

Results from the National Tribal Long-Term Care Study

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— EXECUTIVE SUMMARY —

Long-term care has become an increasingly important public policy issue. As the number of older adults skyrockets, the proportion of those needing assistance with daily tasks is also expected to increase. The National Long-Term Care Study was conducted between 2005 to 2007 to obtain a comprehensive understanding of long-term care service access for American Indians and Alaska Natives (AI/ANs). Mailed surveys were sent to key informants at all federally-recognized tribal entities. Results are based on 417 completed surveys, representing 68% of the 305 tribal entities invited to participate.

The major findings were:

- 62% reported that there has been discussions over the past 12 months regarding the development of long-term care services.
- Strengths in program development included acknowledgement of service need, leadership support, available resources, ability to secure funding, and community respect for elders.
- Common barriers to program development were related to funding issues.
- Most elders, adults with disabilities, families as well as tribal leadership were interested in developing tribally-delivered long-term care services.
- Enrollment in Medicare and Medicaid was low and the most common barriers to enrollment in both programs were lack of awareness/knowledge and mistrust of state and federal government.
- The most commonly available long-term care services were nutrition/congregate meal site, transportation, home delivered meals, and information and referral.
- The most commonly available *tribally-operated* services were home maintenance/repair, wellness/disease management, home modification, and senior center.

BACKGROUND

Long-term care is a set of health, personal care, and social services delivered over an extended period to persons who have either lost or never acquired some degree of functional capacity (Pratt, 1999). With the increases in the number of older adults, life expectancy, and the number of persons with disabilities, long-term care is becoming a more important issue in Indian Country. The need for long-term care services among AI/ANs is great. AI/ANs experience some of the highest rates of chronic disease and disability, which are strongly related to needing and using long-term care. Legislators, policy makers, and tribal leaders are confronted with the task of meeting the related growing chronic care needs. While the Indian Health Service (IHS) budget is approved annually, it is under-funded and access to many types of health services can be limited. AI/AN elders often rely on long-term care services provided by resources from tribes, Medicaid/State Agencies, and the Administration on Aging.

From a research perspective, not much is known about long-term care services in AI/AN communities. In order to help inform tribal leadership and concerned policy makers, the National Tribal Long-Term Care Study of federally recognized tribes was conducted. The purpose of the study was to broadly identify long-term care availability in Indian Country.

The study surveyed federally recognized tribal entities to assess the following:

- I. Tribal long-term care planning
- II. Strengths and barriers to long-term care development
- III. Community interests and needs for long-term care
- IV. Medicare and Medicaid participation
- V. Availability of long-term care services and funding sufficiency

METHODS

This study used a survey developed in collaboration with a 9-member advisory committee listed in the Appendix comprised of experts in AI/AN health care policy. The advisory committee assisted the researcher in developing the survey until the final content was approved by all committee members. The survey was sent to persons who could answer a broad range of questions regarding long-term care issues, which included the tribe's Health Director, Community Health Representative or Community Health Aide Director, Social Services Director, and Older American's Act Title VI Director. A letter and a courtesy copy of the survey were first mailed to tribal leaders to provide a study description and allow the tribes to determine participation. Two weeks later surveys were mailed to the directors at each tribe with a letter explaining the study and a postage-paid return envelope. The letter also instructed the respective director to pass the survey to a co-worker if they felt the co-worker would be better able to answer the questions. A second survey was mailed four weeks later to those who had yet responded. Reminder postcards were sent to those who did not respond two and four weeks after the second survey was mailed out. Lastly, three rounds of telephone calls were made in attempt to improve study participation. Although there are 561 federally recognized tribes, many tribes share services at a consortium level. Therefore, directors at the consortium level that were surveyed represented the tribes in which they provided services. There were a total of 305 tribes and consortiums from which to attempt to survey the directors. To accommodate correlation between multiple surveys received from the same tribal organization, we made use of Stata 10 software's complex sample survey features when calculating frequencies (StataCorp, 2007). Tribal organizations defined clusters, and surveys were weighted to reflect the number of respondents each represented.

Three questions asked about long-term care planning: (1) "Does the tribe have an agency or office responsible for providing long-term care and/or the development of long-term care?", (2) "Does the tribe have any current statistics or information on the elder population and persons with disabilities and their long-term care needs, such as the number with a disability, dementia, or who are living alone?", and (3) "At the tribal planning level, have there been any discussions during the past 12 months regarding development of long-term care programs and services?" An open-ended question asked about the tribe's strengths regarding their ability to develop long-term care services. To identify barriers to the development of long-term care services, the survey asked the respondent to check from a list of 16 possible barriers all those that affected the tribe's efforts to develop services. We asked about interest from the elders, adults with disabilities, their families and elected tribal leadership in the tribe developing services. Respondents were asked what percent of elder and tribal members with disabilities were enrolled in Medicaid and Medicare. A follow-up question then asked about barriers for elders and persons with disabilities tribal members to enroll in Medicaid and Medicare and for each, a list of six

possible barriers to enrollment was provided including lack of awareness/knowledge, cultural issues, belief in federal trust responsibility, language/literacy, mistrust of state and federal government, and welfare stigma. Last, respondents were asked about the availability of 25 long-term care services. If a respondent indicated that the service was available, they were then asked if the service was tribally run or operated and whether the funding was enough to meet the need for the service.

RESULTS

We mailed 1,036 surveys and 417 were completed and returned for a response rate of 40%. Of the 305 tribal entities, 208 had at least one survey from a tribal employee, meaning 68% of all federally recognized tribes and consortiums were represented in our study. Table 1 provides the number of survey respondents by their position at the tribe.

Table 1. Survey Respondents by Position

| |
|--|
| 91 Health Directors |
| 88 Community Health Representatives/Community Health Aides |
| 85 Social Service Directors |
| 80 Older Americans Act Title VI Directors |
| 73 Other (Direct service providers, program managers, elected officials, and unidentified) |

I. Tribal Long-Term Care Planning

Twenty-nine percent of the respondents indicated that their tribe has an agency or office responsible for providing or developing long-term care programs, 40% indicated that their tribe has statistics or information on the long-term care needs of their elders, and 62% indicated that there has been discussions over the past 12 months regarding the development of long-term care services.

II. Strengths and Barriers to Long-Term Care Development

Five major areas identified as strengths in long-term care program development:

- Acknowledgment the need for services
- Leadership support
- Available resources
- Ability to get funding
- Community respect for elders

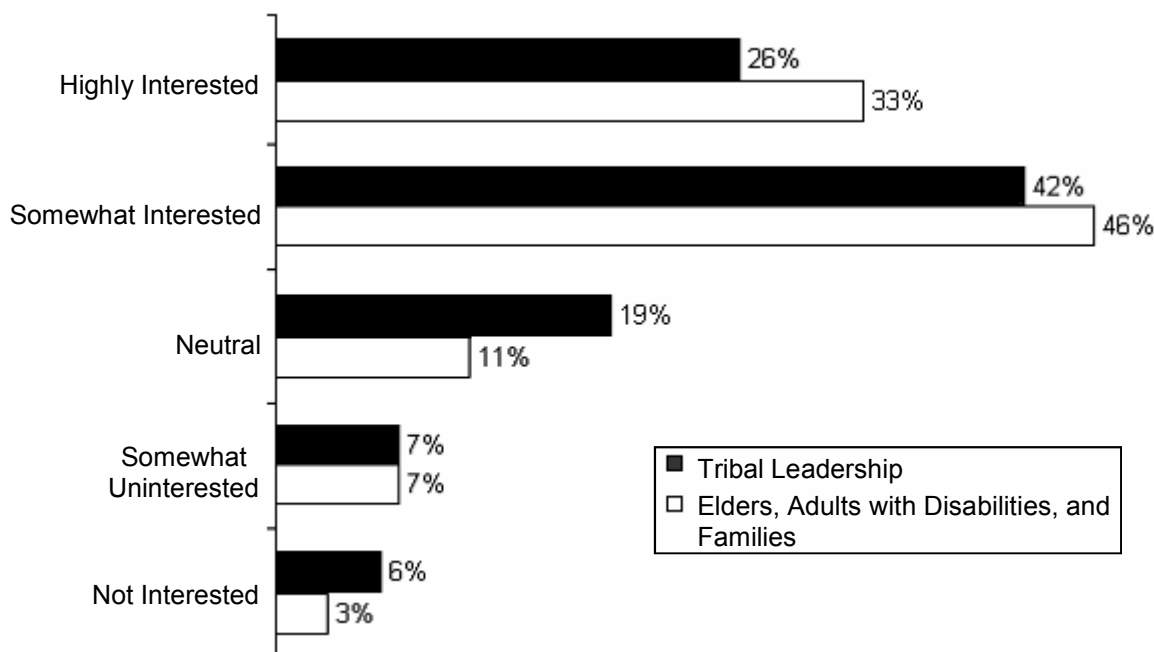
The top 10 factors (out of a possible 16) that were believed to negatively affect the development of long-term care services are presented in Table 2.

| Table 2. Top 10 Factors Reported to Adversely Affect Development of Long-Term Care Services | | |
|---|----------|---|
| Rank | Endorsed | Factor |
| 1 | 76% | No funding for program start-up |
| 2 | 66% | General lack of funding / limited finances |
| 3 | 56% | No funding for program continuation |
| 4 | 49% | Not enough trained staff / high turnover |
| 5 | 37% | Needs being met by family and friends |
| 6 | 33% | Overall limited capacity to develop services |
| 7 | 29% | Persons hesitant / don't want to enroll in Medicaid |
| 8 | 27% | Tribal-state relationship |
| 9 | 26% | Not a current community priority |
| 10 | 25% | Persons not eligible to enroll in Medicaid |

III. Community Interest in Developing Long-Term Care

Overall, perceived interest in the development of long-term care services by elders, persons with disabilities and their families in Figure 1 was high. Seventy-nine percent of the respondents reported that elders, persons with disabilities, and their families would be “highly interested” or “somewhat interested” in the development of long-term care services. Sixty-eight percent reported that tribal leadership was “highly interested” or “somewhat interested.”

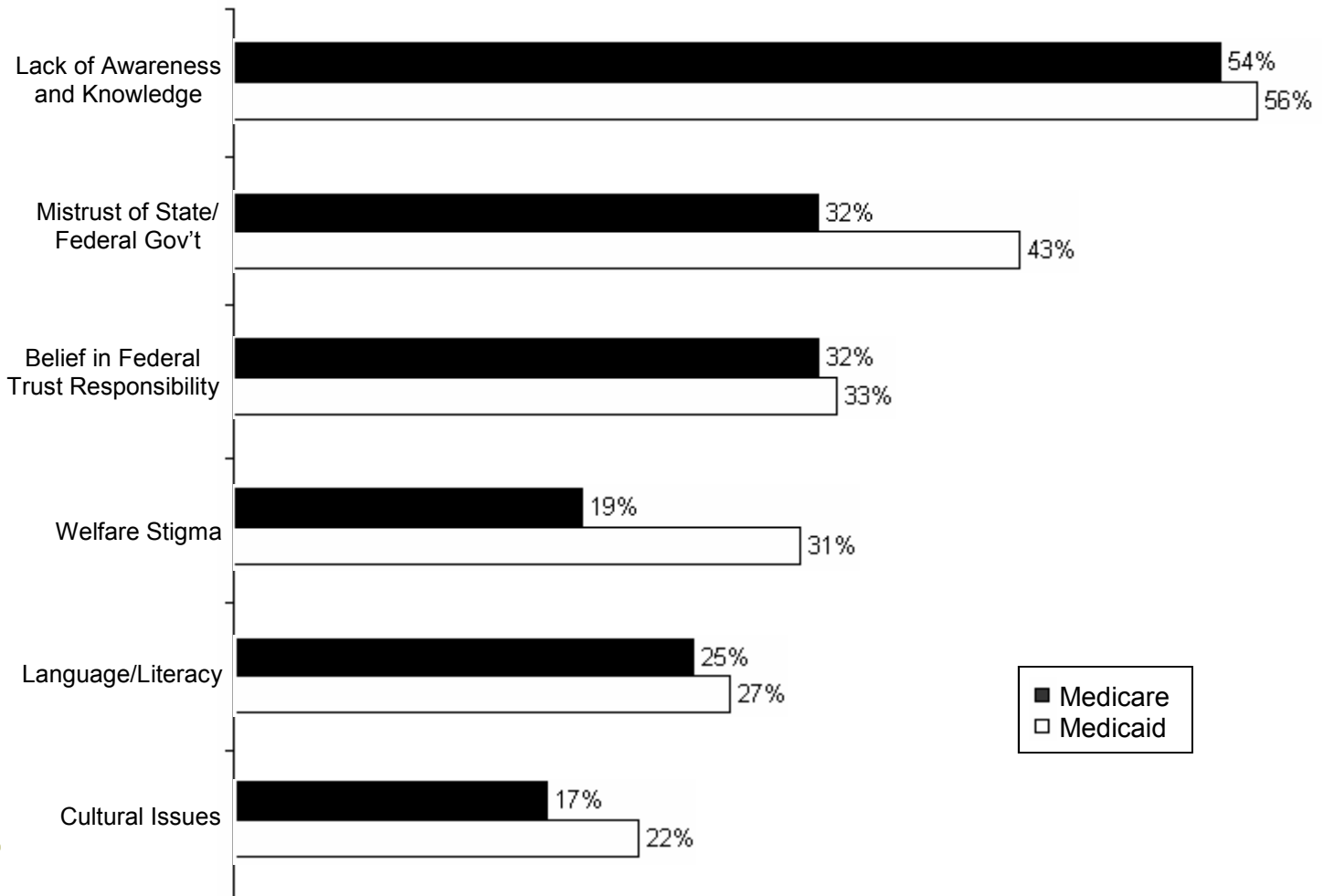
Figure 1. Perception of the Level of Interest in Developing Long-Term Care Programs and Services



IV. Medicare and Medicaid Participation

Forty-six percent of study respondents reported that less than half of elder and/or tribal members with disabilities were enrolled in Medicare. Sixty-three percent reported that less than half were enrolled in Medicaid. As shown in Figure 2, the most common Medicare and Medicaid enrollment barriers were lack of awareness or knowledge, mistrust of state and federal government, and belief in federal trust responsibility. Welfare stigma was another common barrier for tribal members to enroll in Medicaid.

Figure 2. Most Commonly Reported Barriers to Medicare and Medicaid Enrollment



V. Availability of Long-Term Care Services and Funding Sufficiency

The most commonly available services in Table 3 were nutrition/congregate meal site, transportation, home delivered meal program, and information and referral service. The most commonly available *tribally operated* services were home maintenance/repair, wellness/disease management, home modification, and senior center. Tribally operated services most often reported as having insufficient funding were durable medical equipment, translation service, speech therapy, and financial planning.

| Table 3. Prevalence of Available Long-Term Care Services and Percent of These Services that are Tribally Operated and for which Funding is Insufficient | | | |
|--|-----------|-------------------|----------------------|
| | Available | Where Available | |
| | | Tribally Operated | Funding Insufficient |
| Nutrition/Congregate Meal Site | 85% | 93% | 23% |
| Transportation | 81% | 93% | 26% |
| Home Delivered Meal Program | 79% | 92% | 27% |
| Information and Referral Service | 70% | 90% | 23% |
| Senior Center | 67% | 94% | 23% |
| Wellness/Disease Management | 62% | 96% | 30% |
| Case Management/Care Coordinator | 52% | 89% | 21% |
| Independent Senior Housing | 51% | 88% | 24% |
| Home Modification | 51% | 96% | 24% |
| Home Maintenance/Repair | 47% | 99% | 25% |
| Homemaker Service | 45% | 75% | 13% |
| Personal Care Services | 37% | 61% | 16% |
| Durable Medical Equipment | 35% | 59% | 36% |
| Home Health | 33% | 71% | 19% |
| Respite | 33% | 86% | 23% |
| Caregiver Support Group | 31% | 90% | 12% |
| Physical Therapy | 31% | 42% | 28% |
| Translation Services | 27% | 74% | 35% |
| Senior Legal Service | 24% | 61% | 29% |
| Hospice/Palliative Care | 19% | 12% | 19% |
| Assisted Living | 16% | 57% | 12% |
| Nursing Home | 15% | 52% | 23% |
| Financial Planning | 12% | 69% | 34% |
| Speech Therapy | 9% | 17% | 35% |
| Adult Day Care | 6% | 47% | 29% |

CONCLUSIONS

The need for formal long-term care services in AI/AN communities has been recognized by some federal government agencies and tribal communities for over 15 years (IHS, 1993). However, our results show that access to long-term care services is generally limited among the tribes and consortiums we surveyed and there is a lack of resources to support these services. While Medicare and Medicaid could assist in financing long-term care services, we found that enrollment levels in these programs appear to be low. Some of the more common barriers to Medicare and Medicaid enrollment for AI/ANs included a lack of awareness and mistrust of state and federal government, which have also been found in other research (Langwell et al., 2003). Another source of resources for long-term care services is Title VI of the Older Americans Act, and many tribes use this funding to establish the most widely available services, such as nutrition/congregate meal sites, transportation, and home-delivered meals. Of note, Title VI also

provides funding for senior centers, homemaker services, personal care services, respite, caregiver support groups, financial planning, wellness/disease management, translation services, and senior legal services. Our survey revealed that the barriers to developing and delivering these services are considerable and efforts are needed to improve AI/ANs access to these services. Despite limited resources and barriers, AI/AN communities we surveyed have planned and delivered a diverse set of long-term care services depending on their particular leadership, interests, funding resources, and needs.

The IHS does not have a history of supporting long-term care services (Baldrige, 2001), largely the result of limited resources, the need to prioritize health care spending, and the prohibitive costs of providing long-term care. Perhaps the main reason the IHS has not offered long-term care is that until the mid 1990s, long-term care seldom ranked among the top ten priorities presented annually to IHS leadership by either tribal leaders or IHS Area Directors. However, as the AI/AN population continues to grow older, the need for long-term care services will become more evident.

In conclusion, it is important that policy makers understand the long-term care situation in AI/AN communities. In this regard, it is problematic that appropriations for IHS (and through the IHS to those tribes operating their own health care services) have not included significant funding for long-term care services given a life expectancy among AI/ANs that now approaches that of the general U.S. population (Bramley, Hebert, Tuzzio, & Chassin, 2005), and the high rates of chronic diseases experienced by AI/AN elders (Chapleski, Lichtenberg, Dwyer, Youngblade, & Tsai, 1997; Kramer, 1997). Even though our respondents often cited funding barriers for long-term care services, it also appears that many tribes are interested and actively pursuing the development and provision of these services to their members. Additional practical research is needed with tribes to better understand financial as well as non-financial barriers to implementing long-term care policies and to develop and disseminate information on best practices. Also, longitudinal research needs to be conducted to examine what is perceived as an increased desire among tribes to ensure access to long-term care services for their members and obtain a more detailed understanding of the current status of long-term care in AI/AN communities.

Suggestion Citation: Goins, R. T. (2008). Results from the National Tribal Long-Term Care Study. Morgantown, WV: West Virginia University, Center on Aging.

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APPENDIX

ADVISORY COMMITTEE

| | |
|-----------------------------------|---|
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