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Gathering to Listen

Thursday, March 17, 2011
5:30pm – 8:00pm
Farmington, NM

Friday, March 18, 2011
3:00pm – 5:30pm
Gallup, NM

A gathering to listen to your views, opinions, and experiences on finding health information and services.

Agenda

Welcome

Introductions

Listening and Discussion

- Finding health information
- Finding health services
- Reflect on past experiences

Adjourn

Contact information

Joyce Hooker
Project Manager, MSGRCC
Phone: 303-978-0125
Email:
jhooker@msgrcc.org

Liza Creel, MPH
Project Coordinator,
MSGRCC
Phone: 512-279-3906
Email: lcreel@msgrcc.org

Leslie Burkholder, MNM
Director, Idea Infusion
Consulting
Phone: 303-918-7700
Email:
ideainfusion@earthlink.net



Mountain States Genetics Regional Collaborative Center
8501 N. MoPac Expressway, #300, Austin, Texas 78759
512-279-3906, www.MountainStatesGenetics.org



Summary Report

of

Gatherings to Listen

Dialogues with Native American Parents of and Advocates for
Children with Special Healthcare Needs

Facilitated and Summarized by
Leslie Burkholder, MNM
Idea Infusion Consulting
Denver, Colorado

1 May 2012

Summary Report of *Gatherings to Listen*

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Executive Summary

In the spring of 2011, representatives of the Mountain States Genetics Regional Collaborative Center (MSGRCC) traveled to the Navajo Nation within northwestern New Mexico, to host and participate in two gatherings to discuss and share experiences of parents and advocates of children with special healthcare needs. The endeavor was a follow-up to a 2009 meeting held, in part, to address past misunderstandings with regard to genetic services. MSGRCC representatives at the 2011 gatherings arrived with the mandate to simply listen to local parents and advocates. The topics that arose during the meetings covered a variety of subjects that included the promise and problems of healthcare services in the region, as well as participants' hopes for the future of healthcare services for their children with special healthcare needs.

Talking points from the participants' responses during the meetings often centered on four main themes: 1) the vast distances many of the parents had to travel for health services for their children; 2) the challenges that arise in communication (some parents were labeled as "aggressive" or "difficult" by service providers); 3) the varying levels of cultural competence of service providers; and 4) descriptions of the limited connection these parents have to groups and/or providers outside their community. MSGRCC representatives were given a privileged and candid view into the world of a Native American community that encompasses ancient culture, individuality, and contemporary life on the reservation as it includes the element of caring for children with special healthcare needs.

As a result of this relationship-building project, MSGRCC created a platform for future communication and opened the door for similar future gatherings to continue to listen throughout the mountain states region and beyond.

Introduction

In March 2011, the Mountain States Genetics Regional Collaborative Center (MSGRCC) hosted two *Gatherings to Listen* with parents of and advocates for children with special healthcare needs within the Navajo nation—specifically, those living in the northwest region of New Mexico. This venture came about as a result of nurturing relationships over time between MSGRCC staff, project personnel, and local stakeholders; as well as the invaluable coordination support from parents within each community that hosted a meeting. The inspiration for these gatherings arose at the close of a community forum hosted by MSGRCC in 2009—specifically, from suggestions and requests voiced by parents in the region who have children with special healthcare needs. This report provides a summary of the *Gatherings to Listen* and includes the rationale and steps taken to gather the organizers and participants together, the intentional distinctions between traditional focus groups and these gatherings, along with recommendations for action the MSGRCC can take in response to the experiences, information, and requests shared by the participants.

Background and Rationale

On April 3, 2009, the MSGRCC hosted the first Community Conversation on Genetics with the Navajo People at Diné College in Shiprock, New Mexico. The meeting was planned and organized by Murray Brilliant, PhD, at the time a Professor of Pediatrics and Molecular & Cellular Biology with the University of Arizona, and featured presentations and discussions on genetics, newborn screening, genetics and the health of the Navajo People. Dr. Brilliant's work with MSGRCC began in 2004 through a small grant project, and it continued with additional funding through 2009. A consistent goal throughout his relationship with MSGRCC was to create a forum through which service providers and healthcare consumers (and their advocates) could come together in dialogue—the Community Conversation was a first step. There were more than 100 people in attendance at the Shiprock event in April 2009, including:

- Navajo community members
- Representatives from regional academic institutions
- Community-based organizations and programs
- Students of Diné College
- Members of the Navajo Institutional Review Board
- Representatives from the Indian Health Service (IHS)

In addition, representatives and guests of MSGRCC included: Michelle Lloyd-Puryear, MD, at the time the Chief of HRSA Genetic Services Branch; Gloria Wiseman, NCC Evaluation Consultant; Celia Kaye, MD, MSGRCC Project Director; Joyce Hooker, MSGRCC Director of Regional Outreach; and Liza Creel, MPH, MSGRCC Project Manager.

Although service providers were the primary audience for the Community Conversation forum, parents and advocates of children with special healthcare needs were also in attendance. At the close of the event, numerous parents and advocates approached the MSGRCC Project Manager with additional questions and comments. Some comments included that they had learned much during the conversation and that they were eager to know more, as well as continue exploring information to benefit their children's health. It was from these informal conversations that the idea began and grew to host gatherings in the region and provide a forum where MSGRCC representatives could continue to *listen* to parents of and advocates for children with special healthcare needs. The resulting gatherings originated from these initial conversations and through a tremendous amount of time and organizational effort by Yolanda Sandoval, who is Navajo, and Trish Thomas, who is Laguna Pueblo—both of whom were instrumental in making connections with other parents in the region and coordinating the gatherings.

Once it was determined that additional gatherings of parents and advocates within the region were a realistic possibility, MSGRCC was faced with the decision of how to approach and implement such gatherings. MSGRCC staff recognized early on that a balance needed to exist between collecting information, such as within a traditional focus group, and simply being present and listening to the stories and experiences of those in attendance.

After setting a goal for approaching the gatherings with open awareness and receptivity, the MSGRCC organizers took on a deliberate and thoughtful approach to structuring the gatherings. For example, the language that was used to describe aspects of this effort such as “genetic disorders” and “focus groups” were changed to children with “special healthcare needs” and “gatherings to listen,” respectively. The primary reason for not using the term “genetic” relates to the moratorium on genetic research that currently exists within the Navajo Nation. With respect to this moratorium, MSGRCC intentionally committed itself to exclude any activities or action that could be construed as conducting research related to any specific genetic condition. The gatherings focused on listening to the first-person experiences of parents and their children, as well as other advocates. The term “focus group” implies a rigid process through which the facilitators and organizers are seeking responses to specific questions that would be duplicated exactly with each group in order to achieve consistency, as well as a definitive parameter of responses identified in advance. In this instance, the sole purpose was to listen.

MSGRCC intentionally sought to remove the constraints, expectations, and limits of traditional focus groups by removing the emphasis on data collection and replacing the primary emphasis on gathering information to direct future strategic planning for the MSGRCC. To this end, a guide for the facilitator was created that only included possible questions to pose to each group (see Appendix B) rather than a full script, and implementation was dependent on the flow of the conversation. The guide differs from other focus group guides because it was not a formatted, step-by-step script.

In addition to the intention of language used for these gatherings and the structural design, the team working on this project also took time to educate themselves about the region in which the gatherings took place. This research was helpful and necessary. During the short time it was there, this team could not acquire a complete understanding of the region or the full-breadth of the individual experiences of the participants. Nonetheless, the team considered an understanding of the existing culture and regional significance an important component of understanding the communities in which the gatherings took place. The research took the form of visiting local cultural centers, driving the distances to obtain an appreciation for the vast number of miles covered by many participants to access services for their children, and learning some historical aspects of the various tribal nations in the region. While each gathering was approximately two hours in length, the trip for the coordinating team took place over four days and covered close to 500 hundred miles (see Appendix D for a map of the region and distance traveled, as well as Appendix E for a sample of photographs taken of the region).

The Gatherings

Distinctions between Traditional Focus Groups and the Gatherings

In many ways these gatherings resembled more traditional focus groups—questions were prepared in advance as was the designation of separate roles of facilitator and note-taker. The implementation, however, was unique. Although certain aspects were similar to focus groups, this was an opportunity to simply listen without filters and without a predetermined agenda as to what the participants had to say. An example of the distinction between these gatherings and traditional focus groups is that the facilitator in a focus group setting typically follows a preset script and does not deviate from that script while members of the coordinating organization participate solely as note-takers or observers, sit removed from the participants and do not participate in any of the discussion. In comparison, although each person had a role to play during the gatherings, team members were not confined to their roles nor

limited in their interaction with the group; the relationship of the team was dynamic enough to support the fluid process of these gatherings. The team included participating staff from MSGRCC—specifically, the Director of Regional Outreach, Joyce Hooker, and the Project Manager, Liza Creel, MPH. In addition, MSGRCC contracted the services of Leslie Burkholder, MNM, of Idea Infusion Consulting to facilitate the discussions and assist in planning and development of the facilitators guide, as well as structural design for the gatherings. The role of each individual was agreed upon prior to the gatherings along with determination regarding how each role would be somewhat unique from that of a traditional focus group.

At the beginning of each gathering, Ms Burkholder, in her role as facilitator, emphasized her primary duty to observe the flow and rhythm of the conversation. Her additional duties included, but were not limited to, the following: beginning the gathering with an “ice-breaker” question(s) (“Tell us what about your kid(s) makes you smile”, and/or “What do you celebrate about your child/children?”) that provided an opportunity for introductions; asking the first topical question; prompting another question only when necessary; clarifying responses and inviting additional thoughts and comments when appropriate; and, primarily, to *not* impede the direction in which the participants took the discussion. Mrs. Hooker’s role built upon the existing relationships that she has cultivated over years of working within the genetics community in this region, and she served as a participant in the discussion as well. She often posed follow-up questions that were not previously scripted and offered information when questions were asked by the participants. In addition to her primary role of note-taker, Ms Creel also posed questions when clarity was necessary and provided supplemental information to Mrs. Hooker’s responses to participant questions. All three team members collected notes during each gathering and the participant responses (see Appendix C) provided the basis for this report.

Another unique aspect of these gatherings is that consensus existed among the organizers if some of the questions created in advance were not completed or discussed fully during the gathering that this would also be an acceptable outcome. In actuality, the majority of questions were answered by participants during each gathering, and they were rarely answered in the order they were written. Responses were typically offered voluntarily rather than as a response to a direct question, and this contributed to the conversation-style of the interactions. While the dynamic flow created some challenge for taking notes, it did provide the greatest opportunity for an open and continuous dialogue between participants with the team members who were dedicated to listening. No electronic devices, charts, or easels were used during the gatherings. The written notes from team members are the sole record of each

event, and participants could request that their comments not be recorded at any time, although no one took this option and all responses are included in this summary.

Each gathering took place at a local community college, with room accommodations arranged by Yolanda Sandoval, a parent-member of the MSGRCC Consumer Advocacy Workgroup. The room set-up sought to create an environment of openness and comfort to encourage the flow of conversation. Although participants were seated at tables, the tables were arranged in a rectangular formation in order that each participant could see everyone else. Dinner was provided by a local caterer for the first gathering, and everyone spent some time eating dinner together prior to starting the dialogue in earnest. Since the second gathering occurred in the midafternoon, snacks were provided instead of a full meal.

Two Gatherings: General Description and Emerging Themes

The two gatherings took place on March 17 and 18, 2011, in Farmington and Gallup, New Mexico, respectively. All of the participants were women except for one father who took part in both events, and several participants work for community-based organizations that provide support to local families. Each gathering was scheduled for two and a half hours, although the actual time engaged in topical conversation was closer to two hours. Participants had time to introduce themselves to each other as they arrived in the manner that was most comfortable to them. These introductions varied from first names in English to a more traditional greeting in Navajo. A more traditional greeting and initial introduction, as described by the participants, includes identifying one's mother's clan, then one's father's clan, followed by additional information that identifies oneself to another member of the Navajo Nation. Members of the MSGRCC team engaged in opening introductions and welcomed each participant as they arrived, and then participated in the introductions within the context of the dialogue and identified the individual role each team member would play within the gathering.

Participants provided MSGRCC with rich feedback and information regarding their experiences and opinions, with each gathering exhibiting its own unique flow. Due to the fact that this was not a question-and-answer format, at times participant responses encompassed more information than was asked for, and were in fact applicable to more than one question developed by MSGRCC. The primary areas of focus for MSGRCC going into these gatherings included: information-seeking behaviors, service-seeking behaviors, and participants' experiences and feelings related to those experiences (see Appendix B).

Participants were tremendously open and forthright when sharing their experiences with the group. In the note-taking completed by the team, every effort was made to accurately reflect the experience of whomever was speaking—honoring the statement as her/his own truth, and without placement of judgment or bias of the recorder’s experience. Furthermore, in an effort to be respectful of participants’ privacy and remove any potentially identifying information, responses recorded in this report are anonymous. While highlighted responses are listed below, a comprehensive listing of participant responses, along with the best-suited corresponding questions from the facilitator guide, is provided in Appendix C.

Four key themes emerged from the participants’ responses that identified areas of challenge when attempting to access services and information for their children with special healthcare needs: 1) distance to services; 2) communication; 3) cultural openness and capacity/sensitivity of service providers; and 4) limited connection to other groups and/or providers outside their community. Many of these issues are a source of significant frustration for parents attempting to advocate for their child’s health and well-being. As a result, many parents reported that they were labeled by the providers as “aggressive,” “difficult,” and/or merely treated as an “object” and dismissed. The following table provides a brief description of each theme as well as a sample of responses from the participants illustrating their experiences.

<i>Theme</i>	<i>Description</i>
Distance to Services	<p data-bbox="423 1251 1419 1389">The physical distance between where families live and the location of services available for their children—for both urgent care and ongoing care in addition to treatment—as well as ability to use alternative means of access to service providers such as telehealth strategies that use the Internet.</p> <p data-bbox="423 1389 927 1427"><i>Examples from Participants’ Statements</i></p> <ul style="list-style-type: none"> <li data-bbox="423 1427 1450 1527">□ “Shiprock IHS [Indian Health Services] provides services for the entire four corners area so the required travel to even get primary care services can be significant. But IHS is overwhelmed too.” <li data-bbox="423 1527 1419 1627">□ “Right now, IHS doesn’t provide all specialized services so families have to go to the University of New Mexico [in Albuquerque, approximately three (3) hours driving] to get specialty services. This is a major burden to families/parents.” <li data-bbox="423 1627 1170 1666">□ “Frustrating to drive so far to see the doctor for 10 minutes.” <li data-bbox="423 1666 1154 1704">□ “There is limited or no Internet service on the reservation.”

<i>Theme</i>	
Communication	<i>Description</i>
	Parents' ability to find out about available services, as well as the relationship between provider(s) and parents in general, and to obtain information regarding their child's specific condition, treatment options, and any additional available resources.
	<i>Examples from Participants' Statements</i>
	<ul style="list-style-type: none"> □ "Doctors don't explain procedures well and don't always tell the parent the actual name of the disease/disorder." □ "Some doctors forget to think. The doctors give abbreviations or they are simply blunt and abrupt—state the diagnosis with no additional information and then leave." □ "It's a challenge having to tell our story to every new doc. We have to keep a set of our own records to make sure nothing is lost." [Families feel the responsibility to document everything themselves because they are shifted between providers so much and so often.] □ [Primary way of finding out about services is by word of mouth.] □ "It should have been the doctor explaining [to me what was going on with my child] but it was the pharmacist who even told me anything."
Cultural Openness & Sensitivity/ Capacity of Service Providers	<i>Description</i>
	The experience of participants interacting with service providers who may or may not understand the cultural nuances of their patients and patients' families, as well as the limitations of the systems the parents are navigating to obtain services for their children's healthcare needs.
	<i>Examples from Participants' Statements</i>
	<ul style="list-style-type: none"> □ "Doctors don't always appreciate that the parent traveled several hours to see them." □ "There is a language barrier. It is hard to translate modern medicine to native languages, and there are limited translation services available within IHS." □ "There are numerous 'dialects' and it varies from person to person." [For example, the meaning of Navajo words is very dependent on who is using the word and in what context.] □ "There isn't anyone to translate the information into Navajo, thus it takes a long time for families to get information and to understand it." □ "Not treated as a person by the doctors—they treat you like an object!" □ "I was yelled at by a doctor when I was asking for more information."
Limited Connection to Other Groups and Service Providers	<i>Description</i>
	The isolation—both physical and virtual given lack of reliable Internet access—for parents to seek out other parents in similar circumstances, as well as knowledge of other groups and resources that may provide support and information.
	<i>Examples from Participants' Statements</i>
	<ul style="list-style-type: none"> □ "There is limited to no Internet service on the reservation." [Parents said they would like to visit a national group with their child but no funding.] □ "There is a group, <i>Parents Reaching Out</i>, in Albuquerque [no less than 2 ½ hours away] but they had to ruffle feathers to get services." □ [Parents don't see much on rare disorders and can't really afford to participate in national activities.]

Observations, Summary and Recommendations

A key point repeated throughout the gatherings is that there exists a myriad of nuances, unique experiences, and perspectives within the Native American communities. As happens within any group of people, generalities and gross assumptions exclude someone. Each Native American Nation encompasses a spectrum of individuals, with each person having a unique relationship to their identity and culture—ranging from traditional to non-traditional and every distinction in-between. The role that the MSGRCC plays in the region and related to genetic services is limited in that it cannot address the needs of all individuals or the multitude of nuanced experiences reflected by those individuals seeking services for their child/children with special healthcare needs. However, there is much that MSGRCC can do.

The MSGRCC holds a unique position in that it brings people together and provides conduits for links and communication throughout the mountain states region, as well as access to a national forum. It is through this strength of bringing people together and providing linkages for relationship-building that MSGRCC can offer its most robust contribution in response to the themes that emerged from these gatherings. Specifically, it is recommended that MSGRCC host similar gatherings in other locations in the area and continue to listen to parents and advocates of children with special healthcare needs. Furthermore, a tremendous opportunity exists to bring parents and service providers together to begin to listen to each other—MSGRCC has a role to play here as well. The following recommendations are specific with regard to convening a gathering for dialogue between service providers and parents:

Host an event/gathering within the region, as centrally located as possible and provide as much assistance as possible with transportation.

Do not limit the time to a few hours or an afternoon, possibly host over the course of a day (or even two) to be able to not only make the distance traveled worthwhile for all involved but to be able to include various social and cultural interactions in addition to more structured meetings and dialogue.

Structure a portion of the sessions for the service providers to lead, and a portion of the sessions to be led by parent participants.

Seek to identify common areas of concern as well as opportunities and ideas for possible solutions.

All participants contribute to identifying viable next steps and commit to specific action items as a way to begin to build trust.

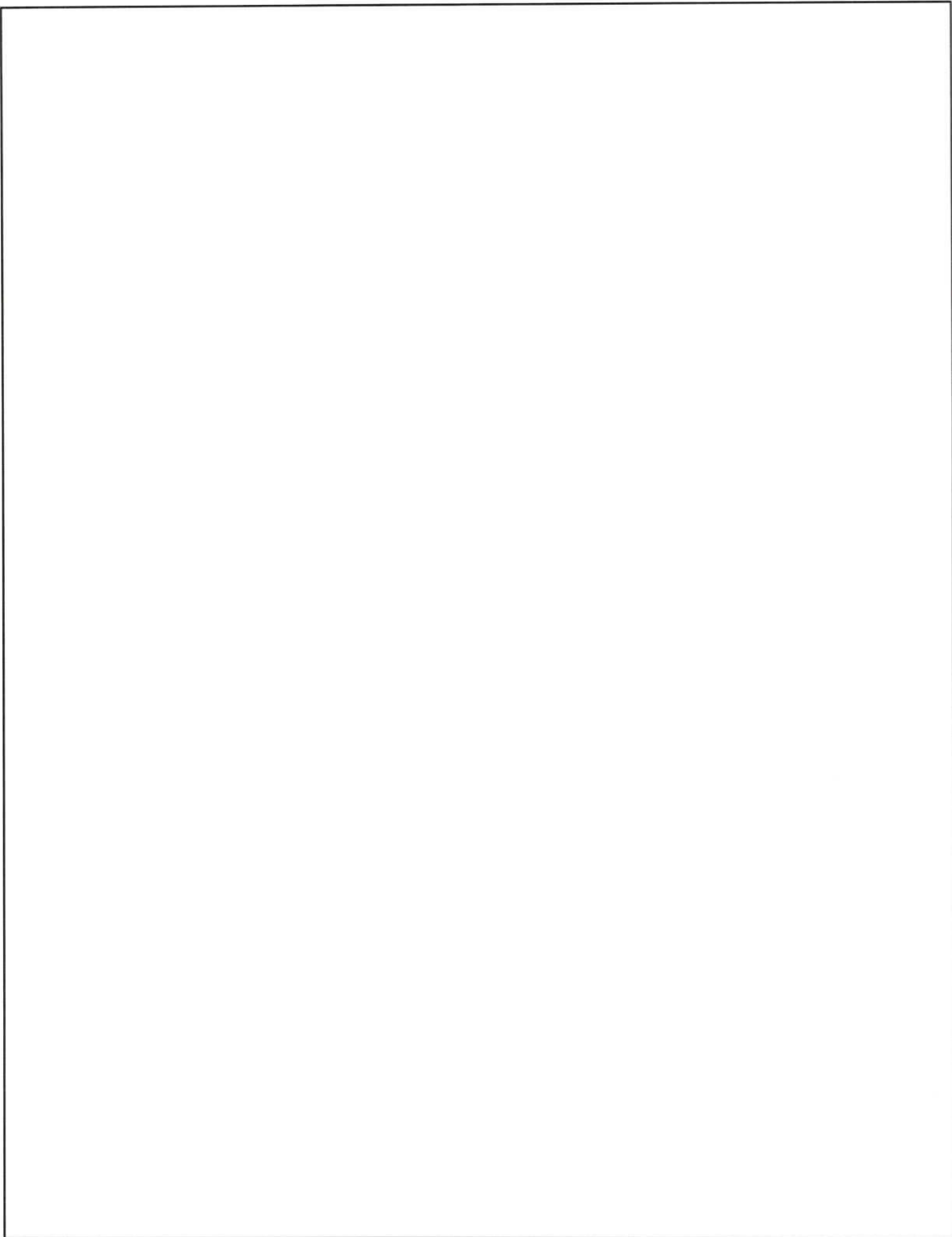
In addition, the following recommendations are offered as a result of these gatherings as well as a description of possible strategies for future action by the MSGRCC.

<i>Theme</i>	<i>Recommended Action Items for MSGRCC</i>
Distance to Services	<p>Although significant barriers exist, telemedicine appears to be a good option for many parents seeking services for their child/children with special healthcare needs in the region. Additional information needs to be made available to parents regarding this option, as well as the establishment of links to providers who offer this service.</p> <p>Link established telemedicine practitioners in other areas within MSGRCC’s region to those in the Four Corners region.</p>
Communication	<p>Include these communities and issues within the MSGRCC Annual Meeting and Mid-Year Meetings to ensure that opportunities for links are not missed, and connect those in attendance with others from the mountain states region. Continue to host <i>Gatherings to Listen</i> within the region. Possibly host a larger “summit” to bring a larger group of parents and advocates together.</p>
Cultural Openness & Sensitivity/Capacity of Service Providers	<p>Work with providers to offer and/or coordinate trainings on-site and work with upper-management to increase potential for greater participation by all members of each service organization.</p> <p>Work with providers to create a system for ongoing training and sustainable support for continued exploration of cultural openness, awareness, and sensitivity.</p> <p>Include local consumers and consumer advocates to contribute to the design of this system (mentioned above) and in delivering trainings for the sustainability of these efforts.</p>
Limited Connection to Other Groups and Service Providers	<p>Continue to work with local leaders of parent support groups, consumers, and consumer advocates to identify new opportunities to improve access to specialty healthcare services.</p> <p>Ensure that these leaders are supported in attending the MSGRCC Annual Meeting and Mid-Year Meetings to bring information back to their respective communities.</p> <p>Work with these leaders to identify additional ways in which MSGRCC can support efforts to create links and generate connections to other topic-related groups and service providers. That is, listen to what they say they need and want (rather than defining it for them), and then take action.</p>

Conclusion

The *Gatherings to Listen*, hosted by MSGRCC in March 2011, succeeded in *listening* to the parents of and advocates for children with special healthcare needs in attendance. What began as an idea stemming from questions and comments by parents following the Community Conversation in 2009, also hosted by MSGRCC, came to fruition in the form of two gatherings that brought together MSGRCC staff with parents and advocates to talk about and listen to their experiences, frustrations, questions, and hopes for the future related to their children's health and healthcare. The intentional decision by MSGRCC to conduct these gatherings in a manner that was distinct from traditional focus group sessions was made in an attempt to honor the culture and experiences of the participants. It appears the format for the gatherings contributed significantly to the success of these events, the information that was gathered, and the subsequent recommendations for future action. As a result of this relationship-building project, MSGRCC created a platform for future communication and opened the door for similar future gatherings to continue to listen throughout the mountain states region and beyond.

Appendix A: Invitation Flyer



Appendix B: Facilitator Guide for Gatherings

MSGRCC: A Gathering to Listen Participant Questions

Desired outcome:	
<p>The MSGRCC seeks to create an opportunity for parents who are Native American and who have children with special health care needs to share their perceptions, opinions, and experiences about access to health-related information and services.</p> <p>Throughout this process MSGRCC is committed to the delivery of the responses of the participants and their stories—in their own words—to decision-makers at the national and state levels.</p> <p>As a result of this gathering, MSGRCC ultimately seeks to positively influence the effective delivery of information and services for all families within the mountain states region.</p>	
Primary Areas of Focus:	
<ul style="list-style-type: none"><input type="checkbox"/> Information-seeking behaviors<input type="checkbox"/> Service-seeking behaviors<input type="checkbox"/> Participant experiences and feelings related to those experiences	
Questions related to Information-Seeking Behaviors:	
Lead Question	Where do you look for and find information related to kids with special healthcare needs?
Follow-up Questions	<ul style="list-style-type: none"><input type="checkbox"/> How do you find out about where to look for this information?<input type="checkbox"/> Who in your family takes on the main responsibility to find this information?<input type="checkbox"/> What barriers or challenges exist when attempting to find information related to kids with special healthcare needs?<input type="checkbox"/> Is this support group viewed as a resource for this type of information within your community?

Questions related to Service-Seeking Behaviors:	
Lead Question	When you first realized that your child had special healthcare needs, to whom did you look to, and where did you go, for the services your family needed?
Follow-up Questions	<ul style="list-style-type: none"> <input type="checkbox"/> Where do you look to find available services now? <input type="checkbox"/> Who in your family takes on the main responsibility for finding these services? <input type="checkbox"/> What information do you and your family need before accessing services for your child? <input type="checkbox"/> What barriers or challenges exist when accessing services for your child?

Questions related to Participants' Experiences and Feelings:	
Lead Question	Please share some of your experiences with trying to find information or services for your kids with special healthcare needs.
Follow-up Questions	<ul style="list-style-type: none"> <input type="checkbox"/> What is an example of an experience when something went well for you and your family related to healthcare for your child? <input type="checkbox"/> How would you change the current status of healthcare for kids with special needs? <input type="checkbox"/> What information is helpful to know from your child's doctor? Do you want to know everything that the doctor knows? <input type="checkbox"/> What would you like to see available (information and/or services) to you and other families with children with special healthcare needs? <input type="checkbox"/> What else would you like to share with us?

Appendix C: Participant Responses

Information-seeking behaviors:

Where do you look for and find information related to your kids' special healthcare needs?

Follow-up questions related to this lead question included:

How do you find out about where to look for this information?

What barriers or challenges exist when attempting to find information related to kids with special healthcare needs?

Is this support group viewed as a resource for this type of information within your community?

Participant responses included:

- Mostly by word of mouth. There is limited or no internet service on the reservation. Parents said they would like to visit a national support group with their child but no funding.
- There are no Navajo words for many medical terms and disorders. Cancer is an example. The TV is air box, radio sing box, turtle is slow shell. Watches are rarely worn by the Navajo.
- There is a language barrier. It is hard to translate modern medicine to native languages, and there are limited translation services available within IHS [Indian Health Services – operated by the U.S. Federal government].
- There are numerous “dialects” and it varies from person to person [the meaning of Navajo words are very dependent on who is using the word and in what context].
- I rely on friends to help me, especially with learning about my child’s disease, advocating for them, and mentoring other parents.
- I would have liked to know about my child’s disease earlier. [Mom said that problem had been identified through prenatal ultrasound but that she was never told.]
- The responsibility is on the parent to find everything out
- Most have limited Internet at home or on the reservation – usually only available at work.
- Parents don’t see much on rare disorders and can’t really afford to participate in national activities
- When a family does want information there is a center for that, but it is based in Albuquerque, they need translation, misinformation is rampant and it takes too long!
- When my child was born, it changed my whole life. I didn’t know anything.
- The Internet is not an option for so many.
- Even if information is available, it’s not often translated.
- Parents Reaching Out* network tries to get educational materials to parents and families.
- Sometimes families receive so much information [in a short amount of time e.g., a brief visit with the provider, or at the time of a health crisis with their child, e.g., a trip to the emergency room] it’s hard to know what’s really important.
- Primary care physician / pediatrician
- PCP referred to specialists
- Typically find doctors by knowing someone who knows someone
- There are limited connection points or entry points for people who are looking for information

- It should have been the doctor explaining [to me what was going on with my child] but it was the pharmacist who even told me anything
- Some used Internet, some didn't
- Limited use of telemedicine, even to transfer information or education.
 - o Joyce described telemedicine and the group had several questions:
 - If the technology is here, why aren't people using it?
 - Do all hospitals have the equipment?
- UNM [University of New Mexico] docs tell families to go back to IHS for more info but it's too complicated to find information within that system.
- Families feel the responsibility to document everything themselves because they are shifted between providers so much, and so often.
- Rely on family for support

Service-seeking behaviors:

When you first realized that your child had special healthcare needs, to whom did you look to, and where did you go, for the services your family needed?

Follow-up questions related to this lead question included:

Where do you look to find available services now?

What barriers or challenges exist when accessing services for your child?

Participant responses included:

- There is a lack of services in this area.
- Primary way of finding out about services is by word of mouth.
- When my child was born, it changed my whole life. I didn't know anything.
- Shiprock IHS provides services for the entire four corners area so the required travel to even get primary care services can be significant. But IHS is overwhelmed too.
- The number of providers in this region is extremely limited.
- Right now, IHS doesn't provide all specialized services so families have to go to the University of New Mexico to get specialty services. This is a major burden on families/parents.
- Parents see a problem with developing long-term relationships with their doctors. There is high doctor turnover within IHS. Part of the problem may be federal loan repayment programs that only require a set number of years of service in an underserved community.
- Major power struggle within IHS.
- Doctors tend to "put a band-aid on it" instead of fixing the problem, especially within IHS.
- Doctors laugh in my face.
- Not treated as a person by the doctors – "They treat you like an object!"
- Very disappointing and very frustrating!
- Not really interested in going to any of the IHS clinics because of these issues.
- My blood pressure is always high when I go to IHS. This isn't true when I go see other providers.

- Doctors don't always appreciate that parents traveled several hours to see them.
- Specialty and rehab services not available in local community (e.g. swim therapy).
- Parents often identified as "aggressive" when they are advocating for their child within the system.
- Doctors don't explain procedures well and don't always tell the parent the actual name of the disease/disorder.
- I had one good doctor but she left because the school system wasn't that good (she had young children).
- Seems that the doctors don't appreciate the parent's urgency.
- The availability of services becomes more and more limited as the child gets older.
- Frustrating to drive so far to see the doctor for 10 minutes.
- The specialist is 3 hours away – there are no specialists through IHS
- Major cultural barriers exist.
- Older kids can't get funding for necessary medical services
 - o Families get so much help up to a point but then it just stops.
 - o As child grows up, the responsibility is on the parent to inform everyone around their child about their condition so the child is still taken care of when the parent is gone.
- There is a group of *Parents Reaching Out* in Albuquerque (no less than 2 ½ hours away) but they had to ruffle feathers to get services. There isn't anyone to translate the information into Navajo, thus it takes a long time for families to get information and to understand it.
- Ft. Defiance and Shiprock have IHS services where the funding is turned over to the Navajo Nation. Navajo told there are federal funds to build a new hospital. It was built, but the funding is slim for services. The 638 contract is a treaty for healthcare services, but there are no specialized services.
- One participant stated most patients don't complain, and concerning medical care that [they are resolved to] "you get what you get".
- IHS does offer some patient education and provides the opportunity to give feedback on their services. It's not clear that the feedback even goes anywhere so people just don't give it.
- There is a perception that the government set it up this way, so "we are now dependent on them."
- Didn't know about NBS until today.
- I really looked for resources within the hospital.
- Parent with two foster children (both with special needs) has really struggled. Once she and her husband became guardians of the two foster children, the social services dropped off
 - o She found it very difficult to get health services in her community; has to travel to UNM (currently travel there 2 times per month).
 - o Parents don't really understand the children's problems.
- Parents don't even know what they can ask for, what to ask, or what feedback loop is available.
- Parents may not even know if a child needs certain services (especially those available at school).
- Mom and Dad both took responsibility, but for different components (e.g. special ed, medical) of their child's care.

General experiences and thoughts/feelings related to those experiences:

Please share some of your experiences with trying to find information or services for your kids with special healthcare needs.

Follow-up questions related to this lead question included:

What is an example of an experience when something went well for you and your family related to healthcare for your child?

How would you change the current status of healthcare for kids with special needs?

What information is helpful to know from your child's doctor? Is this information enough for you? Is it too much information? Please explain.

What would you like to see available (information and/or services) to you and other families with children with special healthcare needs?

Participant responses included:

- When I was pregnant with my son, I noticed he didn't move around much. The MD did an ultrasound and told me everything was fine. At 3 months, he was crying a lot and we took him to the ER in Farmington where we were told they had to go to the ER at the IHS hospital [in Shiprock, approximate 30 miles away from Farmington]. The ambulance took the family to IHS where they were directed back to the hospital in Farmington. At this point the parents were labeled "aggressive parents" by the providers. The MD said the baby had fluid on the brain causing pressure and it needed to be released. He then referred them to a neurologist. The neurologist scared them and didn't explain the procedures or let them know if he was qualified to perform the procedures.
- Numerous parents shared experiences related to advocating for their kids within the schools.
- One mom had many ultrasounds in 3rd trimester and wishes she had been told by medical staff what they saw. She received prenatal care and her son was born at the tribal hospital. She was told that he has a rare disorder, but didn't receive any specific information from them [the providers]. Her elder daughter is mature and wants to pursue a medical career. The family has grown a lot through her son's disability.
- We don't want to be just a number.
- Another mom said she can't get Medicaid for her daughter that is 22 unless it is for family planning. She found out that her daughter has asthma as it is in her chart, but was never given that information by the doctor. Her other daughter has severe lung damage, but again she was never told. The mom kept giving her cold medicine not knowing what the real cause was. She was labeled an unreliable parent by the providers.
- A mom said they [the providers] treat them [parents and their kids] like objects and that from her experiences the medical staff is not professional and acted repeatedly in way that were unethical. When she has to use the medical services for her son, the medical staff makes her mad and it raises her blood pressure. Another mom agreed and said she doesn't like to take her son for the same reasons.
- Another parent was told her son had a hearing loss as he had failed a test. That is the only information she was given. At 2 months of age, she found out it was *not* a hearing loss and she should take him to UNM [Albuquerque] for a plan. She went to UNM and the doctor

didn't show up. The person attending didn't have any knowledge of a plan. This is what she can expect.

- I want my child to be independent and to be capable of advocating for himself.
- Docs do often look to parents as experts but parents are self-taught
- "Some doctors forget to think." The doctors give abbreviations or simply blunt and abrupt—state the diagnosis with no additional information and then leave.
- Parents have to learn fast because that's how you get your kid out of the hospital faster.
- Hospitals do have resources and support groups but parents have to look for them.
- School is a great intervention point. Parents have rights there too.
- Sometimes parents have to ruffle feathers to "get heard"
- I was yelled at by a doctor when I was asking for more information.
- Believe there is a lack of communication between patients and providers, even when patients give feedback... where does it go?
- The doctors looked to us as the experts on our own kids since the disease was so rare.
- It's a challenge having to tell our story with every new doc. We have to keep a set of our own records to make sure nothing is lost.
- When you find a good doctor you stay with them. A good doctor:
 - o Listens
 - o Doesn't push us out on a time frame
 - o Asks about overall well-being

- Responses specific to: Is it possible to fix this?*
 - o Maybe not.
 - o We are in the "150 year war"
 - o "We take what we can get because if they don't do it, no one else will."

- Responses specific to: What information is helpful to know from your child's doctor?*
 - o "if the condition is long-term, I would like to know everything necessary to offer good care for my child."
 - o Parents get the blame if proper care isn't given, even if the doctor didn't tell them to do it.
 - o I want to know all my options
 - o I want the doctors to try the least invasive option first.
 - o I don't want to go to the hospital unless absolutely necessary (because the risk of infection is high).
 - o I want the doctor to listen to my questions and to give me accurate answers
 - o I want the doctor to spend time with me
 - o I want to be comfortable asking questions.
 - o I don't always understand what they [docs] are telling me.
 - o Parents want to know their options
 - o Parents have to learn their patient rights
 - o Want the doctors/nurses to be a friend too...this makes it not as scary.
 - o Want to know all options and all possible explanations
 - o Too little info is scary
 - o Tell me the truth. Tell me everything I need to know. I need help to know.
 - o Sometimes the doctor's approach is brash and "freaks me out"

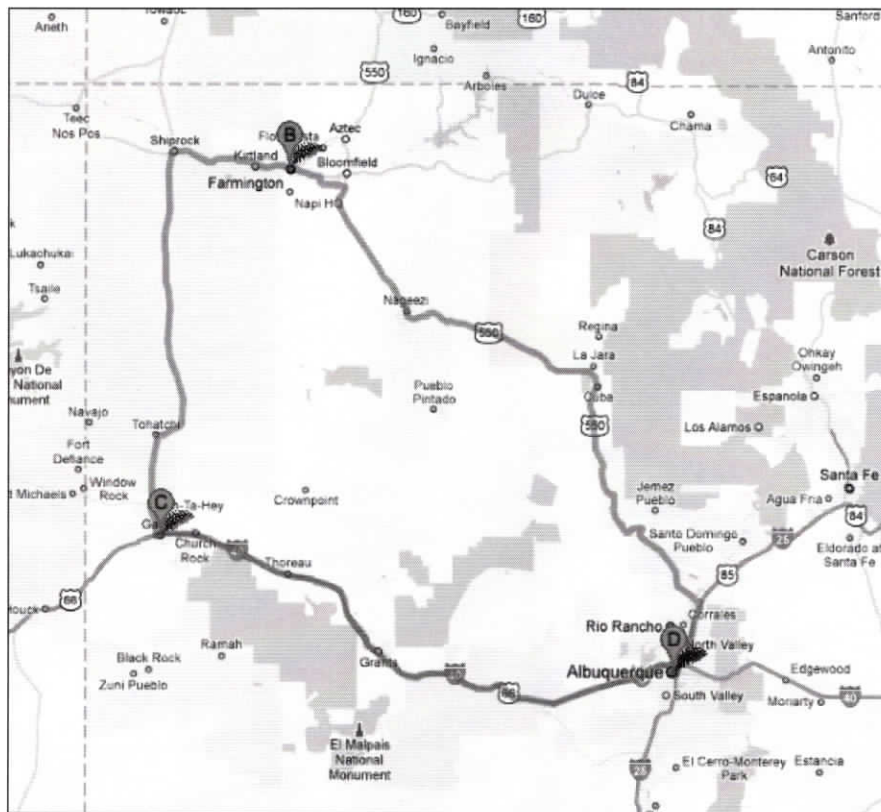
- One parent tried to get all info possible but doctor got angry that they asked for it.
- Look up information on the Internet and then take that education back to their doctor.
- Want to know:
 - The truth
 - What do I expect?
 - What do I do?
- Some ask for brochures / materials but don't always get it.
 - Don't appreciate information in acronyms

Appendix D: Map of Region & Distance Traveled

Location within MSGRCC Region

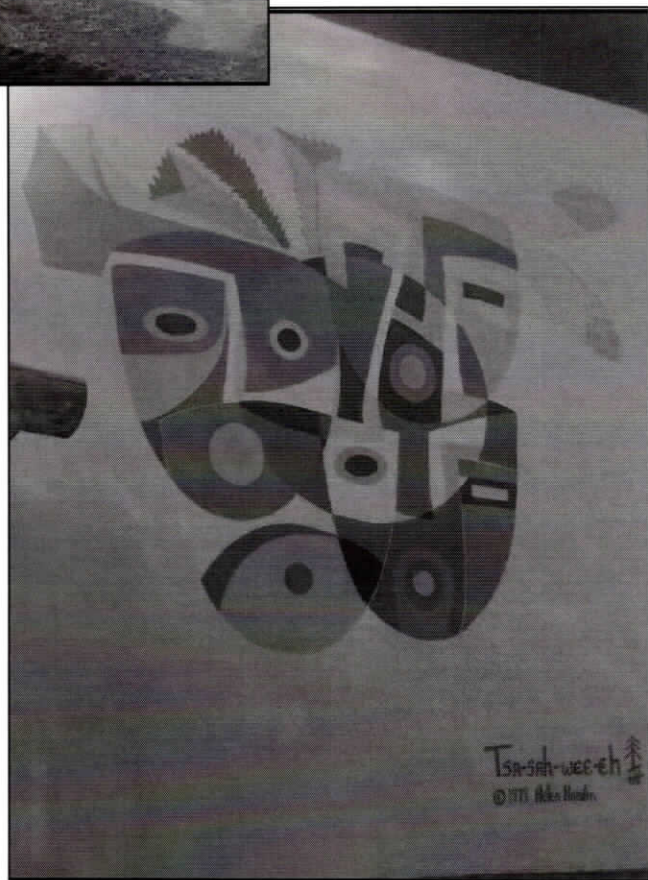


Approximate Travel Route

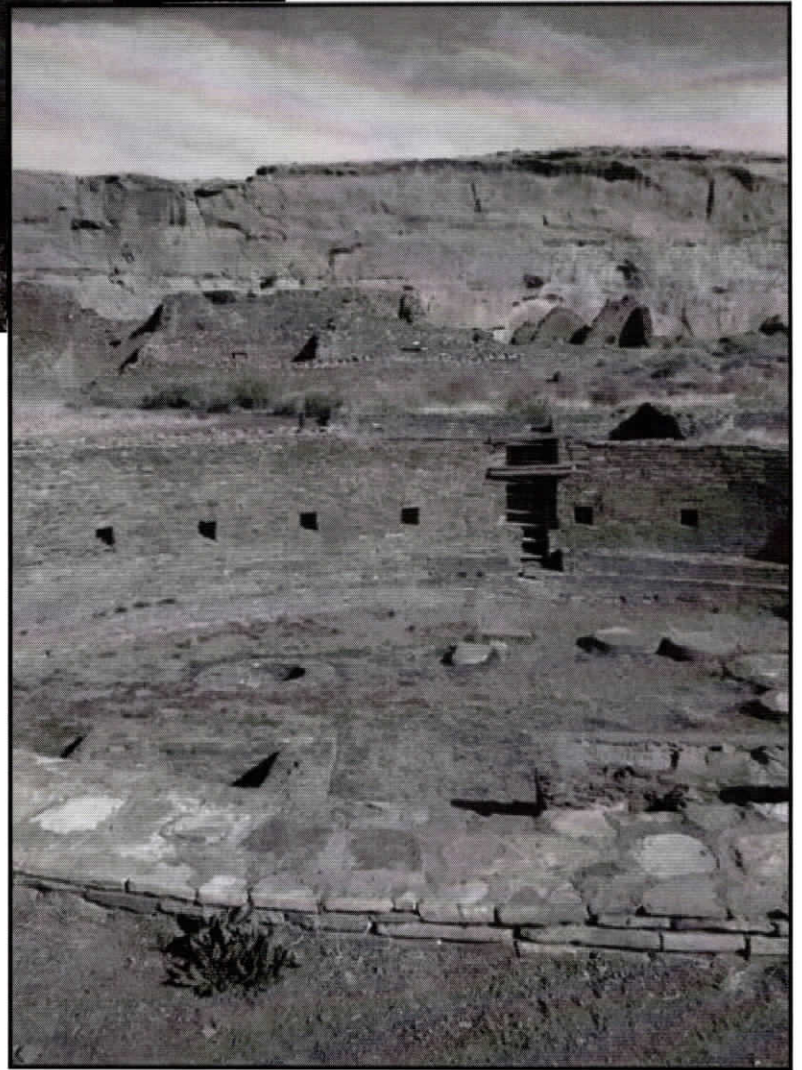


Appendix E: Photos Highlighting the Region

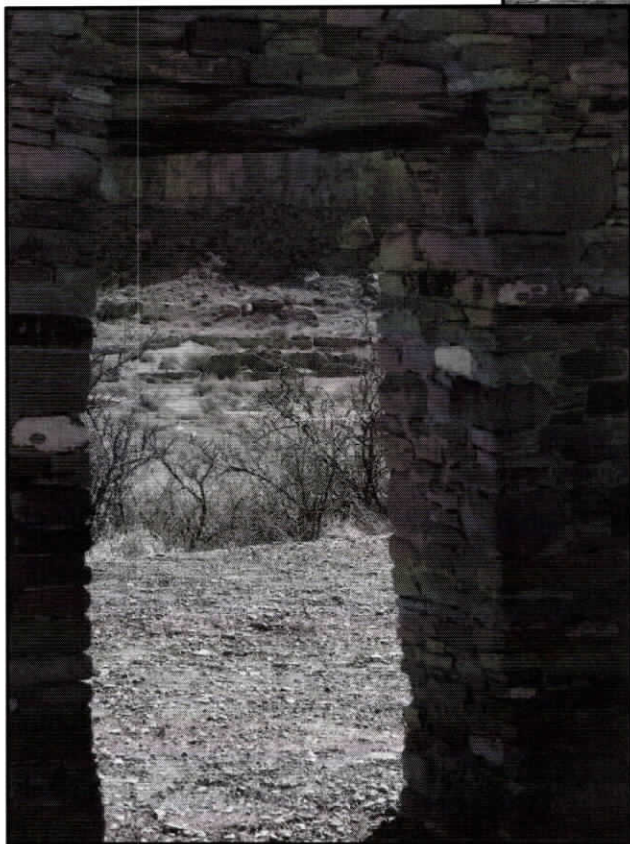
The following photos highlight the region traveled by the team as a part of this journey for the gatherings.



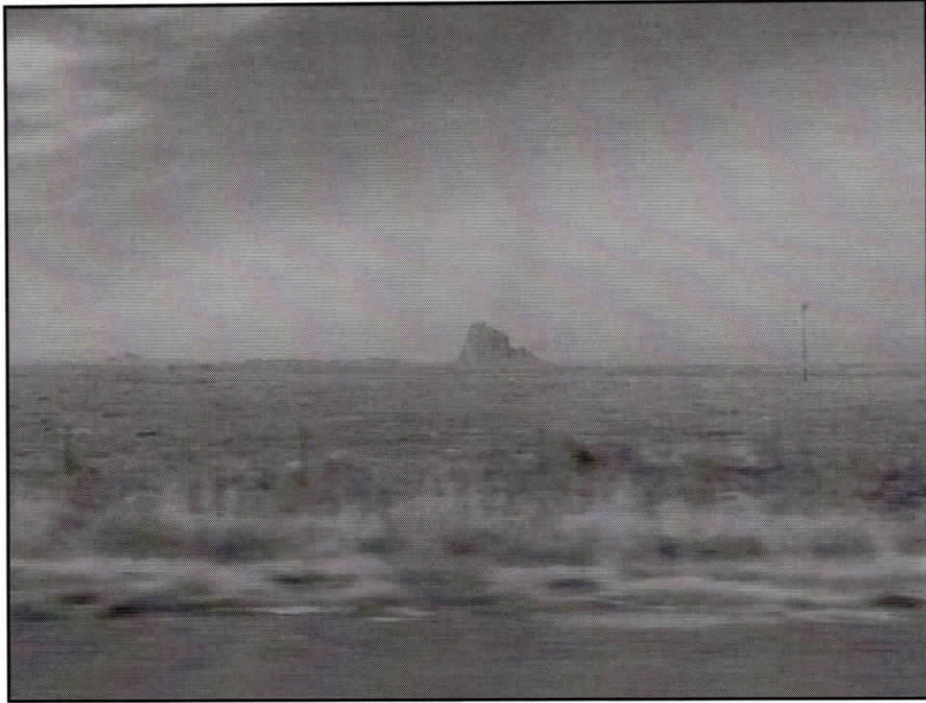
*Large murals in center of the
Indian Pueblo Cultural Center
Albuquerque, New Mexico*



*Images from Chaco Culture National Historical Park
Outside of Farmington, New Mexico*



*Images from Chaco Culture National Historical Park
Outside of Farmington, New Mexico*



*Images from the road
Driving from Shiprock to Gallup, New Mexico*



*Approaching Sky City Cultural Center
Acoma, New Mexico*



Notes from Community Conversation on Genetics
Dine College, Shiprock, NM
April 3, 2009

Video, "A Gift of Life":

Made in 2002, the video, which is in the Navajo language (with English subtitles), began with tribal leaders explaining their views on genetic studies. The first presenter explained that there have been some genetic studies done on the Dine (Navajo) people without their approval. Because of this, a policy was needed to protect the Navajo nation, which the IRB has implemented. Spiritual leaders have discussed genetic research and given their views. Researchers need to follow their guidance because the Dine people will not tolerate ill conceived research on them.

Following this introduction, the video showed another tribal leader giving basic information on genetics and gene therapy ("treatment that can fix damaged genes"). This person explained that because life is sacred and divine to the Navajos, any genetic research needs to be explained to the Dine people.

A Navajo scientist then discussed what research is and why it is good. He mentioned that some young Dine people are becoming researchers themselves and how important this is to the Navajo nation. He also explained the traditional Dine view of life. Researchers need to consult with tribal leaders and medicine men, to be humble and respectful, to understand Dine culture and way of life, and to pray to the Holy People before doing research.

The video then presented the perspective of a medicine man. He explained that the Holy People say that the Dine people will not continue to exist if genes are taken from people. For this reason, the medicine men voted against doing genetic research with members of the Navajo nation.

The next perspective given was that of the Native American Church. The church representative stated that any violation in the "life creation" of the Dine people cannot be tolerated. However, some Dine people are suffering from rare disorders for which research is needed to develop cures and prevention strategies. The Native American Church thus agrees with research that will help the Dine people, but will not support research whose purpose is to bring profit and recognition to the researchers. The Navajo nation, in his view, needs to be "in charge" of any research done on the Navajo people.

A Christian minister gave his view which is that genetic researchers are not obeying the laws of God. In his words, "life is beautiful."

Beverly Becenty-Pigman, the chair of the Navajo Nation Human Research Board (the IRB), then explained how the IRB was started and states that its purpose is "to protect future generations" of Navajos. Diabetes research was done on the Navajo people from 1955 to 1965, but the results

of that research were not shared with the Navajo people. The IRB wants the Dine people to have an opportunity to provide their input on genetic research and gene therapy. The IRB will show this video to members of the community and get their reaction; based on this feedback, it will develop a new human research policy. The IRB chair also stated that some Dine people are becoming researchers; the Navajo nation will be able to rely on their work.

The video concluded with a leader stating that the Navajo nation needs an on-site research facility for genetics research. Such a facility would encourage Dine children to become scientists and researchers and would bring Native American researchers back to the reservation to do research on the Dine nation. Once again, the video emphasized that any genetic research done on the Navajo people needs to acknowledge tribal leaders and spiritual traditions. At the present time, the Navajo nation tends to avoid genetic research because it is not well understood that such research can help the Navajo people.

Opening Ceremony:

Johnson Dennison, an educator, medicine man, and storyteller, read a poem and prayer. The head of Dine college then talked about how the process of getting to this “community conversation on genetics” had to be slow and deliberate. He said that the conversation is an opportunity for the community to learn about “blood” and about its own attitudes.

First Panel—What is Genetics?:

Johnson Dennison explained his perspective as a medicine man. In his words, “We come from our mothers and fathers, but also from the spirit, the earth, the water.” He mentioned that we need to fix mother earth, to deal with the increasingly unhealthy air on the reservation as a result of the new power plant.

Ed Garrison, a professor at Dine College, showed slides of various types of cells and explained how they use the same information (genes) to perform different functions. He then showed slides of DNA and explain the basics of genetics and genetic mutations.

Dr. Murray Brilliant, Professor of Pediatrics and Molecular & Cellular Biology at the University of Arizona’s Steele Children’s Research Center, then talked about chromosomes as the blueprint and record of our ancestors and explained that we all descend from common ancestors. Using volunteers from the audience and two colors of foam rods, he did two exercises to demonstrate recessive and dominant inheritance.

Nanibaa Garrison, who is the daughter of Ed Garrison and a graduate student in genetics, used her own appearance as the child of a mother and a father of different ethnicities, to explain genetics. She showed slides of different types of dogs—including purebreds and “rez dogs” -- and of different color sheep, chicken, and corn to demonstrate how selection works and that breeders and farmers have been “doing genetics” for a long time.

Second Panel—Newborn Screening:

Dr. Randall Heidenreich, Professor of Pediatrics at the University of Arizona School of Medicine, explained the basics of newborn screening and briefly discussed the newborn screening programs in Arizona, New Mexico, Colorado, and Utah.

He was followed by Dr. Susie John, a pediatrician with the Northern Navajo Medical Center (and HIS facility in Shiprock) and Medical Officer at the Shiprock Teen Life Center, gave a presentation entitled “NBS: Perspectives of an LMD (“Local Medicine Doctor”). She explained the history of newborn screening and the consequences to children and families if newborn screening is not done. She explained that many diseases for which we screen are unfamiliar to pediatricians and talked about the kinds of heritable diseases that are found in the Navajo community. According to Dr. John, for newborn screening to fulfill its promise, local medical doctors should: offer a medical home; get the latest, pertinent information for themselves and their patients; provide input to formal and informal registries; ensure follow-up; and ensure periodic specialty visits. She stressed the importance of doctors advocating for patients and their families and working with other medical providers and with schools. She also recommended continuing to have community discussions on genetics and to incorporate traditional teachings and community health promotion into those discussions. She ended by raising workforce and resource issues.

Jennifer Puck, Professor of Pediatrics and Human Genetics at the University of California, San Francisco, discussed whether babies should be screen for SCID (Severe Combined Immunodeficiency Syndrome) using a series of slides. She also talked about the fact that the incidence of SCID is 1/2000 among Navajos as compared to 1/50,000 in the general population.

The next presenter was Yolanda Sandoval, the mother of two children (one of whom has died) with Xeroderma pigmentosum (XP), a rare and very serious genetic disorder, and a disability advocate. She talked about how hard it is to receive specialty services on the reservation and how she has had to serve as case manager for her children. She has done a lot of research and has had to educate her children’s doctors; she stressed that parents are often the experts in these situations.

Third Panel –Genetics and Health of the Navajo People:

Dr. Robert Erickson, Professor of Pediatrics and Genetics at the University of Arizona’s Steele Children’s Research Center, discussed “genetic bottleneck” (founder effect) and how it resulted in certain genetic diseases being more common among the Navajos than other populations. He presented slides about several diseases first described among the Navajo people, including Athapaskan Brain Stem Dysgenesis, Poikiloderma with Neutropenia, Navajo Hepatoneuropathy, and Oral-Facial-Digital Syndrome 9 with Microencephaly. He also discussed other genetic diseases especially common among the Navajos, including Microvillar Inclusion Disease and Metachromatic Leukodystrophy. Finally, he discussed which genetic disorders should have carrier testing among the Navajos.

The next presentation was by Mark Bauer, a science teacher in the Shiprock area for the past 30 years, who is member of the Navajo IRB. He talked about the legacy of uranium mining in the area of the reservation, the fact that radiation exposure can cause genetic damage, and the lack of information given to the Navajo about the possible effects of their exposure to uranium. He also talked briefly about his work with Laura Shields on birth defects.

Martha Austin-Garrison, who teaches the Navajo language at Dine College, talked about her work with the Navajo Health Authority on developing a Navajo cancer dictionary, entitled, "Glossary for Basic Cancer Terminology in the Navajo Language." She then turned the floor over to Anslem Roanhorse, Jr, the Executive Director of the Navajo Division of Health in Window Rock, Arizona and, following him, to Jack Jackson, a Navajo medicine man.

Mr. Roanhorse spoke of his—and others'—concerns about genetic research, particularly in the context of the lack of information given to the Navajo people about the effects of uranium mining. His message was that, "You have to be very careful." He noted that, according to the Navajo belief system, if you take biologic specimens from someone, they can become like a naked person unable to speak for him/herself. He noted that there is currently a moratorium on any genetics research in the Navajo nation and said that it was important to "respect differences."

Jack Jackson talked about cancer and the use of traditional Navajo medicine to cure cancer. He also discussed the need to protect traditional medicine as the "intellectual property" of the Navajos.

Fourth Panel—Genetic Research-Promise and Problems:

Dr. Brilliant began by suggested that the community think about genetics as an automobile—that is, something that is not inherently either evil or good, but that, if used carefully, can benefit mankind. He also noted that there is genetic research and then there are ideas about genetic research. He stated that the purpose of genetic research is to improve human health and that, with the right controls, genetics can be used for good. Dr. Brilliant discussed problems with past research projects done with the Navajo people and the lingering distrust that has resulted from some of these (e.g., the Human Diversity Project, research done with Havasupai nation, diabetes research with the Pima tribe). He also presented slides on the history of genetics in both the United States and Germany. He ended by saying that genetics it itself is neutral and that is up to the Navajo people whether and how to use genetics.

Dr. Erickson was the next speaker. He said that he wanted to contradict the idea that genetics can change people; he stated that even gene therapy, which focuses on changing one particular gene, has been larger unsuccessful. However, he noted that scientists' ability to know about our DNA has increased and that, more important, they might be able to add to genetic screening by identifying carriers through DNA tests for diseases with specific genetic mutations (such as those which disproportionately affect Navajos).

Dr. Puck began by saying that she was speaking from her perspective as a doctor working with individual families. As such she said that we have to be ready to help individuals/families with genetic diseases access the care they need, connect with others facing the same issues, and not

get “sidelined” in their communities. To her, research is a partnership, with families as members of the research team. In her mind, we have to take risks in order to make advances and, often, we do not get a perfect result. For example, while gene therapy for SCID was initially successful when used in France, four of the nine children treated eventually came down with leukemia.

Nanibaa Garrison briefly explained key elements of the Navajo worldview, including the creation story, the clan system, and migration from the first world. She noted that there is linguistic evidence of relationships between Navajos, Apaches, Athapaskans, and Mongolians. However, she noted that many indigenous people object to projects such as the National Geographic’s Genetics and Migration project and the Human Genome Diversity Project. She also noted, as had been mentioned by other speakers, that samples from Havasupai people were supposed to be used for diabetes research, but were also used for schizophrenia and migration studies without the permission of the Havasupais. Ms. Garrison also discussed data sharing and stated her view that removing identifiers does not protect confidentiality; recently mathematical modeling was used to re-identify samples in a research project. She concluded by saying that many good things can come out of genetics, but that you have to be well informed about the pros and cons.

The last speaker on this panel was Beverly Becenti-Pigman, the Chair of the 15-member Navajo Nation Human Research Review Board. She gave an overview of the Navajo IRB process and stated that the community decides what research is done and how. Research projects going through the IRB have 12 phases: (1) community partnership; (2) tribal program partnership; (3) screening of research application; (4) meeting and presentation; (5) study implementation; (6) data analysis; (7) data work session; (8) final report and submission of dissemination plan; (9) transfer of data to the Navajo nation; (10) manuscript publications (optional); (11) community feedback and presentations; and (12) final transfer of data. She told the audience that all research data from studies done on the Navajos becomes the property of the Navajo nation. Ms. Becenti-Pigman said that, in evaluating a study, you need to be aware of what you are giving up and what you are getting out of it, i.e., what benefit is there to the Navajo nation. She was the one who asked for a moratorium on genetic research in the Navajo nation; before such research can be done, she believes that rules and regulations have to be in place.

After the panel members concluded their presentations, here were several follow-up questions from the audience about the participation of affected families on the IRB. One woman, who is the mother of two grown children with Retinitis Pigmentosa noted that she was unaware of the IRB, that she strongly supports genetic research, and that neither she nor her children have ever received genetic counseling. Ms. Sandoval also spoke up, saying that she was unaware of the IRB or its decisions and that she also strongly supports genetic research on Navajos.

Fifth Panel—The Future of Genetics and the Navajo People

The first speaker on this panel was Gilbert John, Associate Professor of Microbiology and Molecular Genetics Oklahoma State University. He discussed the Human Microbiome Project, which is looking at the small organisms inside the human body (human microbiota). These organisms are not part of the body, but are intimately associated with it and have a major impact

on human health. He also talked about metagenomics, which is an analysis of genetic material derived from complete microbial communities harvested from natural environments.

Nanibaa garrison then talked about the promise of personalized medicine, which would use genetics to help prescribe the right medications and right dosages for individuals. She focused on its implications for the improved treatment of diabetes.

The final speakers on the panel were Dory ___ and his wife, Yolanda Sandoval. Dory, who has had three children (only one still living) with XP, told audience members that when genetic illness touches their families, they will change their minds about genetic research. To him, genetic study is a necessary evil and the Navajos will get left behind if they don't change. His advice to researchers was to "stay patient. He also thanked the doctors who had helped his family. Dory noted that he was made to feel ashamed about his children's disease; he was told it was his fault that he had three sick children. In his mind, many Navajos are incapable of making decisions for themselves, but are instead used to going to elders and shamans; he believes this may be a consequence of the Navajo nation's dependence on the government.

Yolanda stated that both screening and genetic counseling are very important. She told the audience that some parents of children with XP are accused of abuse. She needed to know how to ask questions and benefitted from learning from genetics. She also said that doctors need to advocate in the school setting for children with disabilities. She concluded by saying how helpful it was to find other families affected by XP.

Gloria Weissman
April 7, 2009

M, W, #4

Engagement of Diverse Populations for Recruitment and Representation in Genetics

It is getting known that African-American, Hispanic, or American Indian patients are unlikely to encounter counselors of their ethnic backgrounds according to a review appearing in the August issue of the *Journal of Genetic Counseling*. In lieu of that we are attempting to provide some information on how the professionals working in the field of genetics might approach the vast diversity of individuals in our country.

Many of the diverse populations mentioned above are not comfortable with the term "genetics". It implies different things to them and often is seen as a negative. It is important to use what they already know. Such as using diabetes, or high blood pressure that can be linked to genes as a starting point, it is some thing familiar and they knowledgeable of its impact on their health.

It is also important to connect with a local, trusted, community individual, who can assist you in getting into the community you are targeting. Going in "cold" can sometimes add to the time it takes for you to get your foot in the door of the community you are trying to impact. Attending special cultural or other community events allows the community to "see" you as just another person in a community and helps build trust within the community. It also demonstrates that you are interested in them and learning about them, outside of your job. Learning to say hello or good bye in their language be it vocal or gesturing, (i.e. "hey" is used as a form of hello in some areas, a nod ones head, a wave of the hand are also forms of hello) this also builds trust and again demonstrates that you took the time to do learn this outside of your normal routine.

Engaging them in learning about others either individually, or about agencies/programs that are working well in and for the community that you might partner with for example Head Start programs, the Indian Health Services Community Representative Programs, faith based programs, community organizations (Family to Family Health information centers, Parent to Parent) early intervention and senior citizen programs, cultural programs, who can help you not only gain acceptance in the community but help out in the dissemination of your information and materials.

Let them know that you are working towards being reciprocal in your outreach and engagement of the community and you need their input and guidance in doing this.

Let them know that you are unaware of their customs and traditions and that if you do or say something that offends them, to please let you know as you want to learn how to improve your skills in working and providing services to them. Being straight forward and upfront is often a good rule to follow, it is also important to use examples of what you are saying.

There are many quality resources for you to learn from and use such as; Genetic Alliance, Family Voices in the states, the National Center on Cultural Competency, Peace Corps, State Title V programs, National Head Start, Congress of American Indians, National Council of La Raza, and National Alliance for Hispanic Health, besides the city's chamber of commerce you may find that they have a Hispano, Chinese, Native American, African American, Filipino Chamber of commerce all are great resources and easily found by goggling on line.

seek out trusted community indiv.