

DEVELOPMENTAL DISABILITIES PREVENTION AND THE DISTRIBUTION OF RISK AMONG AMERICAN INDIANS

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Abstract: Selected risk factors for developmental disabilities demonstrate an apparent differential pattern of risk for American Indians as compared to the U.S. general population. Indian children appear to experience comparable or even lower rates of certain congenital anomalies which are associated with developmental disabilities and are difficult to prevent. Conversely, Indians are reported to experience higher rates of conditions which can be effectively targeted for prevention, including those related to prenatal exposure to alcohol, cigarette smoking, and maternal diabetes, as well as disabling sequelae of accidents and otitis media. Primary prevention is critical because of the long-term chronic nature of developmental disabilities and strategies focused on risk factors of particular relevance to Indian communities can achieve the greatest potential benefit.

There is a paucity of data regarding developmental disabilities (DD) among American Indians, and the distribution of DD risk factors in American Indian populations has not been described in any comprehensive manner. This review examines the available published data regarding critical aspects of DD risk and Indian health to describe a particular pattern of risk for American Indians which, in turn, has fundamental implications for preventive services planning. The cause of specific disabilities are often unknown, or, in the case of genetic disorders such as Down's Syndrome, not readily amenable to prevention. Certain medical and lifestyle factors, however, are amenable to intervention through community programs which reduce risk factors prior to conception and early access to prenatal services. Primary prevention is critically important since individuals with DD often require life-long care or support services.

Scientific literature on DD is diverse and often relates to specific diagnostic conditions. In order to allow for consideration of risk across a broad spectrum of disability, DD is used here to refer to functional

impairments caused by chronic conditions including epilepsy, cerebral palsy, autism, mental retardation, and other neurological conditions. This definition is reflective of the eligibility criteria for receiving DD services.

Determination of DD Risk Factors

Developmental disabilities have relatively low base rates, are associated with many different disorders, and are often of unknown or complex etiologies. Determination of risk factors can be a difficult task. Describing risk factors associated with DD among American Indians is complicated by the limitations of available data. The literature on DD risk factors is complex with outcome measures varying extensively, placing severe constraints on interpretation. Since this investigation focuses on a broad spectrum of disability, a wide range of research is considered, including studies assessing the relationship of selected risk factors with mental retardation, learning disabilities or other conditions associated with DD. While these measurement differences preclude direct comparisons across studies, it is possible to investigate the nature of risk for disability in general rather than for a specific outcome. This approach allows for discrimination of risk factors which are common to multiple categories of disability.

Since comprehensive DD morbidity information for either Indian people or the general U.S. population is not available, this investigation supplements morbidity data with relevant mortality data. Cause-specific mortality rates are generally poor indicators of morbidity because factors other than morbidity affect mortality except when a disease is uniformly lethal (Mausner & Kramer, 1985). However, in the absence of other data and with appropriate consideration of alternative explanations, mortality rates can be useful in estimating morbidity.

Determining risk based on the Indian health literature is further complicated in that many studies fail to report the tribal affiliations of subjects, and intertribal differences can impact on risk-related behavior. Indian Health Service (IHS) statistics provide the most comprehensive data available, but since their major service areas are in the West, Southwest, and on reservation sites, IHS data are necessarily biased towards these areas. Consequently, discussion is limited here to certain genetic disorders and congenital anomalies, alcohol, cigarette smoking, diabetes, accidents and otitis media as they relate to DD risk among American Indians, and is not intended to be exhaustive. These particular factors are selected because of their relationship to conditions associated with DD and their prevalence in the Indian population. While exploring risk factor distribution with implications for prevention, it is important to keep in mind that any comparison population (e.g., U.S. whites, the general population,

etc.) is not a "gold standard" and includes substantial amounts of preventable disability and mortality.

Genetic Disorders and Congenital Anomalies

Chromosomal abnormalities are a significant cause of mental retardation and are implicated in the development of some motor impairments (Holmes, 1985). Although the published data detailed below is considerably limited, Indian children seem to experience comparable or lower rates of the more common genetic disorders and congenital anomalies associated with DD than do children in the population at large.

The Birth Defects Monitoring Program of the Centers for Disease Control reported rates for common congenital malformations based on birth record abstracts from over 1,200 participating hospitals (Chavez, Cordero, & Becerra, 1988). While these are the most comprehensive birth defects data available, they are not representative of all U.S. births comprising 19.7% of white, 16.4% of black, 17.5% of Hispanic, 9.3% of Indian, and 8.3% of Asian births. Although not significantly different, Down's Syndrome was found to be less prevalent among Indians (6.7 per 10,000 births) than among U.S. whites (8.5 per 10,000 births), as was spina bifida without anencephaly (4.1 per 10,000 for Indians compared to 5.1 per 10,000 for whites). Down's Syndrome rates are particularly important, since it is found in 20–30% of severely retarded (IQ < 50), and 2–3% of moderately retarded (IQ 50–69) individuals (Hook, 1984).

An earlier study (Niswander, Barrow, & Bingle, 1975), using Indian Health Service hospital newborn medical records (primarily reservation births), found even lower rates of most central nervous system malformations among Indians than the Birth Defects Monitoring Program. These data show comparatively lower rates per 10,000 Indian births for anencephaly (1.6 vs. 3.6), hydrocephalus without spina bifida (3.7 vs. 10.8), and microcephalus (1.1 vs. 2.6), but a higher rate of spina bifida without anencephaly (5.5 vs. 4.1).

Indian Health Service (1987) mortality data indicate that congenital anomalies are responsible for fewer infant deaths among Indians (1.8 per 1,000 births) than among all U.S. races (2.4 per 1,000 births). While caution is advised when interpreting infant mortality data in reference to disabilities in surviving infants, the data suggests that Indian infants experience fewer lethal congenital anomalies than the general population, and there is no available evidence suggesting that they experience more disabling congenital anomalies.

Prenatal Exposure to Alcohol

Maternal alcohol use increases the risk of DD by increasing the likelihood of low birth weight, prematurity, and intrauterine growth retardation

(Abel, 1982; *Alcohol Health and Research World*, 1983; Rossett & Weiner, 1984). Prenatal exposure to alcohol also is directly implicated in central nervous system deficiencies (e.g., microcephaly and mental retardation), Fetal Alcohol Syndrome (FAS) and other alcohol-related birth defects (Abel, 1982). While the etiology of most mental retardation remains unknown, FAS is considered the single leading known cause of mental retardation, presently surpassing Down's Syndrome and spina bifida (Abel & Sokol, 1986; Warren & Bast, 1988).

Alcoholism, alcohol abuse and related problems constitute the number one health concern for American Indians (National Institute on Alcohol Abuse and Alcoholism [NIAAA], 1978). The incidence of alcohol use appears to be increasing among Indian women (Lamarine, 1988) and alcoholic cirrhosis of the liver accounts for the death of one in every four, a rate 37 times that of white women (NIAAA, 1978). In terms of drinking patterns, Indians are likely to be either heavy drinkers or abstainers (Lemert, 1982). Although overall rates of consumption are high, many Indian communities have lower rates of alcohol use than the general population and substantial intertribal variation exists (Sievers, 1968; Cohen, 1982).

There is little data on drinking among Indian women during pregnancy. One study of 405 pregnant Sioux women reported that over 30% used alcohol during pregnancy as compared to less than 2% of an unmatched control sample of 342 pregnant white women (Peterson, Leonardson, Wingert, Stanage, Gergen, & Gilmore, 1984). The authors suggest that the figure for Sioux women should be considered a tentative and conservative estimate, citing historical problems with collecting accurate information on drinking behavior among patients seen in Indian Health Service clinics.

Adverse outcomes associated with alcohol use during pregnancy are fairly well documented, with FAS at the extreme end of a spectrum of alcohol-related birth defects. It has been estimated that for every one case of FAS, another four cases of substantial birth defects attributable to alcohol consumption during pregnancy exist (Russell, 1980). The *Sixth Special Report to Congress on Alcohol and Health* (U.S. Department of Health and Human Services [USDHHS], 1987), cites the most common prevalence of FAS to be between 1 and 3 cases per 1,000 live births. The *Seventh Special Report to Congress on Alcohol and Health* (USDHHS, 1990) notes further that most identified cases of FAS in the U.S. were in sites where mothers were black or American Indian and of low socioeconomic status (2.6 per 1,000 vs. 0.6 per 1,000).

Data from the Fetal Alcohol Syndrome Project of the Indian Health Service (May & Hymbaugh, 1982) show considerable intertribal variation in FAS rates. The incidence of FAS per 1,000 births ranged from 1.4 for Navajo infants, 2.0 for Pueblo infants and 9.8 for selected Plains tribes infants (May, Hymbaugh, Aase, & Samet, 1983). While the rates for

Navajo and Pueblo groups are comparable to their estimated prevalence in the general population, the Plains group is much higher. A higher prevalence of FAS per 1,000 children aged 0–4 compared with children 5–14 (3.7 vs. 0.5 for Navajo, 4.7 vs. 1.1 for Pueblo, and 11.7 vs. 10.2 for Plains children) appears to indicate that the diagnosis of FAS is becoming more common in all groups studied. The Birth Defects Monitoring Program found FAS present among Indian infants at 33 times the rate of U.S. whites (Chavez et al., 1988). The possibility that more frequent differential diagnosis of FAS among Indians, due to medical personnel sensitivity to Indian drinking, cannot be ruled out; it is not likely to account for differences of this magnitude.

Prenatal Exposure to Cigarette Smoke

Cigarette smoking during pregnancy is implicated in increased risk for DD through its association with increased rates of prematurity and low birth weight. There is also limited evidence that children of smokers have significantly more perinatal conditions known to cause long-term neurological handicaps, including hypothermia and premature separation of the placenta (Rantakallio & Koiranen, 1987).

Two large prospective studies have been conducted which followed children up to age 6 ½ and 7 and detected differences between the children of smokers and nonsmokers. The first, the Collaborative Perinatal Study (Neaye & Peters, 1984) found significant differences in outcomes at age 7 between 578 full-term sibling pairs in which the mother smoked during one pregnancy but not the other, and between outcomes for children of smokers versus nonsmokers. Cognitive and behavioral deficits present in children of smokers are associated with lower birth weight and higher levels of neonatal hemoglobin, the latter of which is suggested to be caused by nicotine reduction of placental blood flow and an increase in fetal carbon monoxide. These results are particularly interesting because the analysis controlled for the effects of acute smoking-related disorders such as placenta previa, abruptio placentae and premature rupture of fetal membranes. The second study found fewer significant differences at age 6 ½, concluding that children whose mothers smoked have less satisfactory neurological and intellectual maturation than their counterparts whose mothers did not smoke, including differences in school placement and IQ scores (Dunn, Karaa, McBurney, Ingram, & Hunter, 1977).

A smaller prospective study, adjusting for several confounding variables, found maternal smoking to be related to a decrease in motor skills and to lower levels of verbal comprehension among 13-month-old children (Gusella & Fried, 1984). Differences among various age groups are important since the effects of passive smoke in the home are difficult to control for and may have an important impact on subsequent child

development (Rona, Chinn, & Du Ve Flory, 1985). Children exposed to cigarette smoke both pre- and postnatally are expected to show more of these developmental deficits.

No common source for representative data on cigarette smoking prevalence among Indians and the general population is currently available. Reports generally show a high prevalence of cigarette smoking among Indians with estimates ranging from 13% to 70%, with an average of 42% of Indians identified as smokers, compared to less than 30% of the general population (*Morbidity and Mortality Weekly Report*, 1987). Historical data based on a relatively small number of Indian women indicates significant intertribal variation in cigarette smoking among Indian women over 30 years old, ranging from 10.8% to 67.3%, compared to 33% of women in the general population (Sievers, 1968). A study of cardiovascular risk factors in the urban Minneapolis Indian community (primarily Chippewa) found that 67% of women interviewed smoked, with 45% of current smokers averaging 20 or more cigarettes per day (Gillum, Gillum, & Smith, 1984). Peterson and associates (1984) found 42% of Sioux women reported smoking during pregnancy, compared to less than 20% of a white control group.

Prenatal Exposure to Maternal Diabetes

Maternal diabetes during pregnancy is associated with morbidity related to both prematurity and postterm status, which can place a child at increased risk for DD. Children of diabetic mothers are more likely to have congenital anomalies, respiratory distress syndrome, and be either small or large for gestational age, depending on their maturity status (Gabbe, Lowensohn, Wu, & Guerra, 1978). A Danish study compared 853 infants born to diabetic mothers with 1,212 control infants and found higher rates of congenital malformations among newborns of diabetics, particularly for more serious anomalies (Pederson, Tygstrup, & Pederson, 1964). Compared to the control group, infants born to diabetic mothers had more fatal malformations (2.1% vs. 0.3%), more nonfatal major malformations (3.1% vs. 1.2%) and more multiple malformations (1.6% vs. 0.2%), but similar rates of minor malformations (1.2% vs. 1.0%). Although fetal survival has improved dramatically in the past 30 years, the incidence of major congenital anomalies remains at least twice as high for the offspring of diabetic mothers as compared to nondiabetic mothers (Pyke, 1987). Even when maternal diabetes is mild and noninsulin dependent, Pyke (1987) found 17% of infants over the 95th percentile for birth weight.

Substantial intertribal differences in diabetes prevalence estimates exist which may be a function of genetic or environmental factors (West, 1974). However, careful monitoring of glucose levels during pregnancy is often indicated for Indian women, since diabetes is considered epidemic among many tribes (Leonard, Leonard, & Wilson, 1986; West,

1974). Positive family history of diabetes is also related to development of gestational diabetes. Although the risks are not as well defined, a study of gestational diabetes among Pima Indians found a significant linear relationship between third-trimester glucose tolerance and fetal complications including perinatal mortality and macrosomia (Pettitt, Knowler, Baird, & Bennett, 1980). Diabetes prevalence in Pima Indians has received considerable attention since an estimated 50% of the population over age 35 is diabetic. In a study of 1,253 pregnant Pima women, 3.8% were diabetic in comparison to 0.28% of a general population sample of pregnant women (Bennett, Rushford, Miller, & LeCompte, 1976). The sample was divided into normal, prediabetic, and diabetic groups on the basis of glucose tolerance. Outcomes were more severe with increasing glucose intolerance. For the normal, prediabetic and diabetic groups, respectively: perinatal mortality was 1.2%, 3.1% and 25.5%; macrosomia was 7%, 9%, and 43%; and congenital anomalies were present in 3.8%, 3.8% and 19%.

Gestational diabetes is also reported (Massion, C., O'Connor, P. J., Gorab, R., Crabtree, B. F., Nakamura, R. M., & Coulehan, J. L., 1987) to be much higher among Navajo women than other U.S. populations (6.1% vs. 1–3%). While diabetes was not directly assessed in the study of pregnancy risk factors by Peterson and associates (1984), significantly more infants weighing greater than 4,000 grams were born to Sioux women (15% of births) than to white women (11% of births).

Accidents

Morbidity resulting from childhood accidents, particularly head trauma and asphyxia, represent other areas of preventable DD risk. Significant disability in cognitive and motor skills can be caused by brain damage due to head injuries or to accidents which result in oxygen deprivation (e.g., near drowning, strangulation, smoke inhalation, etc.).

In a study of accidents among Navajo Indians (Brown, Gurunanjappa, Hawk, & Bitsuie, 1970), records were obtained for all accident cases treated at medical facilities serving the reservation during 1966–1967. It was assumed that all cases requiring immediate attention would be seen in these facilities because of the prohibitive distance from other service providers. The incidence of accidents requiring medical attention was 4.4 per 100 children aged 0–4, and 4.6 per 100 children aged 5–14. Over 10% of all accidents were head injuries. These data do not include trauma secondary to assault, intentional self-inflicted injury, homicide, suicide, or attempted suicide. The mortality rate due to accidents was also considerably higher at that time for Navajos than for the U.S. population among children aged 0–4 (122.0 vs. 42.9 per 100,000) and among children aged 5–14 (58.1 vs. 19.8 per 100,000).

Indians have had consistently high rates of accidental death (Indian Health Service [IHS], 1987; Schmitt, Hole, & Barclay, 1966).

Childhood accidents continue to appear more frequent among American Indians, with accident-related mortality much higher among children aged 1–14 (23.8 per 100,000 vs. 15.4 per 100,000) than the U.S. general population (IHS, 1987). Nearly half of these fatalities occurred in motor vehicle accidents, which also are a leading cause of head injury in children (IHS, 1987). Age-adjusted mortality caused by fire is nearly three times the rate among Indians compared to the U.S. general population (5.6 vs. 2.0 per 100,000) (*Morbidity and Mortality Weekly Report*, 1987). Despite problems in generalizing morbidity from mortality, differences of this magnitude seem to indicate an increased likelihood of morbidity from head injury and smoke inhalation.

Otitis Media

Otitis media, middle ear infection, is associated with less severe disabilities (e.g., hearing deficits, reading disorders, language delays) and poorly defined long-term outcomes (Zinkus, Gottlieb, & Schapiro, 1978), but it is included in this discussion because of the particularly high prevalence of the disease and associated disabilities among American Indians (U.S. Congress, Office of Technology Assessment, 1990). Chronic middle ear problems, particularly those occurring before age 3, may play an etiologic role in the development of some learning disabilities associated with pervasive auditory processing deficits, delayed language skills, depressed verbal intelligence scores, and significant difficulty in reading (Zinkus & Gottlieb, 1980). Higher rates of recurrent otitis media and hearing disorders have been found among learning disabled children than among controls (Bennett, Ruuska, & Sherman, 1980; Freeman & Parkins, 1979).

A ten-year follow-up of a cohort of 489 Alaskan Eskimo children found that 76% of the children had experienced otitis media, 78% of whom had their first attack before age 2 (Kaplan, Fleshman, Bender, Baum, & Clark, 1973). Children with a history of otitis media displayed associated morbidity including ear drum perforations and scars (41%), hearing loss (16%), and normal hearing with a measurable air-bone gap (25%). Early onset of otitis and hearing loss were associated with significant decrements in verbal ability, and delays in reading, math and language. Children with a history of early onset of otitis with hearing in the normal range at the time of assessment still showed verbal delays.

McShane (1982) describes the prevalence and consequences of otitis media among Indian children, concluding that rates seem to be higher than can be accounted for by low socioeconomic status. Apache and Navajo children seem to be particularly susceptible, possibly due to eustachian tube anomalies. An ear disease screening effort among 15,890 school children on the Navajo reservation found 4.0% with perforated eardrums (Nelson & Berry, 1984). While prevalence rates tend to

decline after age 6, otitis is recurrent in virtually all children who experience their initial episode before age 1, who are then considered "otitis prone." Goodwin, Shaw, and Feldman (1980) found the highest risk of recurrence among Arizona Indian children who had their first attack before age 1 and who had a second attack within 4 months of the first.

Implications for Prevention

Risk factors associated with DD that are amenable to preventive intervention appear to occur more frequently in American Indian populations. American Indian populations could derive particularly strong benefit from DD prevention efforts since an overall greater percentage of disabilities are potentially preventable. The 1986 Amendments to the Education for All the Handicapped Act (Public Law 99-457) require that all eligible children be identified and receive services by age 3, and that outreach activities be directed towards children "at risk" beginning at the prenatal period. Although there is little agreement among professionals as to how this may be accomplished (DeGraw et al., 1988; Lewis & Brooks-Gunn, 1982), interventions directed toward limiting prenatal exposure to alcohol and cigarette smoke, controlling maternal diabetes, and toward reducing accidents and otitis media are clearly indicated.

Preventive efforts have the greatest potential for success when they are Indian community-based, particularly given the extensive intertribal and intercommunity variations in risk factor prevalence. This includes ensuring that community leaders and service providers are given relevant information about the targets for preventive efforts and solicited as stakeholding partners in the development of intervention strategies. Prevention programs also should be consistent with the principle of Indian self-determination, in recognition of the rights of Indian nations and communities to determine their own destinies. Interventions should be tailored to individual community needs. Specific strategies and techniques should be assessed for cultural appropriateness as well, utilizing qualified individuals from the targeted community as full partners in the program development effort.

Research on alcoholism treatment indicates that alcoholism is a heterogeneous disorder, and matching treatment modality to the type of alcoholism should lead to greater success (USDHHS, 1987, 1990). A lot can be learned from the experience of programs like the Fetal Alcohol Syndrome Project (May & Hymbaugh, 1982). That project began to yield data on specific patterns of alcohol consumption among women that can prove useful to developing treatment programs specifically for Indian women aimed at reducing rates of drinking during pregnancy and ensuring the health of the next generation. Birth defects related to fetal alcohol exposure can be eliminated entirely if women do not drink during pregnancy.

Smoking cessation programs abound, but none have been developed specifically for use in Indian contexts. There are other community-based models, such as the "Time to Quit" program described by Smillie, Coffin, Porter, & Ryan (1988), based on a belief that people have a right and a duty to participate in planning and implementing their health care. Programs like this can provide useful groundwork in the development of Indian models.

Good diabetic control in the periconceptional period could lower the risk for congenital malformations and careful monitoring throughout pregnancy can help prevent macrosomia (Pyke, 1987). This is significant since Indian women may be less likely to seek early prenatal care than white women. Sullivan and Beeman (1983) found only half of Arizona Indians received prenatal care in the first trimester compared with 86% of a white control group, and at the beginning of the sixth month of pregnancy, almost 20% of the Indians still had not sought care. Accident prevention activities should target the use of car safety seats for children under 5 and seat belts for all passengers over 5, given the high rate of mortality from motor vehicle accidents for Indian children (May, 1988). Alcohol use by adults also is an important factor contributing to accidental death and disability (IHS, 1987; Schmitt et al., 1966). Home safety assessments may be helpful to target fire hazards, conditions that could lead to falls, or accidental poisonings.

Otitis media in Indian children has been associated with method of infant feeding. Breastfed infants appear less likely to contract otitis media than bottlefed infants (Sheafer, 1971). It has been suggested that this may be due variously to protective immunological factors in breast milk, provocative factors in cows' milk, or the reflux of milk into the inner ear resulting from improper bottle feeding technique (McShane, 1982; Scheafer, 1971). In Manitoba Indian communities, breastfeeding has been shown to protect against infection even after it has been discontinued (Ellestad-Sayed, Coodin, Dilling, & Haworth, 1979). Breastfeeding should be encouraged for all Indian children.

In addition to the notion that a substantial proportion of DD among American Indians is preventable, demographic features of the population also indicate that prevention activities should have a particularly strong impact. American Indians are a relatively young population with a high birth rate. According to the 1980 U.S. Census, 45% of American Indian and Alaska Natives are under age 20, with a median age of 22.9; as compared to 32% under age 20 in the general U.S. population, with a median age of 30.3 (U.S. Bureau of the Census, 1984). Data from May (1988) show striking differences in the calculated crude birth rate for American Indian and Alaska Natives compared to the U.S. (27.9 vs. 15.8 births per 1,000 population); and in the general fertility rate (births per 1,000 women aged 15–44), 112.2 for Indians versus 67.4 for the U.S. general population.

Conclusions

Despite limitations in our current understanding due to the nature of the published data, a fairly consistent pattern nonetheless emerges, demonstrating a distribution of DD risk among Indians that is different from the general U.S. population. Specifically, Indian children appear to experience a smaller proportion of genetic and congenital anomalies associated with DD and more of the risks associated with prenatal exposure to alcohol, cigarette smoking, diabetes, accidents and otitis media. While it is difficult to prevent the genetic disorders associated with the most severe disabilities, the larger burden (numerical and economic) results from less severe degrees of disability and mental retardation (Avery, 1985). Preventive efforts focused on relevant risk factors could achieve substantial benefits in reducing overall DD risk and improving the general physical health of Indians in this generation and for those to come.

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