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Emerging Disabilities: American Indian Issues

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Introduction

The Task Force on Emergent Disability Issues among American Indians and Alaska Natives has evaluated public health data sets and systems, which might lead to planning more effective policies, prevention strategies, and vocational rehabilitation for American Indians and Alaska Natives with disabilities. Socioeconomically disadvantaged groups are greatly over represented with respect to poor health indicators despite public health successes in reducing the incidence of many organic diseases. These and a myriad of health and developmental disorders have been termed the New Morbidity, which rests on the interactions among the following categories of variables (Baumeister et al., 1993, pp. 35-37): (1) Predisposing variables that are demographic, behavioral, and genetic/biologic; (2) Catalytic variables, such as poverty; (3) Resource variables, such as community support and a variety of social, educational, and medical services; (4) Proximal variables, including prenatal factors and prenatal problems; and (5) Outcome variables, including developmental disabilities and other chronic health problems. In conjunction with the New Morbidity model, the Epidemiologic Transition model (Young, 1994, p. 216), which “is characterized by the precipitous decline in the incidence of infectious diseases, followed by the rise of chronic, non-communicable diseases and accidents and violence,” may prove useful in understanding emerging disability issues of concern to American Indians and Alaska Natives.

Three core questions were addressed when evaluating the data sets and systems:

1. Are there detectable emergent disability trends; that is, are there increases in the magnitude and rates of disability among those who are most vulnerable – e.g., American Indians and Alaska Natives who live in poverty?
2. What do existing monitoring systems tell us about these trends? What are the limitations of these systems?
3. What are the resultant policy implications for these systems? What effects will these trends have on planning, services, and personnel development in public health programs?

The methods used here involved a combination of secondary analyses, evaluation of existing public health monitoring systems, expert panels, and the analysis, integration, and synthesis of recent needs and policy assessments. The main sources of data to evaluate these questions were the Indian Health Service (IHS), a division of the U.S. Department of Health and Human Services and the Healthy People 2000 review process.

Results

Specific disabilities and risk factors were reviewed to detect emergent disabling trends among infectious diseases, chronic non-communicable diseases, accidents and violence. Meningitis remains among the 10 leading causes of death for American Indian children between 1 to 4 years of age, and pneumonia and influenza rank among the 10 leading causes of death for American Indians and Alaska Natives across all ages in the IHS service population, at 19.5 per 100,000 between 1991 – 1993. Those same years show that the leading cause death among American Indians and Alaska Natives in the IHS service population was heart disease, including hypertension, and that the cancer death rate is rising. Although the general U.S. rate has been relatively stable, deaths due to malignant neoplasm has climbed to over 74% of the overall U.S. rate. Deaths due to accidents are 212% greater than the U.S. rate, and violence-related deaths, such as homicide is 41% greater than the U.S. average. In addition, age-adjusted suicide rates among American Indian and Alaska Native males has fluctuated around 20 per 100,000, which is an alarmingly high number compared to national averages.

Positive trends in the American Indian population have showed overall improvements in life expectancy, infant mortality rates, and access to primary care, as well as an increase of high school graduates and college and university enrollment. However, negative trends in the American Indian population revealed movement away from targets set by Healthy People 2000 (Office of Disease Prevention and Health Promotion). For example, improvements have not been shown in the prevalence rates of obesity, cirrhosis, fetal alcohol syndrome (FAS), and diabetes.

Healthy People 2000 summarized data available since 1984 and estimates overall prevalence rates of 36 – 48% for American Indians and Alaska Natives, with no clear trend. Alcohol abuse or dependence is still most frequent among American Indians and Alaska Natives than any other ethnic group, and according to RSA-911 files from 1996-1997, is listed as both the major disabling condition and the secondary disabling condition. Hence, disabilities that are alcohol-related show to be well above national averages. For instance, cirrhosis deaths for American Indians and Alaska Natives were 21.6 per 100,000 compared to 8 per 100,000 for the total U.S. population in 1993, and the FAS rate was 40 per 1,000 compared to 5.2 per 1,000 for the total U.S. population in 1990. Diabetes was rarely diagnosed among American Indian populations until the 1930's, but has soared to a prevalence rate of 70 in 1,000.

The age-adjusted rate for American Indian and Alaska Native males has fluctuated around 20 per 100,000. In fact, a national study of life expectancy found that the lowest life expectancies in the country (including inner city ghettos) for both men and women exist in Indian populations, are similar to ones seen in sub-Saharan Africa, and are the lowest of any nation in this hemisphere except Haiti (IHS, 1998, Section VII). To compound these findings, prevailing economic conditions reveal that 32% of American Indians and Alaska Natives live below the poverty level, compared to 13% of the U.S. general population as of 1990.

Conclusions

There are detectable emergent disability trends, in at least two categories: increasing rates of disability and related conditions, and the emergence of new disabling conditions. Although a number of infectious diseases such as meningitis, hepatitis, pneumonia, and tuberculosis continue at rates much higher than in the general population, the overall rate of infectious diseases seems to be decreasing. The most dramatic increase in a chronic disabling condition among American Indians and Alaska Natives is with diabetes and several conditions associated with the disease. Social pathologies due to violence and accidents are also much higher than the national norm. Emerging disabling conditions would include HIV / AIDS, which IHS has been tracking only since 1987, and FAS, which was identified in 1973 but has yet to be recognized by RSA as a disabling condition.

Further examination of data reveals that existing monitoring systems have identified several trend clusters; one associated with diabetes, another associated with alcohol, and a third associated with injuries and violence. Limitations of data collection from monitoring systems point to problems connected with the public health monitoring of American Indians and Alaska Natives, such as determining who is Indian, how to track individuals who lack telephones or unlisted mail addresses, and the variation in the types of data collected when utilizing diagnostic labels versus functional categories.

Policy implications for these systems have revealed Healthy People 2000 prioritizing the monitoring of suicide rates among American Indians and Alaska Natives, yet lack goals for improving their mental health. Policy change may also result from studies conducted by the World Health Organization's committee on International Classification of Impairments, Disabilities, and Handicaps (ICIDH), which serves as a multipurpose classification system that assists understanding the concept of disability (and emergent

disability) in a wider context by systematically grouping consequences associated with health conditions. Other implications involve the ability of the IHS to achieve its performance indicators, which has been lacking due to legislative budgets not meeting the costs of services and staffing needs. For a growing number of American Indians and Alaska Native people, the belief in the assurance of adequate health care is beginning to be perceived as another broken promise from the Federal government. Finally, public health initiatives, which have often stopped short of their goals while attention shifts to other priorities, should have maintained their focus of Healthy People 2000 objectives in their work with American Indians and Alaska Natives.

Recommendations

The following recommendations are offered to address both data issues and future issues related to American Indians with disabilities to plan more effective policies, prevention strategies, and vocational rehabilitation.

1. To have all agencies utilize an accurate tracking information system that would monitor and categorize diabetes and related disabilities.
2. Monitoring systems that can track the disabilities of urban American Indians in a comparable format to that of other data systems, such as IHS and BIA.
3. Monitoring systems need to over-sample American Indians and Alaska Natives to obtain sufficient data to assure reliability, and address a frequent complain of data reviews for Health People 2000.
4. In addition to mail and phone surveys, culturally sensitive methods of collecting information need to be developed that can successfully gather data from rural and remote areas where mail and phone surveys are unconventional.
5. IHS must fully implement their Mental Health / Social Services data reporting system, by compiling collected information in a usable form, to track the mental health status of American Indians.
6. Creation of a standardized categorization of disabling conditions, including secondary conditions, developed by the World Health Organization (WHO) with their International Classification of Impairments, Disabilities, and Handicaps. Tribal vocational rehabilitation programs should be encouraged to use the standardized format.
7. Agencies and health providers have the opportunity to work with individuals and tribes to promote well-being and work towards prevention and intervention of certain disabilities in a culturally competent way. By using information on emerging disabilities effectively, planners can implement more effective prevention and early intervention strategies, thereby eliminating the need for expensive rehabilitation later on.

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