major recommendations, which are in rows highlighted in dark blue, and specific recommendations that are related to each major recommendation. In the table we identify whether we anticipate including the recommendation in the three year

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[16] Enid Kassner, Susan Reinhard, Wendy Fox-Grage, Ari Houser, & Jean Accius (July 2008). ***A Balancing Act: State Long-Term Care Reform***, AARP.

[17] Research and Training Center on Community Living Institute on Community Integration/UCEDD at the University of Minnesota (August 2008). ***Residential Services for Persons with Developmental Disabilities:Status and Trends through 2007.***

action plan (3YAP). We also identify the potential impact that the recommendation will have on each of the organizing principles included in the original RFP:

- Sustainability
- Support in the home
- Support for families
- Integration with Tribal Care
- Transparent and accountable system
- Services must have measureable outcomes and be culturally appropriate

Our ratings of the impact of each recommendation include the following:

+++ = Will likely have a strong positive impact
++ = Will likely have a modest positive impact
\+ = Will likely have a nominal positive impact
o = Will likely not have an affect
\- = Will likely have a nominal negative impact
\- - = Will likely have a modest negative impact
\- - - = Will likely have a strong negative impact

Below we provide more information about the recommendations and a summary of the rationale for each. The major recommendations fall into the following categories:

1. **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.
2. **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.

3. **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 the current CDPCA program. CDPCA also offers individuals less control than the approach used by the Cash and Counseling Demonstration, which extensive research has shown to be very effective. To develop a more effective consumer directed program, we recommend the State fold the current spending for CDPCA under a 1915(j) State Plan Self-Directed Personal Care option, a new Medicaid authority created by the DRA.
4. **Support populations not meeting the Nursing Facility Level of Care (NF-LOC) eligibility criteria**: The NF-LOC creates a significant barrier to obtaining Medicaid FFP for people with ADRD and brain injury. Unfortunately, a lack of data and uncertain federal rules would make it irresponsible to offer a specific recommendation regarding how to address this issue. Thus, we recommend the State engage in parallel efforts to collect necessary data to analyze the implications of changing the NF-LOC and to determine the feasibility of using the 1936 Benchmark Plan authority for providing supports to these individuals.
5. **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.
6. **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.
7. **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.
8. **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.

We also include several other miscellaneous recommendations in the body of the report.

Recommendations not made

The RFP required that we consider whether the current PCA program should be folded within a waiver and to make recommendations regarding the effort to address the Developmental Disabilities (DD) Waiver waiting list, also known as the DD Registry.

We do not think it would be appropriate to shift the current PCA program to a 1915(c) waiver. Taking this action would require that all individuals receiving PCA services meet the NF-LOC. This would result in approximately half the individuals on PCA no longer being eligible for any long term care services. Our recommendations do include substantial changes to the development and oversight of budgets for the PCA program and shifting CDPCA to a mechanism that can be capped. We believe these changes will make the program much more sustainable without decreasing the ability of Alaskans in need of long term care to remain in the community.

We also examined the process the State was using to reduce the DD Waiver waiting list. The stakeholders interviewed and our independent analysis suggested that the State was making substantial progress and no recommendation was warranted other than for the State to continue to actively pursue its efforts in this area.

We carefully explored whether the State should use the 1915(i) State Plan Home and Community-Based Services authority created by the DRA as a means to offer services to people not currently eligible for the waivers, such as individuals with mild to moderate ADRD or Brain Injury. We felt it was more advisable for the State to pursue other options discussed below and not the 1915(i) authority for the following reasons:

- States can only apply for one 1915(i) option and Alaska will likely consider using this option to provide community based services to individuals with mental health needs. Alaska could potentially develop a 1915(i) option that provided services to these individuals and individuals with ADRD and Brain Injury. However, this would need to be done in conjunction with the Division of Behavioral Health and it would be extremely challenging to develop eligibility criteria and service definitions across populations. In addition, while the State could set a cap for the number of people who enrolled in the program, it could only set a single cap. Managing this cap would require constant cross-agency coordination and alterations to program criteria to make sure all populations have equitable access to this option.

- CMS' guidance in the draft rules includes requirements that would be difficult for Alaska to incorporate into their assessment processes, including:
    - The assessment must address impairment in activities of daily living (ADLs) using an "objective" approach, such as having an Occupational or Physical Therapist participate in the assessment. This would apply to all individuals, including people who only have a mental health need and do not have any ADL impairments.
    - The individuals conducting the assessment must have "knowledge of best practices". Implementing this will be resource intensive and challenging because "best practices" continually evolve and in many cases, there is no consensus regarding which practices.
    - The individual conducting the assessment must be free from conflict of interest. Unlike other draft regulations that limit this to prohibiting service providers from conducting assessments, the draft regulations require that the assessors be free from any "concern for the budget." Depending upon CMS' interpretation, this could prohibit State employees from conducting the assessment and/or make it challenging for the State to control budgets.

CMS' regulations for this option are likely to change and future Congressional action may make this a more viable option. We recommend that the State monitor the development of the regulations for this option.

Recommendation Cluster 1: Restructure the Process for Matching People with Funding Sources to Comply with the Administration on Aging's (AoA) Definition of a Full Functioning Aging and Disability Resource Center (ADRC)

The early contacts with potential consumers and their families are important in shaping decisions about what services the person will use. If this process is inefficient and/or not helpful, people will gravitate toward whatever resource they can find to relieve the immediate need and concern. In these circumstances, the

State has lost an important opportunity, and the result can be significantly more expensive in the long run.

The State recognized the importance of this issue and, as a result, has engaged in an effort to build ADRCs. The ADRC model, which was first developed in Wisconsin and then adopted by CMS and AoA as a major policy initiative, tries to improve the process of matching people with supports. The model achieves this goal by accomplishing the following:

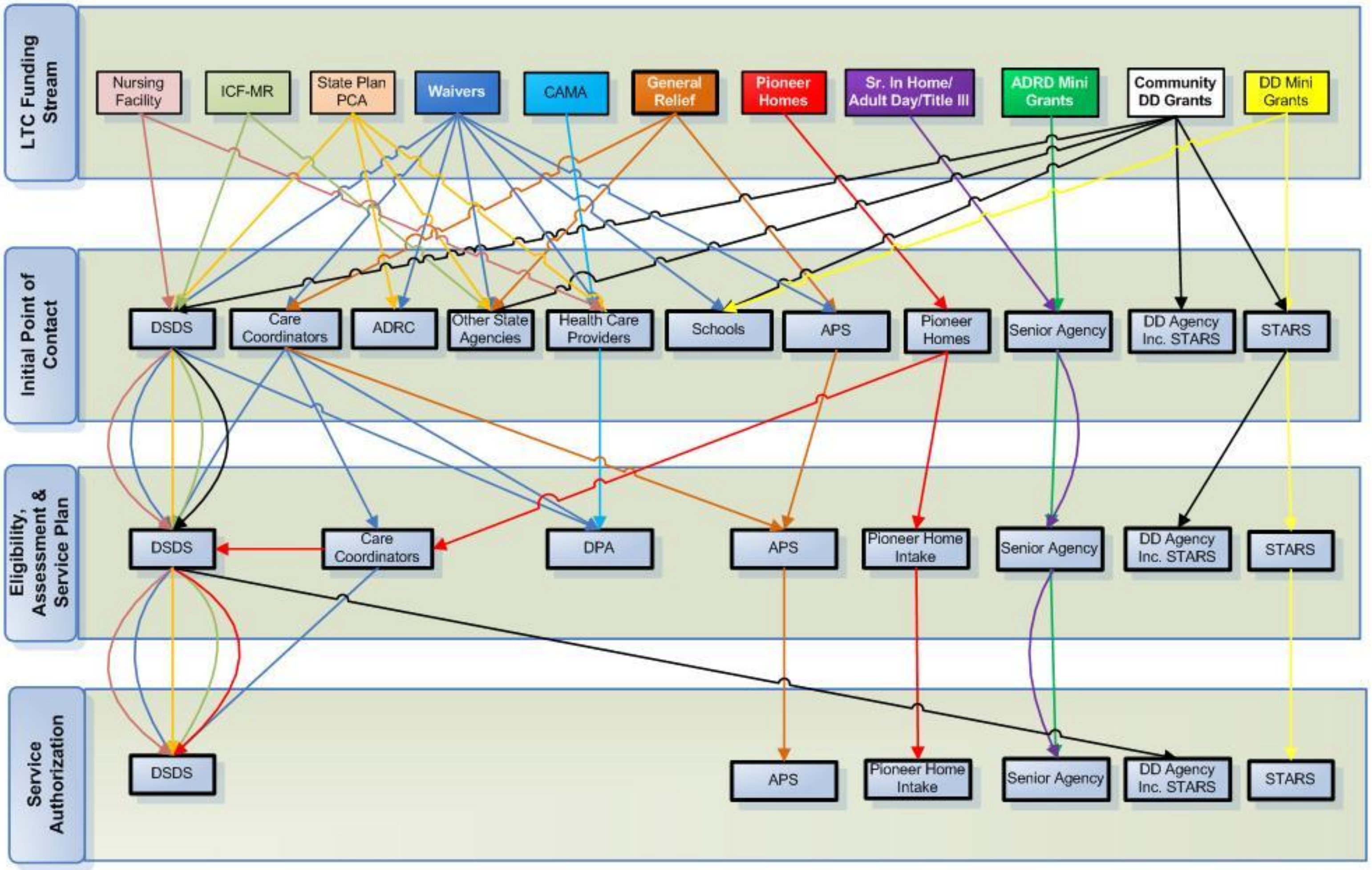
- Providing information and assistance (I & A) about available long term care programs;
- Integrating the initial point of contact for all long term care services into a single point of entry;
- Streamlining eligibility, especially for individuals who have the greatest need for immediate services; and,
- Facilitating the ability for individuals to make informed choices about programs by allowing them to understand all of the services for which they are eligible, the capacity and quality of providers, and providing them with counseling about their long term care choices (LTC Options Counseling).

Alaska's efforts thus far have only targeted the I & A function.

Exhibit 4 delineates key access processes for the Pioneer Homes and the ten different funding authorities for long term care services operated by DSDS. In addition to having separate access processes, most of the programs use different assessment tools and have eligibility criteria that may potentially overlap.

This lack of integration creates challenges for the State in that it must manage each program as a separate effort, thus preventing it from managing the delivery system as a whole. Trying to contain costs for one funding stream will inevitably create pressure for cost increases on other funding streams. The lack of integration also creates a maze that consumers in need of services must navigate.

EXHIBIT 4: LTC ACCESS BUSINESS PROCESSES

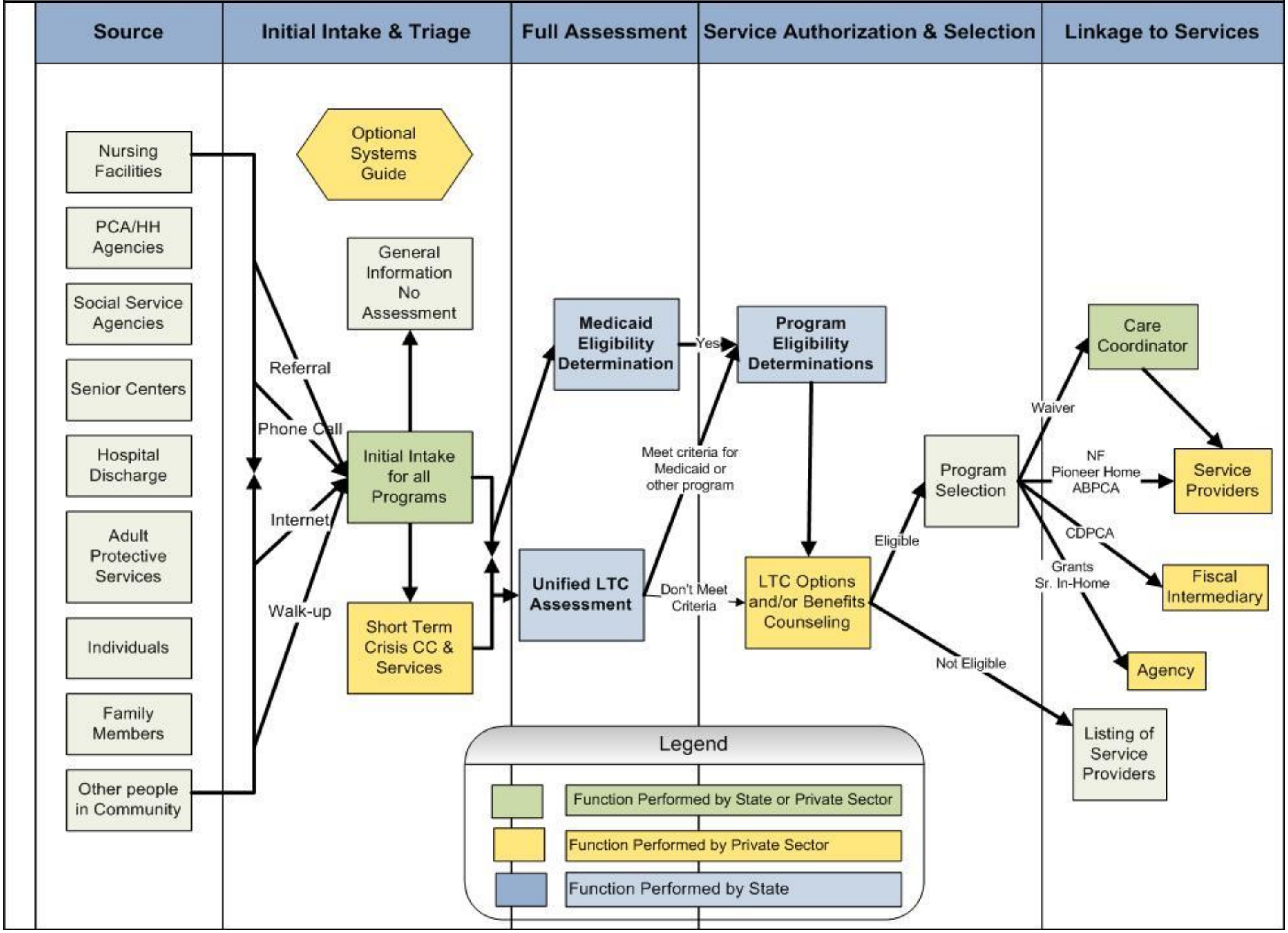


AoA has issued guidance for what it considers to be a full functioning ADRC. The criteria can be found at: http://www.adrc-tae.org/tiki-index.php?page_ref_id=751. ***Exhibit 5*** presents a proposed restructuring of the process in a manner that would be consistent with this model. This model should be considered as a starting point in an effort to build a full functioning ADRC. We would anticipate that as the State implements this proposal, many of the specifics may change.

Initial Intake and Triage: Under the proposed new structure, all individuals in need of long term care would seek services under the same process. Individuals would go through one application process that would determine eligibility for and provide entry to all of the current long term care services. Under this process, the first core business process would be a centralized place that conducts the initial intake for all long term care services. The State could either assume this function or contract this out to another entity. If the State chooses to contract out this function, we would strongly encourage them to select an organization that is not affiliated with a provider organization. The initial point of contact would serve to gather a limited amount of information to determine whether the individual is appropriate for referral for a full assessment and the degree of urgency and gather sufficient information to begin the Medicaid financial eligibility determination process. A substantial portion of the people contacting this entity would not be referred on and would only require information and assistance. Thus, it will be important that this entity have the capability to respond to their questions.

Consistent with the ADRC model, our proposal would make ADRC services available to anyone regardless of income. For individuals who are referred for a full assessment, the initial intake process should triage people into one of three categories: Regular priority, high priority, and crisis. Individuals classified as being in crisis would be those in immediate need of supports. In those cases, the agency would make an immediate referral to an agency that has a flexible State grant, such as from the Short-Term Assistance and Referral (STAR) or Senior In-Home Services Program. These individuals would also be referred for programmatic and Medicaid eligibility. The State could try to receive Medicaid match on a portion of these funds if the person is found to be Medicaid eligible.

Exhibit 5: Proposed Operational Flow for Full Functioning Aging and Disability Resource Center (ADRD)



In designing this effort, the State should pay close attention to how this process intersects with the hospital discharge process. The initial intake and triage process should not create a barrier that results in longer hospital stays because of delays in approvals for nursing facility care or other services. This may require either an expedited process or allowing some individuals to bypass this intake process in certain cases. However, the State will want to make sure that a complete assessment is done for these individuals and they are offered a range of choices including HCBS.

It would be very challenging for a single entity to have the capacity to address Alaska's unique geography and cultural diversity. Distrust and lack of familiarity with State systems in villages and other Native areas will also present a major barrier. Thus, we suggest that the State supplement the initial intake process with an optional Systems Guide program. Systems Guides would be individuals who have received basic training on how the ADRC process works and would participate in the initial contact. They would help explain the process to individuals and family members and help explain the needs of the individual to the person conducting the initial intake (which in most cases would be via the telephone). The State could offer a stipend for their participation. This stipend could be eligible for Medicaid administrative FFP, because it would be related to Medicaid outreach and eligibility determination. This effort could also incorporate infrastructure and personnel developed by the Department of Public Assistance to facilitate Medicaid enrollment in remote areas of the State.

Full Assessment: The full assessment process will be similar to the current assessment process for waivers. DSDS would maintain this function and would closely coordinate the programmatic determination (e.g., meeting the nursing facility level of care) with the Medicaid financial eligibility determination process. One of our specific recommendations is for the Medicaid financial eligibility workers to be collocated with the assessment unit.

Our proposal does differ from current practices in a fundamental way: we propose a single unified assessment process that results in a determination of all of the programs for which an individual might be eligible. This does not mean that they will be enrolled in all of the programs. This would be determined as part of the next phase.

Service Authorization and Selection: The next step in the process would differ depending upon whether an individual is eligible for publicly funded services. Individuals who are not eligible would be offered counseling about their long term care choices (LTC Options Counseling) and provided with access to information about available providers or other community resources.

For other individuals, the information from the programmatic and financial eligibility assessments would be combined to determine for which programs the person meets the eligibility criteria. The individual could also be given information about the potential budget that they might be eligible for if the State were to adopt the recommendation about building benchmarks. This information would inform the LTC Options Counseling process.

LTC Options Counseling is a key component of the ADRC model. It recognizes that decisions about long term care typically involve individuals who are often in an emotionally challenging state and are encountering a new system that offers complex choices. Having an independent person assist the individual in walking through these choices may be more likely to result in a decision that the individual and/or family can maintain. While it is generally preferable to allow someone to remain in the home, a family member may not understand the amount of time and level of commitment that this choice involves.

Requiring that LTC Options Counseling be done by an entity that is independent of both the State and service providers may allow these individuals to be more effective. This independence would remove conflict of interest concerns and could allow individuals to have greater trust in the guidance they receive.

Given the geographic size and diversity of populations with disabilities, we would anticipate that the State would need to have several contracts to perform LTC Options Counseling. Senior Centers and Centers for Independent Living may be the best positioned to provide this counseling. Current STAR agencies that do not provide direct service would also be a logical choice.

Linkage to Services: Once a person has selected a program (or programs, such as a waiver in combination with PCA), there must be a handoff to the actual entity providing the service. This handoff could be done either by the State assessment staff or by the entity doing the LTC Options Counseling. Either way, it will be essential to have a feedback mechanism to ensure that the handoff was successful and the person is receiving services.

In the case of a waiver, the handoff will be directly to the Care Coordinator. If the recommendations regarding consumer direction are adopted and the State establishes an independent fiscal intermediary function, individuals enrolling in a consumer directed program would be referred to this entity. In other cases, the person would be connected directly with the service provider.

Building a full functioning ADRC encompasses the following specific recommendations:

a) **Initial intake, triage, eligibility determination and options counseling**: We recommend establishing a single entry point for all eleven programs that standardizes how people come into the system. The proposed model assumes that the State will work with partners to develop a full functioning ADRC structure and will use existing infrastructure when it is efficient and effective to do so. This helps to assure that access to services is based on accurate information, timely assistance, an efficient process for determining eligibility, and informed choice. This recommendation also addresses existing problems that result in people going to more intensive and costly services because access has been delayed or because they have not received a full explanation of their options. We have not identified crucial design decisions regarding this function, including who will perform the function, how many sites there will be and whether there will be population specific sites (e.g., focused on supporting individuals with DD). The 3YAP includes these design decisions as one of the first tasks.

b) **Unified assessment protocol across programs**: We recommend that the State develop a unified assessment tool and protocol for determining eligibility and identifying needs across programs. This approach provides an efficient way to determine both eligibility for programs and the level of service required by eliminating the need to complete multiple assessments and eligibility determinations for the same individual. It also becomes a useful tool for developing the service plan and identifying active treatment needs.

The unified assessment protocol should be structured so that individuals are only asked assessment items that are relevant. Many assessments include trigger questions that allow an assessor to bypass questions that do not apply to a particular individual. This approach would allow the State to conduct a more comprehensive assessment without subjecting individuals to an overwhelming process that asks many unnecessary questions.

This recommendation should be considered in conjunction with the following recommendation.

c) **Add more domains to the assessment and tie it back to the Minimum Data Set (MDS) Home Care**: The Consumer Assessment Tool/Personal Care Assessment Tool (CAT/PCAT), which is a derivative of the MDS Home Care, includes a relatively comprehensive assessment of medical and activity of daily living (ADL) information. The assessment tools for the other programs are much less sophisticated. The information collected in the CAT/PCAT is relevant and important information that should be collected for all individuals receiving State long term care funding. We have three concerns about simply expanding the use of the CAT/PCAT.

One, the CAT/PCAT has been modified from Maine's assessment tools that were based on the MDS Home Care. These modifications have resulted in a tool that is less clear than the MDS Home Care and has not evolved with the MDS Home Care. In addition, although the MDS Home Care is free, the terms of use offered by the InterRAI program that oversees these tools require that they must be used without any modifications to the items (though states are free to add additional items). The InterRAI effort is building substantial data to benchmark assessments and developing care protocols and other tools that link to the MDS Home Care. Reestablishing the link with the MDS Home Care would allow Alaska to take advantage of this research.

Two, the assessments fail to address a number of other important domains that have substantial influence on the level and type of services required. Notable exclusions from the assessments include:

- A screen for mental illness or behavioral concerns;
- Information about environmental circumstances that have potential impacts on the type and duration of services needed;
- A module that assesses the ability of informal caregivers to continue to provide support; and,
- A person centered interview to elicit information about consumer views of what is needed, what unpaid supports are likely available, and what personal or cultural preferences would be of importance in the delivery of services.

Three, the assessment process should link directly into and create documentation validating the care plan. This will help ensure that the plan adequately addresses the health and safety of the individual and is supported by documented, assessed needs. This documentation will help the State in the event of either a CMS quality or financial audit.

d) **Integrate financial and functional eligibility criteria for all programs**: In some cases, the eligibility rules for State programs overlap with Medicaid eligibility or incorporate a disincentive for people to become Medicaid eligible. In the case of the Pioneer Homes (PH), the State pays the entire cost of care for people who are income eligible but retain a higher asset level than Medicaid. Residents are not required to spend down in these cases and the State will pay the cost of care for as long as the person remains in the facility. Under General Relief, the State pays the cost of care for Medicaid eligible individuals who have not completed the eligibility process. And although General Relief is intended to be time limited, the State is frequently paying the full cost for six months or more.

Given this, we recommend an alignment of policies and procedures in order to reduce the burden on State funded programs.

This realignment will involve altering the functional and financial eligibility criteria for many of the programs to eliminate incentives to use State-only funds before Medicaid funds. The effort should also try to improve the targeting of State-only fund so that they are used to prevent or delay people from needing more expensive long term care services and requiring assistance from Medicaid and to provide services in a timelier manner until Medicaid eligibility could be established. Because many of the programs already have targeting criteria, we do not anticipate that this will result in wholesale changes. In most cases, this effort would involve making the criteria more explicit and based upon data that would be obtained through the proposed unified assessment tool.

It is important to emphasize that under the proposed redesign, State-only dollars would continue to play a vital role in the service delivery system and would help to control Medicaid costs by allowing for quicker and earlier interventions. Thus, it will be necessary for the State to ensure that this funding continues and reflects changes in the number of people needing long term care services.

e) **Offer assessment and Options Counseling to private pay individuals in order to delay entry into the public system**: This recommendation builds off a broad, but efficient information and assistance system. Providing assessment and options counseling to private pay individuals could help them identify less costly support options, thus delaying their spenddown to Medicaid. In interviews with focus groups, we heard evidence that this outreach effort represents a potential area of opportunity to intervene early and prevent unnecessary costs, as families frequently “give up” because they have no assistance in navigating or understanding options that could be purchased through private resources.

f) **Collocate financial eligibility workers within the DSDS assessment unit:** The State has recently taken over the responsibility for the level of care assessments after losing its contractor for this function. The State is to be commended for its ability to quickly respond and establish a unit to deal with this business function. However, the eligibility and assessment approval process was consistently cited as a bottleneck for obtaining services. Collocation would facilitate a more expeditious process for people seeking long term care services by allowing the financial worker and reviewer of assessment/level of care to share cases and work together to resolve issues.

g) **Improve and expand the Pre-admission Screening and Resident Review (PASRR) process:** The PASRR process is a federally mandated screening process that must be done for all individuals who are entering nursing facilities. This process mandates screening for mental health issues and developmental disabilities and requires that each state has a means for ensuring that either these needs will be met within the nursing facility or that they will be met elsewhere. During our review of business operations, we found that the PASRR process was not identifying active treatment needs and ensuring that they were addressed in the service planning process.

We recommend that the PASRR process be incorporated into the unified assessment process discussed earlier. Thus, all individuals seeking long term supports, whether in a nursing facility or in the community, would have a brief mental health screen in the early stages of assessing needs and determining a service plan. This approach was included in the Minnesota Comprehensive Assessment effort. This is an efficient way to meet PASRR requirements without duplicating efforts. It will also help to ensure that appropriate screening is completed and older adults and individuals with disabilities with a mental health diagnosis are referred to the mental health system.

Recommendation Cluster 2: Restructure Waiver and PCA Budget Management

The current mechanisms the State uses for controlling costs may have limited effectiveness and may hamper progress towards other goals, notably allowing individuals to stay in their own homes and with their families. The current approach is either to limit the negotiated rate with providers, such as assisted living, or to cap hours for services, such as PCA, respite or chore. While these mechanisms help to control costs, potential side effects that may actually increase costs and other negative outcomes, such as:

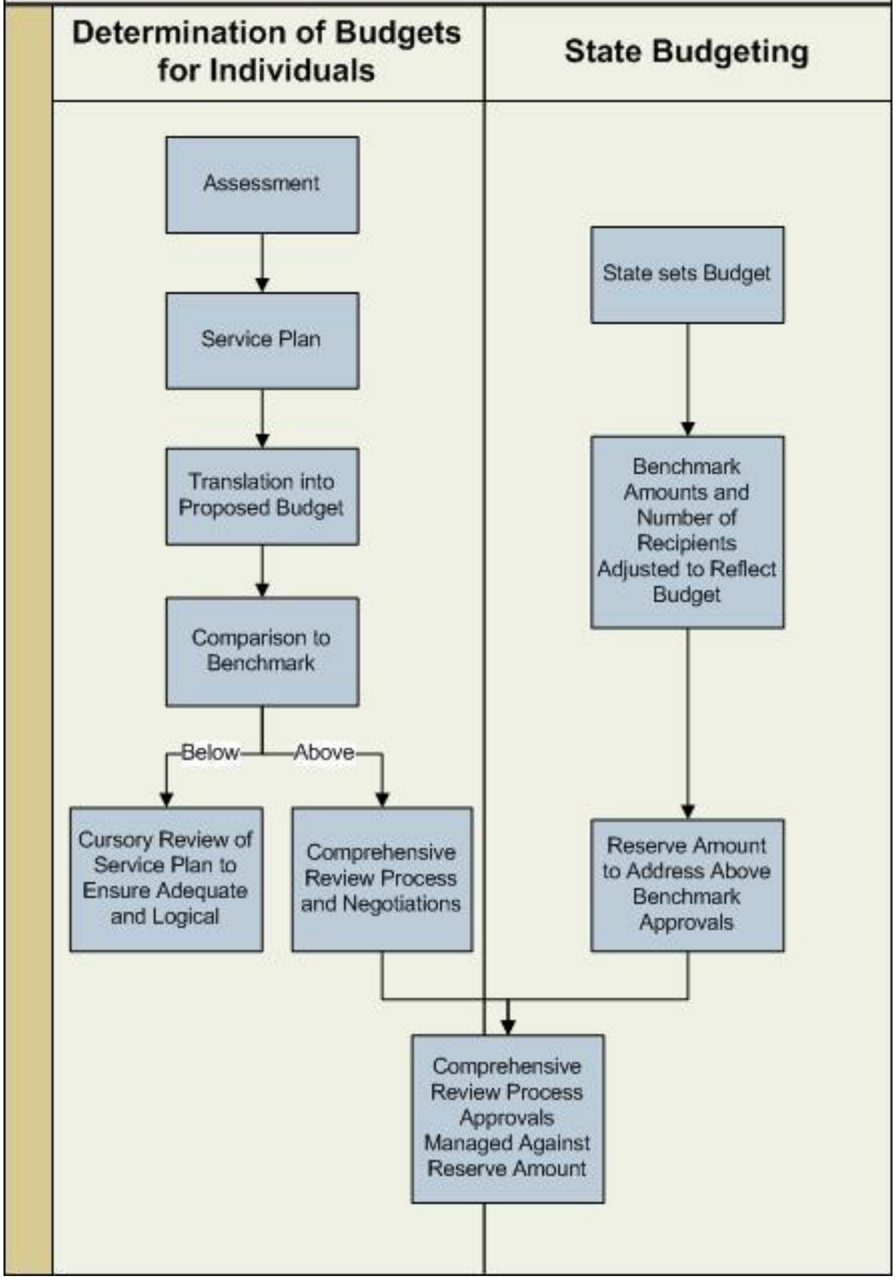
- Providers and consumers will create pressure to bill up to cost caps that have been created; consumers have a tendency to view the cap as what they are entitled to receive. Providers have an incentive to keep their staff busy. Thus, in some cases, there is pressure to provide more services than the person actually needs.
- The structure also tends to favor seeking authorization for assisted living services, because there is less negotiation to be done between Care Coordinators and State authorization staff when using that model.

- The rates that assisted living providers have negotiated may influence which clients they select. They have a strong disincentive to select any client that is staff-intensive and have a strong incentive to serve someone who would not require a significant amount of staff time. The State may be overpaying for this latter group. In many cases, the former group may either be served by a provider who needs to fill a bed but cannot supply sufficient staff or, forced to move into a nursing facility or an ICF-MR located in another state.
- The ability to create a true partnership that integrates publicly paid resources with informal, non-paid supports is reduced. Every family that is supporting an individual in need of long term care at home wears down in a unique way that reflects the circumstances and history of that family. The more limitations the State places on how and where supports can be provided, the greater the likelihood that these supports will be less valuable to a particular family in a long term care crisis. Trying to control utilization by developing rules that micromanage care decisions makes it more difficult to establish a partnership with families.

We recommend that the State adopt a cost control approach that sets process requirements to ensure that support plans are well developed. The State should also use a set of benchmarks for the overall budget as the primary mechanism for controlling costs. ***Exhibit 6*** provides a summary of that process.

This proposal should provide the State with greater ability to predict and manage the overall budget for services while allowing greater flexibility to tailor supports to meet the needs of a particular individual.

Exhibit 6: Proposed Processes for Setting Budgets



The process described in ***Exhibit 6*** will involve the following steps to determine a budget for an individual using waiver services:

- An assessment is completed and translated into a service plan that details the hours and associated budget an individual needs. Under this approach, a detailed support plan would be developed that delineates what role the family will be playing, and when and how much paid staff is required. The plan should include PCA and waiver services. Including both waiver and PCA in this process will assist the State in managing costs across the waivers and PCA.

This process will require a more direct link between the assessed needs and assigned hours. If the individual is not going into an ALF, the care plan would include proposed hours by day and a brief justification for those hours. The same approach could potentially be applied for individuals going into an ALF. However, whether this makes sense will depend upon the reimbursement approach that Myers & Stauffer recommends. For example, if they recommend a flat rate for ALFs, then this step would not be necessary.

- This proposed budget is compared to the amount assigned for the particular benchmark category in which the individual falls.
- If the individual's proposed budget falls under the benchmark, State staff will do a cursory review of the care plan to assess if it appears appropriate and appears to adequately address the individual's needs. The State may want to make these reviews more stringent in some cases. For example, if a particular Care Coordinator always submits plans that are at or near the benchmark, the State may be concerned that the Care Coordinator is using the benchmark to determine supports rather than the individual's needs and preferences. In this case, they may review applications from this Care Coordinator more carefully.
- Proposed budgets that are above the benchmark would go through a comprehensive review process that would carefully scrutinize each of the assumptions used to develop the care plan and likely require substantially more documentation.

A similar process could potentially be applied for individuals receiving only PCA. In this case, the preliminary plan would be developed by the individual (or the individual's family) and/or the service provider.

We are proposing a parallel process for how the State will manage the budget. The first step in this process will be for the State to set an overall budget for services. This budgeted amount would reflect information about the number of individuals served and the benchmark categories in which they fall, as well as projections about growth in the number of people needing services and inflation. A portion of the budget would be allocated to a reserve account that would be used to pay for the cost of services above the benchmark amounts that are approved. This would be the pool of dollars available to pay these additional amounts.

Below we provide specific recommendations that should be considered in implementing this system:

- **Shift budget control mechanisms from caps on services and State-set rates, to the establishment of a system using tiered benchmarks that include acuity in combination with a well delineated authorization process for units of service:** The current cost control/budget setting structure creates incentives to ask for maximum levels of authorized units of services and to allow billing up to that cap. DSDS is currently engaged in an effort to identify benchmarks for the PCA program. We recommend that the Myers & Stauffer work be amended to establish overall tiers for costs for waiver and PCA participants with certain characteristics. This approach would incorporate principles that are included in the Wyoming Doors model, the current assignment of budgets for DD services in Minnesota's Hennepin County, and the proposed resource allocation method for the Illinois Medically Fragile/Technology Dependent Children's waiver.

  The benchmarks would be based on factors such as acuity, age, availability of informal support and the setting in which the person resides (i.e., in home vs. out-of-home), regional cost variances, or other factors. It is important to note that it may not be possible to develop a methodology that addresses all potential factors because of data limitations. If the budget is below the benchmark amount, the State will review the documentation in the support plan and will approve it if it seems reasonable. If the budget is above the benchmark, the State will engage in a much more rigorous review process that will carefully scrutinize each of the assumptions and try to develop less costly approaches to serving the person. Thus, costs will be controlled by this mix of process and benchmarks, allowing greater control while providing more overall flexibility.

  If the Myers & Stauffer work is amended, their current efforts would likely need to be completed before benchmarks could be established. Myers & Stauffer's current scope of work is correcting the lack of a connection between the rates the State pays and actuarially reliable data on what the true program costs are. Trying to develop benchmarks based on historical claims data would, therefore, incorporate and perpetuate these actuarially unreliable rates.

- **Eliminate many restrictions on the use of services to maintain people in their own home, such as limitations on chore and respite services and rethink the service array that is available to people remaining at home.** The State has instituted regulatory limits on many services that serve to control costs. However, these restrictions may limit the ability of these services to prevent institutionalization and/or create unsafe or unsanitary conditions for certain subsets of individuals. By adopting the cost-control approach described above, the State could eliminate many of these restrictions without having to worry about escalating cost.

- **In developing benchmarks, pay close attention to the amount set for individuals on the DD Waiver with challenging behaviors that reside in ICF-MR facilities out of state, or who would otherwise go to ICF-MR facilities out of state.** The approach outlined above will need to pay special attention to individuals with challenging behaviors because Alaska currently does not have the provider capacity to support them adequately. The State should consider either developing benchmarks that would create an incentive for providers to create this capability or including the flexibility to address these individuals on a case-by-case basis.
- **Expand the menu of waiver services to address behavioral issues, crisis outreach services, specialized home modifications due to behavioral needs, or other components that would enable the group mentioned above to return home.** We found that while the waivers offer the ability to address behavioral issues for people on the waivers in the short term, they lacked the capacity to proactively develop and implement behavioral treatment plans. This capacity should be added to the waiver. Implementing this at the same time the State implements a benchmarked system will create an incentive for Care Coordinators and providers to use these services as a tool for reducing the need for direct care staff.

Recommendation Cluster 3: Shift Consumer-Directed Funds to a Medicaid Authority that Provides the State with Greater Control while Providing Consumers with Greater Flexibility

Research on the most prominent model of providing consumer directed care, Cash and Counseling, has shown that this option can be more cost-effective than traditional approaches. One evaluation found that, "Consumers who managed their own care were far happier with their care and their lives in general, and experienced no more—and in some cases significantly fewer—adverse events than those receiving agency care. Caregivers experienced much less physical, emotional, and financial stress."[18] This

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[18] Randall Brown, Barbara Lepidus Carlson, Stacy Dale, Leslie Foster, Barbara Phillips, and Jennifer Schore. Cash and Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home- and

report also noted that programmatic business processes, notably, the process for assigning individual budgets, has a strong impact on whether these services are cost-effective.

The unexpected and dramatic growth in expenditures that occurred as a result of Alaska's implementation of its consumer directed program, CDPCA, demonstrates the importance of carefully developing the underlying business processes necessary to manage one of these programs. DSDS has taken several steps that have resulted in better management of the program. These steps have resulted in PCA costs receding. Most importantly, State staff are now conducting eligibility determinations and authorizing hours of service. While there are concerns about the timeliness of these assessments, the prior system in which providers performed this function was a clear case of the "fox watching the hen house." The State has also responded by placing caps on the number of hours and increasing the scrutiny of the number of hours authorized. We discussed some of the unintended consequences of this approach in the section on restructuring the management of individual budgets.

In our opinion, Alaska's current approach limits both the State's ability to manage expenditures and the amount of choice that individuals have. CDPCA under the Medicaid State plan remains an entitlement under which the most effective way to limit utilization is to make the service less attractive. Our proposed recommendations should remove this quandary.

The current CDPCA option has helped the State address access problems for people that formerly were not able to obtain services through agencies. The program is designed to improve access to services and control over the delivery by allowing individuals to hire, fire, train, and direct their own staff. The current arrangement is that provider agencies act as an employer of record and as a fiscal intermediary for billing, payroll, and tracking of expenditures.

Our stakeholder interviews and consumer forums suggested that the program has allowed individuals to recruit friends and relatives to provide care and there is slightly more control by the consumer over the actual service delivery.

However, the program is less flexible than self-directed individualized budget options (also known as Cash and Counseling). Under a Cash and Counseling approach, a consumer would be allocated a pool of dollars that could be used to purchase personal care or items that substitute for personal care. This option provides greater flexibility

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Community-Based Services: Final Report. Paper prepared for University of Maryland and available at: http://www.mathematica-mpr.com/publications/pdfs/CCpersonalcare.pdf (2007).

than Alaska's current CDPCA program in two important ways. One, consumers can set the way they pay personal care workers. They can set the hourly wage or they can use a different formula, paying a per visit amount, for example. Thus, an individual who needed short bursts of care spread out through the day could pay a higher rate just for that time. Two, individuals can pay for items that substitute for personal care. This may include home modifications or items, such as a microwave, that would reduce the amount of staff time needed.

The dramatic increases in expenditures caused the State to take actions to slow growth by applying new restrictions on the use of PCA services. These restrictions involved limits on the duration and scope of services allowed. Prior authorization became much stricter in defining service units that would be approved. While these efforts have been successful at restricting expenditures, they have resulted in a situation in which the State must be ever vigilant because CDPCA remains an entitlement and providers will adapt to the effort the State makes and may exploit any weaknesses in the process.

Our recommendations are designed to allow the State to expand the consumer's ability to self-direct services, while increasing the State's capacity for controlling costs. These recommendations are meant to work in tandem with the previous recommendations on setting individual budgets. These recommendations would provide the State with complete control over caseload, while the previous recommendations would allow the State to manage per recipient costs.

Our major recommendation is to **reallocate existing CDPCA funds to a self-directed personal assistance option under the 1915 (j) authority.** Created under the DRA, 1915(j) allows states to offer personal care under a self-directed budget that is modeled after Cash and Counseling.

This option would have the following benefits for consumers:

- They would have greater flexibility in determining how and how much they pay their caregivers; and
- They could use funds for items that substitute for personal care.

The option would allow the State to cap enrollment on the program. In addition, the regular State Plan PCA option was never intended to provide consumer directed options, such as the one that Alaska implemented. Now that there is an authority explicitly for consumer directed services, CMS may require that the State shift this program to a 1915(j) at some point in the future.

Once the State successfully implements this option, we recommend that the State add an individualized budget option to the existing waivers or a separate waiver and consider restructuring other federal and State-only funds to provide this option to people who do not qualify for either the waiver or Medicaid PCA. Adding an option under the waiver could allow the State to expand the model to encompass other services that could be more cost-effectively arranged by an individual rather than through an agency, such as chore or respite. AoA is also encouraging states to adopt an individualized budget model for Title III funds under its Nursing Home Diversion Modernization (NHDM) effort. The same fundamental approach of controlling costs at the State level by managing overall budgets and recipients while allowing individuals greater flexibility to determine how to get the most bang for the available buck could work as well for these funding streams as it could for Medicaid PCA.

Implementing the 1915(j) option would require building key operational infrastructure, such as the following:

- **Address the capacity of individuals to self-direct before allowing consumer direction:** The State now has administrative regulations that provide guidance regarding whether a person is capable of self-direction of services. Under either the current CDPCA program or under a 1915(j) option, the State should build upon the experience of other states and translate the policies into a more structured protocol for determining whether the individual or their representatives have the ability to successfully direct services and to what extent counseling and assistance would be required in order to enable them to do so.

  During our research on consumer directed services, we reviewed a range of methods for addressing the ability of consumers to self-direct. The States that have a process start with the assumptions that: 1) the consumer does not have to demonstrate independent ability to self-direct (a representative or designee can be assigned to assist); and, 2) other assistance, through the counseling service or fiscal intermediary, will be provided. The processes tried to determine whether there are circumstances that demonstrate a significant risk to the person or to misuse of the services.

  This process could be incorporated as part of the LTC Options Counseling that was included in the earlier recommendation.

- **Establish fiscal intermediaries:** To pursue a 1915(j), the State would need to establish fiscal intermediaries for which it could claim the Medicaid administrative match. Because the State would not be establishing a Medicaid service, it could award the contract to one or more vendors with an administrative contract.

  Under this model, an individual would be given a budget within which they can designate how the funds will be spent. The fiscal intermediary receives timesheets or other documentation of this spending and cuts checks, pays taxes and addresses other requirements, such as workers compensation. In some states, the fiscal intermediary may also provide other services, such as education about managing budgets and staff.

The State will need to design and implement a transition plan for individuals transitioning from the existing CDPCA program. The current program likely includes individuals who do not have the capability or desire to assume responsibility for fully managing their own services. Implementing the new program will require that these individuals be identified and enrolled with an agency-based PCA provider. Thus, the transition plan must include the following:

- Notice to consumers of option to choose 1915(j) or agency-based services;
- An effort to enroll current CDPCA clients into the 1915(j) program that screens for capacity and willingness to self-direct; and
- An effort to transition CDPCA clients for whom 1915(j) is not appropriate to agency-based PCA.

Recommendation Cluster 4: Support Populations not Meeting the Nursing Facility Level of Care Eligibility Criteria

The State, all stakeholders, and our knowledge of other state's programs all confirm that Alaska's NF-LOC criteria is relatively strict and limits the ability to support certain populations. The NF-LOC is important because it determines eligibility not only for nursing facilities, but for any Medicaid 1915(c) Home and Community-Based Services waiver that uses a nursing facility comparison. Alaska's NF-LOC is strict in that it requires individuals to have substantial ongoing medical care needs; or it requires the individual to need either substantial assistance or be totally dependent in three or more ADLs. This definition of impairment excludes individuals who only require supervision and cueing with ADLs, such as someone with ADRD. The current definition might also be problematic for individuals with a traumatic or acquired brain injury. This limitation also creates a challenge for obtaining Medicaid FFP for individuals in Pioneer Homes who do not meet the NF-LOC and are, therefore, not eligible for the waiver. A large number of individuals who responded to our survey indicated that access for individuals in these two populations was a major concern.

Another potential issue with the current definition of impairment is that it does not account for the differences in the environments in which care is provided. Whether an individual requires help performing an ADL depends upon both the functional status of the individual and the environment in which that ADL is being performed. Recognizing the role that environmental factors play in determining whether assistance is needed with ADLs is even more crucial in Frontier Alaska where performing a bathing ADL may involve chopping wood and hauling water and toileting may include walking a sizeable distance on an unsteady surface to empty a “honey bucket.”

Another concern about the strictness of the definition is that it delays access to services, such as care coordination, until after someone has become substantially impaired. This creates two problems. One, people who meet the eligibility criteria may be provided services that allow them to improve, making them ineligible for these services and at risk of declining again. Two, the delay in people receiving care coordination and other services may cause them to become substantially impaired more quickly and ultimately be more costly.

The major issue with changing the NF-LOC is the potential for a “woodwork” effect, which is a large increase in the number of people who are newly eligible and requesting services. This is a legitimate concern because Alaska currently uses the strict eligibility criteria as a major mechanism for controlling access and costs. Easing this barrier may increase caseloads and costs. However, it may reduce costs by preventing or delaying more substantial functional impairments and worsening medical conditions. In addition, it may result in less pressure on State funded programs that are now paying for services to individuals that would be eligible for waiver services under a modified definition.

To address these barriers, the State has two choices. One, it can alter the NF-LOC so that more people can be eligible. Two, it can pursue a Medicaid funding authority other than a 1915(c) waiver to provide services. Our overall recommendation is that the State engage in parallel efforts to pursue both options. At this point, the State does not have available data to cost out the implications of liberalizing the NF-LOC and federal regulations regarding the alternative authorities have not yet been published and are likely to change with the new federal administration. Thus, it is impossible to know now which choice is best. As the State develops the options, the potential cost implications and likelihood of approval from CMS should become clearer, allowing the State to decide which effort (or combination of efforts) makes the most sense. Below we provide a description of each of the two efforts:

- **Altering the NF-LOC:** The State should investigate three areas for modifying the NF-LOC. One, it could change the number of ADLs on which an individual must be impaired and/or it could alter the definition of impairment. The current NF-LOC requires that an individual need extensive assistance or be completely dependent upon a caregiver to perform an ADL. Extensive assistance is defined as the caregiver providing weight-bearing support or full assistance on at least part of the performance of the ADL, three or more times during the last seven days. The NF-LOC also does not count the two ADLs for which impairment is likely to happen first, bathing and dressing. This effectively means that individuals must have impairment in five or more ADLs to qualify. Thus, the State could alter the definition by: (1) considering other ADLs, such as bathing and dressing; (2) reducing the number of ADL impairments; and/or (c) altering the definition of impairment to count individuals who need limited assistance or supervision or cueing or considering environmental factors, such as the presence of running water.

Two, the State could add a separate cognitive trigger to the NF-LOC. Thus, even if an individual did not meet the ADL criteria, they could qualify if they met the cognitive trigger. While there are widely used and accepted tools for screening for whether someone has a cognitive impairment, such as the Mini-Mental Status Exam, these tools are generally used to refer someone for a more in-depth cognitive assessment. If the State were to adopt a cognitive trigger, it should carefully examine these processes and select a tool and process (including who will administer the tool) that will be reliable and valid and will offer a clear criterion or set of criteria for who is eligible. This will be complicated by the fact that the concern will be to capture cognitive impairments attributable to both dementia and a brain injury because these conditions can express themselves in very different ways.

Three, the State could explore altering the NF-LOC so that individuals who improve could still be eligible for services. Some individuals enrolled in a waiver may improve substantially enough that they no longer meet the NF-LOC, but would once again deteriorate if services were removed. The State will need to be extremely careful in crafting this change to ensure that it does not have the effect of lowering the overall NF-LOC and is consistent with federal regulations.

We recommend that the State explore the implications of altering the NF-LOC that considers both the impact on cost and the number and types of individuals deemed eligible. This effort will be complicated by the fact that the State currently lacks a database on the characteristics of people who are currently eligible.

- **Pursuing alternatives to a 1915(c) waiver:** The DRA created alternatives for providing HCBS under Medicaid other than the 1915(c) waiver. Unlike a 1915(c) waiver, individuals do not need to meet the NF-LOC to be able to qualify for these alternatives. The two primary options are 1915(i) State Plan HCBS and a 1939 Benchmark plan.

  While the 1915(i) option would cover a range of HCBS, there are a number of serious limitations which could make it problematic to implement. In comparison to a 1915(c), the 1915(i) offers a more narrow range of services that can be covered, a more stringent financial eligibility criterion, and several operational requirements that will be burdensome to implement and require coordination with other State agencies that may also wish to use the 1915(i) option.

The Benchmark plans were intended to assist States in controlling costs by allowing them to provide a benefit package that was benchmarked to those provided by another type of insurance, such as a Health Maintenance Organization (HMO). However, the authorizing legislation included the following text, "a State, at its option, may provide such wrap-around or additional benefits as the State may specify." Thus, States such as Kansas have used this option to provide services not covered under traditional Medicaid. Alaska could potentially use this authority to provide HCBS that is targeted to individuals with ADRD or brain injury. There are three potential downsides to this approach. One, because expanding services is contrary to the intent of Benchmark plans, future legislation or regulation could create barriers or prohibitions that make this option no longer practicable. Thus, the stance that the new federal administration takes towards Benchmark plans will likely have a major impact on feasibility. Two, individuals would have to meet the regular Medicaid eligibility requirements and could not be allowed to be eligible with the same amounts of income that they can under a 1915(c) waiver. Three, the State cannot cap enrollment on this type of a program, raising a concern about the impact on costs, especially if the eligibility criteria is somewhat vague.

We recommend that the State pursue a benchmark plan that targets individuals with ADRD and brain injury. The State should consider piloting this plan in one or more regions so that it can fine tune program operations, especially the targeting criteria to limit the exposure costs escalating unexpectedly.

Recommendation Cluster 5: Draw Down More Medicaid FFP for CAMA and Pioneer Homes

A major requirement of the RFP was to examine mechanisms to draw down Medicaid FFP for two programs that are funded with State-only dollars, CAMA and Pioneer Homes. The purpose of this set of recommendations is to reduce State expenditures for these services by replacing State funds with federal funds.

CAMA

We recommend that the State explore developing an 1115 Demonstration to pay for CAMA by reallocating Disproportionate Share Hospital (DSH) funds. The major issue that prevents CAMA participants from receiving Medicaid is that they are not categorically eligible (that is, they are not parents of a Medicaid eligible child, do not meet Social Security Administration disability definition, or are not 65 years of age or older). Other states have used 1115 Demonstrations that reallocate DSH dollars to serve populations similar to those served under CAMA under Medicaid. The 1115 budget neutrality test would be met by tying spending for individuals who meet the CAMA criteria to the amount of reallocated DSH funding. We would recommend careful consultation with hospitals now receiving the DSH payments in the development of this effort. In particular, it is important that the State work with these hospitals to avoid unintended consequences, such as hospitals losing funding they currently depend upon. An 1115 would likely impact the current flexibility that exists under a state-only program and it would require additional administrative efforts in order to meet the conditions of the waiver approval. We propose to include a description of this effort in the planned concept paper that will be submitted to CMS for comment. If CMS responds favorably to this proposal, we recommend that the State develop the Demonstration.

PIONEER HOMES

There are four primary barriers to drawing down Medicaid FFP for residents of PHs:

1. The difference between the amount of assets that PH allows an individual to keep ($10,000 in assets and $4,500 for burial) and what people can keep under Medicaid ($2,000 in assets for an individual and $1,500 for burial) creates a strong disincentive for people who come off the waiting list for PH to become waiver eligible.
2. PHs is covered under Medicaid through the Older Adult Waiver. To be eligible for the waiver, PH residents must meet the NF-LOC criteria, which, as we noted earlier, is very restrictive. As was the case for supporting individuals with ADRD or brain injury, the State can either liberalize the NF-LOC or find another Medicaid funding authority.
3. Administrative complexities create delays in approving people who are eligible for and willing to enroll on the waiver.
4. Current regulations allow some PH residents who are on the waiver to keep a portion of their income that is greater than the personal needs allowance that non-waiver residents receive. This can create problems for these waiver

recipients because they must spend these dollars or they will build up assets that will cause them to lose their Medicaid eligibility.

We propose the following recommendations to address each of these barriers:

1. **Change Pioneer Homes asset criteria/priority for waiver eligible.** The State could increase the percentage of people in PH for whom it is receiving reimbursement through the waiver by reducing the asset level for PH to Medicaid level.
2. **Explore the use of the Medicaid 1937 Benchmark Plans to cover the cost of care in the Pioneer Homes for people who meet Medicaid financial eligibility criteria but do not meet nursing home level of care criteria necessary for the waiver.** DRA created a new authority that may allow Alaska to pay for PH without a 1915(c) waiver. We discussed this authority in the earlier discussion on the NF-LOC. This authority could allow Alaska to obtain FFP for Medicaid eligible individuals without needing to change the NF-LOC criteria. We propose submitting the option to CMS in a concept paper. If CMS denies this option, the only choice the State will have will be to alter the NF-LOC criteria. 1915(i) State Plan HCBS would not be an option because, unlike under the 1915(c) authority, PHs could not fit within the definition of any of the service categories. Potential cost savings from making people eligible for Medicaid FFP should be factored into the studies that we recommended in our section on altering the NF-LOC.
3. **Start reimbursement for waiver eligible individuals sooner by either claiming reimbursement once a person selects waiver services or through an expedited process to authorize services.** Pioneer Homes is currently not billing for Medicaid until the prior authorization is approved. This results in the State losing 42 days of Medicaid reimbursement on average. The State should have everyone sign a form indicating they would like to be on the waiver before they enter a PH and retroactively bill from that date.
4. **Increase the room and board rate or change the cost of care requirements for Pioneer Homes.** We recommend that the State alter either the room and board charge or the cost of care requirement to maximize FFP.

Recommendation Cluster 6: Improve Quality Management Processes

There are considerable efforts and attention already being given to the quality management infrastructure by DSDS. One of the greatest challenges is that there is not an overarching framework on which to hang the various parts of the quality management system. As a result, the current quality management infrastructure for all home and community-based services tends to be reactive vs. proactive and may not meet CMS requirements for the waivers.

Our first set of recommendations aimed at improving quality management involves building a process that is consistent with CMS HCBS Quality Framework, which itself is based upon CQI principles. The DSDS Quality unit has made considerable progress in developing a plan that that will eventually comply with CMS requirements. Our recommendations are meant to support and further this work.

We also propose a number of specific initiatives that would fit within this overall quality framework.

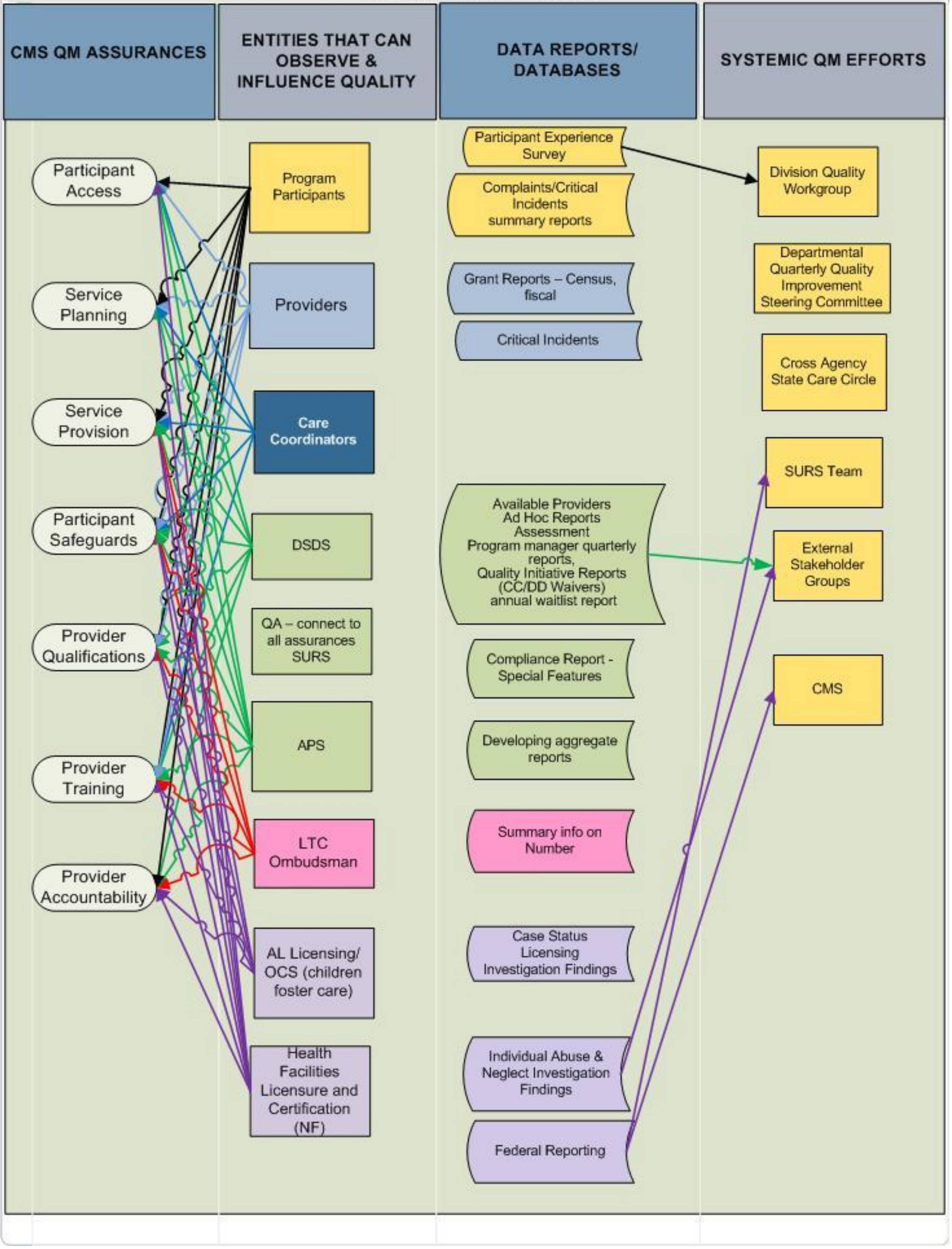
The current structure tends to be built on a “facility based” quality assurance construct. Our final category of recommendations in this area involves assisting the State to adopt a “service based” model by modifying the certification process or the licensing process.

BUILDING A QUALITY MANAGEMENT SYSTEM THAT IS CONSISTENT WITH THE CMS HCBS QUALITY FRAMEWORK

In ***Exhibit 7***, we assess the ability of Alaska’s current quality management processes to comply with CMS’ HCBS Quality Framework. This framework includes selecting relevant performance indicators, collecting data on these indicators, analyzing these data, and using these analyses to remediate problems that are observed.

The first column in this exhibit identifies the areas for which CMS has required assurances in the 1915(c) waiver application. The second column identifies the partners within the quality management system that are in a position to observe and influence the quality of services. This includes individuals and their families, State agencies, and service providers. These entities have information that is key to evaluating the performance of service, and to the discovery, remediation and improvement of services.

Exhibit 7: Flowchart of Quality Management Processes and the Ability to Comply with CMS Assurances



The third column identifies the databases and reports that each of these partners creates. A notable observation from this column is that Alaska is not currently taking advantage of key information available from each of the partners. A major missed opportunity is the failure to collect data from information routinely being collected by the Care Coordinator. Ironically, care coordination by its definition is charged to monitor services and make changes as needed. Case notes, which are done by Care Coordinators on a routine basis, are not incorporated into a quality management process. Thus, Care Coordinators with information vital to measuring service quality are less able to act on problems and to influence quality. Thus, the State is missing a natural opportunity to collect data about performance at the individual service delivery level.

The use of data systems to collect and organize the information from each of the partners is an essential tool in a quality management system. Given the many partners involved and the decentralized nature of service delivery, it would be impossible to organize information without the use of data systems. These systems can be used to translate information coming from the various sources into useful reports that track performance in the system at all levels.

At the present time, Alaska has many reports that are maintained in many different ways ranging from relatively sophisticated databases to paper files. These reports lack clear criteria that allow the person looking at the data to determine whether they indicate that there may be a problem. In addition, the reports are not integrated. This makes it difficult to report on performance of the system as a whole or on components of the system. This also likely means that the State will have difficulty generating documentation necessary to meet the CMS assurances.

The final column identifies the ability to systemically evaluate and manage quality issues. A well executed quality management system is capable of responding to quality issues at all levels of the system. Performance is defined so that each partner understands what is expected. Clear processes for collecting and reporting performance are adopted, and there is well defined set of procedures for communicating and acting upon problems within the service system.

While Alaska has many components of a quality management system, the components tend to operate within silos. The entities most able to observe and influence quality do not have a defined process to work together and to share information. This impairs the ability to identify problems and ensure a coordinated response.

We recommend a number of steps to assist Alaska in meeting CMS requirements and the expectations it has for itself. We noted that DSDS staff recognize these weaknesses and are currently engaged in efforts to address them. We hope that our recommendations will support and enhance their efforts.

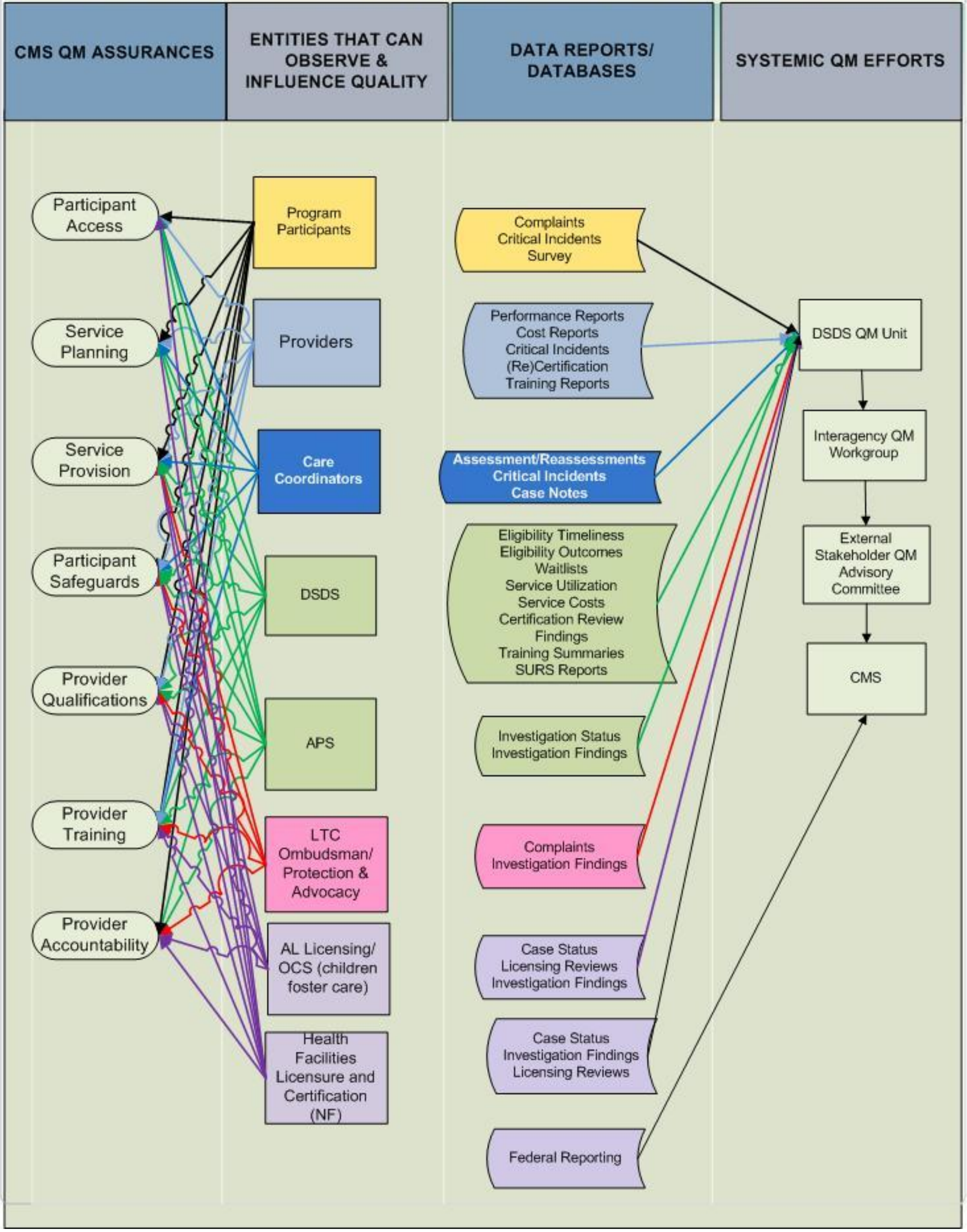
Exhibit 8 provides a summary of proposed revisions to the quality management structure. In the proposed quality management system, we have addressed five areas of primary concern: 1) the need for comprehensive standards and performance measures; 2) improved collection of information available from partners; 3) data reporting and systems; 4) how information is organized and reported; and 5) coordination of quality management across partners. We also have provided recommendations to address needs in related quality areas intended to improve performance at the service level.

A first step is to clearly link existing standards to the CMS assurances, to identify any gaps, and to further refine performance measures related to each assurance. CMS has already identified general outcomes within each of the assurances that the State can use as a template.

The next step and a major strategy is to take full advantage of the existing information already collected by partners within their performance of ongoing business operations. This effort will entail the State determining what data elements will routinely be collected and how each relates to the CMS assurances. New data collection from partners should only be required when information is not available or already being collected.

The third area of focus is to facilitate an efficient gathering of this information. In order to do this, we are recommending that the State build from the work it is already doing to develop its DS3 information system. A fully developed DS3 system should be capable of integrating several subsystems already used for the collection of quality data. For those areas where full integration is not possible, the State should seek other means or portals for incorporating information into its quality system.

Exhibit 8: Proposed Revisions to Systemic Quality Management Processes



The fourth strategy is to convert data that is collected into usable evaluation and management reports that can be incorporated into the CQI activities of the partners. For example, this could include creation of reports for geographic areas, particular service or provider types, or for specific types of incident reporting.

The final strategy addresses the silo effect that has resulted from not having a single place in which all quality information about services is being reviewed. Our recommendation is to have the existing quality management unit be the central focal point for quality reporting, evaluation, and the coordination of response efforts that impact services overseen by DSDS. In addition, we make specific recommendations for incorporating external quality partners in assisting the State to understand more about quality problems from another perspective and to help devise quality improvement strategies.

Our major recommendations for implementing this proposed system include the following:

a) **Establish core performance indicators that correspond to CMS requirements:** There are few, if any, performance indicators in place at the current time. In the area of DD, there is some effort to track business process information, including progress on reducing the waiting list, and elapsed time between assessment and service authorization. However, it is unclear how these data are used to identify problems and to remediate gaps. We recommend that the State establish outcome measures that correspond to each of the assurances that it must make to CMS for the waivers.

b) **Increase capacity to routinely obtain data for indicators through the core business processes (including assessment and reassessment, care coordination notes, critical incidents, licensure reviews and investigations, Adult Protective Services (APS) investigations, provider enrollment, provider certification, and other areas).** The State must identify mechanisms for gathering data for the performance indicators. Obtaining these data from after-the-fact surveys or reviews to determine performance would be costly and less effective than obtaining these data from core waiver business processes. Therefore, we recommend restructuring the means to collect data from business processes and to use that information in demonstrating compliance with performance measures.

   Alaska is currently piloting the use of the Participant Experience Survey (PES), a tool developed under a contract paid for by CMS, to assess whether services that have been provided are improving the quality of life for consumers. While this is useful information, it is costly to do and it most often does not get into the hands of someone in the position to take action if something requires remediation at an individual level. As an alternative, the State should build a client interview into the regular annual review process conducted by the Care Coordinators. Data from this interview can be reported as part of the reassessment and review process. These individual reports can then be aggregated at the State level. In addition, incorporating this as part of care plan development and revision would mean that Care Coordinators could immediately take action to remediate any issues that are observed.

c) **Develop core management reports for State staff, Care Coordinators, and consumers.** Data collected on performance indicators needs to be translated into management reports that guide the actions of individuals in a position to influence quality. We recommend the creation of management reports that would be used by key actors, including State staff, care coordinators, and consumers.

d) **Refine the flow of information about quality problems.** The State should carefully examine how information included in the management report flows. This would include establishing a process to ensure that the right level of data (individual versus systemic) flows to the right people, including: 1) a clear process for sharing information about problems; and 2) a process for determining who will take the lead and the roles of others involved in the process. The State should further develop a protocol for handling cases where active investigations are occurring, where specific information may not be able to be legally shared with others.

e) **Refine systemic quality management system to investigate and coordinate reaction to potential issues. Process should include cross agency and external participants, including a tribal component.** The next step will be to build infrastructure to identify and react to trends that suggest there is potentially a problem. This includes expanding intra and inter-agency mechanisms to investigate and remediate potential quality problems. These groups can collectively use various management reports to identify areas of concern and plan for interventions to preempt the occurrence of incidents or serious failures in service performance. It will be crucial to clearly define the purpose and scope of each group. Alaska has established work groups that could be expanded and formalized to fulfill this need.

Each division that plays a role in the delivery of long term care will need to be represented in this effort. The State should also have mechanisms for external stakeholders to be consulted and to facilitate a better understanding of potential quality issues. This committee will also play a crucial role in vetting and implementing efforts to remediate quality problems. The State may wish to establish subcommittees of the overall quality committee that may focus on the needs of particular populations such as services in remote areas, DD, older adults, etc. It will be important that these groups report back to the main committee to ensure that the quality management process is holistic and does not devolve into silos.

SPECIFIC INITIATIVES TO ENHANCE QUALITY

There are a number of related efforts that will enhance the Quality Management system. These efforts include:

a) **Update provider manuals and make them easier to use by integrating them within other tools and automating alerts to providers that policies and procedures have been modified.** This recommendation has two components. First, when automating business processes (such as certification, reporting, assessment and case notes) the State should create functions within the automation that allow users to easily find policies/procedures relating to the task. This functionality will improve the likelihood that the task is understood and completed correctly. An example of an area where this would be valuable is provider certification. Errors by providers in completing tasks, misunderstanding requirements, and entering incorrect data appear to be reasons that provider certification is delayed. Eliminating these errors would significantly speed up this process.

   Second, the State should upgrade their automated alert system which notifies users of changes to policies and procedures. This upgrade should include providing a link to the change and the policy/procedure so that users can immediately find the information and read it within the context of the broader policy and procedure. The State of Texas currently uses this type of system, which works off of an automated distribution list.

b) **Make online training available and make portions mandatory for service staff**. Ensuring service staff are properly trained is essential to the quality of long term care services. Alaska has established only a few standard training requirements and does not maintain an entry or advanced curricula for provider or service staff. While we realize that providing training in a state that is as geographically challenging as Alaska is daunting, the absence of training requirements and opportunities was something we viewed as a serious problem. Some states have developed internet based online training and testing solutions to help them with similar problems as Alaska has now. DSDS has already done this with the core Care Coordination training. Care Coordinators we interviewed requested advanced training be available using the online system.

   The College of Direct Supports provides an online training system used by at least 33 states. We recommend that the State select a system (whether it be The College of Direct Supports or another one) to adapt to reflect Alaska's programs. Portions of this training or an equivalent training should be mandatory. The State should have a system in place capable of verifying that individual provider staff have taken and passed the online courses. Initial and ongoing training should be required for continued certification to provide services.

Online training should not be seen as meeting all training needs. An online system can help the State in three ways: 1) it can provide a learning system construct which provides a basic framework for training, one that can be paired with mentoring, hands-on training, and classroom training; 2) it can provide assistance to staff supervisors by offering help in remediating the poor performance of some staff; and 3) it can offer the provider and State staff with a management system to track and record staff training activity, completion of courses, and staff test scores. This could lead to career development options such as staff earning a designation as more advanced, by using completion of training courses in combination with years of experience and supervisory evaluation as the means to identify their skill level. We also recommend that the State require that service providers describe how they integrate the online training into their staff training and monitoring procedures.

Nancy Thaler, the Executive Director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) recommends that the State establish and pay for the online training contract. She noted that they did this in Pennsylvania and received Medicaid administrative match for the contract.

c) **Establish greater infrastructure to verify services are actually provided as prescribed.** Because many services are provided at individuals' homes, providers could potentially bill for services that were never actually provided. CMS has recently revitalized efforts in Medicaid Program Integrity as a result of the DRA. The Medicaid Integrity Group is in the process of developing plans to improve federal oversight and state performance in these areas. There are some areas of Medicaid that have long been seen as areas of higher risk for program integrity problems. Among the highest risk areas are those services within long term care that are provided in individual homes. These in-home services are more likely to have problems with fraud, failure to deliver services as indicated, and upcoding (i.e., submitting claims that increase the intensity of service in order to collect higher reimbursement).

Some states have implemented approaches to assist in verifying that services have actually been provided, such as requiring personal care attendants to dial a code in from the person's home phone. We recommend that the State pursue a strategy for service verification, especially in areas such as PCA where there is a higher level of risk for issues. The State may wish to consider a pilot opportunity with willing providers or may wish to create incentives to encourage providers to voluntarily adopt verification systems.

d) **Adopt an ongoing process for evaluating access and service gaps in regional areas, and for determining infrastructure needs.** We recommend that the State adopt a means to evaluate regional service needs on a regular basis. This process is needed in order to help the State ensure that there is an adequate infrastructure at a regional level and to help maintain the appropriate balance of options for consumers/families in those regions. In some areas we heard evidence that there was over-saturation of ALFs, for instance, and little access to home based services. In other areas there were few services in the region, and consumers were forced to move to hub areas. One purpose of this process is to have a means through which the State can evaluate the local infrastructure and take appropriate action to recruit providers, expand needed services, or rebalance the array (including size and scope) of services to meet the needs of people in that location. The data collected through this certification and recertification process can provide useful information, especially if the State modifies the type of information collected to fit with this function. Beyond basic information about provider catchment area, type of service, service capacity (numbers that can be served), and general qualifications, the State should also consider data about other capabilities. This could include provider specialization, cultural competencies, trained personnel in areas of medical or behavioral services, or other unique capacities of the provider. The collection of this information into a database would allow the State to create management reports that chart the location of providers against the location of consumers, and to identify where there are gaps or over-concentration of certain types of services. This can allow the State to address both the needs of consumers and the sustainability of the provider system in a purposeful fashion. This database could also be used in additional ways. It could be available to Care Coordinators as a tool to assist their clients to find services. Another version could be made available to consumers, the broader public, and the Information/Assistance vendors.

e) **Develop alternative approaches to verify the background of potential direct care staff.** The Alaska Native stakeholders interviewed indicated that current requirements for background checks are administratively burdensome and frequently do not appropriately reflect the ability of a potential staff person to provide services in the best interest of individual consumers. We recommend that the State look at alternative approaches for establishing a reasonable expectation that potential direct care staff can be counted on to be trustworthy and dependable.

Revisions to the Licensing and Certification Processes:

The State has several authorities governing the provision of services. There are licensing standards, certification requirements, and related areas (such as those pertaining to protection of children or vulnerable adults) that apply to services. There are also administrative regulations that primarily include standards for operating the service. In general we saw that most areas were addressed (some better than others), but the scope of authority and who is authorized to enforce it was unclear along several lines.

Alaska currently has a combined licensing and certification process under which services are approved. The existing licensing standards are mostly oriented to facilities providing services. Much of licensing deals with various facility or physical plant aspects of the service, and only broad references are made to practice standards. The provider certification system does contain qualification requirements and incorporates administrative process standards, but does not address many practice standards. For some services, such as care coordination or personal care assistance, only certification is required.

We did not observe a clear line of authority for the State to take actions based on a pattern of failure to deliver adequate services, unless the failure rises to the level of maltreatment or is associated with deficiencies in licensing. The certification process results in a provider agreement being either approved or not approved. While the State has some mechanisms for taking action as part of the certification process, State staff and external stakeholders reported that these tools are almost impossible to use because there is not a reasonable mechanism for remediation or sanction, and not a clear process for discontinuing an agreement based on a pattern of poor performance.

We recommend that the State adopt a broad and coordinated strategy of established standards and enforcement authority. These standards and enforcement authorities should apply to all services. The framework of standards covers the following components for each service area or program: 1) qualifications for service providers, including supervision and oversight for staff that directly provide services and ongoing training requirements; 2) practice standards which apply to the service area, including expectations for general outcomes of the service and consumer protections that are incorporated into or are unique to the service area; 3) administrative requirements describing process standards, legal notice requirements, or other requirements that are incorporated into or unique to the service area; and 4) requirements that apply to site of the service (if it is not based in the home), including facility requirements for fire/safety, building or zoning codes, or other consumer protections.

In order to achieve these changes it will be necessary to modify current business processes to determine: 1) the location and legal authority for standards; 2) the lead area for reviewing compliance with the standards; and 3) define the scope of authority to require remediation if standards are not met.

Modify standards for ALFs. The current licensing structure and service definition for ALFs are broadly applied to services provided in a residence that is not the person's home. This has resulted in an ALF system that includes facilities of various sizes, serving people with various needs. Under the current structure, the same license and certification applies to an ALF serving one or two people, or to a facility serving 200 people. While the licensing standards do differ somewhat by population of disability, the differences in requirements are modest. This approach is unusual in our experience. States typically tend to separate residential facilities into more distinct categories to facilitate quality and reimbursement differentiations. By having a universal approach for licensing/certifying assisted living services, Alaska appears to have less control over the nature and array of facilities that have developed or will be developed. While the State can be proud of its effort to minimize reliance on ICF-MR services, the State can easily find itself creating similar institutions under its current system.

The State should require different things from larger facilities than smaller facilities and from facilities serving different populations. For example, the State may wish to include a requirement that facilities that serve younger adults foster community and family inclusion, work, and increasing independence. These goals are harder to achieve and to tailor to the individual when the services are in larger facilities or when a facility is more oriented to the interests and needs of elderly individuals with complex health needs. We recommend that the State modify its approach to licensing and certifying ALFs/providers in two ways:

- **Size**: We suggest that facilities of four or fewer people be treated as a family site. Facilities serving between five and eight people would be designated as small facilities. Facilities serving between nine and sixteen people would be medium facilities. And facilities serving more than sixteen would be large facilities. These differentiations are based on other states' licensing, zoning, and life safety codes, as well as the historical distinctions in federal regulations of sites serving more than four individuals.
- **Addressing Differences in Clientele:** Licensing standards and certification requirements should be modified to ensure that the provider will maintain the expertise and range of supportive services to be able to address the goals for the clientele. A facility could serve more than one type of clientele, but it would have to demonstrate that services are based on age appropriate goals and

individualized service plans. Finally, we suggest that changes made in this area can assist the State with the recommendation in l) below, which pertains to adopting an ongoing process to evaluate service access and service gaps in regional areas.

Recommendation Cluster 7: Restructure Care Coordination

ENSURING THAT CARE COORDINATORS ARE FREE FROM CONFLICT OF INTEREST

Case management, or as it is called in Alaska, care coordination, helps people to access and coordinate needed services. Case management can perform one or more of the following three functions: (1) gate keeping, (2) client advocacy, and (3) quality management. In many states, case managers play all three functions. DSDS has assumed authority for determining eligibility and approving care plans for individuals on waivers. This allows the State to share responsibility for gate keeping with Care Coordinators.

There are inherent structural and financial barriers that diminish the Care Coordinators capacity to act as a gatekeeper, client advocate or help identify and remediate quality problems. In Alaska, with the exception of older adults and individuals with physical disabilities who live in an ALF, Care Coordinators can be an employee of an agency provider other services. This arrangement is attractive for agencies because it is another source of revenue and the Care Coordinator can help the agency in managing the individual's supports.

However, Care Coordinators who are employees of provider agencies have a financial incentive to maximize the amount of service dollars in a care plan. They also have an incentive to steer clients to service provided by their agency and may find it difficult to report quality problems or critical incidents to the State. Consumers identified this conflict of interest as a major issue.

CMS has recognized this as an issue and has included prohibitions against this in draft regulations that would affect care coordination provided under a 1915(c) waiver. These draft regulations do make allowances for rural areas. While there is disagreement regarding what will be included in the final version of these regulations, it is highly probable that some version of the prohibition will be included. Therefore, we would recommend the State require that Care Coordinators not be employed by provider agencies. Consistent with draft CMS rules, the State should make exceptions in rural areas so long as the service agency puts in place provisions to ensure the freedom of the care coordinator to advocate and act on behalf of the individual.

Based on this concern, we recommend that the State **require care coordination provider agencies to be separate from the provision of other services, allowing exceptions in certain circumstances.**

Implementing this recommendation will present two challenges:

- The State will need to facilitate the development of a network of independent Care Coordinators. The experience of the Older Adult Waiver shows that it is possible to establish a viable independent care coordination system in Alaska. However, the State will need to take action to support the development of a sufficient supply of independent Care Coordinators who are not employees of a provider agency nor the State. This effort could include providing training and other resources to individuals who would like to be a Care Coordinator. This effort could include removing bureaucratic barriers that an individual might experience in trying to become certified as a Medicaid Care Coordinator.
- The State will need to carefully delineate when providers will still be allowed to fulfill the Care Coordinator role and the establish requirements that will help limit any conflict of interest that these Care Coordinators may experience.

INTEGRATING CARE COORDINATION INTO THE OVERALL QUALITY MANAGEMENT PLAN

Care Coordinators should play a central role in the State's quality management system. They are in a unique position to be the front line eyes and ears of the State. They may be the first to identify issues that could affect the health and welfare of an individual and are well positioned to assess the effectiveness of a support plan.

Alaska's Care Coordinators have no systemic reporting requirements other than for critical incidents and abuse and neglect. In addition, Care Coordinators interviewed indicated that they have very little authority to remediate quality problems. Our review of the associated regulations supported this perception. A notable exception to this was the State Care Coordinator we interviewed. It appeared that she had this authority because she had routine access to other State officials and represented the State in the eyes of the service providers.

We recommend restructuring the Care Coordinator requirements to include the following:

1. **Collecting at least monthly case notes and key pieces of information that would correspond to performance indicators**: The State could establish an online mechanism for Care Coordinators to track case notes. This system could be structured so that it gathered key information that would provide data

on performance indicators, such as those discussed in the Quality Management section.

2. **Tracking and implementing consumer specific goals and outcomes**: The current plan of care template requires the submission of goals for habilitative services. We recommend that goals be required for all waiver recipients. In addition, we recommend twin efforts of providing training to Care Coordinators on developing meaningful and measurable person-centered goals and monitoring Care Coordinators performance. The effort will be able to utilize the more comprehensive assessment information gathered as part of the unified the development of the unified assessment and the alteration in the development of individual budgets described earlier. Thus, this effort should occur after those pieces of infrastructure have been built. While this effort will require leadership from the State, providers must incorporate this philosophy into their operations. This will require that the development of person-centered goals be incorporated into the development of services, training of staff, and internal quality management processes.
3. **Providing more authority for Care Coordinators to remediate problems**: This effort will involve better definition about the relationship between the Care Coordinator and the provider of services. The most common type of problem needing remediation is a failure to implement or poorly implement portions of the service plan. In these cases, the Care Coordinator should be bringing it to the attention of the provider for either remediation or a reevaluation of whether there have been changes in the consumer’s situation. Care Coordinators need the authority to require that the provider respond and act upon any problems, and act in cooperation with Care Coordinator to see that the service plan is implemented appropriately.
4. **Requiring Care Coordinators to take a comprehensive approach towards meeting individuals’ needs**: States are required to assure the health and safety of individuals served under 1915(c) waivers. In addition, CMS has been encouraging States to design support packages that foster integration within community. Thus, the State should revise its care coordination standard to clarify that Care Coordinators should take a holistic approach towards developing a care plan. This would include addressing acute care, mental health, and other needs. This would also include requiring active treatment when clinically necessary or instrumental to community integration and inclusion. This does not necessarily mean addressing these needs through waiver services; in many cases, this effort would involve in identifying other resources and making referrals as appropriate.

REVISING HOW CARE COORDINATION IS REIMBURSED

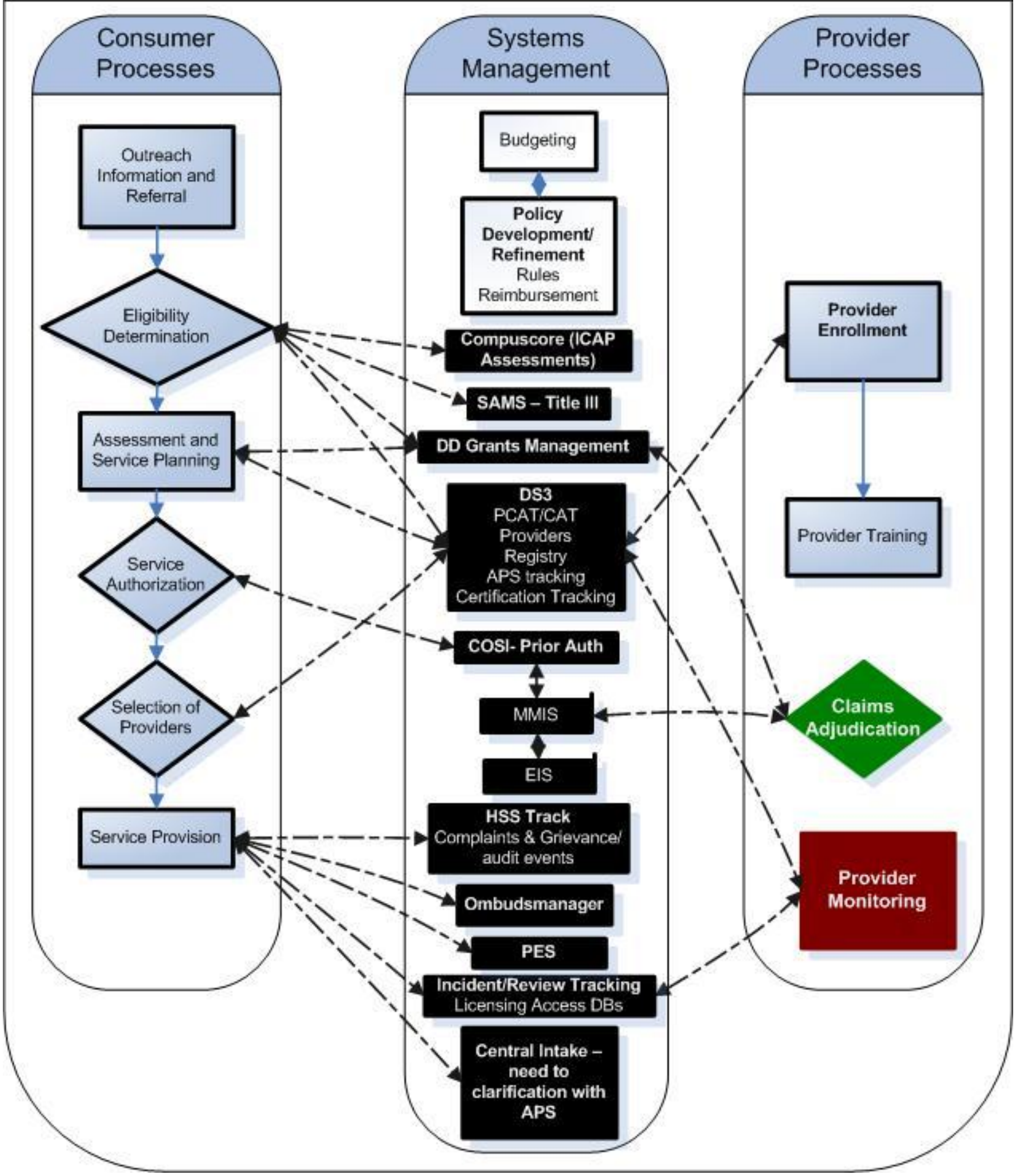
The current reimbursement methodology is weak in several respects. First and foremost, it is not tied to the actual provision of service. Second, it establishes disincentives for Care Coordinators to provide services to people they know will require intense levels of assistance. Third, it is inconsistent with federal direction that would require states to show a direct relationship between payment and provision of services. And finally, it is not tied to the scope of activities that are defined as case management from a federal perspective. This latter issue could place the State in a defensive position to be able to demonstrate that reimbursement is only being made for activities that fall within the federal definitions. Thus, we recommend that the State reimburse Care Coordinators on a per unit basis where the units range from 15 minutes to an hour. If this were done in conjunction with the recommendation to develop an online case note system, this system could also serve as the billing mechanism. Thus, Care Coordinators could meet their utilization tracking and documentation requirements at the same time.

The estimated number of care coordination units should be incorporated into the plan of care and the State should establish a benchmarking and review process for care coordination that is similar to the approach recommended for the rest of the waiver services.

Recommendation Cluster 8: Expand IT Efforts

DSDS has made considerable progress in planning for new IT tools that will better enable staff to manage and track information about what is occurring in the system. **We strongly believe that this effort can be successful because it has been planned with the program staff as the customer**. However, enhancing the DS3 will be essential for the State to carry out the other reform efforts that we have outlined in our recommendations. The State should continue to view IT as a management tool that supports State staff and key partners responsible to see that services are appropriately managed, achieve the intended outcomes, and that there is a means to show public accountability for the results. We encourage the department to develop a business plan to continue to develop this approach and structure. We also recommend that the IT support for long term care services remain within DSDS, so that the programmatic staff continue to be seen as the customer. ***Exhibit 9*** summarizes the IT systems as they currently exist. ***Exhibit 10*** summarizes our recommendation for the direction the State should pursue.

EXHIBIT 9: ALASKA'S CURRENT LONG TERM CARE INFORMATION TECHNOLOGY SYSTEMS



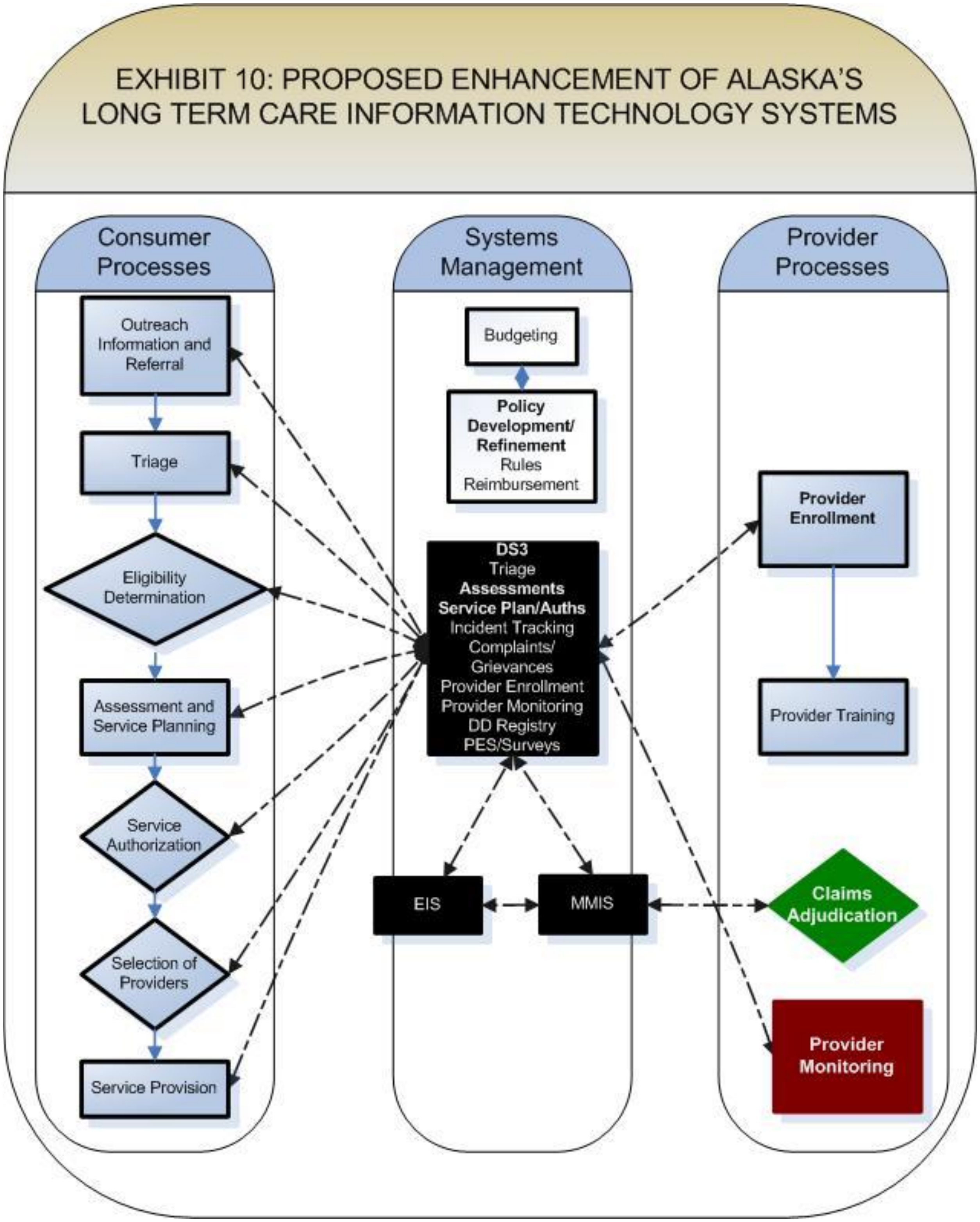


EXHIBIT 10: PROPOSED ENHANCEMENT OF ALASKA'S LONG TERM CARE INFORMATION TECHNOLOGY SYSTEMS

Our specific recommendations include the following:

a) **Establish and implement an IT solution to integrate and automate intake, assessment, authorization, and service planning.** DSDS has already incorporated significant components of these processes into the DS3. However, the main limitation of the approach that it has taken at this time is that the system is not integrating all the information into an electronic record. Instead, many of the core documents, notably the CAT/PCAT are simply kept as electronic documents from which none of the data can be extracted and analyzed. We recommend that in conjunction with restructuring the access processes described earlier, the State expand the DS3 to support the redesign and build electronic records.

b) **Develop a web-enabled, searchable database of available providers, including information gathered through the provider certification process.** The State could establish an online provider application and certification process that collects information to assist individuals and Care Coordinators in identifying appropriate providers. Arkansas and other states have developed a viable system that fulfills this function. Alaska could enhance this system by allowing consumers to rate providers (and allow providers to respond to ratings before they are published) similar to the ebay.com website.

c) **Develop a plan for expanding the use of telemedicine and smart house technology.** This is another tool for addressing the concern that there is not a broad enough array of in-home services and that there also is a shortage of available staffing. The use of technology on a broad scale to address supervisory and environmental needs is not currently being done. However, there are some very effective and interesting examples of the use of technology now occurring in several places. We recommend looking at a couple of examples in the States of Wisconsin and Indiana, where providers are using smart house technology to support individuals in homes of their own in dispersed locations. Telemedicine could also play a crucial role medically complex or fragile individuals served in remote locations.

d) **Build software to support Care Coordinators, including automation for assessment, service planning, service tracking, and case notes.** In conjunction with the earlier recommendation to restructure the Care Coordinator role, we recommend that DSDS build IT that supports their expanded requirements. At its core, care coordination is an information sharing process and the role of the Care Coordinator is greatly enhanced if they have tools that assist them in sharing that information. DSDS would also be in a much stronger role to monitor the program if it had access to all of the information that is currently locked in the Care Coordinators head or files.

Miscellaneous Recommendations

Clearly articulate the State's philosophy towards long term care and incorporate it into program operations. We heard from a number of stakeholders that the State lacks a clear philosophy regarding the delivery of long term care. A guiding philosophy can play a central role in shaping how a program evolves. Enacting legislation for major long term care reform efforts in Oregon, Washington, and Wisconsin all included a preamble that stated their philosophy and required that it play a central role in program operations. We recommend that the State clarify its philosophy and incorporate it into any long term care reform legislation. The State should also institute processes under which the impact of any policy on the goals this philosophy supports is considered.

Establish a sliding scale parental fee for children under age 18. One option for reducing costs is to consider various opportunities for cost sharing. Since Alaska is a TEFRA option state, we suggest that it consider some level of cost sharing by parents of children under age 18 that are receiving services. This recommendation would provide the State with revenues from families over the financial threshold for Medicaid and would require families to participate in the cost of care for their children.

This would likely be a very controversial action to take. Families will argue that the cost to them for caring for a child with disabilities already places an extra financial burden on them and that they are already stretched to the breaking point. Others will view this as a fair way to demonstrate parental responsibility that is commensurate with having access to expensive benefits paid from public funds.

The revenue benefit may not be substantial enough to warrant the action being pursued and the State should carefully weigh its decision. Before the State pursues this, we recommend that it review the family incomes and cost of services, the likely revenue under a sliding scale, and the cost of revenue collection. Because the State does not have information on family income for these children, it would need to develop assumptions about potential revenue using data from other states or national databases. Given Alaska's uniqueness, these analyses will likely include a large confidence interval. However, they should be able to provide the State with a ballpark estimate.

Add a transition service to the waivers for people moving from institutional services, such as to people residing in out of state ICF-MR facilities, to a waiver service. Transition services could be included in the menu of waiver services to assist with moving people from institutional services (i.e., ICF-MR or nursing facilities) into home and community services. Transition services pay for initial costs related to moving and can be used to pay for rent deposits, household items, initial deposits for utilities, and other items as defined by the State. The State can place a maximum threshold on the total expenditures under this service item. Many states use an amount of approximately $2000. To include this option, the State would be required to amend its current waiver plans.

Allow for "shared PCA" services. We are recommending that the State consider allowing two people to share concurrent PCA services when those two people live together in a home that is not owned or controlled by a provider of service and when both parties agree that their needs can be met under a shared service model. This option would facilitate independent living situations for two roommates or spouses with disabilities.

There are a few states that do allow some type of shared arrangement, and each handles the associated issues in slightly different ways. As a starting point for considering this option, we would recommend:

- That the established rate for concurrent services for two individuals would be less than the rate paid for two separate individuals;
- The inclusion of protections to ensure that concurrent service provision meets the needs of the individuals (this could be done during the assessment and prior authorization process); and
- The inclusion of consumer protection provisions to ensure informed choice and notice that individuals are entitled to return to regular PCA services should they decide to do so.

Establish an option to use a universal worker for some in home services, such as PCA and chore services. Because there is a shortage of staff in some locations, a universal worker could be used to provide services under several service categories. One of the existing issues with using a single staff person to perform more than one type of services is the tracking of time and the accuracy of claim submissions. The adoption of the 1915(j) and the self-directed budget under the 1915(c) would negate the need to do this for people using self directed options. However, there will still be individuals choosing to obtain services through agencies who can benefit from the flexibility that a universal worker classification would provide.

In order to do this, the State would need to reconcile some of the differences that exist between the regulations pertaining to PCA and chore services. This would include a plan which deals with payment, qualifications, and supervision when a universal worker is used.

Adopt a strategy to slow/prevent entry of lower income seniors into Medicaid and into more intensive services by adopting a cost share program such as Alternative Care. The Alaska RFP asked that we look at prevention strategies that could reduce costs incurred by the State. As indicated in the earlier section of this report summarizing our research, we focused on prevention in the context of diverting people from using high intensity services and becoming impoverished.

Based on our research we recommend that Alaska look at models used in Minnesota (Alternative Care) and Illinois. Both have State funded programs which are used to slow and prevent entry of lower income seniors into Medicaid, and which share the cost of in-home services with those seniors. Based on fiscal information from these states, this has been an effective strategy for many people and has avoided higher costs for the states.

Alaska could base its program on these programs' core characteristics. These States have financial eligibility criteria that target individuals who are at greatest risk of spending down to Medicaid and functional eligibility criteria that target risk of institutionalization. These programs offer care coordination and a range of other in-home supports.

In order to achieve adoption of this type of program, the State would need to significantly restructure the use of existing grant funds. One of the biggest changes would be that grant funds would pay for a service after it is provided. This is a different approach than occurs now, which is that grant funds are provided to agencies in advance of services, and then agencies direct the funds to individuals in need. The State would have tighter controls under a new program, as the funds would be targeted to individuals at the highest risk of nursing home placement and spending down to Medicaid; and the services would be paid on a fee for service basis.

With restructuring of some of the existing grant programs, we also recommend that there be an ongoing plan for increasing the base for grants, aligned with the increase in the older population. This strategy is potentially helpful in addressing overreliance on Medicaid.

We would also expect to see some effect on the General Relief program. From interviews with State staff, we know that General Relief is frequently used to pay for placement and services into ALFs. If an effective program can be designed to intervene early with home based services and to divert people from placement, we would anticipate that some of the people using General Relief would be served earlier through the new program.

Develop a Public/Private Long Term Care Insurance Policy that integrates with Medicaid. States can offer private long-term care insurance policies that allow individuals to qualify for Medicaid while retaining substantial assets. For example, an individual who purchases a $100,000 policy could qualify for Medicaid and keep $100,000 in assets. This can lower the price for long term care insurance and reduce overall Medicaid costs by inducing more middle income individuals to purchase this form of insurance.

We recommend that the State pursue offering these policies after it implements the full functioning ADRC. Family members who participate in LTC Options Counseling offered under the ADRC will be very aware of the challenges that needing long term care creates for a family. It is common for these family members to want to take action to ensure that they are prepared for when they need long term care. Thus, these individuals could benefit from an affordable private insurance option.

The State should also be careful to construct policies that offer benefits that are sufficient to support the cost of services in Alaska. Although it was beyond the scope of this project, we heard many complaints about limitations under the long term care insurance policies offered to State employees. The State would want to ensure that lessons learned from that offering are applied to this proposed effort.

INPUT FROM THE COMMUNITY FORUMS

Community forums occurred the week of August 24, 2008 in Anchorage, Juneau, and Fairbanks. We made a copy of the draft recommendations available at www.akltc.com. Individuals interested in participating had the option to attend the forums in person or via webinar.

The purpose of the community forums was to solicit feedback about the draft recommendations. Participants identified areas of agreement and disagreement and provided specific examples of changes they would like to see in the draft recommendations. The feedback obtained was then reviewed, categorized, and used to shape the final of recommendations.

We disseminated information about the community forums via the following methods:

Print Media

Print media received press releases one month and two weeks prior to the events to the following print publications:

- The Arctic Sounder
- The Bristol Bay Times
- The Cordova Times
- The Dutch Harbor Fisherman
- The Stewart Phoenix LOG
- The Tundra Drums
- Alaska Star [Eagle River, Alaska]
- Anchorage Daily News [Anchorage, Alaska]
- Anchorage Press [Anchorage, Alaska]
- Bush Blade, The [Cook Inlet, Alaska]
- Capital City Weekly [Juneau , Alaska]
- Daily News Online [Juneau, Alaska]
- Fairbanks Daily News-Miner [Fairbanks, Alaska]
- Homer News [Homer, Alaska]
- Juneau Empire [Juneau, Alaska]
- Ketchikan Daily News [Ketchikan, Alaska]
- Kodiak Daily Mirror [Kodiak, Alaska]
- Nenana Messanger [Nenana, Alaska]
- Nome Nugget [Nome, Alaska]
- Peninsula Clarion [Kenai Peninsula, Alaska]
- Petroleum News Alaska [Anchorage, Alaska]
- Talkeetna Good Times [Talkeetna, Alaska]
- Wasilla Frontiersman [Wasilla, Alaska]

TV and Radio

Local television and radio received press releases one month and 2 weeks prior to the events to the following TV and Radio stations:

- KTUU-TV NBC Anchorage
- KTBY-TV FOX Anchorage
- KTVA-TV CBS Anchorage
- KIMO-TV ABC Anchorage
- KATN-TV ABC Fairbanks
- KFXF-TV FOX Fairbanks
- KTVF-TV NBC Fairbanks
- KJUD-TV ABC Juneau
- KUBD-TV CBS Ketchikan
- KTNL-TV CBS Sitka

- KENI AM 650 Anchorage
- KFQD AM 750 Anchorage
- KNBA FM 90.3 Anchorage
- KSKA FM 91.1 (NPR) Anchorage
- KUDO 1080 Anchorage
- KTOO FM 104.3 (NPR) Juneau

Survey and Focus Group Participants

All focus group and survey participants received an announcement via e-mail. We called individuals for whom we did not have e-mail addresses. Several participants that did not provide contact information could not be contacted. We sent more than 200 emails.

State Website and Provider List

The State issued the press release and flyer to their list of providers and posted this information on their website three weeks prior to the event.

HCBS Strategies Website

We posted the press release and flyer on the project website three weeks prior to the event.

Other Organizations

Organizations such as The Alaska Brain Injury Network assisted us by sending out the flyer to their list. A number of providers, consumers and care coordinators printed the flyer and posted it as well as forwarded via e-mail to their contacts.

Participation in Forums

The number of participants for each community forum was as follows:

Anchorage: 10 in person and 6 via Webinar

Juneau: 21 in person and 14 via Webinar

Fairbanks: 5 in person and 4 via Webinar

We also received written comments from two individuals.

Summary of Input Received at the Forums

Below we briefly describe the feedback and suggested modifications to draft recommendations provided at the Community Forums. Next, we identify potential additional recommendations that were not included in the draft. We also provide our response to each area and identify modifications that we made to the recommendations.

Restructure Matching People with Funding Sources

Most attendees agreed with the recommendation for an ADRC-type approach to helping people access services. There was strong support for making components of the system available to anyone, including people that privately pay for long term support services. Several of the attendees asked for information about the specifics of the plan. Most of these specific questions were about decisions that would be made as part of implementing the model. For example, a few people asked about whether Senior Centers could play the initial intake role. While this is a possibility, our recommendations did not get into that level of operational detail.

There was positive feedback on the use of the systems guide, streamlining and integrating assessments and eligibility determinations and integrating options counseling. A few people expressed concern that the State would attempt to take over functions currently performed by Senior Centers or other traditional Information and Assistance (I&A) Organizations. Attendees encouraged us to recommend continued involvement of these agencies, especially since these resources are currently used by a wide variety of people.

Because the feedback was very positive, we did not change the recommendations in this area. We advised the State about the interest in using existing community I&A resources when developing a plan to implement an ADRC-type system.

Restructure Setting Budgets for Waiver and PCA Services

There was strong support among the attendees for moving to a budget management approach that has the State setting overall thresholds but allows more flexibility at the service plan level. There were a number of questions regarding the method for setting the benchmarks for individual budgets. Attendees indicated a desire for the benchmarks to adjust based on regional or other factors.

Several people noted that a new budget management methodology needed to be coordinated with the Myers and Stauffer report. This was part of our recommendation.

One provider also expressed strong objections to the language used in our explanation of the recommendation within the report. This person indicated that the language seemed to imply that providers “cherry pick” and are poor performing. We explained to this provider that the section to which she was referring was meant to highlight a concern that we had heard from other stakeholders, including providers, that the current rate setting practices and imposed rate freezes had made it difficult for providers to serve clients with greater needs. We revisited that section of the draft report and made modifications to the wording.

In the report, we identified a number of potential factors that the State should consider when establishing benchmarks. Because of the Forums, we added regional variations to that list. It is important to note that it may not be possible to develop a methodology that addresses all potential factors because of data limitations.

Shift the Consumer Directed PCA (CDPCA) Program to a Medicaid State Plan Option Using 1915(j)

Attendees expressed support for a continuation and expansion of consumer directed service options. There were no objections to the recommendation to shift the existing program to a 1915(j) optional Medicaid State Plan service. Attendees did caution that the transition of people from the current CDPCA to the new option might result in unintended consequences, thus careful planning is important. In addition, attendees had a number of questions about how the new option would work.

Based on the feedback received, we supplemented and modified our language about the plans for transitioning people currently on CDPCA to the new program.

Supporting Populations Not Meeting the Nursing Facility Level of Care Eligibility Criteria (NF-LOC)

A number of attendees expressed strong support for serving more people with ADRD and brain injury. In discussing the two options for addressing the need to support people falling into these groups, some attendees expressed frustration that we had not recommended a liberalizing of the current NF-LOC definition. Attendees supported looking at both recommended options (expanding the NF-LOC and using the 1937 benchmark authority) but people expressed a concern that sufficient data would not be available to complete work required for going forward with expanded services using one of the two options. One attendee also expressed a concern about the impact that any expansion would have on providers serving the private market.

One attendee did make a specific suggestion to add a recommendation about the availability of support services for individuals whose condition improves because of receiving services. These individuals may improve substantially enough to no longer meet the NF-LOC, but would once again deteriorate if services were removed.

We agree that it is illogical to build incentives that encourage people to avoid improvements in their condition and independence because they fear losing eligibility. Thus, we modified the recommendations to address maintaining improvements in the condition of the person for as long as possible.

Drawing Down More Federal Financial Participation (FFP) for Pioneer Homes and CAMA

A couple of attendees initially expressed frustration that Pioneer Homes received more favorable treatment than other assisted living facility providers by virtue of our recommendation to enhance FFP. We explained that additional FFP replaces existing State funds now required to pay for Pioneer Home services. We clarified language within the report to explain that new FFP would offset existing and future state costs. There were no comments about the proposed CAMA 1115 Demonstration.

Improving Quality Management

Most attendees indicated strong support for changes in the quality management system. Most comments addressed the need for further clarification on operational components that would be developed during implementation (e.g., identifying specific performance indicators). There was especially strong support for better integration of quality information available from care coordinators.

Several attendees urged the recommendations to include expanded oversight and quality controls for care coordination, PCA, and CDPCA services.

Our recommendations do include an expansion of quality management in the areas of care coordination, PCA, and CDPCA services. However, based on feedback, we clarified the report by explicitly including these service areas.

Restructure Care Coordination

As expected, attendees were very interested in the proposed changes to care coordination. We grouped reactions into three categories: 1) concerns about who would provide care coordination; 2) strong support for enhancing the role of Care Coordinators within the quality management strategy and increasing and clarifying the requirements for care coordination; and 3) support and a concern about the change to the reimbursement methodology.

A few attendees expressed concern and one attendee strongly objected to the recommendation for independent care coordination. This attendee expressed the opinion, “Independent Care Coordinators are in the business for the money, not for the client. Non-profit organizations that provide both services and care coordination are in the business for the client, not the money.“ However, other attendees indicated positive experiences with independent Care Coordinators advocating for additional services or changes in service delivery. Many attendees expressed concern about the State taking over care coordination. These attendees expressed that the State would consider costs over the needs of the individual. Other attendees stated that they were worried that State employees would not be easily accessible in remote areas. We clarified that the report does not recommend that independent care coordination be done solely by State employees and the implementation plan includes an effort to develop private sector independent care coordination. We added language within the report that clarifies this.

There was strong support for enhancing the quality management role and requirements for care coordination. Several people stated that for independent care coordination to work well, training and oversight needed to be improved. Several other attendees also suggested that the State be more specific about required documentation. Attendees expressed strong support for online tools to assist Care Coordinators.

Most attendees supported the draft recommendations for reimbursement changes. One person indicated a concern that a new reimbursement system would increase time spent in documentation, resulting in less time being available to provide services. We discussed the vision of having this occur as part of a system in which Care Coordinators could enter case notes online. This appeared to be a feasible solution to the concern.

We did not change the recommendation for independent care coordination for two reasons. First, agency-based Care Coordinators have a conflict of interest when assisting people in choosing services and in monitoring the quality of services. Although some individuals may overcome this conflict, this outcome depends on the strength and integrity of the individual Care Coordinator. Second, it is likely that the federal government will continue to pressure states to eliminate conflicts of interest for care coordination. CMS has clearly identified independent care coordination as a best practice.

Expand Information Technology (IT) Efforts

There were very few comments regarding recommendations in this area. Attendees familiar with the DS3 efforts seemed to have adopted a “wait and see” attitude. Two or three individuals who had seen the changes to DS3 praised these enhancements.

No changes were made to recommendations in this area.

Miscellaneous Recommendations

- Clearly articulate and incorporate the State’s philosophy: There was strong support for this recommendation.
- Establish a sliding scale parental fee for children under age 18: There was some opposition to this recommendation by a few people.
- Add transition services to waivers: There was strong support for this recommendation.
- Allow for “shared PCA” services: There was limited discussion but supportive remarks for this recommendation.

- Establish a universal worker option: There was limited discussion but supportive remarks for this recommendation.
- Adopt a strategy to slow/prevent entry of lower income seniors into Medicaid: There was limited discussion but supportive remarks for this recommendation.
- Develop a public/private Long Term Care Insurance option that integrates with Medicaid: There was limited discussion but supportive remarks for this recommendation. One or two attendees stated that the coverage should not be as narrow as the long term care insurance available to State employees.

Potential New Recommendations

We also received feedback about areas in which attendees felt we had left gaps in our recommendations. These include:

- State grant programs should continue to grow to reflect changes in population and inflation: Attendees at each of the Forums strongly encouraged us to include a recommendation that State grant money continue to play an active role in the long term care system. Our recommendations do identify several ways in which current Grant funded programs should be included in the redesigned delivery system including in the ADRC and the effort target funding to people most at risk of entry into Medicaid. The general thrust of our recommendations was to use these State-only funds to pay for individuals not eligible for Medicaid and to provide services in a timelier manner until Medicaid eligibility could be established. We have modified the report to include a discussion of the importance of continued growth in grant funds so that they can continue to play these essential roles.
- Care coordination should be available to people using PCA services: One individual recommended making care coordination available as a service to individuals who are receiving PCA services, but are not enrolled in a waiver. The State could potentially do this by developing a Medicaid Targeted Case Management program. We are hesitant to endorse this recommendation for two reasons. One, the State lacks data on the characteristics of PCA-only recipients that would help them to identify whether there is a subset of recipients with needs that are complex enough to warrant care coordination, but not so complex that they qualify for a waiver. The creation of the unified assessment under the ADRC would allow for the collection of data necessary to understand this issue. Two, the report identifies and proposes solutions to several problems in how care coordination is currently provided. The State should not consider expanding this service until it addresses these issues.

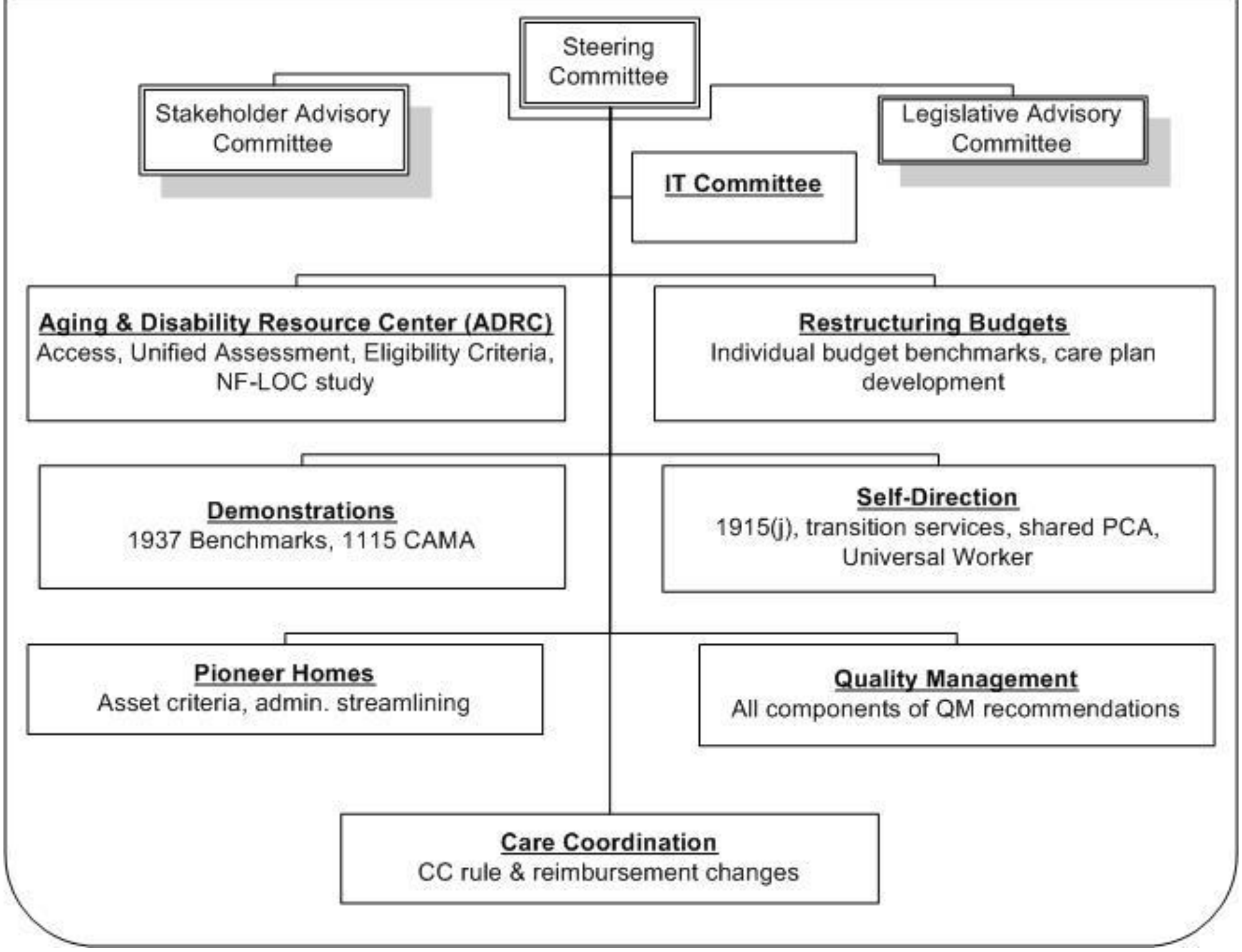
- The Advisory Committee should have expanded representation: One provider thought that the group should include independent ALFs. One consumer indicated that the State should find a way for better participation by consumers in policy change discussions. The current Advisory Committee was intended only to guide this effort. We have proposed an ongoing strategic planning process that would oversee the implementation of the LTCP. This process includes a Stakeholder Advisory Committee and several workgroups for which we have recommended provider and consumer representation.

- The State should hire more staff with disabilities: One consumer felt that because the State staff with whom he interacted did not have a disability, they were “cold” to his situation. He believed that if the State were to hire more individuals with disabilities, they would have a better understanding of the consumers’ perspectives. This recommendation endorses an effort that is already in process, the Governor’s Council on Disabilities & Special Education Alaska Works Initiative. This initiative involves a collaboration of key stakeholders with representatives from the Alaska Division of Personnel within the Department of Administration to increase the number of people with disabilities the State employs. Activities include:
    - Developing and implementing strategies to increase the pool of qualified applicants with disabilities for State jobs through targeted recruitment and outreach activities;
    - Expanding and improving the provisional hire program; and
    - Implementing universal design and inclusive workplace practices that help with recruitment and retention of State employees, including those with disabilities and older workers.

FRAMEWORK FOR AN ONGOING PLANNING PROCESS

The original RFP for the LTCP required recommendations for an ongoing planning process that ensures the plan remains current and relevant. We propose a structure that will maintain, update and expand the work plan and timeline provided in the three-year action plan. ***Exhibit 11*** presents the organizational structure for this process.

Exhibit 11: Proposed Structure for Ongoing Planning Process



Structure and Responsibilities

A Steering Committee consisting of State senior management staff will oversee all implementation efforts. Separate Stakeholder and Legislatives Advisory Committees will provide guidance to this Steering Committee.

An Information Technology (IT) Committee will work closely with each of the seven Workgroups to coordinate and integrate IT components of the overall work plan.

We divided responsibility for implementing recommendations across seven workgroups:

1. **ADRC**: This workgroup will be responsible for all of the recommendations included in building a full functioning ADRC. This includes streamlining access, developing a unified assessment, and integrating eligibility criteria. We have also

include responsibility for oversight of the NF-LOC study, a subtask of the larger recommendation regarding addressing the needs of individuals with ADRD and BI, because this work is germane to the other work being done to develop common data elements and eligibility criteria.

2. **Restructuring Budgets**: This workgroup will focus on the recommendations related to restructuring budgets for PCA and waiver services.

3. **Self-Direction**: This workgroup will focus on efforts to provide consumers with greater ability to self-direct, including all of the recommendations related to conversion of CDPCA to the 1915(j) State Plan Self-Directed Personal Care option. We have also included other initiatives that will support individuals if they wish to live in a setting that they own or control, including:

   a. Transition Services

   b. Shared PCA

   c. Universal Worker

4. **Demonstrations**: This workgroup will focus on the development of the three 1937 Benchmark applications (ADRD, BI, and Pioneer Homes) and the 1115 Demonstration aimed at serving CAMA recipients. We combined these scopes because they all involve developing requests to CMS and participating in the subsequent negotiations with CMS. To streamline these negotiations, it will make sense to coordinate the design of each of these initiatives to avoid the need to justify unnecessary differences in program design.

5. **Pioneer Homes**: This workgroup will have the limited scope of addressing the proposed change in the asset criteria and the administrative streamlining to enhance FFP. The Demonstrations Workgroup will oversee the application of the 1937 Benchmark plan for Pioneer Homes.

6. **Quality Management**: This workgroup will oversee all of the recommendations related to quality management.

7. **Care Coordination**: This workgroup will oversee the recommendations related to improving care coordination.

New State Staff

Implementing each of the efforts will require the investment of substantial amounts of time by State staff. We strongly recommend that these be new State staff solely devoted to these efforts to avoid their diversion to day-to-day operational issues. These staff could be located in a new unit devoted to policy and program development. We propose that 14 new staff be assigned to this effort including the following:

- 1 Manager who oversees all of the proposed new staff with the exception of the IT staff. This individual would also be responsible for the coordination of the Steering and Advisory Committees.

- 2 professional FTEs and 1 administrative FTE assigned to IT development.

- 1 professional FTE and 1 administrative FTE assigned to the ADRC Workgroup.

- 1 professional FTE who is splits time across the following workgroups:

    - 25% ADRC.

    - 50% Demonstrations.

    - 25% Pioneer Homes.

- 1 professional FTE and 1 administrative FTE assigned to Self-Direction. This administrative FTE will also coordinate and oversee the requirement of consumer participation in the Workgroups and Advisory Committee and will oversee a pool of dollars that can be used for travel for consumer representatives and funds for personal care assistance or relief for caregiving responsibilities (e.g., a parent of a child with a disability).

- 1 professional FTE and 1 administrative FTE assigned to Restructuring Budgets.

- 1 professional FTE and 1 administrative FTE assigned to Quality Management.

- 1 professional FTE who splits time 50/50 across the Quality Management and Care Coordination Workgroups.

Committee Membership

We propose that the Steering Committee include top-level management staff and key division directors, such as the DHSS Commissioner, a Deputy Commissioner, the Medicaid Director, and the Directors of DSDS and the Pioneer Homes Division. Leadership of each of the Workgroups and the IT Committee will also be included in the Steering Committee.

The Stakeholders Advisory should include the following:

- Representatives from Steering Committee
- A representative from each Workgroup
- Consumers
- Providers
- Other representatives

The Legislative Advisory Committee should include the Steering Committee and members of the legislature and/or their staff. The IT Committee will consist of IT staff assigned to DSDS and representatives from each of the workgroups.

The Workgroups will include the new State FTEs, State operational staff that oversee areas impacted by the recommendations, and consumer and provider representation in select aspects of implementation.

Committee Process

We propose that the Steering Committee and Advisory Committees meet on a quarterly basis. The IT Committee should meet monthly. Each of the workgroups should meet at least monthly or more frequently depending upon the demands of the work at hand.

Leadership for the groups include: A Deputy Commissioner or the Medicaid Director for the Steering and Advisory Committees, manager of the DSDS IT staff for the IT

Committee, and new State staff assigned to each of the workgroups should lead their respective groups.

The Steering Committee will have responsibility for the following:

- Overseeing progress of each Workgroup in meeting timelines and milestones in their work plan.
- Overseeing the cooperation/integration of workgroups.
- Setting priorities for new work.
- Reviewing requests and obtaining resources from the Workgroups.
- Refining the vision and determining next steps and whether additional workgroups are needed.
- Managing a communication plan, including developing and approving summaries of accomplishments that can be made publicly available (e.g., newsletter/email) and reports to the legislature.

The Stakeholders and Legislative Advisory Committees will be responsible for providing guidance to the Steering Committee.

The IT Committee will provide support and coordinate efforts to add capacity to the DS3.

Each of the Workgroups will have the following responsibilities:

- Developing and implementing initiatives.
- Updating and fleshing out the work plan/timeline.
- Overseeing work of contractors.
- Making recommendations for changes in the strategic plan to the Steering Committee.

We also propose that the State hold an Annual Strategic Planning Summit. This would be a full day Annual Summit (in lieu of Stakeholder & legislative meetings) that will include members of all groups to review progress to date and identify new initiatives and set priorities for the next year.

THREE-YEAR ACTION PLAN SUMMARY

The three-year action plan (3YAP) translates components of the LTCP scheduled for development within the first three years. The proposed timeframe for full implementation of some of these components is longer than three years. In these cases, the action plan timeline exceeds three years. This document is presented as ***Appendix 13***.

The 3YAP is intended to be a living document that will be continually updated and modified during the implementation of the LTCP. The Workgroups identified in the Ongoing Planning Process will assume responsibility for updating this document and will use it to guide their work. It is important to recognize that factors external to the 3YAP, such as federal and State policy changes, will require the State to modify this document. These factors must be considered when monitoring the State's progress in implementing the 3YAP.

We created the 3YAP using Microsoft Project, a type of project management software. We chose this software because it helps to fulfill the following requirements for the 3YAP:

- It allowed delineation of tasks and subtasks for each recommendation;
- It allowed the linkage of tasks to demonstrate where tasks are interrelated and when some tasks must be completed before engaging in other tasks;
- It allowed the creation of timelines that incorporate these dependencies and automatically adjust later tasks when there are delays in earlier tasks.

Almost all of the tasks are contingent upon the passage of some kind of legislative authorization (budget or legislative), hiring of new State staff to manage the initiatives, and securing contractual assistance. If any of these tasks take longer, the rest of the timeline shifts back.

The 3YAP includes the following columns:

- Task name.
- Predecessors (this establishes the linkages among tasks).
- Duration (this measure is in working days, thus five days equals a week).

- Estimated start and finish dates.
- State Staff – we created this column to propose the role for State staff in implementing this effort. We classified their role as primary (State staff would conduct most or all of the work necessary to implement this task) or oversight (State staff would oversee the work of a contractor).
- Contractual – we identified tasks for which the State may wish to hire an outside contractor to assist in implementing the task. We identified an outside contractor as being appropriate when the task required particular expertise that State staff are not likely to have and/or the task involved a temporary burst of work that would not need to be sustained over time.

While the tasks included in the 3YAP mirror the recommendations for the LTCP, we restructured and integrated some of them to create a more logical fit in a linear timeline. For example, in the recommendations, we delineated changes to certification and licensing as a separate recommendation from building a quality management strategy that was consistent with the CMS HCBS Quality Framework. However, because certification and licensure are core components of the discovery and remediation processes, we integrated these tasks within the larger effort.

The 3YAP highlights the complexity and amount of work the State must accomplish to implement the recommendations that we have put forward. Successful implementation of reforms of this magnitude will require a sustained effort that has leadership and resources from both the executive and legislative branches.

APPENDIX 1: CMS AUTHORITY MATRIX

Appendix 1: Medicaid Authority Crosswalk

Criteria	1915(a)	1915(b) - Freedom of Choice	1915(c) - HCBS Waivers	1915(i) - State Plan HCBS	1915(j) - State Plan Self-Directed PC
Thumbnail sketch	Allows for voluntary managed care	Mandatory managed care and limits on # of providers	Provide HCBS to people who meet institutional criteria	State Plan HCBS	State Plan Self-Directed Services
Participants					
Financial Eligibility Cap	Regular Medicaid	Regular Medicaid	Up to 300% of SSI	no more than 150% FPL in countable income	Regular Medicaid
Functional Eligibility Criteria	n/a	n/a	Institutional Level of Care (LOC)	Needs-based - can be for individual services/less stringent than 1915(c) - may need to modify 1915(c) to include needs based criteria/can adjust if enrollment exceeds projections	Must qualify for waiver or state plan PCA
Targeting age or disability populations	Can target based on medical needs		Can target by age and disability population (e.g., DD, PD, TBI, etc.)	Needs-based only - not diagnosis, not age	Can target populations
Cap on enrollment		No	Yes	Yes	Yes
Waiting Lists		n/a	Yes	Yes	Yes
Doesn't have to be statewide	X		X	X	X
Services and Service Planning					
Ability to Pay for Services not Covered Under the Regular Medicaid Program	Same services as state plan, some services may be added according to contract.	May NOT be reduced but plans may add services.	Statute Identifies Homemaker, Home Health Aide, Personal Care, Respite, Adult Day, Habilitation (Residential, Day, Prevocational, Supported employment, & Education), Day Treatment, Partial Hospitalization, Psychosocial Rehabilitation, & Clinic Services). May pay for other services that prevent institutionalization	All 1915(c) services except "other"	Individualized budget that can be used to pay for personal care or items or activities that would reduce the need for personal care
Independent Evaluation	n/a	n/a	Language encouraging independent evaluation. May be included in upcoming revision to regulations.	Yes, must address needs & strengths, must address ADLs using an "objective" approach, such a OT or PT evaluation, individual must be allowed to identify others who should be consulted in evaluation, examine medical records, have knowledge of best practices. Must be independent from both providers and "concern for the budget"	Yes, must address, individuals' needs, strengths, preferences for PAS and use a person-centered process.
Waive Freedom of Choice of Providers		Yes except for emergency services, family planning, FQHC services			
Authority for Managed Care	Voluntary, must meet MCO requirements	Mandatory, must meet MCO requirements			
Where services cannot be provided			hospital or institution	hospital or institution	hospital, institution, or residence controlled by a provider
Can cap dollars provided to individual			Yes		Yes
Specific Requirements for Plan of Care			Likely to be regulations similar to 1915(i)	Natural supports explicitly included in it - can provide less services for people with more support, but can't "compel" natural supports	
Presumptive eligibility	No	No	No	60 day option, but only for program - not Medicaid, FFP only for assessment, not for services	No

Appendix 1: Medicaid Authority Crosswalk

Criteria	1915(a)	1915(b) - Freedom of Choice	1915(c) - HCBS Waivers	1915(i) - State Plan HCBS	1915(j) - State Plan Self-Directed PC
Other Issues					
Quality Assurance	Regular Medicaid	Regular Medicaid	Set several assurances that states must demonstrate that they meet	must have a strategy, measure and maintain evidence at both system and individual level and make information available to CMS upon request	Safeguards to protect health and welfare & ensure financial accountability, Triennial evaluation of impact on health & welfare
Approving Agencies/Difficulty	CMS/Medium - non-standard application	CMS/medium - likely will need (b) in combination with other authority	CMS/low	CMS/medium, new authority, CMS is in process of developing rules and processes	CMS/medium, new authority, CMS is in process of developing rules and processes
Other Issues				Can only have 1 1915(i) across all populations - will be challenging to coordinate across agencies	Must establish mechanism to inform all individuals about consumer directed options. Budget must be developed based on the assessment and a methodology that uses valid, reliable cost data and is open to the public

Appendix 1: Medicaid Authority Crosswalk

Criteria	1937 - Benchmark Plans	State Plan PCA/HH	Targeted Case Management	EPSDT	1115 Demonstration
Thumbnail sketch	Originally conceived to limit Medicaid benefits by allowing states to benchmark plans to HMOs, etc., statute allows states to provide additional benefits as "wraparound" coverage.	State Plan PCA or Home Health	Covers broad definition of Case Management to Targeted Population	All services that a child may need that could be covered under Medicaid	Demonstrate changes to Medicaid as long as budget neutral to federal govt.
Participants					
Financial Eligibility Cap	Regular Medicaid, excludes medically	Regular Medicaid	Regular Medicaid	Regular Medicaid	Can establish criteria as long as within budget neutrality
Functional Eligibility Criteria	Can target populations which would set eligibility criteria	State establish, typically need for ADL assistance	Set by target population	Based on child's needs	States decide whether to have a functional criteria and set it
Targeting age or disability populations	Can target populations	Can target by need	Can target populations	Children	Have flexibility to target
Cap on enrollment	No	No	No	No	Yes
Waiting Lists	N/A	N/A	N/A	N/A	Yes
Doesn't have to be statewide	X		X		X
Services and Service Planning					
Ability to Pay for Services not Covered Under the Regular Medicaid Program	Relevant language from DRA "C) OPTION OF WRAP-AROUND BENEFITS- In the case of coverage described in subparagraph (A), a State, at its option, may provide such wrap-around or additional benefits as the State may specify."	Personal Care/Home Health	Broadly defined Case Management	Any service that could potentially be provided under Medicaid, including a 1915(c). Blurriness around non-medical services.	Have flexibility in providing additional services.
Independent Evaluation					
Waive Freedom of Choice of Providers	Possibly				Yes
Authority for Managed Care	Could only be optional of disabled and dually eligible				Mandatory, could waive MCO requirements
Where services cannot be provided			Institution		
Can cap dollars provided to individual	For additional services		Yes - in reimbursement methodology		
Specific Requirements for Plan of Care			New CMS may apply in future - now in limbo		
Presumptive eligibility	No	No	No	No	Yes

Appendix 1: Medicaid Authority Crosswalk

Criteria	1937 - Benchmark Plans	State Plan PCA/HH	Targeted Case Management	EPSDT	1115 Demonstration
Other Issues					
Quality Assurance		Regular Medicaid	New CMS may apply in future - now in limbo		Specify plan as part of 1115
Approving Agencies/Difficulty	CMS/medium, new authority, CMS is in process of developing rules and processes	CMS/low	CMS/low, unless targeting foster care or schools	CMS/low	CMS, OMB, other agencies in HHS/High - need to demonstrate budget neutrality, lots of players, HHS' Secretarial Discretion gives them lots of authority to approve or deny
Other Issues	Statute not intended as mechanism for Medicaid expansion - subsequent rules may limit this capability.		Rules in Limbo		

APPENDIX 2: SUMMARY OF KEY CHARACTERISTICS OF PROGRAMS FUNDED THROUGH DHSS

APPENDIX 2: SUMMARY OF KEY CHARACTERISTICS OF PROGRAMS FUNDED THROUGH DHSS

	OA	APD	MR/DD	CCMC	PCA	NF	ICFMR	Pioneer Homes	Senior Residen-tial Services	CAMA	DD Grants
Funding Source(s)	Medicaid	Medicaid	Medicaid	Medicaid	Medicaid	Medicaid	Medicaid	State/ Medicaid	State	State	State
Medicaid Authority	1915(c)	1915(c)	1915(c)	1915(c)	State Plan	State Plan	State Plan				
FFS or grant	FFS	FFS	FFS	FFS	FFS	FFS	FFS	FFS	Grant	FFS	Grant
Populations Served											
Institutional Comparison	NF	NF	ICF-MR	NF							
Target Group	Older Adults	Disabled	MR/DD/ Autism	Disabled				Older adults w/out serious mental illness	Target frail 80+, disabled /minority/ low income	chronic conditions, not Medicaid eligible	Older Adults
Age restrictions	65 & older	21-64	None	0-21	None	None	None	65+	60+	21-64	None
Transition		to OA when 65		to APD or MR/DD when 21						to Medicaid & APA	
Other restrictions				Medically Fragile	Not in AL no IADLS assist if on waiver			Residen-cy require-ments			
Individual Cost Limit	No	No	No	No	No	Tiered Payments based on Acuity	Negotiated on case by case basis	Tiered Payments based on Acuity	No	No	No
Additional limits on amount of services	Chore-10/wk, respite-520/yr, respite -14 days/year, EM-$10k/36 mos, CC, $200/mo	Chore-10/wk, respite-520/yr, respite -14 days/year, EM-$10k/36 mos, CC, $200/mo	Chore-5/wk, respite-520/yr, respite -14 days/year, EM-$10k/36 mos, CC, $200/mo	Chore-5/wk, respirat. 10/wk, respite-520/yr, respite-14 days/yr EM10k/36 mos, CC, $200/mo	As many hours as assessment justifies				only in Tanana & Kotzebue	Only 3 scripts, get physician visits & radiation	$3000 per core services, no cost limit on other services
Statewide	Yes	Yes	Yes	Yes				6 Sites	No	Yes	
Services											
Homemaker					X						
Home Health Aide					X						
Personal Care					X						
Respite	X	X	X	X	No						X
Adult Day	X	X									
Habilitation		if DD eligible	X	X							
Residential		if DD eligible	X	X							
Day		if DD eligible	X	X							X
Expanded Habilitation Services as provided in 42 CFR 440.180(c)											
Prevocational											
Supported employment			X	X							X
Education											
Day Treatment											
Partial Hospitalization											
Psychosocial Rehabilitation											
Clinic Services											
Live-in Caregiver 42 CFR 441.303(f)(8)											
Environmental Modifications	X	X	X	X							
Transportation	X	X	X	X							
Specialized ME (inc. PERS)	X	X	X	X							
Chore Services (Homemaker)	X	X	X	X							
Companion Services											
Specialized Private Duty Nursing	X	X	X								
Extended State Plan	None	None	None	None							
Meals	X	X	X	X							
Residential Supported Living	X	X	X					X	AL		
Intensive Active Treatment/Therapies		if DD eligible	X	X							

APPENDIX 2: SUMMARY OF KEY CHARACTERISTICS OF PROGRAMS FUNDED THROUGH DHSS

	OA	APD	MR/DD	CCMC	PCA	NF	ICFMR	Pioneer Homes	Senior Residen-tial Services	CAMA	DD Grants
Nutrition Counseling											
Legal Assistance											
Supplemental Services (flexible funds)											X (core)
Operating Agency	DSDS	DSDS	DSDS	DSDS	DSDS	DSDS	DSDS	PVHD	DSDS	DPA/DHCS	DSDS
OA division of Medicaid agency	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Case Management											
Evaluations	State	State	State	Agency assesses, State determines LOC	State	State	State	PH Social Workers	Grantee	DPA arranges - physician completes a form	Grantee
Case Management Offered	Yes	Yes	Yes	Yes	No	No	No	Social Workers	AL staff member	No	Grantee
State vs. Provider	Provider, w/ a few State CCs	Provider, w/ a few State CCs	Provider, w/ a few State CCs	Provider, w/ a few State CCs				in facility	in facility	N/A	contract (grantee)
Medicaid Admin/service	Service/admin for State	Service/admin for State	Service/admin for State	Service/admin for State				no FFP	no FFP	no FFP	No FFP
Eligibility											
Can Establish Medicaid Eligibility?	Yes	Yes	Yes	Yes	No	Yes	Yes				
Income	$1,656	$1,656	$1,656	$1,656	regular Medicaid	$1,656	$1,656	No income limit, but pay if capable	None	$300 per month	No
Assets (varies for kids)	$2000/ $3000	$2000/ $3000	$2000/ $3000	$2000/ $3000	$2000/ $3000	$2000/ $3000	$2000/ $3000	$10,000	None	$500	No
Buy In	Yes	Yes	Yes	Yes	Yes						
Exclude parental income for children 18 & und	N/A	N/A	Yes	Yes	Yes - if TEFRA or Waiver	Yes	Yes				
Post eligibility treatment of income	$1396 if in AL/$1656 otherwise	$1396 if in AL/$1656 otherwise	$1396 if in AL/$1656 otherwise	$1396 if in AL/$1656 otherwise	regular Medicaid	$75 personal needs allowance	$75 personal needs allowance	$100 personal needs allowance			
Spousal Impoverishment	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes		None	
Level of Care											
Schedule for reevaluations	12 months	12 months	12 months	12 months	12 months	3-6 months	12 months	3 months		every 6 months	annual for plan of care
Assessment Tool(s)	Consumer Assessment Tool (CAT)	Consumer Assessment Tool (CAT)	ICAP	NF Assessment for Children	PCAT (subset of CAT)	Long Term Care Prior Authorization	ICAP	MPAF	each facility has tool	Sheet physicians complete	standardized plan of care
Eligibility Criteria	Mix of ADLs, nursing needs, behavioral & cognitive	Mix of ADLs, nursing needs, behavioral & cognitive	1/5 categ (MR, RC, CP, Epil, Autism) & ICAP criteria	Mix of ADLs, nursing needs, behavioral & cognitive	Extensive assist w/ 1+ADL & limited assist with one other ADL	Mix of ADLs, nursing needs, behavioral & cognitive	1/5 categ (MR, RC, CP, Epil, Autism) & ICAP criteria	Must meet level I Criteria	each facility establishes	Have a qualifying diagnosis	DD eligibility criteria in statute
Waiting lists											
Waiting List	No	No	943 as of 11/15/07	No				Yes	Not currently, but do have		Yes, by each grantee
Prioritization of Waiting List			Yes-risk of harm/ regression justice inv caregiver capacity	enrollment conditional on availability of providers				Yes			Same as waiver for core, up to grantee for other
Limits on any willing provider	None	None	None	None	None	None	None	Only 6	Only 2 facilities	None	Competitive RFP

APPENDIX 2: SUMMARY OF KEY CHARACTERISTICS OF PROGRAMS FUNDED THROUGH DHSS

	Senior In-Home Services	Adult Day Services	ADRD mini-grants	Nutrition, Trans. & SS	NF Transition	General Relief	STAR (short term assistance and referral)	DD Mini-Grants
Funding Source(s)	State/ AMHT	State	AMHT	OAA-Title III/State	State	State	State	AMHT
Medicaid Authority								
FFS or grant	Grant	Grant	FFS (grant to person)	Grant	FFS	FFS	Grants	FFS (grant to person)
Populations Served								
Institutional Comparison								
Target Group	Aged	Need Supervision (ADRD/ Frail)	ADRD/ Trust beneficiaries	minority, rural, poverty	anyone in NF	emergency situations	DD	Trust beneficiaries w/ DD
Age restrictions	60+ or AD	None	None	60+	None	18+	None	None
Transition					to a waiver or other program	to a waiver or other program	to a waiver or other program	
Other restrictions	priority for dementia				require that they transfer to waiver			
Individual Cost Limit	No	No	$2500 per year	up to providers	$3,500 to $5,000	Regional set rates (augmented also)	No	$2500 per year
Additional limits on amount of services	Supplemental Services limited to $500/ year, # hours 40/mo respite, 20 mo/ chore		pay if no other funding source (e.g., waiver) will pay		None		None	pay if no other funding source (e.g., waiver) will pay
Statewide		12 sites	Statewide		Yes	Yes	Yes	Statewide
Services								
Homemaker				X				
Home Health Aide								
Personal Care								
Respite	X							
Adult Day		X						
Habilitation								
Residential								
Day		X						
Expanded Habilitation Services as provided in								
Prevocational								
Supported employment								
Education								
Day Treatment								
Partial Hospitalization								
Psychosocial Rehabilitation								
Clinic Services								
Live-in Caregiver 42 CFR 441.303(f)(8)								
Environmental Modifications								
Transportation				X				
Specialized ME (inc. PERS)								
Chore Services (Homemaker)	X							
Companion Services				X				
Specialized Private Duty Nursing								
Extended State Plan								
Meals				X				
Residential Supported Living						X		
Intensive Active Treatment/Therapies								

APPENDIX 2: SUMMARY OF KEY CHARACTERISTICS OF PROGRAMS FUNDED THROUGH DHSS

	Senior In-Home Services	Adult Day Services	ADRD mini-grants	Nutrition, Trans. & SS	NF Transition	General Relief	STAR (short term assistance and referral)	DD Mini-Grants
Nutrition Counseling				X				
Legal Assistance				X				
Supplemental Services (flexible funds)	X							
Operating Agency	DSDS	DSDS	DSDS	DSDS	DSDS	DSDS	DSDS	DSDS
OA division of Medicaid agency	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Case Management								
Evaluations	grantee, DSDS must approve under 60	grantee, plan of care	AD Resource Agency - non-profit manages	Agencies	State staff	State staff	STAR Coordinator	Distributed through STAR programs
Case Management Offered	Yes	Grantee	no	No	Interim CM	Interim	short-term CM	no
State vs. Provider	contract (grantee)	contract (grantee)	N/A	N/A	In-house	in-house	contract	N/A
Medicaid Admin/service	No FFP	No FFP	No FFP	No FFP	No FFP	No FFP	no FFP	No FFP
Eligibility								
Can Establish Medicaid Eligibility?								
Income	no limit, sliding fee scale	no limit, sliding fee scale	No	Suggested contributions		$2,100	No	No
Assets (varies for kids)	none	none	No	No		Spenddown assets	No	No
Buy In								
Exclude parental income for children 18 & und								
Post eligibility treatment of income								
Spousal Impoverishment								
Level of Care								
Schedule for reevaluations	annual or as needed	Annually	Only initial	annual			None	Only initial
Assessment Tool(s)	Care Coordination Assessment Form	State Plan of care form for Adult Day Sites	No standardized tool	Consumer Characteristics, nutritional health			None	Each STAR designs own tools
Eligibility Criteria	Don't meet NF LOC	Not on waiver	ADRA verifies trust bene and has a ADRD diagnosis	title III eligible	In Nursing Facility	At immediate risk	DD eligibility for services	Trust beneficiary with an ADRD diagnosis
Waiting lists								
Waiting List		Yes, each site maintains waitlist	Yes, waitlist by region	Not currently, but can	No	No	No	each STAR maintains waitlist
Prioritization of Waiting List	Yes-risk of instit/ social/economic/AK Native/ rural	ADRD has priority						
Limits on any willing provider	State funding formula	12 sites			Limited by Contract			

APPENDIX 3: ANECDOTAL EVIDENCE OF THE NEGATIVE IMPACT OF DELAYS IN PROVIDING SERVICES

These stories were emailed to us by external stakeholders.

Story 1:

“I had visited with an elder who lived in a village that frequently requires three days to go to and from its location. At the time I met with her, I felt she would meet PCA and CHOICE Waiver criteria. She was very crippled with arthritis and had great difficulty getting out of bed. Her family was providing 24 hour care for her. I turned in a screening in late March.”

“I was contacted in April by the State Nurse assessor. She wanted to ask if I was able to make the day trip to the village with her when she went to assess the elder. My schedule was very full with travel to other villages and it did not look like we could make the trip together. However, at the last moment, I was able to make the trip with her. We met with the elder and her family. The elder was doing very well at that time because her doctors had placed her on some new medications. She was able to get up and walk and felt pretty good. The family was still doing all the IADLs, but she was able to do her ADLs with minimal assistance. Therefore, at that point she did not meet criteria for PCA or CHOICE.”

“Now a month later, she was brought to the emergency room in Fairbanks. I did meet with her and her family and she is back to her previous physical state. She was being treated for an infection and I will follow her closely to see how she recovers. However, at 89 years old, she may not bounce back that quickly.”

“My question is how can I get her quickly reassessed? What if this was January and not summer?”

Story 2:

Several home care nurses told us stories about people living in remote areas who had died waiting for assessments to be completed. They also told us stories about how cultural barriers had resulted in the elder being unwilling to talk with State nurses about the intimate details of how they live and what they need.

Story 3:

When we met with elders in the villages, several elders talked about the difficulty of obtaining help when it is needed. Frequently elders are not willing to tell outsiders about their struggles. When services are approved, home care workers are scarce and families become unable to continue to provide the help that is required. One elder, with tears in his eyes, talked about having to seek services for his mother in a facility far from his village because he was not able to get the help needed. His mother now lives in assisted living but is not allowed to eat foods from her culture (workers threw away foods that were brought to her from the village) and has limited ability to practice her culture. The mother is essentially cut off from family, friends, and the village that she knows. With earlier help, the son believes his mother could have stayed in the village.

Story 4:

"This story begins in the spring of 2001. I met with an elderly couple who both had come back to the village to live after some time in extended care. The wife had an immune response syndrome that affected her nervous system. The spouse had suffered numerous strokes and was wheelchair bound, not able to speak and had very little use of his right arm and leg."

"The wife, having periods of stability, cared for her husband. They lived in a small, cramped home that was in need of repair. It only had cold running water. The floorboards were rotten in the bathroom. This bathroom consisted only of a small sink and toilet. There was no tub or shower for the wife to use to bathe her husband."

"The husband needed assistance with all ADLs. He had difficulty feeding himself and was incontinent of urine much of the time. He had all the medical equipment and supplies he needed and I worked closely with the wife to make sure they always had the supplies sent out on time. There were a number of family members in the village and they all pitched in to assist the couple."

"Over the years, we were able to hire just one person to work for the family in that village as a PCA provider. The wife was so happy to have a little help and a break from the daily care of her spouse. The spouse looks forward to seeing a new face in the home. The winters are long, dark and cold, and it was just during the warm months that the spouse could be brought out of the home on the plywood ramp that the family built to get him out of the home. However, this person did not stay with the job for long and over the next 6 years, we were never able to hire another home care provider in the village."

"I am not sure why we have had such a difficult time to hire a PCA/Respite/Chore provider, maybe it is the pay, maybe the paperwork that needs to be filled out, or maybe it is the back ground checks."

"The elders moved into another home in the village recently. The home was small, but had hot and cold running water and was in much better shape than the previous home. They were both very happy and had a granddaughter living with them who was helping them with chores in the home. The elderly gentleman passed away this past May and I was able to visit shortly after that. I met the wife as she was rolling her walker to the store. As we hugged, we both had tears in our eyes. I know that she was thankful for the visits and the phone calls I made over the last 7 years and this may be a success story that the elder was able to remain in the village, surrounded by his family, yet to me it was a failure that we would not hire a PCA or Respite provider to improve the quality of care for that elder. At this time, we have recently hired a Home care Provider in the village. I can only hope that in the future I may be able to offer more help as the wife continues to age and her need for more help increases."

Story 6:

Home care nurses serving remote areas told us that when they visit villages, they try to get to know as many elders in the village as possible. Because travel is difficult, it is more efficient for them to combine regular visits with getting to know people ahead of time. This allows them to have some understanding of the situation if something occurs resulting in a health crisis. The home care nurse is better able to help the person, the person's family, health professionals, and long term care providers in dealing with the problem. Many times, decisions have to be made from a distance, with transportation and appropriate services being arranged over the telephone. During a time of crisis, the barriers of distance and culture are often great. It is frequently easier when a familiar person can help.

APPENDIX 4: SUMMARIES OF THE INDIVIDUAL CONSUMER FOCUS GROUP

Focus Group 1: Services for Older Alaskans, Anchorage

Things That Are Working Well:

Models and staff

- The Eden Model is a good model of providing care.
- Some assisted living has improved; the University system has provided some training for providers and staff.
- Committed staff in many of the homes.

Family Participation

- Family members are encouraged to participate in the planning process. It is up to the family to determine how much they want to participate.

Available Services

- Alaska does a good job with health care as compared to other states.
- Respite is a critical service for families caring for a member of the family at home.
    - A small amount of services can keep the family going.

State Agency

- Receptivity of the DSDS staff has improved.

Things That Are Not Working Well:

Quality Issues

- Quality of assisted living services is not sufficient.
- Elder care homes: need “common sense” training.

Staffing

- Limited availability of direct care workers.
- The increase in rates that was recently given to the Choice waiver did not reflect the actual rise in the cost of the care. Direct care staff cannot get health care or other benefits.

- PCAs need higher salaries and better skill development.
    - Cannot draw qualified people without higher compensation.
    - Recommend a career path.
- Emphasized that the quality of an assisted living home is dependent upon the quality of the staff.

Consumer/Person Centeredness

- Regarding forms and protocols related to PCA and chore services:
    - Assessment is a little insensitive and not practical.
    - Authorization should be for a global budget for the services, not in what each discreet activity can bill.
- State system is not sensitive to the consumer having some discretion and interest in directing the services.

Confusing system and not getting information and advice

- Consumers and families are not helped to understand nuances of the system. (The example given is as follows: In the area of transportation, the mother of a focus group member uses transportation to go to and from a day center. When coming home, the transportation was dropping the mother off in front of the house. The mother has Alzheimer’s and can get confused between the curb and door. Daughter sought to get an accommodation made and “was given the run around”, as she obtained different information about this depending on whom she talked with about it. It turns out that there are two programs, each with a different reimbursement. One program is for disabled in which the service will help to the door, and one for seniors in which the service drops in front of the house. She went through the forms again and indicated her mother was disabled.)
- System is confusing and inflexible. Several examples were given. In one case, a daughter who was caring for her mother in the daughter’s home wanted to paint her home and needed the mother out of the house. Because the mother likes to attend plays and stay at hotels, the daughter had wanted to pay for an overnight at a hotel for the mother and respite staff worker. However, regulations prevented this from happening, as respite that is not done “in home” must be provided in a licensed site. In this case, the daughter felt that the State is making the choices and not allowing the family to put together something that makes sense for them.

- Flexibility between in home respite worker and chore services complicates the lives of people and is more costly to the system. In the case of one of the attendees with quadriplegia, he was not eligible for chore services because his wife lives with him. However, the system failed to consider that his wife is a senior and is also caring for her 92 year old mother living within the same house.

People Need Help Earlier Than it is Provided

- Need coordination of benefits for people that may not be on the waiver in order to help the family keep the person in home…need help before a person hits the Medicaid level.
- Spending down to Medicaid is seen by some as demeaning. The system needs to offer a way to access LTC without requiring people to become poor.

Staffing and Providers

- Pioneer Homes is taking staff away from other providers because the State is the employer and can afford to pay more and to offer benefits to its staff.
- Hard to identify good assisted living homes. There is a lot of advertising, but the advertising can mislead seniors. Seniors think they are getting a highly organized and trained service provider, but providers are not qualified or have no special expertise for providing assisted living. There is no place to obtain objective information.
- Medicare doctors are not available. Also need physicians with specialty in gerontology.
- Hearts and Hands…does outings for seniors…. Filling a niche that no one else is doing. State told them that they have to have a center to be able to take people on outings. Therefore, they had to spend funds to make a center.
- Institutional bias in the system….favors assisted living over keeping people in their home.

Improvements That Should Be Made

- Information should be consistent and easily available.
- Advocacy help should more readily available.
- Training should include "common sense" training.
- Higher standards for PCA staff and agencies.
- One attendee thought there needed to be restrictions on multi level assisted living homes because of concerns about individuals being able to safely get to

and from upper levels; however, other attendees thought that the State should avoid blanket restrictions.

- More day care grouped by ability level and smaller settings for some people are needed.

Focus Group 2: Developmental Disabilities and Children with Complex Medical Conditions. Anchorage

Things That are Working Well:

Service/System Availability

- Wait list decreasing every quarter.
- Out of state expertise is great (autism) and available to families.
- Funding is available to pay for services for people lucky enough to get onto the waiver programs.
- Was able to get the State to listen and to change their position about the need for access to behavioral services for children with autism.
- Alaska Mental Health Authority: best practice, funding, advocacy for autism.

Person Centered Services and Choice

- Parents are allowed a choice of agencies to work with.
- Independent Care Coordinators (felt strongly about need for independence) do a good job.
- Services in the home are important to keeping families together.
- Alaska has remnants of individual budgets and the budget follows person.
- There is still a HCBS system after much change in policy direction and changes in administration.
- PCA consumer directed services: has made the biggest difference for their family.

Information, Advocacy

- Governor’s Council is effective.

- Statewide advocacy grassroots is great.
- A lot of information is out there if you know where to look.
- Waiver is tailored to need.
- Variety of services exist.
- Better informed parents are making more of the choices.
- Key coalitions have formed to influence the system and provide information.

Community Based Options

- No ICF-MR facilities.
- Most out-of-home services are small, three or less.
- Good providers.
- In-home services.

Things that are Not Working Well:

Covered Population

- People not meeting the level of care criteria (LOC) for waiver are out of luck.
- Grants have shrunk, so there is no place for people to go.

Quality and Availability of Services/Staff (wages and training)

- Untrained, poorly paid direct care staff workers.
- Cannot find direct care staff.
- Pay and benefits for staff.
- No ladder up for staff…not seen as positions with a career path.
- Staff is not trained except in some very basic things.
- Would like to see some tiers of certification.
- One attendee did not think web solutions for training would work without didactic training; best on line training they have seen uses video examples.
- No local expertise for training.
- Some of the training is not specific enough in individual situation. Families training the person may always be necessary.

- There is a general lack of expertise in the State at the provider agency and at the staff levels.
- Lack of back up staff available to replace the primary staff.
- Some specialties are available; autism specialty is not, behavioral is not.
- State did not invest in home and community services when they closed the institutions.
- Turnover is a problem.

Agencies

- Provider costs have gone up but the increases in reimbursement have not gone up sufficiently to cover the additional costs.
- Not clear that the agencies are passing along increases to the staff when there are reimbursement increases.
- Rate freeze really hurt the less “sophisticated” agencies that were less able to negotiate higher rates.
- Without some ability to recognize actual costs within the reimbursement methodology, higher need people will not be able to find services because providers will have little incentive or ability to meet needs and challenges.
- There is a lot of provider control in the system and within services unless you have savvy parents.
    - Differs by agency.
    - Some parents feel threatened by provider agencies, especially if their child is challenging to support – provider could pull out and leave them without any options.
- Large agencies seem to have too much sway in the system.

Political Issues

- A substantial portion of the voting population includes transient people (e.g., oil workers, members of the military) who do not want to invest in long term care services.

System Choice

- Some internal disagreement and discussion among the focus group members about whether there should be ICF-MR services for people wanting an institutional service. These families are forced to send family members out of state.

- No microboards exist in Alaska.

State Administration and Decisions

State Operations:

- New staff in waiver is not trained and not familiar with the program.
- State tends to work in silos and people needing services have needs across areas.
- Rules not published and the State reinterprets rules.
- Have lost a lot of creativity within the system.
- Fair hearings are not granted in accordance with rules of the system.
- Large amount of money spent on studies and recommendations and then nothing happens.
- Budget is driving the system and service.
- Shift to Medicaid funding has made services less person-centered.
- When you are unable to use PCA budget because of lack of staff, then the State reduces the authorized budget.
- State does not really oversee providers.
- Lack of quality control.
- Parents have little access to information about the “nuances” of services.

State and Stakeholder Relations:

- Distrust between the State and families.
- No/little interaction with State employees that administer the waiver.
- State is off in the lofty tower where families cannot find them.
- Communication is not good.
- Not enough stakeholder involvement.
- Families feel that the State changes the regulations when they do not want to pay.
- Governor’s Council does not listen to people outside the council groups.

- Solutions to problems are contrived by people who do not have the expertise to administer the program.
- Players are too removed from the “target” individual.
- Used to have interactive stakeholder discussions but now much less stakeholder involvement (decrees from on high).

Focus Group 3: Adults with Physical Disabilities (Individual Interview), Anchorage

The participant is getting PCA services authorized through the consumer directed option and is also on a Medicaid waiver, using transportation services, chore services, and care coordination.

The participant used to work a full time job but had to leave his job due to a chronic medical condition and blindness. His medical condition requires that he receive treatments on at least a weekly basis. The participant would consider going back to work if his eligibility for Medicaid would not be affected and if flexibility was given for obtaining needed medical care.

The participant has found staff for PCA services through friends and family. Now a relative provides PCA services under the consumer directed option. The participant indicated that the consumer directed services option was selected because the agency could pay the PCA a higher hourly wage. PCA services are used for a variety of needs including meal preparation and medication reminders/assistance, assistance with laundry, help with getting ready for medical appointments, and household chores. The participant’s medical condition requires monitoring or a method for alerting someone that help is needed.

Things That Are Working Well:

- Likes the PCA services that are provided.
- The majority of the participants’ medications are paid through the Medicaid program and some private insurance.
- The co-pay for medication is a few dollars per month, which is viewed as reasonable.
- Transportation is important and working well currently. However, the participant is concerned about some upcoming changes that are occurring due to rising fuel

costs. Access to transportation may be reduced, which would impact mobility and independence within the community.

Things That Are Not Working Well:

- Would like the option of purchasing a talking GPS system for community mobility, thus allowing more independence and less reliance on the PCA staff person. Participant has access to training to use the device but does not have sufficient funds to purchase the technology.
- Would also like to use technology that would act as a calendar and cue the participant about appointments, etc.
- Would use computer and accessible hardware/software but doesn't have money to buy it.
- The participant receives home delivered meals. Currently, there is only one agency that delivers meals to people under age 65. There is dissatisfaction with the nutritional value or quality of the meals. Currently the meals do not meet the nutritional needs required by the participant's medical condition. The quality of meals, beyond the nutritional content, is a complaint. The participant also reports some problems with delivery services.

Improvements to be Made:

- Would like to see the system cover equipment/technology that would enable more independence. Examples include a GPS or a computer with adaptations for vision issues. Another example included hardware and software in which mail can be scanned and the computer reads the contents aloud.

Focus Group 4: Adults with Physical Disabilities (Individual Interview), Juneau

The participant agreed to allow us to make the following information public. The participant is a 59 year old woman with a neurological disorder that is intermittently worse or better. Recently her condition worsened significantly, and she is only now beginning to regain some physical abilities. She has related sensory and cognitive impairments, as well as balance, coordination, and muscular issues. Currently the participant is receiving support services through the waiver and PCA. She lives in her own home/apartment, uses a motorized wheelchair, and receives physical therapy. Her PCA services are provided through a consumer directed option.

Things That Are Working Well:

- Likes her current PCA and chore service person.
- The help she is receiving has changed her life significantly. She was feeling overwhelmed before having assistance.
- Her customized motorized wheelchair has improved her mobility in the community and quality of life.
- She has been able to obtain durable medical equipment. Sometimes it takes a couple of attempts to get authorization, but she has been able to eventually get what she needs.
- Medicaid has been good at covering the cost of chemotherapy and other necessary medications.
- CDPCA is a good option because it offers greater flexibility.
- Chore service works well and she is authorized sufficient services, except when there is very bad weather and additional hours are needed to help shovel snow.
- Care coordination has worked well and is essential because of all of the program rules.
- “Meals on Wheels” in Juneau does a good job of delivery and checking up on the person.
- Caravan, a transportation service for people with disabilities, is very good in Juneau.
- The personal network and smaller town nature of the local system seems to have some very positive aspects to it, such as the bus service allowed her to practice using the ramps and lifts before having to use the bus when it was full of people.

- Medical services she needs are approved.
- Emergency service volunteers are very good.
- Benefits counseling that was provided to her through the ADRC allowed her to make an intelligent choice.
- Independent Living Program in Juneau is good.

Things That Are Not Working Well:

Assessment and Prior Authorization:

- The assessment process does not take into account the nature of the disease or disability, especially if the disease involves periods of remission (needs can change from one assessment to another or can change very quickly while authorized services do not).
- The assessment looks at a seven day period and does not consider safety. In one case, the consumer was crawling on the floor but technically could transfer herself. Even though this was done by crawling, she was not allowed to obtain services that would have helped her make a safer transfer.
- Process is not cost effective. The participant provided an example of a protracted discussion about one minute of time to allow for verbal cuing to take medications. Involved in the discussion was a neurologist, assessor, herself.
- Length of time to get services: getting the assessment and getting it approved can take an extended amount of time.

Service Availability

- Finding staff to assist in her home is difficult. Cannot easily recruit. Was able to finally find someone through a friend.
- Is concerned about not having a back up for her PCA. Also, the schedule is not as much in her control as she would like.
- Expansion of services is needed in the rural areas so that people do not have to leave home.
- Limitations on chore services cause problems during certain times: weather related and transition/moving of the residence.
- The Aging and Disability Resource Center (ADRC) services are very good, but there are not enough to go around.

Self-Advocacy and Person Centeredness

- People need to be more aware of the ADRC services.
- The system is difficult to understand. For example, at a fair hearing/appeal of services, she received about forty pages of documents that she was not able to understand.
- Need for clearer explanations about changes in policies and services. Information is difficult to understand.
- Input to the program is difficult when there are not clear explanations about how the system works. Requests for input to changes are impossible to provide when you are not clear in the first place. Makes it hard to advocate or self-advocate.
- The process for some people to get to the services and funding they need is not person centered.
- Complex reporting for time sheets and care plans that address minute-by-minute support. An aggregate budget would make more sense and would allow the individual to better direct care than is needed at the time.

Coverage and Eligibility

- Dental services should be improved because they do not pay for some preventative kinds of care.
- There could be more cost effective ways to support people. For example, some individuals need minimal services to remain in their home. However, eligibility for respite, personal care, and chore is so stringent that they cannot access needed services.
- People with Alzheimer’s disease, dementia, and people with traumatic brain injury were examples of individuals who are being excluded from services.
- Not always a match-up between the need and the available resource (e.g., Certificate of Need).

Recommendations:

- More consumer input into programs in order to identify needs and problems so that solutions can be found and implemented.
- Use of teleconferences to distribute information would be helpful.
- Advertising for input that can get out broadly to interested people.
- Plain English explanations of programs, regulations, and changes.

Focus Group 5: Older Alaskans (Individual Interview), Fairbanks

Introductory Remarks:

The participant for this interview agreed to allow us to use her situation as a public example of the experience of one family. Doris is the daughter of an older woman, Gladys. Gladys is currently 100 years old, and Doris is caring for her mother as well as working full time and raising children as a single parent. Doris needs to travel for her job on an intermittent basis and has concerns that she might lose the job because she has had difficulty in fulfilling her job duties due to the daily care Gladys requires.

Gladys and her husband, who is now deceased, set aside savings in order to pay for their potential long term care needs. Gladys also has a private long term care insurance policy. The premiums are paid by Doris. Doris has arranged various services for her mother, including adult day services and respite care. Most recently, Doris has been looking for an appropriate assisted living home in which her mother could live through the rest of her life.

Doris indicated that Gladys is relatively healthy and has good cognitive skills. However, she is very old and requires care that one would expect for a person of Gladys' age.

Doris indicated that her mother had been on the waiting list for Pioneer Homes for over ten years. The staff at the Pioneer Homes had indicated it would be at least another three years before Gladys might have a chance of admission. Doris has investigated other assisted living facilities but does not feel that any would be appropriate for her mother. Doris is looking for a situation in which Gladys can continue to be engaged in activities and can interact with others. She has looked at assisted living but there is nothing available that is acceptable because the facilities she has seen consist of a room in which the mother would live. Doris would like to see her mother in a place that has activities and a peer group that she would enjoy. She also feels strongly that the setting should provide for the transition to the end of life, since multiple moves would be difficult for her mother.

Because of many hours of searching for the appropriate assistance, Doris has made the decision to move her mother out of state in order to get services that better fit Gladys' needs. Doris expressed what a difficult decision this has been. Doris also expressed her strong feelings about the lack of priority that elders are given in terms of the willingness of the State to ensure the adequacy, availability, and quality of services through the investments it makes in services.

This is the backdrop for the areas identified during the focus group interview.

Things That Are Working Well:

- Fairbanks Resource maintains a list of available assisted living facilities, including some limited information about the facility.
- Pioneer Homes staff communication has been excellent: even though the home is very limited in its ability to admit new people, they are very clear about the status of the request for admission.
- The personnel working at the adult center day care program are wonderful.

Things That Are Not Working Well:

Information and Assistance

- Information and access is huge problem. Feels exhausted with trying to figure it out. Either things are not available or she is not getting information to be able to find them with the time and energy she has available.
- Need a navigation component within the system to help people.
- Advertising or some place for people to go to get more information about senior services is very inadequate. Families have few ways to easily learn about what is out there.

Service Availability and Availability of Quality Services

- Availability and quality of respite care for both in home and out of home services is poor. Experience was that respite staff had left the mother sitting in a darkened room during the day to just sleep. The staff person was defensive about it when asked to do more and engage the mother in activities.
- Overnight care does not seem available.
- Transportation is not available for many elders. Cannot get it because she is not in the city limits. Has been told that the special transportation is not available where the city buses do not go. She lives just 400 feet outside of the city limits.
- Availability of assisted living facilities capable of facilitating transition to end of life care is not available in the region. In this case, the daughter does not want to have multiple moves for her mother.
- In this specific case, the consumer needs overnight care for probably one to two weeks every few months while the daughter travels for her job.
- Availability and quality seem to be the biggest issues for this consumer and family.

- In the villages, there may be different policies for native versus non-native. The daughter moved the family away from a village area because she needed to get services for the mother and could not in that location.
- Family based home services are cost effective. Need to let legislature know about this. In addition, the reimbursement should reflect regional cost differences.
- Need expanded long term care facilities to include assisted living homes as well as pioneer-type homes.

Recommendations:

- Expansion of lower intensity supported living, in and out of home: respite, chore, transportation.
- Improved information and assistance.
- Need for long term care options and navigational services.
- Respite care needs to be more flexible, especially for in home and available hours. Also the use of respite for working people. For instance, if work hours need to be made up because the working person is unable to go to job due to care needs of family member, then limits on the in home respite do not make sense.
- Need to make information and assistance and long term care options navigation available to private pay individuals.
- Way to locally address the availability of services.

Other Notes on Consumer Story:

Doris expressed a great deal of frustration about getting the help that is needed. As a private pay individual, there was little help available to navigate the provider infrastructure, make arrangements for supports, and to access needed services. She also expressed strong concern for the quality of services available to people and provided an additional example:

A local provider has provided Saturday respite services for a while. Previously the provider has used experienced staff willing to work overtime in order to provide a Saturday outing for a small group of seniors. The group did activities such as going out to lunch and community trips.

Recently, those staff were replaced because of cost for overtime. Now a new worker has been hired. This new worker left people sitting in a darkened room with no activities. People had to bring their own lunch. Now the people using Saturday respite have been notified that they must buy lunch for the respite worker.

The daughter said that her mother and father had saved and had responsibly taken out long term care insurance. In essence, this "screwed" her mother, in that she would have been better if she had been poor.

Focus Group 6: Developmental Disabilities/Chronic Conditions, Fairbanks

This session was attended by the parents of minor children having a combination of developmental disabilities and severe and chronic medical conditions.

Things That Are Working Well:

- Care coordination supports.
- Glad that services are available…at least there are some.
- TEFRA.
- CCMC waiver.

Things That Are Not Working Well:

- Yearly renewals, with extensive medical evidence on conditions that do not change, are required. This is almost impossible for some parents who described overwhelming situations involving the care of their children. In two of the cases, the parents are single parents with other children. The system is not practical for these parents because of the physical and mental demands of their lives.
- Expertise to deal with autism does not exist in the State.
- Respite care or in home support services are essential to the ability of the family to keep the child in the home. Parents reported some pretty severe circumstances where their own health and welfare are truly at risk. The lack of availability and access to supports, and limits imposed on the use of services such as respite care, are hurting families.
- Wages and benefits are insufficient to find people that are qualified to do the complex tasks that are required.
- Qualified people might not still be available if wages were higher.

- Share care homes are not available and payment is not increased as number of children is increased.
- DD group homes are not available.
- Parent support and training groups are not available.

Recommendations

- Expedited renewal process for situations in which the condition of the person is unlikely to change.
- Explore unique arrangements with the State to balance relocation of a family to offset travel costs related to medically required treatment/emergency care. Example: one mother felt relocation to Anchorage would eliminate the use of costly air transport multiple times per year for her child. However, mother cannot afford all the costs associated with moving.
- Another parent expressed concerns that her family was taking access to emergency flight transport away from others because the child has to have ground level flights due to a medical condition.
- Parent support groups and networks need to be developed.
- More options on services.
- Higher pay and benefits.
- Information on provider availability and expertise.
- Public service information.
- Therapeutic respite home.
- Recommend flying in experts to be available for consultation and/or training to deal with issues such as challenging behaviors, or medical needs that are low incidence.
- Establish a lender closet.

Focus Group 7: Adults with Physical Disabilities, Fairbanks

The participants were not current users of public programs. However, one person has a degenerative disease and is self-identified as a potential user. The other participant is married to someone with significant disabilities who has private long term care services that they consider to be worthless in meeting needs.

Things That Are Working Well:

- Health care in Fairbanks is pretty good given location.
- Hospital is good for its size.
- Good experience with social workers at Denali Center.
- Direct care staff with which the participant interacted with was good.

Things That Are Not Working Well:

- Fundamental issue is that if you are willing to accept Medicaid you can get services. If you are not on Medicaid, then it is extremely difficult to access and arrange services. The cost of the local nursing facility is prohibitive. While Medicaid recipients get costs covered, private insurers will not cover the cost of the local center. This means looking to out of state facilities.
- Alaska Comprehensive Health program, a safety net program, is good insurance but extremely expensive.
- Need more in home services.
- Thinks that government rules evolve from the fear of fraud. Because of this, rules cause the responsible user to have difficulty in accessing services that make sense and are cost effective.
- Would like to have ability to hire off the private hire list and get reimbursed for costs…thinks it would be more cost effective to direct it himself.

Recommendations

- Do not make people have to spend down to Medicaid just to get services.
- Do not punish people who save and act responsibly by throwing barriers up because others act in irresponsible ways.

Summary of Alaskan Native Input

Rather than holding a traditional focus group with representatives of Alaskan Natives, we have obtained information in two ways: 1) visits to the villages of Allakaket and Alatna; and 2) submission of stories from interior Alaska through the Native Alaskan Health Consortium.

Village Visits

We flew into Allakaket and Alatna, accompanied by two home care nurses from the Tanana Chiefs Home Care agency. Allakaket and Alatna are remote native villages located north of Fairbanks. Both have small populations, with Alatna being the smallest (population under 50). During our trip we were able to do the following:

- Tour the local health clinics in each village.
- Visit elders in their homes (two home visits).
- Conduct a focus group with elders in Allakaket.
- Interview the two home care nurses.
- Meet with one in home direct care staff person.
- Tour each village.

Stories Submitted

We also received several submitted stories regarding the experience of elders in rural and frontier Alaska who have attempted to access and use services. These stories were submitted through the Native Alaskan Health Consortium.

Observations and Issues Identified From Visits and Stories

- Basic amenities do not exist in the homes of many elders in the native villages. Water must be carried into the home. Homes we visited did have electricity and telephones. Heating was frequently done with wood. Housing options were poor as compared to what would typically be available in more populated areas. Bathroom facilities were typically outhouses, except for bathrooms located at the village laundromat.
- Transportation in and out of the villages was by boat or plane. Within the villages, people walk or use ATVs during warm weather months. Snowmobiles and snowshoes are used in winter. There was some access to trucks and vans; however, due to the cost of fuel (more than 7 dollars per gallon) most villagers avoided using the larger vehicles.
- Villagers appeared to be well aware of needs and situations of fellow villagers. There tended to be a means for radio contact through use of citizens band radio among residents in the village.
- Both villages, but especially Allakaket, tended to be “spread out”, in that, distances between homes, health clinic, store, etc. would represent local access problems for anyone with mobility issues. Roads were dirt roads with some

gravel. Conditions in the winter would mean that it is almost impossible for a person with mobility problems or poor health conditions to leave the home without substantial assistance.

- During the focus group, elders expressed that it was difficult to obtain in home supports. Training for workers was not readily available, and workers did not tend to remain in jobs providing care.
- Elders talked about the difficulty in making decisions to leave villages for care in assisted living facilities. Because travel is difficult, people moving to assisted living facilities elsewhere tend to be cut off from families and friends.
- Elders also expressed frustration with the failure of assisted living facility staff to understand and/or honor the differences in cultures. Stories were told about how staff refused to even allow traditional foods in some of the facilities.
- It was obvious that some elders had gone through very difficult and emotional decision-making processes with parents needing care, and decisions to move a loved one away from the village was to cut that person off from the family and culture of the village.
- Home care nurses verified stories about problems with the assessment tool and process. Some of the problems included: cultural divides which would inhibit elders or families from providing personal information to “outsiders”, lack of timeliness in completing assessments, lack of timeliness in authorizing services, failure of assessment protocol to consider living conditions in the villages, failure of assessment protocol and rules for services to deal with multigenerational living situations in an appropriate fashion, failure to have a way to for assessments to approach chronic medical conditions which fluctuate in how they impact individuals (this combined with weather and transportation issues left people without vital services).
- Home care nurses also verified that it had been difficult to recruit and retain staff to provide in home services through their agency.
- Alatna did have one in home worker with whom our team spent time. She was fairly new, but had completed training and was providing care to elders within the village. We perceived that someone in this type of staff role was accepting a lot of responsibility and must be willing to work very independently.
- Nurses also indicated that it was challenging to supervise workers appropriately.
- Nurses seemed to have relationships with health clinic staff, and this appeared to be a good means to keep apprised on needs of elders for home based services.

- Because of time and distance involved in getting to villages, home care nurses tended to check on status of a broad group of elders so as to be familiar with new requests for services (since the nurse cannot simply or quickly get to the village location).
- Access to information about long term support options was extremely limited. Internet was available in the village, but not in homes (was located in tribal office and schools). Information appeared to be obtained primarily through visiting nurses or the health clinic, if at all.
- The team did receive other personal stories through the NAHC. These stories again verified many observations already made. In some cases the difficulty in obtaining assessment and authorization resulted in people dying before assistance could be provided.

APPENDIX 5: SURVEY INSTRUMENTS

Survey of Consumers and/or their Family who Need Long Term Care

Current Date	8/22/08

HCBS Strategies has been hired by the Alaska Department of Health and Social Services (DHSS) to develop recommendations for improving the long term care services, including services provided in the home and community, it provides.

This survey is designed to capture how you feel about the long term care services that you or someone in your family receives. You may also complete this survey if you are a guardian of someone in need of long term care.

You may respond to this survey by filling it out electronically and submitting it by clicking the "**Submit by Email**" button at the top of this page or at the end of the survey. You may also print out a copy and fill it out by hand and either fax it to: 410-510-1144 or mail it to:

Kristy Michael
402 Wood St.
Harrisburg, PA 17109

To print this survey please click the **"Print"** button at the top of the page.

Please feel free to share this survey with other persons in need of long term care or their family members that you believe would be interested in providing their input.

Please submit your survey no later than Friday August 1, 2008.

Thank you in advance for your participation!

Please tell us if the person who is answering the questions is:

○ The person who is in need of long term care, including services provided in the home and community

○ Family member or other person responding for the person in need of long term care

If you are not the individual, what is your relationship to the person in need of long term care:

○ Parent

○ Child

○ Spouse

○ Other family member

○ Guardian

○ Other

If other, please specify: ☐

Note: *if you are **<u>not</u>** the individual with a disability or older adult in need of long term care, please answer the remaining questions as they pertain to that person, not to yourself.*

Personal Information:

1. Where do you live?

○ Region I
  - Bethel Census Area
  - Wade Hampton

○ Region II
  - Denali Borough
  - Fairbanks North Star Borough
  - Southeast Fairbanks
  - Yukon-Koyukuk

○ Region III
  - North Slope Borough

○ Region IV
  - Anchorage Municipality

○ Region V
  - Kenai Peninsula
  - Matanuska-Susitna
  - Valdez-Cordova

○ Region VI
  - Aleutian Islands East
  - Aleutian Islands West

○ Region VII
  - Bristol Bay Borough
  - Dillingham
  - Kodiak Island
  - Lake and Peninsula

○ Region VIII
  - Nome Census Area
  - Northwest Arctic

○ Region IX
  - Haines Borough
  - Ketchikan Gateway Borough
  - Juneau Borough
  - Prince of Wales - Outer Ketchikan
  - Sitka Borough
  - Skagway - Hoonah - Angoon
  - Wrangell - Petersburg
  - Yakutat Borough

○ Don't know or unsure

If you don't know or are unsure, please describe where you live:

2. Please check all that apply to you:

- ☐ Age 65 or older
- ☐ Person with a Developmental disability
- ☐ Person with a Physical disability
- ☐ Person with a Mental health issue
- ☐ Person with a Traumatic Brain Injury
- ☐ Person with Alzheimer disease and related dementias
- ☐ A Child with special needs
- ☐ Person with HIV/AIDS
- ☐ Other

Please specify:

3. Are you of Native Alaskan heritage?

- ○ Yes
- ○ No

4. Are you:

○ Male

○ Female

5. Please check all the programs through which people are paid to help you:

☐ Agency Directed Personal Care Services

☐ Consumer Directed Personal Care Services

☐ Waiver Service

    ○ Older Adult

    ○ Adults with Physical Disabilities

    ○ Developmental Disabilities

    ○ Children with chronic medical needs

☐ Grant Program

☐ General Relief Assistance for Assisted Living

☐ Other program

    Please specify: ______

☐ My family or I pay for these services

☐ I don't currently have anyone who is paid to help me

☐ I do not know

☐ None of the above

6. How long have you been getting assistance from this person or people that are paid to help you?

- ○ Less than one year
- ○ One to five years
- ○ More than five years
- ○ I don't have anyone who is paid to help me
- ○ I don't know

7. Is the place that you live or the organization that you get paid help from a tribal health care organization?

- ○ Yes
- ○ No
- ○ I don't know

8. Where do you live?

- ○ My own home or the home I share with a spouse
- ○ My family's home (live with parents, adult children, or another relative)
- ○ Assisted living home
- ○ Pioneer Home
- ○ A group home other than an assisted living facility
- ○ Nursing Home
- ○ Other
- ○ I don't know

9. How many other people who have someone who is paid to help them are there where you live?

- ○ I am the only person who has someone who is paid to help them where I live
- ○ 1
- ○ 2-3
- ○ 4-7
- ○ 8-15
- ○ More than 15
- ○ I don't have anyone who is paid to help me
- ○ I don't know

10. How did you find the people or place(s) that help you (check all that apply)?

- ☐ Through a Care Coordinator
- ☐ Through a friend or family member
- ☐ Through my doctor or other medical provider
- ☐ Through an Aging Disability Resource Center
- ☐ Through a senior center, telephone help line, or internet
- ☐ Through the provider of that service
- ☐ Other

If other, please describe: ☐

11. Were you given a choice about where you live?

    ○ Yes
    ○ No
    ○ I don't know

12. Were you given a choice about who would help you?

    ○ Yes
    ○ No
    ○ I don't have anyone who is paid to help me
    ○ I don't know

13. Once you requested help, how long did you have to wait before you actually started receiving that help?

    ○ Less than 1 month
    ○ 1 to 3 months
    ○ 3 to 6 months
    ○ More than 6 months
    ○ It was too long ago for me to remember
    ○ I don't have anyone who is paid to help me
    ○ I don't know

14. If you had to wait more than 1 month, what were the reasons for the wait (check all that apply)?

- ☐ The State took too long approving my services
- ☐ It took a long time to find someone who would provide the service
- ☐ My care coordinator did not get back to me
- ☐ I don't know
- ☐ Other

If Other, please describe: ☐

15. How involved were you in developing your plan of care for how people would help you?

- ○ I was very involved
- ○ I was involved only a little
- ○ I was not involved
- ○ No one told me that I could be involved
- ○ I don't have anyone who is paid to help me
- ○ I don't know

16. Do you receive your help in the way that your plan of care indicates?

- ○ Yes
- ○ No
- ○ I don't have anyone who is paid to help me
- ○ I don't know

17. How happy are you with the help that you get?

○ Very Happy
○ Somewhat Happy
○ Unhappy
○ I don't have anyone who is paid to help me
○ I don't know

18. Do you feel that the help you get meets your needs?

○ It meets all of my needs
○ It meets most of my needs
○ It meets some of my needs
○ Most of my needs are not met
○ I don't have anyone who is paid to help me
○ I don't know

19. Is there help or services that you need that you are not able to get?

○ Yes
○ No
○ I don't have anyone who is paid to help me
○ I don't know

If yes, what are they?

20. What do you most like about the help that you get?

21. What do you least like about the help that you get?

22. Would you like to have more control over the help that you get?

○ Yes

○ No

○ I don't have anyone who is paid to help me

○ I don't know

23. If you could change something about how help is provided in Alaska, what would you recommend?

Thank you for your participation!

Survey of Long Term Care
Service Providers

Current Date ☐

HCBS Strategies has been hired by the Alaska Department of Health and Social Services (DHSS) to develop recommendations for improving how Alaska provides services for individuals with disabilities and older adults. We have created this survey as part of this effort. The survey is designed to capture your perception of how well the system operates and your recommendations for improvements.

You may respond to this survey by filling it out electronically and submitting it by clicking the **"Submit by Email"** button at the top of this page or at the end of the survey. You may also print out a copy and fill it out by hand and either fax it to: 410-510-1144 or mail it to:

Kristy Michael
402 Wood St.
Harrisburg, PA 17109

To print this survey please click the **"Print Form"** button at the top of the page.

Please feel free to share this survey with other providers that you believe would be interested in providing their input.

Please submit your survey no later than Friday August 1, 2008.

If you have any questions please contact Kristy Michael at kristy@hcbs.info

Thank you in advance for your participation!

1. Which of the following services are you Medicaid certified to provide? Please check all that apply.

- ☐ Nursing Facility
- ☐ Assisted Living
- ☐ Care coordination
- ☐ Personal care assistance
- ☐ Habilitation
- ☐ Adult day care
- ☐ Respite
- ☐ Meals
- ☐ Transportation
- ☐ Chore
- ☐ Environmental modification
- ☐ Specialized private duty nursing
- ☐ Intensive active treatment
- ☐ Other

If other, what ☐

2. Are you a licensed provider?

○ Yes

○ No

If you are licensed, for what service are you licensed and who licenses you (don't include professional or business licenses)?

- ☐ Nursing facility - Health Facilities Licensing and Certification
- ☐ Assisted living - Division of Public Health, Assisted Living Licensing
- ☐ Child Foster Care - Office of Children's Services
- ☐ Other

Type of license and licensing organization

- ☐ Other

Type of license and licensing organization

- ☐ Other

Type of license and licensing organization

3. In what areas of the State do you provide services? Please check all that apply.

☐ Region I

- Bethel Census Area
- Wade Hampton

☐ Region II

- Denali Borough
- Fairbanks North Star Borough
- Southeast Fairbanks
- Yukon-Koyukuk

☐ Region III

- North Slope Borough

☐ Region IV

- Anchorage Municipality

☐ Region V

- Kenai Peninsula
- Matanuska-Susitna
- Valdez-Cordova

☐ Region VI

- Aleutian Islands East
- Aleutian Islands West

☐ Region VII

- Bristol Bay Borough
- Dillingham
- Kodiak Island
- Lake and Peninsula

☐ Region VIII

- Nome Census Area
- Northwest Arctic

☐ Region IX

- Haines Borough
- Ketchikan Gateway Borough
- Juneau Borough
- Prince of Wales - Outer Ketchikan
- Sitka Borough
- Skagway - Hoonah - Angoon
- Wrangell - Petersburg
- Yakutat Borough

☐ Other

Describe where you serve: ☐

4. What types of individuals does your agency serve? Please check all that apply.

☐ Older adults
☐ Developmental disabilities
☐ Adults with Physical disabilities
☐ Persons with Alzheimer disease and related disorders
☐ Mental health
☐ Traumatic Brain Injury
☐ Children with Special Needs
☐ Other
If Other, please specify: ☐

5. Is your agency a tribal health care organization?

○ Yes

○ No

6. How many people do you provide services to?

○ One

○ 2 to 25

○ 26 to 100

○ More than 100

7. Do you have a waiting list for any of your services?

○ Yes

○ No

If so, for which services do you have the longest waiting list?

What is the longest time that someone has to wait for this service?

What are the primary reasons for the wait?

Do you have any ideas for improving long waits?

Do you believe that your communication and cooperation with other providers serving your clients is adequate?

○ Yes

○ No

○ Unsure

If no, what is the biggest barrier to communication across providers?

8. Do you think the standards for Medicaid certification are clear?

○ Yes

○ No

9. Do you think the process for obtaining Medicaid certification is efficient and reasonably easy to complete?

○ Yes

○ No

10. What was most challenging part of completing and obtaining Medicaid certification?

☐

11. How closely do you think the Medicaid certification <u>standards</u> relate to quality of services?

○ The standards provide important safeguards that ensure the quality of services

○ The standards are only somewhat related to providing quality services

○ The standards have little relation to providing quality services

12. Is the ongoing Medicaid certification <u>review</u> <u>process</u> helpful to maintaining quality?

○ Helpful

○ Somewhat helpful

○ Not helpful

○ I have not been through a review

○ I'm not sure what the review process is

13. Which of the following are important sources for client referrals?
Please check all that apply if more than one is a significant referral source.

☐ Individuals who need services for themselves
☐ Care coordinators
☐ Health Care Providers, including doctors, hospital discharge planners, etc.
☐ Adult Protective Services
☐ Aging Disability Resource Center
☐ Family members or friends of consumers
☐ Senior centers, internet, or other general referral sources
☐ Telephone helpline
☐ Schools
☐ Other

14. How would you rate the quality of the initial information and service plan that you are given for people who are newly referred or transferred to your agency?

○ The information is generally good and is a good starting point for being able to provide and arrange services

○ The information is generally adequate at identifying basic needs but frequently fails to identify important needs that effect how services should be delivered

○ The information is generally poor at identifying basic needs and fails to assess risks for health and welfare

15. If you are a licensed provider, how would you rate the licensing standards in terms of assuring competency to provide a licensed service?

○ The licensing standards are sufficient to make sure that all providers are competent

○ The licensing standards help eliminate some potentially poor quality providers, but do not ensure that all providers are competent

○ The licensing standards have little to no effect in ensuring that all providers are competent

16. How would you rate the State of Alaska's ability to take action on licensing issues? Please check all that you believe apply.

- ☐ The current authority to enforce standards is sufficient for the State to enforce licensing standards in cases of imminent danger
- ☐ The current authority to enforce standards is sufficient to require providers to take corrective action in areas that need improvement
- ☐ The current authority to enforce standards is not sufficient
- ☐ The current authority to enforce standards is sufficient but licensing does not follow through
- ☐ The licensing of providers is in serious need of improvement

17. If you were recommending changes to the licensing system, what would you recommend?

18. If you were recommending changes to the certification system, what would you recommend?

19. Please indicate which of the following you use to actively evaluate the quality of services provided by you/your agency. Check all that apply:

☐ Participation in accreditation organizations

Which Organizations?

☐ Performance based management tools
☐ Consumer advisory groups
☐ Consumer satisfaction tools
☐ Regular record reviews
☐ Consumer forums
☐ Complaint management system
☐ Other Please specify:

20. Please rate the degree to which each of the following presents challenges to maintaining and improving the quality in the services you provide.

    Rate from **1** (*least* challenging) to **5** (*most* challenging)

Staff recruitment and retention	○ 1	○ 2	○ 3	○ 4	○ 5
Staff training and skill level	○ 1	○ 2	○ 3	○ 4	○ 5
Reimbursement levels	○ 1	○ 2	○ 3	○ 4	○ 5
Increasing number of complex needs presented by consumers	○ 1	○ 2	○ 3	○ 4	○ 5
Service locations that are dispersed across large geographic areas	○ 1	○ 2	○ 3	○ 4	○ 5
Counterproductive policies and/or regulations	○ 1	○ 2	○ 3	○ 4	○ 5
Unclear policies and regulations	○ 1	○ 2	○ 3	○ 4	○ 5
Other	○ 1	○ 2	○ 3	○ 4	○ 5

If Other, please describe: ☐

21. How helpful are the provider policy and procedure manuals maintained by the State?

    ○ I am not aware of any provider policy and procedure manuals

    ○ Very helpful

    ○ Somewhat helpful

    ○ Not helpful

22. Are alerts and communication from the State about changes in policy and procedures timely?

○ Yes

○ No

23. Are alerts and communication from the State about changes in policy and procedures easy to understand?

○ Yes

○ No

24. Do you believe that the State offers sufficient training for providers?

○ Yes

○ No

If no, in what subject areas should the State offer additional training?

25. How would you rate the provider training the State does offer?

○ Very helpful

○ Somewhat helpful

○ Not helpful

○ I have not attended training

○ Other

Please specify:

26. Which of the following statements best describes your view of the billing and payment process

○ The process generally is accurate and timely

○ The process frequently requires me to resubmit claims due to errors in submission

○ The process is difficult to complete and requires too much administrative time to complete accurately

27. How would you rate technical assistance provided by the State when you call them with questions?

○ The assistance is accurate and helpful

○ Assistance is incomplete and only somewhat helpful

○ Assistance is frequently not accurate and not helpful

○ I have not called the State for technical assistance

28. In order of importance, what are the top five actions that the State should take to improve the long term care system?

1. ☐

2. ☐

3. ☐

4. ☐

5. ☐

Other Stakeholder Survey
For Long Term Care Services

Current Date

HCBS Strategies has been hired by the Alaska Department of Health and Social Services (DHSS) to develop recommendations for improving how Alaska provides services for individuals with disabilities and older adults. We have created this survey as part of this effort. The survey is designed to capture your perception of how well the system operates and your recommendations for improvements.

If you are a provider or a consumer please contact Kristy Michael for the appropriate survey. If you are a direct care worker or other stakeholder you should be filling out this form.

You may respond to this survey by filling it out electronically and submitting it by clicking the **"Submit by Email"** button at the top of this page or at the end of the survey. You may also print out a copy and fill it out by hand and either fax it to: 410-510-1144 or mail it to:

Kristy Michael
402 Wood St.
Harrisburg, PA 17109

To print this survey please click the **"Print Form"** button at the top of the page.

Please feel free to share this survey with others that you believe would be interested in providing their input.

Please submit your survey no later than Friday August 1, 2008.

If you have any questions please contact Kristy Michael at kristy@hcbs.info

Thank you in advance for your participation!

1. In order of importance, what are the top five actions that the State should take to improve the long term care system?

1.	
2.	
3.	
4.	
5.	

2. Please describe what role you play in the delivery of long term care services:

Thank you for your participation!

APPENDIX 6: SURVEY RESULTS

Methodology

We developed three surveys to collect information from key stakeholders, including consumers and their representatives, provider agencies, and other stakeholders, such as direct care workers. We designed the surveys to capture a limited amount of information about the respondent, a few indicators of how the long term care delivery system and State oversight functioned, and recommendations for improving the system. Our Advisory Committee and State staff reviewed the survey instruments.

The final tools incorporated basic demographic and background questions. The provider survey included information about regions served and services provided. The consumer survey included items such as location resided in, gender and if the consumer is of Alaska Native heritage. In addition, we asked respondents questions that addressed their experience receiving services. All three surveys asked individuals to advise what is working well and what recommendations they would make for change in the system. In addition, the surveys were constructed with controlled responses such as scales, pre-selected answers with radio buttons where respondents have to select only one option or checkboxes where multiple answers maybe selected, and open text fields where the question is open ended and the response can be more subjective.

The survey was distributed via a PDF-based format to all licensed providers throughout the State by means of the State's e-mail distribution list. We also utilized consumer advocacy groups and providers to assist in dispersing consumer surveys through their contact lists by e-mail, print and fax methods. In addition, many consumers passed on the survey to their own personal contacts.

Circulation of the surveys began on July 3, 2008 and responses were due by August 1, 2008.

Results

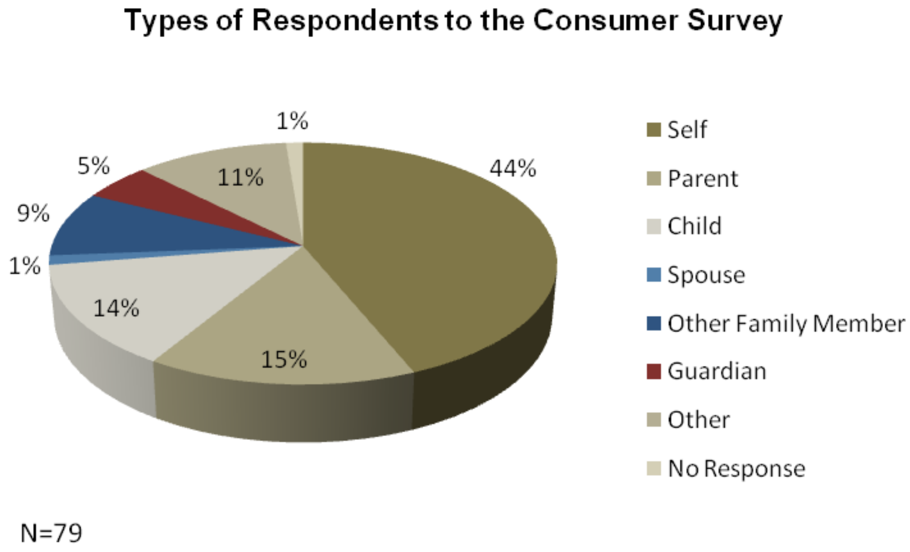
179 respondents completed the three surveys; 77 providers or 43%, 79 consumers or 44%, and 23 other stakeholders or 13% of respondents.

The results provided basic demographic information and specific opinions and ideas of the stakeholders.

Consumer Survey

Of those that responded to the consumer survey, 44% were the consumer themselves, receiving or in need of receiving services. The remaining 56% were family members or another person responding for the individual in need of long term care.

Of the 56% that indicated they were family members or others, the majority were either parents of the consumer or a child. Very few were the spouse of the consumer.

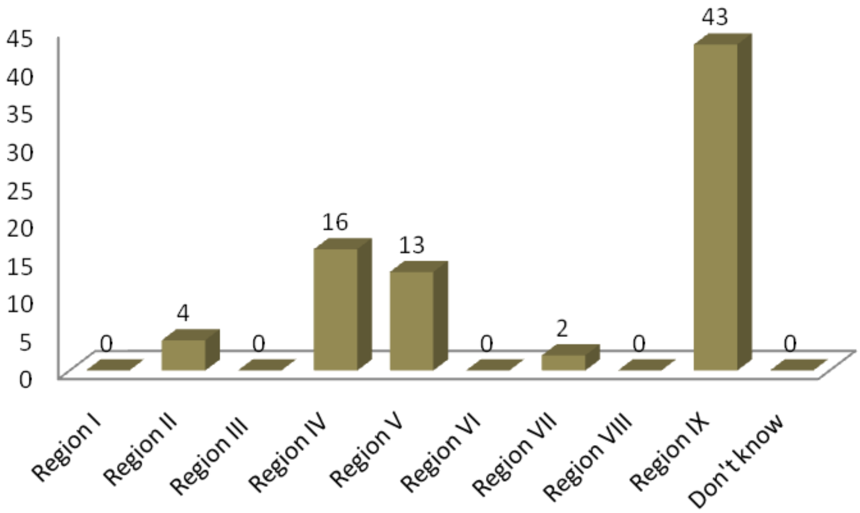


Of the 44 individuals that were the family member or “other”, nine individuals selected “other.” However, three of those nine should have selected “Other Family Member” or “Child” instead. Of the remaining six individuals, three advised that they were a care coordinator or case manager for the individual. One person was a Vocational Rehabilitation counselor, one was a caregiver in the community, and the remaining one was a friend of the elder.

We used DSDS regions for determining where the respondents lived:

- Region I: Bethel Census Area, and Wade Hampton

- Region II: Denali Borough, Fairbanks North Star Borough, South East Fairbanks, and Yukon-Koyukuk
- Region III: North Slope Borough
- Region IV: Anchorage Municipality
- Region V: Kenai Peninsula, Matanuska-Sustinia, and Valdez-Cordova
- Region VI: Aleutian Islands East and Aleutian Islands West
- Region VII: Bristol Bay Borough, Dillingham, Kodiak Island, and Lake and Peninsula
- Region VII: Nome Census Area and Northwest Arctic
- Region IX: Haines Borough, Ketchikan Gateway Borough, Juneau Borough, Prince of Whales –Outer Ketchikan, Sitka Borough, Skagway- Hoonah-Angoon, Wrangell-Petersburg, and Yakutat Borough



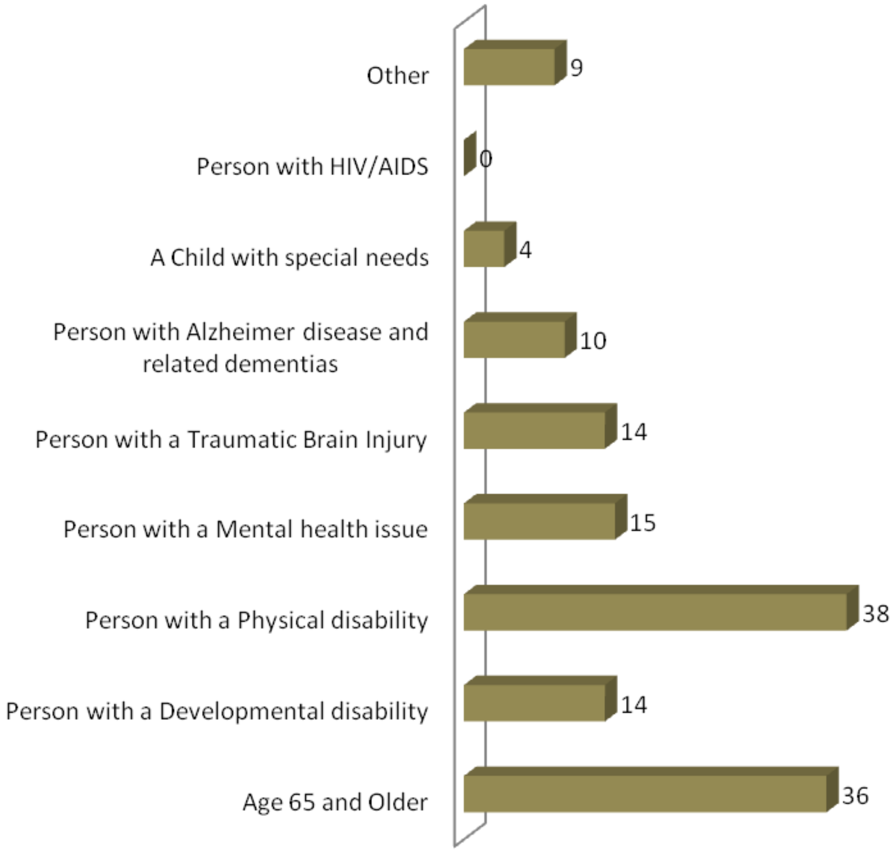
Of those that reported they are from Region IX, 16 noted they are from Wrangell. These 16 respondents were seniors from the Wrangell Senior Center. The Senior Center made sure that the surveys were accessible, promoted, and went to the extent of collecting many and mailing them in for the individuals. Additionally, 98% of those that responded from the Center were very happy with the services they received, as well as the attentiveness of the personnel.

Respondents were asked to choose all those that applied to them. Options included the following:

- Age 65 or older
- Person with a Developmental Disability
- Person with a Physical Disability
- Person with a Mental Health issue
- Person with a Traumatic Brain Injury
- Person with Alzheimer Disease and Related Disorders
- Child with special needs
- Person with HIV/AIDS
- Other

Respondents most often met more than one category. The majority of those that were age 65 and older also had a physical disability. Additionally, a number of those with a Traumatic Brain Injury also had a mental health issue.

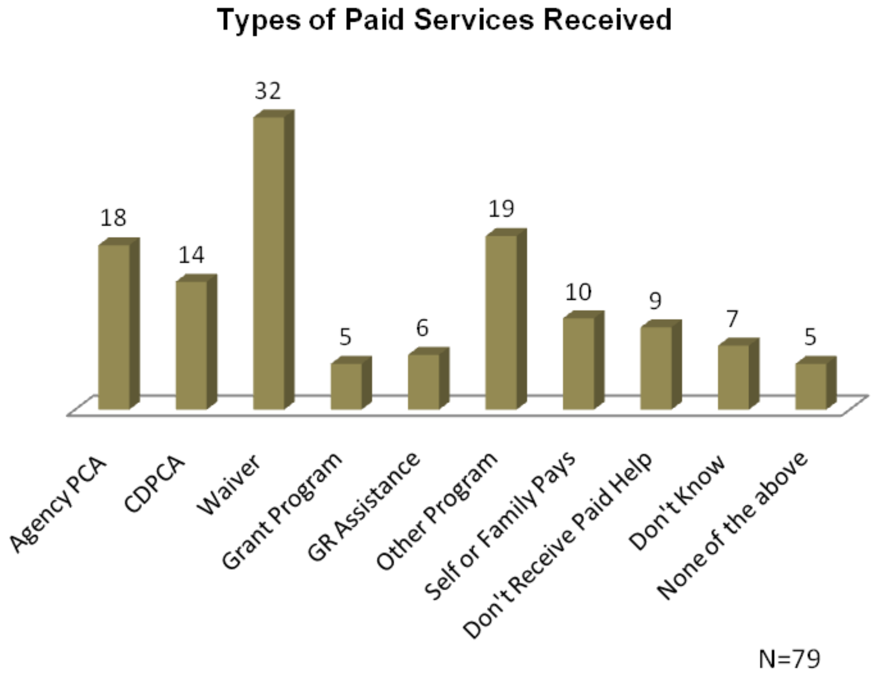
Overall, the two most common areas selected were physical disability or being over the age of 65. Of those that selected “other” it appears four did not understand the question and entered random responses such as “profession” and “I am 64”. An additional person filled in the “other” text even though they did not select “other.” This person had a child with special needs and entered “medically fragile” in the text area.

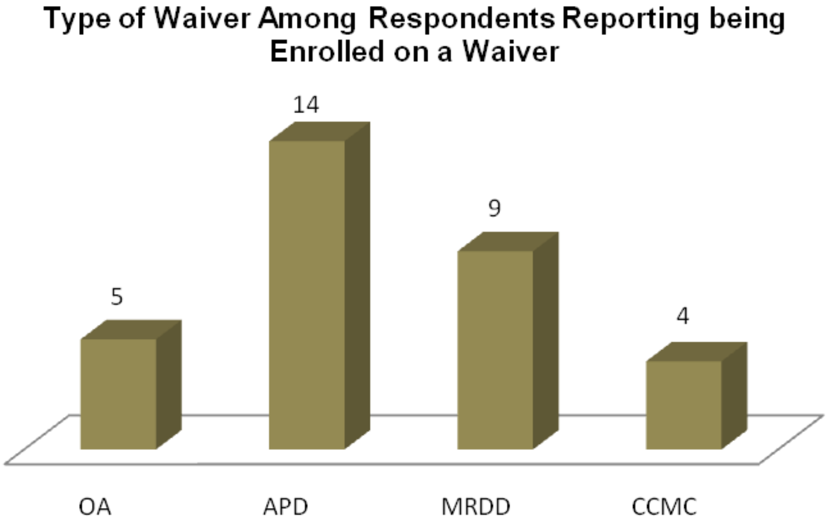


Twenty-two percent of the respondents were Alaska Natives. This was higher than the 13.1% for the State as a whole as reported by the US Census Bureau.

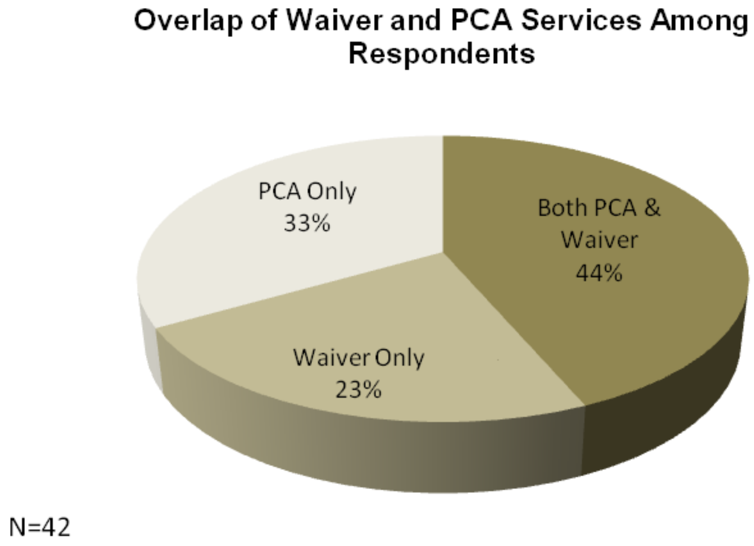
Males were under-represented in the sample. 29% of those that participated in the survey were male, with the remaining 79% being female.

Of the 79 individuals that participated in the survey 41% were enrolled in a waiver, 23% received Agency Directed Personal Care Services, 18% received Consumer Directed Personal Care Services (CDPCA), and 24% indicated they also received other services. Of those that reported they were receiving waiver services, the Adults with Physical Disabilities (APD) waiver was the most common. Many people were receiving services from more than one funding source.





Most individuals that were receiving PCA (either consumer or agency directed) were on a waiver as well.



Overlap of Waiver and PCA Services Among Respondents

Nineteen individuals indicated they received services from an “Other Program” and specified the following:

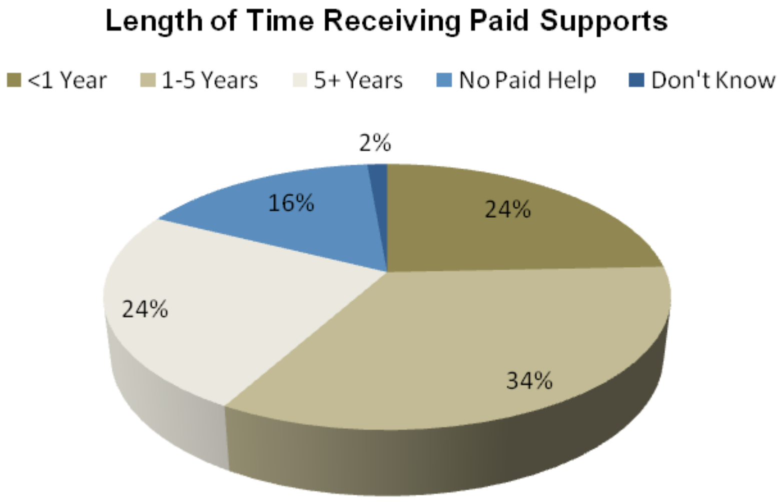
- Vocational Rehabilitation
- Medicaid LTC/ICF[19]
- Veteran’s Administration (VA)
- Housekeeper
- Chore Service
- DVR
- STAR or CORE
- Pioneer Homes
- Currently seeking assistance from VA/Medicaid

---

[19] We presume this referred to an Intermediate Care Facility, which is a type of nursing facility.

- Adult day Care

For those that received services from people that were paid to help them, most have received help for one to five years. Over half of the individuals have had help for more than one year. For those that do not have anyone who is paid to help them, nearly all seemed to be waiting to be approved for services or had been declined for services.

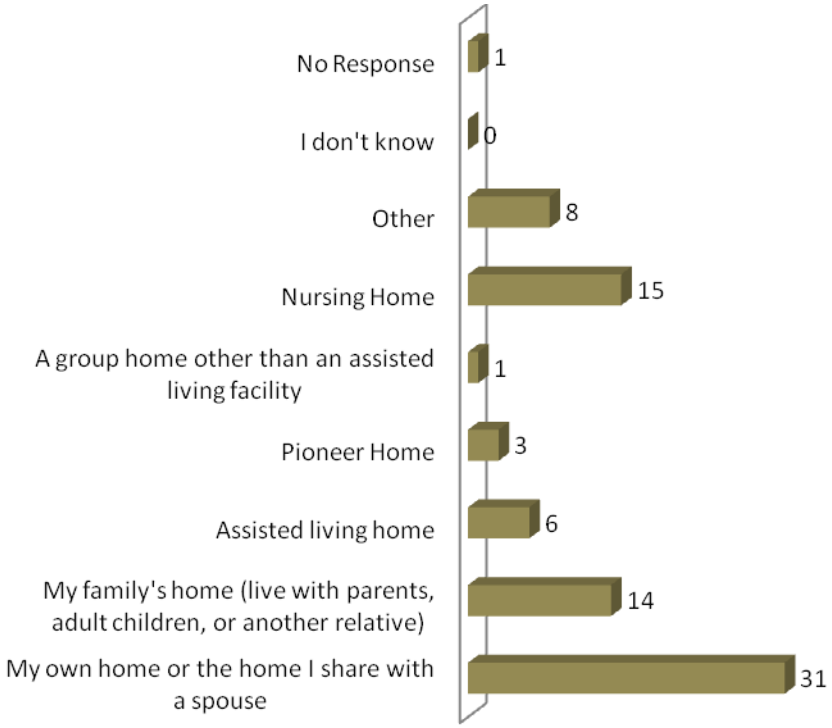


N=74

Only five percent of respondents reported receiving services from a Tribal Healthcare Organization. This compared with the 22% of the respondents who reported that they were Alaska Natives.

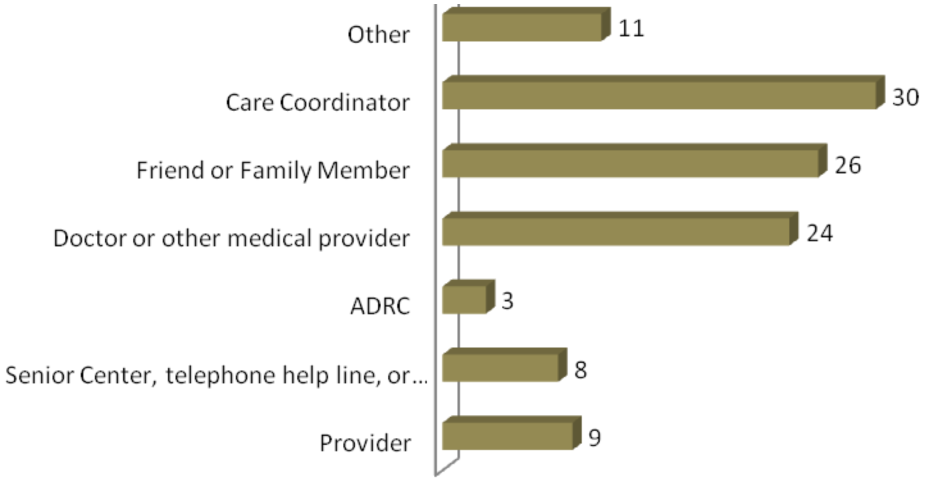
A plurality of respondents lived in their own home. The next most common living arrangements were a nursing home or living in a family member's home.

Respondents Living Arrangement



Although Care Coordinators were the most frequently cited source of information about paid help, doctors, friends and family members were cited nearly as often. An ADRC was only mentioned by three respondents.

Sources of Information for Finding Paid Help

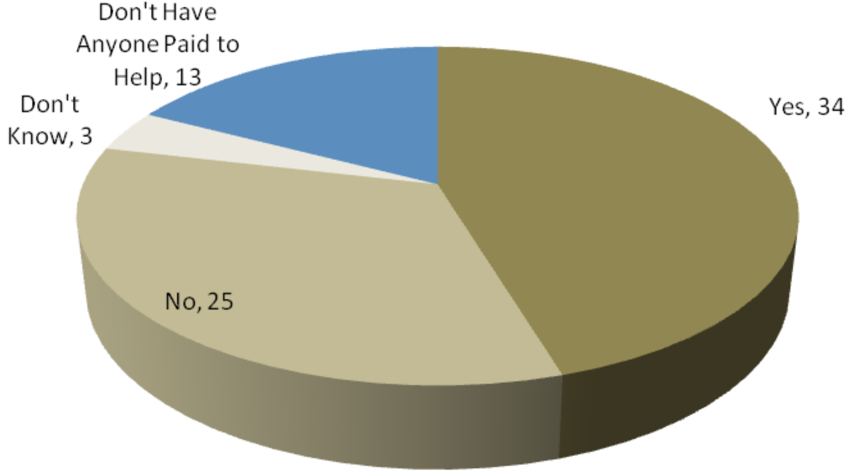


Other sources of information identified included the phone book, a mental health center, their own advertisements posted in local papers and bulletin boards, social workers, and their attorney. Four individuals indicated they were referred by the Juneau Bartlett Hospital.

More than two-thirds of individuals felt they were given an option about where they live, whereas 28% felt they were not given such an option.

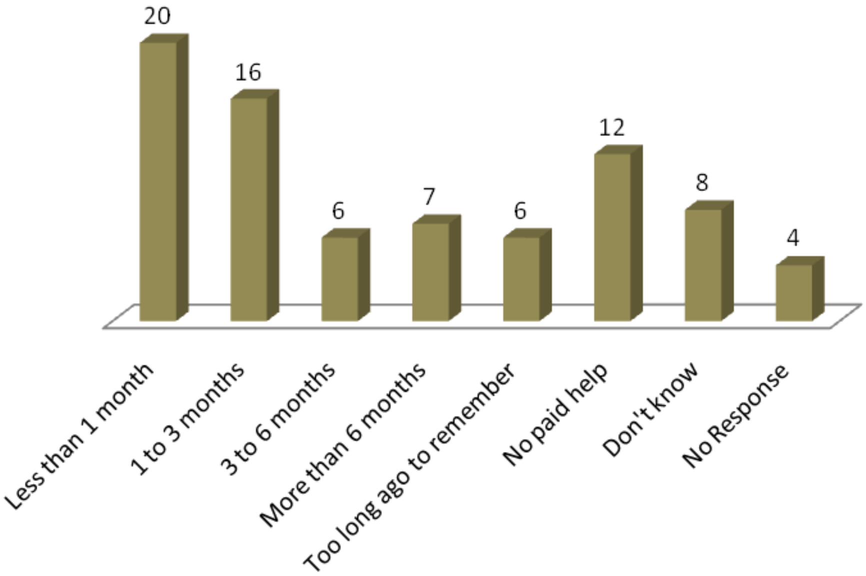
Of the people who responded either 'yes' or 'no' to the question about whether they had been given a choice about who would help them, 42% felt they had no choice.

Respondents Who Reported They Had a Choice about Who Helped Them



For the respondents who requested help and could recall how long it took to begin receiving services (N=49), 41% waited less than one month before they started receiving help, 33% waited one to three months, 12% waited three to six months; and 14% reported waiting more than six months. Several people also reported that they were still waiting or had been denied services.

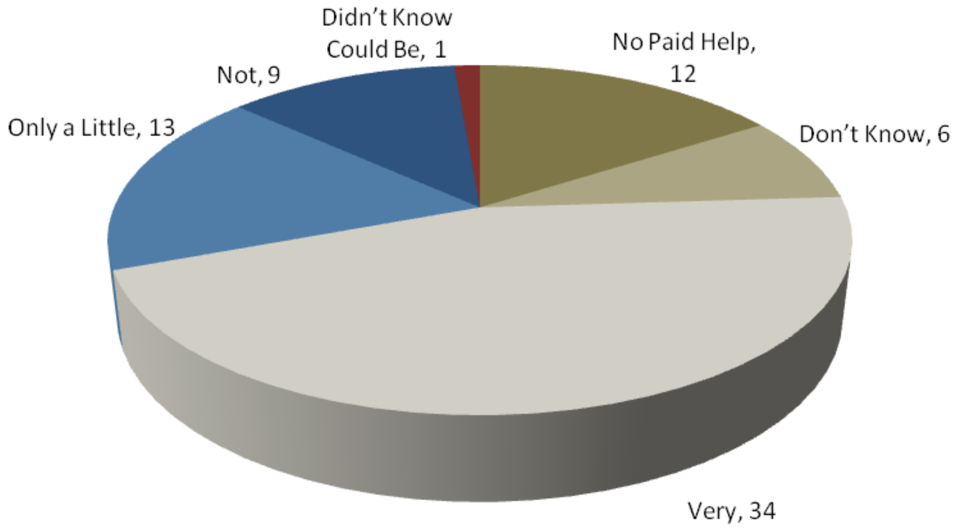
Length of Time Waiting for Service



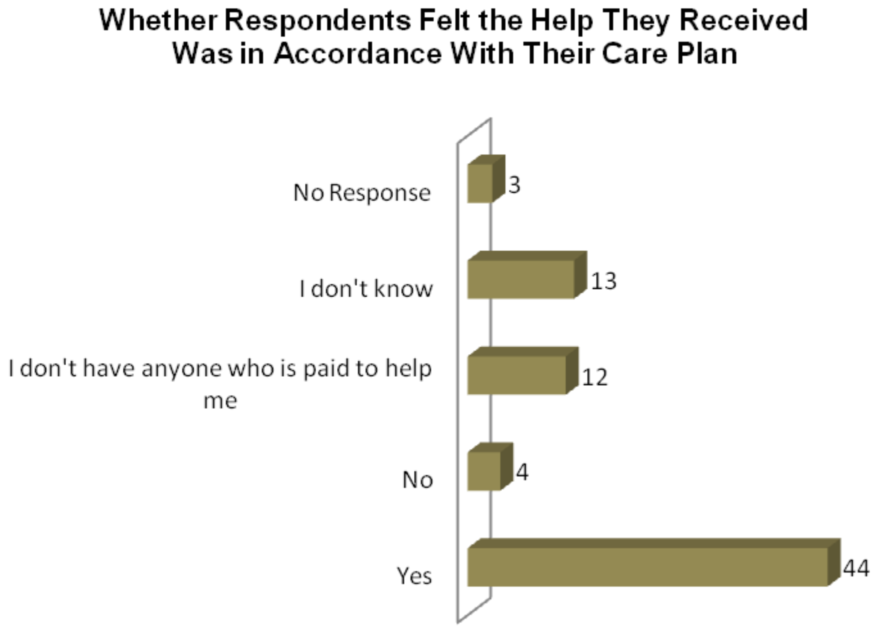
For those that had to wait more than one month, the majority identified they were on a wait list as the reason for the delay. However, one person noted that they were considered an individual that rejected services because they would not accept assistance from the spouse they were separated from because of abuse. Another individual was told that because the person is a GR recipient, the assisted living facilities in the area would not take him due to poor reimbursement levels. Two individuals waiting noted that background checks were to blame for the delay.

Of the 57 people who were receiving paid help and had an opinion about how involved they were in developing their care plan, 60% felt they were very involved. Eighteen percent said they did not know they could be involved or were not involved at all in their care plan.

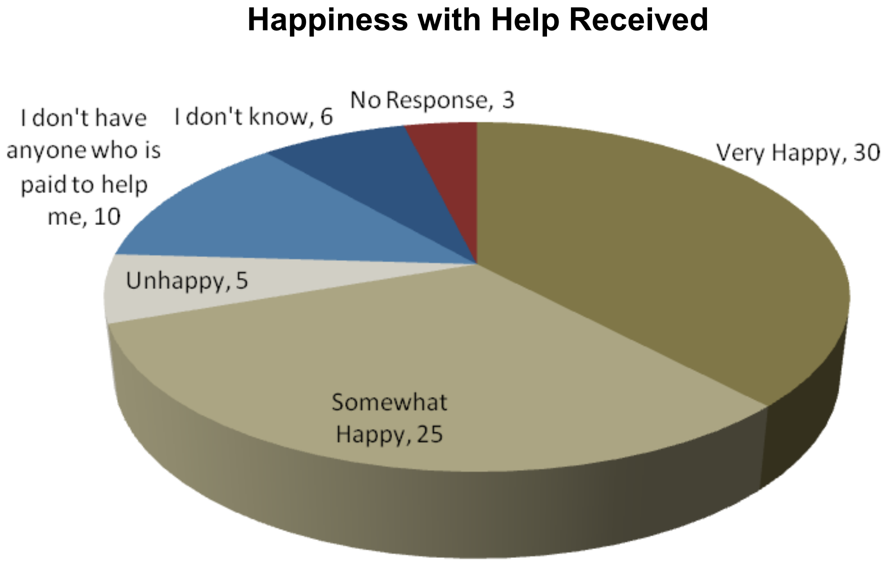
Level of Involvement in the Development of the Care Plan



Four (8%) of the 48 respondents who addressed the question about whether they received help as indicated in their care plan, said that they did not.



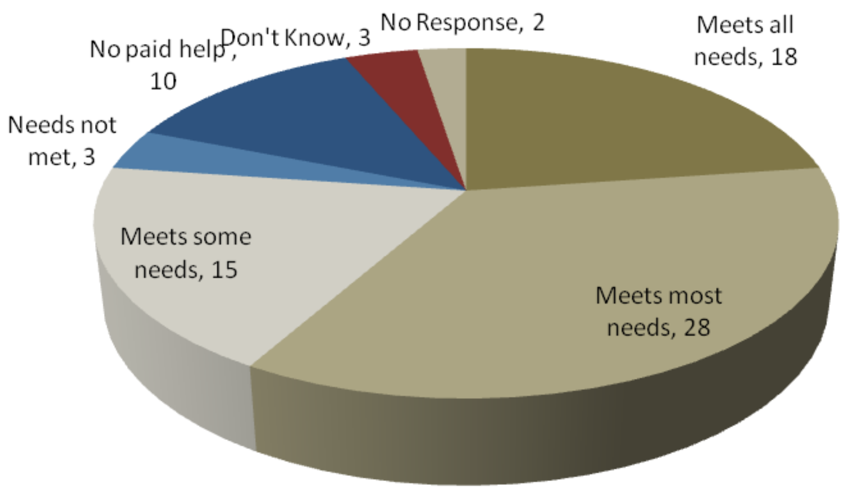
Of the 69 people receiving paid help, 44% said they were very happy with that help, while 36% said they were somewhat happy, and 7% were unhappy.



A few individuals noted that while they were happy with the help they received, they have minor personnel issues such as PCAs not cleaning up after themselves or not arriving for work on time.

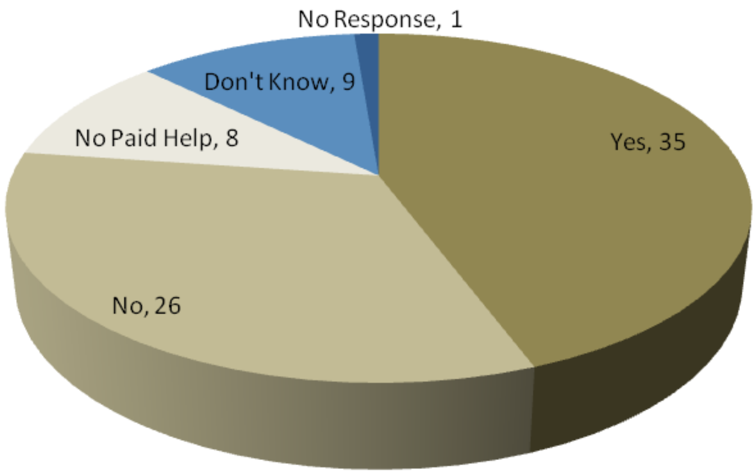
Of the 67 reporting that they received paid help, 46 (69%) felt that the help met all or most of their needs, 15 (22%) felt that it met some of their needs; and 3 (5%) felt that most of their needs were not met.

Whether Respondent Felt Paid Help Met Their Needs



Fifty-seven percent of the respondents who answered yes or no indicated that there were services they needed but could not get.

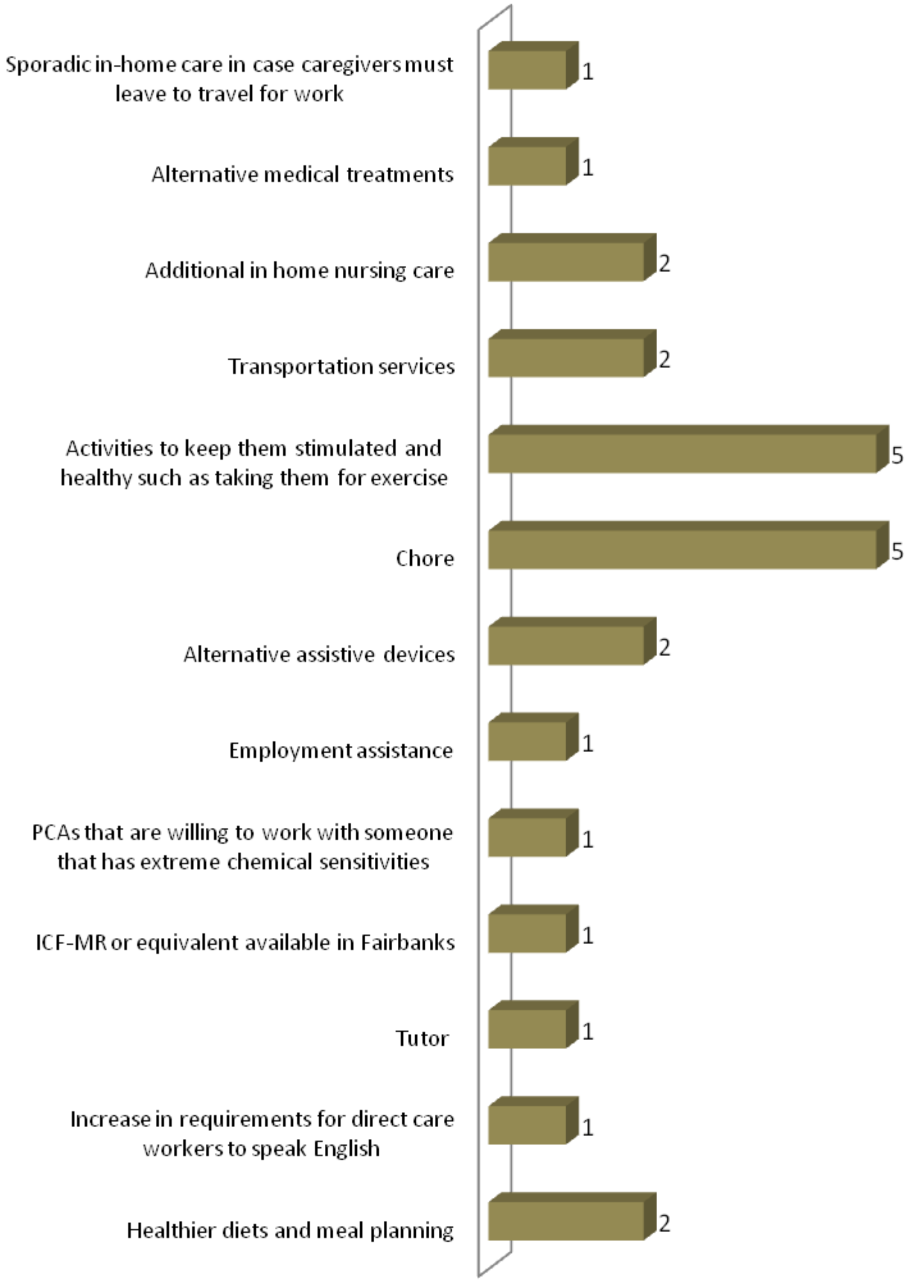
Respondents with Needs for Which They Cannot Get Services



Areas for which respondents indicated that they have unmet needs included:

- Several people wanted assistance being more mentally and physically active;
- Three respondents said that they felt trapped in their homes, beds, or chairs waiting for assistance to get around. One person said that this was depressing and frustrating;
- Several people noted that an increase in chore services would be very helpful and a big stress relief;
- Three respondents identified transportation services as an unmet need; and,
- One person desired access to alternative medicine and treatments, a wider variety of assistive devices covered, and assistance with meal planning and healthier diets/food.

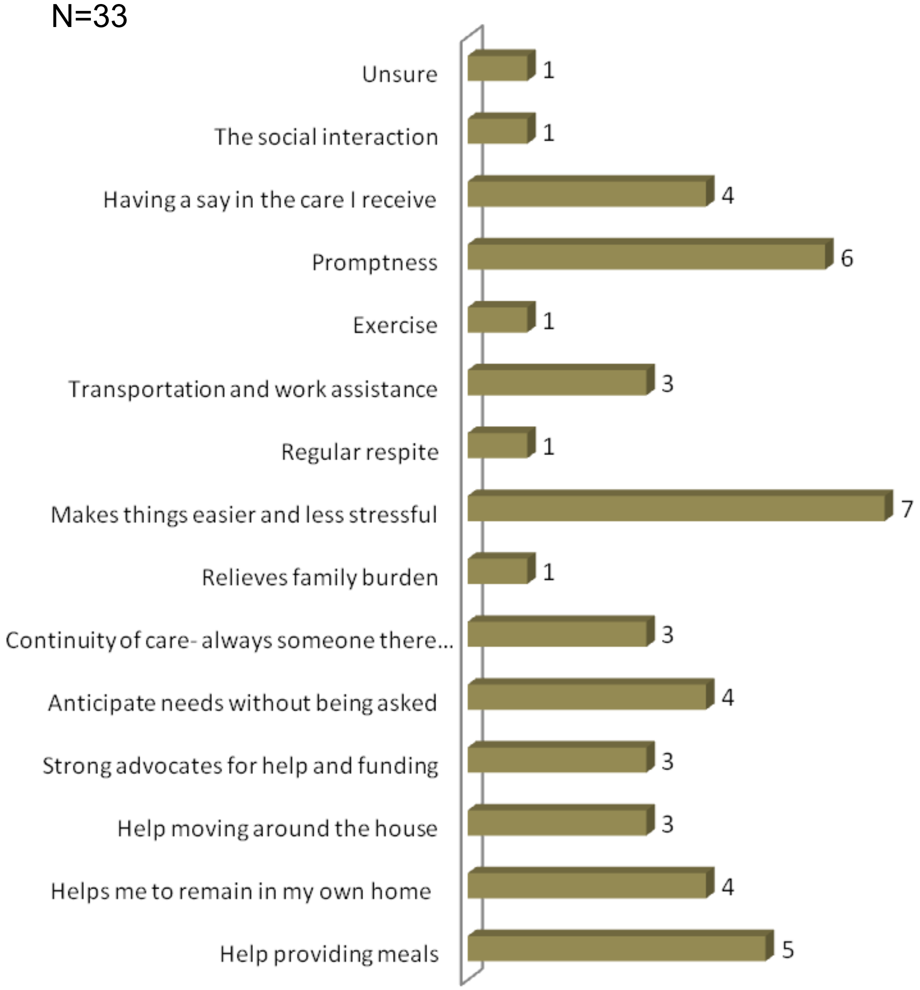
Unmet Service Needs Identified by Respondents



When asked what they liked the most about the services they received, 54 people responded. Of these people, 30% cited having kind and caring paid help as being most important to them.

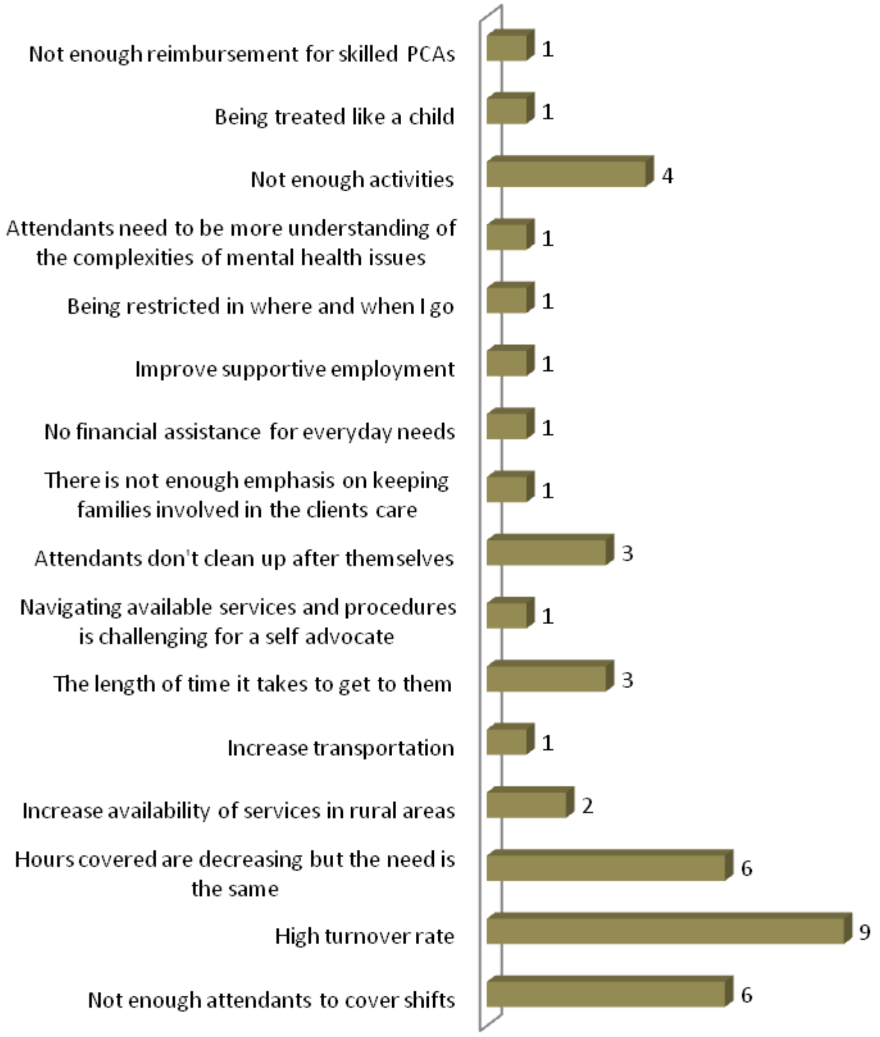
What Respondents Indicated They Liked Most about the Services They Received

N=33



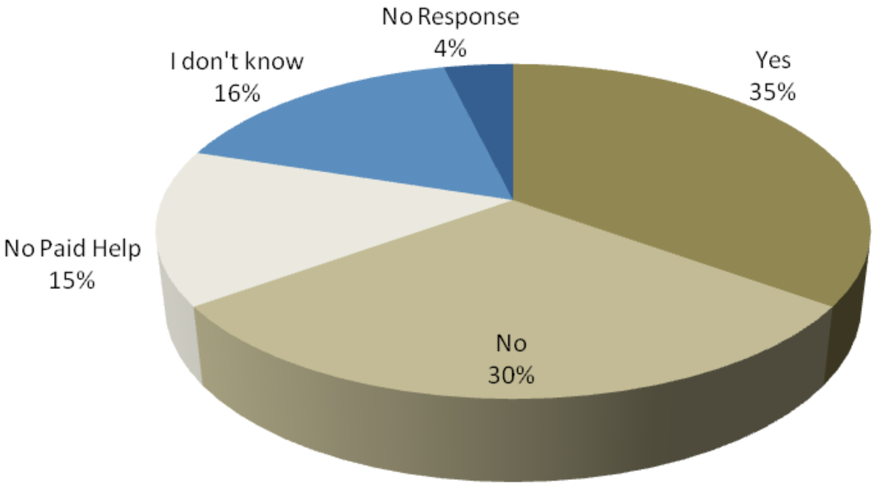
When asked what they liked least about the help they received, respondents mentioned staff turnover and a lack of personal care attendents to cover shifts.

What Respondents Indicated They Liked Least about the Services They Received



Of the people who answered yes or no, 54% said they would like more control over the services they receive. Some of those that did indicate they would like more control noted that they were unsure of what that would mean and to what level they would participate. One person noted that they were not willing to give up their Care Coordinator to have more control over services.

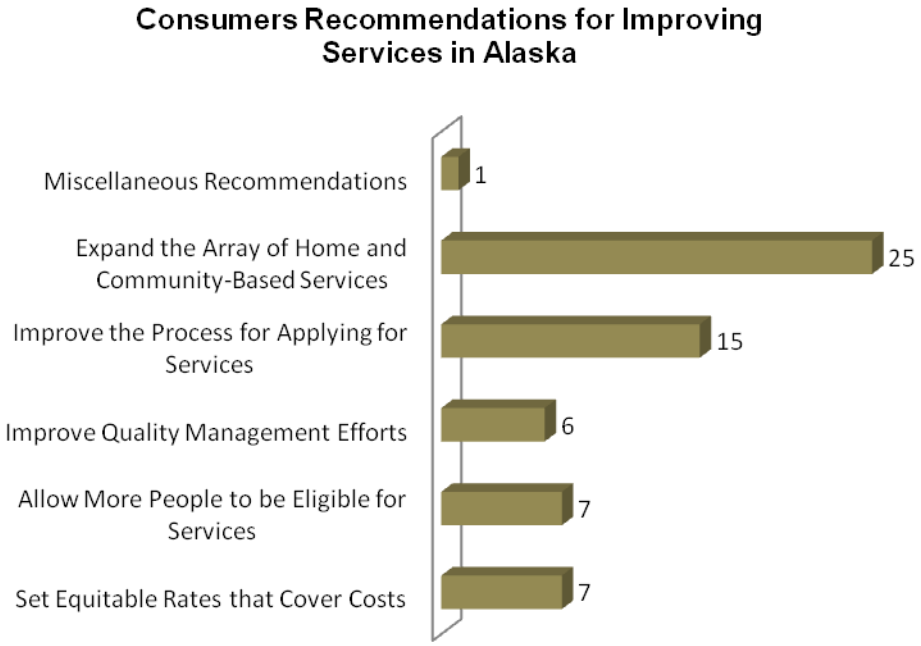
Respondents Who Want More Control over Their Services



Respondents had a wide variety of suggestions for improving services in Alaska, which are summarized in the table below and included in greater detail in the report.

When asked what they would change about the help available in Alaska, many advised that improving the efficiency of the application process is critical. Also noted by individuals is an increase in the flexibility of the services covered and how their hours are used. Improved training opportunities for caregivers and providers and an increase in salaries for PCAs and appropriate reimbursement for providers were seen as being crucial for the improvement of the State's system.

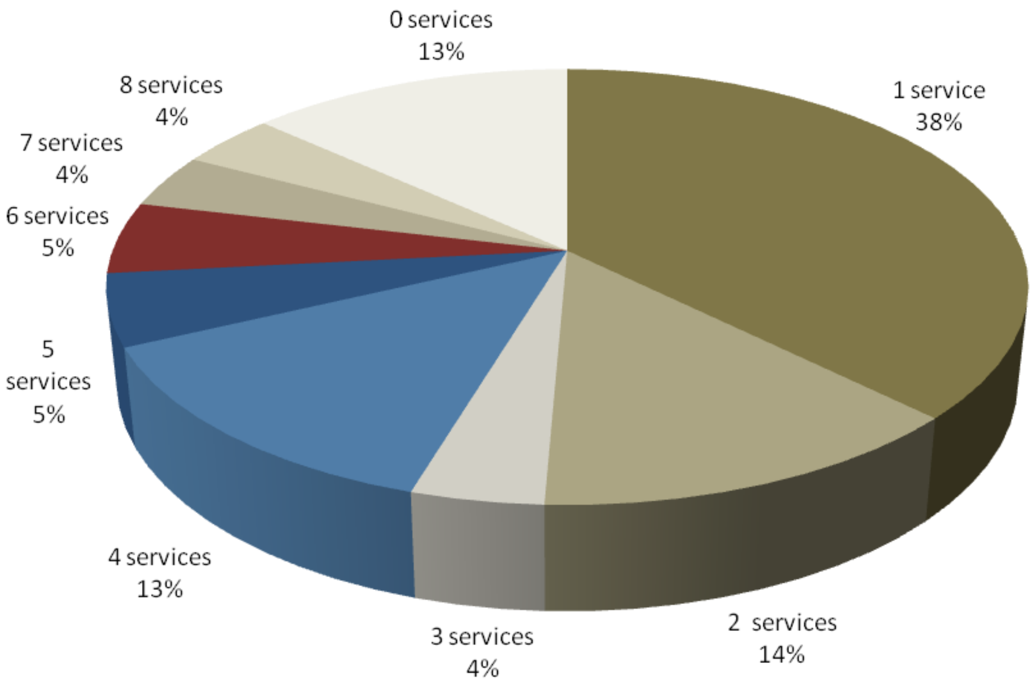
One miscellaneous recommendation was to provide legal consultation to those who receive LTC.


Consumers Recommendations for Improving Services in Alaska
Miscellaneous Recommendations
1
Expand the Array of Home and Community-Based Services
25
Improve the Process for Applying for Services
15
Improve Quality Management Efforts
6
Allow More People to be Eligible for Services
7
Set Equitable Rates that Cover Costs
7

Provider Agency Survey

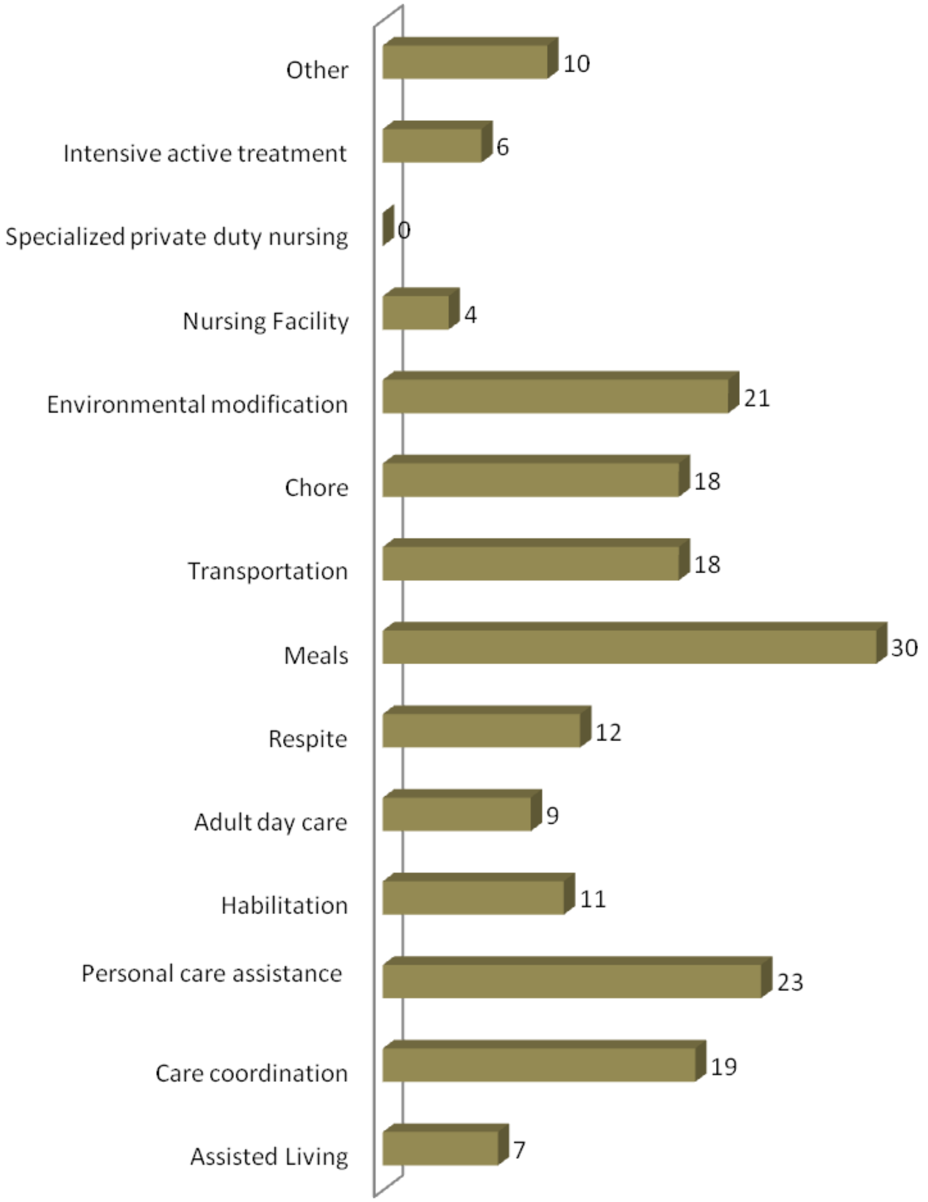
There were 77 respondents to the Provider Survey. Of those 77 providers, the majority (38%) were Medicaid certified to provide one service only. Thirteen percent were not Medicaid certified providers. Another thirteen percent were either not Medicaid certified or did not offer services and may have been filling out the survey from an advocacy or other stakeholder role.

Number of Medicaid Services Offered by Responding Agencies



The most common services provided were meals, personal care assistance, care coordination, environmental modifications, chore, and transportation services.

Types of Services Offfered by Respondents



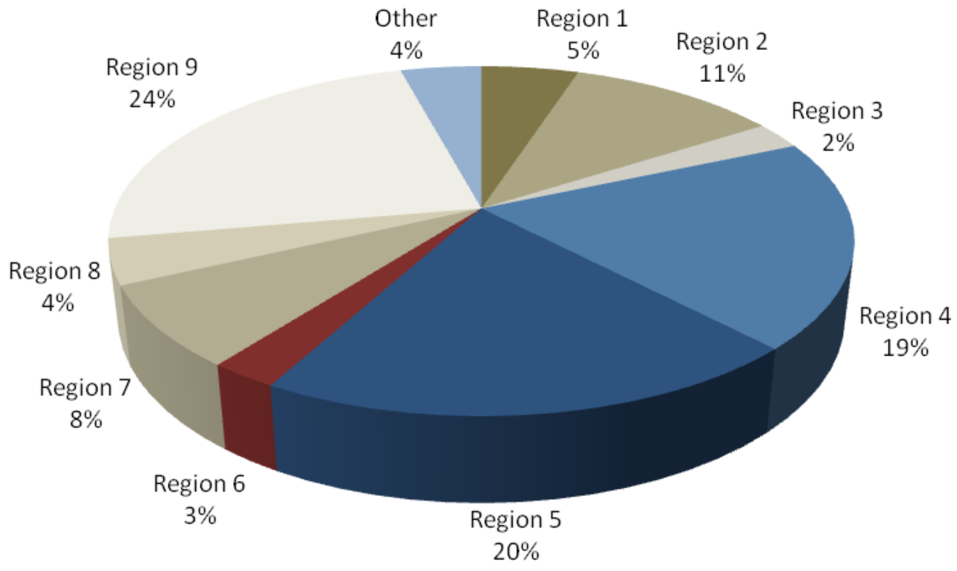
“Other” services reported included:

- Supported employment;
- Mental health services and counseling;

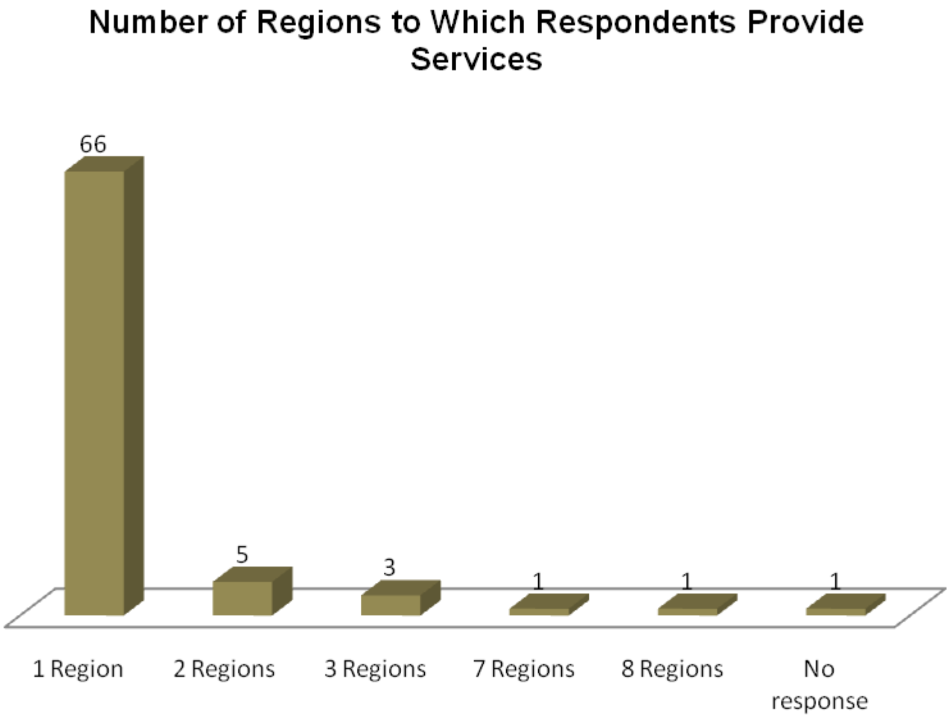
- Escort;
- Rehabilitation;
- Head injury support group; and,
- Outpatient and hospital services.

Most providers responding were providing services in regions 4 (Anchorage), 5 (Kenai Peninsula, Matanuska-Sustinia, and Valdez-Cordova), and 9 (Haines Borough, Ketchikan Gateway Borough, Juneau Borough, Prince of Whales, Outer Ketchikan, Sitka Borough, Skagway, Hoonah-Angoon, Wrangell-Petersburg, and Yakutat Borough).

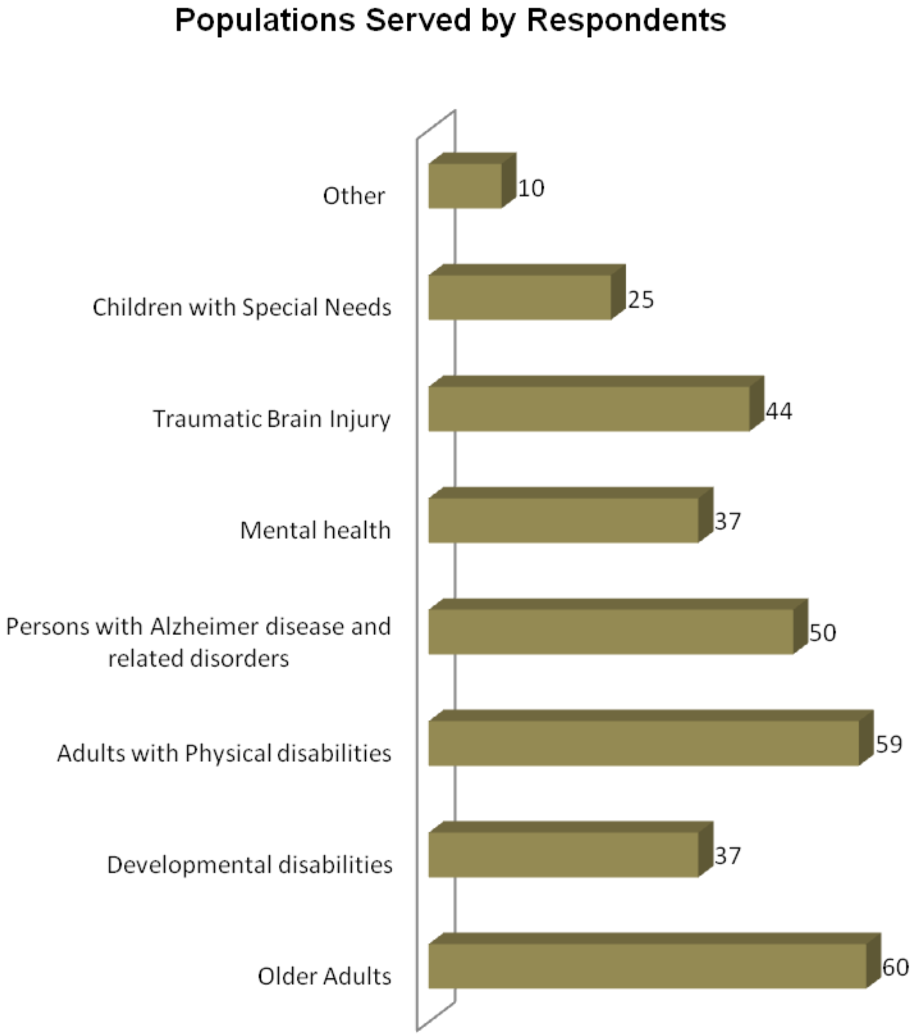
Regions Served by Providers



The vast majority of providers responding to the survey operate only in one region.

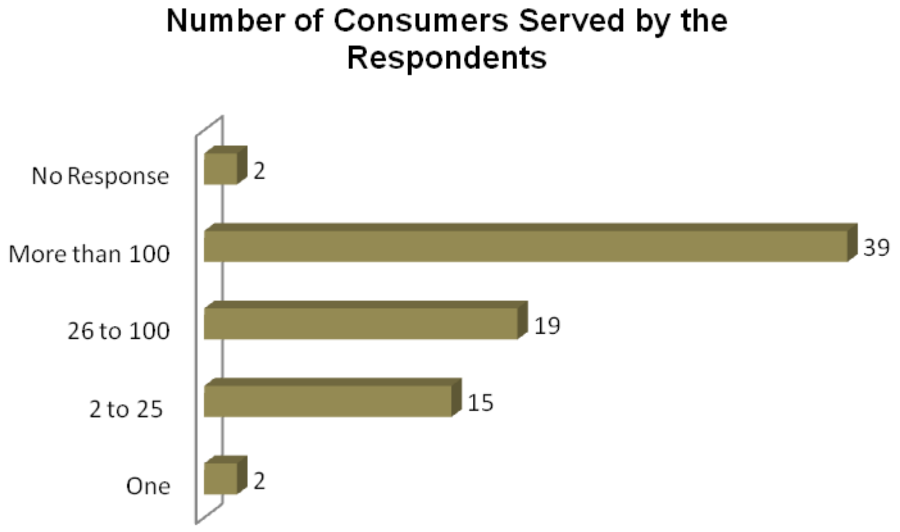


Respondents served a range of populations with disabilities and older adults. Those who indicated “other” listed the following populations: neurodevelopment, TBI, complex medical care, “deaf individuals,” and, “individuals whose disabilities impose barriers to employment.”

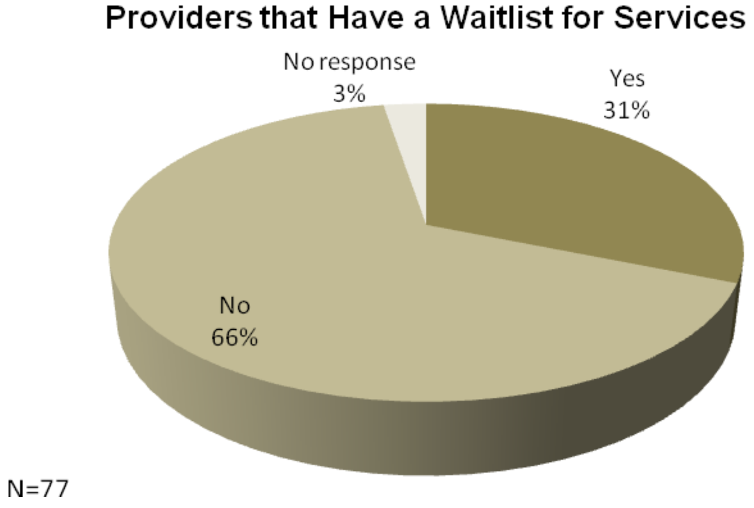


Six of the 77 respondents identified themselves as Tribal Healthcare Organizations.

Most respondents provide services to more than 100 people. Only 17 of the 77 respondents serve 25 or fewer people.

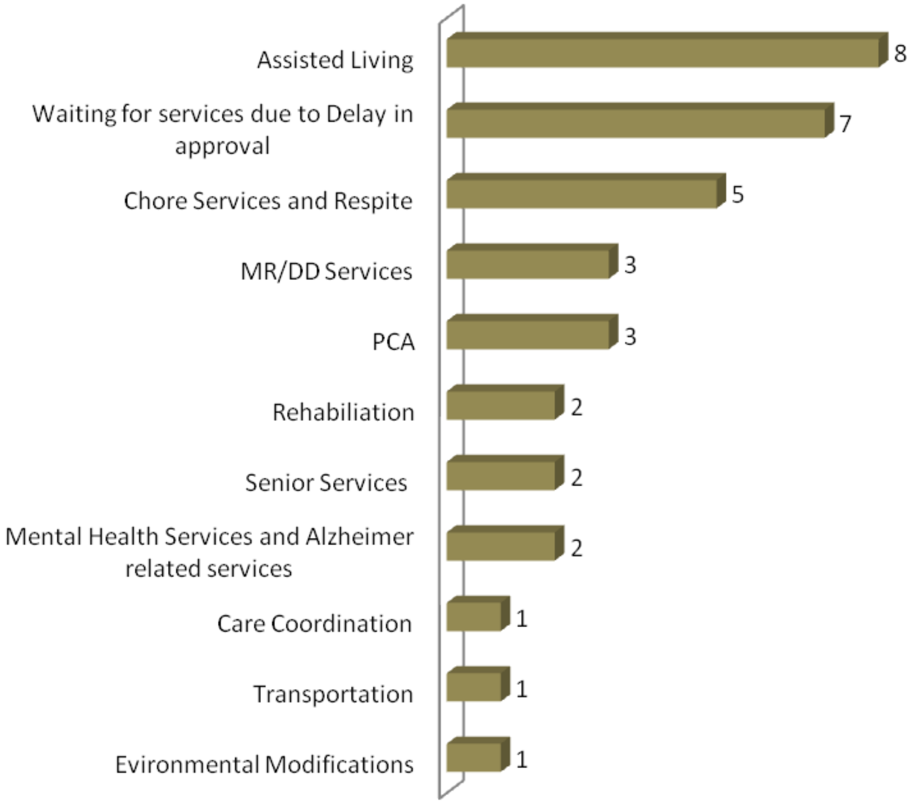


Nearly a third of the responding providers indicated that they have a waiting list for services.

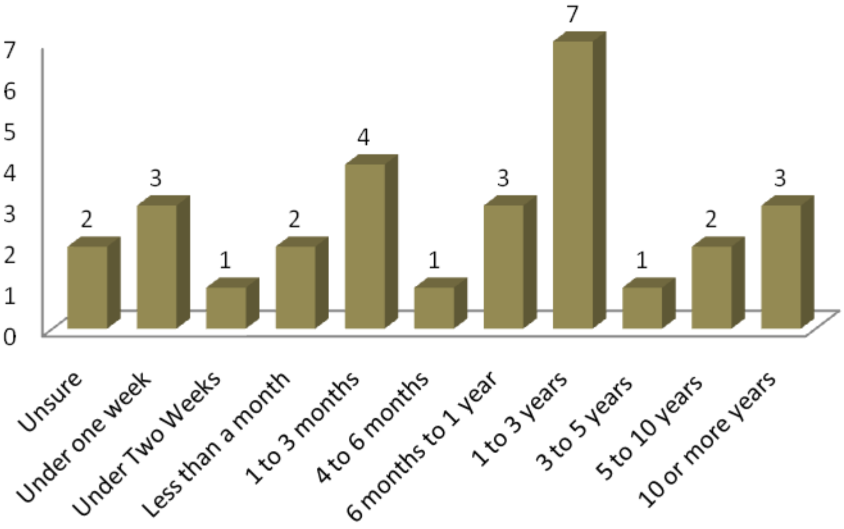


Waiting lists were most common for assisted living services, chore, and respite. Several respondents also identified that they were awaiting approval to provide services to individuals.

Services for Which Respondents Indicated they Have a Waitlist.



Reported length of waitlist varied. The shortest amount of time noted was 72 hours, which was for transportation services. Thirteen respondents reported waiting times as being a year or longer, with three ALF providers serving individuals with DD citing waiting times of ten or more years.



Reasons given for waitlist included a lack of space and shortage of trained staff. Of the 13 respondents who had waiting times of a year or longer, four cited obtaining authorization from the State as the cause of the delay. Two of the three providers that had consumers on their lists for 10 years or more attributed this to consumers who were aging out of a program that served children (e.g., the CCMC waiver). In these cases, a transition plan was developed that allowed consumers to use another funding stream. Because these consumers remained stable, they were not pulled from the waitlist for the DD waiver.

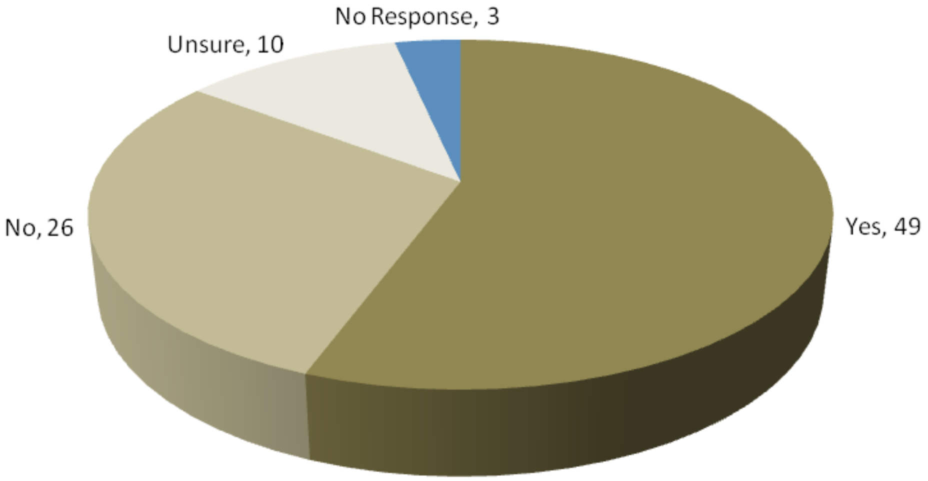
The respondents' recommendations for alleviating waitlists included the following:

- "There should be a reasonable correlation between standards of service and funding available to provide the service."
- "Utilize LCSW, OT, PT or other licensed professionals and train them to conduct assessments rather than just nurses."
- "Restructure the waiver services. Decrease MRDD and CCMC waiver amounts and increase services available for OA and APD waivers. Make the service system equitable."
- "Continue the work of the DD Registry Committee and approve their ideas/recommendations."

Respondents Recommendations for Alleviating Waitlists

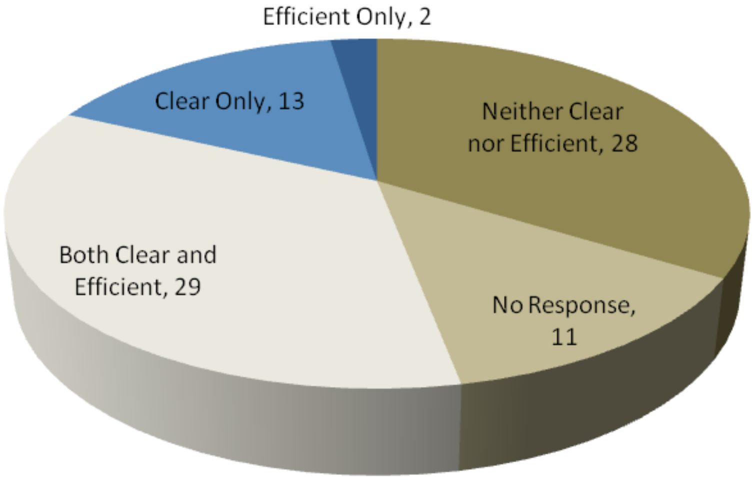
A slight majority of providers (56%) reported that their communication and cooperation with other providers serving their clients is adequate.

Respondents Reporting that Communication and Cooperation with Other Providers is Adequate



When asked if they felt that the process for obtaining Medicaid certification was efficient and reasonably easy to complete, almost half advised that they do not.

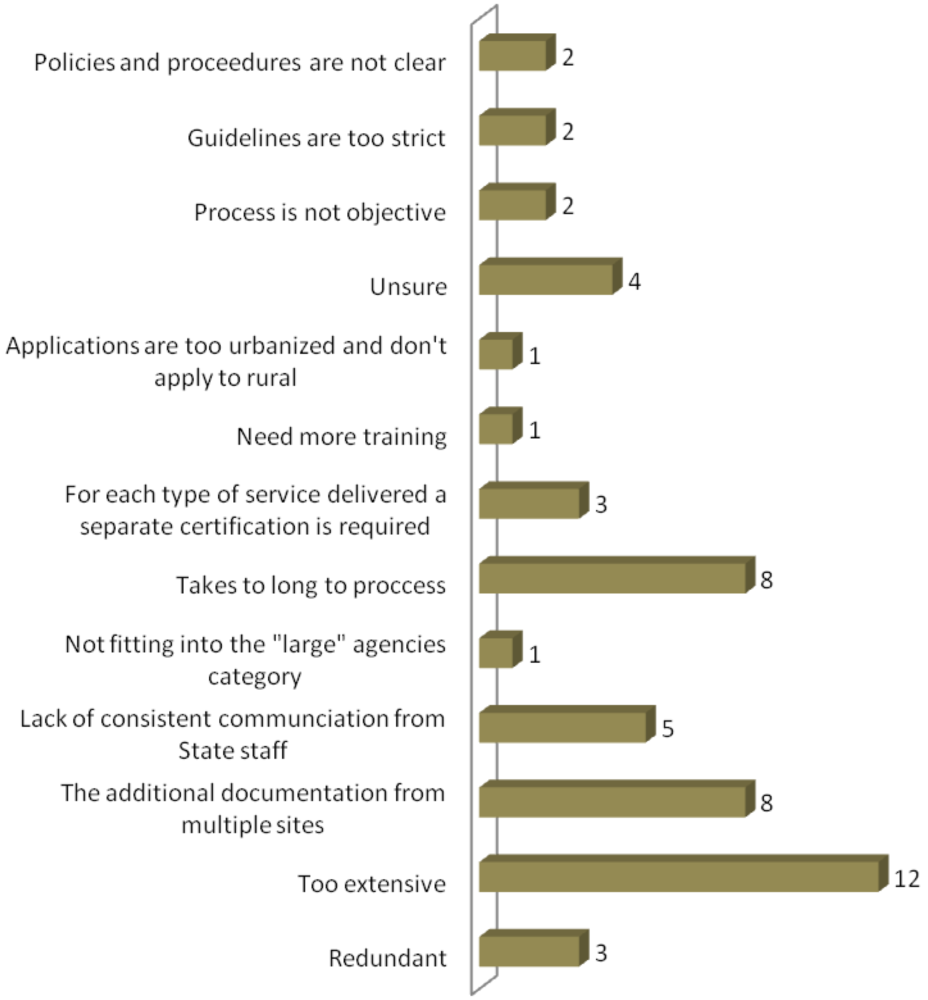
Respondents' Perception of Whether the State's Certification Process is Clear and Efficient



Respondents identified the most challenging part of completing and obtaining Medicaid certification to be an application process that is too lengthy, cumbersome and unclear. Respondents also identified that the application takes too long to process. A number of individuals noted that instructions or advice from the State seems to be inconsistent. Quite a few also noted that it is especially difficult to get documentation necessary to complete the application if they operate multiple sites.

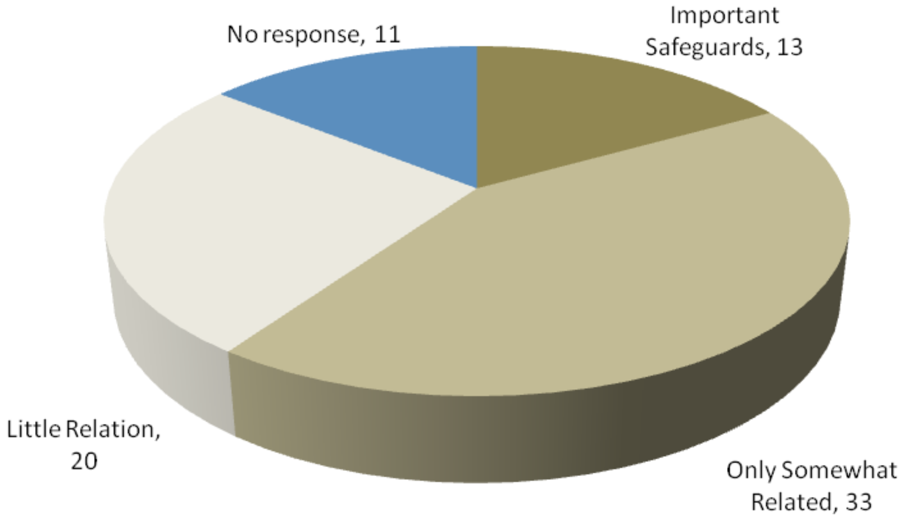
One person noted that the forms are oriented towards urban areas and do not necessarily translate well for rural locations.

Respondent Perception of Challenges in the Medicaid Certification Process



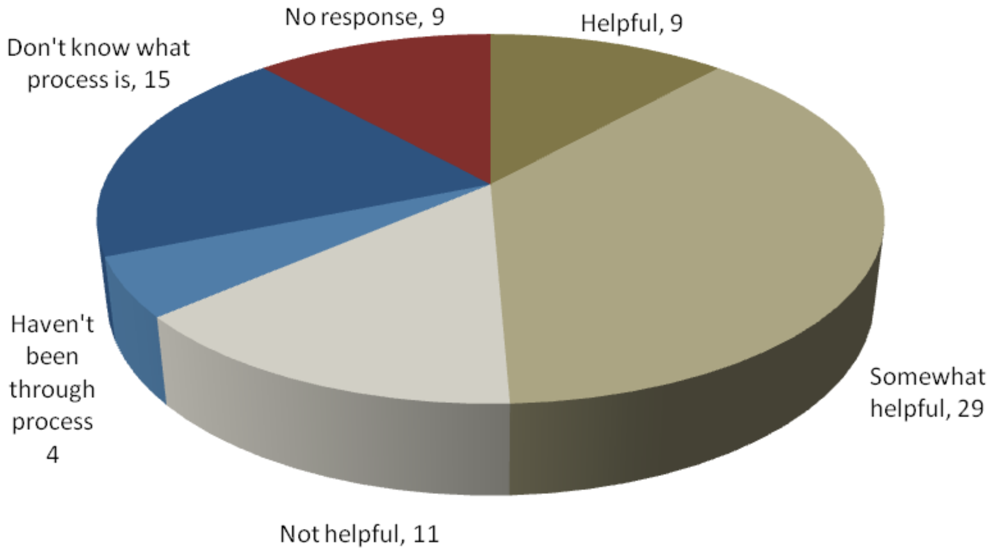
The survey included separate questions about the Medicaid Certification standards and process. Of the respondents who answered the question regarding the standards, one-half felt that the standards provided important safeguards that ensured the quality of services. However, nearly a third felt that the certification process had very little to do with delivering quality services.

Respondent's Belief about the Effect of Medicaid Certification <u>Standards</u> on the Quality of Services



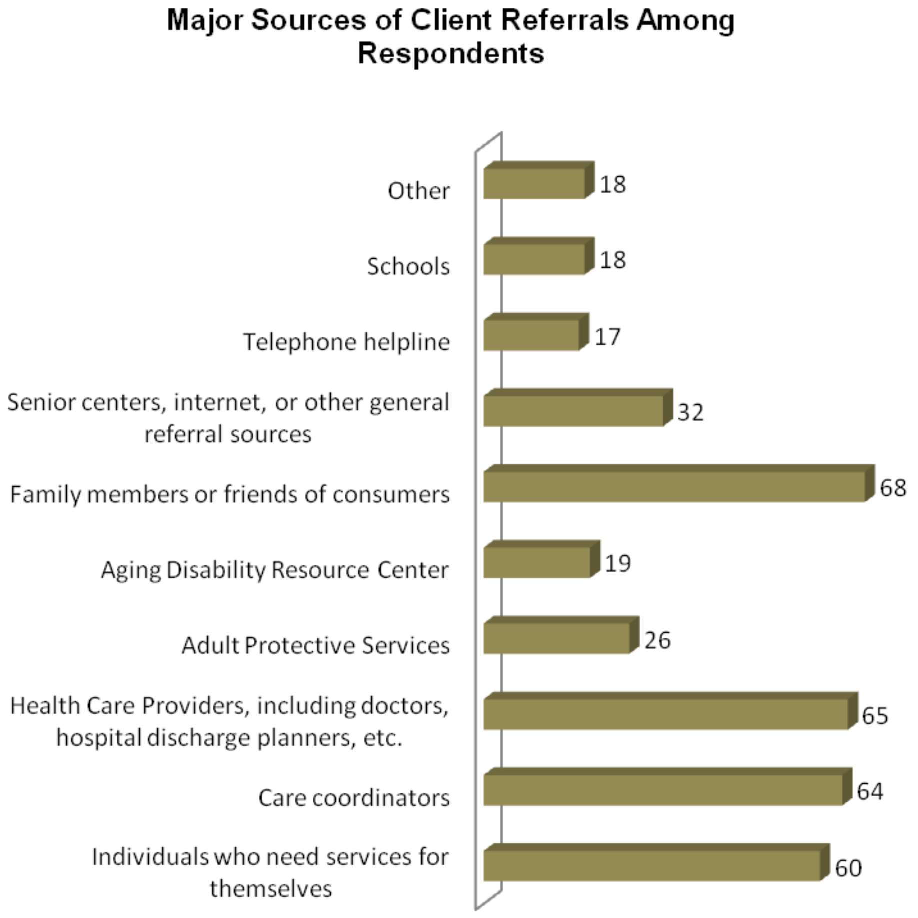
Of the 49 respondents who gave an opinion about the Medicaid Certification <u>process</u>, 18% thought that the process was helpful, 59% responded somewhat helpful, and 22% said the process was not helpful in maintaining quality. Fifteen of the providers said they did not know what the review process was. Ten of these responses came from respondents who said they were not Medicaid certified providers.

Respondents Belief about the Effect of Medicaid Certification Process on Maintaining the Quality of Services



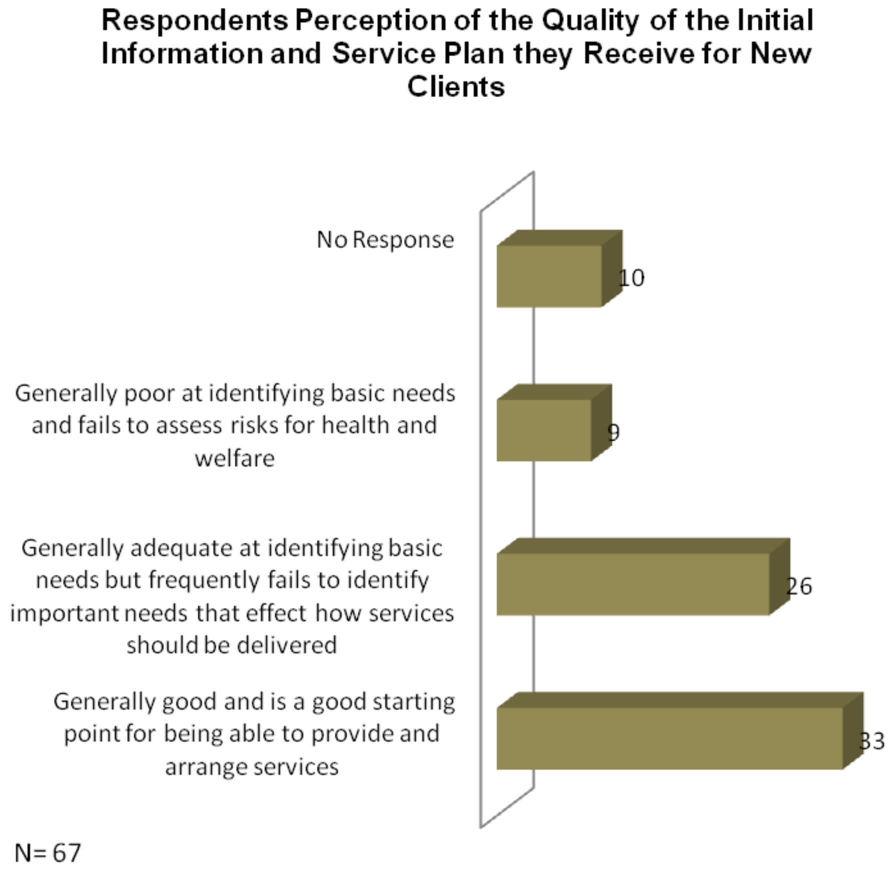
Respondents were most likely to identify family members or friends of consumers, Care Coordinators, health care providers (including doctors, hospital discharge planners, etc.) and the individuals themselves as the most important sources for client referrals.

Those that indicated “other” as a referral source identified the following: the Division of Vocational Rehabilitation, Tribal offices, ALF staff, free medical clinics, professional referral agencies, other satisfied consumers, and advocacy groups such as Alaska Brain Injury network.


Major Sources of Client Referrals Among Respondents

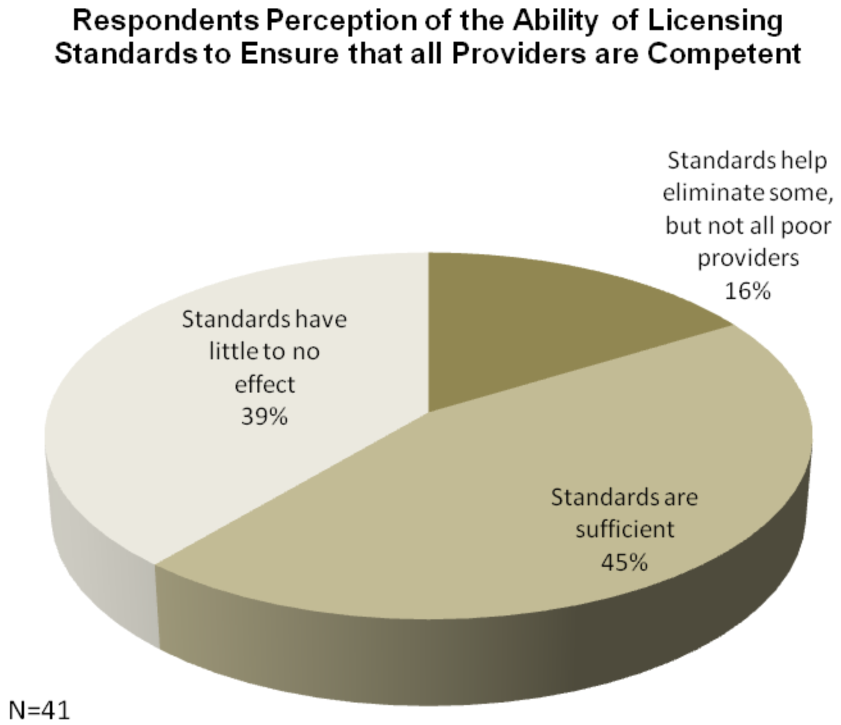
N=76

While most respondents felt that the initial information they received about a client, including the care plan, provided a solid basis for providing services, about half of the respondents that answered the question felt that more information was necessary to identify all of the client's needs.



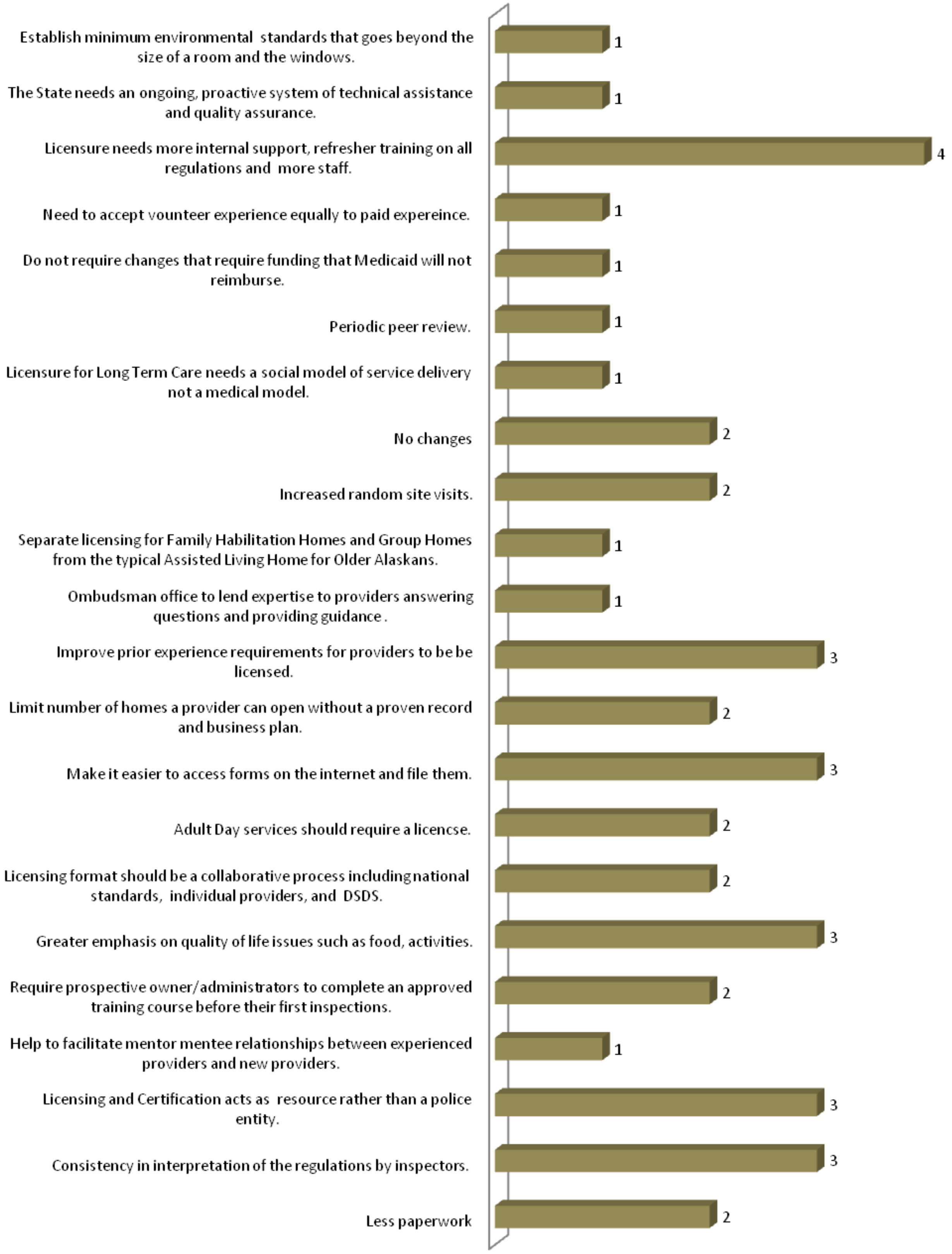
Respondents Perception of the Quality of the Initial Information and Service Plan they Receive for New Clients

Forty-one of the respondents reported that they were a licensed provider. Respondents tended to believe that the licensing standards were either effective or very ineffective in ensuring that all providers were competent, with slightly more having a positive view.



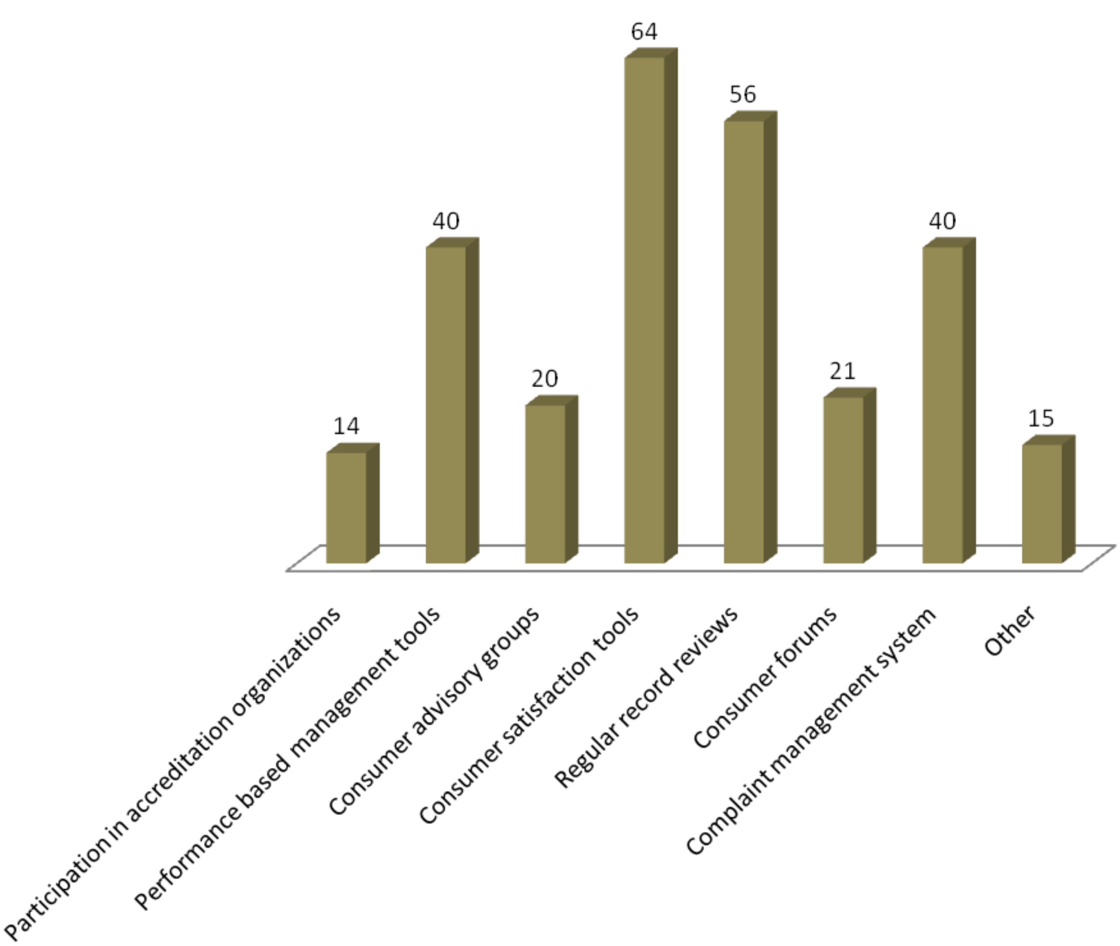
Respondents provided a variety of suggestions for improving licensing. They are included in the chart below.

Respondents Suggestions for Improving the Licensing System



When asked about processes they used to improve quality of services, a majority of the respondents said they used consumer satisfaction tools, regular record reviews, performance based management tools and complaint management systems. In addition to the items cited on the chart below, providers said they performed the following quality management activities: Informal weekly round table discussions; active involvement with families and consumers and the family council; annual surveys; internal utilization reviews; home visits; internal measurements of goals and objectives; and a Quality Improvement Committee that meets regularly and makes monthly reports to the governing board.

Activities Respondents Perform to Evaluate Quality of Services



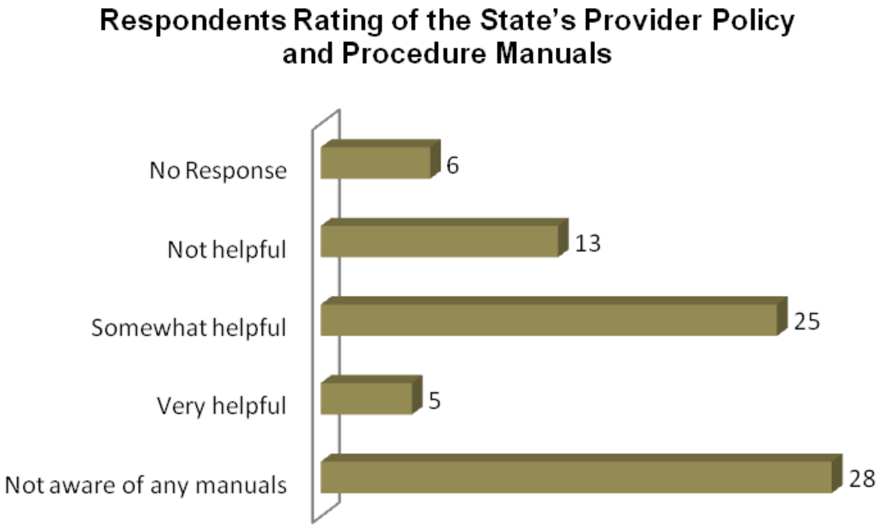
Respondents were prompted to rate challenges to maintaining and improving the quality in the services they provided on a scale of **1** (*least* challenging) to **5** (*most* challenging). The following is the average score for each area:

- Staff recruitment and retention: 4.2;
- Staff training and skill level: 3.5;
- Reimbursement levels: 3.8;
- Increasing number of complex needs presented by consumers: 3.7;
- Service locations that are dispersed across large geographic areas: 3.2;
- Counterproductive policies and/or regulations: 3.6; and,
- Unclear policies and regulations: 3.3.

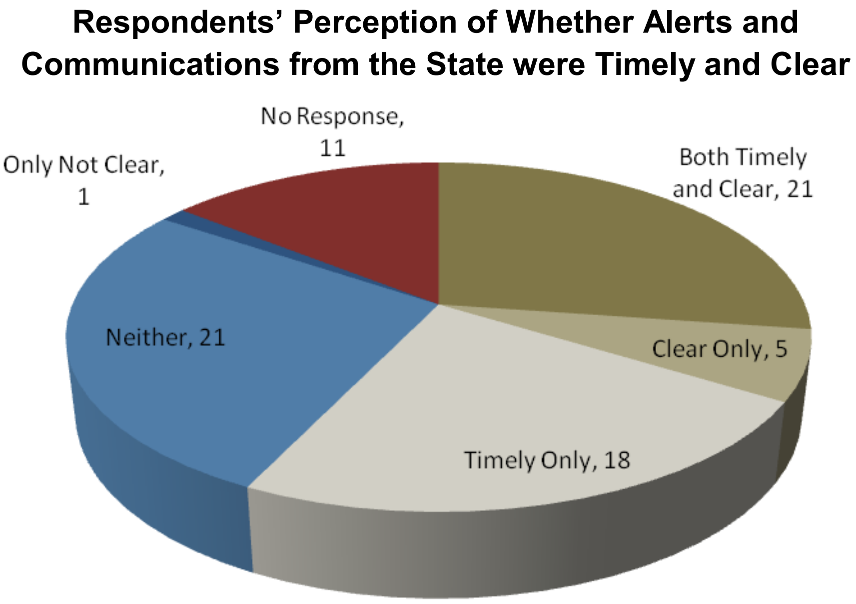
Respondents also identified “other” barriers to quality. These responses included:

- Finding funding for individuals who are not eligible for services;
- Adequate funding across all services;
- Reimbursement rates for nursing facilities;
- DHSS fragmentation;
- Background check;
- Transportation for consumers;
- Medication prompting regulation vs. the nursing board; and,
- "Burn Out" among the most productive and compassionate staff.

Twenty-eight (39%) of the 71 providers answering the question were not aware that the State had provider policy and procedure manuals at all. Of the 43 providers that were aware of the manuals, 38 rated them as only somewhat helpful or not helpful at all.

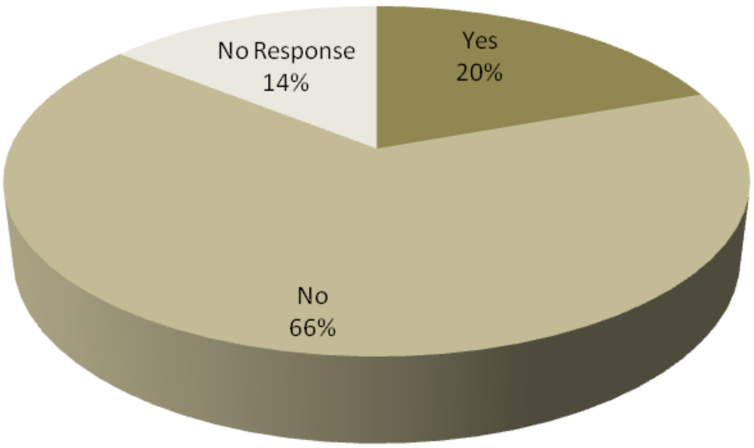


Respondents were split about whether they thought the State's efforts to communicate policy changes were clear and timely. An equal number thought these comminciations and alerts were "both timely and clear" and "neither timely nor clear." A large number thought communications were timely, but not necessarily clear.



More than three-fourths of the respondents who answered the question thought that the State did not offer sufficient training.

Respondents' Perception of Whether the State Offered Sufficient Training



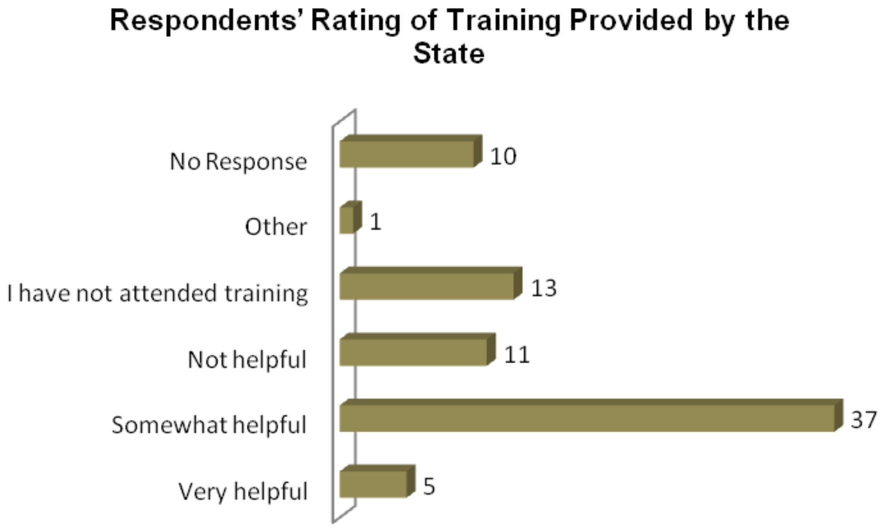
N=77

Responding providers identified the following subject areas as training they would like the State to offer:

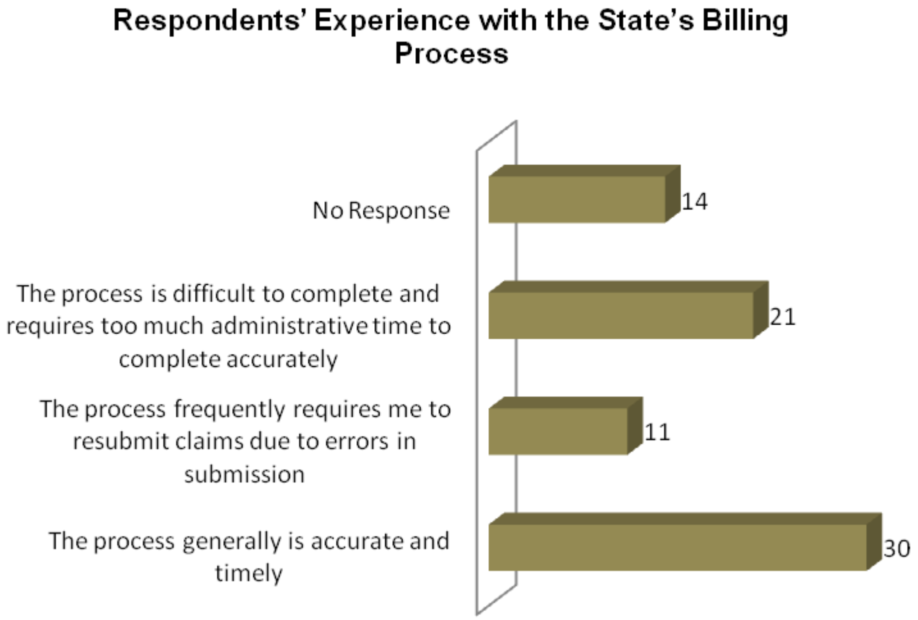
- Care coordination training by a veteran Care Coordinator;
- Documentation requirements;
- Application processes for waivers;
- CHIP enrollment;
- Cultural sensitivity training;
- Auditing expectations;
- Training in more geographic areas;
- Billing requirements;

- MDS interpretation; and,
- Advanced Care Coordinator training especially on TEFRA Medicaid.

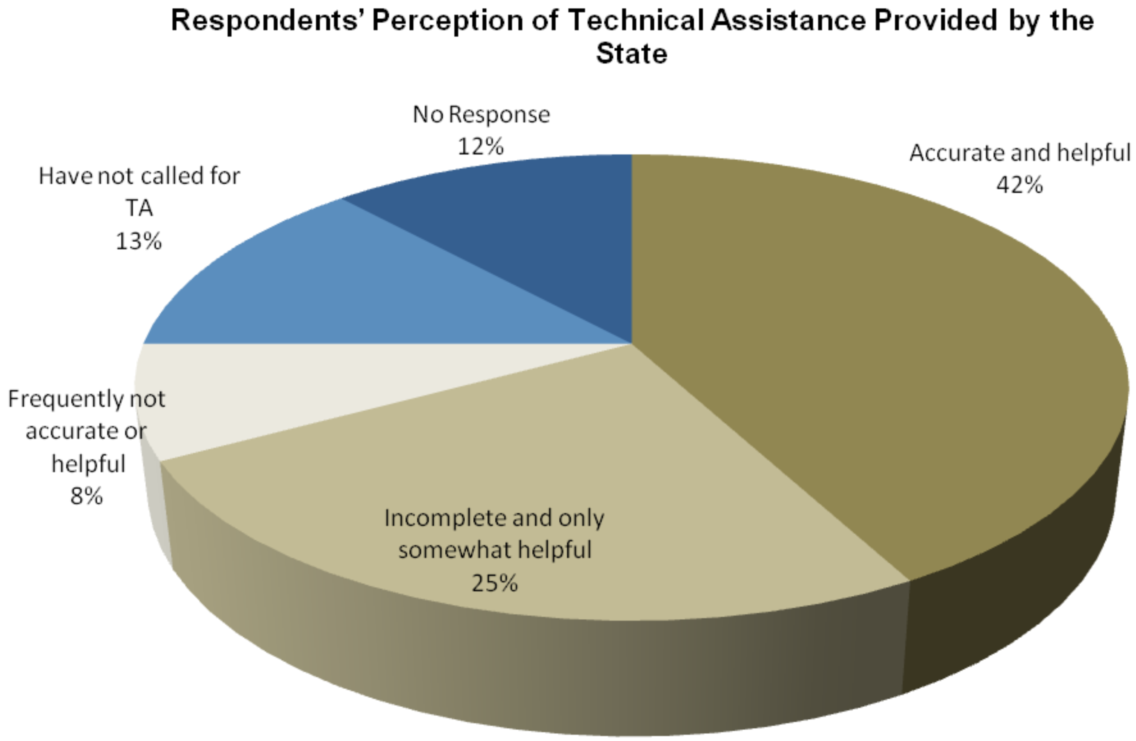
Thirteen of the providers indicated that they have not attended any State training. Of the 53 providers who had been to training and responded to the item, 37 (70%) rated the training as somewhat helpful.



Respondents were almost evenly split among those who had no problems with the State's billing process and those who did.

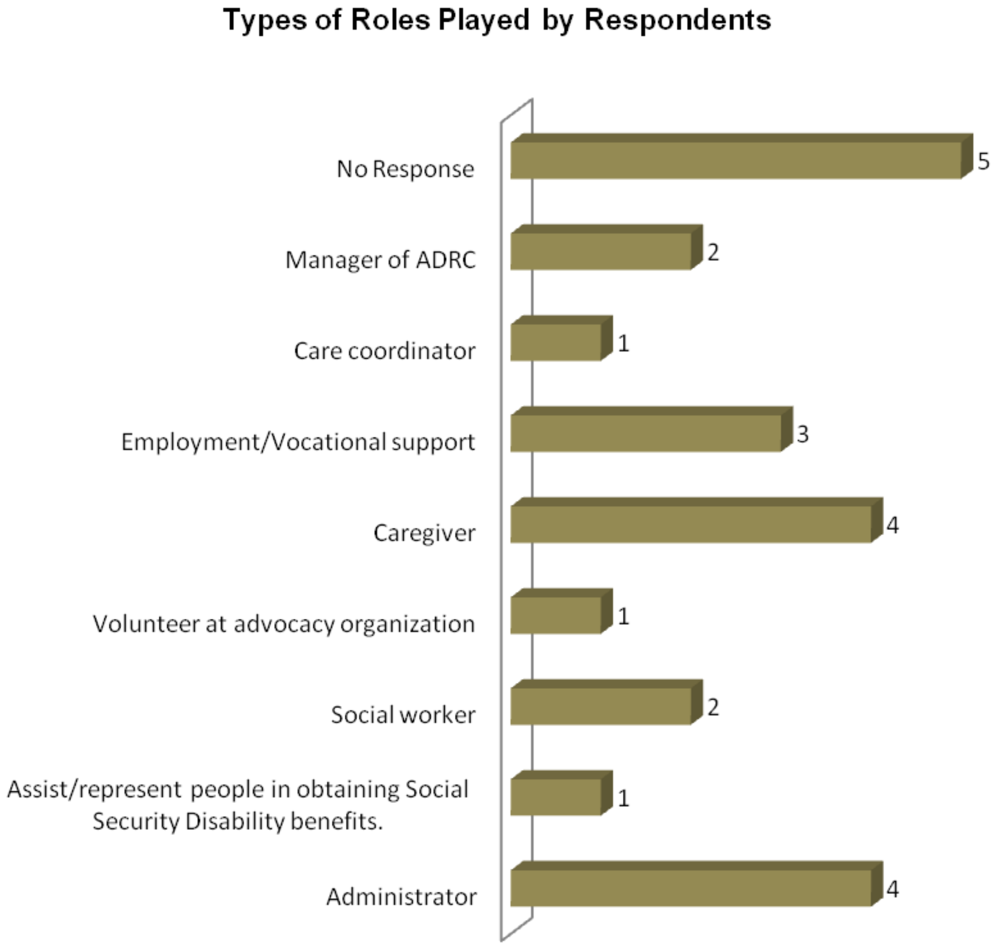


Of the 57 people who had called the State for technical assistance and answered the survey item, 56% said the assistance was accurate and helpful.



Other Stakeholder Survey

We had 23 responses from individuals that viewed themselves as other stakeholders. A few of the respondents could have also filled out the provider survey. When asked what role they played in Long Term Care, 5 individuals did not respond.


Types of Roles Played by Respondents
No Response
5
Manager of ADRC
2
Care coordinator
1
Employment/Vocational support
3
Caregiver
4
Volunteer at advocacy organization
1
Social worker
2
Assist/represent people in obtaining Social Security Disability benefits.
1
Administrator
4

APPENDIX 7: LIST OF RESOURCES USED FOR BACKGROUND RESEARCH TOPICS

Cultural Competence Initiatives:

Websites:

1. Arizona Inter Tribal Council (www.itcaonline.com)
2. National Indian Health Services (www.ihs.gov)
3. Cherokee Nation Elder Care Program (www.eldercare.**cherokee**.org)
4. Centers for Medicare and Medicaid Services (www.cms.hhs.gov)
5. National Congress of American Indians (www.ncai.org)
6. Minnesota Department of Human Services (www.dhs.state.mn.us)

Reports:

1. *American Indian and Native Alaskan Roundtable Discussion on Long Term Care: Final Report 2002,* Prepared by Jo Anne Kauffman, Kauffman and Associates, under contract with Indian Health Services.
2. *Medicaid Home Care for Tribal Health Services: A Tool Kit for Developing New Programs,* Stephen P. Wallace, PhD, Delight E. Satter, MPH, Andrea Zubiate.
3. *Indicators of Cultural Competence in health Care Delivery Organizations: An organizational Cultural Competence*

Documents:

1. Minnesota Department of Human Services Memorandum of Understanding
2. Minnesota Department of Human Services Agreements

Experts:

1. Jolene Kohn, Minnesota Department of Human Services
2. Stephen P. Wallace, PhD, University of California at Los Angeles, School of Public Health, Health Policy

Early Intervention and Prevention Initiatives:

Websites:

1. Illinois Department of Human Services (www.dhs.state.il.us)
2. Minnesota Department of Human Services, Aging (www.dhs.state.mn.us)
3. Minnesota Department of Human Services, Reports and Forecasts (www.dhs.state.mn.us)
4. Wisconsin Department of Health Services (www.dhfs.**wisconsin**.gov)
5. National Association of State Units on Aging (www.**nasua**.org)
6. Centers for Disease Control, National Center for Birth Defects and Developmental Disabilities (www.cdc.gov/ncbddd)

Experts:

1. Jim Varpness, Regional Director, Administration on Aging

Self Directed Services:

Websites:

1. Kaiser Family Foundation (www.kff.org)
2. American Association of Retired Persons (www.**aarp**.org)
3. National Association of State Medicaid Directors (www.**nasmd**.org)
4. Clearinghouse for the Community Living Exchange Collaborative (www.hcbs.org)
5. Centers for Medicare and Medicaid Services (www.cms.hhs.gov)

Reports and Documents:

1. Beyond Cash and Counseling: An Inventory of Individual Budget-based Community Long Term Care Programs for the Elderly Brenda C. Spillman, Kirsten J. Black and Barbara A. Ormond, The Urban Institute
2. CRS Report for Congress: Long-Term Care: Consumer-Directed Services Under Medicaid, Updated January 21, 2005, by Karen Tritz, Analyst, Congressional Resource Services
3. Independent Choices Program: Evaluation Final Report, prepared by Pacific Research and Evaluations for the Oregon Department of Human Services, February 2006

4. Oregon Administrative Rules for Independent Choices Program, Chapter 411, Division 36 (Temporarily Suspended)
5. *Consumer and Consultant Experiences in the New Jersey Personal Preference Program,* by Leslie Foster, Barbara Phillips and Jennifer Schore, Mathematica Policy Research, Inc., under contract with the U.S. Department of Health and Human Services
6. Minnesota Department of Human Services, Program Manual, HCBS Waivers, Consumer Directed Community Services
7. Kansas State Plan Amendment, Working Healthy Program
8. *Improving Home and Community-Based Service Delivery Systems for Older Adults and Individuals with Disabilities: Redesigning Information Technology and Business Processes to Support Participant Control, Quality and Cost Effectiveness,* by Dr. Steven Lutzky

Experts:

1. Mary Ellen Wright, Kansas Health Policy Authority
2. Walter Barrington and Jack Tiner, State of Arkansas
3. Kathleen Kelly, Minnesota Department of Human Services

Appendix 8: Summary of Elder Grant Programs in Minnesota and Illinois

State	Description	Eligibility	Services Offered	Other
MN Alternative Care Program (AC)	Purpose is to provide seniors that are not Medicaid-eligible with services that will keep them in the community or delay transition into a nursing home, prevent impoverishment and delay spending down to Medicaid, and encourage personal responsibility through a cost share arrangement. Program is funded through state general funds.	The person is in need of nursing facility level of care and admission is referred. Additionally the following eligibility criteria are applied: • The person's income and assets would be inadequate to fund a nursing facility stay for more than 135 days; • The monthly cost of AC services must be less than 75 percent of the average Medicaid payment limit for older people with a comparable case mix classification; • The person chooses to receive community-based services instead of nursing facility services; • The person pays the	• Adult day care • Care-related supplies and equipment • Case management • Chore services • Companion services • Consumer-directed community supports • Home health aides • Home-delivered meals • Homemaker services • Modifications and adaptations • Nutrition services • Personal care assistance • Respite care • Skilled nursing • Training and support	The AC program is administered similarly to the HCBS waiver, using the same assessment, long term care consultation, care planning, and care coordination processes. The average projected monthly cost per person as reported by MN Department of Human Services is: Nursing Facility Avg. # Recipients/mo. = 19,485 Avg. Payment per recipient/mo. = $3540 Elderly Waiver FFS* Avg. # Recipients/mo. = 4653 Avg. Cost/mo. = $1423 Alternative Care Avg. # Recipients/mo. = 3635 Avg. Cost/mo. = $795

		assessed monthly fee; and, • No other funding source is available for the community services.	for family caregivers • Transportation	
IL Community Care Program	Purpose is to provide seniors a way to maintain their independence and to avoid or delay entrance into a nursing home. This program also assists with avoiding impoverishment due to the cost of support services.	Eligibility criteria requires that people meet the following: • Are 60 years old or older; • Are U.S. citizens or legal aliens; • Are residents of Illinois; • Have non-exempt assets of $17,500 or less (Non-exempt assets do not include home, car, or personal furnishings.); and • Have an assessed need for long term care. NOTE: Although the level of income does not affect eligibility for the program, an income level is used to determine ability to contribute	• Case Management Services • Homemaker Services • Adult Day Services The Community Care Program is also mandated to implement the following: • Choices for Care (Long Term Care Consultation) • Background checks of Adult Day Center and Homemaker staff • Prevention of Spousal Impoverishment	The governor's budget includes the following projections for SFY 09: • Program will serve nearly 50,000 persons; • The state general fund cost will be nearly 465 million dollars; • Comprehensive assessment and care coordination, including a $43.4 million line item for care coordination; and, • Improved coordination between Title III and the Community Care Program, including partial funding through a Medicaid waiver for some select services.

APPENDIX 9: SUMMARY OF INTERVIEW WITH MINNESOTA ON AGREEMENTS WITH INDIAN NATIONS

We conducted a follow-up interview with Jolene Kohn within the Minnesota Department of Human Services. Minnesota has entered into agreements with three Indian Nations for certain administrative functions and services. Agreement with the White Earth reservation has been in place since 2001. The State is now adding agreements with the Leech Lake and Fon Du Lac tribes. The agreement had been done with respect to Elderly services and PCA, but is now expanding to some disability services. MN is a State supervised, county administered system. Agreement provides legal mechanism for tribes to act in place of county system for certain areas.

Administrative functions include:

- Functional eligibility determinations
- Assessment
- Plan of care and Service authorization
- Service agreements and approvals for providers to provide services
- The above includes direct entry into MMIS

Service functions related to this include:

- Long term care consultation
- Care coordination
- Oversight and monitoring of plan of care

Issues:

- DHS is not paying directly for any of these functions or services on the elderly side. Agreement simply formalizes work that was already being done, but gives more authority to the tribal network to plan and authorize service provision.
- Long term care consultation on the disability side is a fee for service, and could be billed by the tribal network.
- Care coordination, if the person is on the waiver, is a direct service that can be billed.
- Jolene reported that they are currently looking at how to incorporate the tribal work into the random moment time study, in order to allow payment for administrative activities.

Key Considerations:

- The State used overarching authority already in Statute that allows the Commissioner of Human Services to enter into contracts for the prudent administration of services. Jolene noted that AK would need to make sure they have legal authority to do something similar.
- Minnesota tribes were allowed to vary the scope of functions performed and to define the population served based upon the tribal structure and interest. For instance, one tribe decided to include non-native people that are part of a blended family. Another tribe defined its scope to include only tribal members. Another defined its business as within a geographic region for both tribal and non-tribal members. Mostly this was aligned with whatever tribal mission had been adopted by its government.
- Recipients have the option of seeking assistance through the tribal entity or through the county system.
- Tribal entities are also performing similar functions in cooperation with health plans for both the mandated managed care groups and the voluntary managed care groups and the Special Need Plans (SNPs) that are serving dually eligible. Most of the tribes are located within areas that are county based purchasing MCOs.
- The State determined that its stance on separation of gate keeping and service provision was not very workable in the tribal system because the infrastructure was not large enough. While expectations are stated to assure “best interests” of recipients, the State has not required formal separation…as it would not be practical. To date, the State has not experienced problems that are noteworthy. The recipient still has the option to seek assistance through the county if they are dissatisfied.
- Minnesota found that some seemingly “small” operational problems considerably slowed the initial agreement. For instance, coding in the MMIS system for some functions was a three digit code and did not accept the tribal four digit code.
- The State is finding that it has a need to train State staff about tribal systems so that business functions are done appropriately. For instance, there is a specific tribal desk within the provider help desk system. Staff within the broader agency do not understand that there are unique issues and rules pertaining to the tribal health system. If a tribal caller is seeking assistance on a provider issue and is not appropriately referred, they can get incorrect information.

- There has been some issue with coordinating payments across primary health and long term care services.

Other Ideas:

- Jolene indicated that information and assistance and LTC consultation may need to be administered out of a mid level regional office, since local clinic workers would likely have difficulty understanding the entire range of IHS and Medicaid.
- Briefly discussed that there were misperceptions creating some biases that had to be addressed: 1) State staff perceiving tribal workers as being incompetent; and 2) State staff perceptions about tribal corruption. Neither have been experienced in the agreement with White Earth tribe.
- Many native people, especially older natives, have no interest in interacting with government. Their experience in the past has been that government has moved their children to the Indian schools, or that government has taken other things away. This makes using the tribal infrastructure a more effective mechanism for getting needed help to people.
- Montana, at one point, initiated a pilot on PCA Choice with the Rocky Boy nation. This fell apart because the state attempted to dictate what and how things would work. Jolene's experience has been to approach it in a much different way, allowing independent agreements to develop with each tribal entity, since interest and capability will differ.

APPENDIX 10: SUMMARY OF STATES OPERATING PROGRAMS UNDER DRA AUTHORITIES

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
Kentucky 1937 Benchmark Plan	Makes a significant change to the benefit structure for the Medicaid program, imposes new cost sharing requirements and benefit limits. Emphasizes disease management and premium assistance. • Moves people into four targeted benefit plans: Global Choices, Family Choices, Optimum Choices, Comprehensive Choices. • Includes premium assistance to allow individuals to voluntarily choose employer based coverage rather than direct coverage. • Individuals can enroll in "Get Healthy Benefits" after one year of complying with the disease management program. Allows them to access limited additional	• People needing long term care services access through Optimum Choices or Comprehensive Choices. These include long term care benefits at two or three levels of intensity plus the medical services contained within Global Choices. • Optimum Choices covers people with DD and has three levels of long term care services: high intensity, targeted, and basic. • Comprehensive Choices covers the elderly and people with disabilities in need of NF level of	• State has included a self directed option within the HCBS waivers. • Kentucky reform option recently reviewed by Office of the Auditor of Public Accounts. Findings were inconclusive regarding any savings to state expenditures. • State submitted a SPA in November of 2007 to pilot the expansion of consumer direction for up to 200 individuals. Questions were received from CMS in February.	Follow up could be helpful on the following components of the Kentucky model: • The criteria for the levels of long term care eligibility within Optimum Choices and Comprehensive Choices. • The services that are covered within each of the levels. • Mechanism for person to move from one level to another. • Authorization process within each of the

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
	benefit levels, such as dental/vision services, smoking cessation counseling, and nutritional counseling. • Plans include cost sharing provisions and some benefit limits, such as on prescription drugs and therapies (OT, PT). These are not caps. If additional benefit levels are necessary, there is a PA process that is used.	care. It covers two levels of long term care, high intensity and basic. High intensity includes NF. • People in the "basic level" are not guaranteed any service beyond case management.		levels, including any service caps. • Coordination across primary and long term care benefit, especially for people enrolled in the disease management component.
West Virginia 1937 Benchmark Plan	Program is called "Mountain Health Choices" and targeted to healthy adults and children. Allows individuals the opportunity to obtain optional benefits by using a partnership agreement. Individuals are assigned to a medical home and agree to participate in health and wellness programs. Participants who comply with their agreements can access enhanced service options that meet their particular need.	Elderly and people with disabilities are not included in this option.	Questions remain concerning how the agreements will be monitored and enforced, particularly for children who may have little control over compliance.	Low priority for follow up since this does not cover the LTC population.

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
Idaho 1937 Benchmark Plan	Uses the DRA to establish revamped Medicaid option. • Basic Plan is targeted to low income children and working age adults. • Enhanced Plan is targeted to individuals with disabilities and special medical needs. Elderly may also be served here if they need long term care services. • Coordinated Plan is targeted to dual eligibles, primarily elderly not in need of long term care services. The new options are based on prevention, wellness, and personal responsibility. Idaho also made changes to eligibility, including: • Changes to income and	The Enhanced Plan includes long term care services otherwise offered under Medicaid. The Enhanced plan includes health care services that are included in the traditional Medicaid plan, but also includes some additional optional services such as nutrition and preventative health services.	The service delivery for these options is through Primary Care Case Management. While enrollment in the revamped Medicaid program is optional and people have the right to return to the traditional program, the state submitted a state plan amendment that would eliminate optional Medicaid services in its traditional program.	Follow up to: • Understand more about the structure and the coordination between primary care and long term care; • Understand more about the dually eligible if they need long term care services or dually eligible under the age of 65 who do not need LTC; • Understand more about the eligibility criteria for the enhanced level. For instance, individuals needing rehab

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
	assets for people with substantial home equity. - Retention of more assets for seniors who have purchased and exhausted LTC insurance and seek to qualify for Medicaid. - Medicaid buy-in for working individuals with disabilities.			services, kids eligible for services through EPSDT (kids with autism, for instance).
Kansas 1937 Benchmark Plan	Uses the DRA to create the "Working Healthy" program. Eligibility includes all of the following: - Categorically eligible in the State's Ticket to Work and Work Incentives Improve Act buy in program; - Must need PAS and related services; - Working individuals between the ages of 15 and 65 how, except for their income and resource levels, are eligible to receive SSI; - Have earned income verified by FICA/SECA	- This is an optional program for people who would otherwise be using PAS under the traditional Medicaid program in Kansas. - In addition to traditional State Plan services, persons in this option receive person centered assessment, PAS, independent living counseling, and assistance services such as items or equipment that will		Follow up: - Information and access; - Eligibility criteria of group; - Assessment and budget setting process; - Scope of what can be covered through option; and, - Quality oversight.

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
	payments; • Have countable net income no greater than 300 percent of FPL; and, • Have assets no higher than $15,000.	improve their independence, health and safety, employment.		
Virginia 1937 Benchmark Plan	Virginia has instituted a “Healthy Returns” program. This effort is a disease management effort targeted to people with asthma, congestive heart failure, coronary artery disease, and/or diabetes. Excludes: • Managed care enrollees • Dual eligibles • Individuals in institutions • People with third party insurance Provides for additional services focused on education and management of disease. Also include access to nurse call line, care coordination, and		Disease management aspect of this option is through a prepaid ambulatory health plan.	Not a priority for contacting. LTC populations less affected.

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
	telephone health care management.			
Maine 1937 Benchmark Plan	State Plan implanting cost share and premiums on specific groups. This includes: - Families with incomes above 150% of FPL. - Individuals eligible through the Katie Beckett waiver. There are caps on the amounts that can be charged and a sliding scale is used to determine the monthly premium amount.			Medium priority. Could contact to find out more about how premiums are set and collected.
Wisconsin 1937 Benchmark Plan	The Wisconsin effort expands eligibility for categorically needy pregnant women between 200 and 250 percent of FPL. It requires recipients to enroll in BadgerCare Plus if they are in this expanded eligibility group. It highlights preventative care and appropriate use of health care. It also provides additional services including wrap around services for mental health and	Long term care services are not impacted by this change.		Not a priority since LTC populations not impacted.

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
	substance abuse, and full EPSDT benefits for pregnant women under age 19.			
South Carolina 1937 Benchmark Plan	The South Carolina effort allows an option for Medicaid recipients to opt into a high deductible plan. This includes the following: • The state will deposit $2500 per adult and $1000 per child in a Health Opportunity Account (HOA) to be used to pay for costs associated with co pays and deductibles under the terms of the option; • Preventative care is not subject to the annual deductible; • Once the HOA has been exhausted, the individual is liable for a ten percent cost sharing obligation until returning to the traditional state plan; and, • Enrollees also can access preventative care such as annual physicals, routine	This plan is generally limited to Medicaid children and parents, although the approval letter also specifies that it includes individuals in disability based eligibility groups. This health plan option is authorized as the high deductible health plan of the State Employee's Health Plan.	Services are paid on a fee for service basis.	Medium priority for follow up: • Interest would be in whether the HOAs are accomplishing goals for preventative care, especially among those that might be "at risk" of becoming disabled.

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
	prenatal and well child care, and immunizations. The option is limited to 1000 people within Richland County.			
Washington 1937 Benchmark Plan	The Washington effort offers the regular Medicaid state plan services plus disease management services to adult recipients diagnosed with certain chronic medical conditions. This effort is intended to assist people with finding a medical home, or a primary care provider, and to use that PCP appropriately and to improve health outcomes. The plan includes providing individuals access to nurse help lines and referrals for needed services. The State intends to use these strategies to help manage the utilization of services and improve outcomes for individuals. Those eligible include:	This option does not exclude individuals using long term care services. Additional health benefits include: • Condition specific education • Access to nurse call line • Telephonic health care management and support • Care coordination	The disease management component is provided through a prepaid ambulatory health plan. All other services are on a fee for service basis.	Follow up with state to discuss: • Use of option by LTC recipients; • Coordination of primary care with LTC to achieve outcomes.

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
	• Categorically needy aged, blind and disabled who are at least 21. The program is being phased in and will be available statewide.			
Iowa 1915(i) State Plan HCBS	Home and Community Services benefit was added through the 1915(i) authority. Program is targeted to people with functional impairments typically associated with chronic mental illness. The services are designed to assist participants in acquiring, retaining, and improving the self help, socialization and adaptive skills necessary to reside in the community. Services include: • Case management when an individual does not qualify for targeted case management;	Eligible persons include: • Medicaid eligible through already existing coverage group; • Household income cannot exceed 150 % of FPL; and, • Meets needs based eligibility criteria as determined by needs based evaluation. The needs based eligibility criteria includes the following: 1. Meets 1 of 2 risk factors which	• Has limited slots; • Non federal share (38%) is paid through counties for adults and through state for children; • Service plans are entered into information system; • State used this to largely replace the adult rehabilitation option; and, • Operationally works similar to the state's waiver programs.	Follow up with State on: • Functional definition of eligible group; • Assessment process; • Service limits; • Coordination with existing HCBS waivers; • Provider infrastructure; and, • Coordination with other state plan services, such as targeted

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
	• Home based habilitation, which are services provided in the person's home and community, including things such as medication management, budgeting skills, grocery shopping, personal hygiene, etc.; • Day habilitation services that are provided outside the home in a day program setting; • Prevocational services; and, • Supported employment	includes: • Has undergone or is currently undergoing psychiatric treatment more intensive than outpatient care, more than once in a lifetime; • Has history of psychiatric illness resulting in at least one episode of continuous, professional supportive care other than hospitalization. 2. Meets at least 2 of 5 criteria showing a need for assistance for at least two years: • Is unemployed or employed in a sheltered setting, or have markedly		case management.

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
		limited skills and a poor work history; • Requires financial assistance for out of hospital maintenance and may be unable to procure this assistance without help; • Shows severe inability to establish or maintain a person social support system; • Requires help in basic living skills; • Exhibits inappropriate social behavior that results in demand for intervention.		

STATE	SUMMARY OF PROGRAM	LTC POPULATIONS	OTHER	FOLLOW UP FOR IMPLEMENTATION
Alabama 1915(j) State Plan Self-Directed Services	Alabama was the first to institute, and has named the program "Personal Choices". Program uses the Cash and Counseling model.	• Expanded model of consumer direction targeted to people participants of the state's two HCBS waivers (elderly and disabled waivers) to use a state plan option; • Recipients must live in one of 7 pilot counties.		Follow up on: • Caseload management; • Coordination with waivers; • Budget methodology; and, • Experience to date with this option.
Arkansas 1915(j) State Plan Self-Directed Services	Arkansas converted its 1115 Cash and Counseling Program to a 1915(j) state plan service at the end of the demonstration period. The program allows individuals to purchase personal assistance services and companion services (if the individual is also a waiver recipient) under the 1915(j).	• Individuals eligible for personal care services; • Wavier recipients.	• Individuals are the employer of staff; • Fiscal intermediaries use power of attorney to handle financial aspects on behalf of the individual; and • State authorizes 58.7% of what would otherwise be paid to an agency, for the individual budget.	• Interview of state officials.

Resources Used: CMS Website: DRA State Plan Amendments; Kaiser Family Foundation Commission on Medicaid Facts; DRA States' public websites; Families USA website; Kentucky Auditor of Public Accounts report to the legislature; Clearinghouse for the Community Living Exchange Collaborative; Association of National Medicaid Directors.

APPENDIX 11: INTERVIEW WITH KANSAS

This is a summary of our interview with Mary Ellen Wright, Sr. Manager, Kansas Health Policy Authority regarding the “Working Healthy” Self Directed Services under Benchmark Plan Authority.

Background:

“Working Healthy” is the Kansas Medicaid buy-in option for working adults with disabilities. Kansas has had a Medicaid Infrastructure Grant under which the buy-in was created. The new self-directed option offers cash and counseling services for individuals meeting the following criteria: 1) must be eligible for the “Working Healthy” program; 2) must meet the eligibility criteria for HCBS waiver; and 3) must be able to self-direct or if not able to self-direct, must have a representative that is able to direct service.

Kansas undertook an extensive effort to develop and gain federal approval for this option. Several pathways were tried, including the development of an 1115 waiver request that involved negotiations over a three year period of time. No approval was forthcoming. Toward the end of this process, Congress passed the DRA. Kansas originally considered the 1915 (j) option, but was told that they would have to offer both an agency option for personal assistance services AND a self-directed option for personal assistance services. The state was not interested in opening up agency services, as they did not see this as fitting with their intents to target it to the buy-in adults and to offer a state plan self-directed option. It was at this time that Kansas decided that the Benchmark plan would offer them a route.

Kansas used the work done in the 1115 process and submitted a state plan amendment using the new authority. The plan was approved within two weeks of submission.

At the present time there are approximately 64 participants in the program option. The self-directed option includes case management, personal services (including counseling and PAS supports), and assistive services (adaptive equipment or other purchases that could take the place of staff support).

General Summary of Administration:

Services include case management, personal services, and assistive services. Case management services are not mandatory.

Assessment is completed by the state agency for this option (in other services/programs it is done by providers). Kansas developed an assessment tool for individuals choosing the self-directed services. This assessment tool reflects both areas related to waiver eligibility and to areas considered to be closely aligned to the self-directed model. The budget provided to an individual is based on the information from this assessment and the “plan for independence” (service plan). The basic process involves estimating the time that assistance would be needed. An hourly rate of $13.25 is applied and a unit factor is used to create a monthly amount for each participant.

Money can be paid directly to the participant or can be sent to the fiscal entity, which is then responsible to pay bills as directed by the participant. There is monthly reporting done by the fiscal entity and each participant. This reporting reflects the management of the money.

The fiscal entity is allowed to charge 8% of the total participant allocation for its services. At the current time only one person is choosing to have money sent directly to him/her. If a person chooses to directly manage the money, they are required to complete training that has been developed by the state.

At the current time, the state has monthly payments averaging approximately $1500 per person. The range of payments is $300 per month to $7000 per month.

The state currently has one fiscal entity under contract. Others may be added as needed and after experience has been gained. Also, the state feels that it is not currently in a position to provide technical assistance to multiple fiscal entities. Bringing up the new option has involved dealing with unanticipated questions, and it has been easier (given the low caseload numbers using this option) to work with one fiscal entity during this initial implementation year (and probably extended to two years at least).

Participants are allowed to hold money in reserve for future purchases. However, the state is evaluating the utilization of the budget for each participant on a monthly basis. The state typically will question utilization that is less than 75% of the monthly budget amount after a two month period. In some cases there has been evidence of significant underutilization of 50% or more. On a case by case basis, the state will review and determine whether to adjust the monthly allocation downward. The state reported that there had not been, to date, any legal challenge on these downward adjustments.

The issuance of checks is done “offline”. Costs paid under this option do, however, get inputted into MMIS after the fact in order to ensure that total costs paid under Medicaid for the recipient are documented. The monthly checks are issued by the financial office in the department. Originally it was the intent to use the premium payment function within MMIS to issue the checks, however the time and cost of the work on the system was prohibitive for the size of the program. The manual work around is good in the sense that it allows the state to closely monitor and control the program, but it is bad in the sense that administrative support staff are required to spend the time to track this.

There is no Medicaid defined or enrolled “self-directed service” provider or provider of “personal assistance services” for the personal assistance service component. Case management services and assistive services are, in fact, generally enrolled providers, although payment comes through the fiscal entity (or participant if that person is managing the money). No service claim is made to MMIS.

If a person leaves the program, they are entitled to return to the waiver if they had exited the waiver to use the self-directed option. If the person was on the waiting list for a waiver, then they can return to the waiting list and will be placed on the list where they would otherwise have been.

Service Related Policies:

The participant is allowed to determine who they will hire to provide personal assistance. Relatives, including spouses, are allowed to be hired. The state noted two reasons for this. First, self-direction includes being able to hire someone the participant is comfortable with, and secondly, people in rural areas have a difficult time in recruiting staff. The State recognizes that this is a balancing act, in that some families could attempt to take advantage. However, at this time no widespread abuse has been noted.

Staff do not have to meet any certification or pre-qualification requirements. The state encourages but does not require a background check. There are no age restrictions since personal assistance under this option can include chore type services that younger individuals would be capable of doing. Participants are expected to train staff working for them. In general with regard to age, the state has taken the position that younger people would be appropriate for assistance with IADLs or chore type services, and that ADLS should be performed by adults.

Assistive services are generally items which would replace the need for a staff person to do the activity or chore. Prior authorization is required for two reasons. First, many purchases desired may be covered under other parts of the state plan. Second, the state desires to evaluate the types of purchases being made so that clarifications can be made about appropriateness for public expenditures.

An example of appropriateness of an expenditure recently reviewed was a request to purchase a lawn mower. The state determined that a lawn mower would not be an appropriate expenditure if it were purchased for a neighbor or friend to mow the person's lawn. However, an adapted mower which would allow more independence could, in fact, be appropriate in some situations.

In another case the request was for a cell phone that would enable the family to maintain contact with the person. In this case the state denied the request, as the person did not need that level of supervision and contact with the family.

Quality Assurance:

At the present time, because of the small size of the program, the state has been able to closely monitor the expenditure of money and its utilization. And since the population served is part of the MIG, they have folded in a report regarding the program to the required reports about the grant.

The state does have plans to develop additional quality assurance mechanisms to report about quality indicators such as quality of life, cost effectiveness, utilization, and range of goods and services.The state does require that the plan of care (plan for independence) include plans for emergency backup.

At the present time there is no comprehensive policy dealing with fraud or abuse of funds. The state typically would turn these over to the Attorney General. However, in these cases, the amount of money involved in an individual situation does not rise to a level where there is a lot of interest to pursue. In the future, the state is likely to adopt provisions to address this issue that are now used in the HCBS waiver for persons with physical disabilities.

Challenges and Other Observations:

The biggest challenge discussed is sufficiently defining the range of allowable purchases. This is described as a slippery slope that could consume a lot of time as individual situations are reviewed.

Because this is a new program, the state has taken a position of trying to approach it flexibly, making changes that enhance the program's effectiveness and that allow them to administer it prudently. They view themselves as needing a learning curve to identify gaps and to establish the ongoing operation and policies of the program. A recent example of the type of clarification needed involves work performed by personal assistants exceeding 40 hours per week. The state determined that overtime could be approved and that time and a half would be paid in those instances.

APPENDIX 12: SUMMARY OF MAJOR RECOMMENDATIONS

Appendix 12 summarizes our major recommendations, which are in rows highlighted in dark blue, and specific recommendations that are related to each major recommendation. In the table we identify whether we anticipate including the recommendation in the three year action plan. We also identify the potential impact that the recommendation will have on each of the organizing principles included in the original RFP:

- Sustainability
- Support in the home
- Support for families
- Integration with Tribal Care
- Transparent and accountable system
- Services must have measureable outcomes and be culturally appropriate

Appendix 12: Summary of Recommendations for the Alaska Long Term Care Plan

			Organizing Principles					
Primary Recommendations :	**Rationale and Potential Issues:**	**In 3 Year Action Plan**	**Sustainability**	**Support in the home**	**Support for families**	**Integration with Tribal Care**	**Transparency/ Accountability**	**Measureable outcomes/ culturally appropriate**
1. Restructure process for matching people with funding sources to developing a full-functioning Aging and Disability Resource Center (ADRC)								
Restructure initial point of contact, triage, eligibility determination and options counseling.	Current process is not efficient, resulting in service delays and use of more costly services. Potential issues: determining which functions should be done by public vs. private sectors.	X	+++	++	++	++	+++	+++
Develop unified assessment instrument and process that can be used across programs.	A unified assessment instrument and process will allow for eligibility determinations for multiple programs to be done concurrently, identify areas where active treatment is needed, and facilitate development of the service plan.	X	+++	+++	+++	+++	+++	+++
Add more domains to assessment tools.	Current assessments fail to cover pertinent information. Not all information would be mandatory. Additional information could be used for individualized budgets and performance indicators.	X	+++	+++	+++	+++	+++	+++
Integrate financial and functional eligibility criteria for all programs.	Need to ensure that non-federal funds are only used where federal funds are not available and that people don't fall into coverage gaps. Will require revisions of state rules and program policies.	X	+++	+++	+++	+++	+++	+++
Offer options counseling to private pay individuals in order to reduce likelihood of earlier entry into public system.	Earlier long term care options consultation can help identify and steer people toward less intensive services options that meet needs and helps people to make better decisions about how to maximize their resources. Will increase short term administrative costs, but will offer longer term savings.	X	+	+++	+++	+	+	+
Collocate a contingent of financial eligibility workers within the SDS Assessment Unit.	This will improve the flow of the business process and paperwork. Goal should be to expedite applications, help consumer/family move through process , and shorten time between initial application and authorization of services.	X	++	+++	+++	+	+++	+

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Improve and expand the Pre-admission Screening and Resident Review (PASRR) process.	Need to improve the integration of PASSR into screening, assessment, and services planning functions. This will improve efficiency and make it easier for the State to comply with its obligations. It also provides better assurance that the needs of people will be recognized and addressed earlier in the service planning process.	X	o	+	+	+	+++	+
2. Restructure waiver and PCA budget management								
Adopt waiver cost control mechanisms that shift controls from caps on services and set rates to establishing tiered benchmarks used in combination with a delineated processes to authorize hours.	Current assignment of hours or service amount is limited by caps and/or individual negotiations between State assessment staff and individual and 'Care Coordinators (CCs). Difficult to ensure comparability in negotiations and sets up antagonistic relationships and limits flexibility to consider environmental circumstances.	X	++	+++	+++	+++	+	+
Liberalize or eliminate rules that currently restrict the use of services that are used to maintain people in their own home, such as limitations on chore and respite care.	These services are low intensity and help to keep people in their homes. This action should only be taken in conjunction with the adoption of tiered benchmarks.	X	++	+++	+++	+	o	+
In developing benchmarks, pay close attention to the amount set for individuals on the DD waiver with challenging behaviors that reside in ICF/MR facilities out of state, or who would otherwise go to ICF/MR facilities out of state	States have used this mechanism for serving people with very challenging needs. One issue for the State would be to find the needed behavioral expertise and to secure training that would be required for staff.	X	o	o	o	o	o	o
Expand the menu of waiver services to address behavioral issues, crisis outreach services, specialized home modifications due to behavioral needs, or other components that would enable the group mentioned in above to return home.	One issue for the State would be to find the needed behavioral expertise and to secure training that would be required for staff.	X	o	o	o	o	o	o

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			Organizing Principles					
Primary Recommendations :	**Rationale and Potential Issues:**	**In 3 Year Action Plan**	**Sustainability**	**Support in the home**	**Support for families**	**Integration with Tribal Care**	**Transparency/ Accountability**	**Measureable outcomes/ culturally appropriate**
3. Shift consumer directed funds to a Medicaid authority that provides the State with greater control while providing consumers with greater flexibility								
Reallocate existing CD-PCA funds to a self directed personal assistance option under the 1915 (j) authority.	Provides State with greater control on overall expenditures and size of program. Gives consumers greater flexibility. Could be especially helpful in remote areas. Ability to have direct care staff as domestic employees to bypass prevailing wage laws.	X	+	+++	+++	+++	+	++
Address individual capacity to self-direct before allowing consumer direction.	This can be incorporated into a revised assessment process.	X	+++	++	++	++	++	++
Establish Fiscal Intermediaries.	This would help to address the issue of control by providers, but would require efforts to create some new partners in the system.	X	+	+++	+++	+++	+++	+++
Establish other tools to assist consumers in participating in consumer direction.	State would need to establish a counseling component which does not currently exist.	X	++	+++	+++	+++	+++	+++
Create CD option under waivers.	Similar issues as the 1915(j), however, would allow State to authorized individual budgets covering supports for people with greater impairment.		+	+++	+++	+++	+	++
Restructure a portion of the Title III and/or State only dollars to create a consumer directed option for individuals who are not Medicaid eligible.	Allowing consumer direction would allow individuals who don't meet Medicaid financial or functional eligibiltiy to remain in the community and prevent spend down to Medicaid.		+++	+++	+++	+++	+	++

Appendix 12: Summary of Recommendations for the Alaska Long Term Care Plan

Primary Recommendations :	Rationale and Potential Issues:	In 3 Year Action Plan	Organizing Principles Sustainability	Support in the home	Support for families	Integration with Tribal Care	Transparency/ Accountability	Measureable outcomes/ culturally appropriate
4. Modification of the NF Level of Care eligibility criteria to address underserved populations								
Conduct study to estimate the impact of altering the NF-LOC. As part of study, assess the impact on eligibility for individuals in PHs.	The NF-LOC criteria a very strict and limits individuals with ADRD and BI from getting services. Liberalizations could reducte costs by allowing people to access support before they have mor serious decline. However, making the criteria too broad could increase costs by making more people eligible. Therefore, we reccomend the State engage in a study before finalizing recommendations.	X	-/+	+++	+++	+	o	o
As part of study, explore altering the impairment definition in NF-LOC, and PCA eligibility criteria to consider combined need for physical assistance and living circumstances when interwoven. This would be intended to address needs in frontier areas.	Need some flexibility to address the special issues of individuals needing chore and/or personal care in locations where the need for assistance and environmental circumstances are strongly interwoven. Could help people from becoming so impaired that they are relocated.	X	+	+++	++	+++	+	+++
Pursue a 1936 Benchmark plan for a pilot program that would target individuals with ADRC and TBI.	Benchmark plans are new options and unclear if CMS would sign off. Effort should be closely integrated with the NF-LOC effort.	X	+	+++	++	+++	+	+

Appendix 12: Summary of Recommendations for the Alaska Long Term Care Plan

			Organizing Principles					
Primary Recommendations :	**Rationale and Potential Issues:**	**In 3 Year Action Plan**	**Sustainability**	**Support in the home**	**Support for families**	**Integration with Tribal Care**	**Transparency/ Accountability**	**Measureable outcomes/ culturally appropriate**
5. Draw down more Medicaid FFP for services funded only with State funds								
1115 using DSH to fund CAMA.	Potentially provides the State with additional FFP to serve this population. Would require careful planning and negotiation with CMS to gain approval. State may lose some of the current flexibility it has with State only funded programs. And administrative effort might increase in order to meet conditions of the waiver approval.	X	++	+	+	o	+	+
Change Pioneer Homes asset criteria to be consistent with waiver	This would likely reduce the number of people for whom the state is paying 100% of the cost of care. More people would become financially eligible for Medicaid services and potentially would be eligible to have their long term care services financed through the Medicaid waiver.	X	++	o	o	o	+	o
Explore the use of a benchmark plan to cover the cost of Medicaid eligible residents of Pioneer Homes when those residents fail to meet the level of care for a nursing home (and waiver).	This would potentially allow AK to collect federal financial participation for some portion of PH residents. This recommendation requires further examination to determine whether it is feasible.	X						
Expedite collection of FFP for PH through faster authorization process. Have all individuals sign form starting waiver application at entry into NF. Bill retrospectively to that date.	This would allow FFP to flow sooner and would offset State costs.	X	++	o	o	o	o	o
Increase the room and board rate or change the cost of care requirement for PH.	This would eliminate discrepancies and would help to avoid problems for individuals to maintain Medicaid eligibility.	X	+++	o	o	o	o	o

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			Organizing Principles					
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6. Improve Quality Management Process								
Establish core performance indicators that correspond to CMS requirements. Build on work current underway withing DSDS.	There are few, if any, performance indicators in place and being used to manage programs on a regular basis. While there is some tracking of information, the State has not demonstrated use of the information to meet expected standards of performance or to remediate performance.	X	++	++	++	o	+++	+++
Increase capacity to routinely obtain data for indicators through core business processes: assessment/reassessment, CC case notes, critical incidents, licensure reviews and investigations, APS investigations, provider enrollment, certification, and other identified areas.	The quality management structure should be integrated within the business processes performed in the administration of programs. It provides the State with the capacity to demonstrate more accountability, protect public policy interests, and to address the needs of a vulnerable population served by programs. It provides systematic ways to evaluate performance based on service outcomes.	X	++	++	++	o	+++	+++
Develop core management reports for State staff, CCs, and consumers.	Reports will be key to translating raw data into actionable information.	X	+++	+	+	o	+++	++
Refine flow of information about quality problems.	State has started to look at this business process and flow of information, however it appears that there is no well established point of coordination and management. Additionally, quality management appears to be primarily incident related at this point. The State will want to have a more proactive approach.	X	+++	+	+	o	+++	++
Refine quality management system to investigate and coordinate reaction to potential quality issues. Process should include internal DSDS, cross-agency, and external stakeholder committees (external should also have a tribal and non-tribal component).	Similar to the issues identified above. Incorporates other partners.	X	+++	+	+	o	+++	++

Appendix 12: Summary of Recommendations for the Alaska Long Term Care Plan

Primary Recommendations :	Rationale and Potential Issues:	In 3 Year Action Plan	Organizing Principles: Sustainability	Support in the home	Support for families	Integration with Tribal Care	Transparency/ Accountability	Measureable outcomes/ culturally appropriate
Update provider manuals and also make them easier to use by integrating them within other tools, such as assessment, case note tracking, and provider reporting. Manuals should include automated alerts for providers to note that policies or procedures have been modified.	Would improve relationships with providers and understanding of service requirements.	X	++	+	+	+	+++	+
Establish greater infrastructure to verify services are actually provided as prescribed.	This should be a priority for PCA and other in-home services where the highest risk for fraud, upcoding or failure to provide services as directed exists.	X	+++	+	+	o	+++	++
Pursue alternatives to federal background check requirements as the means to verify suitability of potential direct care staff.	Could increase access to workers in rural areas. This could be very important in frontier and village areas. State would need to establish very clear guidelines.		+	++	++	+++	+	++
Make online training available and make portions mandatory for service staff.	There are few training requirements or curriculums that have been standardized for service staff. State should consider a broader training strategy, but minimally make on line training available.	X	+++	++	++	o	+++	+
Adopt an ongoing process to evaluate access and service gaps in regional areas, and to determine need for new service development.	There is a need to routinely evaluate the availability of services and to ensure that a balance of facility and in home services exists within regions. Also have existing problem of access to specialty services for low incidence populations. These issues tie to financial sustainability of services at the local level by ensuring a match up of provider development with consumer need. There appears to be quite a difference in the local infrastructure, depending on the region.	X	++	+	+	o	o	++

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			Organizing Principles					
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Shift standard setting framework for programs to a "service qualification and standards of practice" model. Use certification or licensing as basis for legal authority but ensure that State has legal authority to take a range of actions on problems.	Current service standards have unclear mechanisms for enforcement. Need a broad strategy for establishing standards of practice in services, monitoring, and remediation/enforcement either through a certification process or licensing. Existing model is primarily a facility based licensing model. Certification system is weak for assuring service components meet any standards. As the State shifts to better balance utilization between facilities and in home services, it will want additional tools for managing the quality of service.	X	+	+	+	+	+++	++
Modify standards appliying to assisted living facility services. Change standards to make distinctions in the size of the service/facility and to ensure that the service will be tailored to meet the needs and goals of services for the clientele served.	Changes to the licensing and certification standards will provide the State with improved tools to define the array of services, will help to ensure that services meet the needs and goals of the clientele served, and can allow for variation in the licensing and certification requirements depending upon size of service and the nature of clientele.		+++	o	o	o	+++	+++

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			Organizing Principles					
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7. Restructure Care Coordination								
Require CCs to be independent of service providers. Exceptions to this policy can be made in rural areas where the infrastructure is not sufficiently large enough to support an independent model. In these cases, require a demonstration in the freedom of the CC to advocate and act on behalf of the individual.	Agency based CCs have conflicting interests in areas of advising, assisting with access, monitoring, and remediating problems with service plan implementation. State would need to develop CC capacity.	X	+++	+++	+++	-	+++	+
State should integrate the CC into the overall quality assurance plan because the CC is most likely to be the front line for evaluating the service delivery for individual recipients.	There is no evidence that CCs perform any systemic functions relating to quality assurance. Need to create stronger ties between the CCs and the State agency for quality control, and provide the CCs with more authority to remediate.	X	+	++	++	+	+++	+++
Revise reimbursement methodology for care coordination.	CC payment is currently a monthly unit amount which does not reflect actual service costs and incents CCs to spend less time on case management. Adoption of smaller units would require CCs to be more accountable, would allow the State to track utilization, and would eliminate the bias against difficult to serve individuals. Would also erase an incentive to place people into assisted living rather than do the work necessary to combine several in home support services.	X	++	+++	+++	+++	+++	+++

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8. Expand IT efforts								
Establish and implement plan for integrating and automating the intake, assessment, authorization, and service planning process.	Addresses multiple issues of consistency, timeliness, and program integrity.	X	+++	+++	+++	+++	+++	+++
Development of a web-enabled, searchable database of available providers; information gathered through provider certification process.	CCs and consumers have very little information for selecting providers.	X	+++	+++	+++	+++	+++	+++
Expand use of telemedicine and smart house technology.	Would help as tool to shift away from reliance on assisted living facilities. Some demonstrations are seeing excellent results with investments in this. Wisconsin and Indiana both have demonstrations using new smart house technology. The use of these technologies could reduce reliance on staffing needs, something that is a growing issue in being able to provide services.		++	+++	+++	++	+	++
Build software to support CC, including automated client tracking, assessment and case note support.	This would improve consistency and could also provide the State with a way to collect data and monitor quality.	X	+++	+++	+++	o	+++	+++

Appendix 12: Summary of Recommendations for the Alaska Long Term Care Plan

Primary Recommendations :	Rationale and Potential Issues:	In 3 Year Action Plan	Organizing Principles Sustainability	Support in the home	Support for families	Integration with Tribal Care	Transparency/ Accountability	Measureable outcomes/ culturally appropriate
Miscellaneous Recommendations								
Clearly articulate the State's philosophy towards long term care and incorporate it into program operations	A guiding philosophy can play a central role in shaping how a program evolves. The State should institute processes under which the impact of any changes to policies and regulations on the goals this philosophy supports is considered.	X	+	+++	+++	+++	+++	+++
Sliding Scale Parental Fees for under 18.	Burden on parents and likely to be controversial. Does provide the State with offsetting revenues and is supportive of personal responsibility as a public policy.		+++	o	-	o	+	o
Add a transition service to the waivers for people moving from institutional services, such as to people residing in out of state ICF/MR facilities, to a waiver service	This service could be incorporated into waiver program. Would represent initial one time costs.	X	o	o	o	o	o	o
Allow for shared PCA services. Recommend limiting shared arrangements to two people living in the same home. Shared care allows for concurrent provision of service to two individuals. The rate paid for the combined service is less than the rate paid for two separate people.	This provision would allow people to live at home with a roommate that also has a disability. The home should be controlled by the individuals and not a provider in order to differentiate it from assisted living.	X	+	+++	++	+	o	o
Establish an option to use a universal worker for in home services such as PCA and chore services.	Because there is a shortage of direct care staff in many locations, a universal worker could cover several service categories. Claims submissions would be easier to do and could be reviewed more easily for accuracy by the individual. Developing an individualized budget option for the waiver could substitute for this.	X	++	+++	++	+	++	+

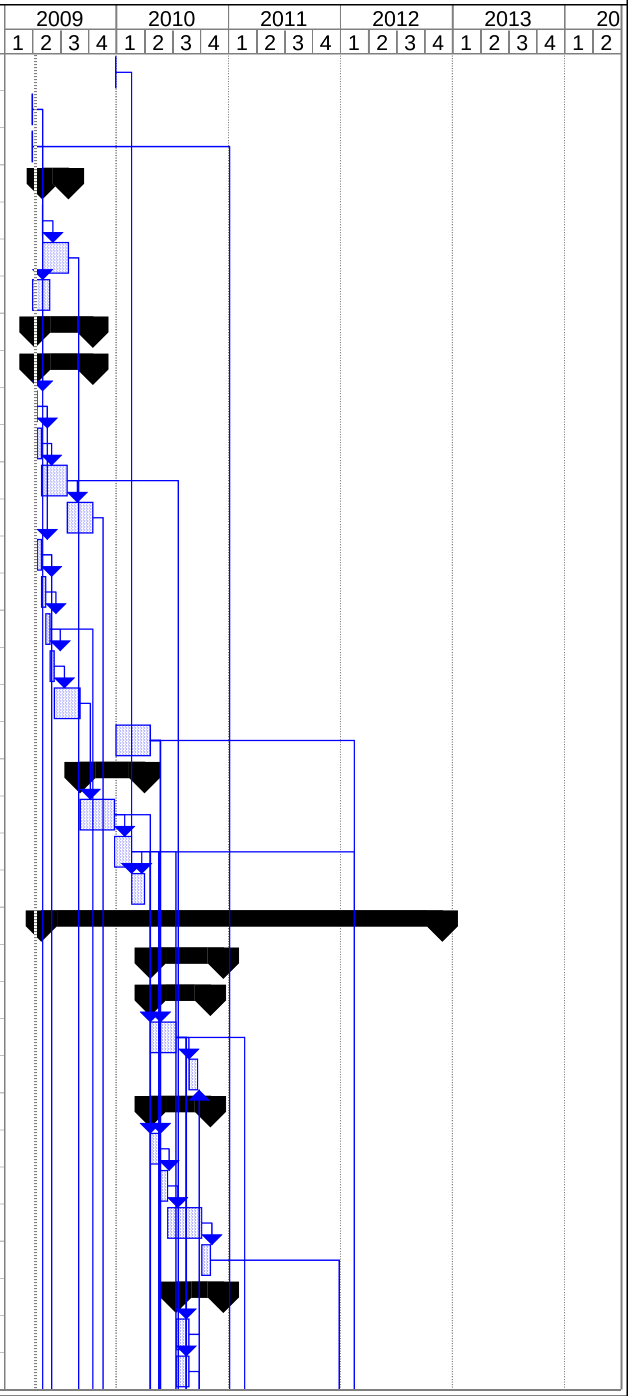
Appendix 12: Summary of Recommendations for the Alaska Long Term Care Plan

			Organizing Principles					
Primary Recommendations :	**Rationale and Potential Issues:**	**In 3 Year Action Plan**	**Sustainability**	**Support in the home**	**Support for families**	**Integration with Tribal Care**	**Transparency/ Accountability**	**Measureable outcomes/ culturally appropriate**
Adopt strategy to slow/prevent entry of lower income seniors into Medicaid and into more intensive services, by adopting a cost share program that offers in home services and supports, or other low intensity care. This would offer services similar to some now provided through grant programs, but would require restructuring.	A low cost program to delay entry into nursing facilities or assisted living and targeting low income seniors who would otherwise spend down to Medicaid fairly quickly can be a very cost effective early intervention. Similar programs in MN and IL work most effectively when tied to same level of care and when the alternative program includes care coordination. Individuals would share in the cost on a sliding scale. This option would require restructuring of existing grant programs.		+++	+++	+++	o	o	++
Develop a Public/Private Long Term Care Insurance Policy that integrates with Medicaid.	This policy could lower the cost of LTCI allowing more individuals to purchase policies.		++	++	++	o	++	+

APPENDIX 13: THE THREE YEAR ACTION PLAN

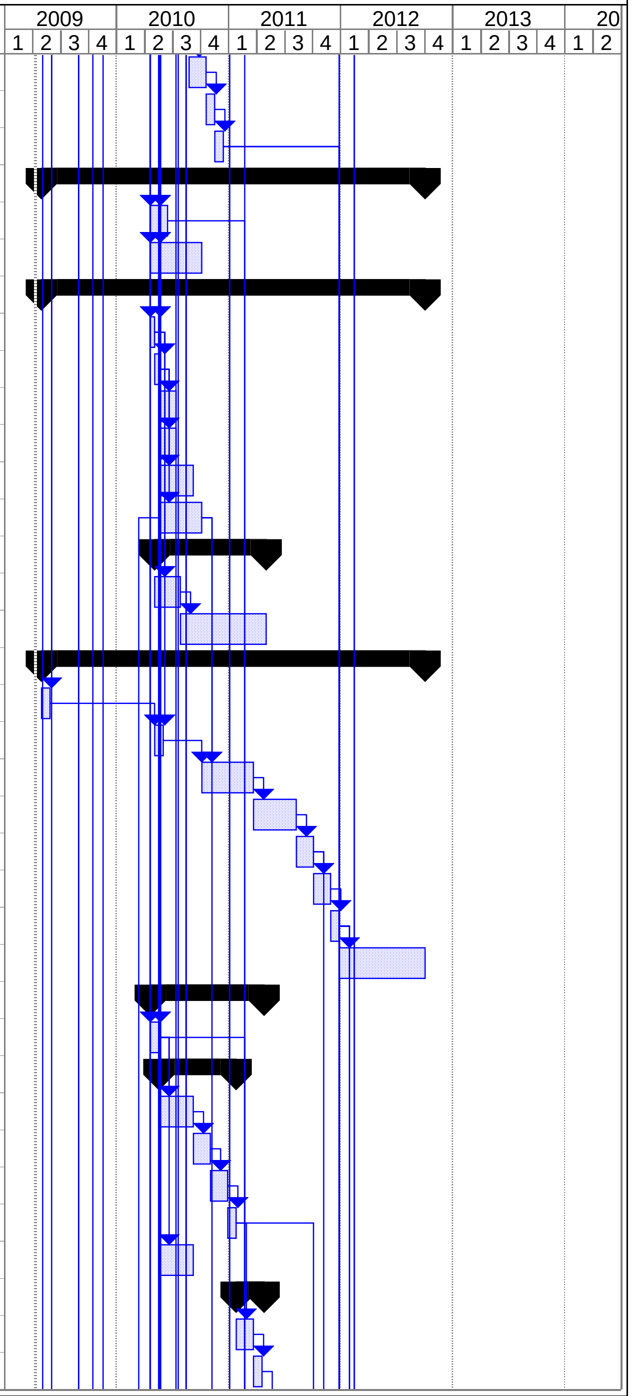
Long Term Care Plan-Three-Year Action Plan

ID	Task Name	Predecessors	State Staff	Contr actual
1	New Fiscal Year 09			
2	LTCP Final Report			
3	Myers & Stauffer Cost Survey Complete			
4	**CMS Concept Paper**			
5	Submittal		Primary	
6	Receive reaction	5	Primary	
7	Initiate Ongoing Strategic Planning Process	2	Primary	
8	**Development of legislative or budget package**		**Primary**	**Y**
9	**Make State’s LTC philosophy more prominent**		**Primary**	**Y**
10	Convene State staff to refine LTC philosophy	2		
11	Obtain stakeholder input	10		
12	Incorporate philosophy into legislation or budget package	11		
13	Adopt procedures to ensure philosophy will be considered in policy making process	12		
14	Developing parameters for package	10	Primary	Y
15	Developing the fiscal impact	14	Primary	Y
16	Submission to OMB	15	Primary	Y
17	Submission to legislature	16	Primary	Y
18	Passage	17	Primary	
19	Hiring new State staff		Primary	
20	**Obtaining Contractual Support**		**Primary**	
21	Develop RFPs	18	Primary	
22	Issue RFPs	21	Primary	
23	Award RFPs	22,1	Primary	
24	**Develop full-functioning Aging & Disability Resource Center (ADRC)**			
25	**Restructure initial contact and triage**			
26	**Development of Initial Intake Infrastructure**			
27	Decisions on who will perform functions (who, how many, regions, etc.)	19,22	Primary	Y
28	DS3-Development of tracking database	27,35	Primary	Y
29	**DS3-Development of information and assistance resources**		**Oversight**	**Y**
30	Develop types of I & A to be included	19,22	Primary	Y
31	Develop platform for collecting and querying information	30	Primary	Y
32	Compilation of information into platform	31	Primary	Y
33	Implement	32	Primary	Y
34	**Development of Triage Infrastructure**			
35	Primary data collection & instrument development	27	Oversight	Y
36	Development of initial contact and triage protocols	27	Oversight	Y



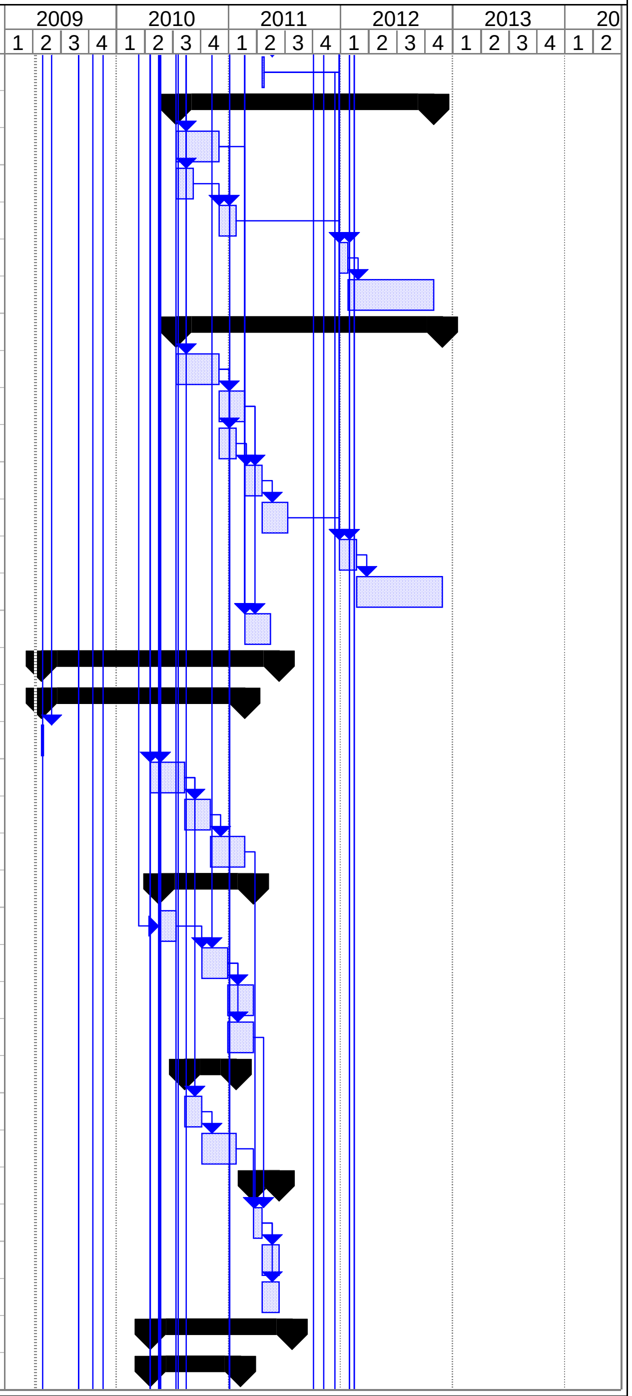
Long Term Care Plan-Three-Year Action Plan

ID	Task Name	Predecessors	State Staff	Contractual
37	Collection of pilot data	35,36	Oversight	Y
38	Validation & refinement of triage protocols	37	Oversight	Y
39	Implement	38	Primary	
40	**Restructure assessment and eligibility determination**		**Primary**	
41	Design review inc. deciding when eligibility determination starts	19,22	Oversight	Y
42	Collocate financial eligibility workers within the SDS Assessment Unit	19,22	Primary	
43	**Develop unified assessment instrument & process**			
44	Decision on whether to adapt and modify MDS Home Care	19,22	Primary	
45	Developing agreement with InterRAI	44	Primary	
46	Identification of necessary modules not included in InterRAI tools	45	Oversight	Y
47	Develop trigger questions and protocol to integrate tools in suite	45	Oversight	Y
48	Develop or incorporate mental health module (ensure meets PASRR requiremei	45	Oversight	Y
49	Develop integrated care plan development module	45	Oversight	Y
50	**Refine & integrate financial & functional eligibility criteria for all programs**		**Primary**	
51	Develop decision logic for use of each programs	44	Primary	Y
52	Make necessary regulatory changes	51	Primary	Y
53	**DS3-Automate assessment tool**			
54	Decision regarding whether to automate in-house or contract	14	Primary	
55	Specification development	54,44	Oversight	Y
56	Software development	55,49	Oversight	Y
57	Pilot	56	Oversight	Y
58	Refine	57	Oversight	Y
59	Train (software and instrument)	58	Primary	Y
60	Implement	59	Primary	
61	Ongoing monitoring & training/retraining	60		
62	**Develop information on providers capacity**			
63	Establish types of information providers should submit	19,22	Oversight	Y
64	**DS3-online process for providers to submit capacity information**			
65	Develop consumer rating of provider capacity	63		
66	Develop specifications	65		
67	Develop background database	66	Primary	Y
68	Develop interfaces for consumers and CC to search database	67	Primary	Y
69	Incorporate provider capacity submittal as requirement for certification	63	Primary	
70	**Implementation**			
71	Outreach	68	Primary	Y
72	Provider training	71	Primary	Y



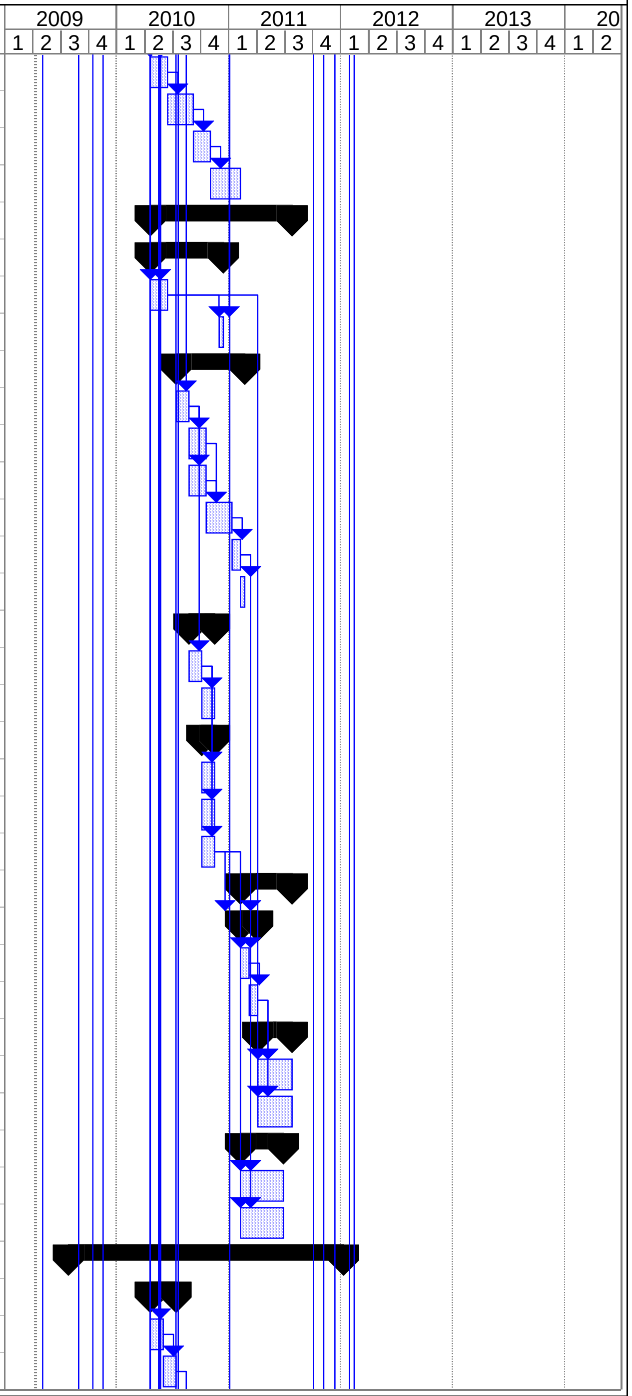
Long Term Care Plan-Three-Year Action Plan

ID	Task Name	Predecessors	State Staff	Contractual
73	Implement	72	Primary	
74	**Establish optional systems guide capacity**			
75	Establish performance requirements and reimbursement	27	Oversight	Y
76	Develop oversight mechanisms	27	Oversight	Y
77	Develop training curriculum	75,76	Oversight	Y
78	Recruit and train guides	77,33,3	Primary	
79	Ongoing monitoring & training/retraining	78	Oversight	Y
80	**Develop Options Counseling Capacity**			
81	Establish Options Counseling approach	27	Oversight	Y
82	Establish performance requirements and reimbursement	81	Oversight	Y
83	Develop oversight mechanisms	81	Oversight	Y
84	Develop training curriculum	82,83	Oversight	Y
85	Solicitation to select Options Counseling contractors	84	Primary	
86	Award contracts	85,33,3	Primary	
87	Ongoing monitoring	86	Primary	
88	Develop modifications to cost allocation plan for administrative FFP	27,41,6	Primary	Y
89	**Restructure waiver & PCA budget management**			
90	**Develop benchmarks**			
91	Decision for process for development of benchmarks (M&S, MDS HC-Rugs, etc.)	14	Primary	
92	Develop cost modeling file	19,22	Oversight	Y
93	Identify characteristics to be included in benchmarks	92	Oversight	Y
94	Develop benchmark amounts	93	Oversight	Y
95	**Adapt process for approving care plans**			
96	Develop infrastructure for linking assessment to care plan	49SS	Oversight	Y
97	Develop tool for documenting hours	96,49	Oversight	Y
98	Develop review process for care plans below benchmark	97	Oversight	Y
99	Develop review process for care plans above benchmark	97	Oversight	Y
100	**Adapt State budget development process**			
101	Develop method for integrating benchmarks and global budget	92	Primary	Y
102	Develop P&P for over benchmark reserve	101	Oversight	Y
103	**Rule changes**			
104	Adoption of new budget management process	94,99,1		
105	Liberalize rules for existing services	104	Oversight	Y
106	Expand the menu of waiver services	104	Oversight	Y
107	**Shift consumer directed funds to 1915(j) authority**			
108	**Application for a 1915(j) State Plan Self-Directed PC**			



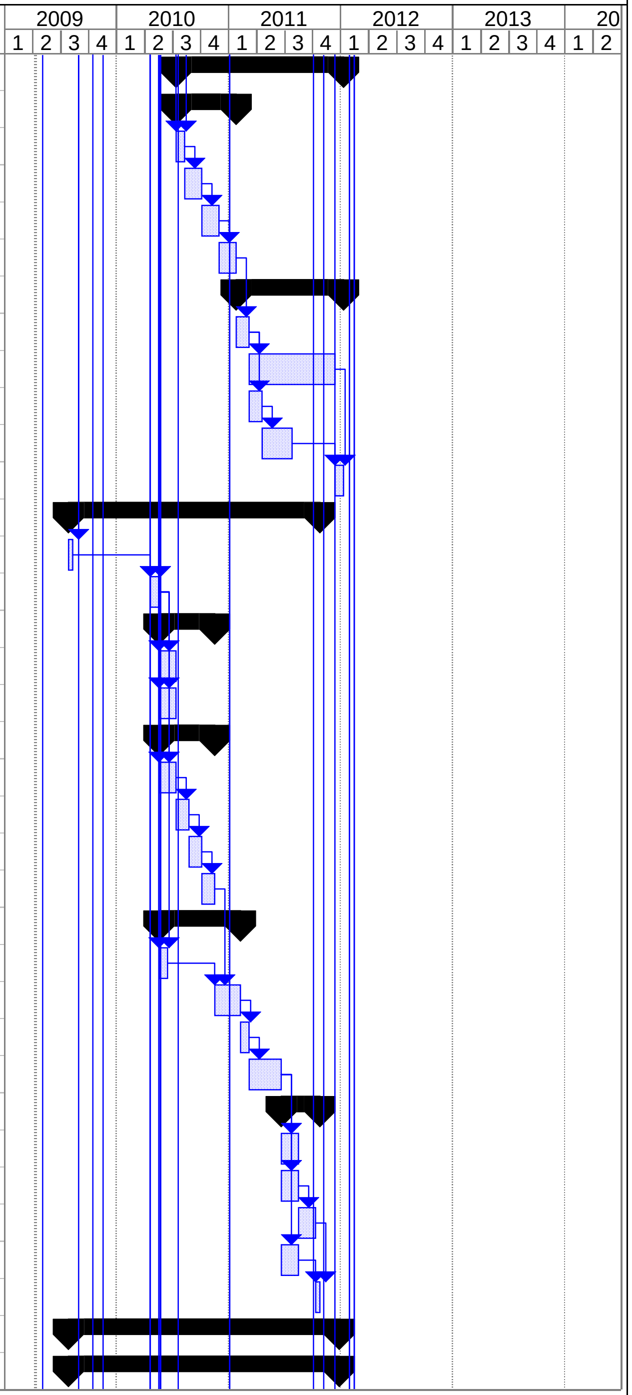
Long Term Care Plan-Three-Year Action Plan

ID	Task Name	Predecessors	State Staff	Contractual
109	Development of program parameters	19,22	Oversight	Y
110	Develop process for setting budget	109	Oversight	Y
111	Submission of application to CMS	110	Primary	Y
112	CMS Approval	111	Primary	
113	**Building infrastructure for Consumer Direction**			
114	**Enhancement to ADRC**			
115	Develop process to assess capacity to self direct	19,22	Oversight	Y
116	Incorporate process for informing consumers about self directed options	115,81	Oversight	Y
117	**Establish Fiscal Intermediaries**			
118	Key program design issues (number, integration w/ consumer assistance, etc.)	27	Oversight	Y
119	Develop performance requirements	118	Oversight	Y
120	Develop reimbursement methodology	118	Oversight	Y
121	Issue RFP	119,120	Primary	
122	Select contractor(s)	121	Primary	
123	Implementation	122	Primary	
124	**Develop Consumer SD Tools**			
125	Manual	118	Oversight	Y
126	Budget management	125	Oversight	Y
127	**Staff**			
128	Recruiting	125	Oversight	Y
129	Training	125	Oversight	Y
130	Managing	125	Oversight	Y
131	**Transitioning current CDPCA to 1915(j)**			
132	**Notice to consumers of option to choose 1915(j) or agency-based services**	**122,130**		
133	Outreach and education	122,130	Oversight	Y
134	Addressing questions	133	Oversight	Y
135	**Enrollment from current CDPCA to 1915(j)**			
136	Ensuring have capacity to self-direct (id who will do-current ADRC contract	134,115		
137	Enrollment by fiscal intermediary(s)	115,134		
138	**Enrollment of CDPCA not choosing 1915(j) to agency-based PCA**			
139	Assistance with locating agency	122,130		
140	Assistance to CDPCA agencies that want to become traditional PCA	122,130		
141	**Modification of the NF Level of Care eligibility criteria to address underserved populatio**			
142	**Obtain Medicaid MDS DUA (Data use agreement)**		Primary	**Y**
143	Obtain or modify DUA (Data use agreement)	19	Primary	Y
144	Get MDS data	143	Primary	Y



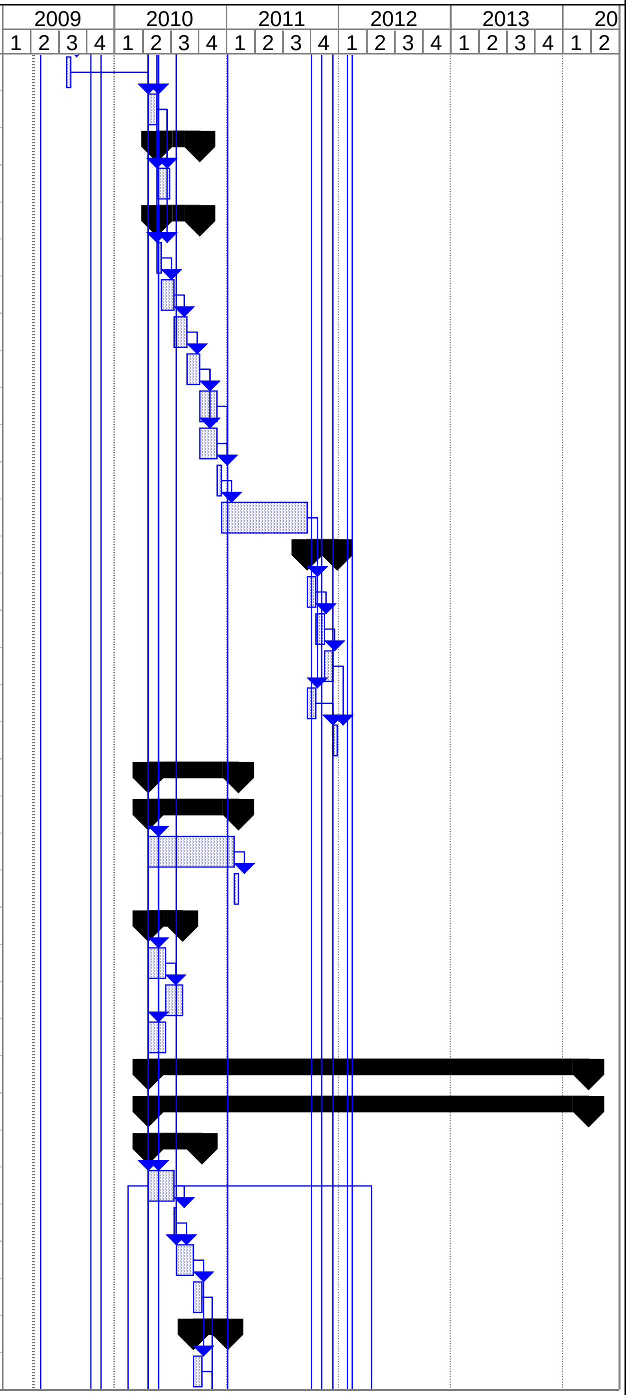
Long Term Care Plan-Three-Year Action Plan

ID	Task Name	Predecessors	State Staff	Contr actual
145	**Conduct study to estimate the impact of altering the NF-LOC**			
146	**NF-LOC Study**			
147	Develop methodology	22,144	Oversight	Y
148	Develop modeling file	147	Oversight	Y
149	Model impact	148	Oversight	Y
150	Proposed recommendations and fiscal impact statement	149	Oversight	Y
151	**Alterations to NF-LOC**			
152	Decision whether & how to modify NF-LOC	150		
153	Regulation change	152		
154	Waiver amendment	152	Primary	Y
155	CMS Approval	154	Primary	
156	Implementation	155,153	Primary	
157	**Pursue a 1937 Benchmark for pilot targeting individuals with ADRD & BI**			
158	Review response to CMS concept paper	6	Primary	Y
159	Decision whether to proceed	19,158	Primary	
160	**Program Design**			
161	Select targeting criteria	22,159	Oversight	Y
162	Select targeting area	22,159	Oversight	Y
163	**Design benefit package**		**Oversight**	**Y**
164	Service delivery model (e.g., ffs, capitated rate, PCCM, etc.)	22,159	Oversight	Y
165	Scope & Requirements for services	164	Oversight	Y
166	Care plan/budget approval process	165	Oversight	Y
167	Quality Management	166	Oversight	Y
168	**Development of Benchmark application**		**Oversight**	**Y**
169	Obtain copies of other state's applications	22,159	Oversight	Y
170	Develop application	167,169	Oversight	Y
171	Submission to CMS	170	Primary	Y
172	CMS Approval	171	Primary	
173	**Implementation**		**Primary**	**Y**
174	Recruitment of providers	172	Primary	Y
175	Outreach	172	Primary	Y
176	Training	175	Primary	Y
177	MMIS, EIS modifications	172	Primary	Y
178	Begin serving individuals	176,177	Primary	Y
179	**Draw down more Medicaid FFP for services funded only with State funds**			
180	**1115 using DSH to fund CAMA.**			



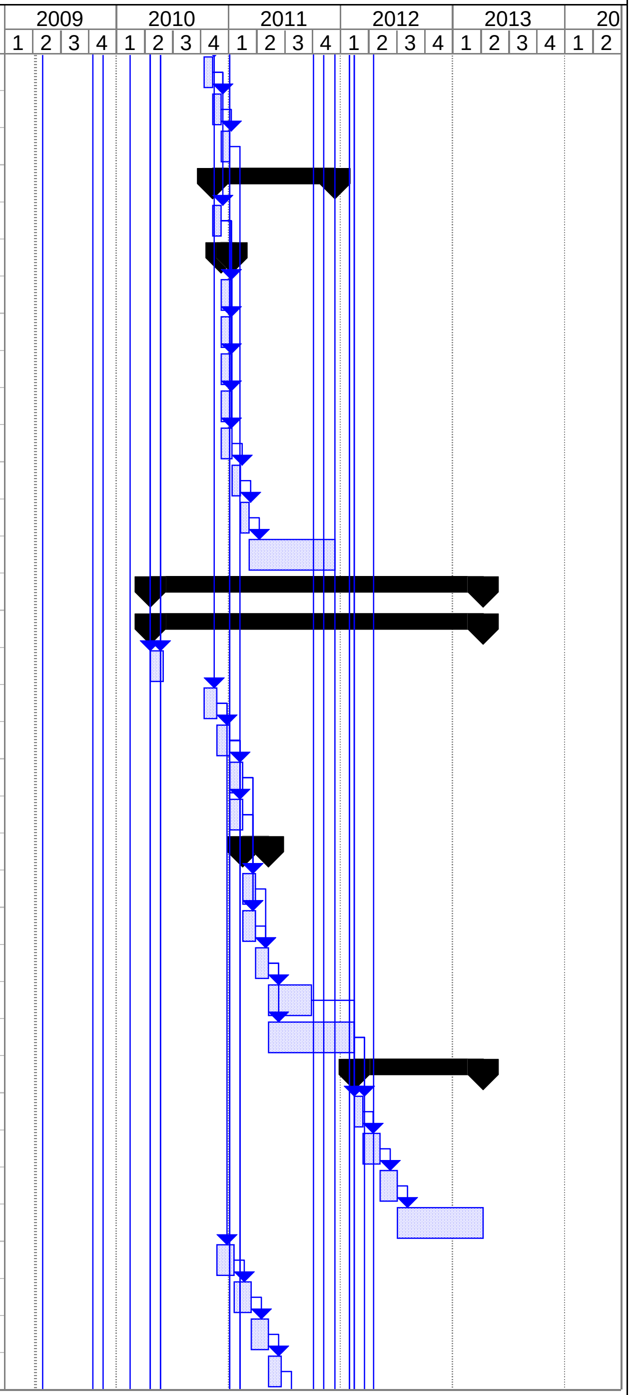
Long Term Care Plan-Three-Year Action Plan

ID	Task Name	Predecessors	State Staff	Contractual
181	Review response to CMS concept paper	6	Primary	Y
182	Decision whether to proceed	181,19	Primary	
183	**Program Design**			
184	Select targeting criteria	22,182	Oversight	Y
185	**Design benefit package**			
186	Service delivery model (e.g., ffs, capitated rate, PCCM, etc.)	22,182	Oversight	Y
187	Scope & Requirements for services	186	Oversight	Y
188	Care plan/budget approval process	187	Oversight	Y
189	Quality Management	188	Oversight	Y
190	Draft 1115 application	189	Oversight	Y
191	Develop 1115 Budget Neutrality documentation	189	Oversight	Y
192	Submission to CMS	190,191	Primary	Y
193	CMS Approval	192	Primary	
194	**Implementation**			
195	Enrollment of providers	193	Primary	Y
196	Outreach	195	Primary	Y
197	Training	196	Primary	Y
198	MMIS, EIS modifications	193	Primary	Y
199	Begin serving individuals	197,198	Primary	
200	**Increasing FFP for Pioneer Homes (PHs) (PH 1937 part of earlier task)**			
201	**Change Pioneer Homes asset criteria to be consistent with waiver**			
202	Rule change	19	Primary	Y
203	Implementation	202	Primary	Y
204	**Expedite collection of FFP for PH through faster authorization process**			
205	Alter process so individuals sign waiver application at PH application	19	Primary	Y
206	Establish ability for retroactively claiming	205	Primary	Y
207	Increase the room & board rate or change the cost of care requirement for PH	19	Primary	Y
208	**Improve Quality Management Process**			
209	**Develop Data-Driven Quality Management Process**			
210	**Selection of Performance Indicators (PIs)**			
211	Development of Possible PIs	19,22	Oversight	Y
212	Compare PIs with LTC philosophy	211	Oversight	Y
213	Obtain stakeholder feedback	212,12	Oversight	Y
214	Revised Indicators	213	Oversight	Y
215	**Data elements**			
216	Crosswalk of PIs with Available Data	213	Oversight	Y



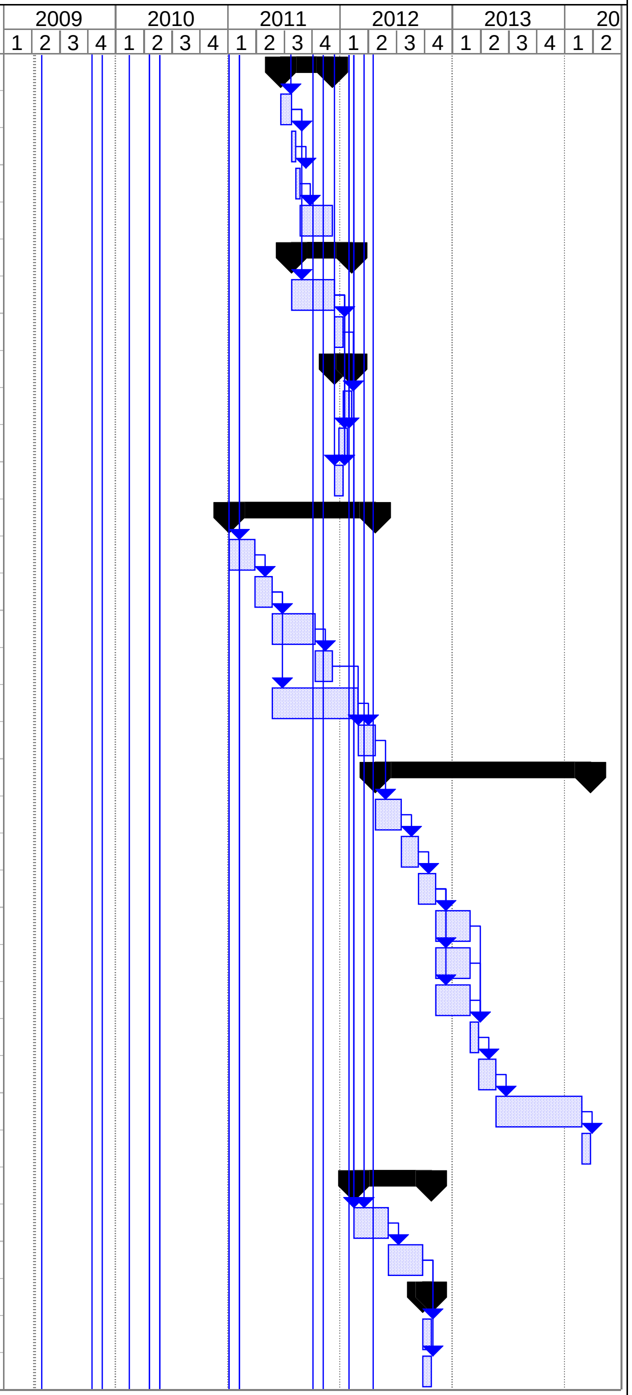
Long Term Care Plan-Three-Year Action Plan

ID	Task Name	Predecessors	State Staff	Contractual
217	Identification of Modifications and New Data to be Collected	216	Oversight	Y
218	Stakeholder feedback	217	Oversight	Y
219	Revised Data Elements	218	Oversight	Y
220	**Development of management reports**			
221	Develop framework for reports	217	Oversight	Y
222	**Develop specific reports**			
223	State	221	Oversight	Y
224	Consumer	221	Oversight	Y
225	Provider	221	Oversight	Y
226	CC	221	Oversight	Y
227	CMS	221	Oversight	Y
228	Stakeholder feedback	227	Oversight	Y
229	Revise reports	228	Oversight	Y
230	Develop additional reports as needs arise	229	Oversight	Y
231	**Remediation Policies and Procedures**			
232	**Shift to "service qualification & standards of practice" model**			
233	Catalogue authorities, enforcement units & scope, & due process req.	19,22	Oversight	Y
234	Delineating core provider & service requirements	214	Oversight	Y
235	Assigning oversight of requirements to lic. or certification	234	Oversight	Y
236	Review & revise remediation capabilities	235	Oversight	Y
237	Review & revise lic. & cert. processes to fulfill new oversight	235	Oversight	Y
238	**Develop fiscal impact estimate for changes**			
239	Review staffing given new oversight requirements	236,237	Oversight	Y
240	Review administrative impact on providers	236,237	Oversight	Y
241	Estimate potential savings from fraud reduction	239,240	Oversight	Y
242	Request additional staff if necessary	241	Primary	
243	Publish rule changes	241	Primary	
244	**Implementation**			
245	Staff training	242,243	Primary	Y
246	Provider training	245	Primary	Y
247	Rollout	246	Primary	Y
248	Ongoing monitoring of impact	247	Primary	Y
249	Develop flowchart identifying information flow	234	Oversight	Y
250	Refine P&P for following up on incidents	249	Oversight	Y
251	Develop policies for response & coordination of QM entities (CC, provider, lic., e	250	Oversight	Y
252	Development of QM Committees (SDS, DHSS, External)	251	Primary	Y



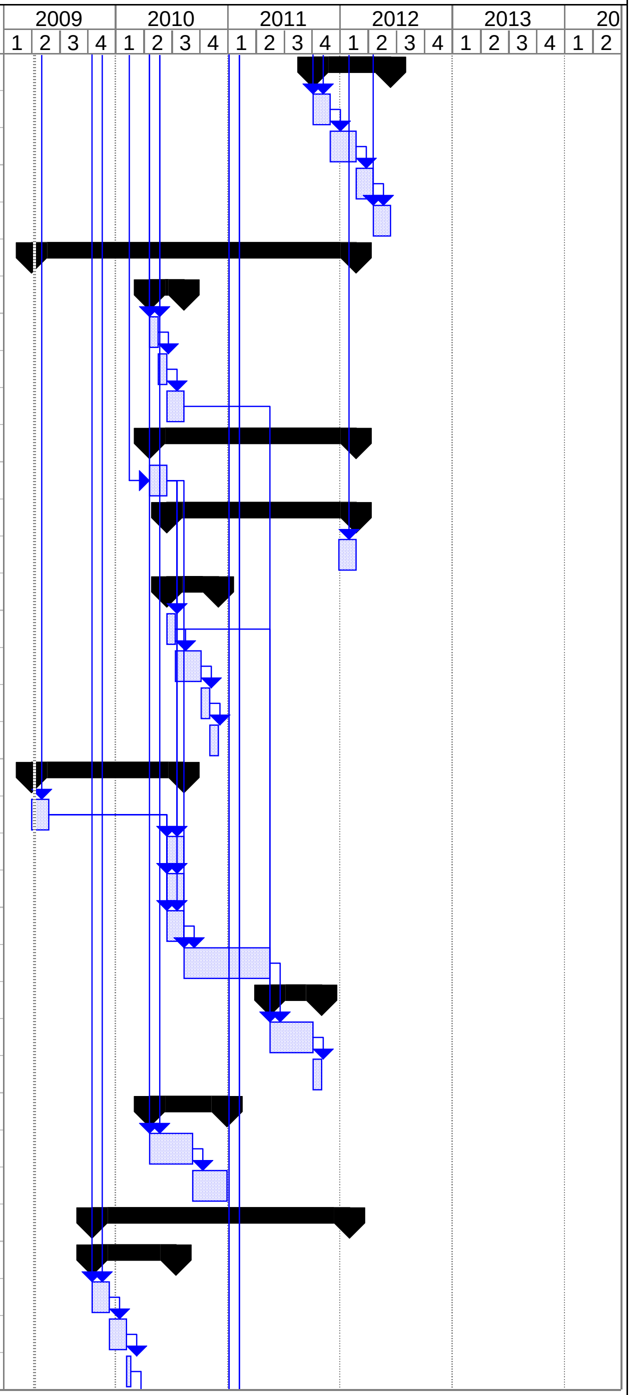
Long Term Care Plan-Three-Year Action Plan

ID	Task Name	Predecessors	State Staff	Contractual
253	**Compilation of Quality Management Plan**			
254	Draft Plan	252	Oversight	Y
255	Incorporate plans into waiver applications	254	Primary	Y
256	Submit waiver amendment to CMS	255	Primary	
257	CMS Approval	256	Primary	
258	**Update provider manuals & notification**			
259	Update current provider manuals	254	Oversight	Y
260	Develop process for updating manuals	259	Oversight	Y
261	**DS3-Integrate policies into online applications**			
262	Develop RSS process for distributing updates	260	Primary	Y
263	Assessment/reassessment/care plan	60,259	Primary	Y
264	Provider certification	73,259	Primary	Y
265	**Develop infrastructure to verify in home services provided**			
266	Develop RFP for vendor to design verification system	219	Primary	Y
267	Select vendor	266	Primary	Y
268	Vendor develops system	267	Oversight	Y
269	DS3-Design system and integrate with DS3	268	Primary	Y
270	Amend rules to incorporate process	267	Primary	Y
271	Implement	269,27	Oversight	Y
272	**Design mechanisms for gathering data on PIs that require new data**			
273	RFP to select vendor	271	Primary	
274	Secure vendor	273	Primary	
275	Review other states' verification processes	274	Oversight	Y
276	Develop approach for verifying all services actually provided	275	Oversight	Y
277	Develop approach to ensure services addressed health and safety	275	Oversight	Y
278	Develop approach for incorporating consumer's perception of quality	275	Oversight	Y
279	Stakeholder feedback	276,27	Oversight	Y
280	Refinement	279	Oversight	Y
281	Amend rules to reflect new tools	280	Oversight	Y
282	Implementation	281	Oversight	Y
283	**Develop online training capability**			
284	Collaborate with vendor to adapt existing modules	19,22,2	Oversight	Y
285	Collaborate with vendor to create new training modules	284	Oversight	Y
286	**DS3-Integrate with DS3**		**Primary**	**Y**
287	Links from DS3 to training	285	Primary	Y
288	Reports on who took training incorporated within DS3	285	Primary	Y



Long Term Care Plan-Three-Year Action Plan

ID	Task Name	Prede cessors	State Staff	Contr actual
289	**Ongoing process to evaluate access & service gaps**			
290	DS3-Coallate data from Online Certification and Care Plans	58,68	Primary	Y
291	Develop algorithms to identify over or under supply	290	Oversight	Y
292	Examine impact of changes on non-Medicaid funded programs	291		
293	Integrate results with QM and provider relations processes	211,292	Primary	Y
294	**Restructure Care Coordination**			
295	**Removing conflict of interest for Care Coordinators**			
296	Develop rule changes to require CCs be independent of service providers	19,22	Primary	Y
297	Develop exemption policy for remote areas	296	Oversight	Y
298	Plan for Outreach & training to develop independent CC network	297	Oversight	Y
299	**Integrating CCs into the overall QA plan**			
300	Develop more specific performance requirements for CCs	211SS	Oversight	Y
301	**Develop reporting requirements**			
302	DS3-Online Assessment, reassessment, care plan (part of ADRC development)	60	Primary	Y
303	**DS3-Online case notes-time tracking**			
304	Specifications	300	Primary	Y
305	Development	304	Primary	Y
306	Training	305	Primary	Y
307	Implement	306	Primary	Y
308	**Revise reimbursement methodology for care coordination.**			
309	Modification to M&S contract	3	Primary	
310	Setting of unit rate (15 minute or hourly)	309,30C	Oversight	Y
311	Develop P&P for controlling utilization	309,30C	Oversight	Y
312	Establishing billing and verification systems	309,30C	Oversight	Y
313	Rule change published	312,30C	Primary	
314	**Phased-in implementation**			
315	No new provider controlled CCs	298,304	Primary	
316	Transition for current provider controlled CCs	315	Primary	
317	**Expand IT efforts - DS3**			
318	Develop comprehensive vision including tasks identified as DS3	19,21	Primary	Y
319	Develop implementation plan for components not addressed in this document	318	Primary	Y
320	**Miscellaneous Recommendations**			
321	**Add a transition service to the waivers for people moving from institutional service**		**Oversight**	**Y**
322	Adapt NF transition policies into service definitions	13,16		
323	Adapt for other populations with disabilities	322		
324	Submit waiver amendment to CMS	323	Primary	



ID	Task Name	Predecessors	State Staff	Contractual
325	CMS Approval	324	Primary	
326	Implementation	325		
327	**Allow for shared PCA services. Recommend limiting shared arrangements to two p**			
328	Adapt PCA service requirements & reimbursement	3,235	Oversight	Y
329	Set CC &/or agency QM expectations	3,235	Oversight	Y
330	Amend regulations	328,329	Primary	
331	**Establish an option to use a universal worker**			
332	Crosswalk the service requirements for direct care services	235	Oversight	Y
333	Create combined application that includes core elements from all items	332	Oversight	Y
334	Amend rules	333	Primary