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Indigenous and Informal Systems of Support

NAVAJO FAMILIES WHO HAVE CHILDREN WITH DISABILITIES

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In the United States, many have come to believe that families and family involvement are the most important factors in supporting children with disabilities. Families exist within an ecocultural environment that is complex and powerful, and it is within the family context that development in all its forms begins and is nurtured. We cannot understand what family involvement means without understanding the culture of families and the informal systems that families use to adapt and operate. In this chapter, the example of Navajo families with children with disabilities underscores and shows in high relief the heavy reliance on cultural support for families that is part of any family system. As early-intervention and family support programs continue to grow in the United States, we need to understand and sustain those benefits of indigenous systems that provide support and relief to families even as we seek to engage families in the use of supports that may be offered by private and public agencies.

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Two complementary systems operate to fulfill the needs of Navajo and other American families who have children with disabilities: one is the indigenous adaptive system and the other is the public health system that has been established nationally in the United States with local options. One example is the Individuals with Disabilities Education Act (IDEA 1997), parts B and C, providing early intervention, preschool, and school-age services. The indigenous system was in existence long before the IDEA, but has not been recognized as such. Both systems attempt to increase the well-being of families, but because all adaptive systems have a cost, neither system is totally benign. Each system extracts some payment for the benefits it provides.

When discussing costs, our intent is not so much to point out financial costs, which are often involved, but to show that costs to families can be more subtle, such as the erosion of family responsibility and satisfaction with the efforts the family makes on behalf of the child with a disability. Thus, in the Navajo sample, families identified medical disabilities and sought help for medical problems from professionals but were sometimes unable to resolve their anxiety until they involved spiritual services or indigenous healing practices. Conversely, Navajo families did not identify learning disorders in the preschool age group that we interviewed. Learning and language disabilities were primarily identified by professionals and schools, who in turn sometimes found families apprehensive and reluctant to adopt an active role in early-intervention efforts that they had not sought themselves.

This chapter will examine the indigenous systems of support that a particular Native American culture uses to adapt to the situation of having a child with a disability. Families use spiritual and other informal supports to meet some of their needs. In addition, bureaucratic systems of support for Navajo families include: the Indian Health Service and other professional medical services, early-intervention programs, financial assistance programs, preschools and Head Start programs, housing programs, alcohol treatment services, and formal support groups. An examination of the indigenous systems of support is essential in any culture in order to understand family involvement and how public health programs might work to either foster, augment, or supplant informal systems. Space and time limitations preclude a thorough investigation of both systems, and this chapter only examines some of the costs and benefits of the indigenous system, leaving the evaluation of public health systems for another time and place. It is hoped that a study of the services provided in the United States and Mexico will explore the most beneficial and least destructive practices when implementing services.

Learning about Navajo Support Systems

The information for this chapter comes from ethnographic interviews of families on the Navajo Indian Reservation who have a child in an early-intervention program. The IDEA provides funds identifying children with "delayed learning" or who are at risk of being delayed so that they can receive education that will help them to catch up to normal children by the time they enter school. A total of twenty-nine children and their families was recruited for this study. Families were identified through program staff in three areas and programs: the school district in the Utah

strip of the Navajo reservation; the Saint Michael's Association for Special Education, which included families in the southeastern area of the reservation in both Arizona and New Mexico; and the Navajo tribal program "Growing in Beauty" in the northwestern district of the reservation. Staff members in all three of the programs were asked to identify and recruit families who had children enrolled in their early-intervention programs.

Each agency provides a different program. The public school district providing services for children living in the Utah part of the reservation has identified many Navajo children as being at risk because of socioeconomic status and language. Saint Michael's Association for Special Education is a non-profit reservation school that provides direct services to children with disabilities and their families. The Navajo Nation "Growing in Beauty" program is primarily a referral service that works with the Indian Health Service and other programs throughout the reservation. The particular area served by "Growing in Beauty" in the study was the farthest from towns and the least accessible to services, though all three were rural. Ten families were referred from the St. Michael's program, ten were recruited from the San Juan School District, and nine families were referred by the "Growing in Beauty" program.

Agencies interviewed families in their own homes, using open-ended but directed topics. "Tell me about your child since he was born," for example, was usually one of the first questions. The primary caretaker of the child was interviewed, as well as other caretakers such as grandparents and spouses. Interviews were recorded so that the interviewer was able to listen and respond to the family. Several of the families were visited more than once, since the interview process was lengthy. The interviews were conducted primarily in English.

Among the topics that were addressed during the interview were: the resources the family used to adapt to the child's disability, the family's daily routine, and the supportive resources that family members used and how they used them. The focus was on the family's daily routine, with particular emphasis on how the child with disabilities was integrated into that routine. Family members were asked to describe typical days at home and normal routines with their children.

Participants

In the twenty-nine families interviewed we found a variety of living situations. The most common was the expanded family, in which more than one nuclear family was represented in the same household. Some families included grandparents or grown siblings who lived together. Other relatively common expanded families included nieces or nephews. The Navajo language uses the same terms for cousins and brothers and sisters. When speaking English, a Navajo might call a cousin "my cousin-brother" or just "my brother."

Over 65% of the families lived in "camps," or compounds, in which extended-family members lived in the same rural area or neighborhood but in separate households. Parents living with grandparents were as common as those living independently. Although 24% of the parents were not married, only 10% lived as the only adult in the family (see table 1).

TABLE 1 *Household composition of Navajo families interviewed*

TYPE OF HOUSEHOLD	N	%
Two Parents living independently	9	31.0
Two parents living in expanded family	11	38.0
Single parent living independently	3	10.3
Single parent living in expanded family	4	13.9
Other *	2	6.8

*Children in foster home.

Parents in any of the above situations may also live in a compounded family, or camp, so that the independent household might be living in a family camp. Nineteen families, representing 65.6% of those interviewed, lived in a family camp. Six families (20.7%) lived in a Housing and Urban Development, (HUD) project in a reservation town. The other families lived in trailer parks or employee housing on the reservation.

Mothers' ages ranged from 16 to 49 years, with a median age of 31.8. Fathers had a similar age range, but were slightly older. Education and employment are shown in table 2.

TABLE 2 *Education and employment of Navajo parents interviewed*

EDUCATION AND EMPLOYMENT	MOTHERS (%)	FATHERS (%)
Educational Level		
Less than high school	31.0	14.8
High-school graduate	37.9	51.8
GED ^a	17.5	14.8
Some college	6.8	18.6
College degree	6.8	0.0
Employment Status		
Not employed	62.1	33.3
Self-employed ^b	7.4	28.0
Intermittently employed ^c	13.8	37.0
Employed full time	24.1	33.3

^aPassed general equivalency.

^bSelling or trading own arts and crafts or ranching and selling or trading livestock.

^cEmployed on temporary basis either full or part time, such as in short-term construction, handiwork, or crafts.

*Some were *both* (b) self-employed and (c) intermittently employed.

Medical Profiles of Children with Disabilities

Most of the children in this study had major medical problems. It is presumed that any sample of children in early-intervention programs on the reservation would be medically involved, because the majority of children was identified by the Indian Health Service. Parents generally did not identify other disabilities or seek services for children who were not medically involved. Some schools in the San Juan School District enrolled children who were at risk. These programs worked with the home-based education program for adults, and they recruited the children in these families for the early-intervention program.

The average age of the target child was 24.7 months. Some 38% were girls and 62% were boys. The majority of children with disabilities had siblings living in the household. The median number of children in a family was 4, and the average number of siblings for the target child was 3.1. Nearly 38% of the households had more than 3 siblings, not including the target child, in the household. The children's diagnoses are displayed in table 3. (Diagnoses are not mutually exclusive. One child may have more than one disability.)

TABLE 3 *Identified diagnoses of Navajo children with disabilities*

DIAGNOSIS	%
Developmental delay	24.1
Chronic medical problem (heart, digestive, other)	24.0
Down's syndrome	17.2
Respiratory disorder	17.2
Seizures	10.3
Speech delay	10.3
Motor delay	6.8
Metachromatic Leukodystrophy	6.8
Fetal alcohol syndrome	6.8
Microcephaly	3.4
Cleft palate	3.4
Brain tumor	3.4
Emotional disorder	3.4
Neurological handicap	3.4
Spinal stroke	3.4
Unspecified syndrome	3.4
Normal/at risk	17.2

Sources of Support

Parents were asked to tell the history of their experiences with their child. Support sources were identified from the conversations as those resources that the family reported as having helped them either instrumentally or emotionally with their child. Descriptions were elicited by asking families to describe things that helped them or gave them strength with their child. If the family said that they sought support from religion, including traditional Navajo ceremonies, that was considered a support source only if they mentioned it specifically as support for coping with the child with the disability. Among this sample of Navajo families spiritual resources emerged as the leading source of support. Other family members and grandparents were the second and third sources of support for families. Relatively few of the Navajo families looked for support from professionals, and a large percentage of the Navajo families used more than three sources of support (see table 4).

TABLE 4 *Sources of instrumental/emotional support*

TYPE OF SUPPORT	%
Church/religious including Navajo traditional	88
Other family members	84
Grandparents	64
Friends	12
Professional therapy	8
Other families with children with disabilities	4

Spiritual Support

When asked if there had been any other help a Navajo woman received for her son, she answered, "Yeah, traditionwise. We had a ceremony about three times for him. . . . They just told me, you know, he's doing good and he'll do better. You know, just talking to me, and it's worked out OK. It took a lot off my mind. It took a load off my shoulders, you know."

Some 95% of the families interviewed mentioned spiritual services as part of their lives, and 88% said that they used spiritual sources in providing support to their child with a disability. Families made a distinction between two different kinds of spiritual services: traditional ceremonies and church services. Navajos used the term "traditional" for ceremonies based on the Navajo creation story, and also at times for Native American church ceremonies. It was clear that a "ceremony" and a "church service" were seen as different types of spiritual practices. One father explained, "I go to church whenever time permits, but I'm pretty traditional since my mother and my father were traditional Navajos. That was just their way. We had ceremonies for her [the child]. I know a lot of people that are . . . they per-

form different types of ceremonies. Traditional Navajo. And I think we went to one person who was NAC [Native American Church] who was over south of Gallup."

"Traditional" Navajo Ceremonies

Briefly, Navajo ritual services or ceremonies are based on the Navajo creation story, *Dine Bahane*, which may be compared to the Judeo-Christian Bible, though the Navajo story is still mainly an oral account. Each ceremony is based on a part of the story, and there are prayers and songs that accompany that section of the story. The Blessingway ceremony is considered by medicine men to be the basic ceremony from which all the others spring. There are variations of the Blessingway ceremony for different circumstances, usually blessings for places or persons. Other ceremonies mentioned by the families studied are the Enemy Way, which is performed in the summer and the Lightning Way and Red Ant Way, which are examples of ceremonies that are still performed, though not as frequently. Some ceremonies are rare, and, if needed, it would be necessary to find someone who would be able to provide them. A *Hataali*, or singer, performs a ceremony for a predetermined fee. The singer or medicine man may talk to the client and determine what ceremony is needed, but often uses a diagnostician to determine the appropriate ceremony. Families sometimes consult a diagnostician (a crystal gazer, hand trembler, or star gazer) before having a ceremony. The specific ceremony depends upon the underlying problem, but the underlying problem must often be determined by a diagnostician. Sand paintings and herbal preparations often accompany the ritual but are interwoven with the prayers and songs in a specific manner based both on the needs of the individual who is being prayed for and the creation story.

Native American Church (NAC)

This religion combines Christianity and Native American ceremonial chanting. The communion host is peyote. There are also NAC ceremonies that do not involve peyote. Services are conducted in the same manner as ceremonies; they are sponsored by a particular family or person requesting the ceremony. A large ceremony that is open to all the members of the church is called a "meeting" or "peyote meeting." Usually the sponsoring family asks for a ceremony for a certain reason or purpose, such as to help a family member who is sick or to give strength in time of need. There are no specific ceremonies as in Navajo religion, but the ceremony is dedicated to the purposes stated by the sponsors. There is a growing body of NAC songs, and they are sold on cassette tapes in some reservation stores. The services are Pan-Indian and open only to Native American Indians. NAC medicine men or ministers are called "roadmen." The religion started in the plains tribes, and for that reason meetings are held in tepees. Usually a tepee on the Navajo reservation means that there is a Native American Church meeting. These have become prevalent on the Navajo reservation.

Bible Churches and Pentecostal Churches

These are Christian churches, with individual ministries operating independently. Pentecostal Churches are also called Bible Churches at times, so it is not always clear

which denomination a Bible Church represents. The ministers are often Navajo, and many have wide reputations for their preaching abilities. Pentecostal Churches are among the most common Christian churches on the Navajo reservation. The religion is characterized as one in which the members seek to be filled with the Holy Spirit. In addition to regular Sunday services, there are revival meetings all around the reservation during the summer.

Other Churches

Nearly every Christian denomination is represented on the Navajo reservation. One of the reasons for this is that when the governing body of the Navajo tribe was first set up, it made the process of acquiring land for church groups relatively easy. Often generations of a family stay with one church. Christian churches that were mentioned by the families interviewed were: Catholic, Baptist, Jehovah's Witnesses, Bahá'í (a non-Christian church), Seventh Day Adventist, Latter-day Saints (Mormon), Church of Christ, and Presbyterian.

Pattern of Religious Support

Of the families interviewed, 74% said that they had used Navajo ceremonies for support, 30% used Native American Church ceremonies, 33% used Bible Church or Pentecostal Church services, and 41% used other churches for support. For many of the families these were not mutually exclusive support systems. Fifty-two percent of the families practiced more than one religion or sought support from more than one spiritual source. In three of these families each parent practiced a different religion. In most of these households, however, both parents practiced more than one religion. The most common pattern was the practice of both traditional Navajo religion and a Christian religion. One Navajo mother said that at first she thought that it might be a problem to marry a traditional Navajo since she was raised as a Baptist, but now they get blessings from both sides, "intermingled or intertwined blessings." Approximately 30% of the members of Christian churches did not want their children to practice Navajo traditional religion. One mother explained, "I was never raised on the traditional ways . . . and from what I've heard from the people that go to church here, it doesn't help them at all . . . They start going to squaw dances [Enemy Way ceremonies] and learn how to drink and take up with boys at a younger age." A more prevailing view in the families was that Christianity was not in conflict with Navajo religion. This view was expressed by a father who said:

We feel that in order to prepare a child for some of the hardships in life that you have to prepare them spiritually as well. And a lot of times we see that children who are not prepared spiritually, they encounter problems, and when they do encounter problems, they don't resort to religion of any type. And then we feel like it's only their choice, but yet we try to instill in them the forms of traditional *Dine'* [Navajo] at the same time as the Christian teachings, you know, so we instill in them that one day they, when they do encounter problems, they resort to either one of them.

Spiritual support was sought during times of crisis in which a child needed to be hospitalized, often away from the reservation. One mother described her situation and the two kinds of spiritual support her family gave:

He just got weak, and we didn't know what to do, so we took him to the hospital over here [Indian Health Service], and I was up that night . . . They told me I had to go into Phoenix [with him] . . . Then my grandfather was down there, and he helped me. He prayed for the baby and me, and about a week later he [the child] was sitting up. Then my side of the family left, and I think they had ceremonies and all that done for the baby, 'cause they asked me for his pictures and all that, and his little clothes.

In the above example, spiritual support is interconnected with family support, medical services, and the extended family's resources. The mother's grandfather, a Christian minister, made a long trip to the hospital to pray for the baby, and the mother felt that her grandfather's prayers contributed to the improvement in the child. Other family members took pictures and articles of clothing so that they could have a ceremony for the child when they returned to the reservation, even though the child remained in the hospital.

Other Indigenous Support

Indigenous services are those that operate to provide services without government application. Examples of these kinds of services commonly found in all families are: baby sitting or emergency child caretaking; emotional support; financial and other help such as food and gifts for ceremonies; wood chopping; coal and water hauling; meal preparation; livestock care, including purchasing and hauling hay; and transportation to agencies for formal services and for shopping for needed items for the child or family such as dog food, diapers, or baby formula.

Indigenous services are encouraged by the kinship terms of the Navajo language for family and extended family. The reinforcement of family implicitly indicates both support and obligation for the family member. For example, when greeting family members it is appropriate to call them by their kinship term. A cousin might be called "my sister" or "my brother," an aunt is called "my little mother." In this way extended family or clan relatives are brought closer to the family. Brothers and sisters are not greeted by using their given names but as "my young sister" or "my older brother." Even people who are not directly related but are related by clan are greeted that way. This acknowledgment strengthens the bonds between family members. One of the strongest cultural tenets of Navajo society is that family members are obligated to one another. Family members are expected to take care of one another when help is needed. Asking for help from family members is normal and anticipated behavior. Typical favors family members ask are borrowing vehicles for necessary trips to town or paying for gas money, helping with ceremonies, donating money or groceries, chopping and hauling wood, butchering and cooking, and attending meetings of extended families.

In obtaining indigenous support, most of the families in the sample engaged in the same activities as Navajo families without children with disabilities. The frequency of activities, however, was greater due to intense needs. Ceremonies and

other supportive activities are requested in times of stress such as funerals, weddings, and illness. When a child has a medical crisis, it is an accepted pattern for the immediate family to ask relatives for help with ceremonies and transportation. This is part of a system that existed before the public health and government programs for families were instituted and that still provides an extensive amount of support for families, though not without costs to the family.

Nearly 86% of the families said that they received financial help from their extended families. Thus several of the grandparents paid for ceremonies for their grandchildren by selling a rug or cattle. Grandparents and other family members also helped pay expenses for off-reservation travel to hospitals. One of the parents talked about her family having a meeting with extended family members in order to raise funds for the hospital visit.

Fifty-seven percent of the families said that the parents moved in order to be closer to their extended family for child care and support. One woman said that she moved in with her mother after her child was born with a disability, but later found that she wanted to move because her mother did not understand the demands of the disability. She found that living near the grandmother, but not with her, was better. Half of the families also talked about relying on siblings and grandparents for child care. A common pattern was for grandparents to become active caretakers for the child when one or both of the parents worked, and this also happened in families in which the child did not have a disability.

Benefits and Costs of Indigenous Formal Support Systems

Culture is not uniform for all families; each family forms its own interactive niche within the systems available. Families attempt to utilize the benefits of the culture familiar to them and to minimize the costs. The benefits of spiritual services for the families were many: parents felt that the services helped their child improve physically and developmentally, and they helped families to accept and cope with their child's disability and to provide material support by gathering their resources. In addition, the spiritual services interacted with formal medical systems in a positive way by helping parents to feel better about complying with medical procedures. There were also costs involved in using the informal services: money for ceremonies, demands on extended-family resources, and the more insidious cost of shame and guilt that developed in some etiologies of disability. In the following examples the families give insight into their interactions with these systems.

Many of the Navajo families we interviewed felt that spiritual services helped their child improve. Some examples are:

Mother whose child was in intensive care at hospital: "Then my grandfather [a Christian minister] was down there and he helped me. He prayed for the baby and me, and about a week later he was—not even a week—he was sitting up. They [the doctors] couldn't believe it."

Mother of child with Down's syndrome: "But now she's [child who had Navajo prayer ceremonies performed for her] gotten to the point she's about a month behind, and other than that she's pretty well up-to-date. So she's pretty alert, and the Doctors say that she wouldn't be."

Grandmother of child with multiple disabilities: "Most the of the time she was in a daze . . . and I had a prayer done for her; then I had a couple of [large ceremonies] . . . and I took her back [to the doctor], and he told me right off, he told me that [the child] was more alert."

Parents whose child was in off-reservation hospital: "We had a traditional ceremonial, and my parents, they mostly did the peyote meetings on her . . . On the peyote meeting, they just put her clothes or anything like that for her there, and on the ceremonial they just sat her there herself, so that she could get well real fast, and it helped a lot."

Parents of child whose development was delayed and who was not sleeping well: "Families also spoke about the peace of mind these services gave to them as parents. All the nightmares went away after she [and older medicine woman] said that prayer over all three of us."

Parent of child with Down's syndrome: "[Be]cause for a while there we were just going in all directions, we couldn't get our minds focused, but that [ceremony] helped. We were like going wild trying to figure out why, why, why, and we were trying to find out answers, but [after having ceremony] it doesn't matter now. I pretty much accept it now; I accept her whole to the point that, ya know, she's our child with special needs, she [just needs special things]."

Spiritual services sometimes gave families more hope and more positive expectations of their child than the medical doctors provided. A doctor, for example, told a parent that her child would need to wear leg braces in order to learn to walk, but the traditional healer told the parent that, "it is just a slow development in her. Other than that, she [the healer] checked from her legs on up to her spine. She said everything is working perfectly, she said, but its just that it is slow getting there. She is going to grow out of it, she said. So I believe that she will." Other parents said, "The doctors sort of like discouraged us. [Then we had a Navajo ceremony], not an all-night [full Blessingway ceremony], just a couple hours of prayers. So she's pretty alert, and the doctors said that she wouldn't be."

In another case, ceremonial healing helped the family to relieve their misgivings and thus increased their compliance with the medical system while their child was in a hospital. A prayer ceremony made them feel much better about the medical procedures, and they felt that the ceremonies helped to protect their child from harm during an operation: "The next morning they [husband and son] took back off to come up [to the reservation] to have more prayers done traditionally. We [mother and child] stayed in the hospital, and we told them [the doctors] to go ahead [with the operation]."

Spiritual services also functioned to provide support in terms of gathering resources for the family. When a family planned a ceremony or a church meeting was held, family and church members provided food and other material support. Groceries, wood, and money were collected for the use of the family in need. In the rural environment of the Navajo reservation, there are few regular meeting places for extended families to get together, but ceremonies and prayer services provided these opportunities.

Spiritual and Navajo family support systems are valuable for some, but not necessarily for all individuals in families. Some members of a family may pay the

cost of keeping family harmony. The families we interviewed recounted cases of people with disabilities who paid the cost. At the same time, the recognition of the harm that these adaptations inflict seems to be a catalyst for change. A Navajo mother talks about what she remembers about people with disabilities when she was growing up:

It's like they were, I don't know, like they had no mind of their own, and I remember when I was ten years old and there was this one handicapped that was tied to the middle of this hogan. I don't know what was wrong with him. I never thought about him until I had [my son with Down's syndrome], then I thought I wonder whatever happened to him. You know, it seemed like those days Navajos didn't understand. They were afraid that this person had a *Chindi* [spirit] in him. That's how I heard it described. I think people have to talk. There's this one lady over here. I keep telling her—I don't know if I'm getting through to her, 'cause I never see her take her baby anywhere. I know her baby's Down's. We need to help each other.

One family who had the Navajo ceremony and felt that it helped them also felt that there were things about Navajo traditional beliefs that were not helpful. When he first found out about Down's syndrome, the father wanted to find out the cause:

When I got more frustrated was when I started talking to some of the elderly and even some of the people who worked in these various programs. [They told us] the only time that [genetic disability] happens is when you are actually related. Baloney, we're not even related . . . our clans did not at all relate in any manner whatsoever. [This person] just comes up to me and says, "Well, it's your fault because you were related or something like that or something that happened in your background." But that's not the case . . .

Another mother explains how her husband's extended family assigned blame when his son had a brain tumor: "That's how the extended family views him as being sick is that one of us did something that caused him to be sick. They will frequently ask questions like 'Did you drive past a cemetery or funeral parlor?' and stuff like that . . . But there was so many things that I was told that caused it . . ."

A few people talked about the financial costs of having ceremonies:

Mother of child with disability: "My in-laws are traditional so they talk to us about it [having a ceremony for their son], but we just haven't had really anything done for him yet; we just don't have the time and money."

Father of child with Down's syndrome: "I bought this real nice basket for her [to be used for a ceremony] because I wanted to get a blessing done, and it cost me a fairly outrageous price. I thought it was well worth it for [my daughter] ."

One of the heaviest costs of spiritual support for families, especially for those who used Navajo ceremonies, were the demands that were made on the families' time and resources. There were cases in which families did fund raising, sold grandparents' rugs and crafts, and provided groceries and other material goods for services. In the sample of families we interviewed, however, there were few negative comments about this. The common attitude was expressed by the parent who said it was well worth it.

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Informal support is greater in families in which a family member provides the spiritual services, as in the case in which the grandfather prayed for the child, or in which the family contributes to a ceremony. This can both strengthen and stress families. When the demands on a family are too great, the stress has the potential to be detrimental. The challenges that families face are often daunting.

A woman whose daughter was born prematurely related how she stayed with relatives for over six months in order to be near her daughter. In this case several different families helped out, and there was no feeling expressed that families were distressed by this.

I stayed with my cousin who lived there at Albuquerque . . . I didn't think she [the child] was going to make it out of the hospital. But [my cousin] said, "Oh, she will." She would talk to me, and she would give me a ride over to the hospital and then back to the house. And then she said that she went through the same thing with her daughter. Then, pretty soon, it was already five weeks went by. Then they said they wanted to send her [the child] to Gallup. We sent her to Gallup on a plane. Over there they put her back in the incubator because she had a few more IVs in her, and she needed to gain about two more pounds. I moved to my sister's over there in Gallup. We stayed with her for a month, and after that we went over to my brother's and stayed with him for three, four months.

Another woman spoke about how her nephews helped her take care of her child, but other family members were reluctant to help.

I wasn't pushing nobody to try feeding him for me or, you know, do things like what I do, give him his treatment . . . They, more or less, you know, whenever they felt comfortable, they can come in and ask if they could do something. My nephew just picked him up and now feeds him through the G-tube, and he would feed him and he's real comfortable with him. And he doesn't even fight. He fights me when I feed him at times, but with his big brother [cousin] he would just sit there and take his feeding. But other than that, my mother and everybody, there's . . . I can tell at times when they're uncomfortable with something he does . . . You can see they just feel uncomfortable at times.

The pulling away of family and friends was extremely difficult for the Navajo families that we interviewed. The father of a child with cerebral palsy spoke about needing someone to talk to who could understand his situation.

They told us he had cerebral palsy and that really hit me hard. It was the worst thing that could happen to me, you know. At that time I started thinking, "Why? Why me? Why is it?" I started having ceremonies done and I was doing everything. I went to church. I talked to people, but it seemed like nobody would understand. They would listen, but they didn't know what was going on inside, and that was harder to deal with than anything else. Not being understood.

The mother of a child with a brain tumor and other disabilities reported:

There were so many things that I was told that caused it. Going past cemeteries, dead dogs . . . working in a special ed classroom . . . I mean, all kinds of things. I felt like I was overwhelmed, and I just felt like all of a sudden my friends pulled away, his family

backed off, it was like there was no support of anybody coming around, nobody to talk to, nobody to get any other information or to share with, so it made it real, real hard.

The grandmother and legal guardian of a child with a disability complained:

It was kind of hard for me to accept, you know, that [my granddaughter] was like that, you know, that her development was delayed. It was kind of hard because I never had any experience with my children like that . . . By talking to somebody with a child like that, it, all those things, it would have helped, you know, but I come a long ways after I experience all that through myself.

The mother of a child with respiratory problems spoke about the lack of family support:

The only people I see a lot are my sisters-in-law. They say everything is my fault. I caused [my child] to be sick. I make my husband drink. There is no one I can talk to that understands. Now this one lady comes around from the Jehovah's Witnesses. She is really the only one that I can talk to now.

Another mother explained that she did not tell her parents and extended family that her baby had Down's syndrome, but she became increasingly depressed and broke down crying during a clinic visit. The doctor at that point spent more time talking to her and convinced her to talk to the family. "We told our relatives and then we had some blessings done for us and then from that point [things changed for the better]." The formal help that this family received served to strengthen the family, which in turn allowed the parents to make a decision. In this case the parents had set up an appointment for genetic testing; after the family involvement and ceremonies, they canceled the appointment and said, "It doesn't matter now."

The above case is a good example of how service providers can have a positive and reinforcing effect on a family and work to reinforce the strength of informal support. In another family the mother avoided the service providers who had set up appointments for therapy with her son, and the service providers could not understand why she did this. The mother explained:

You know, to me he knows what he's doing like when he wants something, so sometimes I think that I don't really have a Down's, and I'm just waiting for him to start walking and start talking. That's what I'm waiting for, you know. I always wondered when he's going to really start walking. At what age, you know. Two, three, you know. I know it's going to take time. I just have to have the patience for that.

This mother acknowledges that her child is delayed, but does not feel she can do anything to hurry him. She feels that patience is the best thing she can provide. She also feels that the outside service providers who come to her house mark her as having a Down's syndrome child. The same mother talks about how her other children take care of her son: "They're really enjoying him, you know. He gets all the caring, and he knows when he's going to get all that attention too. The twelve-year-old, she really helps me out. She knows what he's going through. She does treatment. She helps me out with doing treatment on him sometimes. I'm proud of her you know."

Being a parent of a disabled child drains people emotionally and physically to such an extent that it would probably be impossible to give too much help. The important thing for representatives of outside agencies to remember is that it is critical to bring the family groups together to help the child and not supplant the positive effects the family has to offer in order to achieve positive results. Thus a father whose son has cerebral palsy explained: "There were some ladies down there that were with, I think it was, early intervention. They really helped me out. They really encouraged me. They came out, and they just told me how to take care of him, physical therapy, everything." The father of a daughter with Down's syndrome reported: "I feel very confident in them helping too, the intervention program 'cause right now, the last time I had her evaluated she was maybe two weeks behind schedule over a normal kid."

Conclusions

Families within the study showed many of the common traits of Navajo families with children without disabilities. On the other hand they displayed many traits that form a common bond with families with children with disabilities from any culture in the United States.

First, these families reported, they needed to understand that their child was different from their other children in certain ways. They needed to understand the disability in a way that made sense to them within the context of their cultural traditions. This understanding grew out of interactions with both the indigenous and the public health support systems. Each family constructed its own set of beliefs about the disability or condition and its causes and effects on the child's development and its own sense of the future. Like any cultural group, the families who were interviewed did not share a universal vision with respect to any of these issues. A better understanding of both the cultural and ecological pressures on a family system leads to a better understanding of how the family comes to an understanding of disability. As family members are able to frame the disability in terms they feel comfortable with, they gain a sense of well-being and acceptance.

Second, each family developed accommodations to their daily routine based on the ecological and cultural pressures that they faced. Some families moved in with relatives. Others relied heavily on extended-family members for economic and emotional support. In some families, the extended family routinely took part in the caregiving of the child with a disability. In others, this did not happen. These accommodation patterns demonstrated both the expected cultural norm and the heterogeneity around that norm for the target families. The common features represented by the cultural norm suggested the need for service providers to understand the cultural expectations that operate in a consistent fashion within families. The heterogeneity of expression demonstrated that there is no universal pattern of adaptability rigorously followed by all members of a cultural group. Rather, it is a stereotype held up as a standard that families can recognize and react to even though it may not fit their particular conditions. The adaptive patterns generated by families are by definition the "best-fit" accommodations they are able to construct with the resources at their disposal. The disability of the target child has

forced a redistribution of resources and their ways of getting things done. As Navajo families made these accommodations based on their ecological and cultural resources, so too would any family in any culture.

1. These findings carry powerful messages for service providers within public health services, social services, and education. Stated in simple terms, these messages are: Indigenous systems are constructed in response to enduring cultural and ecological constraints. They are sufficiently forceful so that they are not easily altered without serious consequences to family well-being.
2. Public health systems will be most helpful to families when the services they provide honor, respect, and support indigenous models of belief and interaction. To do otherwise creates conflict and demands further accommodations from families already experiencing high levels of stress. The goal of such programs should be to fit into the indigenous system and require as few accommodations as possible, consistent with the mutually agreed-upon goals of family and child well-being.

Helping Individuals with Disabilities and Their Families

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