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Contract report on alternatives for planning a continuum of care for elderly American Indians.

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CONTRACT REPORT

ON

ALTERNATIVES FOR PLANNING A CONTINUUM OF CARE FOR ELDERLY AMERICAN INDIANS

(This report has been reproduced
especially for the National Conference
on the Health of Elderly Indians
Billings, Montana, August 16-18, 1978)

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Indian Health Service
Health Services Administration
Department of Health, Education,
and Welfare
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Contract Report on Alternatives For Planning a Continuum of Care for Elderly American Indians

FOREWORD

This paper has been developed for the Indian Health Service, Department of Health, Education, and Welfare, to provide information for Indian and non-Indian professionals and others seeking to serve elderly American Indians. Among other things, the literature is reviewed to indicate trends in delivery of care required by the ambulatory, homebound, and institutionalized persons. Information on cultural requirements is highlighted as well.

To accomplish the objective of the contract, the American Indian Nurses Association convened a Task Force to develop this paper:

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EXECUTIVE SUMMARY

The elders of the Indian Nations are living respositories of the cultural and spiritual values of the tribes. Traditionally, elders have been revered for what they represent and cared for by sons and daughters grateful for their knowledge. Within the last decade, however, increasing numbers of elders have been left alone as their children leave the reservations. Many are even victimized by those under the influence of alcohol.

In recognition of the special problems of the elders and in keeping with the philosophy of Indian Self-Determination, ideas are presented which tribes may elect to utilize in promoting quality long-term living for all Indian elderly. The long-term care continuum incorporates acute, sporadic, and continuous care provided in a multiplicity of settings ranging from the home and community through residential facilities. This concept addresses the individual/community/reservation/tribal identified needs of the well, frail, sick, and chronically ill.

Special attention is given to homemaker/home health, day care, and residential services. Discussion focuses on ways to provide a traditional cultural environment within these service delivery modes. For example, tribes can construct/renovate and operate nursing homes on the reservations which incorporate culturally-specific designs. Such elements could include rooms for family members to sleep overnight, room for a sing, room for the medicine man, traditional healing practices, and preferred foods.

ALTERNATIVES FOR PLANNING A CONTINUUM OF CARE FOR ELDERLY AMERICAN INDIANS

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PROJECT OFFICERS' NOTE

One of the principal objectives of Indian Health Service in commissioning this paper on continuum of care was to involve Indian health professionals, Indians and non-Indians specializing in gerontology, and consumers in a purposeful dialogue regarding the health problems and concerns of elderly Indians. This and other objectives have been accomplished. And it is hoped that the action and interactions that took place during the development of the paper are the beginning of continued, meaningful interpersonal, interprofessional, and interorganizational relations that will result in better health care for the elderly.

It is not expected that this and other papers prepared on mental and physical health, environment, and safety* will be all things to all people. However, the papers do represent an extensive review of these subject areas in relation to the Indian elderly; and they should provide a useful frame of reference for future discussions and program development.

This paper will be made available on request to individuals and groups seeking to help the elderly. Immediately, it will be furnished to the National Indian Council on Aging for use in its forthcoming national conference on health of elderly Indians to be held in Billings, Montana, August 16 - 18, 1978.

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INTRODUCTION

In anticipation of the Second National Indian Conference on Aging to be held in 1978, Indian Health Service contracted with the American Indian Nurses Association to prepare two technical papers on long-term care and environmental issues as they impact the Indian elderly. In order to achieve this objective, the American Indian Nurses Association convened a meeting of professionals, both Indian and non-Indian, to contribute their ideas. This meeting was held in Norman, Oklahoma, on February 10-11, 1978.

Upon completion of the initial drafts of both papers, the American Indian Nurses Association convened a second meeting, this one composed of Indian elders and potential consumers, in Albuquerque, New Mexico, on March 17-18, 1978. Participants reacted to the papers and presented their own ideas and recommendations. This paper incorporates content from both meetings.

For the purposes of this paper, "Indians" are defined as American Indians and Alaskan Natives who reside on tribal reservations or in rural/urban areas and are eligible for Federal and/or tribal programs.

PHILOSOPHICAL APPROACH TO PROVISION OF SERVICES TO ELDERS

American Indians occupy a unique position in the United States, being the only group of people who originated here. They have retained their tribal heritage. The tribe is a separate political, economic, social, and cultural entity. The reservation/village is a storehouse of strength and culture of the American Indians/Alaskan Natives.

The concern with the social, cultural, and psychological forces as they impinge upon the aging Native American in particular, although not of recent origin, is especially manifested in the scope and delivery of modern health care. If programs are to be implemented which meet the needs of Indian elderly, providers and administrators must recognize the uniqueness of the people with whom they are dealing. It is imperative that all organizations and agencies tie directly into the tribe's programs for meeting the needs of the elderly.

As with other health-related terms, long-term care implies a provider-patient relationship, with someone other than the consumer in control of the process. Therefore, it is imperative to stress that determination of need resides primarily with the individual and family in collaboration with the health provider. The goal is provision of services to address self-defined needs, not to arbitrarily force services, goods, or behaviors upon the client.

In this context, "living" can be substituted for "care," resulting in the "long-term living continuum." This simply means "living beyond one's own expectations and singular or familial capabilities" (Department of Health, Education, and Welfare, 1977:42). As people live longer, for example, their requirements for income, food, shelter, health care, and so on expand proportionately. In addition many individuals suffer from an increasing incidence of infirmities and illnesses throughout old age, necessitating health and medical interventions as well as assistance from family/community members. The provider's role, then,

In 1975, the National Center for Health Statistics sponsored a conference on long-term care data in Tucson. Conferees agreed on a broad definition of long-term care covering

> ambulatory, domiciliary, and institutional services for that growing segment of the population whose problems are of long duration and require assistance from the medical and related professions (Murnaghan, 1975:ix).

At the conference Rice and Waldman (Murnaghan, 1975) identified a broad range of services which they placed into three major categories:

I. Home Health Services (nursing and related, e.g., rehabilitation, social services) Nursing care, home health aide, medical care management.

II. Other Home Services (personal care) Homemaker, home maintenance, laundry, Meals-on-Wheels, social services, part-time caretaker, nutrition, transportation, activities of daily living, shopping.

III. Facilities Day care, living (residential and institutional), foster/boarding homes, congregate care facilities, chronic disease hospitals, old age, convalescent centers, skilled nursing and intermediate care facilities.

Generally when people speak of the elderly in conjunction with long-term care, the picture evoked is the nursing home. However, according to the Division of Long-Term Care (Department of Health, Education, and Welfare), only 5% of those over 65 years of age resided in institutions according to the 1970 census. As can be seen from the above three categories, the continuum of long-term care is composed of many more elements.

To help visualize the potential range of services from residential/institutional settings to home/community settings, the following list of options is presented. Individual tribes, for

Intermediate

Definition: Nonresidential, less than 24 hours; person goes to agency or service locale.

- Information, screening, and referral services
- Crisis intervention
- Hospital emergency rooms
- Income maintenance and employment assistance, state and local social services
- Neighborhood health centers
- Senior citizen or geriatric centers
- Individual and group practitioners (health, mental health, social services, physical therapy, chiropractic, other)
- Health Maintenance Organizations (HMO's) outpatient diagnostic and treamtent services
- Community mental health centers
- State and local social service agencies for counseling and related services
- Medical, dental, physical therapy and behavioral clinics (including universities)
- State and local public health departments
- Drop-In clinics
- Family planning clinics
- Local children's bureaus
- Sheltered workshops
- State and local vocational rehabilitation services
- Vocational education
- Employment counseling
- School special education classes
- Special day training schools
- Adult activity centers for mentally retarded and other handicapped
- Recreational-therapeutic activity programs for persons-at-risk
- Day camps for disabled
- Day care centers (adult/child)
- Night/day partial hospitalization

Extramural

Definition: Services are provided at the site of the problem, i.e., home, school and all of the facilities listed under Intramural and Intermediate. Services are provided by an individual worker or practioner and/or agency personnel.

They interviewed the subjects and their relatives at varying points in time, and they found the following significant differences.

INSTITUTIONALIZED APPLICANTS	INDEPENDENTS
Older; mean age 6.1 years higher	
Greater number of women	
Greater number living alone	
Lower monthly income	
Contact with and help from others less, but not to the degree of social isolation	
29% received help from community resources within past year; 19% still receiving it	1%
Substantial increase in reports of loneliness and depression	
Increased reports of poor health	
Cerebrovascular disease - 17%	2%
More functional problems (bowel and bladder, sensory)	
Chronic disorders - 81%	52%
Increased dependence with ADL*; Decreased mental functioning	
Participation in clubs, social activities - 9%	45%
Those who reported just sitting around, 7 days a week - 48%	14%

The Consumer Task Force offered many examples from their own experiences of the need of Indian elders to remain independent and in their own communities. They emphasized the need for elders to relate to the young. Such involvement is beneficial to both parties. The elders will be revitalized by the young, but they also have much to teach. As Brenwick (Consumer Task

*ADL means: activities of daily living

countries organize to deliver long-term care services. Such studies were undertaken by Kane & Kane (1976) and Carpenter (1976).

They report similar findings, including the replacement of the medical model with a socio-medical approach which focuses on the impact of illness on both patient and family. Both are included in the planning process.

In Sweden and Denmark, municipalities are legally responsible for locating and assisting elderly individuals in need of services. In Scotland, all citizens automatically receive letters from the Medical Officer of Health when they reach age sixty-five informing them of preventive and rehabilitative services available. A public health nurse makes a follow-up visit to answer any questions.

Multilevel institutional settings are established which offer housekeeping flats, old-age home beds, and long-term care beds. Communities provide sheltered flats and service houses. In Sweden, 2% of the space in new housing developments is designed for and allocated to the handicapped. Municipalities also contribute funds for modifying private homes to enable the old or disabled to continue living in them.

Another common mechanism enabling individuals to remain in their communities is the financial reimbursement of family members for services rendered (nursing, homemaking, meals, etc.). A number of short-term beds are reserved for such individuals should they or their families need a change of pace, vacation time, etc.

--reciprocal programs between elderly and youth

--community outreach via telephone hotline, daily telephone reassurance calls, bus service, Meals-on-Wheels

--educational programs for the patient, family, and community, with involvement of secondary school and college students

Because of the strong communal and family ties within Indian tribes, it is feasible that demonstration projects could be established on reservations/Indian communities incorporating the above elements as appropriate. High-rise apartment buildings, for example, could be architecturally redesigned in culture-appropriate models. For some tribes, living in proximity would be appropriate, but others would need greater distance and increased personal space. Pueblos, for example, choose to live in clusters, whereas Plains Indians prefer to live far apart. For the urban Indian, on the other hand, multilevel complexes offering a range of supportive services might be an approved alternative.

HOMEMAKER-HOME HEALTH SERVICES

As a group, American Indians lag behind the general population in economic and health status. Yet, because of their unique position vis-a-vis the Federal Government's responsibility to provide medical care through treaty rights, legislative, executive, and judicial actions, they have not always benefited by participation in health insurance plans open to the population at large (Primeaux and Banks, 1978).

Traditionally, the cultural expectation has been caring for the elderly in the home, not institutional placement. Combined homemaker-home health care programs, therefore, can accomodate the cultural expectations and practices of the Indian communities.

Homemaker Services*

Homemaker service is an organized community program provided through a public or voluntary non-profit agency. Qualified persons are employed, trained, and assigned to perform a full range of activities necessary to the maintenance of individuals or families in their own homes when long- or short-term illness, disability, psychosocial crises (or combination of these) require supportive, therapeutic or maintenance services to sustain independent living. The appropriate professional staff of the agency establishes the need for homemaker services, develops a suitable plan to meet it, assigns and supervises the homemaker-home health aides, and continually evaluates whether the service given meets the assessed need of its recipients:

1. Patient is homebound or can leave or be taken to needed services only with difficulty.
2. Patient requires only intermittent medical supervision and homemaker services to be maintained in his home.

Home Health

Regional hearings were held in 1976 to discuss the current status of home health care. Topics discussed here have been under scrutiny since then (Department of Health, Education, and Welfare, 12/76; Comptroller General, 12/30/77). Major issues include the need:

*Definition provided by Bernice Harper (Provider Task Force)

Home Health Development and Expansion activities.

Under P.L. 94-63, the Public Health Service provides project grant monies to develop home health care programs. Bills are currently before Congress (H.R. 10553, S. 2474) to extend funding beyond F.Y. 1978. Section 602a of the Law provides money for development or expansion of home health services as defined under Medicare. Section 602b provides funds to train professionals/para-professionals employed in certified home health agencies. In awarding grant monies, preference is given to areas with a high percentage of elderly and a medically indigent population.*

The American Indian Nurses Association (AINA), under contract with the Department of Labor, has developed a program for Home Health Aides in accordance with the philosophy of Indian Self-Determination. The association has worked with individual tribes to formulate needs, goals, and objectives of home health programs. Each tribe recruited a registered nurse (R.N.) from their communities to attend a course at AINA headquarters detailing the procedure for developing a Home Health Agency that would meet state and federal standards. The nurses were also prepared to teach tribal members the basic skills needed to become Home Health Aides. Elders were trained and employed through this program.

The tribes which participated now have Home Health training programs which offer training and employment opportunities to members plus the potential for developing agencies eligible for Medicare/Medicaid reimbursement. The following communities

*See Appendix C for a list of Regional Office Contracts and key dates for 1978.

Planning, and Evaluation (Department of Health, Education and Welfare).* Currently, it is being tested in skilled nursing and intermediate care facilities but will be expanded to include hospital and non-institutional delivery models such as home health. It could then function to promote continuity in care and planning as an individual moves from one health setting to another. In addition, it can serve as the original assessment tool when an individual first requires care. The entire form is filled out initially, then individual schedules are revised periodically according to individual needs. The basic outline of the tool is presented to provide an idea of the information involved.

Pace II Instrument

SECTION	BASIC PACE ITEMS
ADMISSION DATA	
BACKGROUND DATA	1. Facility Identification 2. Patient Identification 3. Date of Admission to Facility 4. Last Principal Provider 5. Date(s) of Prior Admission(s) to Facility 6. Date(s) of Prior Discharge(s) from Facility
DEMOGRAPHIC DATA	1. Date of Birth 2. Sex 3. Racial/Ethnic Background 4. Current Marital Status 5. Usual Occupation 6. Usual Residence 7. Usual Living Arrangement

*As of June 26, 1978, this project was reported suspended.

SECTION	BASIC PACE ITEMS
II. FUNCTIONAL STATUS	A. Range of Motion 1. Lower Extremities 2. Upper Extremities 3. Head and Trunk B. Strength, Balance, and Coordination C. Activities of Daily Living 1. Mobility 2. Personal Care Nutritional Status 1. Special diets 2. Intake problem 3. Output problem 4. Food likes and Dislikes 5. Cultural/Religious Food Constraints 6. Supplementary nourishments 7. Usual dining location E. Psychosocial Factors 1. Patient/Resident's Adjustment to Care Plan 2. Patient/Resident's Social Interaction and Adjustment to Facility 3. Behavioral Problems
III. PATIENT CARE	A. Special Procedures 1. General Nursing Care 2. Rehabilitative/Restorative 3. Teaching 4. Psychosocial B. Professional Visits C. Medications Drug Categories Drug Problems
IV. READINESS FOR DISCHARGE	A. Functioning Status B. Service Needs C. Discharge within the month
DETAILED SCHEDULES	A. MEDICAL DATA B. SKIN C. PSYCHOSOCIAL FACTORS D. MEDICATIONS E. READINESS FOR DISCHARGE

Model II places greater emphasis on supervision and employs more non-professional staff. Participants tended to be less impaired, suffering more from infirmities associated with the aging process. Such programs are more socially-oriented and are multi-purpose compared to the primarily medical focus on Model I.

Day care* is a program of services provided under health leadership in an ambulatory care setting for adults who do not require 24-hour institutional care and yet, by virtue of physical and/or mental disability, are not capable of full-time independent living. The program is designed to meet a variety of care needs including health maintenance and restoration.

The essential elements of a day care service are directed toward meeting the health care needs of participants. However, the socialization elements of the program are considered vital for overcoming the isolation so often associated with illness in the aged and disabled and in fostering and maintaining a maximum state of health and well-being.

1. Patient can come or be transported to day care center with reasonable amount of assistance.
2. Patient requires only intermittent medical and/or nursing supervision and the services provided within the day care center.
3. Patient may be under 65 years of age if other criteria are met.

Potential sources of funding for adult day care centers include Titles VI and XIX of the Social Security Act and Title IV of the Older Americans Act. The National Center for Health Services Research has funded demonstration projects

* Definition Provided by Bernice Harper

elders prefer and still use their tradional wood-burning stoves.

Woodenlegs (Consumer Task Force), for example, described the difficulty the Northern Cheyenne have with maintaining enough wood to last through the Montana winters. Many elders freeze to death because they lack wood. As Woodenlegs phrased it, missionaries told Indians to "sit down, fold your hands, and then we forgot to do for ourselves."

The Mescalero Apaches have a Traditional Counseling Program in which elders teach crafts, games, dances, and other cultural activities, such as puberty rites, to young and old together. As Simmons (Consumer Task Force) emphasized, the tribe feels the need to preserve the culture as embodied by the elders, of whom so few remain. They are needed to instill cultural and spiritual pride in tribal members.

As played among Indians, for example, games differ from those of other cultural groups. Everyone plays together without artificial restrictions based on such characteristics as age, sex, and status.

Games are often characterized more by cooperation than competition. In the Indiana equivalent of "football," for example, players (young and old, male and female) still scramble for the ball. However, the "queen" of the game, chosen on the basis of her age and family position, can walk across the field to the goal line once she gets possession of the ball without anyone touching her.

Gambling is popular, but it is often done with possessions rather than with money. The individual knows that whatever s(he) loses this time may be won back the next time.

and other health services as needed.

The skilled nursing facility is recognized as eligible for both the Medicare and Medicaid reimbursements, if the facility applies and meets certain conditions of participation, including that for staffing mentioned previously.

Intermediate Care

An intermediate care facility is an institution that provides health care and related services on a 24-hour basis at a level less intensive than that given in an acute care or skilled nursing facility. Medical, nursing, rehabilitative, and social services are provided as needed to assist patients in attaining or maintaining their maximum potential for independent living, whether within or outside the facilty setting.

1. Patient needs health-related care and services on a 24-hour a day basis in an institutional facility that provides more than room and board but less than the level of care given in hospital or skilled nursing facility.

2. Patient requires intermittent medical, nursing, rehabilitative, social, and teaching services for the purpose of continuing or supervising the regimen established in the hospital or skilled nursing facility.

The physical well-being and the personal and emotional welfare of individuals in intermediate care facilities should be the prime concern of those who make determination as to the adequacy, appropriateness and timeliness of care and the treatment being rendered. Therefore, the intermediate care facility is designed to provide a protected environment for persons whose health needs require constructive supervision in an institutional

displacement to a nursing home miles away where the elderly will be placed among peoples of various ethnic backgrounds who are unfamiliar with Indian cultures and languages. This can result in severe emotional shock. It has been suggested that American Indians as a group suffer more anxiety and confusion when institutionalized than any other group (Forward Management Associates, 1977).

Members of the Consumer Task Force shared their own experiences with elders who retained some degree of independence and pride as long as they remained in their own homes. Once transferred to residential facilities, however, they regressed. Often they gave up communicating in English, speaking in their native tongues even when there was no staff member or other resident who could understand them. A recurrent theme of the task force, therefore, was the need to provide services for elders in their own communities, villages, and reservations.

One possible option was suggested by Askenette (Consumer Task Force). In Nevada in-home service workers visit the elders and assist with cleaning, medications, etc. During the winter when it is very cold, the elders are sent to institutional settings for their own protection. As soon as spring comes, however, they are returned to their own homes, and the workers begin visiting them again.

Brenwick (Consumer Task Force) drew an analogy between sending a child away to boarding school at age 5 and the elder

Family members can then travel together from the reservation, a round-trip distance of 372 miles, in a bus rented by the tribe.

Placement planning such as this fosters the probability that the administration of the nursing home will plan specific cultural activities for the elders. It also gives the tribe some economic leverage when its members are grouped this way. The home with a 16% Indian population, for example, included two culturally-specific events for them in its outline of program activities for the month. One was a religious service provided by the Native American Church. The second included tribal songs and dances.

Harper (Department of Health, Education and Welfare, 1970) has examined the necessary ingredients for humanizing a (traditional) nursing home and maintaining optimal functioning (health, psychosocial) and well-being of residents. The focus is on the crisis aspect of such placement, the role of the family, and the need for cooperation and collaboration among all concerned. This is most useful in considering off-reservation placements. If, at some point, nursing homes are erected on reservations, the material is still appropriate for urban and other non-reservation Indians (e.g., Oklahoma Indians).

The initial recommendation for placement creates a crisis for the elder and his/her family. The individual needs help to prepare for the transition with a minimum of psychic trauma. This maximizes chances of using the experience positively. Family members need help in releasing the elder to a new living situation. Staff need assistance in understanding the person who is coming to live with them. One way to begin this process

for example, could opt to build a circular facility with the door facing East in accordance with tribal practices.

The Mescalero Apaches have had a center for elders on the reservation close to the Public Health Service Hospital for nearly nine months. All the living units are electronically connected to the hospital. If an individual has trouble of any kind, s(he) can buzz hospital personnel for assistance.

Elders have been allowed to retain their traditional wood-burning stoves in the living units. Community members maintain the necessary supplies of wood for them. Apache is spoken in the facility. The tribe employs elders in the Traditional Counseling program and pays them for their services.

Both Brenwick and Simmons (Consumer Task Force) emphasized the difficulty that elders face when confronted with modern appliances. According to Simmons, one of the functions of community workers on the Mescalero reservation is to check the gas stoves in the newer homes. The strangeness of such an appliance has led to tragedy in the past, with elders becoming asphixiated or blowing up their homes when, without realizing the danger, some would light wood fires next to the stoves.

In the Ahtna Region of Copper Center, Alaska, a long-term care complex will soon be constructed with various levels to serve people in need of services across all ages. It will be designed along the multipurpose center concept with a main lobby, nutritional center to serve traditional foods, and a range of supportive services.

The tribes should be responsible for designing content and designating individuals to teach it. Each could produce, for example, a training manual for health workers, orienting them to such areas as specific healing beliefs and practices which differ from tribe to tribe. At the present time, such material is difficult to find in written form.

Health care providers can contribute their expertise in such areas as physiological and psychological processes of aging and the actual physical care components. Indian Health Service offers courses through the Office of Research and Development (ORD). The main ORD office, located in Tucson, Arizona, provides such courses as "Rehabilitation and Home Health Care" and "Maturity and Aging." Course components of the former include towel baths, transferring the client from bed to chair and in and out of a car, decubitus ulcer care, nutrition, diabetes, arthritis, and circulatory disturbances.

There are various field offices of ORD. One in Talahini, Oklahoma, trains community health representatives. The Black Hills Training Center in Rapid City, South Dakota, offers a variety of courses. The center at Santa Fe specializes in courses on food production, nutrition, and dietetics.

Training programs require an interfacing between native and non-native input. For example, principles of hygiene are important to the majority culture but may carry different significance for Indians. One needs to know the procedure for bathing the bed-confined individual. However, it is equally important to

referred to above, recommended that the elderly be employed in day care centers for children, thus maintaining the tie between young and old. The foster grandparent program is another viable option. The Older Americans Act makes provision for such a program under ACTION, as well as for a Retired Senior Volunteer Program. The Department of Labor, under Manpower Administration, also provides for an Older Americans Community Service Employment Program. The elderly have a role to play as workers in schools, crafts centers, nutrition programs, etc.

Another area with educational implications is preparation for aging, retiring, and coping with stress and loneliness. Richard Chuculate (Consumer Task Force) emphasized this area particularly for the non-reservation Indian. Ideally, such preparation would begin early in the individual's life, thus emphasizing aging as another phase of the developmental process, having it's own intrinsic rewards and potentials for continuing creativity and satisfactions.

CULTURAL INFLUENCES ON HEALTH CARE

It is imperative that health workers understand and accept cultural health practices. They must be willing, therefore, to talk with the individual and family about their beliefs and practices. Primeaux (1977) stresses the intimate relationship between Indian medicine and religion, noting that they are two faces of the same coin.

Illness is taken as a sign that the individual is out of harmony with nature, and the balance must be restored to effect

An item possessing curative powers may be hung on the individual's body or close to the bed. It is imperative that such items not be removed or disturbed.

Bathing and grooming of the elderly need special consideration. Modesty is important. It is always advisable to ask permission to give the bath and ascertain who the most appropriate person is to assist with the bath (sex, age, family member, staff person of a nursing home, community health representative, etc.). Special attention needs to be given to appropriate disposal of hair, nail clippings, etc. "Appropriate" means giving these items back to the family to handle. Navajos, for example, would want hair found in their combs properly taken care of, not just discarded (Kniep-Hardy and Burkhardt, 1977). The Consumer Task Force provided instances where community workers, ignorant of these practices, threw hair into the fire with other sweepings and found themselves barred from homes afterward.

Another important area is that of obtaining a history or consent from the client for specific treatments and procedures. Respect for individual rights is strong. Among the Navajo, for example, no one has the right to speak for another (Kniep-Hardy and Burkhardt, 1977). The health worker must keep this in mind when dealing with the elder and other family members. Rather than trying to obtain information/consent from another, the family member may be utilized more appropriately in helping to explain the purpose of the information to the client. Time must also be allowed for family consultation.

Understanding attitudes toward death and dying is important in working with the elders and their families. Death is accepted as another part of the life cycle. It is important to understand death rituals and taboos, which are vastly different among tribes.

Among the Osage, for example, it is important for the living to touch the dead. This removes any ill feelings that may have existed while the individual lived and is their way to say good-by. For the Navajo, on the other hand, it is taboo to touch the dead.

Among the Ahtna, no member of the immediate family is allowed to touch the dead, be a pallbearer, or help dig the grave. With the Osage, the immediate family is expected to perform all such functions for the dead.

Another important consideration is the definition of "immediate family." Kinship ties differ among tribes. Therefore, this definition also changes from tribe to tribe.

Once the health worker is familiar with the beliefs and practices of a particular tribe, s(he) can plan interventions accordingly, taking cues from the family as to who shall perform which services for the dead. Maxine Chuculate (Consumer Task Force), for example, related an experience of hers as a nurse at Pine Ridge, South Dakota. When one male patient died, she and another nurse found themselves in the position of having to lift the body when male relatives refused. It was taboo for them to touch the body.

For some tribes, such as the Ahtna, an open display of emotion is encouraged whereas for others, such as the Shawnee, it

agencies to develop methodologies. Second, they can examine existing tools (e.g., P.A.C.E.) and modify them to be Indian-specific. Third, tribal planners can develop their own methodologies.

The first step in program planning is a means of identifying individuals currently or potentially in need of services. Examples are given on page 11 describing how countries such as Sweden and Scotland handle this. Each tribe can initiate a community-wide survey of individuals from forty-five on, making rosters and interviewing each to have the individuals identify their own needs. This in conjunction with professional assessment will help the tribe identify the resources needed to meet these needs and monitor the progress of its members. If tribes elect to use the second approach, a review of existing tools is useful.

The literature available on planning covers determination of bed needs, patient and service classifications, and cost analysis across a variety of settings. One study of bed needs for inpatient settings is the Survey of the Need for Inpatient Beds in Monroe County 1974-1975, by the Genessee Health Planning Council of New York.

Because a sizable proportion of patients are misplaced in the beds they occupy, the Genessee planners designed a methodology to sort patients according to medical needs rather than the kinds of beds occupied. In this way they hoped to correct for placement errors and arrive at more realistic estimates of the need for beds.

One nurse and one physician, working independently of each other, conducted surveys in the following types of facilities:

The percentages of persons judged to need each level of care (see chart on pages 47-48) in the five surveys (excluding that of the mental hygiene facilities) were applied to the maximum load of each facility type determined over a twelve-month period (thirteen months for the hospitals). The estimates arrived at were then adjusted according to acceptable occupancy rates at the time, 90% for hospitals and 95% for long-term care facilities (percentages have since changed). This figure was adjusted a second time by the predicted population growth between 1975 and 1980. The new figure was adjusted a third time by the acceptable occupany rate to arrive at the final estimate.

One major advantage to this methodology is the focus on actual patient needs regardless of current levels of care. Because the Genessee planners have repeated the surveys every three to four years, physicians, nurses, and other health care providers have had the opportunity to arrive at definitions and criteria for the levels of care which are clear and precise. This is a prerequisite to evaluating appropriate placement.

The methodology is weak as a planning tool for non-institutional services. Estimates for day care and home health care, for example, cannot be generated from the collected data.

Because the estimates are predicated upon peak occupancy, there may be periods when these are inflated. This has to be balanced, however, by the potential for a shortage of beds in relation to actual needs. The surveys are intermittent. Therefore, there is always the potential for data to lag behind actual needs.

RESULTS OF THE GENESSEE SORTING METHODOLOGY

TYPE OF FACILITY	SAMPLE CHARACTERISTICS	NUMBER JUDGED INAPPROPRIATELY PLACED	AGREEMENT OR DISAGREEMENT	CHARACTERISTICS OF THOSE INAPPROPRIATE JUDGED
Hospitals medical-surgical intensive care coronary care rehabilitation medical-surgical self-care unit	Sample of 189 (10.9% of total) Age range: 16-94 (mean of 58.8) Women: 59.3% Men: 40.7% Length of stay: 1-74 days (mean of 10.5) Some degree of mental impairment: 24.5% Judged appropriate: 93.1%	13 or 6.9% (decrease from 27% in the 1969-1970 survey)	100% agreement	Age range: 36-94 10 individuals over age 65 Number judged appropriate for: SNF 11 (5.9%) ICF 1 (0.5%) PPHA 1 (0.5%) Length of stay: 6-38 days
Skilled nursing facility (SNF)/nursing home	Sample of 302 (8.7% of total) Age range: 20-103 (mean of 80.7) Women: 76.8% Men: 32.2% Length of stay: 1 day-18 yrs., 10 months (mean of 2 years, 1 month) Some degree of mental impairment: 83.4% Judged appropriate: 90.4%	29 or 9.6% (47.9% in the 1969-1970 survey)	Disagreement on 1 case	Age range: 55-93 Number judged appropriate for: ICF 27 (8.9%) PPHA 2 (0.7%) Length of stay: 30 days-18 years, 10 months
Intermediate care facility (ICF)/health related facilities	Sample of 157 (12.4% of total) Age range: 27-96 (mean of 77.9%) Women: 66.2% Men: 33.8% Length of stay: 1 day-18 yrs. 7 months (mean of 2 years 4½ months) Some degree of mental impairment: 50% Judged appropriate: 65%	55 or 35% (23.4% in 1969-1970 survey)	Disagreement on 1 case	Age range: 51-94 Number judged appropriate for: PPHA 54 (34.4%) Own Home 1 (0.6%)

PATIENT DATA SYSTEMS

In 1975 the National Center for Health Statistics sponsored a conference on long-term care data in Tucson. Work was begun on the development of a long-term care minimum data set which would provide a common methodology for acquiring data on the long-term care client for multiple providers across a range of settings.

In 1976 the United States National Committee on Vital and Health Statistics convened a technical consultant panel, chaired by Dr. Ethel Shanas of the University of Illinois, to continue work on the development and refinement of this data set.

Although the final form has not yet been achieved, the following outline provides the content of the March, 1978, draft version of the long-term care minimum data set.*

LIST OF ITEMS IN THE LONG TERM CARE MINIMUM DATA SET

DEMOGRAPHIC ITEMS

1. Personal Identification
2. Sex
3. Birth Date
4. Race/Ethnicity
   - A. Race
   - B. Ethnicity
5. Marital Status
6. Usual Living Arrangements
   - A. Type
   - B. Location
7. Court Ordered Constraints
   - A. Court Ordered Care
   - B. Court Appointed Guardian

*Information provided by Joan Van Nostrand.

The goal of the research group was to devise an assessment procedure which met five criteria (Densen and Jones, 1976:127):

1. Focus on the patient: The classification must describe the individual as he/she is at a specific point in time as well as show changes which occur over time.

2. Multidimensional descriptors: Again, medical diagnosis alone is insufficient. The tool must, therefore, describe the individual in terms of functioning, impairments, risk status, sociodemographic status, etc.

3. Use of objective rather than subjective/interpretive statements: In order to meet this requirement, the tool must provide the information upon which determinations for prognoses/judgements are to be made.

4. Relevance to classification: Items to be included should be chosen on the basis of scientific/epidemiological evidence demonstrating a relationship between item and patient outcome.

5. Flexibility: The tool must meet the needs of diverse users. This translates into incorporation of successive levels for each item, ranging from the broadest categorization to increasingly detailed ones.

The classification tool which the research group arrived at is contained in the 1974 publication mentioned above. In 1976 a companion tool was produced for potential users entitled Patient Assessment: A Training Manual for Use of Patient Classification in Long-Term Care.* It explains the procedure for completing the form and describes how to use the information for preadmission screening, developing care plans, medical evaluation, pharmaceutical review, utilization review, and discharge planning. As with P.A.C.E., the tool would have to be modified and made culturally-specific.

Densen and Jones (1975) report on the testing of the tool among patients with different needs and prognoses. It also indicated whether or not there was progress toward treatment goals.

*DHEW Publication No. HRA 75-3197, 11/74

SPECIAL NURSING PROCEDURES	Eye care Dressings Decubitus ulcers Teaching self-care
PSYCHOSOCIAL	Visitors Recreation/activities, Religious services

Another tool, developed by Mitchell and Sumner (1976) to identify, analyze, and compare costs across a range of services is the Methodology for Finding, Classifying, and Comparing Costs for Service in Long-Term Care Settings. A team composed of nurse and financial analyst used the following instruments: site-visit procedures summary, data collection protocol for patient data, and data collection protocol for cost and care-giver service data. This enabled the researchers to profile patients, classify services, and identify costs. Problems identified during this phase were documented, presented to the panel, and the tool revised as necessary. Phase II plans call for testing the methodology in eleven alternative care settings in 29 States, with the goal of developing a planning methodology for use at the federal, state, and local levels.

This methodology is a promising planning tool incorporating classification of patients and services and cost-finding across a variety of settings in one package. Unlike the Patient Classification for Long-Term Care, the focus is not primarily institutional. Definitions are clearly spelled out.

WAVE II form. Iterative use of Q.E.S. with increasingly larger samples enabled the researchers to refine a tool of over 3,000 items down to 127 in the shortest version, the abbreviated survey form. The WAVE II instrument was tested in 1,350 residents in 65 facilities from November, 1975 to January, 1976.

During WAVE II testing, an experimental design was used with a panel of experts for content validity. Comparison between Q.E.S. assessments and those of the panel showed significance at .85.

WAVE II disclosed other findings. Q.E.S. can be used by a State in certification activities. Neither federal nor state (Illinois) laws prohibit this use. Where federal certification noted major deficiencies in facilities, Q.E.S. did also, rating such settings in the bottom 30%. Q.E.S. detected one deficient facility previously passed by federal certification. The follow-up questionnaire to facility administrators showed that a majority preferred Q.E.S. to federal procedures. The methodology is cost-effective, involving approximately the same expense as the federal procedures.

In addition Q.E.S. is not biased toward one profession but is capable of multidisciplinary assessment. It presents a methodology for incentive reimbursement.

One problem with the use of this methodology is that it is currently limited to a specific population, the institutionalized elderly. This is reflected in the definition used by the researchers (Q.E.S., 1976:1.11): "quality long-term care is that care which predisposes the elderly (or other) individual to achieve his or her highest feasible level of physical, social and

* * *

The Reverend Pinezaddleby (Consumer Task Force) emphasized the contributions of American Indians to the cultural and spiritual values of their country. These values are embodied in the elders. One dominant theme expressed by the Consumer Task Force as a group is the urgent need to preserve the small number of elders who remain as the repositories of the Indian cultures. Woodenlegs (Consumer Task Force) summarized this theme:

> Last, but not least, promote the Elderly in every way to encourage the younger set to gain respect for them, their lives, their heritage, interest, wisdom, culture, abilities and their great devotion of the Great Spirit. Only then will young people be able to look forward to good health, long life and good things for Indian people. And to bear witness when they get old to the greatness of God through gratitude for all things taught to them when they were young.

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GLOSSARY

American Indian: American Indian/Alaskan Native is defined as one who is eligible for Federal and/or tribal programs and resides on a tribal reservation or in a rural or urban area of the United States.

Home Health Agency: Under the Social Security Act, Section 1861(o), a home health agency means a public agency or private organization, or a subdivision of such an agency or organization, which--

(1) is primarily engaged in providing skilled nursing services and other therapeutic services;

(2) has policies, established by a group of professional personnel (associated with the agency or organization), including one or more physicians and one or more registered professional nurses, to govern the services (referred to in paragraph (1) which it provides, and provides for supervision of such services by a physician or registered professional nurse;

(3) maintains clinical records on all patients;

(4) in the case of an agency or organization in any State in which State or applicable local law provides for the licensing of agencies or organizations of this nature, (A) is licensed pursuant to such law, or (B) is approved, by the agency of such State or locality responsible for licensing agencies or organizations of this nature, as meeting the standards established for such licensing;

(5) has in effect an overall plan and budget that meets the requirements of subsection (z); and

(6) meets such other conditions of participation as the Secretary may find necessary in the interest of the health and safety of individuals who are furnished services by such agency or organization;

Except that such term shall not include a private organization which is not a nonprofit organization exempt from Federal income taxation under section 501 of the Internal Revenue Code of 1954 (or a subdivision of such organization) unless it is licensed pursuant to state law and it meets such additional standards and requirements as may be prescribed in regulations; and except that for purposes of part A such term shall not include any agency or organization which is primarily for the care and treatment of mental diseases.

Federal financial assistance. Basic health services may also be provided to persons eligible for medical, but not financial assistance. The basic services include inpatient hospital care, outpatient hospital services, other laboratory and X-ray services, skilled nursing facility services and home health services for persons over 21 years of age, family planning services, and physician services. Early and periodic screening diagnosis, and treatment for persons under 21 years of age must also be included.

Proprietary agencies: Private agencies operated on a profit-making basis.

Skilled Nursing Facility: Under the Medical Assistance Program an SNF provides services ordered and supervised by a physician which can only be provided on an inpatient basis. The institution must be certified under State and Federal standards. A registered nurse must be on duty seven days a week, eight hours a day, with 24-hour nursing services provided. In areas with personnel shortages, such a facility may be allowed to operate with a registered nurse on duty only five days a week, eight hours a day.

Traditional Counseling: Employment of elders by the tribe for the express purpose of teaching younger members the traditional ways of life and cultural values of the tribe (myths, legends, rites and rituals, games, music, dances).

APPENDIX A

A. SUMMARY OF LEGISLATION AND REGULATIONS IMPACTING ON SERVICES FOR THE AGING

Legislation	Coverage	Eligibility	Providers	Regulati
Title XVIII of the Social Security Act (Medicare).	Under Section 1812, program payment can be made for visits to homebound beneficiaries under a physician's plan of treatment for part-time or intermittent nursing care, physical, occupational, or speech therapy, medical social services, part-time or intermittent services of a home-health aide, medical supplies, medical appliances, and outpatient services arranged by a home-health agency and a hospital, skilled nursing facility, or rehabilitation center. Under Section 1812 (a) (3) up to 100 part A visits per BENEFIT PERIOD CAN be made, but beneficiary must have been an inpatient in a hospital for at least 3 days or have received covered services in a skilled nursing facility for a period not exceeding 1 year from the date the home health plan is implemented.	Part A Requirements 1. Age 65 or disabled. 2. 3 day stay in participating hospital. 3. For further treatment of condition treated in hospital or SNF. 4. Need for part-time skilled nursing, physical therapy or speech therapy. 5. Homebound. 6. Physician determines need for care and establishes plan of treatment within 14 days after discharge from hospital or SNF. Part B Requirements 1. Age 65 or disabled. 2. Need for part-time skilled nursing care, physical therapy, or speech therapy. 3. Physician determines need and establishes plan of treatment	Home Health Agencies must be in compliance with Federal, State and local laws. Conditions of participation range from the type of services (e.g. an HHA must include part-time intermittent skilled nursing services and one other specific service), to administration and professional personnel requirements.	Subpart L-Reg #5-Conditions of Participation Part A Intermediary Manua Section 3120-3129.

Legislation	Coverage	Eligibility	Providers	Regulation
				and Home-Based Services may include a wide array of services such as Homemakers, Chore Services Home Health Aide, and Home Management
Title III and VII of the Older Americans Act of 1965.	Under the Area Planning and Social Services (Title III) allotment to the States, home services must be one of four priorities.	Title III-No set age limits are established under these provisions of the Act, however, the Act generally applies to the age group 60 plus. Title VII-Those persons who are aged 60 and over and their spouses regardless of age are eligible to participate in the Title VII programs.	Each State Agency on Aging must divide entire State into planning and service areas and designate Area Agencies on Aging for Coordination of services. There are presently 521 Area Agencies covering 90% of the Nation's persons aged 60 and over.	Title III-45CFR Part 90 Grants for State and Community Program on Aging. Title VII-45CFR Part 90 Nutritio Program for the Elderly.

Source: HOME HEALTH CARE
Department of Health, Education, and Welfare
December, 1976
pp. 56-58

B. CHECKLIST OF SERVICES ACCORDING TO LEGISLATION

Type of Service	Title XVIII	Title XIX	Title XX	Titles III & VII Older Americans Act
Nursing Care	X	X		
Home health aid/homemaker	X	X	X	X
Chore service			X	X
Shopping assistance			X	X
Home delivered meals			X	X
Transportation			X	X
Checking				X
Social and recreational				X
Housing				
Administrative/ legal				
Food, groceries				X
Personal care				X
Continuous supervision			X	

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*First number in each entry is Federal Telecommunications System Network. The second is the commercial telephone number.

D. ONAP*URBAN INDIAN STRATEGY

A. Urban Indian Center Criteria:

To be eligible for funding an Indian Center must meet the following structural criteria:

1. The application Indian Center must be an established agency which has:

   a. Articles of incorporation and bylaws (corporate structure) or an ongoing formalized organizational structure with a constitution and bylaws.

   b. A present economy or means of support. It should have some experience in the budgeting and control of funds.

   c. A governing Board whose membership is at least 51% Indian and which has been publicly elected by the Indian community which the Center is established to serve.

   d. A building or address from which to operate.

2. The Indian Center must be a multi-purpose organization which has the potential of offering a range of services in order to meet basic human needs.

3. The Indian Center must have the capacity for servicing at least 200 people. At present, only Center located in cities with an Indian population of 1,000 or more are eligible. This figure is an in-city figure, not an SMSA figure. (All population figures must be approved by ONAP Central Office) Populsation will be determined by one of three ways:

   a. the 1970 Census
   b. another Federal agency's figure for an in-city population
   c. a survey conducted by an acceptable methodology

B. Grantee Responsibilities

A grantee must perform the following activities:

1. Conduct a needs assessment of the population to be served.

*ONAP (Office of Native American Programs) has been renamed. It is now Administration for Native Americans.

activities as paying the salary of an Executive Director, a planner, an outreach worker or a fiscal officer responsible for the overall Center's budgetary matters. ONAP dollars might also be utilized to assist in the payment of a Center's rent, utilities and basic equipment and/or supplies.

6. Only one multi-purpose Indian Center may be funded per city.

For further information, contact Administration for Native Americans DHEW, 300 Independence Ave., S.W., Washington, D.C. 20201.

Other background papers address:

- Mental Health
- Physical Health
- Environment
- Safety