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Executive Summary

This report summarizes the stories and recommendations of the participants of the First National Native American Summit on Traumatic Brain Injury (TBI) as well as policy issues identified after the meeting. It is intended for the Native American community, State policy makers, and others interested in improving services for Indigenous people with TBI and their families.

Often described as a “silent epidemic,” traumatic brain injury can have disastrous effects on individuals and their families. Every 21 seconds someone in the United States sustains a brain injury, resulting in 1.5 million people annually (Centers for Disease Control and Prevention, 1999). A cumulative total of at least 5.3 million Americans live with disabilities as a result of brain injury. Nationally, TBI is the leading cause of death and disability for young adults (CDC, 1999).

TBI hospitalization rates in the United States among minority groups are greatest for Native Americans/Alaska Natives (Langlois, Rutland-Brown & Wallace, 2003). The Native American/Alaska Native age group with the highest hospitalization rate is 15-24, followed by 25-34 years of age, 35-44, over 44, and 0-14. When compared to other populations, TBI death rates are greatest among Native Americans/Alaska Natives at any age. The CDC statistics reveal that Indigenous people are over-represented in the category of TBI.

On May 3-5, 2003, the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (DHHS) sponsored the First National Native American Summit on Traumatic Brain Injury as the first step in learning about the special circumstances and needs of Indigenous people with brain injury. Members of the Indigenous People’s Brain Injury Association; Indigenous people from the Plains, Woodlands, Northwest, and Southwest cultural regions of the Nation; policymakers; medical, research, and service agency representatives; as well as caregivers came together to:

- 1) Identify the unique challenges related to Indigenous people with brain injury;
- 2) Ascertain what services are currently available;
- 3) Determine the gaps in services; and
- 4) Provide information to agencies that work with Indigenous people with TBI and their families.

Summit participants provided program and policy recommendations around the issues of funding, prevention, the Indian Health Services, visibility of government agencies on reservations, the cultural and spiritual needs of Indigenous people with brain injury, as well as conferences and potential areas of focus.