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ABSTRACT

This paper examines issues related to the screening and assessment of infants, toddlers, and preschoolers with disabilities or at risk for disabilities, from families of various cultural and linguistic backgrounds. An introductory section outlines issues of cultural and linguistic competence and provides definitions of key terms. Interviews are presented with five parents and professionals from states with varied cultural groups. Interviewees describe their experiences with screening and assessment and note the major issues involved in culturally and linguistically diverse backgrounds. Strategies for ensuring cultural competence in screening and assessment are discussed. The strategies focus on policymakers, parents, and professionals. Approximately 35 additional resources are listed. (JDD)



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Cultural Competence in Screening and Assessment

Implications for Services to Young Children with Special Needs Ages Birth through Five

Prepared at PACER Center by: Maria Anderson · Paula F. Goldberg

for NEC*TAS



National Early Childhood Technical Assistance System



NEC*TAS

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Part I Introduction

Early intervention services to young children and their families and cultural competence in serving families and children from diverse backgrounds have become a major interest and concern as states plan and implement services mandated by Part H and Part B · Section 619 of IDEA, the Individuals with Disabilities Education Act of 1990, Public Law 101-476, formerly the Education of the Handicapped Act, P.L. 94-142 and P.L. 99-457.

This paper is the fourth publication on cultural diversity by NEC*TAS. The first was A Bibliography of Selected Resources on Cultural Diversity: For Parents and Professionals Working with Young Children Who Have, or Are at Risk for, Disabilities. The second, Demographics and Cultural Diversity in the 1990s: Implications for Services to Young Children with Special Needs, explored the multicultural diversity of the United States, especially as it is reflected among young children. The third, Preparing Personnel for Pluralism, discusses national initiatives focusing on the personnel needed

to serve families from diverse cultural backgrounds. This paper will examine issues related to the screening and assessment of infants, toddlers, and preschoolers from families with various cultural and linguistic backgrounds.

NEC*TAS offers these publications as tools to raise awareness about issues of cultural and linguistic diversity and to assist in sharing and creating strategies for developing sensitivity and competence as we respond to the challenges and opportunities of our multicultural society.

The remainder of this Introduction will address the main issues of cultural and linguistic competence and provide definitions of the key terms. Part II presents interviews with five individuals discussing their experiences and perspectives on cultural competence. Part III offers suggested strategies for ways to ensure cultural competence in screening and assessment. Part IV lists selected additional resources on the topic.

What Are the Issues?

Changing demographics in our society reflect an ever increasing need for skills in working with children and families from various backgrounds. Questions and concerns regarding cultural and linguistic competence in the areas of screening and assessment will be addressed in this paper. Some of these include:

- Families have valuable information to share about their children. What are some considerations and strategies that will facilitate the inclusion of families from diverse backgrounds and foster their ability to access and participate in early intervention services?
- How significant is the use of bicultural and bilingual staff in the screening and assessment process? What roles do interpreters or mediators play?
- Few screening and assessment tools have been normed for specific cultural populations. What are some other ways of looking at children's development besides using normative data?
- How do currently available screening and assessment tools fail to accurately reflect the development of children from culturally and linguistically diverse backgrounds? Should they continue to be used? If so, how should they be modified and interpreted? If not, how can accurate measures of development be found?



Definitions

Since the terms "screening," "assessment," and "cultural competence" are central to the issue, a discussion of what these terms mean and how they are used is important, as is the role of family involvement and cultural competence in the process of assessment. While the term "screening" does not appear in the language of the legislation, except for a brief mention in Part H under a discussion of procedural safeguards, it is implicit in the intent of the law. IDEA and the comments surrounding its recent reauthorization emphasize the need for equal access to early intervention services; that access is available through speedy and appropriate referral to evaluation and assessment resources.

Screening and Assessment

It is important that our definitions remain consistent with the usage in federal legislation and regulations, as well as current practice. Page 3 provides an overview of the definitions of assessment proposed by the Department of Education in its regulations

governing Public Law 99-457. Although P.L. 99-457 has been superseded by P.L. 101-476, the Individuals with Disabilities Education Act of 1990 (IDEA), and the IDEA amendments in P.L. 102-199, new regulations have not yet been issued.

In Screening and Assessment: Guidelines for Identifying Young Disabled and Developmentally Vulnerable Children and Their Families (1990), Meisels and Provence outline levels of assessment activities in current practice; these are displayed in Table 1, with the sections on Developmental and Health Screening and Diagnostic Assessment highlighted. The authors go on to define screening as "a brief assessment procedure designed to identify children who should receive more intensive diagnosis or assessment. Screening is designed to help children who are at risk for health and developmental problems, handicapping conditions, and / or school failure to receive ameliorative intervention services as early as possible." (p. 58)

Table I: Levels of Assessment Activities

	Purpose	Personnel	Activities
Child Find	To create awareness of typical and atypical child development among the general public	State personnel, public health professionals, volunteers, community members, early childhood personnel, parents, caregivers	Census taking, posters, brochures, media publicity
Developmental and Health Screening	To identify children who may need further diagnostic assessment	Professionals, parents, lay professionals	Administration of screening instruments, medical examinations, hearing & vision testing, parent questionnaires, and review of records
Diagnostic Assessment	To determine existence of delay or disability, to identify child and family strengths and needs, and to propose possible strategies for intervention	Multidisciplinary team of educators, psychologists, parents, clinicians, physicians, social workers, therapists, nurses	Formal testing, parent interview, home observation, team meetings
Individual Program Planning	To determine individual educational/family services plan, program placement, and remedial activities	Parents, teachers, assessment team personnel, other professionals	Home and/or program observation, informal assessment, development of remedial objectives

From <u>Screening and Assessment</u> (p. 13) by S. Meisels and S. Piovence, 1989, Washington, D.C.: NCCIP and NEC*TAS. Reprinted with permission.

U.S. Department of Education Regulations Governing P.L. 99-457

The regulations for Part H [Federal Register, 54 (119), 22 June 1989] define assessment as:

"Ongoing procedures used by appropriate qualified personnel throughout the period of a child's eligibility to identify (i) the child's unique needs; (ii) the family's strengths and needs related to development of the child; and (iii) the nature and extent of early intervention services that are needed by the child and the child's family." (Section 300.322)

Nondiscriminatory procedures are addressed as follows:

- "Each lead agency shall adopt nondiscriminatory evaluation and assessment procedures. The procedures must provide that public agencies responsible for the evaluation and assessment of children and families under this part shall ensure, at a minimum, that --:
- (a) Tests and other evaluation materials and procedures are administered in the native language of the parents or other mode of communication, unless it is clearly not feasible to do so;
- (b) Any assessment and evaluation procedures and materials that are used are selected and administered so as not to be racially or culturally discriminatory;
- (c) No single procedure is used as the sole criterion for determining a child's eligibility under this part; and
- (d) Evaluations and assessments are conducted by qualified personnel. (Section 300.323)

Part B · Section 619 [Federal Register, 54 (80), 27 April 1989] covers assessment and non-discriminatory procedures as follows:

State and local education agencies shall insure, at a minimum, that:

- (a) Tests and other evaluation materials:
- (i) Are provided and administered in the child's

- native language or other mode of communication, unless it is clearly not feasible to do so;
- (ii) Have been validated for the specific purpose for which they are used: and
- (iii) Are administered by trained personnel in conformance with the instructions provided by their producers;
- (b) Tests and other evaluation materials include those tailored to assess specific areas of educational need and not merely those which are designed to provide a single general intelligence quotient;
- (c) Tests are selected and administered so as best to ensure that when a test is administered to a child with impaired sensory, manual, or speaking skills, the test results accurately reflect the child's aptitude or achievement level or whatever other factors the test purports to measure, rather than reflecting the child's impaired sensory, manual, or speaking skills (except where those skills are the factors which the test purports to measure);
- (d) No single procedure is used as the sole criterion for determining an appropriate educational program for a child;
- (e) The evaluation is made by a multidisciplinary team or group of persons, including at least one teacher or other specialist with knowledge in the area of suspected disability; and
- (f) The child is assessed in all areas related to the suspected disability, including, where appropriate, health, vision, hearing, social and emotional status, general intelligence, academic performance, communicative status, and motor abilities. (Reg. 300.532)

Testing and evaluation materials and procedures used for the purposes of evaluation and placement of children with disabilities must be selected and administered so as not to be racially or culturally discriminatory. (Reg. 300.530(b))



Cultural Competence

The entire process of screening and assessment needs to be individualized to each child and family in order to be relevant and appropriate. With many possible variations, even within the same cultural group, it may not be possible to develop a totally nonbiased instrument sensitive enough to be used with all individuals. Rather, professionals need to become proficient and competent in the use of guidelines and questions that help address each screening and assessment from a nonbiased stance.

According to Richard N. Roberts in the Workbook for Developing Culturally Competent Programs for Families of Children with Special Needs (1990b), cultural competence can be viewed as "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." (p. 1)

Roberts goes on to state:

A multitude of terms has 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. (p. 1, 1990b)

Cross, Bazron, Dennis and Isaacs, in Toward a Culturally Competent System of Care (1989), define cultural competence as "a set of congruent behaviors, attitudes and policies that come together in a system, agency or among professionals to work effectively in cross cultural situations." (p. 13) The authors name five elements that are considered to be essential in a culturally competent system:

The culturally competent system values diversity, has the capacity for cultural self-assessment, is conscious of the dynamics inherent when cultures interact, has institutionalized cultural knowledge, and has developed adaptations to diversity. Further, each of these five elements must function at every level of the system. Practice must be based on accurate perceptions of behavior, policies must be impartial, and attitudes should be unbiased. (p. 19)

It is especially important that professionals working with children and families are competent in matters of cultural diversity. As Elizabeth Randall-David, in *Strategies for Working with Culturally Diverse Communities and Clients* (1989), states:

It is, however, critically important to remember that no cultural group is homogeneous, and that every racial and ethnic group contains great diversity. . . . In order to provide the most effective services to any community of people, professionals must be sensitive to the cultural values of the group while recognizing and respecting individual differences. (p. 4)

Screening and assessment must be viewed in terms of cultural biases that could cause either overor under-representation of children from various cultural and linguistic groups. Children must not be considered "at risk" for a disability or developmental delay simply because their cultural or linguistic background differs from that of the mainstream culture. (Roberts, 1990a)

While children reflect the increasing social and cultural diversity of the general population, available screening and assessment instruments often do not accurately measure the skills of children with certain cultural and linguistic backgrounds. There cannot be one uniform and standardized measure of development for all children. We do, however, need to be able to provide nonbiased screening and assessment practices which are reliable and valid.

Family Involvement

Because Part H and Part B. Section 619 of IDEA are family-focused in nature, children must be viewed as having strengths, weaknesses, needs, and resources that are part of a larger family and social context. Screening and assessment procedures therefore must acknowledge and recognize the critical roles of the family and their cultural and linguistic background.

Some cultural variables include language and communication, childrearing practices, how the family is defined, and beliefs about wellness and disability. Other conditions, such as socioeconomic and educational status, are not characteristics of specific cultures but rather are cross-cultural in nature. A combination of such factors may impact children and families and influence screening and

assessment procedures and processes.

Family members may be able to share a perspective on the development of their children that would be unknown to a person involved in screening or assessment. For example, several cultures either carry or wrap young children, which may be a factor in the age at which certain motor skills appear.

There also may be certain family or group members who are key to sharing information or making decisions about other people in the family or group. Involving these key individuals in the screening and assessment process and gaining their trust may be necessary in order to provide services to a child and family of that particular cultural group. (Roberts, 1990a)

Summary

As services are developed for young children and families from diverse backgrounds, individuals need to recognize and be sensitive to the impact that culture and ethnicity may have on screening and assessment. In order to become culturally competent, there must be not only an awareness of the

issues but also efforts made to ensure that services reflect an understanding of cultural dynamics. It is a process that demands and deserves our attention and skill. It is hoped that this topical paper provides information that will be useful to you as you work with young children and families.



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Part II

Learning from Personal Experiences

What follows are discussion of the personal experiences and perspectives of five individuals, who are involved with early intervention services, as these experiences relate to screening and assessment.

The people interviewed included parents and professionals representing state and local agencies, service programs, and the academic community, from states with varied cultural groups. We asked each person the following questions:

- Can you share some of your experiences with young children ages birth through 5 from culturally diverse populations? Do you have experience with screening and assessment of young children in this group?
- From your perspective as a parent, policymaker, or professional, what are the major issues regarding screening and assessment of young children with culturally and linguistically diverse backgrounds?

- What suggestions or strategies do you have that might help to ensure culturally competent screening and assessment?
- Can you recommend any individuals, books, materials, organizations, special projects, or other resources that you have found useful?

While these interviews exemplify a range of ideas, the thoughts and experiences are not necessarily representative of all individuals or situations. Each encounter with children and families is unique. We need to listen to the families involved in the screening and assessment and acknowledge their perspectives and issues rather than superimposing another set of cultural expectations upon them. The challenge to us is to approach each screening and assessment with awareness, sensitivity, and the skills that respect and value each child and family.

As we examine screening and assessment from these perspectives, we hope to both inform and challenge you.



Isaura Barrera Metz

Albuquerque, NM

I have had extensive experience screening children ages birth through 5, but mostly children ages 3 through 5, in Head Start programs. My previous position in New York involved screening children who came from homes where Spanish and Arabic were spoken. We were looking primarily for communication disorders and developmental delay. I have also had experiences with children with very severe physical and mental impairments who came from Spanish-speaking families.

The major issues that I see regarding the screening and assessment of young children with culturally and linguistically diverse backgrounds are language-and communication-related. When we do screening, we cannot treat all children the same. Young children with handicapping conditions can have varying degrees of bilingualism. Some children who speak English at the time they are screened may have spoken English for only two years and may have spoken another language from birth to age 3. These children are bilingual and should not be screened in the same way as a monolingual speaker who has spoken English for five years.

We are not getting enough information about the cultural and language patterns in the home prior to the screening and assessment. Without that knowledge we cannot interpret results accurately. We need three pieces of information: who speaks what language and when (i.e., for what purpose). Most forms have the question, "What language is spoken in the home?" That is simplistic, because we set parents up to answer in a singular fashion, either English or Spanish. Many families are therefore not

Isaura Barrera Metz is an assistant professor of special education at the University of New Mexico in Albuquerque. She teaches special education courses in the areas of bilingual special education and early childhood special education. She previously was project director for CROSSROADS, a cooperative transagency program for preschool culturally and linguistically diverse exceptional children in Buffalo, NY. Isaura was interviewed over the telephone, reviewed her comments, and provided written material.

able to accurately reflect the actual pattern of language usage. For instance, English may be spoken in the home, but the child spends all day with the babysitter who speaks Spanish or all summer with a grandmother who speaks Korean. We need to be more specific in the ways we ask questions about language.

Whenever children have been exposed to another language, degree of language proficiency needs to be checked out carefully; otherwise, there is an increased probability of misinterpreting assessment results. The tendency is to identify a dominant language, and screen and assess only in that language. We need to look at not just at how proficient they are in English but also at proficiency in other language(s). The children may not be verbal, or they may have one language somewhat developed and are just beginning the second language. Those children have as much of a need for modification as children who have fully developed bilingualism. What we need to do is use both languages to some degree in screening and assessment. We need to determine how much proficiency the child has in each language. Bilingualism is much more subtle than what many people suspect.

"We are not getting enough information about the cultural and language patterns in the home prior to the screening and assessment. Without that knowledge we cannot interpret results accurately."

Bilingualism is often examined only when the children are verbal, yet even children who are nonverbal and severely challenged may have bilingual skills. We found that when using Spanish with these children there was a noticeable difference in their affect and muscle tone. We were able to elicit much more optimal behavior. I have found that using the language children are familiar with at home does have a dramatic effect in many cases, primarily because of variations of prelinguistic factors such as eye contact, rate of speech, variations of intonation and rhythm, and use of gestures.

I strongly believe in the use of language and cultural mediators or interpreters, as I have seen

"The language used in the screening and assessment sends a very powerful message to the child in terms of how they respond and what language they will use."

dramatic differences in the benaviors of both children and adults. These people speak the child's language and, if possible, are from the same neighborhood. They are used in the screening and assessment process as well as for program development, and also serve as an advocate for the family. We find a sig-

nificant difference in how quickly the family develops trust and responds, how much information they volunteer, and how well they establish a relationship with the agency.

A large piece of culture is intuitive, and someone from that child's background may do things in a way that is much more natural and free-flowing. I assessed a child from a Puerto Rican background whom I spent time with and tried to hold on my lap, but my Spanish does not have a Puerto Rican intonation and I had little response. The mediator was Puerto Rican, and the child went over immediately and sat in her lap. I don't know what that child was responding to, but something felt more comfortable and familiar.

Children will look at the language environment to

see whether or not it is okay to use a certain language. The language used in the screening and assessment sends a very powerful message to the child in terms of how they respond and what language they will use. If the assessor speaks only English, the child may not use any language other than English. Children who can distinguish language environments have higher pragmatic skill levels, but may seem to have more problems.

We also need to look at the family's degree of acculturation. How closely is the family adhering to the traditional non-mainstream culture? A family may have a home where English is spoken, but the learning style is very traditional Hmong or Lao. Children from these families are easy to misdiagnose. They are brought into a setting and shown toys they have never played with and spoken to in an adult-child interaction pattern foreign to them and they don't perform, yet the family speaks English at home. That sometimes happens with groups such as American Indians who may tend not to look directly at you and initiate, and they may look much more delayed than they are. A language/culture mediator is helpful in these cases, also.

Although the mediator is hired by the program, children and families see the mediator as a neutral person. The responsibility for finding and hiring the mediator or interpreter rests with the agency so as to minimize demands on an already stressed family. We often find people to act as mediators in grocery stores, churches, and other places in the neighborhood where people go. It is good to have the mediator be a non-family member, but a family member should not be excluded from acting as mediator.

The mediator meets with the assessor before the screening or assessment to be shown the test to be used, and/or to be trained in giving it. They need to familiarize themselves with the purpose of the test items, when they can be flexible in terminology and when they need to be specific. Sometimes the mediators will present the items, but in other cases they can simply watch and provide information to and from the family. For example, in some cultures physical and occupational therapy assessments are

considered abusive because it appears that limbs are being pulled and pushed without regard for the child or without being nurturing or kind. The mediator would explain what is going on, why the child is crying, and why the assessor is not picking the child up at that time.

After the screening or assessment the family and mediator meet with the assessor to go over the results. The assessor will give the results, but the mediator could add what the parents had told them about language or culture. The mediator is really there for the benefit of both the family and the assessor. It also is all right for there to be disagreement or differing opinions.

What may often be most prejudicial about assessment is how the assessment results are reported. We need to be careful about how we write the results and be very specific about what we have done. We need to report not only the score the child received on the test, but also how many items were presented, in what language, and who was involved in the process. For example, I may be a monolingual assessor and use the janitor down the hall as the interpreter. This may not be the best information, but it reflects my optimum effort and should be reported as such.

The whole issue of assessment and language performance with bilingual children is very critical, and there is little or no information for use with young children. The work that I have done with children in Head Start programs shows that receptive language delays in the home language or even in the second language are relatively rare. Expressive delays, however, are quite frequent and seem to be a part of "normal" development in these cases. I tested many children and found that an expressive delay of three to six months for a child who is bilingual is fairly normal. When there were receptive delays, however, the children tended to have very significant communication disorders.

There is a question about when to refer and which children to refer. Children who do not really need services are overrepresented but are referred because they speak English poorly. Children with communication disorders are often underrepresented in early childhood, but often are referred as learning disabled in second through fourth grades.

I have three red flags for determining whether or not to make a referral:

- 1. There is no communication disorder in a second language unless it also is there in the first. Many children are being screened and assessed when there is no English spoken in the family, and they are being referred because their English vocabulary is not up to par, without determining level of vocabulary in the non-English language.
- 2. If we cannot access the first language, then we need to look at the rate of English acquisition. If the child is acquiring English like other non-native English speakers of the same age, then chances are there is not a significant communication disorder or significant handicapping condition.
- 3. If there is any identification of an at-risk factor or delay, there should always be a complete language assessment prior to any other assessment. Without knowledge of a child's communicative competence, you can't interpret screening or other results accurately. This is because you don't know if there was no response because the child did not know the answer or did not have words for it.

One last observation: It is important to establish contact with the diverse cultural groups prior to working with children. Agencies don't develop screening and assessment skills because they don't serve the population, but getting ready to do an assessment is not something you do in several days. Word gets around that the agency is not culturally competent. If agencies are receptive and willing to make changes, children often "come out of the woodwork." You need to establish a network and get to know the cultural community before the children are screened or assessed.

Ursula Arceneaux Markey

New Orleans, LA

I loved my father dearly, but when he took me aside one day and told me he thought there might be something wrong with my little boy, his precious grandson. I stopped speaking to him for months. I was crazy with fear and anger. In my family, my father was the one who fixed everything -- not just broken furniture and bicycles, but people. As a child, I saw him put lives back together. Young couples averting each other's eyes, older men and women on the brink of tears, and parents and children at odds would come to him and leave somehow healed. Neighborhood "counselors," like my father, often are a primary resource for problem solving in the African American community. So when my father told me I should seek outside help for my son, I stopped speaking to him because I did not want to face the truth: whatever intervention my son required was beyond my father's resources, and he was giving me his best advice.

To find the kind of help I needed, I was going to have to seek the advice of strangers who lived in a world quite separate and different from mine. I considered these people privileged professionals who had achieved this status by way of institutions that systematically excluded African-Americans and other minorities. I personally experienced such an exclusion in 1963, when I was a senior in high school. My application to the newly established school of physical therapy at a local hospital was denied solely because there were "no facilities for training Negroes."

Although the Civil Rights Amendment had been law for 10 years, vestiges of discrimination still

Ursula Arceneaux Markey is a parent of an 18-year-old son who has autism. She is director of Pyramid, Outreach to Parents of Children with Disabilities in Diverse Communities. Ursula wrote this article in response to our questions and talked with us on the telephone.

remained when I took my child for help in 1975. Many African-Americans and other "minorities" faced an ongoing struggle for quality education, social services, fair housing, adequate health care, and equal employment opportunities. Legislation in itself did little to change negative attitudes toward people of diverse cultures. Services were often offered grudgingly and usually without support or encouragement.

When I walked into the evaluation center to apply for services for my son, the receptionist handed me a long form that asked for, among other intimate information, details of my family history, including names of family members who had medical problems, mental illness, or emotional difficulties. The form had me document my son's problem behaviors without allowing space for positive comments about his strengths and endearing qualities. When I scanned my written descriptions of my son's disruptive and sometimes destructive behaviors, I panicked. I returned the form half completed, and left feeling as though I had betrayed my baby.

He was so young, just 3 years old, and I was worried that the information I provided on the form would, without the benefit of further explanation, predispose the examiners to erroneous conclusions about my child. How could these professionals, so removed from our experiences, be qualified to properly evaluate my son? The last thing I wanted was

"Legislation in itself did little to change negative attitudes toward people of diverse cultures. Services were often offered grudgingly and usually without support or encouragement."



to contribute to his being labeled in some way. I had seen the negative effects on children when teachers' expectations of them were lowered by special education classifications. Such children were rarely presented with age-appropriate tasks or included in challenging activities with their typical peers.

If the screening process exposed my son to these possibilities, I was prepared to find a way to circumvent it. In the weeks that followed, my husband and I doubled our efforts to manage our son's behaviors, but without success. No one from the agency called to question my incomplete application or encourage my return. Soon I found myself at my father's door, desperate and defeated.

I returned to the evaluation center on the arm of my father, whose kind support kept me focused and strong. I wondered what other parents, especially single parents, did when employers, like my husband's, did not consider the screening process a "medical emergency" and denied them leave for that purpose.

A week later the screening process officially began in an interview with a case manager. She went straight to work, explaining the assessment process, the tests involved, and the composition of the inter-disciplinary team that would evaluate my son. By the end of the interview, I felt surprisingly calm and re-energized. This person shattered whatever cultural barriers that may have existed between us by displaying competence, courtesy, and respect for me as a caring parent.

During the screening process, there were, however, numerous other times when I knocked on my parents' door for support as I encountered those "old attitudes" among several members of the interdisciplinary team and their staffs. I recall a psychologist who became annoyed when I asked him how some of the questions he asked my child were evaluated. Questions such as: What are mothers for? What do fathers do? How many toys do you have in your room? Do you like policemen? In my mind, I questioned the examiner's ability to address the cultural implications of these questions. My involvement in the screening process was often viewed as interference. On one occasion, an evaluator told me I was "dismissed" when I insisted that my son could, in fact, perform many of the tasks that he failed to demonstrate knowledge of in verbal tests. When, on another occasion, I pressed for an explanation of the terminology and scores that appeared on an evaluation, I was reminded that this was "highly technical information for the interpretation and use of experts."

Still, there were times when experts overlooked the possibility of culturally based aspects of behavior. For example, without exception, evaluators' reports contained frequent references to my son's 'lack of eye contact' as a negative characteristic.

However, there may be cultural implications in the degree of eye contact in conversation.

In ancient history, European cave-dwellers peered through the darkness and locked into each other's gaze to engage in conversa"Sometimes culture provides avenues to communication and understanding where traditional approaches fail."

tion with each other. Africans, living on the vast savannahs, habitually moved their eyes from side to side to scan the expanse, while maintaining attentiveness during conversation.

In more recent American history, slaveowners punished their slaves for either demonstrating too much eye contact — a sign of arrogance and defiance — or too little eye contact — a sign of shiftiness and dishonesty. We must learn how to weigh the effects of this history upon behavioral characteristics.

Sometimes culture provides avenues to communication and understanding where traditional approaches fail. During one frustrating session, when my son was being particularly non-communicative, someone carrying a radio passed beneath the window of the office. Hearing the heavy and repetitious drum beat, my son sprang to his feet and

"Far too many of us are never touched by outreach efforts and lose the opportunity to benefit from early intervention."

began singing and dancing to the music. The examiner concluded the session, noting "the disruption made further progress impossible." Perhaps my son's response to the African rhythms, incorporated into strategies for future sessions, may well have provided the examiner with a viable inroad to communicating with him.

Diagnostic tests often called for observations of my child's manipulation and use of certain toys and participation in various board games. Yet, for many African-American children unaccustomed to owning factory-produced playthings, a truer indication of typical playtime behaviors lies in their interactions with extended family (cousins) and peers engaged in creative play, i.e., hand games, chants, and other performance-oriented activities.

Surely, parents of all cultures will recognize culturally influenced events in their experiences. However, when cultural bias surfaces in a system, Native Americans, African-Americans, Mexican-Americans, Asian-Americans, and other "minorities" are at greater risk of receiving inaccurate assessments.

Far too many of us are never touched by outreach efforts and lose the opportunity to benefit from early intervention. I know I would have been less anxious about initiating that first contact had I seen more advertisements for services that depicted families of diverse cultures. I know I would not have walked

away after that first visit if I had received just a little support and encouragement.

My father passed away two years ago, but not before he watched his grandson grow into a fine young man who, despite his disability, enjoys living and working in the community. I will always acknowledge and appreciate the pivotal role he played in accessing services for my son. "What goes around, comes around," my father used to say, usually when he was expressing frustration over separatism, discrimination, or some other issue involving social or economic injustice.

Current demographics now indicate that professionals will render services to an increasingly culturally diverse population. Those whose credibility will survive and thrive into the future will be those who:

- · become multiculturally competent;
- accept parents and other nontraditional experts as partners in problem solving; and
- demand a truly integrated society with equal opportunity for all.

Those who cannot or will not consent to these changes may be forced for the first time to join the ranks of the "culturally disadvantaged" in America. As my father would have said, "It has come around to that."



Alice Ngai

Manhattan, NY

I have worked with the Chinatown Health Clinic located in downtown Manhattan for the past five years. The clinic provides comprehensive health care -- prenatal to geriatrics. Most of the patients are new immigrants who are non-English speaking and have been in the United States less than five years. In 1990 we saw 9,500 children, ages birth through 5, and 99% were Chinese from all five boroughs of New York City and the Tri-state area. The clinic is open seven days a week with evening hours. I am trained as a Physician's Assistant and I work mostly with newborns and children at the Clinic. My work involves 70% clinical and 30% administrative responsibilities.

In addition to clinical services, the Clinic has a department that provides health education, both on and off site (e.g., daycare centers, Head Start programs, schools, restaurants, and garment factories). In the past, we had been able to hold workshops for parents at their workplace on weekends, but budget restraints made the program impossible to continue. Everything extra needs resources.

Immigrants to the United States cannot get decent jobs because they are not licensed here. They may have trained in China or Taiwan, and not speaking English is a major problem for immigrants in all professions. Most parents work long days, and they don't make enough money to pay for rent, medical insurance and food. Instead of a 9-to-5, five-days-aweek job, they may work six to seven days a week from 8 a.m. to 8 p.m. or 10 a.m. to 11 p.m. They work hard for their children, but they don't have enough time to spend with them. Usually it is the grand-mother who watches the children. The children get

Alice Ngai was the coordinator of Pediatric Services and physician's assistant at Chinatown Health Clinic in New York City at the time of this interview. Currently she is a physician's assistant in the surgery department of a community trauma center in Queens, NY. She is an adjunct member of the New York State Interagency Coordinating Council Early Intervention Program for Infants and Toddlers with Handicaps and Their Families. Alice was interviewed on the telephone and reviewed her comments.

fed, but they don't get stimulated physically, verbally or intellectually. It is common in Chinatown to see a 3- to 4-year-old walking with a bottle and not talking in complete sentences. This reflects inadequate nurturing due to poor socioeconomic status.

Chinese parents are not used to Western medicine, especially vaccination against childhood diseases which is viewed as a foreign event in their native load. In New York City, we are into the third year of a measles epidemic, and 95 percent of recent immigrants are unaware of it. The majority of Chinese parents listen to the local Chinese broadcasts rather than national radio and television. These Chinese-speaking stations usually do not carry enough current health information. This leads to the general unawareness about health issues in the community and a misunderstanding among traditional health professionals, who perceive the parents as being negligent rather than ignorant

Furthermore, in the Chinese culture health is perceived as the lack of obvious illness. Some parents, especially the grandparents, are strongly against bringing a child for routine check-ups or follow-up of a common childhood illness, such as anemia which requires the checking of blood repeatedly. The language, the cultural differences, as well

"In New York City, we are into the third year of a measles epidemic, and 95 percent of recent immigrants are unaware of it."

as the lack of medical education are the major contributing factors for the 10 percent rate of missed follow-up appointments.

The lack of culturally appropriate screening and assessment tools further deters this population from accessing optimal health care. One example is the growth chart, which is part of a health care maintenance examination. Some children are labeled small for age when plotted in the American standardized growth curve. Another example is the audiometry test, which is performed for all preschoolers. Many children are sent for audiology work when they fail to respond to the 25db hearing test. Inability to follow simple instructions in English is usually the cause of their failure and the reason for many referrals to our Clinic.

Most of our referrals are by a piece of paper and not by phone, and we need more information. It would be nice for the referring agency to play a more active role in communicating their assessment and concern by contacting us directly so that the agency's perception of the child's problem can be clarified.

The lack of bilingual, bicultural human service workers is another problem in screening and assessment of young minority children, as is recruitment and retention of the workers. The Clinic's administration is having a hard time dealing with this issue. It's more than just speaking the language; it's finding personnel who are bicultural as well that makes it hard to find qualified workers.

Parents do not openly express their concerns for their child when they do not trust the provider. They often feel more comfortable and talk more freely with a bicultural person than through a translator. There are many different dialects in the Chinese language. The parents, provider, and even the child may be speaking different dialects.

Once I came across a mother and her three children who never left their apartment because they did not speak English and were afraid to go out. The only time they went out was one day a week with the father, who would stock up the family with milk and

bread for the entire week. The mother did not know how to get on the bus and was unable to go anywhere. The children did not start to go to school until they were older. It took great effort from our Clinic's social worker and another community social service agency before the children were channeled into the mainstream school system. We were initially treated as foreigners because we spoke a different dialect.

Before we can help, we need to understand the weakness and needs of the population. Chinese people may have cultural differences and be hard to integrate, but they are adaptive and willing to learn. We must be willing to work through the problem with them. Parents had no problem with one non-Chinese pediatrician at the Clinic who showed she cared and was able to get across her caring and concern by being available. They learned to work with her through the translator, and she had the family health-care worker call her at home if they were worried about the child. Families often work late, so we find their work number and talk with them there, or call them on the weekends. If they know you care about the children, they will respond. Professionals and policy makers need to tour the community and meet the people.

There needs to be more initiatives for local community health centers for the planning and implementation of screening and assessment programs. There needs to be extra resources. For instance, on Sundays have an open day for screening and a workshop for the parents to examine if their child is developing normally or if there may be a problem. Families also should be able to call a 1-800 number.

There need to be on-going grants available for bilingual personnel training and scholarships available for bilingual psychologists or developmentalists. Reward people for wanting to work more intimately with families of all cultures.

Wanda Hamilton

St. Croix, Virgin Islands

My experiences with young children from culturally diverse populations have occurred primarily in the Virgin Islands. The Virgin Islands are the "hub" of the English-speaking Caribbean. It is paradise not only to the thousands of tourists from the mainland who seek momentary refuge from their daily responsibilities and choose to escape to the beauty and tranquility of the Islands, but it is also paradise to thousands from neighboring Caribbean Islands and elsewhere, who are driven to seek economic refuge here. This means that the characteristics of the population of the Virgin Islands, linguistically and culturally, are not only diverse but dynamic. Moreover, because all of these potentially longer term residents -- especially those from the Caribbean -- bring with them the Afro-Caribbean and colonial experience, several smaller minicultures exist within the megaculture. (I've given up "sub" in favor of "mini" since "sub" tends to suggest beneath or lesser than.) This has presented some unique challenges, especially in the area of assessment, as we attempt to identify and address the needs of the young children with disabilities in these groups and their families. It is the challenge of individualization at its height.

As you may be aware, in the Virgin Islands the Department of Health is the designated lead agency for Part H of P.L. 99-457 (now referred to as IDEA). I work for the Department of Education, lead agency for service to children with disabilities 3 through 5 years old, as the 619 Coordinator. My experience and efforts with issues relating to the provision of services to the birth-through-age-2 group have been concentrated in Interagency Coordinating, assisting

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the lead agency with policy development, and trying to facilitate the development of a comprehensive service delivery system. You may also be interested to know that our ICC is a birth-to-5 council. This will help tremendously as we address issues around transition.

Prior to working with the Early Childhood Special Education Program, I worked with the Department of Education in the area of diagnostics, assessment, and program planning for children with or suspected of having special education needs. During that experience I had occasion to do some screenings and evaluations for this age group. However, since assuming the responsibilities of 619 Coordinator, my involvement with assessment is primarily in the area of selecting instruments, training, and staff development.

To this end, I develop and conduct activities around the administration and interpretation of standard assessment and screening tools, and provide training in reporting results within the confines of the instruments and within the context of the child, family, mini-, and megacultures. The staff members also are provided with supervised practical experiences in observational and interview techniques. I believe that it is here, at the juncture of observation and interview, that the foundation of assessment takes place. Here the key that must be used to frame the manner in which the results are interpreted and reported, needs identified, programs planned and

"When identifying strategies to ensure culturally competent screening and assessment, carefully choosing the tools, instruments, and procedures to be used would be high on the list."



the strategies by which the plans will be implemented, becomes clear.

While an "... informed and sensitive ... skillful clinical interview . . . can be the source of data that sets the tone of the working relationship between parent, child and service provider, and is a major source of guidance for future interactions with the family," the extent to which this process provides the interviewer with information for program planning cannot be stressed enough (Meisels & Provence, 1989, p. 15). This is where I feel a genuine sensitivity to and appreciation for the uniqueness of each child, the child's family, and their needs, must be established as an integral part of screening and assessment. Because if the sensitivity and appreciation are not in place, everything else is truly academic - not humane. After all, we are people working with people, aren't we?

The first major issue in screening and assessment involves the question of personnel and personnel standards, competencies and/or certification. Where are we going to find the competent, sensitive, trained personnel to meet the needs of children and families we identify? Recruiting qualified personnel from the limited pool on the mainland, coupled with the high cost of living in the Virgin Islands, is very difficult. Add the variable of a shared cultural-linguistic experience with the population to be served to the qualifying criteria and it becomes an almost impossible position to fill. Even fairly comparable salaries, and the sea and the sun, are not enough to lure people here.

Secondly, because the population of the Virgin Islands is so diverse culturally and linguistically, we would need several people of different qualifications. (Cultural and language backgrounds include for St. Croix: English with dialects from other English-speaking islands in the Caribbean, Spanish from Puerto Rico and Santo Domingo, Arabic, and assorted Patois of Dutch, French, etc.; and for St. Thomas: English with the same influences as St. Croix, French, assorted Patois, and some Arabic and Spanish.) Either way, such diversity has created low incidence or small pockets of need.

Finally, of course, there is a need to find appropriate tools and instruments. We look for ones that do not show such blatant disregard for and/or lack of appreciation for anything that deviates from the superculture, and that are not so sterile that they offer little or nothing that can be used for planning. That's why I support and stress the use and importance of (family) interviews and observation procedures as sources of information for planning. This carries with it, of course, the importance of a skilled, sensitive, appreciative, competent interviewer and reporter.

When identifying strategies to ensure culturally competent screening and assessment, carefully choosing the tools, instruments, and procedures to be used would be high on the list. But before that, I think it would need to start with selecting personnel who would use these procedures.

The criteria need to be based on standards that stress competencies in the areas that reflect an appreciation for, as well as sensitivity to, the cultural uniqueness of people in general. Personnel need a knowledge of and sensitivity to the issues that face children with disabilities and their families. And throughout, there has got to be respect for the mutual efforts of parents, children with disabilities, professionals, and anybody else working together with the child to realize his or her promise.

The other thing that seems to offer the most potential for the Virgin Islands is finding the personnel we need from within. This would involve establishing training programs at the university, generating interest in careers in special education and related services among high school students, and offering incentive programs to explore special education options to professionals and paraprofessionals already working in education. We also need to encourage parents of children with disabilities to become involved in these training programs and in that way help to meet the needs of their child while expanding their resource capabilities. The use of trained lay screeners from specific cultures would certainly help to ensure knowledge of and a sensitivity to the uniqueness of that culture.



Julie Jackson

Sacramento, CA

The phrase "cultural diversity" almost seems too tame to describe the dynamic mix of peoples, cultures, languages, lifestyles, and ideas that comprise the state of California. The Department of Health Services' Maternal and Child Health (MCH) plan reports some startling statistics: based on the 1990 census, California's population has reached nearly 30 million people; one out of every eight births in the United States in 1989 occurred in California. One third of all live births in California are to mothers born in another country, and "minority majorities" now exist in three California counties: Los Angeles, San Francisco, and Imperial. In Los Angeles alone, 104 languages and dialects are spoken. In the past decade, the African-American population has increased by 21 percent, the Hispanic population by 70 percent, and Asian populations by 127 percent.

Our challenge under Part H is to create a statewide early intervention system that is not only comprehensive, multidisciplinary and interagency, but also culturally competent. From a management and policy formulation perspective, this means identifying issues and finding solutions in three key areas: (1) service delivery, (2) family involvement, and (3) systems change.

There are several problematic issues in the provision of assessment services. As is frequently pointed out, existing instruments for screening and assessment may not be appropriate for the many different populations residing in the United States today. Because this is an issue of national significance, a potential solution would be to fund a national project to refine current tools and/or to create new ones that

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are properly normed for different cultural groups.

Both the law and best practice dictate that assessment procedures be conducted in the native language of the family. The problem in California is that our existing service system simply does not have the capacity to ensure bilingual and bicultural services for every eligible family, given the enormous number of languages spoken. Consequently, we look to alternatives in service delivery, such as the use of interpreters or bilingual family members. Each of these options, however, presents some difficulty. An interpreter may speak the language perfectly well, but may lack understanding of the sensitivity of the process or may slightly change the questions, which may skew the results of the test. Relying upon family members can be a delicate matter in that it can place additional burden upon the family at a sensitive time.

The solution to these problems, from a policy perspective, must center on the improvement of systems for personnel recruitment and training, on both the state and local levels. Local programs will need a multi-faceted strategy for recruiting a multicultural staff and for cross-training all staff to ensure cultural competence. All of these issues relate to being able to communicate with sensitivity, to draw appropriate conclusions from the assessment process, and to be able to relate without cultural bias to the family. Most of us have not been trained to do this. Each of us identifies with a specific

"Local programs will need a multi-faceted strategy for recruiting a multicultural staff and for cross-training all staff to ensure cultural competence"



"If it is still true that families and professionals sometimes do not 'speak the same language,' even though the words are in English, then we face even greater hurdles for families of different cultures and languages."

culture, and each of us has a system of values with inherent prejudices. When different values between two cultures come into conflict, stress is created for everyone.

This brings me to the issue of greatest concern: how to create a family-centered early intervention system that can embrace and empower all of the cultures in California. Even though we have had early intervention programs and services in California for many years, we are calling for a dramatic transformation in how services are delivered. At the center of this change stands the family, in equal partnership with professionals who are available to assist and support the family in meeting the needs of their infant. This concept of family/professional partnership, at all levels of the system, requires a radical change in how we have traditionally thought about human services, and this change in thinking does not occur overnight. We have yet to achieve an even level of understanding by all players in the system, even before we had multicultural issues into the equation. If it is still true that families and professionals sometimes do not "speak the same language." even though the words are in English, then we face even greater hurdles for our families of different cultures and languages.

To achieve cultural competence in our early intervention system, we must devise ways to achieve the presence, participation and, ultimately, influence of parents of diverse backgrounds in all phases of system development and service delivery. We have some excellent models of service delivery that have focused on specific populations. But an even greater challenge is to avoid setting up separate, ethnocentric systems that would then need to be coordinated.

Achieving an ethnically and culturally representative system that recognizes, embraces and values diversity can seem an overwhelming task. But there are some "first steps." One is to ensure adequate input and representation on planning bodies, such as the state Interagency Coordinating Council and local coordination groups. This generally takes some extra effort to recruit individuals and to facilitate their active participation. Another is for leaders within the system to model the values and philosophy of diversity, to set the proverbial "example," and to establish the expectations for the system. We can all write policy statements and procedures with all of the right phrases, but can we influence attitudes? Ultimately, system change of the magnitude envisioned by Part H hinges on the pervasive acceptance of new values and beliefs about services for infants and their families.

Part III

Strategies

The following strategies were selected from the interviews we conducted, a review of literature, and the experiences of PACER and NEC*TAS staff. They are offered as suggestions for examining ways to ensure cultural competence in serving families from diverse backgrounds who have young children with disabilities or special needs. It is our hope that this section can serve as a tool for looking at and developing a personal framework that will assure cultural competence in screening and assessment.

Strategies for Part H and 619 Coordinators and Other Policymakers

- 1. Become knowledgeable about the cultural groups in your state, region, and local community when planning culturally sensitive screening and assessment policies, and deliver services that support the cultural uniqueness of the communities you serve.
- 2. Recruit people who have diverse cultural and linguistic backgrounds from state, regional, and local communities to serve on policy-making committees regarding the screening and assessment of young children with culturally and linguistically diverse backgrounds.
- 3. Develop a mission statement and implementation plan to address cultural competence issues in screening and assessment.
- 4. Develop communication networks and linkages with group leaders from ethnic and cultural minorities regarding cultural competencies in screening and assessment.
- 5. Develop "best practice" standards and guidelines for culturally competent screening and assessment.
- 6. Provide incentives for the recruitment and training of bilingual and bicultural personnel in early intervention services and screening and assessment.
- 7. Require staff training on cultural competence skills in screening and assessment, and set standards for professional cultural competence.
- 8. Find training and demonstration projects that utilize culturally competent standards in the screening and assessment process.
- 9. Create policies and systems that have cross-cultural screening and assessment philosophies and practices.
- 10. Recruit and retain people who have diverse cultural and linguistic backgrounds at all levels of involvement. Hire consultants to assist systems and agencies in the recruitment, training, and retention of people from a diversity of cultural/linguistic backgrounds.



Strategies for Parents

- 1. Talk with other parents in your community for recommendations about schools, clinics, and providers they have used for screening and assessment.
- 2. Look for professionals and other providers who are familiar with and knowledgeable about your cultural and linguistic community and skilled in screening and assessing young children. Ask how experienced the provider is in screening and assessing children from your cultural group.
- 3. Become part of a network of other parents and professionals to gain support and information.
- 4. Insist that professionals and other providers be bilingual and bicultural, or that skilled interpreters or mediators be used and that other staff receive ongoing training in cultural competence.
- 5. Look for cultural and linguistic sensitivity in the screening and assessment process. Are forms and information presented in your language? Is assistance available to help you fill out the forms if needed? Is your child's screening and assessment being done in familiar settings using objects and routines other children in the community are exposed to?
- 6. Learn to trust your feelings and instincts about what does or doesn't work for your child and family.
- 7. Share cultural information that will assist professionals in understanding your child. For example, "My child is not walking yet because in my community children are often carried until age 2." You as a parent and family member know your child better than anyone else.
- 8. Communicate with professionals and other providers so that the screening and assessment process for your child and family is culturally sensitive and competent. Statements such as "I am not comfortable with my child being tested using those toys. He has never seen them before," or "Children in my community do not sit in chairs to do work at a table. Could he sit on the floor instead?" can help to make certain your child receives a nonbiased screening and assessment.
- 9. Know your rights regarding nondiscriminatory screening and assessment, and other special education due process rights. Become involved with your local, community, and state advocacy groups.
- 10. Know where to turn for advocacy and assistance. If you think your child's screening and assessment has not been culturally sensitive, be sure to go to the agency and tell someone so that changes can be made.



Strategies for Professionals Working with Families from Various Cultural and/or Linguistic Groups

- 1. Individualize the screening and assessment process for parents as well as for children. Children and other family members may be at various levels of acculturation and may require similar or varying degrees of modifications, adaptations, or support, such as language interpretation.
- 2. Do a self-assessment of your own cultural background, experiences, values, and biases. Examine how they may impact your interactions with people from other cultural groups.
- 3. Begin the screening and assessment process at the point where the parents are. Find out their concerns, why they are coming to you, and what they hope you can provide.
- 4. Take the time to establish the trust needed to fully involve the family in the screening and assessment process.
- 5. Use bilingual and bicultural staff, or mediators and translators whenever needed. Try to maintain a consistency of providers to allow the family to establish an ongoing communication.
- 6. Allow for flexibility of the process and procedures. You may need to meet with parents at their job site, or call them when they return home from their job. You may need to modify test items to ensure cultural competency.
- 7. Conduct observations and other procedures in environments familiar to the child. These may be at the home of their grandmother, outdoors, or at their parents' work site.
- 8. Provide assistance and be flexible in establishing meetings with parents. This might include providing for childcare of siblings, transportation to a meeting site, or meeting the family in their home.
- 9. Participate in staff training on cultural competence skills in screening and assessment. Strive to achieve standards for professional cultural competence.
- 10. Conduct cagoing discussions with practitioners, parents, policymakers, and members of the cultural communities you serve.

Questions for Professionals to Ask When Conducting a Culturally Sensitive Screening and Assessment

- 1. With what cultural group was this screening or assessment tool normed? Is it the same culture as that of the child I am serving?
- 2. Have I examined this screening and assessment tool for cultural biases? Has it been reviewed by members of the cultural group being served?
- 3. If I have modified or adapted a standardized screening or assessment tool, have I received input on the changes to be certain it is culturally appropriate? If using a standardized tool, or one to which I have made changes, have I carefully scored and interpreted the results in consideration of cultural or linguistic variation? When interpreting and reporting screening and assessment results, have I made clear reference that the instrument was modified and how?
- 4. Have representatives from the cultural community met to create guidelines for culturally competent screening and assessment for children from that group? Has information about child-rearing practices and typical child development for children from that community been gathered and recorded for use by those serving the families?
- 5. What do I know about the child-rearing practices of this cultural group? How do these practices impact child development?

- 6. Am I aware of my own values and biases regarding child-rearing practices and the kind of information gathered in the screening and assessment process? Can I utilize nondiscriminatory and culturally competent skills and practices in my work with children and families?
- 7. Do I utilize parents and other family members in gathering information for the screening and assessment? Am I aware of the people with whom the child spends time, and the level of acculturation of these individuals?
- 8. Do I know where or how to find out about specific cultural or linguistic information that may be needed in order for me to be culturally competent in the screening and assessment process?
- 9. Do I have bilingual or bicultural skills, or do I have access to another person who can provide direct service or consultation? Do I know what skills are required of a quality interpreter or mediator?
- 10. Have I participated in training sessions on cultural competence in screening and assessment? Am I continuing to develop my knowledge base through additional formal training and by spending time with community members to learn the cultural attributes specific to the community and families I serve? Is there a network of peer and supervisory practitioners who are addressing these issues, and can I become a participating member?



Part IV Additional Resources

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