

Disability Access Research Utilization Project

Quarterly Report
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AnnMaria De Mars, Ph.D.
&
Erich Longie, Ed.D.

Spirit Lake Consulting, Inc.
Fort Totten, ND

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EXECUTIVE SUMMARY

In the second quarter, Spirit Lake Consulting, Inc. has made continued progress toward its goal of distributing the results of Disability Access research to a wider audience within Indian country – as made possible by the Research Utilization Award (RUA) from the Research Utilization Support and Help (RUSH) project.

An additional 91 information use surveys were collected in the second quarter, as well as an additional 57 in the first week of the third quarter. During the second quarter, we also achieved a greater balance with regard to the gender of survey respondents. These surveys, along with those collected in the first quarter, have been analyzed and as a result of those findings, Spirit Lake Consulting has made adjustments in the way it promotes its services. Radio, Internet and newspapers have all been shown as effective ways to reach Indian audiences, with radio having the broadest reach.

An in-depth review of available media showed a minimal amount of outreach materials were available. Vocational rehabilitation offices had a moderate amount of information, but most other offices – including Head Start programs and school resources – had minimal to no information. Disability information was available on the reservations, but tribal members would need to actively search for it. Consistent with the documents reviewed, qualitative interviews found that parents had limited information or misinformation regarding disability services and even their own child's diagnosis.

Presentations on the IEP and parental involvement in special education were given at White Earth and Sisseton reservations and the mid-year Consortium of Administrators of Native American Rehabilitation conference. Another presentation was accepted for the National Even Start Association conference to be held in October. Access to the Spirit Lake website has continued the dramatic increases seen during the first quarter. Monthly visitors are over 17,000. Our research and dissemination process has evolved interviews as a result of experiences on the White Earth and Sisseton reservations. The obstacles in dissemination and collection of research data have been documented closely, along with our procedures to address these articles. In the final analysis, it may be that an effective dissemination process will be as valuable a result of the Disability Access – RUSH project as the dissemination and research efforts themselves.

Background

The goal of the Research Utilization Award (RUA) from the Research Utilization Support and Help (RUSH) project is to distribute the results of Disability Access research to a wider audience within Indian country. Three major activities will take place under this award:

- 1) A multi-method information use survey is being conducted to determine the means by which people with disabilities, their family members and non-disabled tribal members receive information. It is hypothesized that greater use is made of electronic media than generally assumed in the research literature.
- 2) A computer-based training module focused on Individual Education Plans will be developed and evaluated.
- 3) Training demonstrations will be conducted on several reservations not included in the original Disability Access project, and at tribal-focused conferences.

This interim report summarizes progress during the second quarter (May- July, 2007) only. Progress during the first quarter, and copies of all data collection instruments were included in the first interim report and are not reproduced here.

Information Use Survey

In the second quarter, an additional 91 surveys were collected, for a total of 234 to date. During the first week of the third quarter, an additional 57 surveys were collected. Data collection for the information use survey will be collected during the third quarter with samples from Trenton Indian Service Area, Sisseton- Wahpeton, Fort Berthold Reservation and United Tribes Pow-wow. We anticipate collection of over 500 surveys by the end of the project. Although data collection of the Information Use Survey as a

stand-alone instrument will be completed in September 2007, we will continue to include these surveys as part of the data collected during the IEP workshops as well.

The Information Use Survey provides a unique dataset on Native Americans, predominantly in the Great Plains states. Data are included on individuals with disabilities and their families and those without a disabled family member. These data will provide a sample of sufficient size to assess media usage for Native Americans by disability status, tribal affiliation and reservation residence. Not only will the data itself provide information heretofore unavailable, but the methods used (discussed in detail under procedures) should be of value to future researchers seeking to collect data or disseminate information on Indian reservations.

In the first quarter, 66% of surveys collected were from female respondents. During the second quarter, 50.5% of surveys were from female respondents. There are two possible explanations for this discrepancy. First, during the first quarter, surveys were collected by two female research assistants. In response to the gender disparity, a male researcher began collecting surveys in the second quarter. This was related to a higher proportion of male respondents volunteering to complete the survey. Second, a female research assistant collected surveys at the Fort Totten Days Pow-wow.

Responses of participants regarding their frequency of use of several types of media are shown in Table 1.

Table 1
Type and Frequency of Media Usage

How often do you ...	N	Almost Every Day	Weekly	Monthly or Less
Read your email	229	35%	35%	30%
Use the Internet	219	38%	22%	40%
Read the newspaper	230	39%	34%	27%
Listen to the radio	231	71%	18%	11%

Data from the Information Use Survey has already been used to refine our plan for dissemination of information on the Disability Access Project. In the most recent Disability Access workshop, held at Turtle Mountain, the site coordinator used a combination of radio spot ads, newspaper ads and ads in our emailed newsletter. The response was overwhelming; 47 participants attended our training, more than double the average attendance at previous sessions.

The responses in Table 1 are somewhat counterintuitive. None of the reservations surveyed had a daily newspaper. Thus, 39% of those surveyed are reading a newspaper daily from a community off the reservation. This is similar to the 40% of Americans who read a newspaper daily found by the Pew Research Center (2006) ¹report on the media. The same survey of 3,204 Americans found only 36% listen to the radio daily, far less than the 71% on the reservations. It should be noted that, unlike newspapers, most of those surveyed live on reservations that have their own radio station.

The assumption of extremely low Internet usage is not supported by the data. One of our corporate clients, a service provider on a reservation, received a negative report

¹ Pew Research Group (2006). Online Papers Modestly Boost Newspaper Readership. Accessed August 10, 2007 from <http://people-press.org/reports/display.php3?ReportID=282>.

from a grant project officer stating that she was ‘appalled’ at the lack of cultural sensitivity that the client was using telephone contacts and a website as a means of gathering community input. In fact, the data above show only a single percentage point difference between the percentage of reservation residents who use the Internet daily and those who read the newspaper daily.

Reports of Internet usage were higher than expected based on the low educational level, low income and rural location of the average respondent. Although only 47% of respondents had Internet access at home, as shown in Table 2, 59% had an email address, presumably through work or school.

Table 2

Computer and Internet Access by respondents

Respondents who have	N	%
An email address	229	59%
A computer at home	227	52%
Internet access at home	222	47%

In-depth analysis of the information use survey, including data specifically on individuals with disabilities and comparisons of families of individuals with and without disabilities will be conducted in the third quarter when data collection is completed.

Qualitative Interviews

A maximum variation sampling method is being 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.

To date, ten interviews have been completed; only nine are included in this discussion as it was determined that one child did not meet the definition of disabled. Eight interviews were conducted by a male interviewer who is an enrolled member of the Spirit Lake Nation. One interview was conducted by a female interviewer. In the second and third quarters, it was originally planned that three of the interviews would be conducted by a pair of interviewers, male and female, and three conducted by a female interviewer. As will be discussed in the procedures section, it was decided that the planned format was not likely to be successful. Respondents were not comfortable discussing their child's disability and experience. Being 'ganged up on', by two interviewers is highly unlikely to make them more at ease.

The educational levels of respondents in the first nine interviews have been 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 first nine interviewees, all had at least a year of college, including two with doctorates, four with bachelor's degrees. In subsequent quarters, interviewees will have a much lower level of education. The nine interviewees had a total of eleven children with disabilities, ranging from early childhood through adulthood. Of these, six were adults, three adolescents, one in elementary school and one young child. The interviews conducted in the second quarter were two parents of school-age children. The third interview, that was dropped from the sample, was with the parents of a child in the infant development age range.

In the first quarter interviews, Dr. Longie noted a significant amount of anger expressed by the participants. It was noted that this same angry reaction was experienced

by staff members collecting data on an unrelated project on the Spirit Lake reservation, which also questioned parents about their child with a disability. Due to the observed responses, limited follow-up questions were asked to clarify discrepancies, as it was perceived that this might harm rapport with the subjects and cause a premature end to the interviews.

It was hypothesized that parents living in poverty with a child with a disability may be angry about the lack of services and the perceived uncaring attitude of disability services staff and project this anger on to the interviewer. In our first quarter interim report, we noted the possibility that parents of younger children may have had more positive experiences and have a different emotional reaction. The two parents of school-age children interviewed in the second quarter did not report experiences that were noticeably more positive than the experiences of parents of older children. In fact, both reported some disagreements with the schools and one stated,

“Well when he was in school we were fighting with the school, well they were more or less fighting with us, and there were times when he would get into trouble and they would want to kick him out and send him to a psych ward. Voc rehab would be there but they wouldn’t do anything so I would have to go out and have Pathfinders send me the information to back up everything so that I could prove that what they were doing was wrong. And it got to the point where I was going to take Justin out of school and home teach him myself. Then it got to the point where it ended up in court for Justin and the judge ended up throwing it out again because the protection of advocacy² helped.”

² State Protection and Advocacy Project

Document Collection

To date, documents have been collected from the following organizations on or near three reservations:

Cankdeska Cikana Community College (Spirit Lake)

Lake Region State College

North Dakota Vocational Rehabilitation – Lake Region

Sisseton-Wahpeton Tribal College

Spirit Lake Diabetes and Fitness

Spirit Lake Even Start

Spirit Lake Vocational Rehabilitation

Tate Topa Elementary School (Spirit Lake)

Turtle Mountain Community College

Turtle Mountain Community School Special Education

Turtle Mountain Head Start

Turtle Mountain Times (weekly newspaper)

Turtle Mountain Vocational Rehabilitation

Documents were also reviewed from the American Indians with Disabilities Technical Assistance Center website (Montana). Unsolicited mailed documents were included for both the Spirit Lake Consulting office and the Turtle Mountain Vocational Rehabilitation office, two reservation-based organizations that work with individuals with disabilities as examples of the types of print material available on the reservations.

Qualitative Data Analysis

We are at the preliminary stages of qualitative data analysis, categorizing excerpts from transcripts and documents and identifying themes. With the limited data collection to date, a few themes have been tentatively identified. These are shown in Table 3.

Table 3

THEMES IN INFORMATION USE INTERVIEWS

Informal sources of information

At first diagnosis

After diagnosis

Formal sources of Information

At first diagnosis

After diagnosis

Unmet needs for information

Information needs at initial diagnosis

Proactive Information Seekers

** Misinformation regarding disability

** Services Received

No themes identified previously were combined, and two additional themes were added, denoted with “**” in the table above. Two examples of the theme, “Misinformatio regarding disability” is given below.

E.L. “Could you describe your daughter’s disability?”

S.T. “She was slow at walking and slow in her speech.”

E.L. “Is there a medical terminology for it?”

S.T. “Learning disability.”

Although S.T. says that her daughter's diagnosis is 'learning disability', her child was identified as disabled in Head Start due to gross motor and speech delays. In elementary school, she is in a self-contained class for children who are moderately to severely mentally handicapped. Whether she did not know her child's correct diagnosis or does not want to state that her child has mental retardation is unknown. It was the decision of the interview not to risk damaging the rapport with the respondent and in the community by pointing out what, to him, was an obvious discrepancy.

A second family to be interviewed was dropped from the sample when the child was determined not to have a disability. The child was born prematurely and had a birthmark that covered part of her face, which was medically treated and removed. She had no developmental delays or other evidence of disability.

Data from the documents reviewed, shown in Appendix A, were consistent with the parental report in that disability information was sparse. Of twelve weekly issues of the Turtle Mountain Times newspaper reviewed, one had an article on an individual with a disability and three had articles slightly related to disabilities, one on wellness, one on methamphetamine use and a third on seatbelts and child restraints that mentioned prevention of disability due to accident. Newsletters reviewed from the high school, middle school and elementary schools had no articles on disability, although there were several articles on alcohol and drug abuse. In the 21-page Head Start newsletter, the only mention of disability contained was:

*"Children who are disabled or who have special needs, and are three or four years of age by **August 31,2007**, also may be eligible for Head Start."*

While disability information was available on the reservation, the overwhelming majority would need to be obtained actively, not passively. That is, material was available in the vocational rehabilitation offices, on the AIDTAC website or other special education service. Very little outreach material was found in public settings such as the Head Start, Even Start, community college or public schools.

Individualized Education Plan Dissemination Activities

The computer-based module on Individualized Education Plans, and accompanying tests, were completed in the first quarter. Since then, training has been conducted and data collected at three sites; White Earth Reservation, Sisseton-Wahpeton Reservation and, during the first week of the third quarter, at CANAR. These three presentations resulted in the collection of only 19 forms from 13 subjects (some, but not all completed pre- and post-test measures). Several obstacles were experienced in the dissemination and data collection efforts, as discussed in detail under the procedure section below.

An article on the Individualized Education Plan was written and submitted to newsletters on three reservations. Publication will be in the third quarter once school is back in session, as most Head Start and public school programs were closed for the summer or maintained with minimal staff.

Presentation at tribal-focused conferences

Staff presented at two tribal-focused conferences during the first quarter. In the second quarter, staff presented at the mid-year conference of the Consortium of Administrators of Native American Rehabilitation. The session was attended by only 10 participants. It seems more plausible that this low attendance was due to the number of

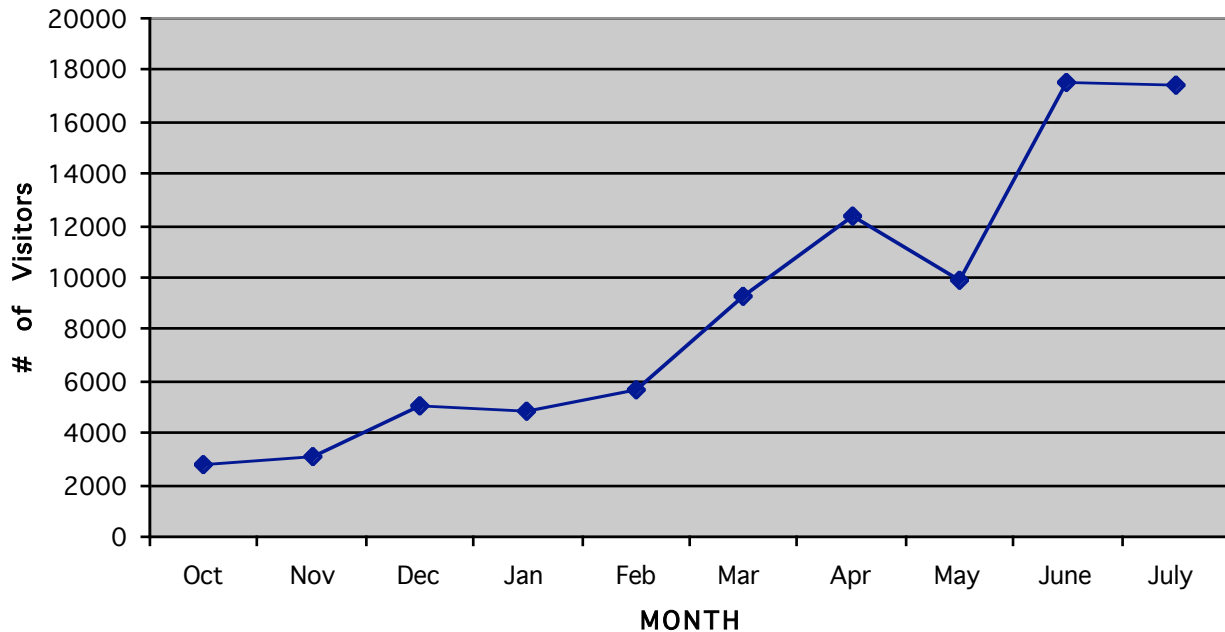
concurrent sessions rather than length of the session or topic, as other sessions we attended during the conference had similarly low numbers. According to the conference organizers, the Spirit Lake presentation received ‘very high’ evaluations, and the majority of those in attendance requested multiple copies of the CD to share with co-workers or consumers.

A presentation has been accepted for the National Even Start Association Conference in October. Although this is not solely a tribal-focused conference, there are eight tribal Even Start projects in the nation, serving children from birth through age 8. This figure is reduced from 28 projects in the 2005-2006 fiscal year. However, the Even Start population is still 4% Native American, four times the proportion of the U.S. population, and therefore this is a cost-effective method for reaching staff working with Native American families, given that the conference occurs within 90 miles of one of the Spirit Lake site offices

SHORT-TERM OUTCOMES

While an imperfect measure, one simple means of measuring the effectiveness of

Increase in Website Visitors Coincides with RUSH Funding



Disability Access dissemination is the increase in visits to our website. As can be seen from the chart, a dramatic increase in website visits coincided with the RUSH award.

Although one should not infer causation from correlation, this award is the only identifiable new factor throughout these two quarters of dramatic increase. The number of visitors to our website continues to expand in the second quarter. In mid-April, Spirit Lake Consulting was featured on Idea Café (a service of Yahoo for small businesses) as an outstanding small business. This resulted in a spike in website visits in April.

Although there was a drop in May, the number of visits set a record in June, after the Idea Café posting expired, and this record was nearly matched in July. The number of monthly visitors to our site has exceeded 17,000 for two months in a row.

Procedure and Directions for future research

A major accomplishment in the second quarter has been in improvement in our knowledge of effective procedures for data collection, and in identifying some of the obstacles researchers, both Indian and non-Indian face. As Dr. Longie stated in his field notes on the Sisseton Reservation IEP training,

At the time of writing the RUSH proposal I mistakenly thought I could waltz into a reservation, conduct a presentation, collect surveys, conduct the interviews... all in one visit. Boy, was I mistaken.

His field notes from the White Earth reservation training contained similar comments.

Although being Indian helped, in many ways I was as much at a disadvantage as a white researcher. One of the terms used at White Earth that I found interesting was "Indianonish". This term was used to describe Indian people who were reluctant to talk to people, trust outsiders or participate in study and didn't really care to acquire material things. One of the people said being Indian means being

quiet, not trusting people, wanting to do things but doing it in your own way, etc. That's exactly the problem I think I am going to run into on every reservation. We certainly have our Indianonish people here on Spirit Lake but there are differences from the Indianonish people on White Earth. I suspect the Indianonish will be different at each reservation I plan to travel to.

Data collection, whenever possible, by personnel from the local community, defined on a finer level than 'the same reservation' has enabled us to collect a substantial number of surveys in a short time period. In the first quarter, use of a Native American interviewer and local contacts made it possible for us to obtain entry to communities. Still, these first data collection efforts were primarily from two reservations where Spirit Lake had site offices. In the second quarter, even though some obstacles were foreseen and noted in the first interim report, a completely unexpected set of obstacles to data collection and dissemination were experienced as well. Again, from Dr. Longie's field notes from the White Earth Reservation site visit.

As a Native American with a doctorate living on the reservation, I am well aware of the problems non-Native American researchers experience when they conduct research on Indian reservations. There are a variety of reasons why researchers have problems obtaining data from Indian people; people are suspicious of outsiders, people have already been studied/ participated in research and they don't get anything from the research. Then, there is the usual lack of transportation, etc.; but the main reason non-Indians have problems is because they have absolutely no knowledge of Native Americans and contemporary Native American culture.

I, on the other hand, am very knowledgeable of reservations having been born and raised on an Indian reservation. ... In addition, having been involved in administration the last 25 years I have had numerous opportunities to be part of, or aware of, research on reservations. If anyone can conduct successful research on Indian reservations, I am that person. Or, so I thought!

The two reservations visited during the current quarter, White Earth (Chippewa) and Sisseton/ Wahpeton (Sioux) are the exact same tribes with which we had such success collecting data in the previous quarter.

Again, I think I made a big mistake assuming that because I was Indian I could come down to any reservation and wouldn't have any problems filling out surveys and conducting interviews and having people participate in my presentation.... The people are polite and they're helpful but you can tell that they have their own work to do or other things they need to address and the research comes a distant last in their priorities. ...The fact is that Indian parents are especially not involved with their child's education. The 'active involvement' they mention in the interviews averages out to one incident a year or less in most cases. Therefore even the best three-hour presentation will not encourage them to come in...

We have to make sure they get something out of the research, maybe a \$10 gift card or \$10 cash or door prizes, but that's what we need to do. Indians are not going to attend a meeting just because a researcher with a doctorate shows up and asks for a meeting. We have to take into consideration that we're probably the least important thing on an Indian's mind and we need to change the budget because of that. It's one thing to develop a survey, develop a great presentation, and have all these good intentions but none of that does any good unless we get people to attend. And to get people to attend there are things we simply need to do such as; we need to contact people ahead of time, we need to do a lot of advertising even though advertising doesn't work because Indians are not

scheduled people. They wait till the last minute and they often wake up and say, "Wow, was that today? I missed it." So we need to look at those things and one of the best ways to get their attention is to make it worth their while and that's with the stipend, door prizes, and a meal. Then and only then will we get enough participation and even then, we won't get the full participation we need. We have to realize that.

Researchers have been making this mistake for the last 50-60 years and it's important we don't make the same mistake. Being a researcher is in some ways like being a salesman. You're trying to sell someone something they may or may not want. For example, for our newsletter articles, we approach somebody and we ask them do you want to put our news articles in your newsletter? Now they may welcome it but on the other hand, they may say, "Why do I need his newsletter?" So I think the idea of doing research really has to be thought over before it's done. It sounds so easy when you put it on paper but it is really a lot more complicated than that when you get on the reservation. Researchers have to look at how we look at the people we are doing research on and if we do that I know we will change our procedures and our process when we do research.... It might appear quite simple to go to each reservation, do interviews, training, and submit our articles to newsletters, but I'm learning it's not even close to that simple. It goes back to how do we get people to buy into something when they see no immediate benefit? In fact, they see no long-term benefit, and they don't see any relevance to their lives at all.

.... Because I am an Indian with a doctorate degree people respect me, are courteous and go out of their way to help me, but, when I say 'help me', I don't mean whole-hearted help, I mean help me by being courteous. People often help me so they don't appear rude. However, if I was a white researcher I doubt if I would get anywhere. In the white world, there's nothing wrong with going to a strange town or strange village and saying, "Hey, I have this survey, could you have a few people fill this out?" That's their culture, that's the way they do things. On Indian reservations, it's not like that and... that's part of the difficulty I'm having as an Indian researcher.

Conducting research on Indian reservations is far more expensive than non-Indian communities for the simple reason that people are reluctant to participate. In non-Indian communities, people seem more inclined to answer a survey or to sit down and give an interview. Indians just don't do that. When a grant is written to conduct research on a reservation there always should be funds in there to cover the salary of an individual on that reservation who will help out with the surveys and the interviews, identifying the buildings and resources that you would need on the reservation. You would also need funds for stipends and food... I know that most traditional researchers would not like that idea, but if you don't do that you're not going to get any data or you will get very little data and that would be basically worthless anyway.

Below is a chart that estimates the cost of the extra trip. I highly recommend dropping Fort Peck and Crow Agency from our list of reservations we plan to visit. Both reservations are several hundred miles away, which would make an extra trip to them prohibitively expensive. In addition, I have traveled across Fort Peck several times and the distance between villages is anywhere from 10 to 50 miles. Although, tribalism is almost dead, there may be some residual antagonism toward me as an older Dakota that would hamper my effectiveness doing research on a Crow reservation unless I had a Crow Tribal member as a guide.

How serious are we about getting good data? It may take a lot more time and money than most researchers are willing to commit. It is not just a matter of paying a person's salary to go to the reservation for one day. White Earth, like some other reservations, i.e. Fort Berthold, Fort Peck, has a few self-contained communities. This differs from my home reservation of Spirit Lake, where there is a recognized reservation center of Fort Totten and people are accustomed to coming there for their social services, college classes, etc. On White Earth and the others I mentioned, people expect to meet most of their needs right in their home communities so are much less inclined to travel to attend a workshop on IEPs or anything else.

In addition to the unforeseen obstacles mentioned above, the anticipated challenges continued in the second quarter. Participants have a negative emotional response to questions regarding their family member with a disability. The interviewers have been successful to date in maintaining sensitivity to these feelings, even if it means not asking follow-up questions in some cases. This quarter included interviews with younger parents and one interview conducted by a female interviewer. There was no detectable difference in the emotional tone of the interviews from the first quarter.

Given the sensitivity many Indian parents feel about the identification of their child as having a disability, Dr. Longie has experienced difficulty obtaining individuals for interviews. Even when parents have been identified or self-identified, getting the parent to agree to a scheduled date and time is a problem, for all of the reasons mentioned above. Once school begins, he will work with the Special Education Department directors at the schools both to identify parents for interviews and to schedule training sessions.

Political differences within reservations continue to be an issue, specific interviewers had to be selected because different communities within the same reservation do not get along. One positive development in the current quarter was the use of a “pow-wow person” to collect surveys at four pow-wows during the second and third quarters. A “pow-wow person” is simply someone who has regularly attended pow-wows in many states and reservations over the years and thus is well-connected with individuals from many different tribes. These individuals, in modern parlance, would be referred to as ‘connectors’, serving as a human connection among many different social groups

(Gladwell, 2000)³. Comparisons of the samples selected from pow-wows (N=40) with those sampled at home on the reservation revealed no significant difference in age, gender or presence or absence of a family member with a disability. An additional 100 surveys were collected at pow-wows during the first week of the third quarter.

A recommended revised schedule is shown in Table 4 on the follow page. Submitted by Dr. Longie, this schedule includes additional visits to all of the reservations originally proposed, with the exception of Crow, which is dropped, and Fort Peck, which is replaced with Pine Ridge. The reason for the substitution of Pine Ridge for Fort Peck is that the director of early childhood programs on that reservation became aware of our work by attending one of the public informational sessions offered. He is very interested in having IEP training delivered on his reservation and is willing to do much of the required advance preparation to secure local attendance.

³ Gladwell, M. (2000). The tipping point. New York: Little, Brown & Co.

Table 4: Proposed Schedule

Dates	From/To	30 IEP participants @ \$10	5 Interviews @ \$5	30 Surveys @ \$5	Total Cost
AT THE CONCLUSION OF 3 MONTHS OF ACTIVITY (MAY 1, 2007)					
	Spirit Lake	N/A	Not Complete	(Task Completed)	
	Turtle Mountain	N/A	(Task Completed)	(Task Completed)	
AT THE CONCLUSION OF 6 MONTHS OF ACTIVITY (AUGUST 1, 2007)					
6/18/07	***FT/White Earth (318mi x .44= \$139.92)	NA	NA	NA	
6/24/07	FT/White Earth	**	*	*	
7/10/07	***FT/ Sisseton	N/A	N/A	N/A	
7/17/07	FT/ Sisseton	**	*	*	
7/30/07	***FT/ Fort Berthold, FT/ Fort Berthold	NA	*	*	
AT THE CONCLUSION OF 9 MONTHS OF ACTIVITY (NOVEMBER 1, 2007)					
TBA	***FT/ Trenton				
TBA	FT/ Trenton	**	*	*	
TBA	FT/ Standing Rock	**	NA		
TBA	FT/ Pine Ridge	**			
TBA	FT/ Crow	Recommend dropping as research site due to unexpected expenses.			
At the conclusion of 12 months of activity (February 1, 2008)					

*We propose a multi-method study on five reservations within the Great Plains region – Sisseton, Trenton Indian Service Area, Fort Berthold, White Earth and Pine Ridge– encompassing six different tribes. A survey of use of information sources will be completed over a four-month period.

**Present the IEP module to 300 individuals at six reservations; Standing Rock, White Earth, Crow, Sisseton, Trenton Indian Service Area and Fort Peck – changed to delete Crow and Fort Peck and add Pine Ridge.

***Additional Trips

Conclusion

The data that is being collected is unique in many ways. We have been able to survey significant proportions of the population in communities on topics that have not been studied previously. Preliminary results seem to be dispelling some stereotypes about Native Americans and other results are leading to questions which seem likely to open fruitful areas of research. While dissemination through on-site presentations has not had the response expected, our presence on the web has attracted far more visits than originally anticipated. Our research process has evolved in these first two quarters to a model which appears likely to produce more and more effective research data and dissemination on the reservations targeted. As much as the data being collected and the results, it seems likely that an equally valuable outcome of the Disability Access RUSH project may be procedures for effectively disseminating and collecting research data on Indian reservations.

APPENDIX A

Summary of Documents Reviewed

Documents reviewed

Document/Author	Discussion of Disabilities
Tribal Council Candidate Campaign Statement	None
TM Student Support Services newsletter	October is Breast Cancer Awareness month. Other than that statement, nothing. ACT testing is announced but no mention is made of the possibility of testing accommodations. SSS services students who are at-risk, including those with disabilities.
TM Head Start Spring newsletter	In the 21-page newsletter that covers all centers, there were several recipes, poems and many reports on classroom activities. The only reference to disability was on a memo regarding enrollment. “Children who are disabled or who have special needs, and are three or four years of age by August 31,2007 , also may be eligible for Head Start.”
TM Elementary School Newsletter, TM Middle School Newsletter and TM High School Newsletter 5/8/07	None of these had any discussion of disability. There were several activities mentioned regarding drug and alcohol abuse, information given on drugs and alcohol in each newsletter.
Georgia State Rehabilitation Council 2005 Report	Very relevant information on examples of successful placement, percentage of individuals rehabilitated. Found at TM Vocational Rehabilitation Office available for reference
Accommodations for Students who are Deaf or Hard of Hearing	Very practical modifications for students. Found at TM Vocational Rehabilitation Office available for reference
Child Trends e-newsletter is emailed to all TMCC users. Author The Atlantic Philanthropies.	Three issues reviewed. First issue focused on substance abuse with no specific disability information. Second issue focused on depression and anxiety. The information presented was accurate on symptoms and recommendations (mainly refer to a professional). The third issue was on overweight, body image and eating disorders. Additional resources contacts are relevant. The test questions included, given our experience on the reservation probably would not be met with much cooperation. We included the latter two issues in our Virtual Library.
Making Life Better One Individual at a Time Consortium of Administrators of Native American Rehabilitation. Found in two tribal VR	A collection of ‘success stories’ in vocational rehabilitation. It does give good examples of what vocational rehabilitation can do, e.g., helping an individual with a business loan, helping a person get their drivers license back. It also gives examples of the diversity of people assisted by vocational rehabilitation, from those

<p>offices.</p>	<p>with substance abuse disorders to developmental disabilities.</p>
<p>Students with Disabilities: Transition from High School to College OK-Ahead 1999 Found in TM VR office. Office received in mail and kept as reference.</p>	<p>Students need to take responsibility for their disabilities when it comes “specific actions.” Misunderstandings and Differences between IDEA and Section 504 “How the post-secondary level institutional role changes” What Post secondary schools are not required to for students with disabilities. Helpful websites</p>
<p>Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities U.S. Department of Education Office received in mail and kept as reference.</p>	<p>Explains the rights and responsibilities of students with disabilities. Obligations of a postsecondary school to provide academic adjustments. Enforces 504, and Title II Creating an environment for success</p>
<p>Real Choices Systems Change Grants Final Report Turtle Mountain Band of Chippewa North Dakota Indian Affairs Commission Office received in mail and kept as reference.</p>	<p>Mentions lack of formal service delivery structure for elders and those with disabilities: <ul style="list-style-type: none"> - Community based/Long-term care - Long standing need for personal, social, & medical services - Inaccessible public transportation - Recommendations for service delivery Focus groups</p>
<p>Independence, Inc. A resource Center For Independent Living People’s Voice</p>	<p>Their mission statement is “To advocate for the freedom of choice for individuals with disabilities to live independently through the removal of all barriers” Articles focus on Disability Awareness and They also offer information on teens with disability as well as independent living and transportation needs.</p>
<p>Assistive Technology Key</p>	<p>A newsletter offering information on assistive technologies including equipment for those with illness related to aging as well as “Alternative Computer Input Devices,” recommended equipment and related upcoming events.</p>

<p>The National Newspaper of The National Spinal Cord Association: SCILife</p>	<p>This is a 20-page newspaper dedicated to creating awareness and bettering the quality of life for those with spinal injuries and other disease. It provides an array of articles on personal experiences, social opportunities, diversity in the workplace, and related advertisements.</p>
<p>Turtle Mountain Times Belcourt, N.D. June 25, 2007</p>	<p>This issue has two related articles:</p> <ol style="list-style-type: none"> 1. July designated as Seat Belt/Child Restraint Month 2. Prayer Ride/Walk Against Meth
<p>Turtle Mountain Times Belcourt, N.D. July 2, 2007</p>	<p>This issue includes:</p> <ol style="list-style-type: none"> 1. Davis Attends Tribal Summit: Owning Your Own Future (Willie Davis). 2. 13th Annual Turtle Mountain Wellness Conference 3. Grant helps develop Tribal Response Programs
<p>Input VR Received Regarding Transition Services Source: Statewide Needs Assessment-Educator & Family Feedback February 2006 State Plan Public Input Meetings April 2006</p>	<ul style="list-style-type: none"> • Responses to “What are the best school-to-work transition services for students with disabilities?” • Statewide Assessment needs
<p>People with Disabilities on Tribal Lands: Education, Health Care Vocational Rehabilitation, and Independent Living</p>	<p>This article contains information on proper practices concerning those with disabilities and the laws that govern U.S. citizens. It goes through the current state of the execution of laws for Native Americans and Native Americans with disabilities, identifying problems and offering possible recommendations.</p>
<p>North Dakota 2006 Interagency Transition Institute “Collaborating for Successful Youth”</p>	<p>Identifies problems with transition service requirements in local districts and postsecondary programs. Offers a plan of action that has already been implemented in various states.</p>

<p>Invitation to Participate: A Review of the School-to-Work Transitional Services Survey in the American Indian Vocational Rehabilitation Service Delivery Program</p>	<p>Survey to “evaluate the needs and availability of support and services for transitioning Indian youth within American Indian communities.”</p>
<p>Bridges Project Received by TMVR</p>	<p>A project created to offer those with disabilities more information on the transition to postsecondary schools in particular towards careers in science and technology. And the problems currently involved with high school students transitioning to postsecondary schools.</p>
<p>Options, Choices, Rights Resource Center for Independent Living Received by TMVR</p>	<p>Provides the latest news for individuals with disabilities who are living independently including information on legislation, recreational activities for children, a swap shop for Adaptive Equipment and related articles.</p>
<p>HEC Reading Horizons Discover intensive phonics for yourself Presented by Judy Wilkie TMCC</p>	<p>A reading program that emphasizes “intensive phonics” for all children, designed to teach them to read.</p>
<p>Family Ties: The North Dakota Family to Family Network Received by SLC, Spirit Lake VR and TMVR</p>	<p>This newsletter focuses on rural health. It contains articles on Genetic Counseling and updated information on IDEA, an ADA timeline, events focused on those with disabilities, and childcare resources.</p>