Health-Related Quality of Life for People Living With Paralysis on the Navajo Nation:

A Report to the Christopher and Dana Reeve Foundation Paralysis Resource Center

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About this Report

This report summarizes the conclusions from an eight-month project by Navajoland Nurses United for Research, Service and Education (N-NURSE) undertaken for the Christopher and Dana Reeve Foundation’s Paralysis Resource Center (PRC). The project was designed to assess the assets, needs and barriers to improving health-related quality of life for people with paralysis on the Navajo Nation from the perspective of community-based direct service providers and make recommendations for future action. The project is an outgrowth of four recommendations made by the Minority and Multicultural Outreach Workgroup of the PRC’s Paralysis Task Force to strengthen the multicultural outreach program of the PRC. Those recommendations were:

- Engage with communities to help design effective strategies within the PRC for outreach to minority communities;
- Identify groups within among targeted minority communities such as lay health workers and spiritual leaders to effectively approach;
- Support peer networking and mentoring to identify leaders in the disability community within targeted minority communities; and
- Identify and establish links with existing groups within minority communities to facilitate PRC dissemination activities.

Through its multi-year cooperative agreement with the Center for Development and Disability at the University of New Mexico, the PRC engaged in a cooperative agreement with Navajoland Nurses United for Research, Service and Education (N-NURSE) to complete this report.

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Introduction

The goals of this project for the Christopher and Dana Reeve Foundation’s Paralysis Resource Center (PRC) were to:

- assess the accessibility and cultural appropriateness of PRC outreach strategies and materials and make recommendations for future PRC actions in this area;

- Acquaint the PRC with the assets, needs and barriers to health-related quality of life for people with paralysis on the Navajo Nation from the perspective of community-based direct service providers and make recommendations for future action by the PRC in this area; and

- Increase awareness among Community Health Representatives (CHR) affiliated with Chapter Houses on the Navajo Nation about access to, contents and use of PRC resources and quality of life grant process.

To accomplish these goals, N-NURSE organized and facilitated six one-day exchange and capacity-building meetings across the Navajo Nation in the second half of 2008. A diverse set of stakeholders were invited, including:

- Navajo Nation Community Health Representatives (CHR's); Navajo Division of Health community based staff, who carry caseloads in Chapter-based communities and provide direct in-home care support, coordinate and advocate for health needs of their clients with disabilities and health-related issues;

- People who are paralyzed, including CHR clients; and

- Caretakers and family members.

The twin goals of the meetings were to inform participants about the resources that the PRC has available, including grants to non-profit organizations through the Quality of Life Grant Program and to hear from participants how the PRC can better reach people and provide more effective services on the Navajo Nation.

These information exchange and capacity-building meetings were scheduled in Chinle, Fort Defiance, Gallup, Crownpoint, Shiprock and Tuba City. The meetings used a combination of oral and visual presentations using Power Point to inform participants of the availability of PRC services, and traditional “talking circles” to gather the views and opinions of participants on issues raised by the PRC.

Over one hundred people attended one of the information exchange meetings. An agenda for the meetings can be found in Appendix A, and a summary of evaluation findings can be found in Appendix B. At the end of the project, N-NURSE, the PRC and the CDD sponsored a mutton fest in Chinle, Arizona to thank participants from the six meetings.

Status of People with Disability and Paralysis on The Navajo Nation

The Navajo Nation, established in 1868 as a sovereign nation, is located in three states - Arizona, New Mexico, and Utah - and is the largest reservation in the United States, covering 27,673
square miles or 17.5 million acres. The Nation is larger than ten of the fifty states.

Over 180,000 inhabitants live on the Navajo Nation. Traditional Navajo people maintain an ancient and vibrant culture based on a matriarchal clan system of kinship. Unlike the Native Americans of the southwest pueblos who live in towns, Navajo people traditionally live dispersed in small family groupings in more rural settings. The Navajo Nation capital is Window Rock, Arizona. The nation is organized into one hundred ten chapters, most analogous to local governments.

The prevalence of paralysis, spinal cord injury and other physical disabilities on the Navajo Nation, as well as other Native American tribal lands, is difficult to estimate. However, a review of available literature on the topic reveals a general consensus that the prevalence of disability, including paralysis and spinal cord injury, is higher among Native Americans than the general population.

- The Executive Director of the only independent living center located on the Navajo Nation estimated in 2005 that approximately 10% of Navajo Nation members have some sort of physical disability.¹

- A 2007 survey of clients by the Native American Disability Law Center found that among respondents (88% of whom were Navajo) 33% reported some form of physical disability.²

- The U.S Census Bureau reported that in 2005, approximately 20.4% of people between the ages of 21 and 64 living on the Navajo Nation had some form of physical or cognitive disability, and that 66% of people over the age of 65 living on the Navajo Nation had some form of physical disability.³

- A 1992 survey of independent living centers (ILCs) to identify the services available to Native Americans residing on reservations reported that the most frequently observed disabilities were spinal cord injury, diabetes, blindness, mobility disability, traumatic brain injury, deafness, hardness of hearing, orthopedic conditions, and arthralgia.⁴

- Finally, a 2008 national random-dial population survey of over 33,000 United States households found an overall prevalence rate for paralysis of 3.7% and a prevalence rate for spinal cord injury of 7.3% among Native Americans.

³ http://factfinder.census.gov/servlet/GCTTable?geo_id=01000US&mt_name=ACS_2005_EST_G00_GCT1803_US34&ds_name=ACS_2005_EST_G00
⁴ Clay J, A Profile of Independent Living Services for American Indians with Disabilities Living on Reservations, University of Montana Rural Institute, Missoula, MT, 1992.
The large land area and rural nature of the Navajo Nation are two factors that make providing services to people with physical disabilities, including paralysis, difficult. A third factor is that the Navajo Nation faces significant economic challenges. Per capita income is significantly lower than the United States average and the percentage of Navajo families living under the U.S. poverty level is significantly higher (see Table One).

Table One  
Key Economic Indicators for the Navajo Nation And The United States

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Navajo Nation</th>
<th>United States Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Household Size</td>
<td>3.77</td>
<td>2.59</td>
</tr>
<tr>
<td>Average Family Size</td>
<td>4.36</td>
<td>3.14</td>
</tr>
<tr>
<td>Per Capita Income</td>
<td>$7,269</td>
<td>$30,821</td>
</tr>
<tr>
<td>Median Household Income</td>
<td>$20,005</td>
<td>$44,473</td>
</tr>
<tr>
<td>Median Family Income</td>
<td>$22,392</td>
<td>$43,200</td>
</tr>
<tr>
<td>% Individuals Below Poverty Level</td>
<td>42.9%</td>
<td>12.3%</td>
</tr>
<tr>
<td>% Families Below Poverty Level</td>
<td>40.1%</td>
<td>16.7%</td>
</tr>
<tr>
<td>% Families with Female Householder Below Poverty Level</td>
<td>53.1%</td>
<td>30.4%</td>
</tr>
<tr>
<td>Telephone Service</td>
<td>60.1%</td>
<td>2.4%</td>
</tr>
<tr>
<td>Housing Units Lacking Complete Plumbing Facilities</td>
<td>31.9%</td>
<td>1%</td>
</tr>
<tr>
<td>Housing Units Lacking Complete Kitchen Facilities</td>
<td>28.1%</td>
<td>1%</td>
</tr>
<tr>
<td>Percentage of Occupied Housing Units</td>
<td>69.3%</td>
<td>91.0%</td>
</tr>
</tbody>
</table>


Challenges Faced by People who are Paralyzed on the Navajo Nation: Learning From the Information Exchange Meetings

The information exchange and capacity-building meetings facilitated by N-NURSE revealed that participants had a number of critical challenges. Many of these challenges are not unique to the Navajo Nation. What makes them especially problematic is that these challenges, any one of which can be a significant barrier to improving the quality of life of a person who is paralyzed, are often experienced together for people we spoke with. 

The information exchange meetings identified nine challenges.

- **Complexity of Multiple Health and Social Service Systems**

The complexity of four different long-term care and social service systems (Arizona, New Mexico, Utah and the Navajo Nation) in combination with the Indian Health Service system makes it difficult to coordinate available services. Each system has substantial bureaucratic barriers and vies to be the "payer of last resort." While Chapter houses purportedly maintain funds for home accommodations if people have been unable to get them from state government systems, many participants at the meetings related stories of clients on waiting lists for home accommodations for years.

The Indian Health Service (IHS) provides contracted acute care and rehabilitation services to community members who
suffer an acute event that resulting in paralysis. The Community Health Representatives who work with the Public Health Nurses on the Nation are a significant asset to Navajos who are paralyzed. These programs insure that community members are visited, assessed and supported.

- **Difficulty in Acquiring Essential Home Modifications**

  As a sovereign nation, the Navajo Nation is exempt from the provisions of the Americans with Disabilities Act. Attaining timely essential home modifications to support people who wish to reside in their communities is a major challenge.

  The Navajo community members expressed preference for maintaining family members who are paralyzed or who have other disabilities at home. Ramps and essential bathroom modifications, however, have proven very difficult to obtain. CHR’s reported delays of three to eight years to obtain basic home modifications for those who received them.

  One result of this has been the transfer of people with paralysis into group living situations in border towns (communities bordering the nation itself such as Gallup, New Mexico) or more distant urban centers. The difficulty in obtaining home modifications not only increases difficulty in mobility, but contributes to separating a disabled person from their family, increasing social isolation and reducing access to important health and therapy services.

- **Difficulty in Providing Grassroot, Community Supports**

  The rural and less modern attributes of the Navajo Nation challenge efforts at connection and socialization by grassroots community-based organizations. Unpaved roads and long distances between remote family settlements is the common. One of the only such groups on the Navajo Nation, the Kayenta Disability Support Coalition, is an example of the critical role these organizations can play. The Kayenta Group received seed funding from the Reeve Foundation Quality of Life grant program some years ago to support social, advocacy and recreational activities, including wheelchair basketball. The Kayenta Group received seed funding from the Reeve Foundation Quality of Life grant program some years ago to support social, advocacy and recreational activities, including wheelchair basketball. & The picture on this page was taken at a Mutton fest held by the Coalition in July, 2008 which members of the project team attended as guests of the Coalition. A more formal discussion of the development and impact of the Coalition can be found in Ellen Lerner Rothman, *A Community-Based intervention to Improve the Quality of Life of Navajo Patients Living with Spinal Cord Injuries in Indian Country*. The HIS Primary Care Provider, volume 29, number 12, December, 2004.

- **Difficulty in Maintaining and Repairing Essential Durable Medical Equipment**

  Groups such as the Kayenta Coalition can play a critical role in improving the socio-emotional quality of life for people who are paralyzed on the Navajo Nation, as well as their families and caregivers.
Many CHR's and clients alike reported difficulty finding services for maintaining and making small repairs to equipment, particularly wheelchairs. Many who attended the meetings remembered a travelling wheelchair clinic that stopped operating sometime in the past. The Indian Health Service provides a new wheelchair only every five years to eligible clients.

- **Transportation**

Transportation services are provided only for medical appointments, and are difficult to arrange as travelling to a medical facility may entail a round trip of hundreds of miles. CHR's are not legally permitted to transport clients in government vehicles. Inadequate transportation access, including reimbursement for mileage costs for private vehicles, prevents people who are paralyzed from participating in community gatherings and events, including important spiritual ceremonies, recreation and social activities.

- **Counseling and Support Services For People who are Paralyzed, Family Members and Caregivers**

Counseling, group support of other forms of mental health maintenance and assistance in meeting the challenging circumstances of living with paralysis are difficult to obtain in Navajo communities, and are exacerbated by many other factors, including distance and economic factors.

- **Accessible Recreation Facilities With Trained Staff**

Facilities to support remaining physically active and fit are limited. Once physical therapy goals for newly-paralyzed individuals are developed, very few opportunities exist to carry through for maintenance, and too few staff of the facilities that exist are adequately trained to assist people in wheelchairs.

One example given was a pool facility in Gallup which has a Hoyer lift, but has no staff trained to use it.

- **Planning for Reintegration into the Community**

People who are paralyzed who need acute inpatient rehabilitation services must travel either to Denver or Phoenix, 357 and 231 miles respectively from the Navajo capital, Window Rock. These distances not only prevent regular visits by family members, but are a barrier for people who are paralyzed to make plans for reintegration into their communities.

This includes pro-active planning for home modifications and other necessary supports.

- **Training and Resources for Caregivers**

Knowledge of where to access optimal care giving techniques and resources is frequently unavailable to caregivers, many of whom are family members of the individual who is paralyzed when they are living in the community.

**Recommendations to the Paralysis Resource Center**

**Introduction**

In considering next steps for action by the PRC to assist with these challenges for people who are paralyzed on the Navajo Nation, it is difficult to prioritize given the scope of both the need and the challenges themselves. N-NURSE has chosen to focus on recommendations based on a hierarchy of needs addressing the most fundamental challenges which offer the greatest potential for impact.
N-NURSE recommends that next steps focus on building capacity within the community to meet these needs. The project should include some combination of multiple low-cost initiatives described below that together focus on building the capacity of the Navajo Nation to respond to the needs and improve the quality of life of people who are paralyzed and assist their family members, caregivers, and health professionals.

Recommendations are divided into two categories. Three recommendations are targeted at mitigating health-related barriers to quality of life for people who are paralyzed on the Navajo Nation. Five additional recommendations are targeted at revisions and additions to PRC outreach strategies and activities. These recommendations are designed to improve and increase access to PRC services by people who are paralyzed, family members and caregivers and health professionals on the Navajo Nation.

**Recommendations Related to Addressing Health-Related Quality of Life for People with Paralysis on the Navajo Nation**

- **Recommendation One: Fund a Feasibility and Pilot Project Leading to Partnerships for Sustainable Programs to Increase the Capacity Within the Navajo Nation to Make Essential Home Modifications.**

  As discussed above, a major concern of participants at the Information Exchange meetings were the extraordinary waiting periods faced by people who are paralyzed for home modifications needed to maintain a high quality of life in their homes, and thus in their communities. Most-frequently mentioned was a lack of suitable ramps which would allow a person access to their homes without assistance.

  While it is clear that the timely availability of these services is a barrier, less clear are the reasons for the unavailability of these services. A feasibility study that identifies these barriers and recommends ways to overcome them can lead in turn to designing a program to produce low-cost modifications, including ramps, on the Navajo Nation.

  The feasibility study should include (a) examination of benefits during the rehabilitation discharge process; (b) potential ways to develop local capacity to produce ramps at a reasonable cost within the Navajo Nation (e.g., community college or vocational school construction education programs); (c) production of a “how-to” manual with specifications for building low-cost ADA-compliant ramps; and (d) ways to secure funding to sustain the program over time.

- **Recommendation Two: Initiate a “Mobile Wheelchair Servicing, Assessment and Repair” Program.**

  Both manual and power wheelchairs are a necessity for many people with moderate to severe paralysis, including spinal cord injury, on the Navajo Nation. Given the rural nature of the Nation, the lack of paved walkways, sidewalks and roads and the long distances people must travel for services, wheelchair life is shorter than in many other areas and obtaining adequate maintenance at a reasonable cost is difficult or impossible. New wheelchairs are provided to clients of the IHS or Veteran’s Administration every three or five years – too long for many wheelchairs to operate in the physical environment of the Navajo Nation.

  One suggestion made at many of the Information and Exchange meetings was to utilize a “circuit rider” concept based on the nineteen century model of judges who travelled to cit-
ies to hold court for a wheelchair serving, assessment and repair program. The program would require an enclosed trailer outfitted with common parts for wheelchairs and trained community members who could perform basic repairs (including replacement of tires) and maintenance on wheelchairs.

The mobile wheelchair clinic would move between chapter houses on a published schedule. Services would be provided either free of charge or a minimal cost. Initial funding could be provided by the PRC, but early discussions should be held with the Navajo Nation Government, tribal disability organizations and related organizations such as independent living centers concerning ways to sustain and sponsor the program over time.

- **Recommendation Three: Build Community Capacity to Provide Social, Psychological and Spiritual Support to People who are Paralyzed By Developing Community Support Groups Across the Navajo Nation.**

Medically-based mental and emotional health services on the Navajo Nation are limited to meet the needs of people who are paralyzed, their families and caregivers. The community’s strengths are a commitment to traditional culture and a desire to build upon Navajo ways of addressing community challenges.

Grassroots, community-based organizations such as the Kayenta Disability Support Coalition exist and play a critical role in addressing the socio-emotional health and reducing the social isolation of people who are paralyzed. However, groups such as the Coalition are far too few in number and almost always have insufficient resources to carry out their own activities, not to mention assisting in the development of additional groups.

However, the need for additional grassroots, community-based support groups is pressing. The PRC should provide resources for a project that allows existing successful support groups to reach out to other communities and provide assistance, support and knowledge to establish and nurture additional support groups.

Supporting the development of new groups would provide a starting place for communities to build social capital for advocacy and sustainable community-building programs. Funds for transportation support (e.g., gas cards) to travel to other communities and for people who are paralyzed to attend events by new support groups would need to be a part of the effort given the profoundly rural setting of life on the Navajo Nation.

**Recommendations Related to PRC Outreach Strategies and Materials**

- **Recommendation Four: Sustained Follow-Up Contact With Community Health Representatives (CHRs) and Other “Intermediaries” On and Near the Navajo Nation.**

Community Health Representatives and other health care professionals on the Navajo Nation are a potentially invaluable resource for the PRC in its efforts to increase use of PRC resources. They are “intermediaries” who over years, see many people who are paralyzed, family members or caregivers.

While the information exchange meetings achieved their goal of providing CHRs with initial information about the PRC and the Quality of Life grants program, one contact is not enough. Many of the comments made on evaluation forms (see Ap-
Appendix B) dealt with institutionalizing these sessions on a long-term basis and/or expanding them to include new audiences.

The PRC should develop and maintain a long-term, systematic effort to maintain contact with CHRs. This campaign should include such things as regular contact by mail (e.g., new resources available) and presentations at future gatherings of CHRs and related organizations on the Navajo Nation.

**Recommendation Five: Disseminate Information Throughout the Navajo Nation About the Availability of Navajo Translation Services and Monitor Evaluation Services on a Regular Basis.**

Participants at the information exchange meetings were surprised to learn that translation into Navajo is available when calling the PRC hotline. This is very important because 80% of households speak Navajo in the home, a proportion that is increasing.

While most Navajo speak English, they are more comfortable speaking their native language when asking questions and expressing needs. Availability of individuals to talk to people in their communities by phone was seen as a major strength. Translation services should be monitored and evaluated on a regular basis to ensure that the quality of the translation remains high.

**Recommendation Six: Develop Alternatives to Use of the Web as a Major Information Dissemination Strategy on the Navajo Nation.**

While the PRC uses its well-developed and regularly revised web site as a primary tool for dissemination, this environment is not ideally suited to the Navajo Nation. Few citizens of the Nation, particularly those outside population centers, have high-speed internet access. At one time each Chapter House had internet access, usually with one computer available for citizen and government workers alike. At the present time, this is no longer true.

For these reasons, many Navajo citizens do not have the skills or the familiarity to use the web as an information-gathering tool. Alternatives to the dissemination of information should be developed, including short information briefs translated into Navajo, DVD-based videos and other means that incorporate visual media. Navajo culture is primarily oral and visual, and film and story formats will make the information most accessible.

**Recommendation Seven: Develop Alternatives to Web-Based Application for Quality of Life Grants.**

The web-based grant application process for Quality of Life grants is well-done and streamlined for people accustomed to web-based “fields.” For the same reasons discussed above, the web-based application format for Quality of Life applications is a barrier to organizations on the Nation applying for grants. In the same manner, budget categories are likely to be unfamiliar to staff of community-based organizations on the Nation.

The PRC should develop and offer on a regular basis technical support workshops for individuals and groups on and near the Nation on the application process, including offering a local individual who will support the completion and submission process. This individual should also be empowered to use the web-based application on behalf of the community-based organization.

**Recommendation Eight: Develop Alternative Formats and Content for key Elements of the Paralysis Resource Guide (PRG).**
The Paralysis Resource Guide is a very practical compilation. However, the format of the book and the amount of text can be a barrier for people where English is a second language— with an oral and visual, not a written, tradition. English is a second language for 80% of the population of the Nation, and it has been designated a limited-English proficient area by the United States Census Bureau. Further, randomly-selected paragraphs from the PRG (not taken from the research or conditions section) have a reading level between 8.8 and 10.2 grade-level.

The PRC should consider a variety of format modifications for the PRG. These modifications could potentially serve many population-based groups whose members prefer to get their information from non-text sources and/or have lower literacy levels.

These modifications could include (a) selecting key content areas from the PRC and recasting them in accessible plain English with extensive use of photographs and (b) creating DVD-based formats for selected portions of the PRG that use extensive video and individuals speaking.
TOWN HALL MEETING FOR CHRISTOPHER AND DANA REEVE FOUNDATION PROJECT

Location: [Location]

Purposes:

To hear from you about how you meet the challenges to maintain quality of life with paralysis and to learn what are particular issues within your reservation lifestyle and culture.

To share information about accessing the small grants program and resource center of the CDRF and receive community input on ways to improve access to these resources.

8:30 am  Coffee
9:00  Introductions
9:30  The Resource Center: What is it and how do families use it?
10:30  Morning Break
10:45  Talking Circle: living with paralysis in your community and ideas about the Resource Center.
12:00  Lunch
1:00 pm  The CDRF Quality of Life small grants program: Who can apply, how and when; Getting technical assistance to turn your idea into a small grant.
2:00  Talking Circle: Making connections for opportunities and feedback to the CDRF
3:00 pm  End of Meeting: Travel safely

Appendix B: Summary Of Evaluations
Christopher and Dana Reeve Paralysis Resource Center  
Information Exchange and Capacity Building Meetings  
Evaluation Summary

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>A Little</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you learn things about the Resource Center you did not know before?</td>
<td>56 (100%)</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think you could access the resource center for yourself or a client now?</td>
<td>51 (89%)</td>
<td>1 (.02%)</td>
<td>5 (10.8%)</td>
</tr>
<tr>
<td>Did you get information about the small grants program that may be helpful to you and your community?</td>
<td>54 (98%)</td>
<td>0</td>
<td>1 (2%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Completely</th>
<th>A Little</th>
<th>Not at All</th>
</tr>
</thead>
<tbody>
<tr>
<td>How confident are you that you could organize and write a small grant to the Christopher and Dana Reeve Foundation?</td>
<td>19 (35%)</td>
<td>33 (61%)</td>
<td>2 (4%)</td>
</tr>
</tbody>
</table>
If offered, would technical assistance for grant organizing and writing be helpful?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>51 (100%)</td>
<td>0</td>
</tr>
</tbody>
</table>

### Responses To Open-Ended Questions

The Christopher and Dana Reeves Resource Center would like to learn from our gatherings ways to better respond to information needs of rural and reservation-based Indian communities.

1. What suggestions do you have for us to improve further gatherings?
• Have this gathering every year in our area
• Need more time
• Doing a great job!
• Invite others or more people with disabilities to these sessions.
• Went too fast, confusing for me…laughter was good for me.
• How to get transportation for disabled people.
• More time to digest information
• Provide inservices
• Outreach to local chapter meeting
• Keep up good work, great jobs, etc.
• Would your foundation and staff be part of CHR 40th anniversary conference in October 2008 to host one day.
• Continue to give up updated info; include caregivers by giving emotional support
• Need more education on resources and grants
• We need to get together more often to talk more on this; one day is not enough
• Presentation should be brought to the Council Delegates
• Find more money to help our handicap patients
• Assist with more information
• I hope we get a grant.
• Assist with application
• Thank you for bringing the information and bringing it back yearly to see how everyone does. One meeting a year & PSA
• I would be interested in having this same gathering within our local chapter area and provide adequate interpretation to make people understand what the program can do for them.
• Recommend to program that we need a one day workshop with professional assistance to write the grants
• It would be nice to have a DVD on the program presented. It was great and very informative and especially good for us CHRs.
• Presentation to the chapter officials also because of who can apply for the grant. It was mentioned at the chapter house level. Other than that….thank you for the food and plenty of information.
• Grant writing in class
• Repeat session to get info to other hospital disciplines (social service, case managers, PHNs, Health education)
• Keep up the excellent work and continue to inform the public on PRC. Hands on or visual presentation are always beneficial especially for our population.
• Doing a great job
• Have another paralysis info session next year.
• More examples on types of grants, approve and costs
• Sample booklet of type of cost.
• To bring individuals that have paralysis, we need to have input from them, because they are the one’s living this kind of life.
• Go to chapter officials or council delegate
• Thanks for free access to material on the web site.

2. What suggestions do you have that could make their resources and grant process more easily accessible or more useable to you and your community?

• Invite more to attend the meeting: Chapter, NAAA, Sr. Center, other departments so they can take part on this
• Get more organizations/programs involved
• Have access to internet in remote areas to utilize the resource center. We don’t always have access.
• Have someone on location for awhile instead of one day.
• People waiting on their list... (cannot decipher writing).
• Have hands-on training with your staff on spinal cord injuries
• Need a good grant writer
• Training for I.H.S or clinics or by Public health nurse
• Make presentations at reservation chapters
• We need assist with grants writing
• Help us out with grants writing
• Form a support group and have more meetings.
• Come out more often, you have very good and useful information
• Send or email us information—news letters—what you have to offer.
• The CHR program needs workshops in each service units
• Public campaign-PSAs
• Have a grant writing workshop for the language & computer usage
• Need to go to other resources and make it available to everyone
• Easily accessibility for ramp or bathroom entrance or main entrance into home.
• Knowing that we live in remote area, distance of travel to available resources is hard. No proper resource in local chapter
• Parking area with community mtg places-etc…senior center, chapter mtg
• Ramp for home
• More comfortable transportation services for client’s in W.C.
• Bathroom modification for client
• Share information with community
• People need to identify the needs beforehand…than request the grant
• Need more posters, newsletters, flyers
• Go to chapter official
• Make available a catalog of what equipment is available for the client
• Social marketing needs to be capitalized and strengthened
• Put the PRC on Navajo Nation web page and perhaps NAIHS web page.
• Repeat the sessions for those who were unable to attend this session.
Appendix C: About N-NURSE
Navajo nurse leaders and faculty and staff from University of New Mexico College of Nursing have worked together since 1996 to implement a variety of projects that affect nursing. Throughout these endeavors the importance of collaboration and partnership to bring these projects to fruition has been greatly appreciated. Following is a short history of how N-NURSE, Inc. came to be and how nurturing collaborations and partnerships help model success.

### Interest and Needs Survey

In 1994, The Robert Wood Johnson Foundation launched the Partnerships for Training initiative to address the pressing national need for practitioners in rural and underserved areas. It was envisioned that Partnerships for Training would increase the number of mid-level primary health care providers living and practicing in such areas by recruiting its students from those communities. The “grow your own” hypothesis proved itself successful in many rural and inner city regions of the eight nationwide projects.

The University of New Mexico Partnerships for Training (PFT) project was successful in recruiting students for this community based educational opportunity in eastern and northern New Mexico and graduated 3 cohorts of students from 2000 to 2002 but was unable to recruit
students from western New Mexico and eastern Arizona. This region, with its unique historical, cultural, and socioeconomic circumstances, posed barriers that were not fully understood during the recruitment phase of PFT in the area. PFT project faculty and staff anticipated these barriers prevented health workers from participating in education projects successful in other areas. From this premise a survey of interests and needs for health career development was developed and implemented in 2002-2003 by PFT Principal Investigator Barbara Overman and Co-Investigator Linda Petri at 10 health facilities in the Navajo Nation to better understand factors that impact development of health careers for health workers in New Mexico and Arizona Indian Country.

This study was unique in that is sought to directly assess the interests, dreams, experiences, and barriers of local health-care workers related to health career advancement. The majority of participants were American Indians who intended to stay in their communities. The survey gave voice to a tremendous human resource potential for advancement of human health in this area with significant health needs.

### Mentorship Project

The Mentorship for Nursing Careers in the Navajo Nation Project emerged from findings of the health worker survey conducted 2002-2003. The project is collaboration between American Indian nurse leaders in the Navajo area and University of New Mexico College of Nursing faculty and staff. The Mentorship Project was funded by the William Randolph Hearst Foundations for 2 funding periods from January 2004 through March 2006.

The project's objectives:

1. Create a Navajo Nursing Consortium for Higher Education. Progress: The Consortium was formed and is a collective of accomplished and successful Navajo-area American Indian nursing professionals dedicated to increasing the number of Navajo persons entering the nursing profession and advancing to higher levels of responsibility and leadership in clinical and academic settings.

2. To develop a “network” of nurse mentors across the Navajo Nation. This was accomplished through the development of The Navajo Nurse Mentorship Pathway curriculum; a culturally appropriate mentorship training, and providing Mentorship Workshops throughout the region. The purpose of the mentorship network:
   - To promote understanding of nursing in culturally appropriate contexts
   - To increase knowledge of younger people about the nursing field,
   - To mentor pre-nursing workers to continue their goal to be a nurse,
   - To help nurses at any level into advancing their role and
   - To develop a cadre of nurses prepared to move into teaching and advanced nursing roles in the Navajo Nation.

   Progress: Eight Mentorship Workshops were held across the Navajo Nation and approximately 112 mentors were trained using the Navajo Nurse Mentorship Pathway.
3. To provide community based mentors access to more accurate regional education resource information for nursing as a career through the development of a nursing resource web site and resource manuals given to all participants during workshop training sessions. The resource web site is now part of the N-NURSE, Inc. web site. *Progress:* Manuals distributed to all attending workshops and N-NURSE, Inc. web site is on the internet at http://www.n-nurse.org.

4. The Navajo Nurse Mentorship Pathway is an exemplar for other American Indian groups in their development of mentorship models and is currently available to share beyond the Navajo area. *Progress:* Trainings in Tuscon (July 2005) and Phoenix (January 2006) for regional and national IHS nursing leaders.

The Navajo Nursing Consortium members created the existence of a sustainable organization to continue work began in the mentorship project. Navajoland Nurses United for Research, Service and Education, Inc. (N-NURSE) is that organization.

**N-NURSE, Inc.**

The N-NURSE organization emerged from the Consortium for Higher Education. The members of the consortium determined that a voice for nursing on the Navajo Nation that crossed boundaries of institution and health delivery systems was to continue after the Mentorship Project's funding came to an end. A strategic planning session was conducted spring 2005; the organization was born and incorporated June 5, 2005 by the Navajo Nation Business Regulatory Agency. N-NURSE was granted tax exempt status under section 501 (c) (3) of the Internal Revenue Code on May 17, 2007.

The First N-NURSE Annual Symposium for Navajo Health was held October 20-21, 2006. Each subsequent event continues with collaboration and partnerships that have sustained the health worker survey, the development of the mentorship project and now the development of a “voice” for nursing on the Navajo Nation.

**N-NURSE Board of Directors**

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