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ABSTRACT

This monograph provides a framework for programs, states, and organizations to think about the issues in developing culturally competent programs for families of children with special needs, and offers a variety of examples from programs across the country that are providing exemplary services. The monograph is designed to help program makers compare their efforts with others, to provide options for planning additional services or altering services in existing programs, or to develop new programs. Monograph sections cover the following topics: (1) general issues in developing culturally competent programs as they relate to community-based family-centered care; (2) specific issues in policy and practice, such as assessment, outreach, family involvement, staffing, use of translators, client load, professional-paraprofessional partnerships, and training and support; and (3) descriptions of programs funded by the Bureau of Maternal and Child Health that serve families in several different types of settings. (15 references) (JDD)

DEVELOPING CULTURALLY COMPETENT PROGRAMS FOR FAMILIES OF CHILDREN WITH SPECIAL NEEDS

2nd Edition

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September,1990

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The Minority Initiative Resource Committee (MIRC) from the Child and Adolescent Service System Program (CASSP) Technical Assistance Center was responsible for the publication of an independent monograph, ***Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who are Severely Emotionally Disturbed,*** *prepared by T. Cross, B. Bazron, K. Dennis, and M. Isaacs. The work of the MIRC in creating a conceptual framework through which cultural competence can be viewed within all allied health professions is much appreciated. We would also like to thank MIRC for reviewing this monograph and workbook.*

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INTRODUCTION

This monograph and its accompanying workbook is designed to help programs, states, and organizations improve their ability to provide culturally competent services to families. The monograph provides a framework for you to think about the issues in developing culturally competent programs as well as a variety of examples from programs across the country that are providing exemplary services at this point. The accompanying workbook provides an opportunity for individuals and groups involved in program planning to examine their own efforts against a set of questions and activities which are drawn from the issues in the monograph. The two publications are designed to be used concurrently as programs and states work together with their communities to provide services to families in the most culturally competent manner. Both the monograph and the workbook represent our best efforts to understand the issues related to cultural competence. As such, they are open to continued input and development as we learn from programs and groups striving to effect service delivery systems. The goal of this effort is to make them more responsive and competent in their interactions with families of children with special health needs across the cultural spectrum of the United States.

Several different audiences may find this series useful. If your program is already providing culturally competent services to families and children, you may wish to use the monograph to find out what other programs are doing across the country and to compare your efforts with others. New contacts and ideas may come from such an exercise. If your program is interested in expanding services to reach groups currently not being served, the material in this book can provide options for you to consider in planning additional services or alter services currently being provided to families. If your group is interested in starting new programs to meet a particular need within your community, this monograph provides the opportunity to learn from the experience of others. Again, contact can be made and ideas learned from some of the hard roads others have taken.

If you are part of your state's interagency coordinating council for P.L. 99-457, you have the opportunity to insure that services relevant to all cultural groups within your state are provided as you develop new initiatives for young children and their families. The planning and implementation of all components of this law are affected when the issues involved in multicultural programs are addressed. This includes the definition of handicapping conditions, outreach efforts in Project Find, service delivery models, assessment procedures, both preservice and inservice training efforts, parent participation, and how the Individualized Family Service Plan is developed. Members of Interagency Coordinating Councils and other state-wide planning efforts will find a separate study guide for their use in the workbook.

This monograph is organized into several sections. First, general issues in developing culturally competent programs will be discussed as they relate to community-based family-centered care. Then, specific issues in policy and practice are discussed in the context of culturally competent services. Next, programs that have been developed to specifically serve families in several different types of settings are described within the context of community-based, family-centered and culturally competent care for children with special health needs.

The Community Base of Culturally Competent Services

The concepts which underlie the principles of culturally competent health care are not new. However, it has become a more compelling and relevant issue as America continues to become a more pluralistic society and health care systems work to become more universal and effective in their coverage (Cole, in press; McAdoo, 1982). The recent emphasis on community-based, family-centered care for children with special health care needs underscores the necessity for models that provide these services consonant with the cultural patterns of individual families (Koop, 1987). It is a very important step from the community-based, family-centered, and coordinated care model articulated in the Surgeon General's Conference (Koop, 1987) to a model which, in addition to these efforts, provides service in a culturally competent manner.

The United States has a long history of developing service delivery models to provide needed health, social, and educational services to recently immigrated families as they struggle to adjust their lives to the new ways of their adopted homeland (Levine & Levine, 1970; Wasik, Bryant, & Lyons, 1990). Efforts also have been made at the federal level to provide services to groups whose ancestral home has always been America. These services are mandated through treaty arrangements as well as the recognition that Native American groups are citizens of the U.S. and are, therefore, entitled to equal access to services.

While some groups or individuals have moved quickly into the mainstream, others remain separate and maintain the lifestyles and language of their ancestral homelands. Still others retain some portion of their cultural identity and adopt components of mainstream culture in their daily lives. The heterogeneity that exists along this continuum is as great as the differences among families in general. This effort to preserve lifestyles and nonwestern practices in the face of complex social and political forces which do not value them has been a very difficult task. All of these lifestyles are equally valid possibilities. It is not incumbent on families who immigrate to the United States to abandon their language, history, modes of interaction, religion and belief systems and adopt a western view to become American. In fact, many would argue that it is not possible to do so because of the deeply rooted value systems inherent in culture. We would argue that it is neither necessary nor desirable for families to do so.

To the extent that families do adopt western styles, it is clear that they have not had an easy experience in learning new modes of interaction and the language necessary to operate within the complex systems of commerce and daily exchange of America. Health delivery systems are no exception to this concern. If families have been motivated to seek help from a formal system of care, problems in language, different patterns of interaction, and the need to negotiate a complex system may require a Herculean effort to reach the point where appropriate and effective services can be provided. If agencies involved have a strong commitment to providing services to families in a culturally competent way which respects and encourages the belief systems and patterns of interaction inherent in a family background, then this task is made somewhat easier.

Many ethnic groups have been chronically underserved within the United States for a number of reasons. Some of these reasons are based on the difficulties inherent in the process of change for any newly immigrated group. They may have difficulty in adjusting to the political, economic service and interpersonal systems of a different society. Other rea-

sons for this underservice are based on the lack of knowledge or interest on the part of the service system to make services culturally competent by making them responsive to the unique needs of the various ethnic groups they are mandated to serve. This lack of service, combined with the increased immigration from Third World countries, has created a strong mandate for outreach efforts that challenge some of our traditional views of how services should be delivered and what services are appropriate. These new efforts require a more participatory model of program development that ensures strong participation of ethnically and culturally diverse groups in planning, implementing and evaluating new programs. Pragmatically, it is the only way that workable programs can be implemented and not meet the fate of the program designers saying, "We tried to help them, but we couldn't get them to come in to the clinic." As we know from the movement to include families in decision making and program development as part of P.L. 99-457, this inclusion strengthens the program in the long run. The same is true in creating programs that are culturally competent. Inclusion of constituencies in developing programs or a state plan for services to the wide variety of cultural groups living within its catchment area provides a solid base for program acceptance and growth.

Programs and systems which have incorporated the values and practices of family-centered, community-based, coordinated care should find it a natural step to incorporate cultural competence into their philosophical and practical orientation. Programs which remain unclear on the application of these family-centered concepts to their current programs will begin this effort at another starting point. The accompanying workbook provides a self-study guide to help programs at all levels in creating family-centered, community-based, culturally competent systems of care. Programs interested in more detailed descriptions of the family-centered issues are referred to a recent publication by the Association for the Care of Children's Health (Shelton, Jeppson, & Johnson, 1987).

A recent conference on family support programs and P.L. 99-457 enumerated a set of basic assumptions about families and programs that serve them.

Strong community-based service systems that recognize the family-centered nature of practice share common beliefs about families, which include:

1. Families are composed of basically competent individuals as well as competent caregivers.

2. The family is an important social institution that needs to be preserved.

3. Families should and can make the important decisions about their interactions with agencies and service providers.

4. The rights and beliefs of the family need to be recognized and respected. (Roberts, 1988)

These beliefs about families lead to a set of principles about the practice of family support programs and how services should be provided:

1. Practices and services should be based on the strengths, wants, and needs of the family.

2. Practices and services should be designed to help families achieve their own potential.

3. Practices and services should be culturally competent.

4. Practices and services should be based on sound policy and design and must be implemented by sensitive, caring, and well-trained staff.

5. Practices and services should be integrated within the community and its other systems of services and supports.

6. Practices and services must be built upon a firm foundation of research and program development and continue to contribute to that knowledge base. (Roberts, 1988, p. 5)

These principles should serve as a foundation for building strong culturally competent programs. They recognize the primacy of the family unit and the rights of families to make decisions about their own futures. Agencies should provide assistance and help consonant with the priorities set by the family. Consultation and support by the agency may be necessary to assist families in decision making, but it is recognized that family members will ultimately create solutions to problems that are the best adaptations they can make based on the cultural, economic, and psychological forces at work.

Agencies can facilitate or create barriers to families coming to these solutions. A better understanding of the competing forces operating on a family will increase the likelihood that the agency will be seen as facilitative. The emphasis here is on the cultural aspects of that process.

What Makes a Program Culturally Competent?

In our daily talk, we use the term "culture" in fairly loose ways to describe a set of beliefs, behaviors, and interactional patterns that identify a person with a larger social or ethnic group. Here, we distinguish between culture and ethnicity. Within ethnic groups, there are many cultures and subcultures, though some common history may be shared. Within the context of this monograph, then, *cultural competence refers to a program's ability to honor and respect those beliefs, interpersonal styles, attitudes and behaviors both of families who are clients and the multicultural staff who are providing services. In so doing, it incorporates these values at the levels of policy, administration and practice.*

A multitude of terms have been used in the field to relate cultural issues to practice. Among these terms are cultural competence, cultural sensitivity, cultural diversity, cultural relevance and cultural awareness. We have chosen to encourage programs to employ the term "cultural competence" for several reasons. Competence implies more than beliefs, attitudes and tolerance, though it also includes them. Competence also implies skills which help to translate beliefs, attitudes and orientation into action and behavior within the context of daily interaction with families and children.

Importantly, these concepts have been discussed in some detail in a recent monograph by Cross, Bazron, Dennis and Isaacs (1989) with respect to minority children who are severely emotionally disturbed. Cross et al., define cultural competence as " a set of congruent behaviors, attitudes and policies that come together in a system, agency or among professionals and enable that system, agency, or those professionals to work effectively in cross cultural situations" p. 13.

Alternately, Hanson, Lynch and Wayman use the term "ethnic competence" to decribe the need for early intervention programs to honor the cultural diversity of families in providing services. They cite a definition of ethnic competence from Taft (cited in Green, 1982) which states "ethnic competence means act-

ing in a manner that is congruent with the behavior and expectations of the members of a particular culture."

Jordan et al. (1985) in describing a culturally competent educational system, used this phrase "coming home to school." In the program she describes, the educational system is challenged to alter those key components of the school environment to reflect the social organization and learning styles familiar to Hawaiian children in their homes. Importantly, the locus of the problem is not viewed as an inability of Hawaiian children to profit from an educational experience, but that the educational system is incompetent in developing an appropriate learning environment.

Likewise, culturally competent systems of care for children with special health needs do not ask families to accomodate their beliefs, attitudes and behaviors to those of the dominant culture but ensure that the system changes so that families feel like they are "coming home to the clinic." For a further discussion of these concepts as they pertain to Hawaiian children and education, the reader is referred to Tharp et al. (1984).

As stated earlier, cultural patterns are deeply ingrained systems of social behavior and beliefs. They are important determinants of behavior, though other factors will also affect how we act from moment to moment. Initially, outward manifestations of culture, such as dress, the color of our skin and the language we speak may suggest stereotypes to someone who is meeting us for the first time.

When we have some notion of a person's cultural background in the absence of other information about him or her, we may believe that their behavior is caused by their cultural identity. As we get to know more, we understand the wide variety of forces which affect how a person behaves, and that culture is one of these determining factors. As such, it provides a context to talk about how a family with a child with developmental disabilities reacts to the challenges they face and some of the issues which will be present in dealing with the professional community assigned to help them and their child.

Bronfenbrenner's (1987) ecological model of child development provides a useful heuristic to view levels of influence on a person's behavior as a series of concentric circles. As one moves away from the epicenter of these circles, the influence becomes more subtle and less predictive of behavior moment to moment, but very predictive of patterns of behavior available within an individual's repertoire. It is this type of influence that culture exerts on people. We learn our initial beliefs and ways of interacting with one another from family members who are influenced by the community, which is, in turn, influenced by long-standing cultural patterns. The circles of influence continue to expand in the ways alluded to above. What we are learning, how we are learning it, and from whom we are learning it vary both by the situation and the cultural patterns embedded within the family and community structures which surround us.

However, individuals rarely remain within one system. We are all part of several microsystems which act like intersecting sets. These microsystems are not static but continue to evolve and mutually influence each other. A handicapped child and his or her family is one microsystem in which the roles and patterns of interaction within it are defined. This same family becomes a part of another microsystem when it visits the physician, the physical therapist, the infant development clinic, the faith healer, or a religious leader in the community.

Any family experiences some problems in learning the new set of roles, rules, and

expectations when they become part of a new system that is designed to provide a service for that family. This experience is somewhat easier when the family system and the new intervention system share most of the same common concentric circles of influence (e.g., as cultural patterns of interaction). In short, both the professional and the family members know how to behave and know the roles the other person will play in a broadly defined way. At a basic level, they may share a belief that the child's problem is caused by a medical condition that is amenable to some form of medical intervention. They may also share a belief that the professional has knowledge that will assist the family to help their child progress and develop as normally as possible. At the level of daily interaction, they may agree that (a) one does or does not shake hands when they meet, (b) eye contact is important or should be avoided, and (c) who in the family should receive information and who will be responsible to ensure that activities prescribed by the professional are carried out.

If the beliefs, interpersonal interaction patterns, and learning roles of the helping professionals are very different from that of the family, the "givens" described above may not be "givens" at all. This reduces the chances that families will either use services that are potentially available to them or follow through with the prescribed regimens if they do get to the clinic. If families do persevere because of their concern for their child, these differences in styles will add additional stress to the parent and the professional. It can also make it very problematic for a professional to gain access to information that is vital to diagnosis, treatment, and helping the family in decision making. An Indian mother has described the experience of many Indian parents in the following way when she spoke on a training tape developed by Southwest Communications Resources, Inc. to help sensitize professionals to issues in native American culture:

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Just like anyone else, it takes us time to get used to working with a new doctor before we trust him. More traditional families may take longer. Some of us were brought up to avoid looking directly at a person and not to ask questions. As parents, we care about our children, but sometimes we feel uneasy when people ask us too many questions. In our culture, that is often considered rude. If a nurse or doctor needs to ask a lot of questions, they should explain why they need that information. That helps us to feel more comfortable. Sometimes the doctor doesn't even give us enough time to answer, so we often say nothing. When we're not feeling rushed, there is time to think of the questions we need to ask. That is why we often bring a relative with us--they can ask questions and help explain about the child's illness.

When a serious decision must be made, we talk it through with extended family members or listen to our elders. Then, together we decide what is best for the child. Some doctors get upset with us if we do not make an immediate decision on the treatment they recommend for our child. But others respect our cultural way of making decisions. They invite family members to take part in the discussion and give us time to decide what makes it much easier for us. Our traditional ways are important to us, and we respect them. We also know some of our children have special needs, and we try our best to take care of them. Sometimes we use traditional methods; other times we take the child to the doctor.[1]

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The decisions and conflicts articulated by this mother represent the basic issues families must deal with daily in contact with health professionals. Families experience stress from a wide range of sources when they discover that their child is developmentally different. Fami-

lies will seek help in times of stress from formal and informal sources, which helps to reduce this stress and bring the family back to a more harmonious, less stressful way of coping. In this monograph, we refer to formal and informal systems of support and care which are part of a family's social support network.

As defined by Gottlieb (1981), "Social support consists of verbal and/or nonverbal information or advice, tangible aid, or action that is preferred by social intimates or inferred by their presence, and has beneficial emotional or behavioral effects on the recipient" (p.28).

Informal systems of care include the methods by which families solve problems within their own ecosystems of friends and family. For example, it may include a neighbor who can always be relied upon to care for children when needed or who can help in housekeeping with elderly family members. The uncle who has a car and drives family members to important meetings or appointments is also part of this informal system.

Formal systems include those service providers which have been sanctioned by society to provide services of one kind or another. A priest or medicine man is part of a more formal system and each carries honored ceremonial and social responsibilities. Within a western health care system, professionals such as nurses, psychologists, physicians, therapists, teachers and social workers are all part of a formal system, regardless of whether services are provided in the home or the clinic. Lay counselors, aides, parent trainers and paraprofessional home visitors are all part of the formal system as well.

As you can see, this definition of formal systems of care includes both western and nonwestern formal systems. You may be accustomed to thinking of nonwestern formal systems such as medicine men or shamans as part of a natural system, traditional or informal systems. We have chosen to include both western and nonwestern healers in the formal system, and to distinguish them from informal systems because they share common attributes and perform important sanctioned formal roles in their respective cultures. They are sanctioned by their respective societies to provide specific services; they may be reimbursed for their services; they have undergone formal training and/or apprenticeships; and there is a system of rules which relate to their behavior and how one gains access to their expertise.

Though informal helping and support systems are more enduring within families, these systems may need more technical expertise and knowledge in areas vitally important to the developmental progress of children with special needs. Informal systems probably will not be able to teach parents how to perform healing ceremonies as would a medicine man or how to operate a home ventilator as would a respiratory therapist.

In most cases, nonwestern formal systems are more compatible with informal systems because they are of the culture and derive their legitimacy from the belief systems and values held by members of that cultural group. Unless western formal systems such as clinics, hospitals, schools and early intervention programs are designed to be compatible with these nonwestern formal and informal systems, it is likely that families will not gain access or use the information they need.

There are other barriers to the use of services by culturally different groups beyond those mentioned above. Families may lack information about services in general or what specific services a clinic could provide. At a more basic level, they may not see the relevance of a formal intervention regarding the developmental problems their child may be experiencing. Further, families may hold differ-

ent beliefs about the causes or the nature of problems that are viewed in our western tradition as medical or developmental in nature. Each culture has a mechanism for dealing with these issues, which is constant with its belief systems. The goal of a culturally competent program is to bridge the gap by making treatment and related services relevant to cultural patterns. Families then have a choice in treatment where none existed before.

The goal of a culturally competent program is to bridge the gap by making treatment relevant to cultural patterns.

Another Indian mother speaks for many Indian parents when she talks about the interplay of the two systems.

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To my people, having good health means living in harmony within ourselves and our families. We see illness as a disharmony, and it cannot be separated from the mind and spirit. We respect western medicine and the doctors, but sometimes it's better for us to use traditional healings and medicines. Our religion is woven throughout our lives, but these things are very private. We may find it difficult to be asked directly about our beliefs and ceremonies by those not of our tribe, but sometimes we use traditional medicine for a family member in the hospital and appreciate medical staff cooperating and understanding. We just want them to respect our privacy.[1]

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The recent emphasis on community-based, family-centered coordinated care for children with special health care needs creates the opportunity to help bridge this gap between traditional practices and western systems of care. By emphasizing the community-based nature of programs, it is more likely that the culture and mores of a family will mesh with that of the agency providing services. Agencies at the community level are more likely to be responsive to community concerns and input. As suggested above, programs that are family centered are more likely to solicit and be responsive to family involvement in treatment. They are more likely to accept a family's decisions about priorities and to create the conditions under which a family is able to interact effectively with professional staff. These values, which are part of community-based treatment programs, suggest the values that must be present in culturally competent, community-based, and family-centered coordinated care for children with special health needs.

Types of Programs Providing Services

Different types of agencies are more or less likely to be able to provide culturally competent support to families. For purposes of discussion, four types of programs are presented. A recent publication describing culturally competent services within the mental health field identifies these four models for services (Cross, Bazron, Dennis, & Isaacs, 1989):

1. Mainstream agencies which provide outreach to minorities.
2. Mainstream agencies which support services by minorities within minority communities.
3. Agencies which provide bilingual/ bicultural services.
4. Minority agencies which provide services to minority people.

In the first case, a mainstream agency such as a local hospital or state division of maternal and child health may identify a need to begin services to a previously underserved minority

population within its catchment area. This agency begins an outreach effort to serve this group. Unless they have taken great care to ensure they are family-centered and community-based, the agency could be seen as insensitive to the cultural concerns of the target group simply because it is either part of the state bureaucracy or is "that hospital on the hill." The mainstream agency must be able to be sufficiently flexible to create trust within the local community and to build a strong community support for its activities with meaningful and consistent guidance provided by community representatives and the parents involved. It must be able to deal with ambiguity and to welcome the opportunity to alter procedures and services to meet the expectations of another cultural group before that group can begin to trust the agency and work with it.

Frequently, large institutions have difficulty developing or maintaining the flexibility to operate at this level of community responsiveness. Other workbooks within this series detailing issues in the development of community-based networks and programs will serve as a useful guide in helping programs to develop this emphasis if it is not already present (see reference list under *Rainbow Series)*. The important point here is that mainstream institutions will find it particularly difficult to develop culturally competent programs if they have not simultaneously or previously made a serious commitment to family-centered community-based services.

The second model involves a mainstream agency sponsoring a community-based program that is staffed by members of the cultural group which it serves. The Southeast Asian Developmental Disabilities Prevention Project, which will be discussed in some detail in the next section, is an example of this model in action. A larger umbrella organization sponsors a program for recent southeast Asian immigrants whose children are at risk for or have developmental disabilities. The program is located away from the main center in the section of San Diego that is home for many new immigrant families. The staff is almost entirely made up of representatives of the various ethnic groups targeted in the program.

This model recognizes that mainstream services are not appropriate for the target community, and that a very different response is needed in order to provide these needed services to families. The physical and administrative separation of the program from the umbrella organization allows for the autonomy necessary for the program to flourish. At the same time, the umbrella provided by this larger organization makes it possible to reduce the administrative overhead of new programs. Staff from the umbrella program are available to consult and advise in program and administrative matters as needed to assist a new program in getting started.

The third model involves bicultural and bilingual programs that emphasize the multicultural aspects of a community and strive to provide options for families within a mainstream setting. Staff are recruited who can effectively enter into the microsystem of the family both because they speak the natal language of the family and they have relevant experience living within the cultural niche shared by the family. However, since the staff is also bicultural/bilingual, they will have had sufficient relevant experience within the mainstream culture to act as effective brokers and negotiators in getting needed services in the system for a family. Families are more likely to relate to the staff who can speak their language, and the staff are more likely to be able to identify the issues of concern represented in the family. Typically, staff within such programs are professionally trained, though some may also be at the paraprofessional level.

Programs seeking to become bicultural/bilingual face several obstacles including

internal staff resistance to changes in hiring criteria and job qualifications. The move to a bicultural/bilingual staff requires a close examination of job descriptions to ensure that these skills are present in staff. Other sections of this monograph and accompanying workbook discuss this issue in more detail. Here, it is important to note that the commitment to hiring bilingual staff may be challenged by charges of lowering standards, reverse discrimination, lack of qualified applicants, etc. All of these challenges can be overcome with involvement of community and family members in decision-making and a willingness on the part of existing staff to closely examine their own biases within the area.

The fourth option involves agencies that are entirely composed of a cultural minority serving that population and doing so without the support of an umbrella mainstream agency. These programs may have the highest degree of autonomy and self-determination. Such programs may be difficult to sustain because of the complex nature of maintaining their funding. Groups that maintain themselves distinct from the larger mainstream culture may be less financially stable. Consequently, they must rely on funding from state or local agencies who may not value the service being provided or who may offer the service through one of the other options mentioned above.

Despite the funding difficulties these programs may face, grass roots efforts are multiplying within communities at the local level. Their persistance suggests both that mainstream systems have not met the needs of families and that community ownership and cultural competence are strong values which work together to ensure that families are appropriately served. Smaller grass roots efforts may not be able to provide more specialized and technical help because it is often too expensive and beyond the expertise of such programs. Crisis services and outreach efforts in support of families are services which are frequently offered. Free-standing or storefront clinics are another example of this type of program. Professional volunteers may provide services that would be too costly otherwise.

One such program in Hawaii involved a local group that identified natural helpers in the community and provided training and support for these individuals to work with families in crisis. The program was primarily staffed by and served native Hawaiians. Funding was provided through small grants from the Aloha United Way and some state funding by the State Department of Mental Health. Professional staff were few. Most were paraprofessional. The staff were highly motivated and very committed to their program. Services were delivered at low cost, and referrals were made to other programs in the community when appropriate.

Another example of this type of program is Avance, which serves primarily low-income Hispanic families from the barrios in San Antonio and Houston. Over the past 16 years, it has grown from a program funded by a small grant of $50,000 to a much more extensive effort including multiple sites and multiple funding sources. It has, however, maintained a consistent theme of its community-based, locally controlled beginnings. Over 80 percent of its staff are from the community, and have gone through the program.

Avance is an important example of this type of effort for several reasons. It provides appropriate role models for individuals in the program. It also provides employment for a significant number of families who were previously unemployed. Also, it demonstrates that grass roots efforts can continue to grow and mature without losing the very important community base of their original efforts. As they grow, they are able to exert influence on staff

agencies by the example they set and the cultural competence they bring to all of their interactions with mainstream agencies. Finally, it shares a common thread with other culturally competent programs in the valuable service it provides to families who, for a number of reasons, do not utilize mainstream services. Such programs provide a variety of services in their own right to families, and also help families gain access and utilize services provided by mainstream agencies.

Issues in Policy and Practice

We have said that a culturally competent program is community-based, but it is more than that. What are the additional components that must be present for a program to work? These issues involve several areas of program design and include policy, practice, and training issues. Each model described above can move toward better services in this domain as they consider issues discussed below.

Policy

Programs that are culturally competent do not become that way by accident. They are culturally competent because of a commitment at all levels within an organization to provide to all families services which are consistent with their cultural beliefs and styles of interaction. This is a clearly established policy; understood and publicly stated so that both staff, clients, and the larger community are aware of this orientation of the program. It may be formally stated in long-term plans or part of the written philosophy statement within the organization. It should make clear that the state/agency/organization is committed to serving all children who fall under their established medical and developmental guidelines within their catchment areas. This information should not be filed in the minutes of a meeting, never to see the light of day! For it to represent an effective policy decision, it must be broadly understood within the organization and its constituency. It must be disseminated through the formal and informal channels that exist within the community. In short, the policy must be a living part of the organization reflected in its practice and administration. One way to ensure that policy is followed is to create the circumstances in the daily policy making structure of the organization which require that constituents' cultural concerns are given voice. Members of ethnic and cultural groups, including parents and community leaders, must be well represented in policy-making groups. For example, the makeup of State Interagency Coordinating Councils should reflect the cultural diversity of a state. Local service provider agencies should ensure that members of the community being served are adequately represented on boards that make real decisions about how the program is to function. It is only as an agency begins to work with natural leaders within a community that it can begin to translate an intended purpose into a reality. This process, if successful, will change the ways an agency operates in policy formation, hiring, training, and daily delivery of services. It may also change the intended purpose. For these reasons, agencies should be clear from the beginning if there are areas that cannot be easily changed. If there are non-negotiable items and ones which are not open to community input, these parameters need to be made clear to participants as the process begins. It is then up to the community members to decide the degree to which they can operate within the constraints imposed. As this process unfolds, the policy-making body, which includes community participation, will be able to set standards of practice that reflect a culturally competent, community-based, and family based approach.

An example of how a constituent concern can change the direction of a program can be found in a report of a community needs

assessment conducted by Ymori and Loos (1985). A program for ethnic Hawaiian pregnant and parenting teenage mothers had been in operation for several years when a more formal network of services was formed to provide better case management for this population. The first step was a felt needs assessment in which agencies and clients were separately asked to rank order a number of needs and potential services that could be provided by the agencies in the network. Agencies in general thought that the teenage mothers in the program were most in need of the following services: parent training, couples counseling, birth control counseling, and job training. Teenage mothers, on the other hand, listed a different set of needs as their highest priority. These included a permanent home for themselves and their children, a reliable child care arrangement so they could continue their schooling, and food stamps so they could eat. This information was used in interesting ways. Neither group was made to feel that their list was "wrong." Rather, each group had an opportunity to see the list of the other group and to talk with them about the differences in the two lists. The result was a better understanding both on the part of the teen mothers of the agency concerned and a commitment on the part of the network to help the teen mothers to meet some of these primary needs.

Practice

The creation of a community-based, culturally competent family-centered program is not a static event but an ongoing creative collaborative process. There are several guiding principles which may help to ensure that the intended policy of culturally competent services is translated into an ongoing effort to shape practice. These include:

1. *Culturally competent services must be, by definition, also family-centered and community-based.* The principles of practice enumerated on page 3 of this monograph underline the principles described here.

2. *Staff should be aware that families are unique and must be treated uniquely.* It is as culturally insensitive to assume that all families within a given cultural group will react the same way as it is to ignore the fact that culture is an important variable in determining how we behave.

3. *Care must be taken in separating cultural issues from the effects of poverty and discrimination experienced by many minority groups within the United States.* For instance, the economics of being poor may require models of child care different from ones which are culturally preferred. Families may have few options and resources at their disposal, and these resources dictate the most economical ways of providing care.

4. *Program staff should have the capacity and opportunity to assess for themselves their own cultural values and understand the impact of their backgrounds on their ability to provide culturally competent services.* This cultural self-awareness is an ongoing discovery process and can be a valuable tool in defining new program and training needs.

5. *It is not necessary to be of a culture to provide services to members of that culture.* However, it is important that staff understand the dynamics of the inherent tension caused when two or more cultures interact to provide a service or solve a problem. It is critical to ensure that members of the cultural group being served are able to effect decisions concerning practice, training, hiring staff and policy.

6. *It is recognized that good programs are the product of hard work in developing personal relationships and networks across agencies and communities.* Even so, mechanisms are needed to insure that components of a program have been institutionalized and are not dependent on one person from the institution and one person from the community to maintain them over time. The commitment needs to be at the institutional level with sufficiently broad-based involvement that the institutional commitment survives staff turnover and changing interests.

7. *The development of programs such as these requires a paradigm shift on the part of service providers to share ownership and decision-making.* As with many shifts of this nature, once program staff and administrators make that shift, it becomes a very natural way of viewing the world. However, such a shift is not without risk. It requires a higher tolerance for ambiguity as programs, parents, and community leaders map a course together. Those who enter into the process, however, have the potential to create programs with a high degree of community and family satisfaction. This leads to higher staff morale and higher calibre level of service.

Specific Issues in Practice

The principles described above related to practice affect a number of areas in practice, including assessment, outreach, family involvement, evaluation, and staffing. Each will be separately addressed below.

Assessment

Programs working with culturally different populations face a particularly critical issue in providing an appropriate assessment of young children with developmental or medical problems. If standardized assessment tools are used, there are problems in translation of components into the natal language of the child, as well as lack of appropriate norms for groups other than those included in the norming sample. The additional possibility exists that the tests contain an inherent cultural bias that discriminates against children of different cultures. As an example, the PREP program in Hawaii, discussed in more detail in the next section, conducted routine language testing on all of the children in the program. Since many children lived on or near the ocean, parents and neighbors would keep their boats for fishing in the backyards. One of the standard questions in the battery was, "Where do you find a boat?" The correct answer, according to the manual, was "on the ocean or in the water." Many of the children in this program would answer "in the backyard" or "in the driveway." Though this situation is humorous at one level, the program was confronted with the dilemma of following the manual or renorming the test. Programs and states must carefully review their eligibility criteria for services to ensure that they do not contain cultural biases that would either overinclude or underinclude children of culturally different groups in their criteria.

Programs and states must carefully review their eligibility criteria for services to ensure that they do not contain cultural biases....

The goal of any assessment should be to point the way that professionals can be helpful to families in maximizing the developmental growth of their child. Deficiency and deficit models of assessment do not serve this purpose. The inclusion of the "at-risk" category under P.L. 99-457 is particularly worthy of note in this regard. Care must be taken to ensure

that children are not "at risk" primarily because of cultural differences.

Issues in assessment go beyond what is assessed. "Who" is involved in assessment can be as important as "what" in developing an accurate picture of a child's strengths and needs. As noted earlier, the decision-making patterns within a family must be understood in order to ensure that complete information is received. If families generally defer to the grandparents or if the father is the traditional spokesperson for a family, these patterns need to be reflected in the information exchange which is part of the assessment/ intervention process. If the parent feels most comfortable in talking when a member from the extended family is present, it is important to create the atmosphere and the opportunity for all concerned to participate. Additional issues in family assessment will be discussed in a later section on family involvement.

The major point here for programs to remember is that assessment of children and families is a clinical skill. This skill involves sensitivity to and an understanding of the cultural niche which constitutes the world of experience for a family. The clinician must have knowledge of and experience with the family's background in order to provide a valid assessment that accurately describes the child's current level of functioning, that child's potential for continued growth, and the supports available to the family.

Outreach

Programs and states must carefully develop an outreach effort that invites culturally different groups into the service system. Though it is appropriate to develop information pamphlets about a program in the native language of the target group, this is just a beginning of a strong outreach program. Care must be taken to ensure that materials are competently translated into concepts meaningful to the target population. A recent example serves to reinforce the need for care in preparing materials. A program was translating a child abuse pamphlet from English into a second language. The original document had a picture of a young child on the cover with the caption "This child is a victim of child abuse." The translation was made and the pamphlet was distributed. The agency discovered after some time that the term "child abuse" had been incorrectly translated into "This child has committed a crime."

Outreach begins with an effort to discover the number of children within the target area who meet the eligibility criteria for service and to compare that number with those who are actually receiving services. There are several ways to begin to develop an estimate of the number of eligible children once the criteria for eligibility are firmly established. One method is to develop an accurate estimate of a given population in the catchment area. For example, eight percent of the total population in a state or a catchment area may be of a particular ethnic or cultural group, and yet only two percent of the actual client load is of this ethnic or cultural group. In this case, only one of four children who are probably eligible for services are receiving them. If the conditions which make a child eligible for service are exacerbated by conditions of poverty and substandard living conditions, the 8 percent estimate is probably an underestimate of the real incidence in the community. Still, this can be a beginning point for programs to monitor their progress in attracting minority clients.

Alternately, if good birth records exist for children in a catchment area, one can estimate the number of children a program should be serving based on the known incidence of a disorder or developmental problem within that population. The Indian Health Service, for instance, has excellent birth records on all children born on the Navajo reservation and can state with some certainty the numbers of children born with a variety of disabling condi-

tions within the Navajo nation. Again, this leads to a way to monitor progress in reaching eligible children and families. Acquired conditions, however, are not covered in this procedure.

Knowledge of the numbers is Step 1 in outreach. Recruiting community support for the programs is Step 2. The issues discussed above with respect to community involvement are central to a good outreach effort. Often, members of community network know which children would benefit from services. They can be a valuable ally if tapped and invited into the system. The reader is also referred to other workbooks in this series which specifically address the issue of community involvement in program development for a more thorough discussion of these issues.

Family Involvement

Service providers and planners have gradually come to realize the enormous benefit to children when family members are routinely invited into the entire process of assessment, care, and treatment. This is no less so for families from cultural or ethnic minorities. Families within a given ethnic or cultural group vary with respect to patterns of interaction, family size, authority roles within the family, and decision-making processes. However, there are general patterns that are seen as enduring trends within a group and can serve to guide a program as service providers learn more about an individual family and how these roles are assumed within that family unit. A recent publication by the National Center for Clinical Infant Programs describes some of these general themes by cultural groups (Anderson, 1989).

The important lesson a number of programs have learned in working together with families is that cultural styles of interaction are strong predictors of family patterns. Even if families move away from many of the tangible manifestations of their culture over time, patterns of interaction within the microsystems of the family are likely to remain. Thus, a family's language may change to English, and western forms of clothing may be adopted as well as western foods. Members of the family who have frequent dealings with the mainstream culture may adopt many of the interactional styles of the group while they are involved with mainstream people. Even as all of these changes take place, the patterns of interaction and rituals within the family unit as defined by that culture are much less likely to be influenced by external forces.

The enduring nature of these private family patterns is particularly relevant in times of crisis and stress when family members turn to one another for support. The problem-solving strategies and internal uses of resources to manage the stress are probably those of the natal culture. Professionals are initially most likely to come into contact with the family precisely at the time that these strategies are being mobilized to handle the birth of a child with a disability or the discovery of medical or developmental problems with an older child. This is the hardest time for everyone; yet it is the most critical in terms of developing a long-standing bond with a family which will allow agencies to continue to provide quality services to the family and target child. If the agency representative ignores the authority relationships and decision-making processes that the family uses and imposes another system on the family, it is very likely that the family either will not return for treatment or will become what the agency may see as a problem family, resisting suggestions and only minimally following regimens.

The concepts discussed above are not specific to culturally different families. Again, we are reminded of the natural step from community-based, family-centered care for chil-

dren with special health needs to culturally competent program development. An excellent publication by the Association for the Care of Children's Health provides a great many insights into the issue of family-centered care (Shelton, Jeppson, & Johnson, 1987). All of the issues raised in that publication are relevant to culturally competent programs and expand upon the concepts enumerated in this document.

Staffing

Ultimately, the way people from agencies interact with people who are seeking services is the critical variable in whether or not a program is perceived to be culturally competent. The bottom line in many of the issues discussed thus far has to do with the qualifications, training, and support provided to the staff who interact daily with clients. In this section, general issues in hiring, training, and supporting staff will be discussed.

A wide range of staffing patterns exist within programs which serve cultural minorities. Many positions that require licensure have built-in standards with respect to the professional qualifications that must be met. Positions such as home visitors may be filled either by professional or paraprofessional staff depending upon the skills required and the types of assignments the staff person is expected to complete with the family. Other positions such as aides are more clearly at the paraprofessional level.

A recent conference on family support in the home suggested a minimum set of qualifications for home visitors, but this set of qualifications has broader applicability to all individuals working with families. In addition to the professional qualifications set by licensing boards or the technical knowledge required for a specific position, they must have good interpersonal skills, organization, effective coping skills and problem-solving abilities, and relevant prior experience, which need not be in the form of a paid position (Roberts, 1988).

Relevant prior experience for staff working in programs with cultural minorities should include experience in working with culturally diverse populations. Since job descriptions and advertisements for positions should specifically state the skills necessary for a person to be effective within a particular job, positions which require staff to provide services to minority groups should require skills in this respect. The staff need not be of the culture to be able to serve families within that culture, but other types of relevant experiences are needed to ensure that the cultural differences of families and all staff are honored. This training can come from a number of sources, though it is doubtful that formal instruction alone (e.g., coursework at a university) would allow a person to have the requisite depth of knowledge to translate theoretical information into everyday practice.

Programs serving minority and culturally different populations are interested in providing the highest standard of service possible, but competing demands create constant tension in defining who should provide this service. Frequently, it is very difficult to hire individuals with all of the relevant experience necessary to be effective within a particular position. In placing a high value on relevant experience with different cultural groups, programs may be particularly interested in minority candidates for a position. There are fewer professional staff with formal degrees available from minority groups than from Caucasian groups. Though professional schools are working to address this imbalance, the demand for professionals from minorities is keen, and programs may not be able to hire someone with the relevant life experiences within a culture as well as the professional qualifications to work in their program. An

applicant may have the professional qualifications for a position but no relevant cultural experience. Likewise, an applicant may have considerable experience with a given population but lack important professional qualifications. In either case, programs are confronted with having to make choices between various qualifications for applicants. Programs which do ensure that they have a culturally competent staff will gain many benefits from doing so. Services to families will be more effective. Staff will have more opportunities to learn from one another. There are no easy solutions to reaching this goal. Programs may wish to take into consideration several factors in making these hiring decisions.

First, how does this person's skills fit into the constellation of skills represented by other staff members with whom he or she will be working? If the candidate brings skills not represented by others and has the relevant cultural background, perhaps some of the other duties could be shifted to other staff during a training period for the new staff person.

This leads to a second issue. What types of supervision is available within the agency for new and existing staff? If this person will be working in a situation with minimum support and supervision, there will be little opportunity to learn new skills not present when the person is hired. On the other hand, some missing skills may be more easily learned on the job if a full inservice training program is available and supervision is routinely provided, or if opportunities for peer supervision and case conferences are available. Community members can be a valuable source of information and faculty for inservice efforts.

The personal characteristics of applicants obviously are important issues in the decision. Are they flexible with a history of being able to pick up new information and use it effectively in new situations? Do they display an openness to learning and to differences among families? Are they family centered in their attitudes toward intervention?

Finally, the involvement of the community in the hiring practices of a program will help in making the hard decisions, such as those suggested above. Some programs feel more comfortable allowing and encouraging community input into the hiring process than others. This is an individual program decision. Each community will differ in their priorities concerning staff hiring. Some may see professional qualifications as paramount, while others may be more interested in a blend of professional and cultural qualifications. Parents can be valuable allies in this effort and provide important information about how comfortable they are with potential staff. Parents are resources which should be used.

Use of Translators

It is also important to consider problems in language and communication in staff patterns for clients/patients whose native language is not English. If community members know that their initial point of contact with an agency will involve someone who speaks their language, then one barrier to seeking services is already gone. Some programs have decided to use a receptionist or secretary who is multilingual

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and speaks the languages of the populations to be served. The receptionist at the Southeast Asian Developmental Disabilities Prevention Project in San Diego, for instance, communicates fluently with families in Laotian and Hmong and is able to identify Vietnamese and

Cambodian languages and connect the family with the appropriate counselor.

Many times programs will need to think of innovative ways to provide service in the language of the family if workers within the program are not of the culture. The most culturally competent way to provide services is by hiring staff who speak the language of the cultural groups to be served. Though this may raise many challenges for a program, it is clearly the most preferred and sensitive option. If a program is experiencing difficulty in hiring staff with the appropriate language competencies, it may need to review its hiring criteria and policies to ensure that the importance of this skill is appropriately emphasized. Program staff who have reviewed this manuscript have emphasized the interim nature of the use of translators. It cannot be a long-term solution because it suggests a lack of commitment to families whose native language is other than English. When programs find they have no immediate alternative other than the use of translators, it is preferable if translators have experience with families and can be consistently available each time a particular client is in the clinic. Otherwise, a new interpersonal relationship has to be established each time. Some clients who do speak English will still prefer to use their native language and a translator, because it is easier to understand concepts and provide information during the interview. Every effort should be made to provide translators to clients so that the interview can be conducted in the language that is most comfortable for the client.

Client Load

Programs that are family based and culturally competent must take the time necessary with individual clients/patients to ensure that their needs are being met. It takes more time to provide these services than one might find in programs which do not have this focus. Many clients are not only unfamiliar with the educational, social service, and health care services available to them, but do not understand the reasons for their necessity. It takes considerable time to explain the rationale for services as well as to develop a plan which incorporates both traditional approaches and western approaches to the problem. This is the core of culturally competent, community-based care and is essential for program effectiveness. Unless staff are able to spend the required time with clients, these goals of the program will not be met. Therefore, caseloads must be adjusted as required to allow the necessary conditions for this relationship to develop. The average caseload in a home visiting program in Hawaii, designed to help native Hawaiian families maximize the health, social, and educational outcomes of their children, was 12-15 families per full-time home visitor. An even lower caseload may be necessary in situations where families are new immigrants and do not speak English or are on reservations where driving time either to the clinic or to a client's home may be several hours.

It is also important to consider the period of time over which contact may be necessary with families. In family support efforts, contact may be required for several years until family members feel competent to handle the systems of care with less assistance. In some cases, families will never feel completely comfortable and would be unable to serve as their own case managers within the system. Here, agencies must make hard choices with respect to following a given family for an unlimited amount of time or to shift resources to a new family.

Professional-Paraprofessional Partnerships in Culturally Competent Programs

Programs serving cultural minorities may find that they use some combination of professional and paraprofessional staff more fre-

quently than other programs. Some of the reasons for this have been discussed above with respect to decisions programs must make in hiring practices. Other reasons have to do with the possibility that good programs may seek out and hire program parents or other community members to work in the program in a number of capacities. In many cases, these workers will not have degrees and will fill paraprofessional positions. Care must be taken to ensure that the appropriate supervisory and consultative roles are clearly defined within these relationships. Paraprofessionals from the community have much to offer professional staff with respect to the value systems and interactional styles of a cultural group. Unless mechanisms are developed to ensure that communication, education, and mutual respect are two-way streets, this knowledge may not be made available, and, consequently, services will be less culturally competent.

Training and Support

This leads to the final issue with respect to staffing, training, and support issues in culturally competent programs.

Inservice training programs should attend to both the affective and content-oriented needs of staff in working with culturally diverse populations. As noted above, opportunities should be provided that invite staff, in a nonthreatening and supportive way, to explore the impact of their own cultural heritage on their professional relationships with families.

In addition, information about cultural practices should be openly presented by the most qualified people. This may include parents, community representatives, leaders within a cultural group, or other staff. It must also be recognized that certain cultural practices are very private events and are not typically discussed or shared outside of the cultural group. This practice must also be respected. For instance, it is sufficient to know that Indian families may want medicine people to perform traditional ceremonies in a hospital room of a sick child, and that certain objects used in the ceremony may be left there and are not to be disturbed. Staff outside of the culture do not need to know more than this. They can respect and support the rights of the family without intruding on private and deeply felt religious beliefs.

Staff working with families from various ethnic and cultural groups need a supportive atmosphere in which to work. Though this is no different from staff in any program, it still must be emphasized because of the high turnover and staff burnout experienced by many programs. Reinforcers for staff may be few and widely spaced. One home visitor reported working with a new immigrant family for two years before the family consented to allow their deaf child to be tested. In this period, the child's language had not developed, and other developmental milestones had been seriously delayed. The home visitor had worked very hard with this family and felt justifiably proud that he had stayed with them for the period necessary to help them make the decision to have their son seen by western medicine. Without the strong support that the home visitor received from his peers and supervisors, it could have been very discouraging to continue to support a family in this very slow decision-making process.

SUMMARY

In this section of the monograph, principles of community-based, family centered, culturally competent care for children with special health needs have been discussed. The point has been made in several ways that it is a small but very important step from community-

based care with a family focus to one which also incorporates cultural issues in program design and implementation.

Programs in Action

This next section reports the results of an informal survey of programs funded by the Bureau of Maternal and Child Health, which serves cultural or ethnic minorities and takes several programs across the country that have been recognized as examples of these principles in action and presents important aspects of each program. The descriptions are not intended to completely describe all of the components of each program but to highlight issues.

Informal Survey

In preparation for writing this monograph, all of the programs funded through the Bureau of Maternal and Child Health and Resource Management in 1988 that mentioned a cultural or ethnic minority in their published abstract were interviewed to glean common issues among the programs.

First, without exception, project directors were willing to facilitate our efforts. Projects were focused on either serving ethnic or cultural minorities or working with specific problems within a cultural or minority group (e.g., genetic counseling services). Invariably the strongest point from each interview concerned the advisability of involving members of the community in the project. Service delivery was more sensitive toward cultural needs when an attempt was made to include community members in the decision-making processes, planning process, or employing persons from the community in the intervention and implantation of services.

Programs that seemed most successful in providing services to cultural minorities were ones which adopted a more flexible and realistic attitude toward their program. For example, a project was involved in working with Hispanic women and infants on the Texas/Mexico border who frequently traveled back and forth across the border. Health care tended to be noncontinuous, and a close relationship with the counterparts in Mexico expedited more effective health care. Food vendors at street stands represented a health hazard for program participants in small Mexican villages. Rather than closing down the vendors who would probably open up again somewhere else, an education program aimed at increasing the frequency of hand washing was implemented with some success. A Mississippi outreach prenatal education project also gave an example that addressed a practical issue to increase program viability. Providing transportation to the mothers and infants between their homes and the center increased the numbers of individuals served.

Certain themes among the most successful projects included the following:

1. **Flexibility**. It was important to have the ability to place the project's own agenda on temporary hold and listen to the needs of the community. Compromises and adaptations were frequently necessary. Most often, the projects evolved to include more community input as they moved along in development.

2. **Sensitivity**. Certain behaviors had specific meaning to a particular culture, and successful communication often entailed understanding that meaning for the people that the project was serving.

3. **Trust.** Trust took time to develop, it was often aided by soliciting the sup-

port of an important community member (i.e., church leader). Consistency and follow-through were mandatory characteristics if the relationship was to develop into one which included trust.

4. **Recognition of priorities**. More successful programs understood that if the family was not having more basic needs such as food and shelter met, it was unlikely they would listen to someone lecturing about preventive health care.

In summary, most projects took the time and had sufficient respect for the communities with which they were working to find out about them and involve them in the partnership for program development.

PROGRAM DESCRIPTIONS

KAMEHAMEHA SCHOOLS PREKINDERGARTEN EDUCATIONAL PROGRAM

The first program to be described (PREP) is a community-based early intervention program drawing on the strengths of contemporary Hawaiian culture and involving education, health, and social service providers to create programs for Hawaiian families with young children. The sponsoring organization for PREP is the Kamehameha Schools/Bishop Estate, which is a private school system dedicated to developing on-campus and outreach programs for ethnic Hawaiian families. The PREP project was partially funded by the Office of Human Development Services and the Bureau of Maternal and Child Health and Resource Management.

Despite the good efforts of a number of social, educational, and health services within the state, native Hawaiian children are at risk for a wide range of problems virtually from birth. Hawaiian babies are the most at-risk group of the four major ethnic groups in the state. Hawaiian children as a whole are overrepresented in all of the categories associated with negative developmental outcomes. Only 14% of Hawaiian 4-year-olds in the preschools passed a routine hearing screening. The health, education, and social problems of Hawaiian children are complex. What emerges is a picture of a major ethnic group that is under severe stress across the board. This is in direct contrast with what one sees of Hawaiian family's when they are able to function and nurture their children with support systems adequate to meet their needs. The PREP program was designed to help foster these supports. Although the approach emphasized in PREP was an educational one, the project sought the cooperation and active involvement in health and social service agencies so that all three components could work together to provide a coordinated support system for families.

A cornerstone of the PREP model is a commitment to strong community involvement in planning and implementing programs. Another important aspect of the project is the incorporation of cultural factors in program design. Traditionally, native Hawaiian children grow up in a loving and warm family environment that encourages individual responsibility to the welfare of the entire household. Child-rearing typically fosters early independence and strong identification with the peer group, which often consists of extended family members around the same age. Family members are close knit and draw upon one another for support in a wide range of areas. This O'hana, or family system, creates opportunities for family members of all ages to work together and support each other in times of crisis as well as when things are going well. While this system is not universal in Hawaiian families, it represents the stereotype many

families hold as the ideal. Even though it may add further stress to the family system, it acts as a strong motivator to maintain bonds within families as a powerful force within the contemporary Hawaiian culture.

The PREP program does not attempt to mirror all aspects of Hawaiian culture. Some cultural components are explicitly woven into the model, while others naturally emerge from the interaction of the families with educators who are embedded within the culture themselves. Patterns that are particularly important in the program involve how adults interact, develop friendships and support each other within the extended family system, and how Hawaiian children learn information about their social and cognitive world within this same system. Families can begin to participate in PREP as soon as the mother knows she is pregnant, and they can remain in the program until the child enters kindergarten. During pregnancy and until the child reaches the age of 2, parents are involved in PREP's home visiting component called Kupulani. Two- and 3-year-olds and their families participate in traveling preschools, while 4-year-olds attend center-based preschool classrooms. Since many families have more than one child in PREP, families may be involved in one or more program components.

PREP's first goal is to help the family deliver a healthy full-term infant. Thus, health issues are emphasized early in pregnancy. The home visitor who sees each family weekly encourages parents to become more effective consumers of the services available within the community. The home visitor who is usually from the community presents information in a culturally compatible way. Early home visits may be used to establish binders between the home visitor and the family members. Through informal discussions, they discover common friendships, experiences, and overlaps in extended family membership. This process legitimizes the home visitor's role within the family and provides an opportunity for her to become a trusted "auntie" who offers suggestions and advice.

Rather than adopting a didactic style, the home visitor uses a "talk story approach," interweaving information into the general ebb and flow of the conversation. In this way, the home visitor informally assesses the child's development and passes the information along to the parents, preparing them for new stages in development and offering suggestion about how they can encourage new skills.

Activities during home visits before the baby is born center around making a quilt. The Kupulani quilt is based on Hawaiian quilts which are a traditional Hawaiian art form and as such, represent a tie to the Hawaiian community.This concrete experience, the construction of the quilt with four panels, is used to convey information to the family about the developing child. Each of the panels are colored in liquid embroidery by family members and has a picture imprinted depicting family members interacting with a young baby. By using the panels on the quilt as a guide, the parents and the home visitor have an opportunity to discuss different ways babies receive stimulation and why each is important, and the home visitor is able to offer practical tips on health and child-rearing issues. The quilt serves several functions: (a) It is the focus of interaction during several of the prenatal visits; (b) it serves as a welcoming blanket for the infant; and (c) because it remains in the home, the quilt serves as a continuing reminder of the ideas it depicts. It also serves as an important part of the dissemination and recruitment effort, because parents in the program talk about the quilt to other family members who then also want to participate.

After the child is born, families move into the second phase of the home visiting pro-

gram. Each month of the baby's first year and every month of the second year, the home visitor gives the family a t-shirt with a picture on it depicting a baby at a corresponding developmental stage. For example, the 4-month-old t-shirt shows a baby lying on its back making eye contact with the mother, who is very close. The t-shirt is captioned, "I can say Ooh. Can you?" This t-shirt prompts a discussion between the home visitor and the family about early language development and how parents can help foster this development by talking to their babies during such daily routines as diapering or bathing and mimicking the cooing sounds they make. One mother, after being introduced to this t-shirt, commented that she didn't know she was supposed to talk to her infant, since he couldn't talk back to her. Frequently, home visits occur in groups where two or three sisters who may have children at the same age will get together and visit with the home visitor in an extended family style. Home visits occur anywhere that families may be living from abandoned cars on beaches to modern apartments in downtown Honolulu.

The t-shirt is captioned, "I can say Ooh. Can you?" This t-shirt prompts a discussion between the home visitor and the family....

The second phase of the program for toddlers is the traveling preschool program. Two mornings a week, a van pulls up to different communities within the state to provide a traveling preschool experience for families with young children. The location may be a park, a church parking lot, or a community recreation center. Parents and children help the traveling preschool teacher unload the van and set up the traveling preschool under a banyan tree or some suitable shady area. There are five or six learning centers that are set up within the school, and materials are prepared ahead for each center. Typically, 20 to 30 families and children come to the program each day who may range from infants to 4-year-old children. The program emphasizes the use of extended family members in their care-taking role with children and encourages these family members to come to the traveling preschool with the child. The teacher's role throughout the several hours that the school is in operation is to circulate among the parents demonstrating ways that the inexpensively made toys and materials that are available at each center can be used. Parents and extended family members are encouraged to interact with their children around the materials provided.

On any given week, there may be an art center set up where children make prints of fishes or leaves of native plants. The bookmobile visits, and parents are encouraged to sign out books to take home for the week to use with their children. A toy lending library is available so that parents can borrow inexpensive toys and take them home and use them with children. The emphasis is to provide a wide range of experiences for families to think about how they interact with their children in a fun way. The other emphasis is on using inexpensive materials found on the beach or in the parks as part of the experience. Thus, Kukui nuts are used for sorting tasks, and sea shells may be used to help children learn to count.

The traveling preschool also provides a perfect opportunity for public health nurses to visit children in this relaxed setting and to conduct well-baby checks on those children who are attending that week. Typically, during each session, parents meet for a short time while the children are having a snack and juice, and the teacher leads them in discussion on an issue of common interest. During this parent time, the public health nurse may talk to the parents about hearing problems with children, the importance of immunization,

or where the well-baby clinics are conducted in that neighborhood. Alternately, a social worker may come and talk with families about services that are available, either free or at little cost.

The third component of this program is the preschool for 4-year-old children. In many ways, it mirrors a typical 4-year-old preschool with the exception that it very strongly emphasizes language production with young children. Recent tests of 4-year-olds in the PREP preschool program suggests that over half of the children have chronic and longstanding hearing problems, which affects their ability to use productive language and to learn in a classroom setting. Thus, a strong emphasis has developed in testing children and referring children with chronic hearing problems to physicians for continued follow up. Other aspects of the preschool that suggest components of a Hawaiian culture include encouragement of family members to be present in the preschool classroom and to help in ways that they feel comfortable with the teacher. Parents or older siblings or relatives are encouraged to come early and spend time reading to the children in comfortable and relaxed settings that foster a nurturing attitude towards books.

Two important components of the PREP program should be highlighted for the purposes of this workbook. First, each of these programs began as pilot a project within one community and then expanded to other communities in nearby neighborhoods. The experience in expanding the home visiting component to a second community is worthy of note. Program developers learned very soon that success in one community meant little in developing the program in the second community. New contacts, new relationships, and new trust had to be developed with each component of program expansion.

A second lesson learned from the development of this program involves the importance of community-based training for staff. Careful time was taken to nurture community involvement in developing a training program for staff when the program expanded from one site to new sites. All of the home visiting programs in Honolulu contributed to the training program. Community members were consulted in developing the curriculum and were actively involved in defining the kinds of skills home visitors needed to begin service to families. Much time was spent in the training program itself in helping new home visitors identify their own cultural backgrounds and understand how their backgrounds would affect their ability to work with Hawaiian families with young children.

References

A series of technical reports are available from the Director, Prekindergarten Educational Program, Kamehameha Schools, Bishop Estate, Kapalama Heights, Honolulu, Hawaii, 96817. These technical reports cover the development of curriculum materials, the development of various aspects of the program, the cultural aspects of program development, and training issues. A series of videotapes have also been developed which describe each component of the program and may be obtained from the above address. The program has also been described in the publication by the Office of Human Development Services called **Children Today**, and can be found in the July-August 1988 issue of that journal.

CENTER FOR SUCCESSFUL CHILD DEVELOPMENT (THE BEETHOVEN PROJECT)

The Center for Successful Child Development (The Beethoven Project, CSCD) represents a major effort by private sources, the federal and state governments and the community to affect the educational, social,

and health outcomes of entering kindergarten classes of elementary schools serving the Robert Taylor Homes. All project participants are African American. This project is located in the Robert Taylor Homes community on the south side of Chicago, which is a series of 28 high-rise apartment buildings housing 20,000 residents located between freeways within a bleak inner-city environment with little or no softening touches surrounding them. The crime rate, drugs, and all the problems of inner-city high-rise housing are exaggerated within this community. In this context, The Beethoven Project provides early intervention and family support services to families who support school success.

An attempt has been made to locate every pregnant woman regardless of age within the catchment area of the Beethoven Elementary School. A medical clinic has been established within the program, and prenatal care is provided in-house. When children are born, home visiting services are provided to mothers in the program. These services involve a team approach to home visiting. In light of the increased awareness of family needs, CSCD has expanded to include additional support for the home-based program. Home visits are made by a team consisting of home visitors and child development specialists. Home visitors continue to make their weekly home visits to provide social support information and linkage to CSCD center-based services and other apprcpriate community services. The expanded services, however, provide bimonthly support by specialist who join them on the visits to provide major emphases on child rearing early child development and care giver infant interaction. The health specialist and social worker also serve as members of the team when their services are needed in the home setting. A family drop-in center and infant toddler day care center have also been established within the center. Thus, a combination of center-based and home-based programs are available to the families participating in the project. The home visitors primarily come from the public housing development project and have been trained to deliver home visiting services to families within the community.

Outside agencies may characterize many families within this project as being without hope. Stereotypes prevail in blaming families for conditions caused by economic and social neglect of this community. However, program staff have had a unique opportunity to develop trusting relationships with participants in the program and have come to understand the range of ways families have been able to cope with the unreasonable societal pressures inherent in these living conditions. The location of the project within the Robert Taylor Homes buildings has made the development of this relationship possible. By virtue of their location staff experience some of the stressors families experience on a daily basis. They work with parents and the community to emphasize the positive aspects of what can be done and the affirmation that every child has a chance to make it.

An example of this attitude involves the celebration which occurs annually to recognize the birth of children within the program for that year. Rather than viewing the birth of a new child as another burden to the family and the problems that are associated with it, the project has created an atmosphere where babies are welcomed into the community, and the community is charged with the responsibility of providing community and social support to the parents of that child.

As described by the leaders of the program, this ceremony has its roots in African social systems in which a naming ceremony occurs for each child. The naming ceremony is called an "Adinto." Useni Perkins, an expert on African American cultural celebrations and an author, designed the ceremony. In the tradi-

tional African society, each child is considered to be the responsibility of the entire community. Although the child's parents provide the foundation for the child's development, the community reinforces this foundation through its institutions, values, culture, and concern for the child's welfare. The child becomes an extension of the community, and members of the community become the extended family of that child. Therefore, the naming of the child is extremely important. It allows the entire community to celebrate the child's birth.

The naming ceremony within the Beethoven Project is an African/American adaptation of this traditional Ghanian "Adinto" ceremony. It is a festive occasion and features a range of community talent such as poetry, drama, art, music, and food. All children who have been born within the community within that year are presented to the community, and the community is charged to actively support families of children. During the ceremony, the presiding adult explains to the community the purpose of the Adinto and talks with them about their responsibility in helping children to grow and be nurtured. This explanation is followed by a reading of Langston Hughes' poem, "I've Known Rivers," to acknowledge the community's relationship to mother Africa. After reading the poem, he calls on some of the elders for words of wisdom. After each of the elders have been given an opportunity to speak, the presiding adult calls on the community to celebrate the birth of the newborn children from that year. Recognizing its importance, the speech of the presiding adult is captured here in full.

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"At this time, we will celebrate the newborn children in our community. As a community, we recognize that these beautiful children are the seeds of our heritage, fruits of our labor, and the future of our people. We must care for them, we must protect them, we must educate them, and we must love them. As a community, we must share these responsibilities. Will each parent please step forward with his or her beautiful child." At this point, the parents step forward with their children. "We welcome your beautiful child to our community. May he or she live to be strong, healthy, and wise." The parent then announces the name of the child. After each child's name is given, the presiding adult repeats the following words, "The community congratulates you on your children and pledge that we will help them grow to be strong, healthy, and wise." The presiding adult then presents each parent with a gift from the community and recites the poem "Hey Black Child." After the poem, the drums beat again, and the parents take their babies back to their seats and receive congratulations from other members of the community. A celebration then continues with music and food.

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Unlike the ceremonies and traditions that new immigrants may bring to a country and continue there, this ceremony represents a reaffirmation of culture that has struggled to maintain its integrity in spite of efforts to diminish and extinguish it by the dominant culture. It is a reaffirmation of the strength within a community if it works together to nurture and raise children successfully. It does not negate the very serious social, economic, and political issues that stand as formidable barriers for children and families within this program to make it within modern society. Nonetheless, it reaffirms the value of each child and provides an opportunity to celebrate the importance of their birth as he or she is introduced into the community. It serves as the foundation for building a sense of community in the midst of social and physical isolation.

As with the programs described in this section, the CSCD staff and the community of families with the Robert Taylor Homes have learned important lessons from each other as the program has developed. First, the enor-

mous heterogeniety of families with respect to their goals, strengths and cultural values had to be understood for progress to be made. Though community involvement solicited from the beginning, a partnership could only develop as trust was nurtured by caring staff willing to listen and learn. The reaction of staff and family participants to aspects of the program designed to reflect cultural values was being individualized and was a function of the learning histories of each person.

FAMILIES FACING THE FUTURE

Families Facing the Future (FFF) is a program of a neighborhood community human service center in Pittsburgh, PA. This program promotes positive development for children at risk of developmental delay by encouraging families to become involved in early intervention efforts. The service is concentrated in three low-income neighborhoods and delivered through weekly home visits by parent-aides. The parent-aides are full-time employees, indigenous to the targeted community; trained, supported, and supervised by a social worker and child development specialist.

Associating status rather than stigma with service use is a primary goal. The status comes from a culturally sensitive atmosphere that encourages learning and empowerment. The parent-aides recruit families by means of a door-knocking campaign. Their approach is upbeat, fun, and supportive. They encouraged families to **choose** to become involved. During the home visit, a collaborative partnership is formed between parent and parent-aide. These partners promote positive interactions in the parent/child relationship. They facilitate developmental growth of the child through play, games, and celebrations. Also, they discuss parenting issues and techniques. In addition to the home visit, parent education/ support groups and family field trips are offered.

In many cases, the job of parent-aide represents the first full-time permanent employment these home visitors have experienced. Because they are **of** the community, the parent-aides represent hope. They convey respect for the community and understanding of cultural and ethnic values. The parent-aides are trained to recognize and use the strengths, competencies, and skills of the families they serve. They also recognize the context of the family's life and can locate tangible resources when needed.

Training/supervising/support parent aides.

The preservice training program for parent-aides was designed and implemented by a group of community professionals and leaders who joined together to form the Network Team, a support system for Families Facing the Future. The basic framework for the training--a month-long intensive session--was used as a mechanism for developing group cohesiveness while preparing the parent-aides for working with families. More than 30 individuals participated in the training as lecturers and trainers. An honorarium of $50 for one-half day was paid for this service.

The amount of group identification engendered in participants alone was an invaluable result of this experience. It was clear to the trainees that they were a vital, in fact, the central factor of the program. Several aspects of the training program can be considered as instrumental to its success:

1. The curriculum allowed for ample discussion of concerns, ideas, and observations.

2. The course director was upbeat and supportive.

3. There was an underlying respect for the integrity of the individual and

acknowledgement of the importance of the program and the rule of the parent-aides.

4. There was a sense of joint effort rather than a student/teacher atmosphere.

5. There were numerous occasions during the training period for the trainees to meet with and learn to know the members of the Network Team.

6. The training program provided partici pants with exposure to role models which were appropriate to their own potential.

The on-going training, supervision, and support for the parent-aides is provided in a variety of ways. On-going training, beyond teaching in weekly staff meetings, take place monthly through paid or volunteer consultants, case conferences at Children's Hospital, or staff designed review sessions. Weekly supervision is conducted by the neighborhood health center's social worker for case review and planning.

For additional support, the agency contracted with a community professional identified by the parent-aides as one of their favorite trainers. This woman is a Ph.D who was once an indigenous worker and a home visitor. She meets weekly with the parent-aides in a group for a confidential support group. This model allows discussion of issues of major importance including the difficulties of having their first job and becoming paraprofessionals; difficulties in dealing with the families on their caseload within the community; and, the interaction of their own family history with their ability to work with families in the program. This overall model requires communication and coordination by the professionals, but it provides support and professional growth for the home visitors.

This woman is a Ph.D who was once an indigenous worker and a home visitor. She meets weekly with the parent-aides in a group for a confidential support group.

The training component of this project was emphasized to illustrate the need for culturally competent training and the community base of this effort. In addition, this model endorses the principle that staff must have the **capacity** and **time** to self-assess their own cultural values and relate them to their on-going work with families.

SOUTHEAST ASIAN DEVELOPMENTAL DISABILITIES PREVENTION PROJECT

The Southeast Asian Development Disabilities Prevention Project (SEADD) is a SPRANS project awarded to a large community agency called the San Diego Imperial Counties Developmental Services Inc. SEADD is a separate project under the umbrella of the larger corporation and is subcontracted to the Union of Pan Asian Communities agency. As mentioned earlier, this is an example of the kind of program which is located within a community and operated by members of that community, but has a larger mainstream organization as its administrative head.

SEADD began out of a concern for the needs of newly arrived immigrant families from Southeast Asia settling in the San Diego County area whose children were at risk for or who had developmental disabilities (ages 0-3). In large part, these families were not being seen by the regular service providers, though it was evident from birth records and other community knowledge that a high percentage of these children required services. Typical

caseloads carried by a counselor in the San Diego Regional Center were as high as 80 and this made it very difficult for the case workers to provide adequate services to the newly arrived immigrant families.

There are four immigrant groups served by SEADD, each of which has its own language, culture, and distinct problems. These include Cambodian, Vietnamese, Hmong, and Laotian families. The program employs four bicultural/bilingual counselors who are from the same community that they serve. The receptionist/secretary speaks enough of each of the four languages that she is able to greet families when then call and refer them to the appropriate counselor. Each of the counselors is an immigrant and has experienced the same hardships of refugee camps and dislocation/relocation of families in the program. The counselors help bridge the gap between the services families need and the network of services that are available to them in the community. In most cases, families do not speak English, are recently immigrated, and carry with them strong belief systems and cultural experiences quite far apart from western medicine and practice. One of the counselors was recently interviewed and described his experiences with families this way:

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Most of the referrals that I receive are from the hospital. Other referrals are from family to family. By serving this family or that family, I help a child with a special condition. So it is within the community that we go and try to explain to new immigrants how we can help them. We tell them, "We are set up to work with families with special needs children."

As an example, one of the children that I worked with was microcephalic and also had an infectious disease called CMB. His condition was pretty bad, and we saw him at birth. Well, I got the referral in the hospital. The family was already mad at one another and mad at the mother. The mother was about 16 and the father was about 17. They were both very young, and they had extended family living with them in their home. They all blamed each other, but particularly blamed the mother for the child's condition. While the child stayed in the hospital, the extended family refused to visit the child. I mean, the husband and the grandparents, because they blamed the mother and thought that she did something bad to cause the condition.

While the child stayed in the hospital, [the husband and the grandparents], refused to visit the child... because they blamed the mother and thought that she did something bad to cause the condition.

So, when I got the referral and I went to the home and I tried to see what was going on with the family and they had already fought with each other about what the mother might have done. Maybe she had an affair with some other man who had a disease, you know, or maybe she had done something wrong on her side of the family in the past generation and now it came back as punishment. The mother was very lonely and very sad, and she felt very guilty too. She was feeling guilty because everybody said it was her fault, so I tried to pull everybody back together, and the grandparents and the sisters and the husband and all the other relatives.

I tried to explain to them about the condition and what the doctor told me. I tried to make sure that everybody understood. I wanted to make sure they didn't blame the mother. They did not believe me because they didn't see anything that could correct the condition. I told them, yes, nothing could correct the condition. The only thing they could do was what the doctor told them and continue

to try to help their child. I continued to work with them, and I started from there in getting them to accept their child and to accept what the doctor was saying about what they could do to help this baby. I spent many visits at the hospital and with the family getting them to understand what the doctor told me. After a while, the family began to look at the baby and not to make anybody at fault for the problem. I still see the baby and the family and work with the family in the school where the baby is now.

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The developmental outcomes of this case are still very much in question, and it is unknown how far this child may develop. The counselor's intervention with the family helped them make contact with services they needed but would not have used without intervention. He was also able to do this without questioning or destroying the family's beliefs. Rather, their energy was refocused with respect to what they could do in the present situation and not lay blame on who was at fault. The family continues to need considerable support from the counselor, as it has over the 3 years of this young child's life. No doubt the counselor will continue to work with this family and work as their interpreter/translator in a very complex world of social, health, and educational need programs available to this young boy.

The strong bicultural/bilingual philosophy which underlies this project is one of its important features. Staff must be the bridge for families from their natal culture to Western systems of care. To act in this capacity, staff must have a firm understanding of the cultural systems of families in the project and what is possible within Western systems of care. The willingness to work within the family's goals is also a critical element for SEADD staff. They are willing to take time needed to ensure that a family's goals are met.

TRANSGENERATIONAL PROJECT

The Transgenerational Project sponsored by Howard University's Child Development Center is noteworthy as an example of a program that changed the kinds of services it provided in order to be more responsive to the needs of families. This project primarily provides diagnostic services for young Black children referred to the clinic by local schools for diagnostic testing for learning disabilities and other related educational problems. Over the course of testing children in an individual testing situation, the clinic staff were concerned that no attempts were made to incorporate parent education/counseling within the program. As children would be tested, their parents were involved in simultaneous education and counseling sessions. Parents were given the results of the child diagnostic study and shared these results with the school and other involved agencies. Most of the families coming to the center were poor, inner-city Black families in Washington, DC. School had been a negative experience for many parents who found it difficult to confront or interact with school personnel. This transgenerational cycle of strained school relationships had to be redirected to ensure that the recommendations developed by the clinic were carried out.

The goal of the Transgenerational Project was to maintain open lines of communication between the family and child, health agency, and the school. They continued to accept referrals for screening of children, but accepted the family rather than just the child for services. Special sessions were developed for family members to help them understand both what was going on in the testing procedures and what they could do in helping their son or daughter in school. Counseling of family members helped them feel a sense of partnership with respect to the school system. Family members were taught how to work with the teachers and principals and with the IEP process. This networking effort helped to

ensure that recommendations which came from the clinic were systematically followed through in the classroom. Parents also learned ways that they could work with their children at home to enhance their educational progress. As one mother said of the program:

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When I was in school, I hated school. I tried to hide the fact that my daughter was having trouble in school. I tried to ignore it and make it go away. The project has helped me see that it can only go away if I go away, if I get involved. They helped me see ways that I could talk to the teachers and help my daughter learn more so that she won't be afraid of school when she graduates.

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EPICS

The next program to be discussed is the EPICS project in Bernalillo, New Mexico. This project is part of Southwest Communications Resources Inc., a regional resource center which has a larger mandate to serve families within the community and county. The agency sponsors twc projects which specifically serve Native Americans including EPICS, a parent training and information project funded in part by the U.S. Bureau of Maternal and Child Health, and the U.S. Office of Special Education and Rehabilitative Services. This project serves Native American families throughout New Mexico and provides technical assistance to other families and programs nationally. The second project is the Pueblo Infant Parent Education Project (PIPE) which is a local early intervention program which provides direct services to the area. All community families are eligible for service in this program.

EPICS will be discussed in some detail below. It uses indigenous case workers to work with Indian families whose children have developmental disabilities to obtain the kinds of services which their children need. On a parallel track, it works with professionals within the Indian Health Service local hospitals and clinics to help professionals understand the cultural values of Indian families and how these values affect the services they should be providing. Thus, it very appropriately addresses both sides of the issue. Families understand that they can choose traditional healing practices and those that are available under western medical system. They understand that they need not abandon one approach in order to use the other. On the other hand, professionals are encouraged to understand the perspective of families and their cultural heritages. Professionals are encouraged to understand the rights of parents in making decisions with respect to the types of care that their children should receive. EPIC's goal is to help create conditions where Indian parents do not feel they have to choose between traditional practices and western practices. Agencies should work together with sufficient collaboration that parents feel comfortable working within both systems and do not feel a conflict with respect to the best treatment for their children.

One important aspect of the Navajo culture, for instance, is harmony with nature and a holistic approach to wellness. Families may view medical and developmental problems as a result of disharmony within that natural system. These beliefs lead Navajo parents to a different set of interactions with the health system than mainstream or Anglo parents. First, problems may not be brought to the attention of the physician or a nurse, since it is not seen as a medical issue. Only when a child reaches school age may a problem become apparent to the educational or medical system. Second, within the Navajo belief system, treatment involves regaining harmony through traditional means rather than developmental or medical intervention. In fact, from the family's perspective, western intervention alone may create more disharmony.

Training for parents involves the work of three parent trainers, all of whom are parents of special needs children. The makeup and the interactional patterns in each parent training meeting are governed by the preferred cultural style of the group in attendance. For instance, when training is done with Navajo families, two separate groups are held simultaneously. One is in Navajo and the other is in English. Families are free to choose which groups they would prefer to attend. In working with families from the Pueblos, however, only one group is held and the talk and discussion are simultaneously translated in to the Native language. Thus, English speakers and non-English speakers are together. Within the culture, separating the two groups would be inappropriate and cause concern. The parent trainers respect these differences in the way they run parent training groups in different communities.

As the EPICS project began, leaders in each community were contacted to help parent trainers understand (a) the networks within those communities, (b) how information should be provided, and (c) how programs and meetings should be run to make it comfortable for those who would attend. Community leaders were also important in helping to keep track of ceremonies that may have been scheduled within a community village and to ensure that meetings were not scheduled in times that would conflict with traditional tribal ceremonies. The goal of the parent training meetings was to help parents understand the systems that were available for their children and help them become better consumers of the services that were available. One mother, who was also a parent trainer, described her experiences this way:

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Within my family, there are family members who are very traditional and others who are very acculturated. If you live in a village that is highly traditional, then tradition will precede above all else. You have to respect and balance that between your family members as well as other involved individuals. When our child was diagnosed as having a disability, we sought out the elders within the family for advice and direction in the traditional treatment for our child. At the time, western medicine was not answering questions that we were seeking about our child's disability. We were given several traditional ceremonies that we could follow to help his progress and to mend the disharmony that was caused. A spokesperson was selected for us who assisted us with the process of accessing the traditional medicine. We were guided through this process step by step by the spokesperson and other appointed persons who were very knowledgeable with what steps to follow and the people to contact. In the use of traditional ceremonies, the entire family is often involved in what western society would call the treatment program. So that the possibility of having the disharmony continue is eliminated because everyone is treated. As for the ceremonies themselves, they are highly respected, and we seldom if ever talk about them, as they are a sacred part of our lives that we choose not to share with the outside. All we ask is that you continue to provide us with the same respect we give others in their practices of their cultures.

Other families with whom I work have similar ceremonies. At one time or another, it always comes up, and it is always dealt with when it comes up. A lot of the times, these families do not let us know that they have had the ceremony. It is a very sacred part that we don't talk about, but it is important that they do know that what happens is a valuable course for us as Indians to utilize. It keeps everything going in harmony for us, because if we are not in harmony, then it builds up. As far as tradition goes, they try to go and get you to go ahead and set everything back in harmony.

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One goal of the parent training is to help families who are in conflict between the use of western and traditional medicines feel comfortable about the decisions they make with respect to these two types of treatment for their children. In some cases, this is directly discussed, and in others it is handled in a more indirect manner. Parent trainers have described times when issues regarding traditional ceremonies have come up in their training meetings, and it has not been discussed in detail, because parents at the meeting were not comfortable discussing it. Later, however, parents have called them and asked them how they dealt with these issues themselves. This gave the parent trainers an opportunity to describe their own experiences to families and help the family make a decision as to what they wanted to do outside of the context of the larger group meetings.

The same parent trainer describes her difficulties in working within the western medical tradition in getting the appropriate services for her child. Her child was hearing impaired, and she knew that there was something wrong with him, but did not know what the problem was. Again, in her own words:

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I took him through a number of evaluations with the doctors, but we never saw the same doctor twice. It made it very difficult for me as I had to explain everything over again each time. The audiologists also changed, making it additionally hard when I wanted or needed input or confirmation on an evaluation that the doctor was questioning. I had voiced my concerns to my family before he was identified as having a hearing loss, and we had traditional ceremonies done for him. After they were done, there was progress, but it was slow. I didn't know who else to ask for direction or help in seeking western medicine, as I had been labeled an over-protective mother by the doctors and other medical staff. It was so different from using traditional medicine, because I was assigned a spokesperson who lead me through the process of accessing traditional medicine. The spokesperson acted as my "case manager" in this process.

As time passed, a new audiologist came on board, and she was willing to listen to my concerns. She disagreed with the labeling of him as being "just a boy and that boys are slow and he would eventually catch up." She listened to my descriptions of his actions at home and validated my feelings and concerns. She was willing to go along and test my child in the way I suggested, which was to move the console out of his line of vision and then test him. I knew how visual my child was and had in the past tried to get others to take this into consideration, but up until this time, no one took my suggestions seriously. My son was tested once more using my suggestions. This time, the testing showed a definite loss of hearing in both ears that were very different from one another. Although I was satisfied in finally finding out that in fact he did have a disability, I was also very angry because they had not taken me seriously and so much time had lapsed, only adding to my child's delay. Most parents coming from culturally diverse populations are not comfortable dealing with western service providers. It is out of line in many cultures to be persistent. Many of them find it too overwhelming and don't go back to get the services they were seeking for their special needs child, and this I find very disheartening.

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The EPICS project has created several videotapes that are designed to point out the cultural differences between Indian families and the way most clinics are run. They help health care professionals understand the cultural patterns of Indian families and to interact in a more effective way by understanding some of the reasons behind the communication styles families use in the clinic. For exam-

ple, some time is spent describing why many family members may be present in an assessment or why it is important to get information from both the grandparents or an auntie.

The PIPE project, a direct service early intervention program, works with families at the level that is comfortable for the families. Some families may not be ready to accept early intervention efforts with their children, but may be willing to accept financial assistance to help pay for things that the family needs so that the child's needs can be met in other ways. In this case, PIPE would assist the family in gaining access to financial assistance and other resources. The focus of the early intervention project is to work with the entire family, building trust with that family and helping them understand the kinds of things they can do to increase the developmental outcomes of their children. Sometimes it takes several years for families to come to this point. It is the strength of this relationship and the length of time over which it is built which helps families bridge the difference between traditional views of disability and those of western medicine.

Both projects are making an impact on health care professionals and families. In the words of the Executive Director of the project:

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Bridging the gap means looking at both sides of it. It is not just training parents to understand the professionals, but taking the next step and helping the professionals understand the parents' perspectives. It's not just the health care professionals that have problems. We talked about it in our own agency. We have early childhood staff that have come in new to our agency, and we have helped prepare them when they have never worked on a reservation. We try to find people who are able to do that and feel comfortable. We look for ways to help them feel comfortable to learn and not to feel that this is so foreign and alien to them that they just give up and walk out. You know, because that is what we are seeing--is a lot of turnover, and we don't want to keep seeing turnover, but there is no training that we know of now for health care professionals, and that is one of our goals--to help develop that training.

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The family-centered, community-based focus of this program is the cornerstone of all of its efforts. It demonstrates the ability of programs to continue to learn from the communities they serve as the program becomes increasingly culturally competent. Not only must families be treated uniquely, but so must communities within cultural groups. In this sense, it shares this lesson with the PREP program first described. Program staff take time to ask advice from community members and form a partnership with them. In this way, the community is invited into the process of designing a program to meet the needs of its members.

This program also demonstrates effective methods for helping famlies to feel comfortable using both their cultural and the Western systems of care.

THE AVANCE FAMILY SUPPORT AND EDUCATION PROGRAM

The Avance Family Support and Education Program, which began in 1973, is a non-profit organization whose mission is to strengthen the family unit, to enhance parenting skills which nurture the optimal development of children; to promote educational success; and to foster the personal and economic development of parents.

Avance strives to accomplish its mission through providing support and education to low-income Hispanic parents and their young

children in five communities in San Antonio and Houston, Texas. Avance believes the intervention to the family must begin in the home, be community-based, be comprehensive in scope, be preventive in nature, have children (0 to 3) as the entry point, and must provide sequential services to child and parent.

Its core program is the parenting education program where mothers and fathers of children under 3 years of age attend a 9-month, 3-hour weekly program to improve their capacity to become more effective parents and teachers of their young children. The first hour is devoted to making educational toys; the second hour to lectures and culturally relevant class discussions relating to child growth and development; and the third hour is used to familiarize parents with the various social services in the community. One of the toys the mothers make is a mobile with "El Ojo de Dios" (the eye of God) design that is found in many homes to have God protect our young infants. The class discussions are divided by

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the parent's proficiency with English. Non-English speaking parents must have a bilingual teacher. In other classes, Black and Anglo individuals are the teachers. Even though they are not Hispanic, they are sensitive and very familiar with the Hispanic culture.

Avance brings existing under-utilized social, educational, economic, and mental-health services to the families and makes these systems work for them. While the parents attend the parenting classes, their preschool children participate in Avance's Day Care Center. Parents who attend class on a different day volunteer to care for the children. Transportation to and from the Center is provided.

In addition to the center-based component, the Avance staff visits the mother at her home twice a month to record and to videotape her and her child at play with a toy that the mother made at the Center. The home visit serves as an opportunity for private, one-to-one conversation on problems the mothers might be facing and provides a forum for feedback on the progress of both parents and child.

Avance offers numerous family trips to the library, zoo, Sea World, rodeo and circus, and celebrates holidays with a Halloween parade, Thanksgiving dinner, Christmas party, and an Easter picnic. At the Easter picnic, the mothers and children participate in an Easter egg hunt--for the adults, the eggs are Cascarones (colored egg shells filled with confetti) that the mothers crack on each other. The children participate in breaking the Pinata. The fathers attend camping trips with their children, make kites, participate in the Avance Boy Scouts, as well as attend their parenting classes. The Hispanic father holds a high position in the traditional Hispanic family. One cannot leave the father out of services to the families. One-to-one counseling and support is also provided to the fathers.

At the end of the 9-month program, the parents and children participate in a beautiful formal graduation ceremony at a local university where the parent(s) receive a certificate, and their children, dressed in cap and gown, receive a reading book. Mariachi music plays as the families proceed to the reception where Mexican pastry is served.

Of the 100 employees, 80 percent are graduates of Avance who reside in the same

communities, speak their language, and understand their culture and their problems. The Executive Director, Gloria Rodriguez, and the two associate Directors, Carmen P. Cortez and Mercedes Perez de Colon, are from the same poor communities and after receiving their education returned to help the community. The staff are hired based on their sensitivity, compassion, and willingness to learn. They serve as role models for others in the community.

The guiding principle that is used throughout the year, and a vital programmatic element, is that the parent be treated with the greatest respect, and made to feel extremely important and welcomed. Many parents did not receive love and nurturing as children and Avance is filling the void. The parents immediately establish a rapport with the staff and they then become receptive to services.

By coming together as a group on a weekly basis for nine months,sharing common concerns and joyous moments, the parents form close mutual friendships that continue to grow beyond the program. This important support system recreates a sense of community where neighbor helps neighbor with child care, protecting each other's homes, or just being around whenever needed.

The core program gets to the soul of the person. They begin to trust and to believe in themselves. They go from a state of hopeless depression and despair to one of hope and motivation. They begin to set goals for themselves and for their children. They begin to feel a sense of power that their quality of life and their communities can change.

After completing the Avance Parenting Program, the parents are ready to enter Phase II, which is the Adult Literacy Program. Parents attend English classes, G.E.D. classes and college courses. Eighty percent of the parents had dropped out of school with a mean educational level of the eighth grade. Hundreds of parents have obtained their high school diploma, 10 have completed or are just about to complete their Associates degree, and one has become a school teacher. Like the parenting program, transportation and day care are essential support services provided to the parents. Parents who have obtained their G.E.D. or completed college courses are also recognized at the Avance graduation ceremonies. This motivates other parents to continue their own education.

Phase III is job training and job placement. Avance has a fuli-time counselor assisting the parents in obtaining and maintaining employment. One can find women and men who were once on welfare employed as nurses aides, bus drivers with the city's transit system, in the police department as switch board operators, in banks, as teacher's aides, etc. Avance recently had a ceremony where some of these parents were recognized, again reinforcing positive behavior and promoting social learning.

With employment, the families' quality of life is improved, and many parents leave the housing project (which was originally designed to be temporary) to rent or buy their homes. Some decide to stay and become leaders of the Resident Association or the local schools.

The children also have their own continuum of development. Many go from the parenting program to a Head Start program. Avance just re-established the tutoring program where older children assist younger ones with learning basic skills and concepts. Avance acquired 10 computers that will be used in the Tutoring Program. With a strong early childhood foundation, and support and assistance provided from the parents, the Avance children have a better opportunity of staying in school and achieving academic success. As the children are ready to gradu-

ate, Avance works with the local institutions of higher learning to get them scholarships or offers scholarships to the parents' children to get them into college. Two cases in point are Peggy Cortez, who, like her mother, obtained an Associates degree; or Sandra Garcia, who, like her mother, wants to become a school teacher. All four women were once on welfare.

Avance serves over 3,000 mothers, fathers, and children. It has numerous other programs such as providing components of the comprehensive community-based model in the schools. Avance recently received a 4-year Even Start contract through the Department of Education to provide parenting classes and home visits in eight schools.

Avance also recently received a 5-year Comprehensive Child Development Program (CCDP) grant from ACYF. Avance will work with 120 low-income families in two housing projects, when the mother is pregnant, and support the family comprehensively for five years. The objective of the program is that at the end of five years, the target child will be ready to meet with academic success, and the parents will become productive, contributing members of society.

Avance also has a program serving referrals from Protective Services on Child Abuse and Neglect, and it received a three-and-a-half-year grant from the Carnagie Corporation of New York to evaluate the effectiveness of the program model. Preliminary data demonstrates that Avance had a significant impact on the home environment and on parent-child interactions.

Avance gets its funding from various sources, including the City of San Antonio, United Way, State and Federal government, foundations (Carnagie, Mailman, Hazen), corporations (Kraft-General Foods, who provided the funds to replicate Avance from San Antonio to Houston, Texas, and Hasbro, Arco, UPS) and others. Its budget has grown from the $50,000 originally provided by the Zale Foundation to $2,000,000.

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FOOTNOTES

[1]The reader is referred to two excellent videotapes produced by Southwest Communications Resources, Inc. entitled "Listen With Respect" and "Finding the Balance." The videotapes are designed to help professionals working with Indian families to gain a perspective on cultural issues which interact with western medicine. For more information on the videotapes, contact:

Randi Malach
EPICS Project
P.O. Box 788
Bernalillo, NM 87004

[2]The Rainbow Series is published by Georgetown University Child Development Center, National Center for Networking Community-Based Series. For further information, contact the series editor.