

Disability Access Research Utilization Project

Final Report
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Introduction

The goal of the Research Utilization Award (RUA) from the Research Utilization Support and Help (RUSH) project was to distribute the results of Disability Access research to a wider audience within Indian country.

Three major activities took place under this award:

- 1) A multi-method information use survey was conducted to determine the means by which people with disabilities, their family members and non-disabled tribal members receive information. It was hypothesized that greater use is made of electronic media than generally assumed in the research literature.
- 2) A computer-based training module focused on Individualized Education Plans (IEPs) was developed and evaluated.
- 3) Dissemination of research results occurred through training demonstrations conducted on several reservations not included in the original Disability Access project, presentations at tribal-focused conferences, articles in community newsletters and articles written for publication in academic journals.

This final report summarizes activities of survey design and data collection, plans for information use report, qualitative interviews, document collection, IEP Test and IEP involvement form data collection, dissemination, conference presentations and short-term outcomes. All of these topics were discussed in detail in quarterly progress reports previously submitted. Outcome data are discussed for the Individualized Education Plan training evaluated on seven reservations; Spirit Lake, Turtle Mountain, Fort Berthold, Fort Peck, Sisseton, Standing Rock and White Earth. The report concludes with an extensive discussion of perceptions regarding the impact of the Research Utilization Award

and implications for other National Institute on Disability and Rehabilitation Research (NIDRR) grantees doing research on American Indian populations.

Data collection instruments were submitted separately. These include the Information Use Survey, IEP Test with IEP involvement form, short form of the IEP Test and structured interview questions. Conference presentations and copies of articles for community newsletters have also been submitted prior to this report.

ACTIVITY #1: Information Use Survey

Information Use Survey – Quantitative Data

The Information Use Survey provides a unique dataset on Native Americans, predominantly in the Great Plains states. These data provide a sample of sufficient size to assess media usage for Native Americans by disability status, tribal affiliation and reservation residence. A total of 507 surveys were collected, of which 305 were from individuals with disabilities or members of their immediate families. Although data collection of the Information Use Survey as a stand-alone instrument was completed in September 2007, we continued to include these surveys as part of the data collected during the IEP workshops as well, resulting in over 200 more responses of families of people with disabilities. These responses have yet to be combined with the original 305 surveys as data collection from the IEP workshops has just completed. While the other 202 surveys from tribal members without disabilities may be used at some point for comparison of people with disabilities to the general population, the present report focuses only on those surveys collected from persons with disabilities and their families.

Far more respondents than anticipated reported getting news at least weekly from the radio, newspapers and Internet. Also unexpected, about as many

respondents stated they surfed the Internet daily (41%) or read email daily (39%) as said they read a daily paper (42%).

These results, e.g., 62% of respondents are on the Internet at least weekly, provide strong evidence for the usefulness of Web sites as a means, albeit not the sole means, for special education and disability services departments to reach consumers. Some findings were as expected, a substantial minority of respondents reported getting information on disability programs from newsletters from Head Start or their child's school, and the majority gave flyers posted around the reservation as another source of information.

Information Use Interviews: Qualitative Data

Could the results from the Information Use Survey represent a socially appropriate bias in the responding, with those surveyed not wanting to admit a lack of computer proficiency? To cross-validate results from the survey, qualitative interviews were conducted with a focus on how parents received information on special education and disability services. A maximum variation sampling method was used, with subjects sampled to include people with disabilities, mothers and fathers. Subjects were selected to represent a range of disabilities, from mild to severe and an age range from early childhood through adulthood. Elders with disabilities were not included as they do not fit within the scope of the project.

Twenty-three interviews were completed. All respondents were the parent or guardian of a child with a disability. Respondents included mothers, fathers, grandmothers and one sister. Twenty-one of the respondents had one child with a disability; two had two children with a disability. All interviewees were enrolled members of the Spirit Lake Dakota Nation. Interviewees were enrolled members in the Spirit Lake Dakota, Turtle Mountain Chippewa, Mandan, Hidatsa or

Arikara tribes. After the first set of interviews, all conducted by a male interviewer, yielded a predominantly female sample, two female interviewers were added in an attempt to increase the response rate from fathers/ grandfathers. This was not successful in increasing the rate of male participation; the resulting sample was 78% female. The educational level of respondents were significantly higher than the reservation as a whole. This represents a selection effect. Those who have email, cell phones, home telephones and a less chaotic lifestyle are easiest to schedule.

Of these caregivers surveyed, six of twenty-three specifically mentioned searching the Internet, e.g.,

When they first diagnosed him ... and I really didn't know very much about it and I was trying to understand what exactly it meant and asking his doctors and asking his therapists and they didn't really ... they didn't really give me very much. I mean it was really vague, so I decided I would just go myself and I looked on the Internet ... different ah ... like WebMD.Com and I ah ... that's where I got a lot of my information from.¹

Details on sampling, procedures, further data analyses and implications will be provided in an article currently being written for publication. In brief, these data suggest that disability service organizations that wish to reach Native Americans living on Indian reservations are underestimating the effect of electronic media sources such as e-mail and Web pages. Such sources, however, should be off-set by more low-tech offerings as radio and flyers posted in the community. A combination of these sources would be most effective for those organizations for which comprehensive dissemination of information is most

¹ The use of an ellipsis (...) represents respondent's pause in speaking as she reflects on her answer.

important, e.g., Child Find. Data from the Information Use Survey have already been used to refine our plan for dissemination of information on the Disability Access Project, including more announcements of reservation activities on our Web site and Spirit Lake Forum, as well as use of announcements on reservation radio stations.

Activity #2: Creation and evaluation of a computer-based module focused on Individualized Education Plans

The original Disability Access project provided empirical evidence for the effectiveness of a two-day computer-integrated training course as a means for residents of American Indian reservations to increase knowledge of disability, interventions, best practices and legal rights. There are financial, practical and logistical barriers that prevent many individuals with disabilities and their families from attending a two-day training session. A goal of this study was to test the effectiveness of a time-limited, focused segment of training. The Individualized Education Plan sections of the Disability Access computer-integrated course were compiled into a single three-hour module.

The home page for the computer-based training module is shown in Figure 1 on the following page. The presentation covered the following topics:

- Introduction to special education,
- Legal rights,
- Individualized Education Plans,
- Example of an IEP for a child with Attention Deficit Disorder, including needs of children with Attention Deficit Disorder (ADD) and modifications that could be requested,

- Example of IEP services for a child with learning disabilities, including modifications that can be requested to meet specific needs.
- Parent's role in the IEP process,