

Development and Evaluation of a Community Disability Planning Method for American Indian Tribal Concerns Report

Background: Today, two million American Indians and Alaska Natives are members of more than 557 tribes, and a reported 26% of them, more than 490,000 American Indian people, live with a significant disability. Research has shown that tribal leaders are interested in integrating members with disabilities and improving services to them but lack the needed information and technical expertise.

Purpose and anticipated benefits: A need exists for methods to identify and organize disability issues on reservations. Such methods must be responsive to tribal diversity and respectful of tribal sovereignty. The Consumer Concerns Report Methods (CCRM), a community development and planning tool, is one such method. It offers a framework with many advantages to tribes and disability advocates. First, it is a flexible tool that can be adapted to diverse cultural contexts. Second, its primary focus is on environments in a way that is consistent with the new paradigm of disability. Third, its previous applications have demonstrated validity, impact, and the ability to accumulate concerns across communities. Fourth, it has also been used to help set applied research agenda that develop solutions to real problems. Finally, it is consistent with principles of participatory action research. The overall goal of this project is to create and test a Tribal Disability Concerns Report Method (TDCRM) that can be used to identify and organize potential issues of importance to more than 490,000 American Indians with disabilities living with a significant disability. It can be used to help tribe and village members assess their needs, develop a consensus agenda, and build commitment to an action plan.

Who: Hank Scalpcane, training associate of the American Indian Disability Technical Assistance Center, Rural Institute at the University of Montana, used Concerns Menus to create two Concerns Surveys under the direction of Tom Seekins, Ph.D., the director of the Research and Training Center on Rural Rehabilitation Services in Wyoming, and worked with members of several tribes, including the Tse-vesta-hase, a disability group of the Northern Cheyenne Tribe. Julie Clay also has assisted in disseminating study results.

When: 2002-2004

Method: The steering committee created a brief, eight category survey and used Concerns Menus to create two Concerns Surveys, one for reservation dwellers and the other for those residing in urban areas. Four alternative rating scales were developed, and feedback was obtained to identify the best one, in terms of ease of completion and

respondent preferences. A number of tribes tested the instrument in partnership with their representatives. The final products, two Concerns Menus, one for Tribal and one for Urban Indians, each has a different number of items. A list of 171 items, organized under 10 categories (e.g., Tribal Advocacy, Healthcare, Traditions), was used to create a TDCRM survey that reflects the tribe's unique strengths and weaknesses. After the TDCRM survey was designed, it was then distributed to tribal council members or a survey reviewer identified by the steering committee. Upon approval, it was distributed to tribal members with disabilities in the community. Returned surveys were then analyzed by the American Indian Disability Technical Assistance Center (AIDTAC), which wrote a report of the findings that were discussed at community planning meetings designed to formulate an action plan for addressing the issues most important to tribal members with disabilities.

Results: A small pilot study showed a high level of acceptability for the traditional concerns report question format but also revealed a preference for the survey questionnaire to be in large print. Field testing also showed a need for a separate report method for urban American Indians. Also, there was increased scrutiny and increased number of steps for approval due to heightened concerns over research conduct on reservations or that in any way impacts American Indian artifacts or issues. To encourage effective use, a manual, titled *The Concerns Steps*, for implementation of the CCRM was developed.

Conclusion: The TDCRM is adaptable to each tribe's and each urban Indian center's particular circumstances and contributes to the concept of self-determination that is recognized by tribes to be the best approach to addressing tribal disability issues. It can be easily adapted for use by different tribes to address their disability infrastructure issues (housing, employment, accessibility, and transportation). The TDCRM survey can also be designed to focus upon creating laws and policies that benefit tribal members with disabilities. One of the most important aspects of the TDCRM process is the voice that it gives to the people involved in the process by helping them identify where they are and to provide a clear direction and purpose that is beneficial to all participants with disabilities. In working with tribal organizations, one should anticipate much more time in organizing, educating, and making arrangements to conduct projects than might typically be required. Similarly, with urban Indian programs that are organized as private, not-for profit agencies, selecting sites should carefully consider organizational stability.

Project output: The manual *The Concerns Steps*, for implementation of the CCRM, was developed and the September 2005 *Practice Guideline: Tribal Disability Concerns Report Method: Respecting Sovereignty and Building Capacity* (<http://aidtac.ruralinstitute.umt.edu/Concerns.htm>)