

APPENDIX A

Project Staff Resumes

Principle Investigator:

Brian Saylor, PhD, MPH, is the Principle Investigator on this project. Saylor has been active in Alaskan health affairs since 1974. He became interested in health care planning and policy as a Peace Corps volunteer in Malaysia in the early 1970s. Since then, he has been a health systems planner, Legislative staffer, University faculty, health care and long-term care facility and hospital administrator and Deputy Commissioner of the Department of Health and Social Services. He holds a undergraduate degree in Psychology from Penn State, a Masters of Public Health from the University of Michigan and a Doctorate in Health Policy from the Heller School at Brandeis University.

Saylor has extensive experience in health systems planning, conducting health needs assessments, moderating public forums and facilitating groups. He has administered an Alaskan community hospital which provided long-term care services (Alaska Nursing Home Administrator License expired), He has also administered the Alaska Psychiatric Hospital.

Project Staff:

Kay Burrows has been active in Alaskan health planning and administration for 20 years. She started her Alaskan health career at the Alaska Hospital in 1976 as a Medical Care Evaluation Specialist. Ms. Burrows was instrumental in the development of Alaska's first accredited private home health service in 1983, and has been associated with home care in Alaska ever since. Most recently, she served as the Assistant Administrator for Providence Alaska Medical Center, Alaska's largest health care system. Burrows holds a Masters of Science in Health Administration from the University of Colorado, Denver.

Beth Vann has worked in home based support services since 1976. She has served in both direct patient care and supervisory positions in home-based chemical dependency systems and large home care organizations. Most recently, Ms. Vann held the position of Director of Alaska's largest hospital-based home care organization. Vann holds a Masters of Social Work from the University of Georgia, and has advanced training in case management, gerontology and geriatrics, dementia, and home and community-based health and social services.

Jackie Pflaum is Associate Professor of Nursing at the School of Nursing and Health Sciences at UAA. She has been a public health nursing practitioner and educator for 25 years. After starting her public health nursing career in the Minneapolis Health Department in 1970, she joined Bethel Alaska Public Health Nursing Team in 1973. She served in Bethel for five years. After completing her graduate nursing studies at the University of Hawaii in 1979, she returned to UAA to teach others about public health nursing. She has now completed her doctorate.

Josef Reum has been involved in health and human services issues in Alaska since 1981 when he served as the Director of Community Support Services for the Anchorage Department of Health and Social Services. This experience gave him an in-depth understanding of community-based programs in Alaska. Moving to Juneau, Josef assisted the Alaska State Legislature develop the State's budget as Special Assistant to the Senate Majority Leader. He has served in

senior executive positions as Assistant Commissioner or Commissioner in Massachusetts and Indiana, addressing long-term and community-based health and social services. He then moved to George Washington University in Washington D.C. to administer a national program with a specific focus on service organizations for people with chronic and complex health conditions. Reum holds a Masters in Public Administration from Harvard University and is a doctoral candidate in health policy at George Washington University in Washington D.C.

John Booker, Ph.D., Director of the Institute for Circumpolar Health Studies will be the principle investigator on this program evaluation. He has extensive research experience in Alaska health care issues and has served on the faculty of the University of Alaska since 1983 and the School of Nursing and Health Sciences since 1988.

Stacy Smith is the research assistant for this project. She was born in Sitka, Alaska and attended the University of Alaska Fairbanks and the University of Alaska Anchorage where she earned an interdisciplinary BS degree in Health Promotion. She has assisted in various projects and reports, including community health needs assessments and the evaluation of health projects. She is particularly interested in public health and the media, and is currently pursuing an MFA degree in creative writing.

Consultant Staff:

John Amson Capitman, Ph.D. is Director of Long-Term Care Studies at the Institute for Health Policy and Research Professor, Heller School, Brandeis University. He is Director of the National Resource Center: Diversity and Long-Term Care. This administration on Aging sponsored program provides research and technical assistance to long-term care decision-makers at the national, state, and local levels. The Center is focused on how race, gender, age, class, and residence differences among frail elders and other persons with disabilities can be recognized and respected in long-term care policies and programs. Capitman also lead a Health Care Financing Administration study of quality in home care and an evaluation of the Robert Wood Johnson Foundation's Dementia Care and Respite Services demonstration. Capitman is Co-Principal Investigator of the Commonwealth Fund survey of Assisted Living program residents. He has published extensively on financing, organization, and delivery issues in community long-term care. A text coauthored by Dr. Capitman entitled Care for Frail Elders: Developing Community Solutions (1992) will be used as a guide in conducting this project.

Mark Sciegaj, PhD, MPH is a Research Associate at the Brandeis Institute for Health Policy. Dr. Sciegaj's research focuses on issues of autonomy and choice in long-term care and the effects of race/ethnicity and gender on consumer preferences for community long-term care. Some of his current responsibilities include project management for a recent Commonwealth Fund study on resident-centered care in Assisted Living. Dr. Sciegaj is also involved in two Administration on Aging projects: Ensuring Choice in Case Managed Community Long-Term Care, which is being conducted in three states and details how service structures and procedures influence client autonomy. The second AoA project is Realizing Empowerment and Service Possibilities for Elders in Community Together (RESPECT), for which Dr. Sciegaj is developing a proactive network of elder volunteers who will assist other elders in accessing appropriate community long-term care services in Roxbury Massachusetts.

Walter Leutz, PhD, MSW, is an Associate Research Professor at the Brandeis University's Institute for Health Policy. An expert in managed care, long-term care and health care financing, he is the task leader for a Health Care Financing Administration (HCFA) project to

develop a demonstration of a managed care systems for Medicare End Stage Renal Disease beneficiaries. He recently completed a study for the Administration on Aging of service planning guidelines used in 24 state home care systems. He is currently working on a strategic planning guide for aging network survival as managed care organizations extend their reach into aging network services and populations. He is the author of numerous articles on health care issues as well as two books on the practical development of primary health care systems: Changing Health Care for An Aging Society (1995) and Care for Frail Aged (1992).

Steve Berkshire, EdD is the Chair of the Management Department at Alaska Pacific University. His past experience includes 25 years in health care administration, including hospitals, government relations and private consulting. He is familiar with health care administration and financing in Alaska, having served as the Administrator of the Sitka Community, Charter North and NorthStar Hospitals.

Dr. Berkshire is a Diplomat in the American College of Healthcare Administration, and holds a Masters in Health Care Administration from Indiana University. He obtained his doctorate from Boston University.

Evaluation and Research Organizations:

The Institute for Circumpolar Health Studies (ICHS) is housed within the University of Alaska, Anchorage School of Nursing and Health Sciences. ICHS was created by the Legislature in 1988 to provide information, coordination, research, training and professional development for the international medical and health sciences community. Sponsoring legislators envisioned ICHS as a major new step in finding new solutions to health problems of Alaskans and other people of the circumpolar north.

There is a long-standing arrangement between the Alaska Department of Health and Social Services and ICHS based in Alaska Statute. AS 14.40.088 specifically directs ICHS to “provide a mechanism for communication and cooperation between the University and the Commissioner of Health and Social Services in addressing the needs of Alaskans for health care services, opportunities for education in medical and health sciences, and other mutual concerns of the University and the Department. As a health care provider and a major funding vehicle for state supported programs, the Department of Administration health care programs may fall under this same umbrella.

In accordance with AS 14.40.088, ICHS provides the Alaskan community with expertise in health policy analysis, health services research, program evaluation and epidemiological studies. Recent work includes the increasing prevalence of diabetes among Alaskan Natives, an assessment of the numbers, distribution and clinical specialties of primary care providers throughout the state, an analysis of the health care providers response to domestic violence and an application of geographic information systems technology to health services planning.

Staff, professional resources and technical assistance will be available to support the research design, project implementation, data collection, input, management and analysis and report production.

The National Resource Center for Diversity and Long-term Care will support ICHS in reviewing the principles and guidelines to assure their consistency with developments at the national level and in the field of community-based long-term care, assist in development of the

cost analysis and evaluation methodology, an independent evaluation of the ALTCA and the Risk/Priority Level Assessment, and periodic reviews of draft reports. They will also come to Alaska to support the presentation of the final results.

The Center is located at Brandeis University in Waltham, Massachusetts and is housed at the Heller School for Advanced Studies in Social Welfare. The Heller School for Advanced Studies in Social Welfare at Brandeis University has been a leading research and training institution focused on major social issues for more than thirty years. The programs at Heller are built on an integrated, multidisciplinary approach that incorporates the economic, political, sociological, and quantitative perspectives of the policy process. Research within the Heller School focuses on health care delivery and financing, aging, long-term care, income security, human resources, child and family welfare, criminal justice, substance abuse, mental retardation and human resources.

The Long-Term Care Division of the Institute for Health Policy (IHP) at Heller performs its research, technical assistance and education on health and long-term care services for disabled chronically ill persons. With Administration on Aging (AoA) funding, a National Aging Resource Center: Long-Term Care was established (1988-1990) to provide technical assistance to the aging network in many States on issues such as long term care infrastructure development, quality assurance in home care diversity, and recruitment and retention of workers. Multi-year collaborative projects were also funded by AoA to develop Eldercare Institutes on Older Women (1990) and on Long Term Care (1990-1993), both of which involved long term care service providers, service system administrators, and others within and across states in discussions of how service approaches and provider staff recruitment can improve responsiveness to the increasing ethnic diversity among the aged.

Since 1993, IHP has hosted the National Resource Center: Diversity and Long-Term Care in partnership with the University Center on Aging, San Diego State University. The Center has focused on how differences in age, race/ethnicity, gender, class, region, and source or type of disability should be accommodated in long-term care services, programs, and policies. Central concerns for the center have been issues of diversity in resource operation of congregate services such as adult day care, senior centers, and assisted living.

IHP studies on the quality of home and community based services include a multi-year project funded by the Health Care Financing Administration (HCFA) to develop standards for measuring the adequacy of home care and outcome measures of quality. One survey pilot tests a national survey of frail elders: it measures access to and adequacy of home care based on standards developed by the project with a sample of 400 aging network clients. The other surveys assess state program and home care agency efforts to train and retain home care workers. Two other recent studies in quality assurance include a survey of paraprofessional workers in a home care agency and a survey of case managers in the Massachusetts Home Care Program. Additionally, a current five year project funded by the Robert Wood Johnson Foundation focuses on assessing alternative strategies for increasing adult day care and respite services from the perspectives of provider financial viability, caregiver affordability and satisfaction, and how providers' operational choices are related to quality care.

Brandeis has ample library facilities, including extensive holdings of volumes, microfilm holdings and periodicals, and serves as a Government Repository for all public government documents. Additionally, Brandeis has access to a variety of electronic reference sources. The IHP also has several specialized collections in long term care and aging, health and economics, mental health and mental retardation.

Alaska Pacific University Management Department conducted the financial analysis. The Chairs of the Management and the Accounting Departments supervised the work of advanced graduate students who tabulated and analyzed program financial data and developed unit cost information.

APPENDIX B

Communities Served 1994-1996 (by region)

Bristol Bay	Norton Sound	Tanana Chief	Southeast	Mat-Su Valley	Anchorage	Kenai/Kodiak	Yukon-Kuskokwim	Maniilaq	Fairbanks
CLARKS POINT	BREVIG MISSION	ALLAKAKET	ANGOON	BIG LAKE	ANCHORAGE	CLAM GULCH	AKIACHAK	AMBLER	DELTA
DILLINGHAM	ELIM	ANVIK	AUKE BAY	BUTTE	CHUGIAK	COOPER LANDING	AKIAK	BUCKLAND	ESTER
EKWOK	GOLOVIN	ARCTIC VILLAGE	CRAIG	CHICKALOON	EAGLE RIVER	CORDOVA	ALAKANUK	DEERING	FAIRBANKS
KOKHANOK	LITTLE DIOMEDE	DENALI	DOUGLAS	CHITNA	GIRDWOOD	HOMER	ANIAK	KIANA	NENANA
KOLIGANEK	NOME	EAGLE	HAINES	COPPER CENTER	PETERS CREEK	KASILOF	BETHEL	KIVALINA	
MANOKOTAK	SHISHMAREF	EVANSVILLE	HOLLIS	HOUSTON	PORT HEIDEN	KENAI	CHEVAK	KOTZEBUE	
NAKNEK	ST. MICHAELS	FT. YUKON	HOONAH	PALMER	PERRYVILLE	KODIAK	EEK	NOATAK	
NEW STUYAHOK	TELLER	GALENA	HYDABURG	SUTTON	UNALASKA	MOOSE RIVER	HOOPER BAY	NOORVIK	
NONDALTON	WALES	GLENALLEN	JUNEAU	TALKEETNA		NIKISKISKI	KASIGLUK9	SELAWIK	
TOGIAK	WHITE MOUNTAIN	GRAYLING	KAKE	TRAPPER CREEK		NINILCHIK	KIPNUK		
TWIN HILLS		HOLY CROSS	KETCHIKAN	WASILLA		OLD HARBOR	KWETHLUK		
		HUGHES	KLAWOCK	WILLOW		SEWARD	KWIGILLINGOK		
		HUSLIA	SITKA			SOLDOTNA	MEKORYUK		
		KALTAG	WARD COVE			STERLING	MTN. VILLAGE		
		MENTASTA	WRANGEL			VALDEZ	NAPAKIAK		
		MINTO					NUNAPITCHUK		
		NICOLAI					TUNUNAK		
		NORTHWAY					UPPER KALSKAG		
		NULATO							
		RUBY							
		SALCHA							
		SLANA							
		STEVENS VILLAGE							
		TANACROSS							
		TETLIN							
		TOK							
		TWO RIVERS							
		VENETIE							

APPENDIX C-E

Available at [ICHS](#)

APPENDIX F

Management Evaluation Methodology

The management evaluation was conducted using key informant interviews. An outline of the areas to be addressed at each site visit is included in this appendix. The interview schedule for all programs was arranged in advance by the evaluation team, with the clinical site visit preceding the management site visit. The two evaluators communicated with one another following the clinical site visit, only discussing information about specific areas of further investigation, or about information that had been given to the clinical reviewer relating directly to the management review.

Prior to each site visit, the management evaluation reviewer (MER) called each site and spoke with the program manager to confirm the visit. Several visits had to be rescheduled, due to the MER's schedule or the program manager's schedule. On-site visits were completed for all programs except Kotzebue and Peninsula Home Health. Prior to the visit, the agenda and fiscal worksheets for the review were faxed to the programs.

Each site visit took 4 to 6 hours. At the first appointment, the MER met with the program manager, discussing the agenda for the visit and making interview appointments with other key informants. The first questions posed to the program manager related to the governance of the program (organizational charts were collected from each program). For those programs with independent voluntary Boards, Bylaws and minutes of the Board were reviewed to understand the Board's decision-making process for the program. For those programs that belonged to a larger, more broadly focused organization, questions focused on the decisions the Board made on behalf of the programs versus the decisions senior leadership made on behalf of the program. The MERs also examined documentation of Board involvement in education opportunities regarding home care.

The MERs requested and reviewed all reports for FY '96, including the reports required by DPH and the reports that are internal to the program. Questions were asked regarding the use and usefulness of these reports. MERs reviewed a copy of the program's mission and goals, as well as the budget and income statements (when available). Other topics discussed include expenses not included on the reports, and the education and experience of the program manager as it relates to the home care programs. MERs also read and discussed program management reports for the previous two quarters.

Next, MERs reviewed paperwork relating to the policies and procedures of the program, and asked questions relative to the personnel issues for the program. Issues explored included recent hiring, firing, recruitment, retention, training, the success and failure of training programs, and PCA versus CNA training as a standard for the program. Other areas reviewed included all continuing education programs and plans, and any quality assurance programs that the agency had in place. Any formal or informal referral agreements with community providers were also reviewed and discussed.

Key Informant interviews were next completed, including in-depth discussions with the fiscal staff, and a meeting with administrative leadership. MERs attempted a fiscal review of all costs associated with the program, which required completing a worksheet (included in this appendix). The reviewer completed the worksheet with assistance and information from the

fiscal staff. The reviewer questioned the fiscal staff regarding all possible costs for the program, regardless of where the expense was "booked" by the organization.

The site visit ended with an interview with key administrative leadership or Board members, depending on the organizational structure of the program. With questions focusing on the strengths and weaknesses of the program, and of state support to the provider agencies. Specific questions include:: 1) What is working well in this program?, and 2) What needs to change in this program at the state level?. The site visit concluded with asking the program manager these same questions.

Site Visit Plan for Kay Burrows Management Evaluation, Governance Overview

Prior to Site Visit: Telephone interview with program manager

1. General information about agency, Governing Boards, program goals
2. Organizational chart (from Beth Vann or fax to me)
3. Preparation and agenda for visit

Site Visit:

1. Meet with Program Manager
 - a) Review Bylaws, articles of incorporation, IRS documents, insurance policies
 - b) Minutes of last four Board or Admin. Council meetings
 - c) Documentation of BOD educational opportunities regarding homecare services
 - d) Fiscal reports to Board or administration for last year
 - e) Mission, vision, values, Goals for FY 96 for agency
 - f) FY 96 Budget/Actual income statements through March 1996
 - g) Program management reports for last twelve months
 - h) Program manager - resume or background and experience
2. Review documentation on:
 - a) Policies and Procedures
 - b) Personnel:
 - 1) Job Descriptions
 - 2) discussion regarding:
 - a) one person recently hired
 - b) one person recently evaluated
 - c) last person terminated for performance
 - c) Advertising or other methods of recruitment
 - d) Continuing education or training documentation
 - e) Quality Assurance program - documentation results
 - f) Management/Grant reporting systems to state
 - g) Referral agreements with other community agencies
3. Key Interviews with:
 - a) Administrative leadership or Board of Director
 - b) Fiscal staff

c) Community representative

Note: Key questions for each interview are:

What is working well in this program for you?

What needs to change in this program at the state level?

APPENDIX G-H

Available at ICHS

APPENDIX I

Financial Analysis Procedures

A financial spreadsheet was developed to help capture fiscal information on the Home Care program. The following process was used to obtain this information for analysis:

1. A spreadsheet was created for use by the PCA agencies and the management audit specialist.
 2. After a pilot test with one program, and necessary refinements, this spreadsheet was sent to each agency ahead of the management audit date. The program managers, with their fiscal personnel, completed the form as completely as possible.
 3. When the management audit specialist visited each agency, a priority was made to spend time with the program manager and fiscal personnel to review the spreadsheet, answer questions, and seek any additional details that would help determine the "true" cost of this program.
 4. The spreadsheet and narrative were completed by the management audit specialist after her return from the field. Following a review by the program manager for inaccuracies, it was forwarded to an APU fiscal team for entering into their model. Questions that arose were handled by the management audit specialist, the APU Team, and the Program manager.
 5. Preliminary fiscal information from all programs was available at the May 31, 1996 Advisory Committee meeting.
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APPENDIX J

Comparison with other States

A. Introduction

Although most state community long-term care programs are quite specific in defining groups that are eligible to receive new long-term care benefits, they are vague on requirements for care. With funding from the Administration on Aging, the National Resource Center: Diversity and Long Term Care at Brandeis University (NRC) surveyed state program managers serving elders in 24 states during 1994. The purpose of the original survey was to document whether states have written guidelines to help case managers decide what type of service to use, how much to use, or how long to keep a service in place. The survey also sought to document what written guidelines and training case managers receive in promoting client autonomy in care planning. In discussions with respondents and review of written materials provided by states, we explored whether clients received written information about services, the structure for seeking client input into care planning, and the structure for soliciting client feedback once the care plan was in place. The original survey findings demonstrate that few states have developed service planning guidelines or provide training to help case managers choose services or promote client autonomy beyond the notion of "best practices."

As part of the Home Care Evaluation conducted by the Institute for Circumpolar Health Studies (ICHS) at the University of Alaska Anchorage, the NRC staff interviewed program administrators for the Home and Community Based Waiver Program (CHOICE for the Elderly) and the Home Care Services Program. Comparing the responses from these interviews and the written materials from these programs with the original 24 states shows that Alaska's approach to the issue of service planning guidelines is similar to 17 other states. Like these states, Alaska relies on program structures (e.g. eligibility requirements and care planning instruments) to provide case managers with some general guidance.

B. Prior Research and Significance of Topic

Community long-term care has developed primarily as a way to reduce demand and use of costly nursing home services and to satisfy individuals' desires to maintain independent living in the community. State governments are often central actors in designing and managing community long-term care systems--even those portions of the system that primarily are federally funded, such as home and community-based Medicaid waiver services and Title III Older Americans Act programs. In addition, the standards and procedures set up in state systems also shape the environment in which expanding private financing systems operate.

In community long-term care systems, clients and services are linked through case management. The care plan developed under the direction of the case manager in consultation with the client (and often the client's family) typically details the mix, frequency, duration, and timing of formal services. It is no surprise, therefore, that case

management is a central feature of almost all community long-term care programs and experiments. It has been included in almost all legislative proposals to increase community care coverage under Medicare and Medicaid. However, the scope of the case manager's authority over service allocation varies significantly from system to system (Leutz, Capitman, MacAdam, & Abrahams 1992). In some systems, authority is restricted to making referrals only. In other systems, the case manager can authorize and purchase services from single or multiple funding sources. In much policy discussion, however, the structure and operations of case management have not been clearly defined (Leutz, et al. 1992).

While there has been considerable study regarding case management in community long-term care (e.g. case manager credentials, case loads, services covered, service caps, and client eligibility requirements), a gap remains regarding the extent to which states provide case managers guidance, training, and/or monitoring in either service planning, quality assurance, and/or client satisfaction. A number of policies and financial and organizational options have been tested in community long-term care settings, and analysts agree that case management approaches to service planning have varied significantly (Laudicina and Burwell, 1988; Lipson and Donohoe, 1986; Capitman, 1990; Leutz, et al., 1992). Only a few analyses have considered the implications of differences in case management practice for community long term care clients (Kemper 1990; Leutz, Capitman, and Abrahams, 1993).

Previous research demonstrates that the way community long-term care services are managed is key to controlling costs (Weissert, Cready, and Pawelak, 1988). However, the scope of the case manager's authority over service allocation varies significantly from system to system. In some systems, the case manager's authority is restricted to making referrals only. In other systems, the case manager can authorize and purchase services from unitary or multiple funding sources. Incorporating client preferences in the development of care plans is also a significant issue currently being discussed as a way of increasing the client's sense of control (Kane & King, 1991; Capitman & Sciegaj, 1995). While a recent national study reports that most state community programs offer their clients care plan choices (Justice, 1991), it is not clear to what extent these choices are meaningful, or if these systems provide structured and assured opportunities for clients to make choices about the services they receive. While there are ongoing discussions regarding the development of service planning standards and guidelines for case managers (CCCI, 1994; Geron & Chassler, 1995), there has been little study of what guidance states currently provide for facilitating client participation in care planning (Leutz, et al., 1995).

C. Study Methods

In both the original survey and the Alaska home care program survey, a NRC researcher conducted a telephone interview of administrators of elder services programs. The original States were selected to balance the sample geographically and by size. Services to elders from three sources of funding were followed: Medicaid home- and community-based waivers, Older Americans Act community services funded under Title III, and major

state-funded community long-term care programs. The first point of contact in each state was the State Unit on Aging, where the study team asked how services funded under the three sources were managed, and who the most knowledgeable informant would be concerning case management and training policies in each program. In states that use a consolidated case management model, this was a single person for all three funding sources. More commonly, as with Alaska, it was two (in some cases three respondents) per state, in agencies such as the health, social services, or human services departments and Medicaid agencies.

The informants were interviewed by telephone using interview guides that contained both closed-ended and open-ended questions to ensure comparability across states and programs on basic questions and allow interviewers and respondents to explore issues. All States were requested to provide any available written materials that described the program's case management system. Out of the 25 states, 18 sent material on their case management practices. The remaining 7 states either were in the process of revising their written documentation or did not have written guidelines regarding case management practices.

Results of interviews and reviews of written materials were prepared in both tabular and narrative form. In writing up the interviews, separate tables were developed for each funding source that was managed separately. A copy of the written description of the state program was returned to each informant for confirmation or correction. Once confirmation or correction was received from all the respondents, key tables were combined to provide a single state-by-state picture of the extent and nature of guidelines. The tables note where guidelines differ by program funding within states.

D. Findings On Guidelines On Type And Amount Of Service

For some respondents, deciding whether their state had guidelines or not was difficult, due to existing program structures such as eligibility criteria, service caps, and reassessment timetables that they considered to be guidelines of a sort. We had to emphasize with all respondents that the focus of the study was on the existence and character of guidelines that come into play only after these structures place eligible clients in front of case managers. However, even then, the distinction between having guidelines or not was again difficult to make. Therefore, before describing examples of states with written guidelines, examples of these systems or methods that fall short of our criteria are described below. These include overall spending caps, limits on particular services, priority ranking systems, structured assessment instruments, detailed descriptions of what services do, inclusion of diagnostic and medical information, and rules for reviewing or terminating service plans.

Individual spending caps: Many respondents pointed to global limits on the dollar value of services an individual can receive as a guideline. Such service "caps" are common in Medicaid waiver programs (Leutz and Sadowsky, 1992) and were in place in 19 of the 24 waiver programs studied here including Alaska. Although caps are guides of a sort, they do not provide help choosing services within the cap, nor do they show how long or how much of each service to provide.

Caps on specific services: A few states place upper limits on particular services, with the most common being respite services. Examples of service limits are 25 days of respite care per year in Montana's waiver program, a \$150 per year cap without supervisor's approval on supplies and equipment in Minnesota's state/local Alternative Care Grant program, and limits in Texas on home repairs paid with Older American Act funds to about \$300.

Priority systems: Like Alaska, several states build in priorities for rating applicants' service needs or risk if services are not provided. Although these are, in effect, extensions of eligibility systems rather than guidelines for particular services or amounts, the nature of the needs identified may point to particular services. For example, Florida has a guide for assessing health risk in which low, moderate, and high risk conditions are listed. The moderate and high risk categories almost all deal with some medical or nursing conditions. Alaska currently uses a Risk/Priority Form to prioritize clients according to need, thus addressing situations where either general funds or available PCAs are insufficient to meet regional needs for services.

Assessment and Care Planning Instruments: Many survey respondents, including those in Alaska, pointed to the assessment itself as a form of guidance. They said that by the time the assessment is completed, the service coordinator has identified the client's current needs, the needs being met by informal caregivers, and what additional help is needed. For example, the Georgia manual of Case Management Standards has a general admonition to list needs identified on the assessment in problem/need statements on the care plan. Given the lack of guidance on care planning in most state systems, this appears to be how most such decisions are made. This is where "best practice" and the "art" of service coordinators comes in. However, studies show that decision makers who are provided with the same case information can choose very different types and amounts of service (Abrahams et al. 1989; Sager, 1980).

Service Descriptions: Most states provide service coordinators with descriptions of each service available. In most states these descriptions are brief and general, but in others they are more detailed and keyed to specific functions. For example, in South Carolina, state quality assurance standards provide useful definitions of service content, to whom services are available, and who provides them. These are not quite guidelines but would be useful to service coordinators in deciding whether a service fits a need. Another example is found in California's MSSP manual, which has a fairly detailed description of each service that can be authorized, and a description of what a PCA can do. It does not, however, go over how it is decided what specific tasks the PCA will do for a particular client.

Diagnostic and Medical Information: Several states provide service coordinators with summaries of the meaning and implications of medical diagnoses and drugs commonly prescribed or used among the clientele. For example, the Florida manual has a 35-page section on common diagnoses, conditions, and drugs. Such information can help service

coordinators understand client limitations and needs and also decide when to bring in help from skilled care providers.

Duration: Many states have written timetables for reassessment and revision of the care plan, as well as conditions for termination. However, these seldom include criteria for reviewing whether a particular service should be terminated or changed in intensity. For example, in Hawaii the criteria for termination include, among other factors, not being able to ensure safety, and unwillingness of providers to serve a particular individual. Indiana's Guidelines and Procedures Manual has 5 reasons to cut back and 10 reasons to terminate state-funded services. Included in cutback reasons are decreased need, insufficient state funds, general cutback, and becoming eligible for waiver or other community long-term care service funds. Included in reasons for termination are lack of need, detrimental services, refusal, and refusal to pay share of cost.

E. State Examples Of Structured Guidelines Regarding The Type And Amount Of Service

In contrast to the 18 states (including Alaska) that rely on these program structures to provide case managers with some general guidance, several states have a more thorough degree of guidance. The following includes a description of the most structured, Oregon and Texas, which have developed and implemented scoring systems for the broad range of ADL, IADL, and nursing needs. Their assessment forms are structured to yield priority scores for receiving services, as well as guidance on type and amount of service. Also described is Missouri which is moving away from such a structured system.

Oregon

Oregon commonly is acknowledged as a national leader in consolidating of the financing and management of their community long-term care system. The state has an electronic assessment system (EAS) that uses data from a pre-coded (SKS 360) comprehensive assessment form to compute a summary of needs and options. The SKS 360 is a structured, pre-coded instrument in which virtually all questions are set up as multi-category items. The items are divided by the level of difficulty or deficit the client has with the area, and thus the categories relate to the level or frequency of need. Both functional and nursing activities are covered. The interventions are detailed by category, e.g., under "oxygen" in the nursing area, an activity is "administration in conjunction with inhalation therapy"; under "skin and nails" is care of skin and nails for persons with diabetes. Each intervention is assigned codes for who, frequency, and whether it is provided or not and why. Using the EAS and the SKS 360 form, the service coordinator identifies electronically when the client's next review is due.

There is a complex and coded system of algorithms for scoring and summing ADL and other scales to determine priorities for service. For example, there are critical and less critical areas, and each of the areas is subdivided into independent, assistance, and dependent levels. The highest need client is one who is dependent in areas of mobility, eating, toileting, and cognition. This is tied into the eligibility system, and the state can

move up and down the scale in terms of level of needs served depending on funds available.

In addition to determining levels of need by area and overall priorities for service, the system goes on to calculate whether and how much a person needs in particular areas. For example, the EAS takes scores for single variables (e.g., the service coordinator judgment of whether there is a special diet) and then computes the number of hours associated with each area and level of need, taking into account calculations in other areas. A complex set of algorithms for weighing concurrent needs is embedded in the EAS.

Although the EAS can thus actually produce individualized care plans, the respondent reported that there is no requirement that the service coordinator exactly follow the care plan produced by the system. In fact, experienced coordinators often will begin discussing a care plan with the client during the assessment interview, knowing the parameters of eligibility and service levels that will be suggested based on item scoring. After entering item scores, the algorithm-based care plan becomes a context from which the actual care plan (a different computer screen than the algorithm screen) is entered.

Although frequent use may make the SKS 360 understandable to service coordinators, its pre-coded layout and the absence of worded questions on the form make it more abstract than most other assessments reviewed. The highly coded care plan is not a user-friendly form from the client's point of view. Some ratings seem difficult for a service coordinator to score (e.g., the client's "adaptation to change") but these may be addressed in additional training manuals that we did not receive.

Texas

Texas was the only state to use the Frail Elderly option for funding long-term care services under the 1990 Omnibus Budget Reconciliation Act (OBRA). The option allows a state to pay for new community long-term care services without a waiver application so long as the state takes risk for total LTC costs. More recently the state developed an additional strategy, a Nursing Facility Waiver (now called the Community Based Alternative -- CBA) program that targets adults eligible for nursing home care. This program, implemented in March of 1994, has a capacity to serve 22,000 people, but only 600 people were served in the program by the spring of 1995. If Congress abolishes the Frail Elderly option (as some fear-- due to an absence of state response), as many as one-third of Texas's Frail Elderly clients might become eligible for the CBA program. The state also has thousands of other frail elders receiving Medicaid PCA services, the program in which the prototype for the guidelines that will be used in the CBA program were developed.

The CBA program has a case management guidebook with strict and specific guidelines on how care plans are to be made and how particular services are to be considered. For example, in assessing clients for personal assistance services, the guidebook has a one-page form that scores 23 functional areas, 5 of which (eating, toileting, transfer,

medications, and meal preparation) are priority areas that define the total number of hours for care that can be authorized.

Following the PCA program prototype, applicants are scored on personal care needs in the assessment of ADLs, and there is a guide for how many personal care hours go with each of four levels of scores. There are fairly detailed descriptions in each functional area of the two middle levels (minimal/moderate and severe/extensive) of need on a four point scale (the no need and total need levels are more self-explanatory and require less discretion as to whether and how much service to provide). There is also a "support score" which is derived from assessing the chance that priority tasks would not be performed if the worker did not show up on that day (scores indicate "good" to "very poor" on a four-point scale). Consumers are "priority one" clients if they have a "severe" functional score and a "very poor" chance of having tasks done without the worker, or if the service coordinator judges that "the client's health, safety, or well-being would be jeopardized if family care or primary home care services were not provided on a single given shift."

The waiver program guidelines build on the PCW program guides by adding additional guides for nursing, therapies, and home modification. A task-time guide gives instructions for deciding on how much time to allot. The guidebook provides help to choose a mix of nursing and aide services. There are also additional instructions in the guidebook for choosing levels and mix of nursing and therapy services, even though contracted home health agencies have primary responsibility for identifying nursing and therapy needs. There are 11 levels of care in TILE (Texas Index for Level of Effort), which is used to score waiver clients. The dollar amount runs from about \$45 to \$100 per day. There is a 50 hour per week cap on PCW assistance in the Frail Elderly program. The only minimum is related to not scoring high enough on assessment to qualify. Service coordinators are trained to change care plans as needs change. Reassessment is required every 6 months.

Missouri: A state in transition

Missouri has operated for a number of years with a system of specific guidelines. For example, no more than 20 hours of Homemaker per period, or one nursing visit per week, or diabetic foot care if certain conditions are met. They decided to drop this system because changing care plans became too difficult and expensive. Also, with caseloads over 125 per service coordinator, and with increasing diversity of caseload, it became cumbersome to manage.

The new system implemented in early 1995 moved from case manager control to a more cooperative relationship with service providers and with clients. Under this new system, there will be general guidelines only (e.g., to meet the needs of the client within overall cost ceilings). However, the assessment process will be constructed to steer the case manager toward meeting unmet needs. There will be nine levels of care: 5 medical levels and 4 ADL levels, plus additional information about IADLs. The informant believed that by the end of the assessment the service coordinator knows what needs there are, who is

meeting them and how well, and what the unmet needs are. The state's new policy is to then give the service coordinator the maximum flexibility to meet those needs, but the state will maintain control over the units and kinds of service it funds. For example, a provider will be given authority to use Homemaker services or PCA workers, but the provider will then decide on the specifics to be done by the PCA or Homemaker. Previously, the state service coordinator authorized specific tasks within each kind of service. It generated a big questionnaire, but no one used it. At the time of the interview, materials were not yet available on how the negotiation between the provider and the client will be structured concerning what tasks will be done and how.

F. Guidelines on Client Involvement in Care Planning

Overall, of the 25 states, 15 provided some written guidance to case managers on involving clients and others in the care planning process in either the Medicaid waiver program, OAA services or state-funded community long-term care programs. Alaska was not one of the 15 states. Of the states that had a waiver program, 10 provided “limited guidance” and 3 provided “extensive guidance.” In the 9 states that manage OAA and/or state funds separately from waiver funds, 3 provided limited guidance, 2 extensive guidance.

The researchers considered “limited” guidance to be a written admonition for case managers to solicit client participation in care planning decisions, yet has no clear place on the form to record client input, or has space on the form but little or no guidance about including clients. “Extensive” guidance was considered to be the existence of written guides regarding client participation and a clear place on the form to record client input. With those states that had guidelines, the researchers then discussed with respondents and examined the written material to explore whether the guidelines included providing clients with written materials, the structure for seeking client input into the care plan, and the structure for soliciting client feedback.

Providing written materials: Of the 24 states with waiver programs, 17 routinely provided general brochures concerning program operations, 6 provided no written information, and 1 (Hawaii) provided more extensive information to clients in the form of a guide. Brochures were provided in some of the programs funded separately by state or OAA funds, and 1 (Hawaii) provided more extensive information. In both the waiver and state-funded program in Alaska, clients receive general program brochures, which provide basic information regarding program services, sponsorship, eligibility, and grievance procedures. A number of respondents said it is difficult to develop statewide materials with so much local variation in operations and services. For this reason, local programs may provide more extensive written information and training for case managers on educating clients about how to use services.

Client input into care plans: The most common example cited by respondents (including the Alaska respondents) as evidence of client participation in care plan decisions was that clients must approve their care plans by signing them. Fifteen of the 23 waiver programs required client signatures on care plans. However, this

requirement is presented on the written materials of most states in a way that signing may be little more than a formality. Even when soliciting client preferences is mentioned in the written materials, the language of most of the material reviewed tended to put the professional in charge and to give limited attention to talking about obtaining the opinions of the client.

Even when soliciting client preferences is mentioned in the written materials, the language of most of the material reviewed tended to put the professional in charge and to give only limited attention to talking about obtaining the opinions of clients. For example, the 50-plus page request for proposal (RFP) sent by Connecticut to solicit a case management contractor states that clients should be "involved in and informed about decisions, concerns, and progress" of care and that the case manager must discuss the plan with the client and obtain the client's agreement (Connecticut DSS, 1993).

However, the predominating view of the client in other sections of the RFP is passive, with the case manager educating, advocating for, planning for, etc. Similarly, the Georgia draft standards state the "participation of the client and the informal support system is essential in developing a care plan and the client's acceptance is given by the signing of the care plan" (Case Management Task Force, 1994). However, no mention of client involvement is made in the description of how services are to be arranged. The form for the Georgia Medicaid waiver program is careful to record client choice of community or nursing home and to require a choice of provider if options are available, but no information about how to help clients make the choice is provided (Georgia DHS, 1994). Finally, the section on care plan development advises case managers to "make decisions with client about services needed," but the assessment and care plan forms have neither questions that indicate that the client was asked nor any space to record preferences that were stated.

The survey also explored whether there were written requirements to record client preferences about services. On this item, almost all states with Medicaid waiver programs cited the federal requirements that clients qualifying for the waiver services (1) be provided a choice of receiving care in a nursing home or at home, and (2) be given a list of providers to choose from for services to be authorized in the care plan. Few states went beyond meeting these required criteria by, for example, providing clients with information about how to choose among the providers listed.

Client Feedback: Interviewers asked the state administrators about a number of ways clients were allowed or encouraged to give feedback, including how grievances and complaints are handled and how a client might ask for a change in case manager. Respondents for virtually every program reported a grievance procedure for complaining about decisions and actions of the program--particularly concerning decisions to reduce or terminate services. In 12 states respondents reported a mechanism for asking for a change in case managers, but none could provide a specific provision covering this issue. Generally, respondents said clients could

complain to the case manager, the supervisor of the case manager, the agency director, the state administrator, or go through the formal grievance process.

The grievance materials provided to clients that were reviewed generally did not assist clients in understanding whether they had legitimate grounds for filing a grievance or complaint. This was consistent with the limited requirements and processes found in most states for including clients and their families in decision making. The grievance process appears to be another point in the system where client participation is formally allowed but not actively encouraged—since clients are provided only limited information about program operations, their preferences are solicited only in formalistic ways, and they participate only minimally in care plan development.

Few respondents reported having a state requirement to train clients to actively participate in the process of care planning, and to provide feedback after the care plan is in place. One example of a state with such a requirement was the Hawaii OAA program. In this program there is an initial follow-up and monitoring of new clients by the case management supervisor. During this period, the client is encouraged by the supervisor to be candid about both care providers and the case manager. There also is a random selection of clients who are interviewed after the initial follow-up. In the care plan the client selects from a printed list of service options. In the follow-up process, the supervisor checks to see if client wishes have been followed.

G. Conclusions

There are a number of limitations to this study that must be remembered in drawing conclusions. First, only 25 of 51 states (including Washington, DC) were studied. Although geographic and size diversity were sought, there may be other models for service planning guidelines in the states not studied. It does not seem likely, however, that the distributions of states with and without guidelines would differ greatly from the 25 studied here. Second, the method of interviewing state management staff and reviewing formal manuals and instruments has limitations in its ability to reflect what actually is happening in local agencies. From our survey we could not determine how well local implementation incorporates state guidelines (if guidelines exist), or whether local agencies use their own guidelines, training, etc, that are not reflected in state requirements. Finally, many state community long-term care systems are experiencing changes in administration, service providers, manuals and forms, benefits, and other program features that affect service planning practices. Some of those changes are noted herein, and others are in process. Rather than see the findings as a final count or static picture, it is more appropriate to see a general assessment of state programming, capabilities, and directions.

The stakes of the study are raised by the finding that Medicaid waiver funds and at least one other source of funds are managed together in most states. This means that guidelines that exist or that could be developed would apply to more integrated systems of care than if sources were managed separately. Moreover, even when there are limited or no service guidelines by our standards, there are extensive efforts to make

these systems more equitable and efficient through uniform assessment systems, coordinated eligibility and referral systems, and the work of service coordinators. OAA agencies are usually centrally involved in these integrated systems, either as lead agencies at the state or local level, or as one of the local service coordination focal points.

This study was not begun with the expectation that many states would have extensive systems of service planning guidelines. Rather, the goal was to find out how many states are even trying to get inside the "black box" of service planning decision making and to begin to understand how they are involving clients in decisions. On these questions there are three clear findings:

Few States Have Developed Guidelines: Few states have developed and implemented systems to help service coordinators choose services beyond the "black box" of "best practice." These states use one of two basic approaches: (1) fairly rigid formulas that point to types and amounts of services based on scoring of particular functional, medical, and other needs, and (2) decision-making guides that steer service coordinators to particular service types and levels by describing types of clients, types of needs addressed by particular service modalities, and level of intensity that may be appropriate to address types of needs. The former approaches appear to be stronger than the latter in promoting equity, but they limit the chance to use judgement and to individualize care plans based on factors outside the guidelines.

There is a Need for States to Develop Comprehensive Consumer Information: Clients need adequate information to make meaningful care plan decisions. Of the states in this survey, 7 do not provide clients with any written information and 16 provide a brochure outlining basic information regarding program services, sponsorship, eligibility, and grievance procedures. Only the state of Hawaii provides a detailed "user's guide" to all of its community long-term care program clients. Other states should work with local programs to develop more extensive written information for educating clients about how to use services.

The idea of such a guide would be to furnish clients with complete information regarding the care plan, care giver, the type of services offered, the time, length, and duration of service, as well as the process to change the initial agreement if a problem develops later on. This information could be made available equally to everyone involved with decisions in community long-term care --particularly case managers and clients--but also to families and related providers such as physicians and home health staff. The idea would not be to provide the "right" answers or courses of care to participants, but rather to provide a more level playing field across programs, staff members, and clients. The goal would be to empower all staff and all clients--not just the most articulate or educated-- find the service package that is right for them.

States Need to Provide Leadership in Case Manager Training: Providing clients with adequate information is just the initial step to supporting their autonomy in the care planning process. A second step is to be sure that they understand the information--

this requires more than just handing out a brochure or even a written user's guide. Therefore, in addition to information, most clients need advice and others even need the complexities of the long-term care system translated for them to make meaningful care plan decisions. For this reason, training case managers to guide client choice without undermining client autonomy is critical.

Of the states that participated in this survey, all currently conduct some form of training for case managers. Training participants and the frequency of training varied considerably. Of these states 14 conduct mandatory training sessions for new case managers. Beyond this training of new case managers, 3 states provide mandatory training at least annually, 6 provide training on an "as needed basis," 1 state provides training for case manager supervisors, and 3 states did not have a mandatory training requirement for case managers. We recommend that states work with local programs to ensure continuity in the training of case managers in supporting client autonomy in the care planning process.

Finally, in making these recommendations, it should be remembered that the paucity of care planning guidelines, comprehensive consumer information, or emphasis on training at the state level neither shows that they are unimportant nor that they are not being considered at the local or clinical levels. Case managers and supervisors often are best able to articulate how they must approach and treat each person differently in order to individualize and treat them fairly. The problem with not having statewide guidelines and training is that appropriate responses cannot be assumed to occur consistently at the local level, nor can they be systematically monitored. The notion of "best practice" is valid only if there is attention to make it occur.

APPENDIX K

Summary Findings of Ladd Report

A copy of the recommendations included in Long-Term Care In Alaska: Recommendations For Reform prepared by Ladd & Associates is attached. These recommendations have substantial implications for home and community-based long term care policy. The summary below highlights some of the issues that may be of concern to the Home Care Advisory Committee.

Program Strengths

1. The quality of long-term care services in Alaska, including home and community-based care, are of high quality.
2. Providers of long-term care are enthusiastic about the services that they provide.
3. Alaska has an innovative and viable home and community-based long-term care system that can be enhanced.
4. Alaska's expenditure for home and community-based care shows a high commitment when compared to other states.

Program Weaknesses

1. There is no comprehensive policy guiding the development of long-term care services in Alaska.
2. The fragmented administrative structure (Long-term care services are administered by four different divisions of State government) results in poor coordination of services.
3. Institutional costs are very high, suggesting that there should be an increased emphasis to bring better balance to the long-term care system by encouraging the development of lower costs home and community-based long-term care services.
4. There are currently insufficient services to meet the growing service demand, driven largely by rapidly increasing elderly population. This has resulted in long waiting lists for services.
5. The process for determining eligibility for Medicaid funded home and community-based services is too long, currently requiring four to eight weeks to process an application.
6. Medicaid does not pay for non-medical activities of daily living assistance, but focuses on medical reimbursement. Therefore, medical services may be reimbursed under Medicaid at a higher cost than more appropriate non-medical services.
7. There are differences in the costs of wavered (CHOICE) services from program to program, with services to the developmentally disabled adults being the highest per case cost. This disparity in costs could not be explained by the researchers.

Some of the findings in this report parallel the findings of our evaluation team in assessing the home and community-based long-term care services system.

The following was taken directly from: Ladd & Associates. (1996). Long-term Care in Alaska: Recommendations for Reform. Austin, Texas.

The report makes several recommendations for balancing the long-term care system. These include:

- * Alaska should authorize no new nursing home beds for the foreseeable future. The report gives three alternative methods of controlling nursing home bed growth, but recommends that the certificate of need process for nursing homes be eliminated, and that the state of Alaska control bed growth by contracting directly with nursing homes for the number of beds needed. Alaska might have to apply for a federal Medicaid 1915(b) freedom of choice waiver. This waiver would allow Alaska to choose which nursing homes they would contract with, for how many beds, and at what reimbursement level.
- * Alaska should establish small assisted living facilities in the isolated areas of the state to serve people who would otherwise have to move to the Anchorage area to receive long-term care services. These remote assisted living homes should be linked to or operated by the regional health care provider system.
- * Alaska should facilitate the movement of current nursing home residents who have lower care needs, to an assisted living facility as soon as possible.
- * Alaska should allow hospitals in the Anchorage area to swing current beds to sub-acute (or skilled nursing home) beds. Hospitals should be allowed to do this for one year, with extensions dependent on the number of empty nursing beds in the Anchorage area.
- * Alaska should create two classes of nursing homes (one with 45 beds or more, and one with under 45 beds), and should reimburse these two classes differently. Alaska should also commission a study of the property and administration cost centers in nursing homes.
- * Alaska should continue to convert Pioneers' Homes to assisted living facilities and continue to focus Pioneers' Homes on the care of persons with Alzheimer's disease and related disorders. All Pioneers' Homes should be licensed as Assisted Living Care facilities by the end of June, 1996.
- * Alaska should adopt, with some modifications, the Pioneers' Home's Advisory Board's recommendations for co-payments.
- * Alaska should institute personal care, and home and community based care waiver programs in Pioneers' Homes to help defray these costs. This would become a moot recommendation under the 1996 proposed federal Medicaid legislation, which would limit Medicaid growth.
- * Alaska should allow a nursing home level of care determination based on complex functional needs as well as medical necessity for the project CHOICE home care waiver program if the proposed 1996 Medicaid/Medicaid federal legislation

becomes law.

- * Alaska should develop a plan for the future use and the future public and private financing of assisted living facility care. These facilities should be expanded.
- * Alaska should expand and strengthen all of the home and community based waivers, including Project CHOICE, and create more slots for home care services.
- * Alaska should expand care coordination services for all people requiring long term care statewide, including the elderly, and implement a nursing home pre-admission screening program performed by care coordinators independent of the nursing homes.
- * Alaska should streamline the eligibility process for Medicaid and all of the home and community based waivers, and decrease the time needed to approve applications, from 4 to 8 weeks to less than one week in most cases.
- * Alaska should fully investigate managed care and managed long-term care, and implement these programs, if feasible.
- * Alaska should restructure state government to better focus on long-term care.

If the above recommendations are implemented, then it was shown over the next twenty years more people could be taken care of for less money. The number of people receiving government sponsored long-term care services would rise from 3,425 in 1995 to 13,614 in 2015, if the recommended changes are made to the long-term care system. During this same period costs expressed in constant 1995 dollars would increase by 106 percent. By the year 2000, the reformed long-term care system would serve 502 more clients and save \$9,111,007 a year.