

# American Indian Caregiver Policy Study

An analysis with findings of the barriers to Federally funded and  
State and tribally administered caregiver programs in the State of  
Washington



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### Summary

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Indian governments and the government of the State of Washington seek to serve the needs of a growing American Indian elder and disabled population through the services of individuals caring for family members and individuals employed to provide care. The American Indian and Alaska Native elder population that is disabled as a result of dementia rely on the care and help of an estimated 3,160 individuals in tribal communities (the vast majority of whom are women) on and near Indian reservations and in cities in Washington. Tribal governments and the state government depend on federal program support to provide elder American Indian assistance. To achieve effective benefit for elder American Indians, direct assistance and support services have been defined under federal legislation to be delivered by the state of Washington through the Agency on Aging and Area Agencies on Aging working at the county level. Tribal governments also deliver support and services through caregiver programs and elder programs. Despite these efforts, support and assistance are often obstructed and qualitatively diminished for those providing care to elders and for assistance directly available to elders American Indians and Alaskan Natives.

Under this **Caregiver Policy Study** researchers learned from state and county informants about their experience attempting to implement policy and provide services to elder American Indians and Alaska Natives. Tribal informants provided information about their experience attempting to provide direct services and to follow state policy directives; all informants discussed at length what they believe to be obstacles working with and through tribal agencies, county agencies and with state agencies. Duplication of services, cultural insensitivities, confusion about county and tribal service and assistance policies, lack of culturally appropriate needs assessments, insufficient and limited demographic and population descriptive information, mismatched services, inflexible and

complicated regulations from state agencies, inexact cross-cultural communications between tribal and county agencies, and mismatching eligibility criteria are among the many suggested obstacles to effective and beneficial support, and assistance to Indian elders.

Individual family members and individuals employed through county and tribal programs provide care and support to elders. Neither county nor tribal support or assistance programs specifically include social, health and economic services aimed at the persons providing the care to the elder population. Perhaps the most important element in the change of support and assistance for elders—the person providing the care—is at major risk due to stress, traumatic events and chronic health problems. The diminishing capacity of those providing care may involve as many as 90% of all such persons adversely affecting their quality of life and the quality of life for those to whom care is being provided.

### Background of the Study

The Center for World Indigenous Studies, an independent research, policy and education non-profit 501 (c) 3 organization in Olympia, Washington received in 2004 a two-year National Institutes of Health–National Center for Complementary and Alternative Medicine grant award in support of its clinical agency, the Center for Traditional Medicine to undertake an exploratory study of the efficacy of Polarity Therapy on American Indian family caregivers of people with dementia: *The American Indian Caregiver Stress and Health Study*. Polarity therapy is a holistic healing, touch therapy intervention designed to reduce stress and pain and improve the quality of life. It is widely practiced across all life stages for health and well-being. It is well established that family caregivers of individuals with dementia experience stress, depression and increased risk of serious illness, however very little research has been done with American Indian caregivers and none in the Pacific Northwest. The clinical study applied physiological, biological, and

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psychological assessments and personal narrative data to understand more about caregiver stress and how a culturally congruent healing touch therapy might reduce stress and depression.

The American Indian Caregiver Health Study research team drew an important conclusion after two-years of clinical study about the subjects participating in the study:

**While the enrolled participants (average age 50) were considered to be healthy they had significant decrements in physical and psychological health such as chronic stress and pain, depression, digestive problems, hyperlipidemia and adrenal exhaustion. Coupled with their high rates of exposure to traumatic events earlier in life, these caring individuals were on the verge of near total “burn out” and some were at risk of sudden death due to low heart rate variability.**<sup>1</sup>

In addition to the focus on Polarity Therapy as a culturally acceptable treatment for stress, the study uncovered a wealth of information ancillary to the main research project. Our findings concur with the findings of The Administration on Aging survey of 68 programs funded through the Native American Caregiver Support Program (NACSP) that identified multiple barriers faced by caregiver programs and staff.

During the clinical research recruitment process the team learned directly from tribal providers and program managers throughout western Washington about the actual delivery of support services to caregivers. As a result researchers decided that a parallel Caregiver Policy Study should be designed with the participation of the Principal Investigators Dr. Rudolph C. Rysler and Dr. Leslie E. Korn and a research assistant Ms. Clara W. Berridge, University of Washington School of Social Work masters degree candidate, to examine the legal framework, policy and practices and attitudes of the main participants in the service delivery stream for American Indian caregivers. The Policy Study team began

this inquiry in May 2005 and completed gathering data in May 2006. We then undertook to review, evaluate and analyze the data through the remainder of 2006 and much of 2007. The central question of this Caregiver Policy Study is:

**Tribal Governments, county governments and the State of Washington government with financial support from the Federal government seek to deliver support services to American Indian caregivers in tribal communities. Is there sufficient programmatic capability, legislative and administrative clarity, and intergovernmental cooperation to effectively serve and support American Indian caregivers?**

The review of programmatic policies and practices as well as foundational literature and legislation is the product of this yearlong study. We have attempted to confine the study to the central question as noted. Individuals directly involved in the delivery of support and services, policy makers and those who guide and direct practices at the county, state, federal and tribal level were interviewed in Western Washington State and Washington, D.C. Meetings and conferences of state and tribal organizations were also observed. We have carefully documented our analysis and findings and offer concrete findings and recommendations drawn from tribal, state and federal informants and the facts as we found them. We have also carefully reviewed the extant literature as well as the legislation, existing law and the roots and original intent of legislation supporting the delivery of support and services to American Indian caregivers.

Initial Caregiver Policy Study findings expose a communications gap between tribal and non-tribal actors significantly affecting cross-institutional cooperation effectiveness. Yet, there is also a growing consensus among these affected parties suggesting that American Indian tribes can benefit from caregiver supports and services as a result of cooperation between tribal and non-tribal agencies.

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<sup>1</sup> Clinical Research Team members drew this conclusion after careful review of the Heart Rate Variability data. (McCarty, 2006)

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The Center's Polarity therapy study conducted under a grant from the National Institutes of Health, National Center on Alternative and Complementary Medicine found that American Indian caregivers who enrolled in the study in Western Washington State have been exposed to both physically and, emotionally traumatizing events of both an interpersonal and/or accidental nature. Virtually all of the subjects participating in this study had experienced an elevated and sustained level of stress before participating in the study.

Traumatic events are known to contribute to chronic depression, anxiety, pain and sleep problems. Most of the participants of this study were women and most had survived one or more traumatic events; some still had ongoing traumatic exposures in their jobs, family or community life. The rates of exposure to traumatic events were 90% in this sample. (In a parallel study of nine non-Indian female caregivers Researchers found that 50% had experienced at least 1 traumatic event.)

Current caregiver program design provides "respite" and "training." The evidence strongly indicates that American Indian caregivers may require more specialized supports and services—particularly through culturally appropriate stress reduction methods as well as support for family health and nutrition. These need to be integrative, tailored to specific needs, and responsive to the age-specific cohorts. Clinical research among non-Indians shows that individualized and intensive services are the most effective and beneficial. (Shulz & Czaja, 2000) Tribal-specific methods should include approaches that draw upon traditional healing practices, support customary food gathering and preparation opportunities and provide complementary and alternative medicine (CAM) interventions for both the caregiver and the family member. While many of these are currently practiced, there is virtually no formal, policy-driven or funded support for any of these activities.

Advocacy and informal counseling are also essential components that may be available through programs designed in law, policy and practice to assist them. Most caregivers are intensely private and reject the idea of anyone coming in to the home to

provide assistance in the form of respite or cleaning activities. This is especially true with older or more traditional caregivers. Hence respite or home care services routinely go unused. Yet employment of family members who are accepted in the home or reimbursement for chosen program supports may instead suit many caregivers. The policy mandates that often preclude these innovations are ripe for revision.

Improved cross-cultural communications is also needed to maximize the benefits of inter-agency cooperation. Informants repeatedly told researchers about the cultural misunderstandings, programmatic miscommunications, the perceived discrimination and bigotry during communications between state and tribal personnel. In some cases the effect of "local politics" was seen as an obstacle to effective service delivery from the point of view of state/county personnel. On the other hand, informants also reported that some of the most effective staff and managers had spent time working in both state and tribal agencies and were able to navigate both worlds, serving successfully as translators across the barriers to cooperation between tribal and state players. Failure to provide such specialized support and services to American Indian caregivers effectively defeats the purpose and intent of legislation, policy and practices aimed at ensuring long-term care and quality of life for tribal elders and disabled persons.

### Major Recommendations:

*(NOTE: Bracketed capital letters at the end of a recommendation relates to the corresponding letter designation for findings and recommendations in the report.)*

#### **[A] Bi-annual Intergovernmental Elder Care Conference focusing on cooperation and coordination of policy and practices, information, training and networking (O)**

An initial conference followed by a series of bi-annual meetings to promote cooperation and coordination between the federal, state and tribal governments to improve information dissemination, training and networking will improve coordination. The conference joins key players from American Indian social and health agencies and non-Indian social and health agencies as well as legislators in

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these fields. This will significantly reduce obstacles, and lead to the establishment of bridges between the affected parties that will improve communications and facilitate improvements in the Older Americans Act Title VI, Part C making it more appropriate, effective and beneficial for Indian communities.

### **[B] Revise Title VI, Part C – Tribally Organized Area Agencies on Aging (F)**

Adjusting federal (Older Americans Act Title VI, Part C) and tribal laws to permit the establishment of tribally organized agencies that match county and state Area Agencies on Aging will increase cultural suitability of support and services at the tribal level while providing an institutional mechanism for coordinating relations between tribal and state agencies. Establishment of agencies of equal authority and competence will ensure a balance in institutional relations between Tribal and State/County governments.

### **[C] Intergovernmental Cooperation Agreements (B)**

An intergovernmental agency between tribal agencies on aging and county and state agencies on aging should be established to facilitate tribal-state cooperation, communications and policy. Such an intergovernmental agency must reflect a full recognition of the separate jurisdictions of tribal and state authorities.

### **[D] Establish Tribal Specific Policy and Practice on direct and indirect compensation of family caregivers (H) (N)**

Tribal legislation should be introduced and adopted describing a policy on payment, financial supplement and other services for caregivers. Where the tribal specific legislation defines financial payment funding must be appropriated at a rate commensurate with need. Where tribal specific legislation addresses uncompensated labor, transportation, food, etc. that is “community subsidized” then a carefully defined plan must be instituted responsive to these needs. State agencies should incorporate guidance from tribal government policy into agency policy on caregiver eligibility and payment.

### **[E] Provide integrative personal health support**

### **for tribal caregivers (I)**

Tribal governments should take steps to reorganize tribal social and health services into collaborating service teams permitting caregivers and elders to draw on integrated social and health service provider teams so as to provide social health, physical health, mental health, and spiritual health support. Massage and touch therapies, stress reduction, nutritional therapy, herbal therapies and trauma resolution therapies should be incorporated into the whole health and social service system for caregivers. These traditional healing and CAM interventions should be coordinated and organized in an integrative fashion to reduce costly, unnecessary and excessive pharmaceutical use and in the support of other health goals such as cardiovascular disease and diabetes, both of which are rooted in stress. State and federal agencies should work to complement tribal whole health and social service program reorganization.

### **[F] Bidirectional Cultural Competency (D)**

State/County agency personnel and Tribal agency personnel must participate in bi-directional cultural competency training to facilitate greater understanding and improved communications. The training program should be provided on a regular and refresher basis by an experienced and proven independent agency whose services should be purchased by both Tribal and State/County agencies. A structured program of inter-agency personnel exchange would also provide an opportunity for the exchange of program staff to spend 12 –24 months working in a ‘sister’ agency manner.

### **[G] Stabilization of Permanent Staff in Tribal Governments (J)**

Tribal human resource departments must become more proactive. They should provide professional development for managers and for service delivery personnel to maximize improved professional skills and confidence. Emphasis must be placed on (a) strengthening managerial knowledge about the stressors associated with their own work (b) strengthen managerial knowledge of the work of the service delivery personnel so they can provide guidance and sustained support to encourage understanding of Agency policies and practices, and (c) systematically define and implement best

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practices within the specific tribal community.

Adjustments in intergovernmental cooperation and policy coordination will relieve the major obstacles to effective elder care and improvement of American Indian and Alaskan Native caregiver quality of life and reduction of stress.

### **[H] State Promote Simplification and Flexibility**

County agencies should have greater flexibility delivering support and services to tribal and county caregivers. Tribal specific demands are similar to the county community needs: both require greater simplification and flexibility to maximize responsiveness. State government regulators should support on-the-ground responsiveness with reduced regulatory control.

### **[I] Replace Assessments with Progress Monitoring**

Tribal assessments are not generally conducted. Instead of emphasizing a costly process, tribal programs with the support of county agencies should seek to monitor for positive outcomes and thereby avoid excessive costs.

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## American Indian Caregiver Policy Study

An analysis with findings of the barriers to Federally funded and State and tribally administered caregiver programs in western Washington

Families in western Washington tribal communities have historically practiced the ancient custom of extended family living and life-long care for disabled and elder members. The American Indian family has experienced extensive pressures during the 176 years since the beginning of non-Indian immigration and settlement in western Washington. The longhouse and the extended family are the social institutions that historically provided care for disabled and elder members. These social institutions inform and powerfully influence attitudes toward disabled and elder care today. The breakdown of longhouse living has decidedly interrupted the shared responsibility for many modern Indian families, but the custom remains strong in numerous families.

Tribal populations are rapidly growing and the number of elders and disabled members in tribal communities is growing at an accelerated rate. The demand for long-term care is growing even as social institutions are themselves changing. The customary practice of long-term care was historically carried out by many members of a family—within the framework of the extended family. The modern tendency is for the extended family to be fragmented leaving individuals—usually women—with the responsibility for providing long-term elder and disabled member care. The consequent social, economic and personal health stressors on individuals providing care directly affect the quality of life and care received by disabled persons and elders in the tribal community.

Longhouse societies in western Washington once defined the cultural and institutional mechanisms necessary for supporting long-term care. It is now the modern tribal government that has the responsibility for creating new social and economic institutions that support and serve those providing disabled and elder care on a long-term basis. Tribal governments have initially contributed to long-

term elder care by supporting the establishment of elders' programs and providing some support for caregivers. While important steps, they do not yet constitute a comprehensive response to the serious concerns arising from changes in population demographics.

The Older American's Act (July 14, 1965) is the federal government's response to the demands for direct care support and services to elders and disabled persons throughout the United States. The State of Washington acts to offer support and services to elders under the federal Act through Agencies on Aging and Area Agencies on Aging. The act provides limited support to persons providing long-term care, but does provide significant support to elders.

The generations old approach to long-term care rooted in tribal communities sits along side the more than forty-year old Older Americans program approach of the federal and state governments. When the Older Americans Act of the United States and state government meets the long-term elder care customs of tribal communities, adjustments become essential if elders and those who provide long-term care are to maintain a good quality of life, good personal health and stable social and economic lives.

In May 2005 the Center for Traditional Medicine of the Center for World Indigenous Studies in Olympia, Washington authorized this study to discover barriers and recommend solutions for the successful delivery of caregiver services provided to American Indians living on-and-near Indian Reservations in the State of Washington. This question arose while the Center was undertaking a randomized and controlled clinic study (**The American Indian Caregiver Health Study**) to evaluate the efficacy of a healing therapy known as Polarity therapy as an intervention to reduce stress and improve quality of life among American Indian

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family caregivers of people with dementia. The clinical research was carried out with major funding support from the National Institutes of Health, National Center for Complementary and Alternative Medicine.

As the work proceeded in the clinical research, it became increasingly apparent that a separate policy study would be necessary to determine why federal, county and tribal caregiver agencies were experiencing obstacles to effective service delivery contributing to disparities in Indian communities. It was increasingly clear that public and private institutions were not consistently able to reach American Indian caregivers. The present study was initiated as an eighteen-month inquiry to identify barriers and recommend solutions to effective support for American Indian caregivers and those whom they help.

### Overview

There is a dearth of published documentation characterizing the relationship between American Indian family members as care providers for elder or disabled family members. Even as studies are conducted on minorities, the collection of data on American Indian caregivers is not done “because of the cost of identifying individual caregivers in a small community” (John, 1999). Data on caregivers is not collected in tribal health clinics and it is generally the community health representatives who are working on-the-ground who are aware of caregiver and elder status, yet that knowledge does not often translate into service remedies.

There is virtually no systematically studied or reported information describing the specific circumstances of tribal communities in the Salish cultural region—from the southern coastal region of Oregon to the coastal border of the State of Washington with Canada and then to the interior of north central Washington State. In that area we estimate more than 177,575 American Indians live in cities and on more than 29 reservations (US Census, 2004).

Family members provide 90% of long-term care in American Indian households, yet despite this extraordinary figure discrepancies in the level of support and services received by both the caregiver and the elder are little understood or rarely addressed in programs (Redford, 2002). The rate of poverty among American Indians is nearly double that of the general (12.7%) U.S. population (Parker, Haldane, Keltner, Strickland, & Tom-Orme, 2002); and a major factor in this figure is elder-poverty. American Indian elders have incomes lower than the established US poverty level of one person over 65 determined by the US Census Bureau to be \$8,259<sup>2</sup> annually. American Indian elders disproportionately suffer from obesity, and in comparison with other elder populations, American Indian and Alaskan Native elders engage in a fraction of leisure-time physical activity and suffer from higher rates of diagnosed diabetes. (Clark, Holtzman, Goins, & Croft, 2005; Eschiti, 2004) In some American Indian communities, more than half of the elders have diabetes (Benson, 2004). Testimony before the U.S. Commission on Civil Rights caused that body to conclude that common barriers preventing American Indians from maintaining health and receiving quality health care include environmental factors, culturally inappropriate health care delivery, discrimination, geographic isolation, provider turnover rates, IHS service management, and long wait-times (USCCR, 2004).

As American Indian and Alaska Native elder populations increase<sup>3</sup>, more families will be comprised of three or four generations—increasing the extended family nature of these families and establishing greater numbers of individuals having the responsibility to care for elders or disabled family members. Hennessy and John (1998) refer to the family as “extenuated” rather than the oft romanticized extended family of American Indian caregivers because of the increasing pressures on the whole family to provide care most often without any additional supports. Modern housing and community patterns, compartmentalized institutional organization in tribal government, schools, health

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<sup>2</sup> The US Census Bureau figure was established in 2000...a figure here used to provide relative context.

<sup>3</sup> The aggregate total of elders from 29 Indian tribes in Washington 60 years and older in 2000 was 14,744, but that same cohort is estimated to reach 21,044 in 2007 (US Census 2000).

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agencies and economic agencies may combine to increase stress on individuals delivering care while compromising the important cultural strengths of extended family systems.

Many current or prospective American Indian caregivers tend to be younger than the general population and hence may be potential recipients of program support and services for a significant duration of time. In our study and one completed in the Santa Fe Service Unit, (Hennessy & John, 1998) the average age of the caregiver was 50. They performed at least 4 hours a day of direct care, 50% were daughters caring for parents and most worked at least half-time. Many caregivers served both disabled elders while they were still raising children and grandchildren. In our study 60 percent had provided care for 6 months to 3 years 17% between 3-5 years and 20 % for over five years. The majority of these individuals balance dual care responsibilities for an elder and a child or grandchild. (DHHS, 2003) With funding from the North Dakota Department of Human Services, the Center for Rural Health and the University of North Dakota School of Medicine and Health Sciences (CRH) conducted a study of American Indian caregivers and compared those needs and characteristics with the state's general population of caregivers. Their findings reveal that Lakota tribal members are on average more likely to work full-time, are not officially retired, and they care for more children than the general population. (CRH, 2003)

The intersection of health disparities in American Indian populations with caregiver burden are understudied and therefore not well understood by social and health service agencies. Chronic disease significantly affects the ability of individuals to function independently. Individuals are often disabled at earlier ages as well as at older ages. Chronic disease such as diabetes, arthritis, cardiovascular disease, Post Traumatic Stress Disorder (PTSD) and obesity in American Indian populations contribute to greater numbers of disabled individuals. Thus there is an increasing need for individuals providing care for elders or other family members. In our study of American Indian Caregiver Stress and Health, many of the participants had significant heart rate variability problems, which result

directly from chronic stress. If treated early heart related problems have the potential for amelioration through intensive stress reduction activities. It is well established that diabetes is directly associated with high levels of chronic stress (Korn & Ryser, 2005) and that exposure to trauma early in life often reduces the biological capacity to cope with stress later in life.

Demand for caregivers in Washington tribal communities will significantly increase during the years ahead in part due to growing numbers of elderly and individuals disabled due to chronic disease. We estimate that 3,160 individuals in tribal communities (the vast majority of whom are women) now provide care for elders and disabled persons in Washington. Since these are primarily unpaid individual family members or trusted friends performing caregiver services their work bears virtually no publicly recognized costs. However, using a pay rate of \$8.00 to \$12.00 per hour for services delivered for four to six hours a day we estimate the value of this unpaid service in Washington State Indian communities ranging from \$54.6 million to \$81.9 million in 2006. These amounts translate to individual direct and indirect expenditures ranging from \$17,065 to \$26,419 per caregiver in a year. While for many individuals the cost is paid in uncompensated labor, transportation, food, housing, sundries and other out of pocket expenses, the cost is clearly quite substantial.

### **Those who care for elders**

Virtually all American Indian and Alaskan Native family caregivers are unpaid like many in non-Indian communities. None of the federally mandated services under the Older Americans Act or State/county services and supports include provision of payment for the services delivered. The added financial burdens associated with caring for a family member simply adds stress to the already overly stressed caregiver's daily life. As noted elsewhere in this study the role of a person taking care of a family member is often determined by cultural norms in each tribal community. In some communities it would be unthinkable to receive a wage or salary while taking care of a family member. The common view held in such communities is, "If there is money to be paid...provide the money to

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help the elder.”

Despite such cultural norms, it is quite clear that tribal family caregivers suffer considerable stress from financial burdens. It is possible for a Tribal community to provide supports and assistance for caregivers without direct financial aid in the form of child-care, gas allowances, special health services, house cleaning, nutritional supplementation, and regular exercise delivered in the form of service supplements. Tribal budgets and State/county agency budgets do not contain such support and services for caregivers. The consequence can be degradation in the health of the caregiver and a decline in the quality of life and support necessary for the person receiving care. It is probably safe to suggest that the cost of providing such support to caregivers in the state of Washington would range from \$59 million to \$89 million in 2007. Without support for Indian caregivers the cost of acute care for the caregiver and the declining conditions of those who are being cared for may exceed \$120 million per year—a burden carried by the individual caregiver and communities.

The American Indian Caregiver Health Study research team drew after two-years an important conclusion about the subjects participating in the study:

While the enrolled participants were considered to be healthy, they had significant decrements in physical and psychological health such as chronic stress and pain, depression, digestive problems, hyperlipidemia and adrenal exhaustion. Coupled with their high rates of exposure to traumatic events earlier in life, these caring individuals were on the verge of near total “burn out” and many were at risk of sudden death due to low heart rate variability.<sup>4</sup>

In addition to the focus on Polarity Therapy as a culturally acceptable treatment for stress, the study uncovered a wealth of information ancillary to the main research project. Our findings concur with the findings of The Administration on Aging survey of

68 programs funded through the Native American Caregiver Support Program (NACSP) that identified multiple barriers faced by caregiver programs and staff. They include inadequate funding and staffing, geographic isolation, and the cultural mismatch of the NACSP focus on caregivers instead of on elders (Wright et al., 2003). The findings from our American Indian Caregiver Policy Study demonstrate additionally that structural barriers prevent Area Agencies on Aging and tribal social service directors from better serving American Indian elders and their family members in western Washington. The primary identified obstacle is a failure to engage each other in service coordination, a problem rooted in the historical structure of institutions that provide inadequate mechanisms for tribe/county/agency negotiation. We believe this is the root cause of the other problems observed in the service delivery failures.

American Indians and Alaskan Natives have cared for their elders for hundreds of years but enabling cultural elements are not identified as a basis for a caregiver support program, rather, the Native American Caregiver Support Program entails 5 components of caregiver supports that are identical to the components of the National Family Caregiver Support Program (NFCSP). There is little recognition through this policy that caregiving is a community process as opposed to an agency process, and that each tribe is a unique community. The word “caregiver” is a new name given to an age old practice in Indian Country, yet ironically the name is fraught with meaning either unknown or threatening to many family or informal “caregivers.” Lack of personnel and training for coordinators to adhere to the Older Americans Act Title VI, Part C is endemic. Elders and caregivers alike experience eligibility assessment procedures as invasive and coordinators identify a general confusion about the five components of the Native American Caregiver Support Program.

The added information suggests that institutional services and supports available to American Indian

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<sup>4</sup> Clinical Research Team members drew this conclusion after careful review of the Heart Rate Variability data. (McCraty, 2006)

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caregivers may be inadequate or inappropriate. Furthermore, tribal, state and federal laws, policies and practices may prevent American Indian caregiver access to personal services and support needed to ensure their good health and quality of life.

As the main clinical study continued it became increasingly apparent that all the care delivery participants (caregivers, caregiver service delivery personnel, and officials at the tribal, county and federal level) had substantially different understandings of what was actually being delivered to family members at the tribal level. It also became gradually clearer that tribal family caregivers were not consistently receiving either training and respite support or services. Indeed, when county agencies proffered such assistance to the tribal elder programs for Indian caregivers these services were commonly rejected on grounds of inappropriateness or intrusiveness. Generalized resistance appears to arise from the belief that caring for a family member is a deeply private and personal matter of primary concern to the immediate family. These observations led us to believe that there are important breaks in what is supposed to be a seamless service stream from agencies to caregivers to family members.

Support services and assistance to American Indian caregivers appear to be inadequate or non-existent with the possible result that services to American Indian elders (particularly persons suffering from dementia or individuals physically or mentally impaired) is proportionately degraded. No personal health support is made available to caregivers to improve stress and quality of life. Obstructed relations between tribal, county and state services agencies appear to directly contribute to the lack of support for American Indian caregivers with the consequent impairment of services to American Indian service recipients.

A recent study on long-term care needs concludes that American Indian elders wish to remain in their communities, maintaining their roles and relationships. (Wright et al., 2003) *Instead of moving to facili-*

*ties remote from tribal territory, elders choose their own home; and this circumstance creates a greater demand for individuals providing care.* The Retirement Research Foundation conducted a national needs survey (receiving one or more responses from 109 tribes) and found that the least available elder services were adult day-care and resources for people with Alzheimer's disease. When asked how often tribal elders get all of the help they need, 39 % of respondents indicated "some of the time," while 25% responded that elders got help "most of the time" (Benson, 2003). Sixty-eight percent replied that "most" family members would benefit from care-giving assistance. Respite-care and personal care were often described as being most helpful, yet these services were seldom available (Benson, 2002).

Support for caregivers has been provided through legislation and grants in Indian communities and through Area Agencies on Aging for many years. The level of funding for individual service providers varies considerably from program to program. The Areas Agencies on Aging through their Family Caregiver Support Program provide a limited number of discretionary supplements that range from about \$500.00 to \$1000.00 per caregiver available to caregivers who require either special home modifications, or counseling services. It is unclear whether any tribal members access this support. Through this program the Lewis-Mason-Thurston-County Area Agency on Aging (LMTAAA) has provided eligible caregivers with access to up to 8 hours of Polarity therapy, relaxation and wellness counseling and this program is accessed by both Indian and non Indian caregivers. Success of communication between the AAAs and tribes vary widely with some AAAs feeling "closed out entirely" and others having closer, though still limited relationships. The most successful coordination was observed when a well-experienced tribal elder worked at one of the agencies serving as a dynamic navigator. This highlights both structural issues as well as the vagaries of locale and experience.

The 2005 funding for a single grant under the NACSP ranged from \$16,990 to \$67,990.<sup>5</sup> The pro-

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<sup>5</sup> Source: U.S. Department of Health and Human Services

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gram received \$5 million its first year, \$5.5 million in FY 2002, \$6.2 million in FY 2003, \$6.3 million in FY 2004, and \$6.3 in FY 2005 and FY 2006.<sup>6</sup> Nine demonstration projects were also funded through the NACSP at \$100,000 over three years for fiscal years 2001-2004.<sup>7</sup> Present funding levels in support of Tribal programs is clearly too low to meet the needs. While this is often the refrain about any social program, there is clear evidence that Tribal programs are seriously under-funded.

Tribal programs suffer from a number of limitations and obstacles—many of which require tribal leadership and attention in the form of tribal legislation and policy changes.

### Methodology

This policy study was structured to include interviews of primary participants in the delivery of caregiver support services and direct services including Tribal, County and Federal officials and service providers; and a review of the literature and statutes relevant to American Indian caregiver policy. The research assistant conducted interviews asking each informant a set of predetermined, open-ended questions providing a consistent framework for responses without determining the responses. After conducting several interviews the research assistant reviewed initial responses with the Principal Investigators and a record was made of the discussion providing documentation on interpretation of responses. The Research Team comprised of the Caregiver Policy Study Principal Investigator, Caregiver Study Principal Investigator and the Research Assistant conducted a thorough review of the literature relating to caregiver programs in Indian communities and their effectiveness throughout the United States.

The enabling federal legislation (USC: Title 42, Chapter 35, Subchapter 3057) was reviewed emphasizing the existing language contained in the law as it relates to county and tribal programs, the Congressional intent and the role of such organizations as the National Congress of American Indians, National Indian Council on Aging, National Indian Health Board, and the National Indian Child Wel-

fare Association.

### Statutory Policy

The Federal government enacted the Older Americans Act (July 14, 1965); and in succeeding years the Act was amended in 2000 (Public Law 106-501-Nov 13, 2000 – 114 Stat. 2267) to improve community employment for older Americans. At the time of its reauthorization in 1992, the Congress inserted a new Title VII, Chapter 3 addressing “prevention of abuse, neglect and exploitation of older Americans.” The Congress recently reauthorized the Older American’s Act and amended it with House Resolution 6197. (“Older Americans Act Amendments of 2006”, 2006) The section concerning American Indians was added in August 31, 1988.

The Act was originally designed to serve (1.) family caregivers and (2.) grandparents or older individuals who are relative caregivers. Specific programmatic services include:

- (1) information to caregivers about available services;
- (2) assistance to caregivers in gaining access to the services;
- (3) individual counseling, organization of support groups, and caregiver training to caregivers to assist the caregivers in making decisions and solving problems relating to their caregiving roles;
- (4) respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- (5) supplemental services, on a limited basis, to complement the care provided by caregivers.

The initial delivery mechanism for these services to all recipients has developed to include 53 State Units on Aging, 650 Area Agencies on Aging and 240 Title IV American Indian Programs (AAA, 2006).

The Congress of the United States enacted the Older American’s Act with a specific chapter concerning American Indians, Alaskan Natives and

<sup>6</sup> Source: Agency on Aging – Region X, and Department of Social and Health Services

<sup>7</sup> Source: Agency on Aging, Region X.

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Hawaiian Natives which was recorded in statute as the United States Code Title 42, Chapter 35, Subchapter 3057. The Congress made the following determination in this part of the law that American Indians:

- (1) are a rapidly increasing population;
- (2) suffer from high unemployment;
- (3) live in poverty at a rate estimated to be as high as 61 percent;
- (4) have a life expectancy between 3 and 4 years less than the general population;
- (5) lack sufficient nursing homes, other long-term care facilities, and other health care facilities;
- (6) lack sufficient Indian area agencies on aging;
- (7) frequently live in substandard and over-crowded housing;
- (8) receive less than adequate health care;
- (9) are served under this subchapter at a rate of less than 19 percent of the total national population of older individuals who are Indians living on Indian reservations; and
- (10) are served under subchapter III of this chapter at a rate of less than 1 percent of the total participants under that subchapter. (“Older Americans Act”, 2005)

Accordingly the Congress expressed its intent with legislation as follows:

“The Assistant Secretary shall carry out a program for making grants to tribal organizations with applications approved under parts A and B of this subchapter, to pay for the Federal share of carrying out tribal programs, to enable the tribal organizations to provide multifaceted systems of the support services...” (“Older Americans Act”, 2005).

In addition to funds for program support, the Congress decided that surplus facilities should be converted to the benefit of American Indian Senior programs:

...the Secretary of the Interior through the Bureau of Indian Affairs shall make available surplus Indian educational facilities to tribal organizations, and nonprofit organizations with tribal approval, for use as multipurpose senior centers. Such centers may be altered so as to provide extended care facilities, community center facilities, nutrition services, child care services, and other supportive services (“Older Americans Act”, 2005).

The most recent action amending the Older Americans Act was signed into law in October 2006. These amendments placed a strong emphasis on the reduction of elder abuse and neglect, volunteerism, community planning for elder care, caregiver outreach and service and inter-governmental coordination.

Upon passage of the reauthorization and amendments to the Older Americans Act Wyoming Senator Mike Enzies, then Chairman of the Senate Health, Education, Labor and Pensions Committee described improvements to the Act this way:

- Direct the Department of Health and Human Services’ Assistant Secretary of Aging to appoint a full time officer to take charge of federal elder abuse and prevention services and to coordinate federal elder justice activities;
- Promote the development of systems that enable older individuals to receive long-term care in home and community-based settings based on individual needs and preferences;
- Improve access to programs and services under the Act by addressing the needs of older individuals with limited English proficiency;
- Encourage both States and area agencies on aging to plan for population changes and require state agencies and local area agencies on aging to coordinate activities and develop long-range emergency preparedness plans;
- Improve access to supportive services that help foster independence and maintain quality of life, including assistive technology services and devices, mental health services, and activities to promote life-long learning;
- Expand Caregiver program services to older adults caring for children of any age with a disability; individuals with Alzheimer’s disease; and grandparents or relative caregivers, age 55 and older, caring for children of any age; and,
- Ensure that the Older American Community Service Employment Program, a job-training program for older Americans, provides on the job training to unemployed seniors in community service programs – helping seniors build new jobs skills while providing skilled workers for programs serving low-income families and individuals (Enzies, 2006).

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The Agency on Aging in Washington, D.C. interpreted improvements in the Act in slightly condensed and imprecise terms after the Bill was signed into law.

- Enhanced Federal, State, and Local coordination of long-term care services provided in home and community-based settings
- Support for State and community planning to address the long-term care needs of the baby boom generation
- Greater focus on prevention and treatment of mental disorders
- Outreach and service to a broader universe of family caregivers under the National Family Caregiver Support Program
- Increased focus on civic engagement and volunteerism
- Enhanced coordination of programs that protect elders from abuse, neglect and exploitation (Carbonell, 2006).

The Amendments do touch on the concerns of Indian communities, caregivers and elders primarily in connection with the formation of “coordinating councils” concerned with advising Federal Government official on appropriate “models” to “combat elder abuse, neglect, and exploitation...” (“Older Americans Act Amendments of 2006”, 2006). The reauthorization also includes proposals for modest cost of living budget increases resulting in status-quo funding levels.

### Commentary

The United States Congress intent when it passed and later amended the Older Americans Act of 1965 has been consistently clear in connection with American Indians: elders and their caregivers must receive financial and service support to assure a good quality of life and health. Examining the on-the-ground outcome of Congress’ intent affecting Western Washington Indian Tribes suggests a dramatically different reality: there are funding, structural, cultural, and jurisdictional obstacles to achieving “a good quality of life and health” for American Indians who are to benefit from the Older Americans Act. The on-the-ground players who seek to implement the intent of Congress in the State of Washington and in Tribal Governments in Western Washington are faced with daunting ob-

stacles and American Indians on-and-near Reservations are being short-changed.

Area Agencies on Aging (AAA) like the Lewis-Mason-Thurston, Pierce County and Northwest agencies and tribal social service directors seek to serve American Indian elders and their family members in addition to their primary responsibility for the non-Indian population. The Washington State Department of Social and Health Services affirmed this commitment by publishing a memorandum to Area Agency on Aging Directors spelling out its policy on AAA relations with Indian tribes. The memorandum reflects a state bureaucracy working with Indian government officials and other representatives as unfamiliar and distant from official state government experience. The memorandum emphasizes “matrixes,” “goals,” and “objectives” for planning processes with “Tribal entities” (Black, 2005). The intent is clearly reflective of a desire for efficiency, but also a need to have tribal governments and their representatives function according to the policies of state government employees. Tribal governments and their service officials often express an informal policy of distancing the tribe from the state government; and individuals in tribal service positions convey their lack of confidence in and suspicion of state policies and practices. The primary obstacle to effective cooperation between tribal government and county officials as this memorandum suggests is an awkward breakdown in efforts to engage each other in true collaboration. This awkwardness in county and tribal government persists despite agency, state and federal mandates to incorporate tribes into the Aging Network.

Tribal agency and county agency informants to this Study expressed frustration with the failure of communications between AAAs and tribal programs. The perception by several informants on both sides is that official communications obscure rather than explain policy and practice. Some noted that communications problems often arise as a result of lack of training at the tribal and county levels; and still others noted that staff turnover contributed to a breakdown in communications. Caregiver service practice may be at variance from policy in the tribal government and in the state gov-

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ernment as a result of limited training, imprecise communications and limited funds.

The tribal side and the county side independently agree that there are advantages to improved communications, cooperation and collaboration, but they seem, according to some informants not to understand the advantages from the other side's perspective. Neither side seems to understand the responsibilities, pressures, concerns, goals and objectives of the other side. The inability for each side to understand or appreciate the perspective of the other side contributes to a reduction in confidence and cooperation.

Other informants on the county side say they want to develop closer coordination with tribal service providers, but they see themselves as "spread too thin" with their work responsibilities that such personal contact is rarely possible. Consequently, there is little opportunity for service providers and coordinators at the county and tribal levels to develop strong working relationships.

Some informants on the tribal side believe the quality of communications between their agencies and county agencies could be improved if the county employs a "native person." Where Area Agency on Aging liaison roles have been filled by a "native person" there has been improved communications between that person and tribal personnel. Several informants note, that while it is true that communications between the county agency and the tribal agency is improved, the relationship between the "native person liaison" and the county agency is often strained and occasionally estranged to the point where there is a conflict between county policy and the tribal liaison.

Achieving benefits from caregiver support is prevented by:

- The term "caregiver" appears to have little currency in the Indian Communities in which we worked.
- Lack of tribally appropriate needs assessments for tribal programs.
- Limited and generally unsuccessful efforts to disseminate information, reaching out to Indian communities, networking and facilitated coordination between agencies: Area Agencies

on Aging and tribal agencies and governing authorities and fairly low levels of trust among American Indian caregivers toward the Area Agencies on Aging; lack of bi-directional cultural competency.

- Tribal personnel turnover and inconsistent tribal policy and practice.
- Deficiencies in the number of agency personnel are widespread, and
- Ineffective provisions in the **Older Americans Act Title VI, Part C** policy and limited procedural training for affected parties contribute to a breakdown in the conduct of successful support for American Indian caregivers.
- Interagency Power mismatch where the asymmetrical relationship between the tribe and the state places the state in the position of dominance where the state sets policy and guides practice, and the state controls many sources of funds.

These shortcomings undermine virtually all participating parties despite statutory mandates that facilitate communications and coordination through the training of personnel within the organization of affected parties.

The word "caregiver" is an inexact term in Indian Country. It is a term originally coined by non-Indian health professionals, academics and federal agency personnel seeking to capture in limited language a specific target audience. Most Indian families customarily apply an age-old practice where certain individuals (family members, or chosen individuals) are given or assume a duty to care for an elder or disabled individual—the word "caregiver" is simply not commonly used. Caregiver connotes a "job" instead of a customary duty or responsibility. Ironically the term is fraught with meaning either unknown or threatening to many persons who have the duty in a family. Elders and family members who have the duty to look after an elder often consider state and federal guidelines and procedures for eligibility assessment socially invasive and insulting—even destructive of customary community norms. This manifests in several ways:

- The state-mandated assessment process of caregivers and their family member(s) who wish to receive services is understood to be intrusive

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and unnecessarily prolonged (requiring many hours) by both state agency and tribal staffs, and as a result on and off reservation Indians often forgo services rather than become subject to the process.

- The paperwork required to receive services is often prohibitive; one tribal elder stated: “I would spend all day filling out paperwork and it would never come to anything.”

Caregiver program coordinators at the tribal level (an employed role) acknowledge their general confusion about the five components of the **Native American Caregiver Support Program (NACSP)** on which they are required to rely. Confusion and conflict with the NACSP provisions is another layer obstructing effective program execution. Other obstacles are institutional and cultural communication strategies, which often fail in part because they reflect common non-Indian biases regarding Indian communities and society and common Indian biases regarding non-Indian program and agency officials.

These obstacles are not all solely associated with caregiver support services, but rather, speak to larger structural issues faced by other social and health coordinators and delivery agencies. The conflicting meanings of the word “caregiver” is emblematic of the problems of cross-cultural and cross procedural and policy communications that appear to result in service delivery failures common to many health delivery systems serving Indian Country. Addressing these barriers in the field of “care-giving” will tend to illuminate the need for policy and procedural changes in other social and health service arenas.

Tribal specific needs assessments addressing long-term care and caregivers is generally lacking. The process of needs assessments is understood by program personnel to be needed, and if completed that such needs assessments require frequent updating and review. The cost of such assessments combined with limited experience and personnel turnover frequently prevent the possibility that the long-term health care assessment is actually carried out. Additionally tribal program personnel have limited access to models of needs assessments suitable for their unique tribal communities, and cultural

contexts. Such models are not necessarily transferable between tribal communities even if they were available. Recognizing this problem, the National Resource Center on Native American Aging (NRCA) has attempted to develop a partial answer in their “The Long Term Care Tool Kit” (McDonald, Ludtke, McDonald, & Allery, 2005). Offering guidelines for the development and conduct of a long-term care needs assessment the authors of this “kit” focus a conventional research approach that employs an “objectivist” methodology. Indeed, the approach is typically used in the academic environment with its main focus on the recipient of care—the elder—while failing to note the importance of the family and the caregiver’s needs as a part of a whole case assessment. Integrating quantitative and qualitative information is commonly appropriate to evaluating needs in a tribal community. The NRCA approach provides a survey and technical assistance to tribes to conduct their own needs assessments. This approach is a good start but may sometimes be unsuitable for the tribal context, since it often requires technical training and funds not commonly available.

Tribal agencies and Area Agencies on Aging aiming to serve caregivers and the persons they help frequently fail to communicate effectively between themselves and with the service population. Methods of communication with service populations commonly used to disseminate information in metropolitan areas (radio, television, newspapers, posters, flyers and pamphlets) are generally ineffective in tribal communities. Successful communications in many tribal communities are more labor intensive: visits in homes, conversations at gatherings, public presentations and supplemental written material outlining key elements of information. Tribal communities tend to be more conversational, person-to-person communication environments. This is not to say that written material is not useful. But when written material is presented in the language of “bureaucratic jargon” either by the tribal program or the state/county agency, the degree of understanding and confidence in the information is frequently reduced or very low. Communications between tribal agencies and Area Agencies on Aging or other state entities concerned with long-term care are similarly complicated. Local tribal circum-

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stances (social, economic and cultural) color and define how tribal officials communicate. Similarly, agency ethos and the agency personnel's own living environments shape and define how Area Agency on Aging and other state program personnel communicate. Neither tribal nor state/county officials share a common experience so they are prone to misunderstandings. Greater bi-directional training to improve communications is clearly essential.

Tribal social service and elder health programs experience frequent personnel turnover. Changes in personnel destabilizes the program, complicates communications, often slows a program due to interruptions from the need for new personnel to learn about the program and results in inconsistency. Changes in personnel or other program interruptions result from episodic funding, management or personnel conflict, competition for limited employment opportunities, lack of tribal specific professional development training, and uncertainties about the intent of the program. Changes in state/county agencies are similarly affected by personnel changes. These agencies have attempted to improve their coordination with tribal programs by employing "tribal liaisons" who are a member of an Indian tribe. These positions tend to be unstable. Merely employing an individual, who happens to be a member of a tribe, does not ensure that the individual can deal with or work with the programs in various tribes in the agency's service areas, though as noted above many individuals serving as liaison have improved communications. Indeed, even if an individual is accepted and trusted, the policies and practices they must present to tribal programs may still conflict. Personnel stability is an essential element in program effectiveness, and neither tribal nor state/county agencies is able to ensure such stability.

In tribal programs social service and elder programs are often under-funded and/or staffed by individuals who are themselves under immense social stress. Like funding for social services outside of tribes these jobs are generally held by women who are paid minimum or near minimum wage. This contributes to lack of stability because they are seeking other jobs. Likewise because caring for elders and the aging requires the develop-

ment of trust, high levels of trust occurs over time and requires staff who are there for the long haul. Our findings were iterated by focus groups held in the Dakotas, which point to this endemic problem. The payment structure for the positions of caring cannot be separated from the valuation afforded the positions by both tribal and society at large. These basic service positions are the foundation of care for the elders and yet they pay the least.

A hard look at the valuation of care must be undertaken as part of cultural restoration programs within the tribes and understood as part of the educational process of the young and adults of all ages. A new model for integrating values and economics of care can be created at a tribal specific level in order to more fully use the abundant human resource capacity within the tribe and as a method of economic returns within families.

### **Sovereignty and Jurisdiction**

Tribal sovereignty is negotiated through interactions defined by a government-to-government relationship meant to support tribal self-determination, and tribes' "right to opt into negotiations is the exercise of sovereignty just as much, or more, than attempting to operate independently" (Ashley & Hubbard, 2004). It is particularly difficult for the state contracted social service provider on the ground to define its role in coordination relative to the government-to-government protocol with ambiguous implications for tribal/state agency interactions. As one AAA manager put it, "I guess tribes don't want to deal with us lowly providers." This comment reflects a general lack of understanding of tribal legal and political status in relation to the State of Washington and the United States. It also reflects the longstanding unresolved problem identified by the Intertribal Study Group on Tribal-State Relations that conducted a yearlong study between 1979 and 1980 in Washington State on tribal and state government conflicts. The tribal government leaders' panel was co-chaired by Quinault Nation President Joe DeLaCruz and Yakama Nation Councilman Russell Jim and included Squaxin Island Chair Cal Peters, and Makah Nation Councilwoman Mary Jo Butterfield. Their report in 1980 asserted that conflicts between tribal governments and the state government result when there is no

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co-equally created intergovernmental mechanism established to facilitate government-to-government relations (Ryser, 1980). In partial reply to the Intertribal Study Group on Tribal/State Relations, the governments of the State of Washington and twenty-six Indian nations and tribes nine-years later signed the **Centennial Accord** ("Centennial Accord", 1989) establishing ground rules for the conduct of government-to-government relations. The framework setting agreement established between tribal governments and the state government was amplified and reaffirmed by a subsequent **Millennium Agreement** signed in Leavenworth, Washington ("Millennium Agreement", 1999) further providing definition to structured government-to-government relations. Both tribal governments and the state government took steps to establish intergovernmental liaison positions specifically designed to deal with subjects of mutual concern. Considerable improvements in tribal/state relations have been achieved as a result of these important intergovernmental measures. Both tribal governments and the state government did reduce legal and jurisdictional conflicts that characterized the decades before 1990.

While these important agreements contributed to important changes in intergovernmental policy and practices, still more changes in relations between state government and tribal governments are warranted as communications and procedural problems between tribal caregiver and elder health programs and Area Agencies on Aging suggest. The power relationship between agencies of tribal government and state government are significantly out of balance in terms of funding, personnel experience, and the reach of governmental jurisdiction. One important consequence of this imbalance is reluctance on the part of tribal and state/county program and service personnel to work collaboratively. As the Intertribal Study Group on Tribal-State Relations indicated in 1980, the imbalance cannot be corrected *when there is no co-equally created intergovernmental mechanism established to facilitate government-to-government relations*. As one informant said: "A missing structure for coordination creates tension based on fear of stepping on toes or unwittingly into tribal politics."

There is little recognition in current policy that caregiving is a community process as opposed to an agency process, and that each tribe is a unique community. Much of our information at the tribal level suggest that caregiving is a process of community, not of an agency, tribal or state. Tribal informants suggest that caregiving has been done in Indian Country for millennia but no one is asking why it works (peer pressure, familial obligation), when it doesn't, or what is needed. Those elements must be the basis for any caregiver program.

### **Findings and Recommendations:**

#### **[A] Tribal service coordinators express confusion as to the intent of county and agency actors – the purpose of Title VI Part C.**

##### **1. Recommendations**

AAAs hold the knowledge of and training experience on national caregiver grant components and are active members of the Aging Network while tribes face deficiencies in the number of personnel and effective Older Americans Act Title VI, Part C policy and procedure trainings.

The state mandates that the allocation of resources shall require outcome evaluations that are culturally inappropriate and unrealistic for tribal social services to produce. Aware of these burdensome regulations, tribes are reluctant to request or accept AAA assistance. One AAA county informant stated, "It [collaboration] is not worth it for tribes. They don't want AAAs involved if they come across as control freaks and frankly I don't blame them."

##### **Federal**

No Action

##### **Tribal**

Tribal Service Managers should provide regular in-service training explaining state and federal policies and practices and compare them against tribal policies and practices in the field of long-term care services.

##### **State**

State/County Managers should meet with tribal managers to answer questions concerning the intent of state and agency actors carrying out the pur-

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poses of Title VI.

**[B] The asymmetry of power between AAAs and tribal social services is fundamental to tribes' inability to deal effectively with state agency mechanisms for coordination.**

Area Agency on Aging organizations have the power and influence of the State government and the federal government in support of their policy and practices that are mainly designed to address the needs and interests of the wider population of the state. The more particular needs and interests of tribal communities can be effectively addressed in relation to state/county agencies within a framework of government-to-government relations as framed by the Centennial Accord of 1989. Functioning mechanisms including balanced, authoritative representation from tribal government and state government should coordinate policy and practices on long-term care. This is an enhancement to a system that is only partially complete.

### **2. Recommendations**

#### **Federal**

The Older Americans Act should be amended to include financial support for multiple intergovernmental agencies providing for tribal and state representation addressing long-term care.

#### **Tribal**

Each tribal government or the governments of cooperating tribal governments should introduce and enact legislation authorizing the creation of an intergovernmental agency on long-term care, providing tribal budgetary support and designating representatives.

#### **State**

The state government should introduce and enact legislation authorizing the creation of an intergovernmental agency on long-term care, providing state budgetary support and designating representatives

**[C] The components of the Native American Caregiver Support Program (NACSP) address needs that have been defined outside tribal communities.**

American Indians have cared for their elders for

hundreds of years but enabling cultural elements are not identified as a basis for a caregiver support program. Rather, Title VI Part C entails 5 components of caregiver support that are identical to the components of the National Family Caregiver Support Program (NFCSP) and applied universally. There is little recognition through this policy that caregiving is a community process as opposed to an agency process, and that each tribe is a unique community.

Paid respite is preferable to other NFCSP components such as support groups and counseling that may not appeal to many members of small tribal communities. Tribes spend the vast majority of their grants on respite by training and employing caregivers. This was not defined as a problem by each affected party but is a concern of an intertribal organization that assists tribes with federal grants, the Administration on Aging central office and AAAs as there is a strong emphasis on supporting unpaid caregivers among NFCSP advocates.

### **3. Recommendations**

#### **Federal**

No Action

#### **Tribal**

Each government should develop tribal specific long-term care policies and practices that reflect the cultural, social and economic realities of the particular communities served emphasizing the needs of caregivers as well as the individuals they provide care to. Policy statements must also address the question of payment or supplemental financing for caregivers. These policies must then provide guidance to service managers and personnel.

#### **State**

Consistent with the spirit of the Millennium Agreement of 1999 the State and County Area Agency on Aging should engage tribal officials and request their specific statements of policy and practice on long-term care, caregivers and their care recipients.

**[D] Area Agency on Aging staff lack the tools to communicate with tribal members across cultural difference and time to work through cultural differences and form working relationships with staff of tribal social services.**

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**State and agency cultural training guidelines are well-meaning but unfunded and disconnected from practice. AAAs want to coordinate but don't have tools beyond what they have already tried.**

Staff are spread thin and it is easier and makes more sense from their standpoint to devote precious time to serving those ethnically diverse caregivers and elders who are eagerly standing in line requesting services. AAA staff recognize the cultural importance of relationships yet lack time, cultural understanding and confidence or precedence to risk making persistent efforts. AAA program managers do not know appropriate contacts on the tribal end to exchange information about caregiver services or events. Furthermore, often the people providing direct caregiver support work function outside of the “formal” or funded programs. Without close working relationships, the AAA program manager would not gain access to the behind-the-scenes reality of caregiver support.

### **4. Recommendations**

#### **Federal**

No Action

#### **Tribal**

The health and social service agencies of the tribal government should establish close program coordination then establish, develop and conduct regular bidirectional cultural competency training that provides experience and learning about state and county social and health services ethos as well as tribal culture.

#### **State**

Establish, develop and conduct regular bidirectional cultural competency training that provides experience and learning about state and county social and health services ethos as well as tribal culture.

**[E] Tribal caregivers and elders widely regard eligibility assessment procedures as invasive and disruptive of family norms.**

### **5. Recommendations**

#### **Federal**

No action

#### **Tribal**

Tribal policy and practices should define tribal specific eligibility assessment procedures.

#### **State**

State managers should support a customized approach to eligibility assessment to be carried out at the discretion of Area Agency on Aging entities working with tribal managers. Should recognize tribal specific eligibility assessment procedures as valid.

**[F] There is a consensus in tribal government agencies that American Indian family members can benefit from caregiver support services, but coordination between western Washington tribal social and health agencies and county Area Agencies on Aging is limited and often non-existent.**

The Older Americans Act contributes to the existence of an asynchronous relationship between tribal governments and the state government on matters of policy and practice serving caregivers and elders. By virtue of the federal authority conveyed to the state government, tribal governments are relegated to a “grant recipient role” and not included in the policy-making position necessary for tailoring caregiver and elder care service delivery at the tribal level. Because of the imbalance, tribal governments are left to implement policies generated in Washington D.C. and in Olympia, Washington without the full ability to define and implement policy most beneficial to tribal community members. To redress the imbalance, it is necessary for tribal governments to take the initiative exercising their separate sovereign powers by independently establishing service and coordinating agencies that equal the role of the Area Agency on Aging. Further redressing the imbalance demands the establishment of a working intergovernmental mechanism between tribal agencies and state agencies established pursuant to the 1989 Centennial Accord.

### **6. Recommendations**

#### **Federal**

The Older Americans Act should be amended to authorize, fund and recognize Tribal Agency on Aging organizations established under the authority of tribal governments.

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### **Tribal**

Each tribal government or a coalition of tribal governments should adopt legislation establishing either a single tribe or multiple-tribe “Tribal Agency on Aging.” Initially drawing on their own financial and professional resources tribal authorities should establish Tribal Agency on Aging as a support for tribal service programs providing training, health support, and coordination and policy guidance. The Tribal Agency on Aging should also function as the coordinating Agency that interfaces with the County and State Agency on Aging.

Each Tribal Agency on Aging should participate in an **intergovernmental coordinating commission** made up of tribal officials and Area Agency on Aging Officials that is formed by tribal governments and state governments as a working intergovernmental mechanism established to facilitate interagency coordination and cooperation. The mechanism may rely on the Centennial Accord for initial authority.

### **State**

Each Area Agency on Aging should participate in an **intergovernmental coordinating commission** made up of tribal officials and Area Agency on Aging officials that is formed by tribal governments and state government as a working intergovernmental mechanism established to facilitate interagency coordination and cooperation. The mechanism may rely on the Centennial Accord for initial authority.

**[G] Tribes spend the greater portion of their respite grants on training and employing caregivers.**

### **7. Recommendations**

#### **Federal**

New funds should be appropriated to support both respite and personal health care for caregivers.

#### **Tribal**

New legislation should be introduced in tribal council to provide and authorize funding for respite and personal health care for caregivers.

#### **State**

No action

**[H] There is a strong emphasis on supporting UNPAID caregivers among National Fam-**

**ily Caregiver Support Program coordinators, which creates a division between state and tribes; however other components such as support groups and counseling may not be appealing to members of small communities.**

We estimate that 3,160 individuals in western Washington tribal communities (the vast majority of whom are women) now provide care for elders and disabled persons in Washington. Since these are primarily unpaid individual family members or trusted friends performing caregiver services their work bears virtually no publicly recognized costs. The burden for delivering care is paid in the form of uncompensated labor, transportation, food, housing, sundries and other out of pocket expenses. Tribal cultural norms historically provided support from the community through longhouse extended families and giveaways. Some tribal communities may still desire this approach while various forms of direct compensation may be desired from the view of other cultural communities.

### **8. Recommendations**

#### **Federal**

No Action.

#### **Tribal**

Tribal legislation should be introduced and adopted describing a policy on payment, financial supplement and other services for caregivers. Where the tribal specific legislation defines financial payment funding must be appropriated at a rate commensurate with need. Where tribal specific legislation addresses uncompensated labor, transportation, food, etc. that is “community subsidized” then a carefully defined plan must be instituted responsive to these needs.

#### **State**

State agencies should align their policies regarding the provision of caregivers to supporting family caregivers through tribal community systems and provide alternative support for unpaid caregivers beyond training—to include cooperatively developed tribal/state support and assistance options for caregivers.

**[I] Tribal health and service delivery is fragmented as a result of compartmentalized administrative structures that separate caregiver and elder needs into separate services**

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### **preventing the delivery of effective whole health services when these services should be collaborative and integrative especially for caregivers.**

Compartmentalization of social and health services in tribal government fragments and reduces the quality of services available to caregivers and elders. The services needed require a whole health integration of services working together. A special study prepared for the National Congress of American Indians in 2005 by the Center for Rural Health makes the case for this approach to reservation-based health services in this way:

“Health promotion should become a major goal infused into programs of health care, community education, human services and in-home outreach programs. While the target population of elders is imperative, prevention must also address younger age groups such as those in pre-retirement cohorts.

The advantage of this approach is that an environmental, multi-disciplinary community approach to health promotion will have the greatest chance of making a lasting impact. Furthermore, implementing successful health promotion strategies across the age spectrum is critical to addressing the poorer health status experienced by the majority of Native American communities” (Ludtke & McDonald, 2005).

Informants for this Study note the importance of combining social and health services in a collaborative fashion, but advise that the different social and health programs provided by tribal governments do not always work together for the benefit of caregivers and elders. The structure of social and health services is compartmentalized, reducing or preventing effective whole health support for caregivers and elders (Ludtke & McDonald, 2005). The delivery of holistic health services during the caregiver study met with great interest and benefits to caregivers who expressed their need for health interventions closely aligned with their own cultural practices as well as using methods associated with complementary and alternative medicine (CAM). Research shows that 63% of the US population uses some of CAM but its use is often paid for out of pocket. Research also shows that the majority of clinic visits are due to stress related illnesses, which

is what CAM is specifically designed to help. In the American Indian Caregiver Stress and Health Study sample 78% of participants had used some CAM and/or Traditional healing methods. The integration of service delivery is the macrocosm of the integration of whole health methods for the health of the whole person.

### **9. Recommendations**

#### **Federal**

New legislation ought to consider the need for structural and organizational flexibility in tribal administration and operation of social and health programs.

#### **Tribal**

Tribal governments should take steps to reorganize tribal social and health services into collaborating service teams permitting caregivers and elders to draw on integrated social and health service provider teams so as to provide social health, physical health, mental health, and spiritual health support. Massage and touch therapies, stress reduction, nutritional therapy, and trauma resolution therapies should be incorporated into the whole health and social service system for caregivers.

#### **State**

State and county Area Agencies on Aging ought to incorporate whole health, integrated social and health service training at the supervisory and service provider levels.

#### **[J] Tribal Agencies experience personnel turnover, lack Title VI coordinator personnel and training for the position.**

The stability of professional personnel working in caregiver service agencies is critical to providing consistent services to caregivers and to the persons they serve. State, county and tribal informants all note that frequent changes in personnel in tribal agencies contribute to service inconsistencies and to interagency communications problems. Adequacy of funding, management support, in service training, and support personnel are all factors affecting the stability of personnel in any program. In tribal agencies personnel turnover is also related to community-sensitive, policy-level pressures on management and service providers forcing early departures.

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Individuals employed by Area Agencies on Aging who liaise with tribal agencies, governments and communities often lack experience and knowledge of the Agency's philosophy of operation contributing to difficulties working with Agency personnel and policies. Similarly, informants advise that the role of liaison between the Agency and tribal agencies is complicated by the strictly observed Agency policies and procedures and the service practices and cultural realities in tribal communities. Coordination between Area Agencies and Tribal Agencies is frequently limited, stalled or obstructed due to contrasting Area Agency and Tribal Agency policies, practices and levels of interagency experience possessed by personnel in both agencies.

### **10. Recommendations**

#### **Federal**

Funding authorization and appropriations specifically directed at strengthening tribal and county service agency professional training to stabilize employee retention and to support improved cross-cultural communications.

#### **Tribal**

Tribal management systems should consider establishing guidelines for professional conduct and organization of quarterly professional development training opportunities for both management and service delivery personnel focusing on the solution of specific service delivery and managerial problems. Closer organizational support between social and health services and interagency cooperation will contribute to cost reductions and improve support to service personnel.

#### **State**

State and county Area Agency and related social service agencies should organize and conduct quarterly professional development training opportunities focusing on multi-cultural best practices. Agency managers must directly engage individual tribal liaisons to identify and resolve obstacles within the Agency to effective Agency and Tribal agency coordination arising from failure of cross-cultural communications.

**[K] The term "caregiver" is in some instances a barrier to the effective provision of services.**

The US Congress defines the term "caregiver" in  
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the "Older Americans Amendments Act of 2006 (HR 6179) as "an individual who has the responsibility for the care of an older individual, either voluntarily, by contract, by receipt of payment for care, or as a result of the operation of law and means a family member or other individual who provides (on behalf of such individual or of a public or private agency, organization, or institution) compensated or uncompensated care to an older individual" ("Older Americans Act Amendments of 2006", 2006). Despite this definition, the term remains problematic.

The conflicting meanings of the word "caregiver" is emblematic of the problems of cross-cultural and cross procedural and policy communications that result in service delivery failures common to many health delivery systems serving Indian Country. Informants repeatedly advise that the term "caregiver" implies a "paid position" when taking care of a family member or honored individual is considered a responsibility—a duty an individual is given. To accept money as a caregiver may create the impression that the individual receiving care is not getting assistance. "My elder should get the funding support and help, not me!" is the expressed view of many persons caring for family members.

Federal, state and county policy and practice guidelines commonly use "jargon" that fails to communicate in tribal agencies and in tribal families. The on-the-ground realities of the tribal culture are not only physically remote from county, state and federal agencies, they are remote in terms of experience and how one understands that experience. The breakdown in communications and levels of willing cooperation is obvious at the tribal level. When a problem is defined and explained in meetings outside and separate from the community most directly affected, the likelihood is considerable that the solutions applied will often be implemented with difficulty, if at all.

### **11. Recommendations**

#### **Federal**

Amend the Older Americans Act to incorporate a mandate to recognize and adopt tribal specific guidelines and definitions for the role of individuals who care for disabled or elder persons.

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### **Tribal**

Tribal Councils should develop and adopt tribal specific legislation providing guidelines and definitions for the role of individual who care for disabled or elder persons.

### **State**

State and County legislation should incorporate a definition of individuals who care for disabled or elder persons in tribal communities—noting that such definitions may differ from community to community.

### **[L] Tribal caregiver agencies lack needs assessments.**

Tribal caregiver programs have not always prepared needs assessments that are tailored specifically to the circumstances of communities they serve nor the specific cultural context within which caregivers must function.

## **12. Recommendations**

### **Federal**

No action

### **Tribal**

Tribal Councils should develop and adopt legislation to support the organization and conduct of tribal “caregiver needs assessments” that consider the needs of caregivers as well as the persons to whom they provide care with a specific emphasis on the cultural and community context.

### **State**

State and county Area Agencies on Aging ought to adjust their program approaches to reflect, in part the community-specific needs as described in tribal needs assessments.

### **[M] AAAs and tribes are duplicating elder and caregiver services**

## **13. Recommendations**

### **Federal**

No Action

### **Tribal**

Preparatory to Finding 2 above, seek to meet with the State Agency on Aging leadership to negotiate a provisional accord delineating services and practices for caregiver and long-term care programs.

### **State**

Preparatory to Finding 2 above, seek to meet with the Tribal leadership to negotiate a provisional accord delineating services and practices for caregiver and long-term care programs.

### **[N] The personal uncompensated direct and indirect cost to individual tribal caregivers is substantial—estimated at \$17,065 to \$26,419 or in the aggregate \$54.6 million to \$81.9 million in 2006—and contributes to high stress levels among caregivers.**

While personal uncompensated costs are substantial for individual caregivers, cultural norms in tribal society frequently reject payment in the form of wages to caregivers. Widely recognized evidence supports the contention that: caregiver stress is substantially exacerbated by financial stressors associated with taking care of an elder or disabled family member. Decision-makers should consider alternative means of supplemental and indirect support to caregivers and their families when wages prove to be unacceptable.

## **14. Recommendations**

### **Federal**

Amend legislation providing for annual appropriations of supplemental and compensatory support for individual caregivers based on tribal specific policies established by tribal governments.

### **Tribal**

Tribal legislation, policy and practice ought to be introduced and adopted to provide for naturally grown and healthy community food gathering, nutrient supplementation, tribally provided housing supplements, and community supported transportation as supports to caregivers. Where compensation is considered appropriate, tribal authorities ought to introduce and adopt policy and practices permitting the payment of wages to caregivers from public funds.

### **State**

Recognize the tribal specific policy and practice concerning compensation and support of caregivers. Where appropriate, provide funds to tribal governments for supplementation or direct compensation.

**[O] Cooperation and coordination between tribal and state elder care and support agencies is limited especially in terms of policy and practice at the tribal community level and at a state-wide level.**

Federal, tribal and state elder care policies and practices are under constant adjustment and revision giving rise to frequent confusion and operation disconnects. Legislators, administrators and service providers all play a part in the process of delivering support and assistance to elders yet they do not actually interact directly; and they do not actively engage the practical consequences on a real-time basis of legislative, administrative and service policies and practices. Each of the governments (federal, tribal and state) influences and determines one or more aspects of the elder care chain. Collaborative cooperation between each of the jurisdictions to coordinate policy and practice is fundamentally lacking. A bi-annual Intergovernmental Elder Care Conference including representation from the administrative, legislative and service provider elements of the elder care chain should be participants.

**15. Recommendations**

**Federal**

Agency on Aging officials should designate an intergovernmental coordinator specifically responsible for securing federal administrative and legislative participation in a bi-annual Intergovernmental Elder Care Conference specifically concerned with coordinating policy and practices at the federal level with state and tribal elder care policies and practices. The federal agency should provide the designated intergovernmental coordinator as the federal representative to join with an intergovernmental (federal, tribal and state) conference planning body.

**Tribal**

Tribal governments in Washington State should designate an intergovernmental coordinator specifically responsible for securing federal administrative and legislative participation in a bi-annual Intergovernmental Elder Care Conference specifically concerned with coordinating policy and practices at the federal level with state and tribal elder care policies and practices. The tribal governments should

provide the designated intergovernmental coordinator as the federal representative to join with an intergovernmental (federal, tribal and state) conference planning body.

**State**

The Office of the Governor in Washington State should designate an intergovernmental coordinator specifically responsible for securing federal administrative and legislative participation in a bi-annual Intergovernmental Elder Care Conference specifically concerned with coordinating policy and practices at the federal level with state and tribal elder care policies and practices. The state government should provide the designated intergovernmental coordinator as the federal representative to join with an intergovernmental (federal, tribal and state) conference planning body.

**[P] State Promote Simplification and Flexibility**

County agencies experience conflicts between the demands of service delivery (especially in connection with tribal communities) and the fairly complex and inflexible regulations set by the state. Undue complexity and inflexibility contribute to obstacles preventing effective service delivery.

**16. Recommendations**

**Federal**

No Action

**Tribal**

No Action

**State**

County agencies should have greater flexibility delivering support and services to tribal and county caregivers. Tribal specific demands are similar to the county community needs: both require greater simplification and flexibility to maximize responsiveness. State government regulators should support on-the-ground responsiveness with reduced regulatory control.

**[Q] Replace Assessments with Progress Monitoring**

Tribal assessments are not generally conducted. Instead of emphasizing a costly process, tribal programs with the support of county agencies should seek to monitor for positive outcomes and thereby avoid excessive costs.

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### 17. Recommendations

#### Federal

No Action

#### Tribal

Tribal program ought to recognize the limitations they experience and the fact that often program assessments do not actually occur. A more useful approach will be to undertake efforts to evaluate outcomes and identify those actions that actual produce positive results.

#### State

The County AAA ought to work in support of tribal programs to identify outcomes and actions that produce positive results.

\* \* \* \*

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