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Young American Indian/Alaskan Native Children with
Disabilities: Implications for Policy, Research, and Practice

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Introduction

AFTER MUCH DIALOGUE and debate regarding early childhood education among American Indians and Alaskan Natives, I was charged by the National Center for Rural Early Childhood Learning Initiatives and the Pennsylvania State University's Center for Rural Education and Communities and the American Indian Leadership Program to answer two questions:

1. How is the incidence of disabilities among infant and pre-school-age American Indian and Alaska Native (AI/AN) children related to rural (reservation and non-reservation), suburban, small town, large city, etc. residence?
2. How can early childhood programs accommodate AI/AN children with disabilities?

Given my own research and interests in the education of AI/AN children with or at-risk of developing a disability, I was eager to undertake this charge. However, after many hours of research and reading, I find myself facing a lack of published data to allow me to effectively answer these questions.

Although AI/AN students are disproportionately represented in special education programs in public and Bureau of Indian Affairs (BIA) funded or operated schools (see e.g., Faircloth & Tippeconnic, 2000), little is known about the status of these children prior to their entry into the educational system as well as their early years within this system. Given this lack of published data, I will use this venue as an opportunity to review what we do know about the status of AI/AN children with disabilities and to facilitate a dialogue around what we need to know about these children, particularly those from

birth to age 5. In doing so, I will provide a demographic profile of young American Indians and Alaskan Natives with disabilities, define Early Intervention services, identify and explore factors that place American Indian/Alaskan Native children at risk for developing or acquiring disabling conditions, explore ways in which early childhood programs may accommodate AI/AN children with disabilities, and briefly address the impact of disability across the lifespan. I will end with implications for policy, research, and practice and suggestions for next steps to address the issues and concerns identified, not only in this paper, but also as a result of the collective body of papers and discussion presented at this forum.

Demographic Profile of Americans/Alaskan Natives with Disabilities

Two thousand six hundred and thirty four AI/AN children ages birth to 2 were served under Part C of the *Individuals with Disabilities Education Act* (IDEA) during the 2003-2004 school year. In total, 2.46% of AI/AN children ages birth to 2 received early intervention services, compared to 2.26% of Asian/Pacific Islanders, 2.16% of Blacks, 1.99% of Hispanics, and 2.34% of Whites. In addition, 9 states or territories, including California, Hawaii, Indiana, Massachusetts, New Hampshire, New Mexico, North Carolina, West Virginia, and Guam, reported the number of AI/AN infants and toddlers, ages birth to 2, identified as at risk of developing a disability. This number totaled 176. Examples of early intervention services provided include: assistive technology; audiology; family training; health, medical, nursing, and nutrition services; occupational and physical therapy; psychological services; respite care; social work services; special instruction; speech and language; transportation; vision services; and other services not specified. During the 2002-2003 school year, AI/AN infants and toddlers with disabilities and their families were served in the following settings: developmental delay programs, typically developing programs, home, hospitals (inpatient services), residential facilities, service provider locations, and other settings (U.S. Office of Special Education Programs, n.d.).

Eight thousand eight hundred and forty eight AI/AN children ages 3-5 were served under Part B of IDEA during the 2003-2004 school year (U.S. Office of Special Education Programs, n.d.). In total, 8% of AI/AN children ages 3-5 received early intervention services, compared with 3.6% of Asian/Pacific Islanders, 5.94% of Blacks, 4.26% of Hispanics, and 6.37% of Whites. Of these, the largest number were served under the category of developmental delay (4,113) followed by speech or language impairments (3,897), mental retardation (123), autism (122), other health impairments (114), specific learning disabilities (113), multiple disabilities (93), hearing impairments (84), orthopedic impairments (84), visual impairments (45), emotional disturbance (44), traumatic brain injury (12), and deaf-blindness (4).

In both cases described above, ages birth to 2 and ages 3 to 5, a higher percentage of AI/AN children received early intervention services compared to Asian/Pacific Islanders, Blacks, and Hispanics.

Early Intervention Services Defined

Early intervention is defined in IDEA (20 USC§632) as developmental services that are:

- provided under public supervision
- provided at no cost except where federal or state law provides for a system of payments by families
- designed to meet the developmental needs of an infant or toddler with a disability in any one or more of the following areas:
 - physical development
 - cognitive development
 - communication development
 - social or emotional development
 - adaptive development
- to the maximum extent appropriate, [early intervention services]

are provided in natural environments, including the home, and community settings in which children without disabilities participate

- are provided in conformity with an individualized family service plan

Early intervention services include (20USC§631(4)(E)(i-xiv):

- Family training, counseling, and home visits
- Special instruction
- Speech-language pathology and audiology services
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination services
- Medical services (diagnostic/evaluation purposes)
- Early identification, screening, and assessment services
- Health services necessary to enable the infant or toddler to benefit from the other early intervention services
- Social work services
- Vision services
- Assistive technology devices/services
- Necessary transportation and related costs

In legislating early intervention services, Congress identified the following needs (20 USC§ 631):

- To enhance the development of infants and toddlers with disabilities and to minimize the risk of developmental delay
- To reduce educational costs by reducing need for special education and related services
- To minimize the likelihood of institutionalization and to maximize potential for independent living
- To enhance the capacity of families to meet the special education needs of their infants and toddlers

- To enhance the capacity of state and local agencies and service providers to meet the needs of historically underserved populations

Children with disabilities who qualify for special education programs and services transition from early intervention to school age services at age 3 and are eligible for such services, unless deemed otherwise, until the age of 21. During the 2000-2001 school year, approximately 47.2 million students were enrolled in elementary and secondary schools in the United States (National Center for Education Statistics, 2002). Of these, approximately 5.8 million students, ages 6-21, were served by special education programs and services. Although American Indians and Alaskan Natives accounted for slightly more than 1% of the total school age population, they accounted for nearly 1.5% of all students in special education. Nearly 15% of the approximately 600,000 AI/AN students attending U.S. public schools were served by special education programs and services (U.S. Department of Education, 2002). They were more likely to be placed in special education than students from all other racial or ethnic minority groups except African Americans. In comparison, the Bureau of Indian Affairs (BIA) and tribal schools served approximately 48,000 AI/AN students during the 2000-2001 school year. Of these, approximately 17% or slightly more than 8,000 AI/AN students were in special education programs (Bureau of Indian Affairs, 2002).

Identifying Factors that Place American Indian/Alaskan Native Students at Risk for Developing or Acquiring Disabling Conditions

Regardless of the location (e.g., rural, urban, suburban, etc.) in which American Indian and Alaskan Native children live, they tend to be disproportionately affected by health problems including speech and language impairments, respiratory tract infections, fetal alcohol syndrome due to maternal use/abuse of alcohol, diabetes, and obesity (Marks, Moyer, Roche, & Graham, 2003). Each of these factors may increase children's risk of developing or acquiring a disability which

may result in eligibility for special education programs and services. These conditions may be related to socioeconomic and environmental factors such as poverty, smoking, poor nutrition, lack of adequate healthcare, stress, drug and alcohol use and abuse, recurrent otitis media¹ or middle ear infection, poor diet and nutrition, etc.

In addition to physical health, mental health has been cited as "... the largest unmet health need for Indian people today" (Neligh, 1990, as cited in Marks et al., 2003). Although there is conflicting data regarding the incidence of mental illnesses and other related disorders among American Indian/Alaskan Native children, there is some evidence to suggest that these children are more susceptible, than their peers, to depression, abuse, and neglect, factors that are thought to be correlated to behavioral problems, psychiatric symptoms, and risk-taking behavior (Marks et al.).

Although no studies were identified that specifically addressed similarities or differences in the incidence of disability among American Indian/Alaskan Native young children based on location of residence, one study did examine differences in perinatal and infant health among rural and urban American Indians and Alaskan Natives (Baldwin et al., 2002). The authors found that rural mothers received less adequate prenatal healthcare than did those in urban areas. They suggest that this may be related to factors such as distance to and from health services, limited transportation, and greater distances from health services than those located in or near urban areas, etc. that interfere with women's receipt of prenatal care. The authors also found that "...urban mothers were more likely to be unmarried, to be having their first child, and to be smokers... [while] rural mothers were more likely to have preexisting medical conditions, complications of pregnancy, and a prior preterm or small-for gestational-age infant" (Baldwin et al., 2002) and that the incidence of low-birth weight was approximately 10% higher among urban AI/AN mothers than those in rural areas.

¹ Shriberg, Flipsen, Thielke, Kwiatkowski, Kertoy, Katcher, et al. (2000) (cited in Hammer & Demmert, 2003) found a connection between recurrent bouts of otitis media and increased risk for speech disorders among American Indian children.

Other factors that contribute to poor health care and outcomes among American Indians and Alaskan Natives include: lack of financial resources, cultural barriers, suspicion of health care providers, and poor sanitary conditions (The Health Care Challenge, 1999, as cited in Office of Minority Health, n.d.). These findings are important given that health-related factors may place children at risk of developing or acquiring disabilities or other impairments later in life.

How Can Early Childhood Programs Accommodate AI/AN Children with Disabilities?

A synthesis of research (Marks et al, 2003) in the area of early childhood education and American Indians/Alaskan Natives identified the following issues or concerns:

1. Lack of culturally appropriate curricula and practices
2. The need to emphasize the development and use of language and literacy
3. The need for improved teacher training and professional development
4. The need for increased parent involvement
5. Improvement of assessment tools and practices
6. The need to address the physical health and well being, as well as the mental health, of young AI/AN children

Although this is not an exhaustive list, it underscores the need to develop and implement a comprehensive set of services for young AI/AN children regardless of their disability status that is cognizant, foremost, of the linguistic and cultural diversity of these children and the communities in which they live. According to Paul (1992), “As society moves forward in its efforts to improve conditions for early childhood care and education, deeper issues must be considered by Native Americans. Programs for young Native children need to be designed within the context of each child’s culture, home language, and family. This cannot be done without community input and support”

(p. 39). Further, Paul (pp. 40-41) suggests the following strategies for the provision of successful early childhood care and education:

- Train more Native teachers and administrators through incentives to enter the field of education and to use alternative certification procedures.
- Include cultural awareness courses in teacher training.
- Hire Native aides trained in child development principles a language and culture models.
- Increase Head Start availability for all who wish to participate.
- Establish a culturally based curriculum relevant to the local community.
- Promote, maintain, and encourage Native language use.

As illustrated, effective early childhood programs are essential, not only for AI/AN children with or at risk of disabilities, but for all AI/AN children. This is underscored by findings (e.g. Beiser & Attneave, 1982, as cited in Fisher, Bacon, & Storck, 1998) that suggest that AI/AN children tend to do well in school during their early childhood years. However, marked differences become evident during the adolescent years. The question, then, is what happens to the child and/or the educational system during the adolescent years and how can we use this knowledge to retool educational programs so that AI/AN continue to fare well in the educational system?

Impact of Disability Across the Lifespan

Although the focus of this paper is on early childhood education for AI/AN children with disabilities, it is important to acknowledge that the existence of a disability has implications throughout one's entire life span. Current reports indicate that 22%, or 550,000, American Indians and Alaskan Natives report having one or more disabilities, compared with 20% of all racial groups, 20% of Whites, 20% of Blacks, 15% of Hispanics, and 10% of Asians (National Council on Disability, 2003). The most frequently occurring disabilities among

AI/ANs include (National Council on Disability, 2003):

- Spinal cord injuries
- Complications of diabetes
- Blindness
- Mobility impairments
- Traumatic brain injuries
- Deafness or hardness of hearing
- Orthopedic impairments
- Anthralgia (joint pain)
- Emotional or mental health conditions
- Learning disabilities
- Alcoholism or drug related dependencies

Some of the barriers and challenges faced by AI/ANs with disabilities include (National Council on Disability, 2003):

- Attitudes and perceptions
- Lack of awareness
- Lack of uniformity/coordination of services among federal, state, and tribal governments and other service providers
- Lack of public transportation in rural and remote areas which also has implications for independent living and mobility
- Limited infrastructure among rural communities (e.g. lack of wheelchair accessible buildings, sidewalks, ramps, etc.)
- Limited access to tribal and federal offices, as well as housing and other physical structures
- Difficulty navigating the educational system
- Need for personal care assistance

Implications for Policy, Research, and Practice

As illustrated, the education of AI/AN children with disabilities impacts and is impacted by policy, research, and practice at the tribal/local, state, and federal levels. To effectively serve this population, we

must examine what the current landscape looks like in terms of the incidence and prevalence of disability among American Indian and Alaskan Native communities. This will provide data that will allow us to better understand which categories of disability are most prevalent and then to create, or in some cases, finetune existing services that target these particular disabilities. For example, we know that nationally, a problem exists with the high incidence of fetal alcohol syndrome that is related to maternal use and abuse of alcohol during pregnancy. However, we do not know the extent to which this condition is found among all AI/AN communities, or if the incidence rate is higher among certain tribes, and/or those tribal people residing in rural versus urban areas.

Nationally, we must advocate for the inclusion of American Indians and Alaskan Natives in sufficient numbers in large-scale research studies to enable valid and reliable analysis of data. It is also recommended that the Indian Health Service (IHS) collect and analyze national data comparing maternal and infant health status among all Native groups served by IHS facilities as well as tribal health care providers (Baldwin et al, 2002). At present, no such data were available.

As demonstrated by the lack of a comprehensive body of research and publications regarding the education of young American Indian and Alaskan Native children with disabilities, it is no longer acceptable to argue that American Indians and Alaskan Natives are an insufficient percentage of the overall population, who do not warrant statistical analysis. As we know, the current administration, and in large part the education community, heralds the use of evidence-based, empirical research. Without such research, we can not adequately argue for the development and implementation of appropriate services, nor can we accurately portray the current status of this population. This argument is bolstered by the Administration for Children and Families (Marks et al, 2003):

AI/AN children have not always been the direct beneficiaries of knowledge that has been gained through research. Very little evidence has been systematically gathered from Head Start programs that serve

these children. To date, understanding the differences across and within AI-AN populations has remained largely outside the body of knowledge derived from systematic, large-scale research on early childhood development. To the extent that studies have been conducted, they often are ethnographic or case studies, which, although rich with detail and understanding, may be limited in their generalizability and are not necessarily the best method for producing knowledge that can be turned into strategies to better serve American Indian and Alaska Native children.

There is a strong consensus that American Indian and Alaska Native children bring unique aspects of their culture and background into Head Start. Based on studies and practitioners' observations, it is likely that many American Indian and Alaska Native children have learning approaches, develop language skills, exhibit behavioral characteristics, and are affected by health matters in ways that are different from those of other racial and ethnic groups. Moreover, American Indian and Alaska Native children differ from each other across tribal and ancestral affiliations and across the cultural norms that affect their families and the types of environments in which they live. Any research efforts must take into account the unique cultural characteristics of the children and families served as well as the goals and directions of the local communities in which they live.

Although AI/AN children are often absent from data analysis and reporting, it is important to note that they are included in existing large scale data sets compiled at the national level, such as the Early Childhood Longitudinal Studies (ECLS-B and K). We need to ask what can we learn from such data sets and how can we facilitate the systematic analysis and publication of these data? What we do know is that preliminary analyses of these data indicate differences in early childhood disability status based on location. For example, in one study, researchers found that rural students were 60% more likely to be placed in special education in kindergarten than their peers in other settings (National Center for Rural Early Childhood Learning Initiatives, 2005). Additional informal analysis shows that young American Indian students are disproportionately represented in

special education programs and services in public schools.² Although this is a starting point, this database again does not include a large sample of American Indians thereby limiting the generalizability, reliability, and validity of these data. However, one of the exciting things about this database is the potential to recommend to the National Center for Education Statistics or other research groups skilled in large-scale quantitative data collection and analysis, that this study be replicated solely with American Indians and Alaskan Natives in order to provide more useful data.

In addition to quantitative analysis using large-scale data sets, there are a number of other questions that can be addressed using more qualitatively based methods of research. Questions to consider include:

- What is the current status of early childhood education among rural American Indian/Alaskan Native children with or at risk of developing disabilities? (e.g., How many eligible children? What are the most prevalent conditions? Are these children located in rural or urban areas?)
- What types of services are provided? What types of training and professional development are available for early intervention service providers? To what extent do available services meet the unique cultural and linguistic characteristics of American Indian and Alaskan Native children, their families, communities, etc.?
- Is there a correlation between residence (e.g., rural, urban, suburban, etc.) and the incidence of disability? If so, why? How does location of residence impact access to and provision of early intervention, as well as preventive services for young AI/AN children who have or are at-risk of developing a disability?
- What are the current best practices in the field of early childhood education as it relates to the education and care of young

² The author has received a small grant from The Pennsylvania State University's Children Youth and Family's Consortium to analyze the data from the Early Childhood Longitudinal Study to factors that place American Indian children at risk for receiving special education programs and services.

- American Indian and Alaskan Native children with disabilities?
- Does the Individuals with Disabilities Education Improvement Act recognize the role of language and culture in the development and implementation of Individualized Family Services Plans and Individualized Education Plans? If so, how? If not, what can we do to ensure that such provisions are mandated and implemented?
 - Are there differences in the provision of early intervention services in rural versus urban areas? If so, what? Why?
 - What is the role of tribal governments in providing early intervention services?
 - What is the role of the Indian Health Service as well as tribal health care programs in providing services to AI/AN children with disabilities?
 - What is the role of Head Start, Early Head Start, Family and Child Education programs (FACE) and BABY FACE programs in the provision of early intervention services?
 - What is being done to ensure the seamless transition of AI/AN children from early intervention services to school age special education services? What needs to be done to improve this transition?
 - What happens to the provision of services among transitory children who migrate between rural and urban areas? How can we facilitate the seamless provision of services?
 - How can early intervention programs interpret and operationalize the definition of parents to facilitate extended family and community involvement in the special education process?
 - What can school leaders do to facilitate the seamless provision of early intervention services? Are school leaders adequately prepared to assume responsibility of school-based early intervention services?
 - Are definitions of disability culturally bound?³ Do Native communities view disability in the same way educators and other service providers do? What implications do these differences or similarities have for the provision of early intervention services?

- How can we make the assessment and identification process more culturally appropriate and relevant for use among young American Indian and Alaskan Native children?

Regardless of what questions are asked or how the data are collected and analyzed, we must be careful to avoid the frequently occurring disconnect between research and practice.

In addition to the lack of research, an ongoing area of concern is the use of standardized tests in the assessment of AI/AN students. This practice has been linked to the disproportionate representation of culturally and linguistically diverse children, including AI/ANs, in special education programs and services (Hammer & Demmert, 2003). Dynamic assessment, which is a comprehensive approach to assessment that takes into account linguistic and cultural diversity, has been suggested as an alternative or compliment to standardized testing (Ukrainetz, Harpell, Walsh & Coyle, 2000, as cited in Hammer & Demmert, 2003). Banks (1997) has also studied the perceptions of caregivers and professionals regarding assessment of American Indian/Alaskan Native families. Her research found a disconnection between current “best practices” in assessment and actual practices in the field.

Another ongoing concern is the need to develop and implement effective means of preparing, recruiting, and retaining highly qualified cadres of Native special educators (e.g., early intervention specialists, speech and language therapists, etc.) as well as early childhood educators and care providers. Current models such as the one at Northern Arizona University Reaching American Indian Special/Elementary Educators (RAISE) (see <http://coe.nau.edu>) are instructive as to how we can grow our own and provide incentives for them to work in their own communities upon earning their degrees. Just as training

³ For example, Beiser, Dion & Gotowiec (2000, p. 435) (as cited in Demmert & Hammer, 2003) found that “there is nothing culture-bound about the symptoms of either hyperactivity or attention-deficit.” However they recommended that researchers examine ways in which “cultural context may affect the response of parents and teachers to these potentially long-lasting problems of childhood.”

of staff is important, parents also need to be made aware of and encouraged to access all available early intervention/early childhood services for AI/AN children with disabilities. One way to facilitate this is the development and implementation of parent training and information centers such as the Native American Families Together Parent Center in Moscow, Idaho, which is specifically designed to serve American Indian and Alaskan Native parents and families (see <http://coe.nau.edu>). This can serve as a valuable resource to all involved in the education of young AI/AN children with disabilities.

Next Steps: Where Do We Go From Here?

Although the questions we posed in the introduction are not fully answered, the most important lesson, I believe, gained from this discussion is the need to not only study and examine the current state of the education of young AI/AN children with disabilities, but to emerge from this forum, with a renewed commitment and plan of action to identify, develop, and/or implement effective practices that will ensure that our children, regardless of disability status, receive the most effective educational and supportive services, including the appropriate use of tribal languages and cultures. Such work requires that we, as a community of Native practitioners and researchers, and local, tribal, state and federal governments, collaborate specifically, as this is our focus, with rural AI/AN communities to address the issues outlined not only in this paper, but as a collective result of this forum. This type of approach recognizes the fact that the education of young AI/AN children, particularly those with or at-risk of developing a disability, cannot be adequately provided in isolation. Their education is, in fact, impacted by the cultural, social, economic, political, legal and historical conditions within which this population exists. The lack of a systemic approach to early childhood education, including early intervention, will result in the failure to provide appropriate services. In turn, we will continue to see the disproportionate representation of AI/AN children in special education programs and services not only from birth to age 5 but also throughout the school-age years.

In the end, it is not sufficient to pose research questions and identify areas in need of improvement. We must take this work a step further so that this forum will positively impact the education and care of young American Indian and Alaskan Native children with disabilities residing in rural or reservation-based communities, using the information gained from this forum, as well as the work that has been done and continues to be done in our own communities. In order to accomplish these goals, we will require adequate funding, commitment and ongoing collaboration. My charge is to leave this forum with a formulated plan of next steps that is not limited to discussion, but is actionable.

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