



Achieving Healthy Outcomes
for
Children and Families of
Diverse Cultural Backgrounds

A Monograph for Health and Human Service Providers

Compiled and Written by
Valerie S. Nelkin and Randi S. Malach
for
Southwest Communication Resources



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TABLE OF CONTENTS

Acknowledgments	1
About this Monograph	2
Introduction	3
Methods	3
Findings	7
Summary and Recommendations	18
Appendix	29
OPUS Family Focus Group: Lessons Learned	
Family Focus Group: Community Organizer's Checklist	
Family Focus Group: Moderator's Guide	
Other Products Available from the OPUS Project	

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ABOUT THIS MONOGRAPH

Over the past two decades, state and local efforts have continuously worked to address the multiple needs of children with special health care needs and their families. However, families of diverse cultures whose children have special health care needs experience additional struggles. Given the increasing cultural diversity of the United States today, it is extremely important to identify and replicate positive examples of cross-cultural relationships between these families and health care providers.

This monograph summarizes the results of the OPUS Project, a three-year federal Maternal and Child Health Bureau SPRANS* grant awarded to Southwest Communication Resources in Bernalillo, New Mexico. It documents the background of the OPUS Project, methods used, findings, and recommendations. The distinctively personal approach of gathering information from families and health care providers is illustrated throughout the document with quotes and stories from personal experience.

The monograph targets health care and human service professionals who want to improve their collaboration with culturally diverse families who have children with special health care needs. Providers can use the monograph as a guide to develop better communication with and understanding of families from different cultures. In addition, professionals can incorporate the lessons learned from the OPUS Project as they develop and implement programs for families whose children have special health care needs.

Culturally responsive collaboration in health care is an evolving concept. We hope this monograph stimulates some thoughts, ideas, and actions that result in stronger relationships and improved outcomes for both families whose children have special health care needs and professionals.

* Special Projects of Regional and National Significance

INTRODUCTION

OUR CHANGING NATION: CHALLENGES FOR PROVIDERS

The racial, ethnic, and cultural diversity of our nation continues to rapidly increase as we move into the next century. The growth of culturally distinct groups in the United States presents many challenges for health care, human services, and education professionals. Language differences are an obvious barrier to effective communication between families and providers. However, providers also encounter differences in family structures, values, beliefs, customs, and communication styles. To achieve healthy outcomes, providers must continually learn how to communicate and work with children and families of diverse cultures.

THE OPUS PROJECT

Southwest Communication Resources in Bernalillo, New Mexico, was awarded a three-year grant from the federal Maternal and Child Health Bureau in 1993 to implement a project to improve services to children with special health care needs. The goal of the OPUS Project was to develop a culturally responsive model to improve family-provider communication and collaboration. The project was designed to accomplish the following objectives:

- ◇ identify barriers to cross-cultural communication and collaboration;
- ◇ describe effective strategies to help providers and families; and,
- ◇ disseminate this information to a national audience.

METHODS

The OPUS Project staff included a Project Director, a Project Associate, and an Administrative Assistant. The project also contracted with an outside evaluator, focus group co-facilitators, community coordinators, and others with cross-cultural expertise. Many of the staff and contractors were from the targeted cultural groups and/or parents of children with special health care needs. All staff and contractors were part-time.

Major OPUS Project activities included:

- nationwide focus groups with families from four major cultural groups;

- meetings with a provider/policy maker task force;
- a day-long conference with a group of consultants specializing in cultural diversity issues and health care;
- networking with coordinating agencies and national groups;
- an extensive literature review/annotated bibliography; and,
- materials development and dissemination.

Family Focus Groups

The family focus groups were the heart of the OPUS Project. They proved very effective in exploring cross-cultural issues, barriers, and suggestions for improving interaction between providers and families. Focus group participants described both positive and negative experiences in obtaining health care for their children with special health care needs.

It was interesting that many of the families who related their stories did not often talk directly about their culture. Although they did not consciously think about their culture, their stories illustrated how integral their culture was to their lives. For other families culture was very private and personal. It was much easier for these families to share experiences that were not related to culture like financial barriers to health care access. Culture issues were often clarified by staff during the actual focus groups or in later discussions with community leaders, interpreters and consultants from the cultural/ethnic groups.

Families from four major United States cultural groups - African American, American Indian, Asian (Southeast Asian and Chinese), and Hispanic/Latino - participated in 19 separate focus groups from April 1994 to June 1995. A total of 122 family members representing a broad cross-section of cultural heritage participated in the focus groups. Participants came from different regions throughout the United States.



The following table and bulleted items give a profile of family focus group participants.

Table 1: Family Focus Group Composition

Cultural Group	No. of Groups/Location	Female	Male	Total
1. African American	5 groups: Milwaukee, WI Washington, D.C. Detroit, MI Seattle, WA New Orleans, LA	26	5	31
2. American Indian	4 groups: Laguna Pueblo, NM Menominee Tribe, WI Muckelshoot Tribe, WA Mixed group, Bernalillo, NM	15	15	30
3. Asian (Southeast Asian and Chinese)	5 groups: San Diego, CA Washington, D.C. Seattle, WA Columbus, OH Akron, OH	21	8	29
4. Hispanic/Latino	5 groups: Bernalillo, NM Taos, NM Washington, D.C. Denver, CO New Orleans, LA	27	5	32
TOTAL	19 groups	89 (73%)	33 (27%)	122

- ◇ the vast majority of participants were parents of children with disabilities. A small number were other relatives (grandparents, uncles, aunts);
- ◇ most participants lived in rural areas;
- ◇ slightly less than half (42%) of the participants were between 31 and 40 years of age, 27% were between 21 and 30 years, and 22% were between 41 and 55 years of age;
- ◇ about one-third of the participants had completed high school or their G.E.D.; another third had completed some college or university education;
- ◇ half of the participants had annual incomes less than \$15,000; the next largest group (38%) had incomes between \$15,001 and \$30,000 (notably, seven participants declined to respond to this question, indicating a sensitive topic for some families);
- ◇ the disabilities of participants' children ranged widely, including physical impairments and illnesses; behavioral disorders; communication disorders; mental retardation; sensory impairments; learning disabilities; and multiple impairments.

A majority of OPUS Project staff time was spent on family focus group activities, and many challenges surfaced during the entire process. For more detailed information on the lessons learned and a "how to" guide on conducting family focus groups, please refer to the Appendix section of this monograph.

Provider/Policy Maker Task Force

A task force of fifteen state providers and policy makers was convened to gather information on the providers' experience of working with families and children with special health care needs from diverse cultures. The original idea for the task force was to complete a process similar to that of the family focus groups. However, task force members struggled with issues of culture and changes in the health care field. Many providers saw the cultural aspects of health care receiving low priority given the many other health care system changes currently taking place, such as managed care, shifting federal mandates, and "information overload."

The task force evolved into an advisory group to the OPUS Project. The group initially described the providers' perspective when providing services to families and children with special health care needs from different cultures. The task force then discussed how changes in health care systems affected their agencies and their clients. OPUS staff presented initial findings from the family focus groups, and task force members discussed the results, offering suggestions and recommendations. Task force participants also suggested strategies for helping service providers appreciate families' perspectives, and advised staff on the best format to present information. For example, they suggested that direct quotes from family members really helped providers to focus on cultural issues affecting children and families.

The task force met five times in New Mexico during the three-year OPUS Project. Fifteen task force participants represented seven different types of organizations, with over half working in MCH programs and state agencies. Active participation in state health care activities was a key factor for selection as a task force member. OPUS staff considered it advantageous for participants to "wear more than one hat," so the information and ideas coming out of the OPUS Project could be shared with other providers and policy makers throughout the state. (For example, several members were administrators and also provided services directly to families in different communities.)

Nearly 70 percent of task force members had worked ten or more years with families of other cultures who had children with special health care needs. All of the participants who were currently policy makers or administrators had worked directly with families at some time during their careers. Three task force members were also parents of children with disabilities. Thirty-three percent were from cultural/ethnic groups, and 47% were bilingual.

Culturally Responsive Collaboration: Barriers, Attitudes, Experiences

The information gathered from the OPUS Project family focus groups was remarkably consistent across all the focus groups conducted. However, the findings and conclusions cannot be generalized, and may not apply to other families in the four cultural groups studied.

OPUS Project family focus group and provider/policy maker task force participants identified many barriers to accessing health care common to all families regardless of cultural background. These barriers included lack of transportation, poor communication, too few financial resources, and violations of confidentiality. There were also many problems within the health care system that families described, including confusing eligibility criteria, inconvenient location and hours, unhelpful personnel, and repetitious record keeping.

In addition, family focus group participants consistently described specific cultural barriers they experienced when communicating with and seeking care from health care providers. However, it should be noted that families also gave examples of positive cross-cultural experiences with providers and health care systems, and took the time to describe what worked well for their families and children.

The barriers directly related to cultural differences are listed below. Each is described in more detail on the pages that follow, including illustrative quotes, key points and examples.

Providers who showed:

- ◇ a lack of respect for families' cultural beliefs and values;
- ◇ cultural stereotyping and racist attitudes;
- ◇ a lack of respect for family spirituality;
- ◇ a lack of respect for family privacy; and,
- ◇ a lack of understanding of how and when to use interpreters appropriately.

Differences between family and provider:

- ◇ language use and communication styles;
- ◇ concepts of family and time; and,
- ◇ perceptions of disability and illness.

Cultural Beliefs and Values

"Providers often ask why a family does not move to where the services are. If the family leaves their community it is easier to get the 'western' services, but it becomes more difficult to participate in cultural activities which enhance the whole family's wellness."
(Hispanic/Latino Parent)

"Our doctor is someone you can talk to and joke with. We tell those other service providers a joke, and they look at you strange. When we invited our doctor to our Pow Wows, he came. That meant a lot to us." (American Indian parent)

"They (providers) want to learn the language, a little bit of your culture, and I noticed when they do that they tend to understand you better and they value you . . ."
(Hispanic/Latino parent)

Differences in cultural perspectives often inhibit positive relationships between providers and families of diverse cultures. The cultures that families come from are very different from the culture of institutions, doctors' offices, and hospitals. These differences can cause conflict and misunderstanding.

Example: Most health care, social services, and educational systems value data collection and documentation. In contrast, families place high value on personal, trusting relationships. Some cultures may be uncomfortable with providers collecting information because they are totally unfamiliar with the process, or because of previous negative experiences.

Key Points:

- ◇ Members of a particular cultural group are not all alike. For example, although people of Hispanic/Latino heritage share a common language, they may have very different national origins, cultural beliefs, and practices.
- ◇ Many factors affect acculturation, including length of time in a new country, cultural community networks, and intact family ties.
- ◇ Acculturation is not always a linear process. Family members can be at different points in the cultural continuum at different points in their lives. For example, family values and practices may be more traditional with infants than with young adults.
- ◇ When family members are at different levels of acculturation, conflicts can arise within the family. Children may adopt new ways quickly at school, but also feel family pressure to preserve traditional practices.
- ◇ Some families incorporate both cultures into their lives, using both modern health care and traditional healing services.
- ◇ Trust and respect in relationships with providers are vitally important for families from all cultural groups. Trust and respect are earned over time.

Cultural Stereotyping and Racist Attitudes

"If you are African-American/Black, you are immediately perceived as uneducated or not able to handle information that's given to you . . . or that you might be using drugs."
(African American parent)

"Providers typically call all people 'Asian' or 'Oriental' who look a certain way."
(Hmong & Laotian parents)

"'Macho' in our culture means a strong loving male. This is a quality that is valued. How it came to have a negative meaning to some people, I don't know."
(Hispanic/Latino parent)

"I took my child in and they asked me how much I drank. They assume all Indians drink too much." (American Indian parent)

"There was a doctor that we had on my home reservation, and he was there for ten years, and he was so much part of the community . . . he was just a special person. And the Indian people there just loved him. He was part of everything." (American Indian parent)

Families from all four cultural groups reported negative experiences due to providers' racism and cultural stereotyping. Many family members shared their painful experiences when they were not treated respectfully, were denied services or had to wait longer for services, and were not given enough information about their children.

Despite these experiences, families also related positive interactions with more sensitive therapists and physicians who showed a genuine respect and interest in their children, family, and culture.

Example: Many African American/Black parents felt the quality and type of services available to them was determined by "the color of your skin and how much money you have." Family members recalled when providers assumed that the family could not afford particular services for their children. Family members also reported that providers equated "being Black with being uneducated and poor, drinking, and using drugs."

Key Points:

- ◇ Families talked about being ridiculed and treated rudely at clinics, hospitals and offices. Family members felt unwelcome because they had an accent, or were "different" in other cultural ways.
- ◇ African-American families, in particular, talked extensively about racism, both overt and subtle. A key concern was providers' negative beliefs and attitudes about Black men and their role in the family. Mothers talked about how providers often assume that the father is not involved in their children's lives or care.
- ◇ Families nationwide perceived that stereotypes were perpetuated by the media and gave examples of advertising and movies that portrayed "people of color" in negative ways.

Family Spirituality

"When my son was in the special care nursery . . . I had a pastor come in and pray for him. They wrote down on my son's chart that I was crazy . . . because I had a pastor coming in there." (African American parent)

"I realize my daughter wasn't going to change, and so my mother suggested we go to Chimayo to pray. I went through this whole process . . . One doctor said, 'why the heck are you doing that?' . . . I told him I need that part. I need to be in touch with my spirituality, because there is nothing else right now. They (providers) are not giving me answers." (Hispanic/Latino parent)

"Most Indian families go to the 'western' doctor for a second opinion. They go to the medicine man first . . . The medicine man gives advice, and helps the family to understand and take care of the problem." (American Indian parent)

For many families, spirituality is a primary part of their culture and plays a key role in health care. Spirituality guides decision making and gives families strength and support. A common concern among family focus group participants was that providers often misunderstood and criticized their spiritual beliefs and practices.

Example: African-American parents talked about being "rooted" in the church and how their beliefs and spiritual practices were integral to the healing process for their child.

Key Points:

- ◇ Providers should be careful not to make assumptions about a family's religious or spiritual practice.
- ◇ Providers need to acknowledge and support the spiritual or religious part of families' lives.
- ◇ Providers should ask families if they would like to involve religious or spiritual advisors as part of the health care team.
- ◇ Family privacy around religious or spiritual practices must be honored.

Family Privacy

"I do this dance all of the time (trying to elicit information) with families. Sometimes it's forthcoming and sometimes it just simply is not." (provider)

"The American way of speaking up and support groups is new to us. Everyone is very private in our culture . . . If you bring up the subject of being disabled, everyone is uncomfortable and becomes very quiet . . ." (Southeast Asian parent)

"It is a very delicate balance when trying to obtain information from families that is deemed personal." (provider)

In every family, there are topics considered private or personal. Many cultural groups have rules or traditions about the kinds of information that may be freely shared with outsiders. Families described their serious discomfort when asked a great deal of personal information by health care providers. They did not know why such details were important and how the information might help their children. Providers shared their frustration with the scheduling and time constraints that prevent them from taking the time to go over questions with family members.

Example: In many Asian cultures, children are not allowed to discuss adult topics, and men may not discuss "women's issues" like pregnancy and childbirth. It can be a shameful experience for Asian families to disclose that their child has a disability.

Key Points:

- ◇ Many family focus group participants thought questions about ethnicity, financial information, education, living situations, and drug and alcohol use were too personal. Family members were concerned that they would be labeled as uneducated and poor because they are often stereotyped that way.
- ◇ Many families who do not speak English are concerned about privacy and confidentiality when an interpreter is used.
- ◇ Confidentiality is particularly important for families who live in traditional cultural communities where providers can easily share personal information with other staff without permission.
- ◇ It is important for providers and staff to learn about a culture's communication protocols, or "who talks to whom about what." It is also important to find out what kind of information is okay to share outside the family.
- ◇ Providers are aware that some of the questions they ask families are intrusive, but sometimes this information is needed to make a definitive diagnosis or to structure a treatment plan.
- ◇ Families who use traditional healers are asked few questions but receive a great deal of guidance and support.

Interpreters

"The doctor wanted our child to interpret for us. This is not a good idea. The child is young and does not know medical terms. Children are not supposed to explain to their parents." (Southeast Asian parent)

"Some doctors grab anyone (to interpret). This is not good. I am uncomfortable discussing private information with a stranger." (Southeast Asian parent)

Several family focus group participants described troublesome situations when providers used interpreters to translate written and spoken information. Inappropriate or untrained interpreters can cause families embarrassment and discomfort. Untrained interpreters often cannot translate medical and other technical information, and incorrect information may be communicated to families. Additionally, many families from different cultural groups do not discuss personal information with strangers, and untrained interpreters usually do not understand the rules of confidentiality.

The lack of available interpreters is also a serious problem for families from different cultures. This can prevent the child and family from receiving the services they need. Often, hospitals and providers expect families to bring their own interpreters.

Example: New immigrants who have children with special health care needs are often overwhelmed when confronted with the United States health care system. Without appropriate and sensitive interpreters to assist them, families may give up and never return for much needed services.

Key Points:

- ◇ Most providers have not been trained to select and work with interpreters.
- ◇ Interpreters may know a particular language, but may not be accepted and respected within the family, community, or culture.
- ◇ Family members are not appropriate interpreters. For example, using children as interpreters is problematic: it reverses traditional authority, and children in many cultures are not supposed to talk about certain adult health information.
- ◇ Using family members as interpreters can also cause problems because personal involvement with the family may result in serious internal conflict. Allegiance to the family and cultural ways usually overrides the accuracy of or need for information.
- ◇ Use bilingual family members as support, but not as interpreters.
- ◇ Written materials are usually not available in languages other than English.
- ◇ Many concepts and words, especially medical jargon, are not easily interpreted or translated into other languages.

Concepts of Family

“Everybody raises that child . . . everybody. That is the way it is in African American families.” (African American parent)

“Being Hispanic, we're very close to our kids . . . we took our whole family . . . to the hospital. They said we could only have two visitors at a time. I asked the doctor to meet with my whole family . . . ” (Hispanic/Latino parent)

“ . . . Health professionals need to understand how important the extended family is to us. There are a lot of grandparents and aunts taking care of children. Our family members are going to stay there because it's part of our family culture to be there when people are sick . . . ” (American Indian parent)

Family focus group participants expressed strong feelings about family life. The extended family is central to many cultural groups because it provides stability and strength. Additional family members often accompany parents and children to appointments, interviews, and treatments. Many families experienced providers' lack of appreciation and respect for extended family involvement in the care of their children with special health care needs.

Example: In some American Indian tribes, it is an elder male or female family member who is responsible for making all child-rearing decisions for the entire family. If a provider is not aware of who has the decision-making responsibility in the family, confusion and misunderstanding can result.

Key Points:

- ◇ Policies, procedures and environments of health care institutions are designed to work for small, nuclear families. Health care facilities often lack the space for providers to meet privately and comfortably with large and extended families.
- ◇ Large families with many children are valued as wealth in many cultures. For example, in Hispanic families, “wealth is determined by the number of people who surround you at the dinner table.” Historically, the tradition of large families in Southeast Asian cultures evolved as a result of high infant mortality and the need for children to work in the family fields.
- ◇ Cultural traditions surrounding extended family continue even though family living conditions change.
- ◇ Providers should not assume that all family members will be involved with the child's care. It is important to ask the family who they would like to include in meetings, discussions, decision making, or even who is allowed to visit their family member in the hospital.

Concepts of Time

"Timelines and requirements are made to help and protect families, but the truth is that they are not friendly to families." (provider)

"Scheduling appointments is difficult . . . it's not a calendar year thing. You have to prepare for a ceremony . . . you have to go. So you can't make the appointment . . . then there's a big NO SHOW in your chart. They need to be flexible." (American Indian parent)

"Western providers are always in a hurry . . . Asian families are more accustomed to a slower pace, and are hesitant to sign documents unless they understand them." (Southeast Asian parent)

The lifestyles of different cultures are often less formal and move at a slower pace than western health care systems. Time is taken to establish trust and build relationships. In contrast, health care systems limit the time providers spend with families and their children. Many families interpret the time limits and hurried pace to be a lack of concern and a sign of disrespect.

Example: Families are overwhelmed by numerous service options, decisions, and the speed of medical procedures. When appointments with providers are so brief, families do not have time to discuss their concerns.

Key Points:

- ◇ Formal appointments are not a familiar concept for families new to the health care system, and may not be kept.
- ◇ Work hours, family obligations, and spiritual practices can conflict with appointments. Many cultures place a high value on work and take their work responsibility quite seriously. Family members may feel that taking time off from work is not possible.
- ◇ Traditional healers will often see families without appointments.
- ◇ A waiting list may be an unfamiliar concept for families from different cultures.
- ◇ Families from different cultures will often take whatever time is needed to make decisions regarding their children. The decision-making process cannot be rushed.
- ◇ Both providers and families are frustrated with the "managed care" approach to health care. These changes push providers to see more patients, and spend less time on family concerns that take further explanation and attention.

Language Use and Communication Styles

"You go to a meeting concerning your child, and they talk 90 miles an hour, and you're hearing it at 5 miles an hour, and understanding at maybe 2 miles an hour."
(Hispanic/Latino parent)

"I'd recommend that a health care provider say, 'You know, I'm really glad that you're here. I don't know a lot about your particular culture. If anything I say or do makes you feel uncomfortable, tell me.'" (Hispanic/Latino parent)

"Communication is more than delivering the message. It's the other persons receiving it, understanding it, and then reacting to it." (provider)

"It's just that I need them to bring that high level language down to a place where I can understand. Professionals talk among themselves and don't talk to us." (Hispanic/Latino parent)

"Just because we don't understand English doesn't mean we are deaf. They yell at us. That's a put down . . ." (American Indian parent)

Good communication is the cornerstone of fruitful and trusting relationships between health care providers and families. However, communication becomes very complex when different languages, communication styles, and cultural norms are introduced. Both family members and providers who were involved in the OPUS Project agreed that good communication is essential. However, they were also quick to point out the many difficulties that can surface when communicating across cultures.

Example: Communication is much more than spoken language. Nonverbal communication is seriously influenced by culture. For example, eye contact with an authority figure is considered disrespectful by some American Indian and Asian groups. Families' lack of eye contact is often misinterpreted by providers as lack of attention or interest.

Key Points:

- ◇ In many cultures, the time taken for introductions and "small talk" shows respect. These activities are an essential part of establishing rapport and trust.
- ◇ Communication may be indirect. Among some Asian and American Indian groups, silence is considered appropriate and productive. In contrast, many western providers find periods of silence during an appointment uncomfortable.
- ◇ Families who speak limited or no English may hesitate to ask questions or admit they do not understand.
- ◇ In many cultures, it is disrespectful to ask questions, request information, or disagree, particularly with an authority figure.
- ◇ Honor, humility and privacy are important values in certain cultures (e.g., Southeast Asian). These values can contribute to communication differences.

- ◇ Providers may unintentionally offend families through their body language (e.g., waving or pointing) and use of personal space (standing or sitting too close to family members).
- ◇ Providers should familiarize themselves on cultural rules regarding touch. For instance, in some Asian cultures, a child's head should not be touched because it is sacred. Hispanic/Latino groups are generally more comfortable sitting close to a provider than are American Indians or Asians.
- ◇ Workshops and conferences for parents can be intimidating for some cultural groups. Hispanic and American Indian parents said they would attend these events and listen, but asking questions might be uncomfortable.

Perceptions of Illness and Disability

"If a child is born with a disability in our culture, we believe that it is because a grandparent or . . . someone else did something wrong. It could be during the time of the grandparents . . . or even one thousand years ago." (Southeast Asian parent)

"Most Indian families go to the 'western' doctor for a second opinion. They go to the medicine man first. The family helps you arrange the meeting with the medicine man. The medicine man gives advice and helps take care of the problem." (American Indian parent)

"When a child has a serious or chronic condition, the family will seek the wisdom and assurance of an elder (natural healer or shaman). These elders use spiritual and other traditional treatment methods . . . healers will recommend the family seek 'western' medical care when appropriate." (Asian consultant)

"I think all of us around here have had a good taste of goose grease and honey. Grandma said it would be good for you." (African American parent)

Views of health, illness, disability, and healing are culturally based. In many cultures, "western" medicine may be a last resort. Many cultural groups describe and treat health problems differently than the modern health care system. A condition that is considered a problem by western standards may not be a problem at all in another culture.

Example: Families from different cultures feel providers have an underlying assumption that their children with special health care needs must be "fixed." This is often accomplished by pursuing an unending variety of medical interventions. This kind of situation can be frustrating for families who believe that their children are just fine without so many (or any) interventions. Serious conflict can arise between providers and families over the child's "needs."

Key Points:

- ◇ In some cultures, health or developmental problems are kept strictly private and treated within the family or community. The family may be discouraged from seeking help outside their own cultural community.

- ◇ For many families from different cultures, the medical system may be a second opinion or the last resort.
- ◇ Families often use traditional herbal remedies instead of, or in combination with, western medicine. Some family focus group participants believed their family home remedies were not taken seriously, and so they stopped discussing them with providers.
- ◇ Families want providers to respect their traditional healing methods.
- ◇ Providers should not assume that all families from different cultures use traditional healing practices.
- ◇ Providers should not ask a lot of questions about traditional healing practices. These questions are considered intrusive and are uncomfortable for families to answer. It's best if providers ask a few simple questions without expecting a lot of details about traditional healing methods.
- ◇ There are many "costs" to families when they seek out western medical interventions, like conflicts with family members or traditional healing methods.



SUMMARY AND RECOMMENDATIONS:

PROVIDERS AND FAMILIES WORKING TOGETHER FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

The OPUS Project was an insightful and productive learning experience for everyone who participated in the project's process. There were many opportunities for families and providers to learn about and from each other's different cultural perspectives. The final recommendation section of this monograph is based on the findings of the OPUS Project. It provides suggestions for families, providers, policy makers and those professionals who develop and implement health care programs. The recommendations take the valuable information learned during the course of the OPUS Project a step further into actual practice and action.

Contrasting and Conflicting Value Systems

Health care, social services, and educational services in this country have all developed value systems. The greater the gap between the values of providers and the values of families from different cultures, the more difficult it is for professionals and families to communicate well and build positive working partnerships.

The findings from the OPUS Project provided a wealth of examples contrasting the values of professional systems and families from different cultures. The following table outlines, in a generalized way, these differences in cultural values.

Table 2: Conflicting Values

Professional Systems Place High Value On:	Families From Different Cultures Place High Value On:
<ul style="list-style-type: none">• Facts rather than feelings and personal relationships	<ul style="list-style-type: none">• Building personal, trusting relationships with providers as people, not systems
<ul style="list-style-type: none">• Impersonal communication (written, documented)	<ul style="list-style-type: none">• Sharing information through conversation, not documents
<ul style="list-style-type: none">• Formal appointments and strict timelines	<ul style="list-style-type: none">• Appointments and schedules determined by family and cultural relationships
<ul style="list-style-type: none">• Cost effective services	<ul style="list-style-type: none">• Family involvement in and support from the culture for health care choices
<ul style="list-style-type: none">• Speedy delivery of services	<ul style="list-style-type: none">• Taking whatever time is needed to accomplish healing

In order to create bridges between these contrasting values, families and professionals need to find ways to respect each other, ask good questions, listen to each other, and feel comfortable working together. Strategies to help facilitate these family-provider partnerships are outlined in the following recommendation section, including:

1. **Recommendations for health care professionals** on how to create positive, trusting, and collaborative relationships with families from different cultures; and,
2. **Recommendations for families** on how to learn more about the providers and health care systems that care for their children, including methods to help themselves and other families.



RECOMMENDATIONS FOR HEALTH CARE PROFESSIONALS

"Interesting how few people who are in a position to shape services to benefit families have such little contact with families." (provider)

"We in the bureaucracy try to do good and end up doing a lot of bad or wrong in the name of good." (provider)

"There is very little opportunity built into our jobs that gives the opportunity to meet with families or include them on committees or even visit programs. It creates real communication problems." (provider)

The ALERT Model

The ALERT Model can give practical assistance to health, human services, and education providers working with families from different cultures who have children with special health care needs. The ALERT model was developed by the OPUS Project. The five components of the ALERT model include:

ACCCEPT: Accept the family's beliefs, values, and practices, even if you don't agree;

LEARN: Learn about the culture of the community and the individual families you serve, and remember to **ask questions** rather than assume;

EXPLAIN: Explain to families why you need information, why time and appointments are important, and how their child will benefit;

RESPECT: Respect the family's cultural ideas, beliefs, values, and practices. Find culturally appropriate ways to show respect;

TRAIN: Training and education enhance understanding. Support and elicit the participation of families in the education and training of providers.

1. ACCEPT A FAMILY'S CULTURE

Cultural responsiveness is an ongoing process that takes time and patience. It takes an eagerness to learn as much as possible about other cultures and their values. Cultural responsiveness and acceptance also require a willingness to look at one's own cultural values and biases.

Suggestions:

- ◇ Avoid generalizations about families and cultures. There are similarities and differences both within and among cultural groups.
- ◇ Cultures often evolve over time. Family values, beliefs, and practices may also change over time.
- ◇ Do not rush families to make decisions regarding their children. Before making a decision, they may need to consult with several other people, including extended family members and cultural leaders.
- ◇ Work with families to develop a program that is comfortably paced and incorporates family traditions whenever possible.
- ◇ Be as flexible as possible in scheduling appointments and meetings.
- ◇ Reduce the burden on families by combining appointments with other services and activities "batching."
- ◇ Understand that a family may choose to stay closer to home instead of choosing a particular intervention or course of treatment that takes them away from their family, community, and traditions.

2. LEARN ABOUT OTHER CULTURES

Providers can learn about other cultures by reading, observing, listening, and asking questions. One of the best ways to learn is through day to day interactions with families and colleagues.

Suggestions:

- ◇ Avoid making assumptions about families from different cultures. Ask families basic questions, such as:
 - ✓ What can you tell me about your child?
 - ✓ What have you already done to help your child?
 - ✓ What can we do to help you?
 - ✓ What are your concerns?
 - ✓ Is there anything else you would like to tell me?
 - ✓ Is there anything else I should know?
 - ✓ What do you hope will happen?
- ◇ Learn about family and cultural perspectives on child rearing and child development. Some cultures do not value or use developmental milestones. Ask about significant childhood events that are recognized and celebrated. Ask about the characteristics that are valued in children.
- ◇ Promote collaborative learning so that providers and families are learning about each other by learning together.

- ◇ Consider working with bicultural community liaisons (respected elders, community leaders) who can assist in learning about families.
- ◇ Make time each week to learn more about the cultures of other families and communities.
- ◇ Identify language and cultural barriers **before** providing services.
- ◇ Obtain training on specific cultural groups and cultural competence offered by local and national organizations.

3. **EXPLAIN TO FAMILIES**

Providers need to take time to explain to families what they plan to do and how it will make a positive difference for the child. This often requires that providers take extra time and patience to satisfy a family's questions. It also helps to work with families to explain the "whys and wherefores" of medical institutions like hospitals and specialty providers.

Suggestions:

- ◇ Families who are new immigrants generally need more help and explanation than families who have been in the United States for awhile.
- ◇ Develop simple fact sheets for families describing the information requested, why the information is needed, and how it will benefit their child.
- ◇ Translate fact sheets and medical history forms into appropriate languages.
- ◇ Record audio tapes for families who are non literate and/or have limited-English. Also, record audio tapes for families who do not have written material available to them (for example, some American Indian languages are not written).

4. **RESPECT FOR FAMILIES**

Respect was probably the word that families used most frequently throughout the OPUS Project. Respect needs to flow in both directions between families and providers. It is the essence of positive cross-cultural relationships.

Suggestions:

- ◇ Respect is shown in different ways in different cultures. Learn what is appropriate for each culture.
- ◇ Demonstrate respect for family ideas and decisions.
- ◇ Show respect for each family spiritual beliefs and customs.
- ◇ Respect family efforts, not just achievements.
- ◇ Address family concerns about privacy and confidentiality.
- ◇ Greet and acknowledge all family members.
- ◇ Be formal rather than informal (for example, use Mr. or Mrs. instead of first names).
- ◇ Focus on the families as much as possible, not on forms or reports.
- ◇ Be aware of cultural behaviors like avoiding eye contact.
- ◇ Be sensitive to the use of body language and personal space.

5. TRAIN PROVIDERS

Provider education and training offer many opportunities for health care professionals to learn, first-hand, different family cultures. Involving families in ongoing provider education and training can help bridge the cultural gap.

Suggestions:

- ◇ Provide opportunities for professionals to experience field placements in different cultural communities.
- ◇ Use parents, elders, and community leaders as faculty, to help with curriculum design, and as speakers on panels.
- ◇ Identify resource persons (e.g., elders, respected community leaders) who can provide information and act as community liaisons.
- ◇ Train providers on verbal and nonverbal communication methods, cultural protocols, and responsive interventions.
- ◇ Work with representatives from the cultural communities served. They may act as outreach workers, interpreters, care coordinators, home visitors, and role models.
- ◇ Recognize families and community members who help agencies improve cultural understanding.
- ◇ Offer start-up funding for grassroots community agencies that are working with providers and families of diverse cultures to improve cross-cultural communication.

Language and Interpreter Considerations

Language and interpretation services are extremely important for many families from different cultures, particularly new immigrant families. Interpreters often lack the skills and training to be effective. Many health care organizations and providers don't understand the importance of good interpreters.

Suggestions:

- ◇ Involve families in selecting appropriate, trusted interpreters. Avoid asking family members, friends, or untrained staff to serve as interpreters.
- ◇ Select, train, and hire interpreters who are bilingual-bicultural, and respected in the community.
- ◇ Develop or identify a "bank" or resource pool of trained interpreters. Resettlement agencies (e.g., Church World Service and International Rescue Committee) can provide information on availability of local interpreters.
- ◇ Train interpreters in confidentiality.
- ◇ Try to use the same interpreter at all meetings.
- ◇ Allow extra time for sessions with an interpreter.
- ◇ Use basic words and simple sentences. Avoid using colloquialisms and metaphors.
- ◇ Address patients or clients directly, even when an interpreter is present.

- ◇ Translate written materials and forms into appropriate languages with suitable reading levels. Use minimal jargon. Pilot test these materials before using.
- ◇ Consider audio tapes and/or videotapes for non-literate or limited-English family members.



RECOMMENDATIONS FOR FAMILIES

"Parents are like tea bags: you don't know your strength until you get into hot water."
(African American parent)

"Sometimes the doctors need to know more about our background, because it can help them know what happened to our child . . . I think we should work together."
(Hispanic/Latino parent)

"If I was going to tell a parent anything, it would be that doctors are human beings and they are capable of mistakes . . . take anything they say in that context . . . they deserve respect . . ." (Hispanic/Latino parent)

"At our hospital . . . they picked a few parents who were doing really well taking care of their kids and had a doctor's meeting. They asked all the parents to come in to receive certificates . . . all the doctors were there. And we brought our son . . . that was the first time I got a standing ovation from a group of doctors. I think . . . we need to look at whether the community can invite docs who are doing some of the culturally competent things and recognize them for that. That would encourage other providers to do the same as well . . . because I really think sometimes they do need a pat [on the back] and they deserve it." (American Indian parent)

1. Learning about and Working with Providers and Health Systems

Families from different cultures can begin to acquaint themselves with the way "western" providers and systems work by observing, listening, and asking questions. Trying to figure out agencies, services, and institutions can be overwhelming at first. Families should seek out other families, support groups, or community leaders who are familiar with "the system." Some organizations may also offer assistance or training (e.g., La Raza, NAACP, Urban League, etc.).

Indicating a willingness work with providers and learn about **their** culture can go a long way. Developing a comfortable relationship with at least one provider can help the family negotiate other services or systems. Family and community groups should acknowledge providers who work with families to bridge cultural differences.

Suggestions:

- ◇ Learn about the structure and operations of health care systems and services.
- ◇ Understand that many providers often have a lack of time and resources, but a surplus of patients or clients.
- ◇ Look for and work collaboratively with culturally responsive providers.

2. Families Helping Themselves and Others

Families often underestimate their own abilities and power when searching out and obtaining services for their children. While families from other cultures experience additional barriers to receiving good health care services, there are many ways that family members can learn to be assertive, knowledgeable, and helpful to other families.

Suggestions:

- ◇ Ask providers for needed services. Advocate for children. Be persistent. Bring a list of questions and concerns to medical appointments.
- ◇ Bring another person to appointments for emotional support, and to help listen.
- ◇ Carry a notepad and take notes, at home, school, doctor's office, clinics, etc.
- ◇ Keep copies of medical records and reports, and take them to different service providers. Developing an ongoing care record can be very helpful.
- ◇ Help educate providers about cultural beliefs and customs, including how to work more effectively with families.
- ◇ Don't assume that all providers treat families negatively.
- ◇ Share experiences with other parents. Tell other families when a culturally responsive and friendly provider is discovered.
- ◇ Seek out or start family support groups.
- ◇ Ask other families for names of culturally-responsive providers.

3. Training and Educational Opportunities for Families

Ongoing training and education are also important for families. Learning more about the health care system and about their children with special health care needs can give family members new knowledge, comfort, and self confidence.

Suggestions:

- ◇ Consider working with families one-on-one or in small groups. The privacy and intimacy this allows are particularly helpful to new immigrants or families with little or no English proficiency. It also supports cultural groups who are foreign to sharing experiences with strangers.

- ◇ Advocate for family training and education (for example, how to fill out forms, how to obtain and organize records, where to obtain financial assistance and other support services, where to find interpreters, etc.).
- ◇ Work with providers to sponsor joint training events (providers and families together).



APPENDIX

OPUS FAMILY FOCUS GROUP: LESSONS LEARNED

Pilot Focus Group

OPUS staff first conducted a pilot focus group with parents in New Mexico. The pilot process was a beneficial first step that allowed learning and facilitated family involvement in process development. The experience was a "walk through" for the subsequent groups, and allowed opportunity for feedback on the entire family group process. Participants commented on the OPUS Family Focus Group Moderator's Guide as well as the report summarizing the findings. They recommended ways to explain the purpose and forms used. Their input was used to improve the process and make revisions in the written materials.

Collecting Demographic Information and Focus Group Process

Staff planned to collect demographic information on focus group participants. However, certain items such as education, income, and marital status were sensitive topics for some families. Based on the pilot focus group, the demographic forms were revised. Notably, marital status was eliminated because it often did not correctly describe household structure. Income was left on the form, with the provision that the moderators provide adequate explanation and assurances of confidentiality. In subsequent focus groups, staff read and explained the reason why each item on the forms was requested.

Staff discussed group process techniques, like how to draw out the "silent participant" in a group (for example, gently ask the person who is not speaking for opinions once, but do not push). Staff also decided that the ideal group size was eight to ten participants. This allowed for the possibility that a few invited people might not be able to participate on the day of the group.

Focus Group Implementation

Following the pilot focus group, 18 additional focus groups were arranged, conducted and recorded, transcribed, and analyzed. As the OPUS Project evolved, staff encountered a variety of implementation issues. At times, there were difficulties with transcription or recording devices. In these instances, staff used their notes and discussions with community leaders and interpreters to summarize group responses.

Staff worked with local grassroots organizations and parent associations to arrange the focus groups. Local community coordinators, who knew their populations and facilities were used to finalize arrangements. However, local coordinators needed additional guidance to understand the OPUS focus group process. Many coordinators were not familiar with focus groups. Consequently, they thought a focus group was like a workshop or support group meeting. This led staff to develop detailed written guidelines for coordinators arranging focus groups. The guidelines are seen in this Appendix. Project staff also communicated via phone with local coordinators to answer questions and provide further explanation. This experience and the new guidelines benefitted future groups, and also helped staff document the focus group process.

An important implementation issue was the use of interpreters during the family focus groups. Interpreters were used with all of the Asian focus groups and some of the Hispanic/Latino focus groups. Interpreters were essential for families who spoke little or no English. However, conducting focus groups with interpreters presented additional challenges. In two of the Southeast Asian groups, there were two distinct languages spoken, and therefore two interpreters were needed. In those groups the interpreters and moderators were the only ones who spoke English fluently. When interpreters were used, more time was needed to conduct the focus group. In general, they lasted one hour longer than the other groups. In addition, the project's verbatim transcription service was unable to transcribe these groups. Staff worked closely with the interpreters and community leaders to ensure accurate interpretation of family comments. After each group, a debriefing meeting was held to clarify that information recorded was accurate.

FAMILY FOCUS GROUP: COMMUNITY ORGANIZER'S CHECKLIST

Location: An important factor is where the focus group will be held. It must be a place that is easily accessible and comfortable for the participants.

Room Set-Up: There should be enough chairs (plus two for the facilitators) for everyone participating. A conference table is ideal to gather around as it provides a place for the tape recorder, microphones and refreshments. Place cards with first names only create a comfortable atmosphere for conversation.

Materials:

chairs and tables for discussion and refreshments
tape recorder, tapes, microphones, extra batteries, long extension cord
place cards (first names only) and large black magic marker
writing tablets, pencils/pens (for facilitators)

Forms: Place forms face down on the table. Everyone will complete them at the same time as part of initial group activities. See Moderator's Guide.

Materials:

consent to participate forms
demographics forms
pens

Refreshments: Refreshments should be appropriate for the cultural community and time of day. If children are in child care in an adjacent room, refreshments should be provided for them also.

Materials:

beverages: cups, coffee pot/hot water pot, filters, coffee, tea
snacks/food, sugar, cream
utensils, plates, and napkins

Stipends: It is strongly recommended that stipends be given to participants. It is also recommended that you find out in advance if there are any cultural reasons why this would not be acceptable or culturally appropriate ways in which the distribution of the stipend should be handled. For example, in some Asian cultures money is not given outright. It can be given in a special envelope in the form of a gift. Stipends are distributed at the end of the meeting. Cash is best. Some people may not have bank accounts or may need the money immediately to pay for gasoline or child care.

FAMILY FOCUS GROUP: MODERATOR'S GUIDE

- A. Introductions and Welcome** (2 - 3 minutes)
- B. Background and Purpose of Group Discussion** (3 - 5 minutes)
- Moderators introduce themselves, who they work for, where they work.
 - Explain the purpose of the family focus group.
 - Explain how information collected will be used and how participants will benefit.
- Confidentiality:** Discuss how it will be respected and addressed. Participants may have questions about who in their community will have access to this information.
- C. Handout, Review and Complete forms** (15-60 minutes)
- Explain purpose of each form. Answer questions.
 - Go over each question or statement on each form as a group. If interpreters are used this will take longer. This procedure ensures that families understand what information is requested. Answer questions. Provide assistance as needed.
 - Forms used: (1) Consent to Participate, (2) Participant Demographic Information
- D. Ask for Questions and Explain Tape Recording** (2-3 minutes)
- If tape recording, explain reason and who will listen to it.
 - Ask if anyone has questions, and ask if anyone does not want to participate.
- E. Review Discussion Ground Rules** (2-3 minutes)
- This will be an informal discussion.
 - This discussion will last two hours. There will be no formal breaks. Please feel free to get up, stretch, go to the bathroom or get something to eat or drink.
 - There are no right or wrong answers to the questions we will ask. We will listen to each of person's ideas and experiences. Everyone's input is appreciated.
 - We would like only one person to talk at a time.
 - Because of the limited time, if anyone gets off the topic of discussion or if one person is talking more than others, one of the facilitators may interrupt to get everyone back on topic or give others a turn.
- F. Ask Participants to Introduce Themselves** (10-15 minutes)
- First name, number and ages of children, brief description of child w/special needs.
- G. Begin Discussion Questions** (60 minutes)
- H. Summary and Closing** (15 minutes)
- Summarize Key Points: "What I'm hearing from you is . . ."
 - Ask for additional comments
 - Thank participants
 - Distribute Stipends
- Total Time without interpreters: 120 minutes**
Total Time with interpreters: 180 minutes

FAMILY FOCUS GROUP: SAMPLE LIST OF QUESTIONS

TOPIC: Culturally Responsive Communication Between Families and Professionals

- A. What are the major barriers/problems you have experienced when talking with service providers about your child with special needs (doctors, etc.)?
- B. How important is it that providers be culturally responsive when they talk with you?
- C. Have you needed an interpreter? Were you offered one? Did you bring your own? Does this help? How?
- D. Do you have difficulty understanding what professionals tell you about your children?

TOPIC: Overall Attitudes and Experience with Health Information

- A. Have you found it easy or difficult to get information about your child with special needs (e.g., reports)? Is the information you receive understandable? If not, what would make it better?
- B. Do service providers who work with your child share information with you about your child's care regularly? Is it helpful? Why? Why not?
- C. When you take your child to a doctor or other service provider, what documents or information do you need to bring with you?
- D. Are professionals sensitive to and respectful of your family's values and customs? What do they need to know about your family or culture to be more sensitive?

TOPIC: Organizing Information

- A. What health papers/records do you keep at home? How do you keep it?
- B. Would it help you to have training on ways to organize your child's evaluation or treatment reports, or other health and education information you need to keep?

TOPIC: Privacy Issues

- A. Many times service providers ask families a lot of questions, especially during the first few visits. Some of those questions may seem very personal and may be uncomfortable to answer them. (e.g., it may be inappropriate to ask a father about the pregnancy or birth). In your culture, what kind of information is considered too personal to talk about? What information can only be discussed with specific people? Who?
- B. Some state health departments are considering using computers to keep track of certain health information. What information would you want kept on computer? What information would you not want kept on a computer?
- C. When is it okay for a service provider to share information about your child, and with whom?

TOPIC: Suggestions and Recommendations for Change or Improvement

- A. What advice would you give service providers to improve their communication with families whose culture is different than their own?
- B. Are there any changes in agency or system policies and procedures which would improve the way information is collected from and shared with families?
- C. What advice would you give other families to help them to improve their communication with service providers from outside their culture?

OTHER PRODUCTS AVAILABLE FROM THE OPUS PROJECT

For those readers who want additional information about the OPUS Project, there are three other project products available.

Educational Fact Packets for Health and Human Service Providers

**Family Perspectives: Cultural/Ethnic Issues
Affecting Children with Special Health Care Needs**

Annotated Bibliography

**Cross-Cultural Communication Issues:
Children with Special Health Care Needs**

A Colorful Poster suitable for framing and display in offices (18" × 24")

Rx for Healthy Families, Support Culture in Health Care

For more information:

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