

PROJECT PUEBLO CONNECTIONS

NEEDS AND SUPPORTS FOR PERSONS WITH DISABILITIES IN FOUR SANDOVAL PUEBLOS:

FINDINGS FROM FOCUS GROUPS SUMMER 2006

■ INTRODUCTION

Project Pueblo Connections was created in September 2004 as a collaborative partnership between the University of New Mexico's Center for Development and Disability (CDD) and Five Sandoval Pueblos, Inc. It provides a network of support in the pueblos for families who have members with a disability. There is a Family Support Center in each pueblo with a Family Resource Specialist (FRS) who is available to offer support and resource information. Each Pueblo also has its own Family Planning Council consisting of 3-5 members from the community who have a child with a disability or have a disability themselves. The Councils meet monthly to guide implementation of all aspects the Family Support Center in their Pueblo. The Project also awards grants worth \$2200 to at least 20 eligible families a year for them to spend on services or items which will help their individual circumstances.

Four focus groups were held in Cochiti, Jemez, Santa Ana and Zia to assess the impact, process and further community needs following the Project's first 18 months of operation.

■ PROCEDURE

- Using the notes from a brain-storming discussion involving staff members of Project Pueblo Connections, a series of six key questions were produced to present at each focus group (see Attachment 1).
- The Family Resource Specialists (FRS) from each of the four pueblos were designated to invite interested parties to attend meetings held in June and July, 2006, and to find a suitable, convenient room in which to hold the meeting.

- There were 31 participants in total, and attendance ranged from nine in both Zia and Cochiti to five in Santa Ana. Participants included 12 with roles in Program Services, ten family members, three with roles in Education, three Family Resource Specialists (who also have family members with disabilities), two tribal Council members, and one healthcare provider.
- Each household with family members attending received a \$25 stipend after the meetings to cover any costs incurred by their attendance.
- Rachael Sanchez, Project Pueblo Connections Coordinator, moderated the meetings, assisted by Patricia Peebles, a research associate at CDD, and Tanya Baker-McCue, Director, Family Support Division at CDD, who both took notes. The meetings were not recorded and participants received assurances that no names would be mentioned in the subsequent report.
- The notes from all four meetings were examined to establish common themes.

■ FINDINGS

A general summary of the themes to emerge from the four meetings is accompanied by a selection of comments by participants. Unless stated otherwise, it may be assumed that the theme arose at all four meetings.

I. SUPPORT FROM FAMILIES

The strongest source of support for people with disabilities comes from their own families. Participants cited many examples of their own families providing support and understanding, such as:

“The family itself is a good support system. My granddaughter was born with a cleft palate and has gotten speech and language services – but from day one as a family we have supported her emotionally.”

“My family shows support. My sister has taught my nieces and nephews to be very careful with him (son), and they defend him. They’re always watching out for him. It teaches other kids by being role models for them. It teaches them respect.”

It was felt that the support process starts with the family and then spreads out to the community:

“Families are very supportive of their own family members. This rubs off on community as a whole. They see respect for an individual with disabilities.”

“Someone needs to explain, slowly but surely, individual by individual, how hard it is to face a life with disabilities. Let’s be nice and kind and gentle. It starts with the household, being positive about your own family and in your family.”

a) Word of Mouth

The family units are also supportive of each other and use the power of word of mouth as a means to communicate within the pueblos:

“Informal communication or ‘word of mouth’ is very strong in the village and can be very powerful. There’s a certain individual everyone talks about and is concerned for. Talking about individuals can help get things done.”

“If one family gets help, then they let others know.”

“Word of mouth is working to get more referrals. Families are talking to each other about it.”

There can be a negative side to this in that it raises issues about confidentiality:

“As a service provider you need to have boundaries and protect confidentiality. We need to be encouraging without giving away too much detail. Have to balance gossip with need for service.”

It plays in to the fear of stigma and being labeled which is widespread in the pueblos.

b) Stigma and Labeling

This issue was mentioned numerous times by participants:

“People are fearful to openly accept services in their own community because someone may see them.”

“No one wants to admit their family has a problem. We’re afraid our problems will come out in public, and we worry about confidentiality. Families need help to be proactive about their problems.”

“Younger individuals with disabilities are cared for by their families. Some families are very protective and don’t want services.”

“People don’t want to be categorized or labeled or assessed, so they don’t step forward.”

“Parents make their children stay back because they fear people laughing at their child.”

It was suggested that meetings should be open to all the community, not only because everyone needs education in disability issues, but also to help those families that suspect they may have a problem:

“The collaboration and communication between the programs should be open to all community members, not just those with family members with disabilities. Sometimes there’s too much pride in the family, so if they’re trying to keep a suspected disability quiet, they can get the information without drawing attention to themselves.”

II. NEED FOR EDUCATION

Although the immediate and extended families of adults and children with disabilities may provide a lot of material and emotional support, there was a clear message from all four meetings that there is still a large segment of the population in the pueblos who are not aware of issues around disabilities, particularly ‘hidden’ disabilities, such as learning disabilities and mental health issues:

“My grandson has ADHD. People in the village don’t understand their problems”.

“Everyone knows what’s happening with X’s son and we know his limitations and know not to be offended at what he says. People in this room understand, but not so much in the community.”

“Some children still tease and laugh at other children with disabilities.”

However, there was also a generally positive feeling that, although there’s still a long way to go, gradually people are becoming more aware of disabilities issues:

“Community has a responsibility. But people are becoming more familiar and compassionate, and more understanding.”

“There’s more awareness, more acceptance – not fully, but people are learning that these people exist and are part of the community.”

There was broad agreement that education is the key, not only for those families who have a member with a disability so that they understand it, but for every segment of the community.

“Disability is not a priority – it isn’t high on the tribe’s agenda. Falls back on education. Tribal members, community, families, etc. don’t know about it.”

“Most people think it will be a quick fix, and our clients don’t access mental health care. They just see a doctor about physical problems, and forget the mental aspect.”

“We need to support the whole community, make them aware. If the community is going to accept our children and grand-children then they need to be educated. We need to set up workshops which involve both tribal and community members. These kids are their children and this is everyone’s problem”.

They pointed out that people with disabilities also need community support to help keep them safe:

“My daughter was sent to school, and she’d get lost and be standing in the middle of the road. She looked normal but had major disabilities. People in the community don’t understand that a lot of things can go wrong.”

In addition, care plans cannot be left to the schools as often happens, nor can adequate care be achieved with a ‘quick-fix’.

“Need information for all disabilities and learning disabilities, including mental health and more hidden disabilities. Parents tend to leave it up to the schools, but if the school isn’t doing it then they need other sources of information, e.g. mental health services.”

“For older people who have a disability, community often doesn’t understand. They think there should be a quick fix. There’s not enough information out there about disability.”

“Even the individuals themselves don’t understand what’s wrong with them. I’ve been to so many conferences and I have so many certificates, but we need a person to answer their questions. It’s a long fight, and there’s still a lack of understanding.”

“Even professional people don’t know where to direct you.”

III. BARRIERS TO EDUCATION

Even when cost was not an issue and a training was set up, the lack of awareness about disabilities can halt education attempts. For example, one educator described:

“We were scheduled to go to a training on disabilities, at no cost, but the tribal staff stopped it because they didn’t think ‘disability’ was part of the education program. We need to educate other staff that work with the tribe on disabilities.”

“More children with health and learning disabilities are going to school locally, but they have hidden issues.”

a) Role of Tribal Councils

As would be expected, the Tribal Councils play a large part in what happens in the pueblos, and how much funding will be devoted to disabilities issues. One participant related what had happened at her tribal council meeting:

“There’s a general lack of awareness. When the budget for the upcoming year was presented to the tribal council, one of its members questioned the amount for psychological services, saying we don’t have that many people using it, and asking the council members “Which ones of you here are crazy?” It signifies labels and ignorance. The stigma is there which people don’t want to accept. They don’t want to learn about the norms.”

Another remarked that even getting on the Tribal Council agenda is a challenge, because *“Only the male head of household gets to be on the council – ladies aren’t able to attend.”*

Another talked about the issue of denial:

“It can be hard to know how much to push. The council may not want to hear. It’s the same thing with alcoholism and domestic violence. There’s denial and they don’t want to admit a problem exists. It may be better to approach council members individually or in small groups to get the message across.”

b) Poor Attendance at Education Events

Even when there is tribal council backing there are still immense problems in educating the wider population, not least the problem of getting people to attend such functions:

“We could hold a disabilities awareness fair, but the challenge would be in getting people to attend. The attitude would be ‘it doesn’t affect me or my family’. Also when passing out flyers, it’s too easy for them to say, they didn’t receive one.”

“Getting the community to attend educational presentations is a big problem.”
With the next response *“Exactly – how do you get them here?”*

Some suggestions were offered:

“You’d need food and door prizes for any function, and you’d need to put pressure on the extended family to come because “it’s important to me.” Word of mouth will help.”

“Sometimes evenings aren’t the best times, except maybe in Autumn or Winter. Summer isn’t a good time.”

“Let the children do recreational things then whop ‘em with something educational. Maybe talk about having respect for each other. The challenge is getting their attention. Hands-on activities help.”

“I had a very successful parent group. Initially I used to sit there by myself, and gradually the parents started coming through word of mouth. The middle of the day turned out to be a good time to hold the group.”

Another participant told the meeting about a successful education day at another pueblo that could provide a model for future events:

“One pueblo had a community awareness day where each tribal program created a brochure and gave a 5 minute presentation. High School kids were given a half day off school and also came to it, and they went round the offices. It also let High School kids know about career choices.”

c) Attitudes among Families

Another barrier to successful education is often the family itself that has a member with disabilities.

“The problem is getting people to WANT to be educated. Unfortunately the quick fix solution is often to send away the family member with a disability to an institution or nursing home.”

“An individual has to want to be helped. You can’t force them.”

However, gradually there are signs of improvement. One participant described not only the increased availability of conferences, but also her own experience in ‘coming out’ about her disability at one of them:

“Finally we’re having conferences for all programs, that people are starting to attend. Education is the key word. At the last vocational rehabilitation meeting I attended my goal was to come out of the closet. I’d previously been afraid to approach programs. There’s a fear of speaking out at conferences. I’ve never heard anyone talk of individual problems.”

IV. LIMITED SERVICES IN THE PUEBLOS

Although participants from one of the pueblos spoke highly of their public health service, in that: *“We have a great medical social worker – very committed and dependable - who has been in the village a long time. The IHS team is very good and dedicated too.”*, the general feeling from all four meetings was that services in the pueblos are severely limited. There are several factors contributing to this situation,

a) Difficulty in Getting Qualified Staff

Generally, qualified staff do not want to travel out to the pueblos, despite there being money available in some cases. For example:

“Money is there for 0-5 but isn’t used because I haven’t the staff to get the program going.

“We need to bring in more training and service providers – they’re too far away”.

“Programs in the pueblo are limited to those with available staff and resources.”

“(We need) a health center in the pueblo for elders. A lot of health programs don’t come to this pueblo.”

“Therapists don’t want to drive to the pueblo. I had to drive my daughter to Albuquerque as they would only do an evaluation there and didn’t want to continue with hands-on therapy.”

“We’re constantly looking for therapists as they don’t like the drive and then quit on the kid.”

Another problem cited with outside service providers coming into the pueblos was with translation *“We need translators.”*

b) Difficulty introducing New Programs

The bureaucracy required to get a potential program accepted by the tribal councils was cited as a further problem.

“Your project may be ready to go but it has to go through administration. It comes up against a lack of understanding and then gets put on hold. A project needs a lot of work to get through tribal administration. It needs one of the tribal governors to understand the issues.”

“Tribal sovereignty presents a challenge. The tribe wants to retain control of which outside agencies can come onto the pueblo, but it’s a very long approval process. People in the pueblo have a right to services to better themselves.”

This problem is compounded by the yearly rotation of council members and governors. As one participant pointed out:

“The tribal administration/governors are appointed year to year. Sometimes they may be very supportive of social programs while others have a different focus. By the time you have educated one governor on social needs, he is leaving.”

However, it was also noted that *“The Pueblo is letting other programs come in, starting partnerships.”*, so the situation is beginning to improve. In addition, the participants at one of the meetings felt that their *“Office of the Governor listens to issues and gives the time to hear things out, even if a decision isn’t made immediately.”*

c) Services Needed

Participants talked about the services they felt their pueblos really needed. The list included:

Respite Services.

“There aren’t enough respite services. We can’t find sitters. Children with disabilities need constant supervision, so you need a knowledgeable sitter prepared to give their whole attention.”

“Need respite care in the pueblo. We have to drive to Bernalillo. There are carers around but they have to train with the agency”.

“There’s no respite at all in this pueblo. We’re pushing for day care. We need an accessible and dedicated building. It would be a real good thing for many parents.”

Adult Day Care

“There’s a need for an adult day care. If the family needs to run errands they could drop their family member off. It could provide respite even for an hour or so. Families face the choice of work or staying at home. Adult day care would mean at the end of the day, families could have dinner together around the kitchen table.”

Home Care Provider or Companion

“Older seniors don’t have a home care provider or companionship, although seniors can stay as long as they want at the senior center – and many do spend the afternoon there. The city of Albuquerque’s Senior Companion Program provides two senior companions for us for four hours a day.”

Other services mentioned were: Early Intervention programs, 3-4 year old programs, better clinic hours (*“Our clinic is only open twice a week so people have difficulty getting an appointment. This service after 5 o’clock would be good.”*).

“We need more programs with well-qualified individuals, including: probation officers, trackers, child therapists (specializing in play), cultural motivators for the young people, and more support groups, such as AA or Al Anon.”

It was mentioned at one of the meetings that there is a disabilities coordinator with the Head Start program in the pueblo, which works well, as it *“helps catch disability for Early Intervention.”*

A final problem is with some of the villagers themselves, even if services were abundant and available:

“People prefer the traditional methods of treatment over professional care. It’s a cultural thing not to go to the doctor. This repositioning isn’t going to happen over night.”

d) Research and Grants

One participant pointed out that:

“If we have more programs, we would need more qualified people and will have to pay them accordingly. We need at least two full-time grant writers. We also need inter-tribal cooperation.”

However, successful grant applications necessarily entail back-up data to show a need, but *“We don’t like our people to be studied”*. A suggested solution was *“to push to do our own IRBs to do the research and evaluation.”*

It was felt that more research would be helpful to establish the community’s real needs. One participant commented:

“The community members are all stakeholders and we should all have a say. A survey could find out what is needed.”

e) Need for Collaboration between Programs

“We all need each other. I can’t imagine doing my work without the support of families or community – we’re all inter-dependent.”

There was common consensus that better collaboration between programs and better communication about what they can offer would make a big difference to the quality and effective use of services in the pueblos.

A few participants who work with people with disabilities felt collaboration worked well for them:

“Collaboration among departments works well. I feel confident calling upon different departments. For example if I want someone transported to an appointment, I’ll call CHR. Once it gets going, the ball starts rolling, and the focus is on the individual.”

“We have more programs now and we communicate together as teams. We work together within other programs, which aren’t necessarily disability-based. You get ‘I never knew about this till you guys came around.’”

However, for the most part, the impression was of ignorance and confusion about what programs existed, what they can offer, and who is eligible:

“We need agencies to work together. Social Services don’t carry applications you need. We don’t know what Medicaid will pay for or who is eligible for what.”

“Don’t know anything about it, how it works, how many different offices/programs serve people with disabilities, how does collaboration work? A community meeting is needed so that we know about it. Otherwise we have to really search for this information.”

“Getting programs to come together to work with each other (is a problem). It needs a facilitator or leader, otherwise everyone wants it their way as programs come with their own agenda and ideas.”

Collaboration between the tribes was suggested, especially in training:

"We could have combined trainings with a neighboring pueblo."

f) Need for Advocacy

As suggested in the last comment, there is a need for leadership and advocacy for people with disabilities. Many participants want that leadership to come from parents with children with disabilities:

"We need more trainings and parent advocates. You need the support of another parent, so you can feel I'm not the only one going through this. It hurts to hear teachers say your child isn't up to grade level. I didn't want to go to meetings to hear this. I was in denial. It's better to hear things from another parent."

"I was told I couldn't get SSI, told they couldn't help me. I needed someone to back me up, otherwise it's discouraging to keep going back."

"We need parent advocates who can spread the word."

"Need to build advocacy even between neighbors."

"Take vocational rehabilitation. When they go there, they are sent to school right away. They need an advocate there for people with disabilities. Why can't we have a person to accompany them?"

"People suffering from alcoholism and depression need an advocate to go with them. People in the village cannot explain their problems. Kids like this don't want it, but no place to go. They can't express themselves. There's a lack of advocacy and knowledge."

Along with the need for advocates is the attendant need for specialized training:

"We need to be educated about available programs and disabilities law. Professionals use terms like IEP and other terminology we don't understand. We need information to understand what to expect. Parents sign things they don't understand."

"When there are different therapies available, you need to shop around for one that suits your family. Parents don't know they have the right to choose."

"We need education on parents' rights. It took my grandson 90 days to have his IEP implemented. It should happen within 30 days, but didn't know how to ask for help."

"A lot of us as parents need to know our rights and what we can ask for. The kids' disabilities are invisible and the tribes don't realize. I don't think our administration knows how many of our children have disabilities. There's the attitude, you're labeled, so get the services."

This same participant remarked *“Even at an Indian Education Summit no one mentioned children with disabilities.”*

Another participant spoke about the particular cultural need for someone to advocate on behalf of the villagers:

“As Indians, if we are denied, we give up. We don’t want to be labeled or to be seen begging for help. We need an advocate to help appeal.”

V. INFRASTRUCTURE

a) Transportation

The infrastructure on the pueblos adds to difficulty obtaining services, particularly transportation. As one participant remarked *“There’s too much travel required for the area served.”*

“Personal transportation is a challenge, as vehicle adaptation needs money. It’s hard even to go to the grocery store or to pick up commodities. The GSV (government service vehicle) van is not available as there’s a lot of bureaucracy to go through.”

“We need more GSVs with drivers.”

“Insufficient transportation and limited availability. Even people going for dialysis have to sit and wait.”

“Transport is a problem if your own vehicle isn’t equipped with a ramp. It can make people housebound. They need to call in for help with transport. CHRs try to bring people to appointments. Families often don’t have transport. They need social community integration, or they get isolated.”

“CHR needs 3 days notice to ensure transport is available for appointments. However, it’s easy for people to use lack of transportation as an excuse not to attend.”

The option of **Tele-health** was raised by the facilitator as a possible solution to transportation problems.

Our clinic is only open twice a week so people have difficulty getting an appointment, so this service after 5 o’clock would be good.

Participants also felt it could solve the problem of service providers, especially therapists who would not drive out to the pueblos. However, they expressed doubt about whether the seniors would accept this form of health service easily, also whether the pueblos generally were far enough into the technological age to embrace this mode of service.

“A lot of elders don’t use a computer. Younger people may be more interested but not too many have a computer.”

It suggests much preliminary work is required to educate the population in the advantages for them of this kind of health care.

b) Physical Access Round the Pueblos

Physical Access round the pueblos seems to vary. Participants spoke of wheelchairs having to be carried onto the plaza and the need for a special trail suitable for wheelchairs. Participants also spoke of *“a lack of accessibility in homes”* and the further difficulty associated with *“finding qualified reliable builders”* to do the necessary remodeling. However, another participant felt that in her pueblo:

“Apart from the older buildings where the doors are too narrow, most tribal buildings have handicapped access, and restrooms have been modified. Public Service now makes new housing accessible too. The tribe has done a good job”.

VI. How can Service from Project Pueblo Connections Improve?

a) Process

Some people had comments on the process for getting the grant offered by PPC.

“Application is vague – not enough criteria as to where the line is drawn, when you can use the money and when you can’t. The intention is for the FRS not to ‘lead’ families into their decision. However, you need someone to help fill out the application who understands their needs. That could mean a gym membership or a play station. There’s an example of a little boy who has a hip problem and is inside a lot and got a play station. Another needing physical therapy got a swing set. Determined on an individual basis. Needs a professional to help families think of diverse ways they might help themselves with the grant money.”

“You need to review the process. Do the family plan first and then the grant application afterwards.”

“Families should not have to pay taxes on the items. Sometimes families don’t have money up front and can’t wait to be reimbursed. We need flexible ways of getting goods. Our finance dept has helped PPC to get goods for families. It’s important to work together.”

Another participant speculated whether *‘grants should be smaller in order to serve more people.’*

b) Family Resource Specialists (FRS)

The feeling among all participants was that *“The average person doesn’t know she’s there.”* and those that do *“wish FRS could have more hours”*.

“You definitely need to offer more hours. People come looking and the FRS is not around.”

“(We need) more visibility of people working with persons with disabilities, doing more PR work with directors. We don’t even know who they are.”

Participants also felt that the FRS should try to team or collaborate with other agencies:

Part of it is networking with other agencies. For example PPC brought in an outside agency, Parents Reaching Out (PRO) and Parents for Behaviorally Different Children.

“FRS could be available for collaboration meetings, etc., so we don’t duplicate services.”

Suggested ways to increase visibility and reach included:

“You need to get in front of the Council, get on their agenda and make a presentation. You may need to give them examples, i.e. numbers and specifics. For example show them a piece of paper and have it look like what the child sees. Also show them how the money has been spent and what it has done for individuals. You need to keep explaining why the money has been spent in the way it has. For example a play station is very important for a child who can’t get out. You need to do this every year since there’s a change of government every year.”

“PPC needs more visibility in working hours to communicate with other agencies. There’s a general lack of awareness. CHR and the elderly program didn’t even know about PPC. This could be achieved, for example, by having lunch at the senior center. It’s a good place to do PR. They could also do a presentation at one of the monthly health advisory meetings, or for the CHR program. You could also have periodic meetings with the office of the governor to keep relationships strong. And you need regular meetings with service providers at the tribe level to spread the word.”

It was also suggested that the FRS could act as the intermediary for other services that might not be so obviously needed, such as:

“Program could help find other suitable services eg finding a qualified reliable builder to make a ramp. Make this network of services from both inside and outside the community available.”

Also the FRS should keep a *“ list of resources. It would be nice to have a current directory.”*

c) Family Support Centers

Each pueblo has a designated room which is the Family Support Center for the Project, and which the FRS uses as her base. Client files are kept here in locked cabinets, as well as resource materials. The centers seem to suffer from the same lack of visibility as the Family Resource Specialists themselves. Participants suggested more advertising would help.

“Family Support Center needs to be more visible. Use flyers, signs, posted hours.”

“You need more advertising, and information about the different kinds of disability – it’s not just people in wheel chairs. People don’t understand what a disability entails. People don’t realize there’s help for people with disguised disabilities.”

“Need advertising. Not many people know about your services. In a newsletter, for example, you could give information about the FRS. There used to be a newsletter every month. There should be something every month, either meetings or descriptions.”

“It needs to be utilized more with office hours posted. People shouldn’t have to call for an appointment. Members come to the office and may not take the initiative to make the call. I have issues with that, and would like to see consistency in using the office, and more accountability.”

The location of the centers varies between pueblos, but it was recommended that:

“It needs to be in a central area where health, education and social services can work together. FRS needs to be closer to the community center.”

“Have the Family Support Center be a resource center where everyone, providers/therapists are based, from where they go into the homes.”

The provision of support groups, which could meet at the Center, is a popular idea:

“Parent – to – parent would help. More support groups would help.”

“I’d like the Center to provide Family Support Services including a support group for exchange of information, etc.”

“There’s been talk of starting a support group for parents and siblings. It should be geared to the family and include siblings, who often feel left out. When you live with a disability in the family, siblings wonder why that child gets more attention. My boys have learned to deal with their brother. They know to leave him alone, but family therapy or counseling would help my family.”

Overall, though, the effect of “PPC has been helpful bringing services to families instead of them being isolated.”

■ ISSUES FOR CONSIDERATION

- More hours for the Family Resource Specialists
- Use creative measures to increase awareness of PPC in the community
- Introduce a newsletter
- Offer training for all segments of the community and between pueblos on disabilities issues
- Introduce innovative ways to encourage attendance at training events
- Make presentations to the tribal councils on a regular basis
- Introduce support groups at the centers
- Take a proactive approach in working with other programs and services in the pueblos
- Facilitate needs assessments and grant writing in the pueblos

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Questions for the Pueblo Community Focus Groups to be held
June/July 2006

Purpose of the focus groups: To assess the impact, process and further community needs following the creation of four Family Support Centers created to serve the needs of children and individuals with disabilities in four pueblos in Sandoval County

Opening question

(Designed to establish common ground and to encourage all participants to talk early on)

- Tell us your name, whether you have members of your family who have already used the Family Support Center, or may do so in the future, and tell us the best thing to come out of it for your family.

Introductory question

(Typically an open-ended question allowing participants to say how they see or understand the core issue)

- When you hear the phrase “services for people with disabilities in the Pueblos”, what’s the first thing that comes into your head?

Key questions

(4-6 questions for a 90+ minutes session, which will include probes or follow-ups by the moderator)

- Considering all the possible forms of support – health, education, social services, friends and family, and so on - what do you see as working well on the Pueblo for people with disabilities?

Probe: How and why do some forms of support work better than others?

- How could the Family Support Center function better?
- What are the particular difficulties for individuals with disabilities on the Pueblo?

Probes: Acceptance on the Pueblo? Awareness of their problems? Accessibility problems (e.g. ramps, wide doorways in public buildings, etc.? Transportation? Access to information and services? Technical issues?

- What are the challenges in coming up with solutions?
- How would you describe an ideal set-up for people with disabilities and their families on the pueblo?
- Is this a realistic aim? How does it differ from the current situation on the pueblo?

Probes: Is there a willingness among pueblo residents to make necessary changes? Is it likely to be a priority? How costly will it be? How long would it take? Will the changes last?