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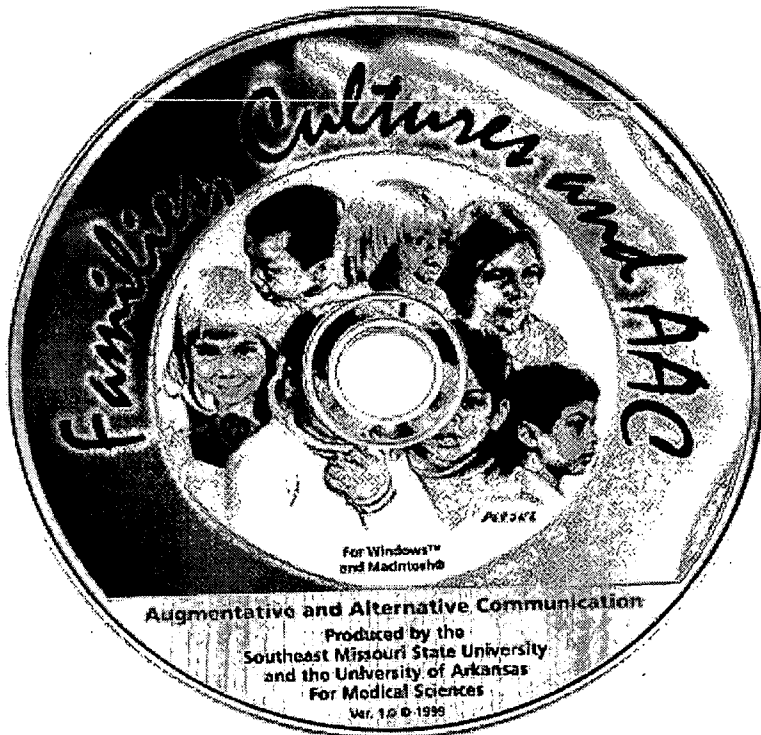
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ABSTRACT

This report details the outcomes of a project designed to develop decision-making strategies and materials related to the prescription of augmentative and alternative communication (AAC) devices for children with disabilities. The project resulted in the development of the first interactive, bilingual CD-ROM designed to be used by related services personnel, vendors, and family members from diverse cultures to develop competencies that assist in effective AAC decision-making. Instructional materials were developed to provide information and multimedia vignettes designed to sensitize related services personnel to child, AAC device, family/social, cultural, and system issues prior to the selection and use of AAC devices, provide structured procedures and checklists to use during the planning, implementation, and evaluation of AAC devices. Multimedia vignettes also provide simulated practice in the use of the procedures. These interactive materials will enable service providers to make the most appropriate decision about the prescription of AAC devices while balancing child, AAC device, family, cultural, and system resource considerations. The report includes a description of the different phases of the project, findings from family and professional focus groups that led to the development of the interactive materials, and information on project dissemination. (Contains over 150 references.) (Author/CR)

Culture, Families, and Augmentative and Alternative Communication (AAC) Impact:

A Multimedia Instructional Program for Related Services Personnel and Family Members



Executive Summary

U.S. D. E. CONTRACT NO.
H029K50072

*Funded by
Special Projects*

U. S. DEPARTMENT OF
EDUCATION

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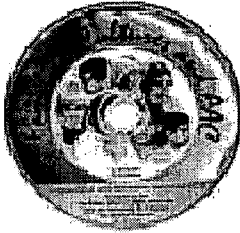


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EXECUTIVE SUMMARY

Overview

Funded in 1995 by the U. S. Department of Education, this Special Project targeted the development of decision-making strategies and materials related to the prescription of AAC devices for children with disabilities. The strategies and materials were embedded in a family-oriented, culturally sensitive, interactive, bilingual CD that was disseminated nationally for use as a training media for related services personnel and family members.

Numerous sources of information were used to compile content for the CD: (a) focus groups and structured interviews with family members and professionals ($n=85$) across five cultures at five different sites (Arkansas, California, Illinois, Missouri, and New Mexico), (b) Expert Panel, (b) Consumer Advisory Group, and (d) literature reviews.

Focus group and structured interview transcripts were analyzed using established qualitative analysis procedures. Themes were identified for each group proceeding or structured interview. AAC Impact Questionnaires and General Information Forms were also completed by participants to provide additional sources to guide CD development.

Family Findings

Family focus group and structured interview data were organized around three themes that addressed the broader question of the project: *What do families of different ethnic backgrounds want professionals to know about AAC decision-making?* More specifically the themes answered three related questions: (a) *How do families want professionals to build family-professional partnerships?* (b) *How do families want professionals to demonstrate respect for family values and ethnicity?* and (c) *What can professionals do to help families learn how to use AAC devices?*

Professional Findings

Findings from professional focus groups were represented in five themes that addressed the broader question of the study: *What are professionally-held perceptions regarding the roles of professionals and family members in AAC decision making?* More specifically the themes answered five related questions: (a) *What are the communication styles needed by professionals and family members to build family-professional partnerships?* (b) *What is the responsibility of professionals to address family information needs?* (c) *What*

values should professionals and families acknowledge in working together on teams? (d) What teaming skills should professionals demonstrate in working with families? and (e) What do professionals and families want regarding AAC implementation and training?

Recommendations

In general, the themes identified by families and professionals in this study, coupled with other sources of information suggest practice patterns that have implications for AAC.

Recommendation 1

Professionals should understand that families have many demands placed upon them. Sources of these demands come from both outside and within the family unit. Such concerns may affect the family's ability or willingness to accept and implement AAC.

Recommendation 2

Professionals should realize that the presence of a disability in the family affects *all family members* within the immediate family. Extended family members may also be affected. The importance of AAC and its relationship to a child's disability may need to be understood by all family members.

Recommendation 3

Professionals should be aware that every child with a disability has unique needs. Similarly, each family member has individual expectations, traditions, values, and hopes for all interventions, including AAC.

Recommendation 4

Professionals should identify the child's communication needs in the home, school, and community. This requires more coordinated and comprehensive approaches than historically used.

Recommendation 5

Professionals should be able to recognize differences and strengths in families. This includes the communication styles of persons from varying ethnic backgrounds, and identifying the different priorities, preferences, and realities within each. Such an understanding will enhance family and professional relationships during AAC decision-making.

Recommendation 6

Professionals should spend time with each family member before discussing the AAC intervention. This serves to establish comfort, rapport, and trust.

Recommendation 7

Professionals should become competent in implementing ethnically sensitive action plans. These should use multi-language materials (including symbol sets), and employ persons from non-dominant cultures, when necessary, to help design the AAC strategies.

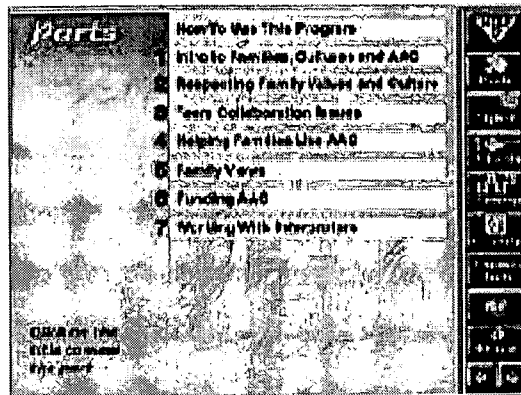
CD Development

The primary product of this project was a new interactive multimedia educational tool designed for AAC planning from a family perspective. The *Families, Cultures and AAC* CD focuses on family and cultural issues related to augmentative and alternative communication (AAC) devices, though it has potential broad implications for a wide range of assistive technology devices.

Unique features have been built into the CD which are not often found in other information and training multimedia products. Figure 1 presents a number of key components of the CD. The CD can be used in many ways: as (a) a tutor, (b) a decision-making tool when working on teams, (c) learning games, (d) an encyclopedia on AAC, and (e) a research tool. This program contains video vignettes of family members from five different cultural groups who express their thoughts and feelings about aspects of the assistive technology decision-making process. Interactive games are also available to provide alternative means of accessing information and to reinforce concepts and content presented. The program incorporates Universal Design features including information redundancy, multiple strategies for expression and control, and multiple options for engagement and motivation. In addition, the program represents one of the first multimedia programs in special education that provides for bi-lingual access. Narration and essential program features are provided in English and Spanish - a simple click of a button switches language modes.

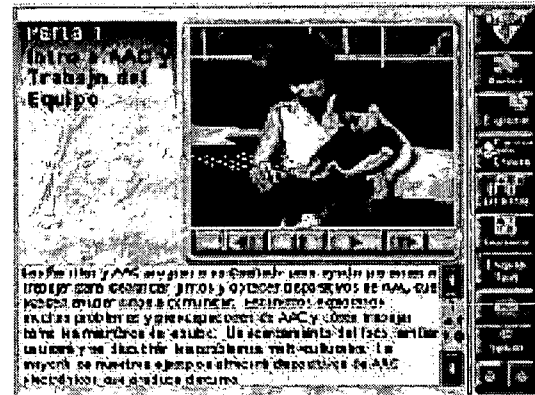
The CD also includes research materials that may be of interest to personnel in higher education and clinical settings (see <http://cstl.semo.edu/palette/homepage/database.pdf>). These include focus group transcripts, an AAC knowledge base, instruments used in collecting data from families and related service personnel, and a concept paper.

FIGURE 1. SELECTED COMPONENTS OF CD.



Content is organized into eight chapters of Parts.

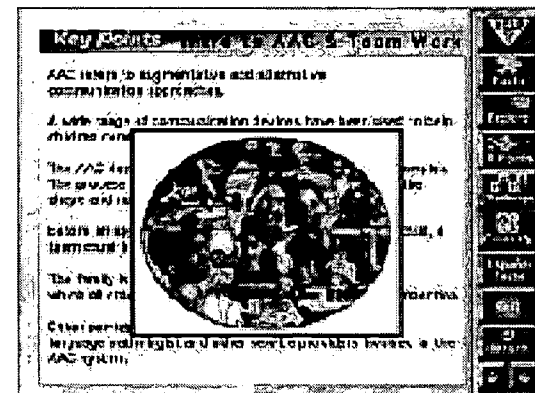
Families, Cultures and AAC Augmentative and Alternative Communication



Digital videos can be easily controlled by the user. Audio narration is synched with text in English or Spanish.



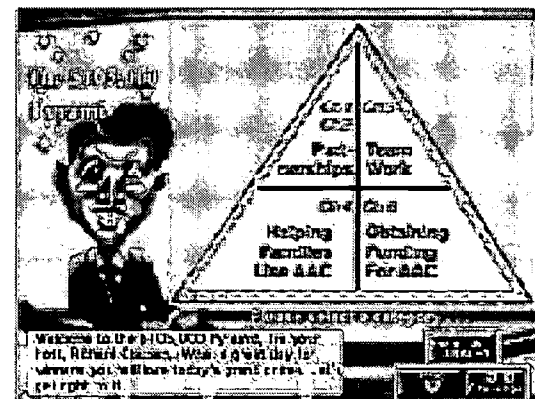
Information is presented in interactive exhibited formats.



A multimedia Glossary, Topic Index, and Key Points are available for review and supplementary information.



Challenge activities present opportunities to review and test your knowledge in game formats.



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ABSTRACT

1

This project was one of 22 Special Projects funded in 1995 and was designed to develop decision-making strategies and materials related to the prescription of AAC devices for children with disabilities. It was also designed for use as a training media for related services personnel and family members.

Little attention has been given by related services personnel (e.g., speech/language pathologists, occupational therapists, physical therapists, technology specialists) and vendors to the impact of AAC devices on family functioning and cultural diversity prior or subsequent to the introduction of devices (e.g., demands placed on families to attend training sessions, stress and changes in routines which may result, cultural values and their relationship to AAC prescription). This can result in the provision of inappropriate AAC devices.

The Project resulted in the development of the first interactive bilingual CD-ROM designed to be used by related services personnel (at the pre- or in-service level), vendors, and family members from diverse cultures to develop competencies that assist in effective AAC decision-making. The instructional materials will: (a) provide information and multimedia vignettes designed to sensitize related services personnel to child, AAC device, family/social, cultural, and system issues prior to the selection and use of AAC devices; (b) provide structured procedures and checklists to use during the planning, implementation, and evaluation of AAC devices; and (c) provide simulated practice in the use of the procedures. These interactive materials will assist personnel in schools, state, federal, and private agencies and organizations to more effectively serve children with disabilities and their families. They will also enable service providers to make the most appropriate decisions about the prescription of AAC devices while balancing child, AAC device, family, cultural, and system resource considerations.

The project objectives were achieved through activities during three phases. **Phase 1** involved identification of critical AAC family and cultural impact variables using a range of information-gathering approaches: an Expert Panel, a Family Advisory Panel, literature reviews, and focus groups. Groups conducted in five states using families from various cultures, vendors of AAC devices, and related services personnel. *Family concerns* generated through

focus group findings centered around three themes: (a) How do families want professionals to build family-professional partnerships? (b) How do families want professionals to demonstrate respect for family values and ethnicity? and (c) What can professionals do to help families learn how to use AAC devices? Professional concerns identified in focus groups centered around the following themes: (a) What are the communication styles needed by professionals and family members to build family-professional partnerships? (b) What is the responsibility of professionals to address family information needs? (c) What values should professionals and families acknowledge in working together on teams? (d) What teaming skills should professionals demonstrate in working with families? and (e) What do professionals and families want regarding AAC implementation and training?

Phase 2 involved development of a draft version of the interactive AAC training materials, creation of initial versions of the materials, alpha testing in urban and rural field sites, and creation of a prototype CD-ROM.

Phase 3 involved mass production and widest dissemination of the training materials along with multifaceted training activities nationally. A total of 500 copies of the CD were distributed nationally to targeted individuals and groups, including Part B and C Coordinators, Parent Training Institutes, Alliance for Technology Access Centers, Tech Act Projects, the American Speech-Language-Hearing Association (ASHA), the American Occupational Therapy Association, the American Physical Therapy Association, and AAC practitioners who were members of the ASHA AAC Special Interest Group.

INTRODUCTION & REVIEW OF LITERATURE

2

The purpose of this section is to provide information related to the preliminary phase of the project, i.e., identification of critical AAC family and cultural impact variables. Comprehensive reviews of the existing AAC and related literature were conducted in the Spring and Fall of 1995, and Spring of 1996. These literature reviews culminated in the creation of an online document containing a variety of project documents (see: <http://cstl.semo.edu/palette/homepage/database.pdf>; VanBiervliet & Parette, 1999). The following section presents selected literature from these sources, as well as more recent literature, to provide the reader with a rationale for CD development.

Related Literature: Family Involvement

Family involvement is both a *philosophical* and *legally mandated* underpinning of the field of special education. In recent years there has been a shift away professionally dominated decision-making practices in which professionals have traditionally defined the type and nature of services for children and families towards family-centered decision making (McBride, Brotherson, Joanning, Whiddon, & Demmit, 1993). Family-centered decision-making emphasizes the role of families, in which family expertise is recognized, supported, and nurtured in a collaborative partnership with professionals (Dunst, Trivette, & Deal, 1994; Winton & DiVenere, 1995).

Concern for sensitivity to family ethnicity has called attention to the growing need to have the "voices" of families heard during educational decision-making. (Dennis & Giangreco, 1996). Voice implies meaningful input by family members, and requires professionals to listen to family needs, concerns, and priorities when identifying and developing appropriate educational interventions for children with mental retardation and developmental disabilities and their families.

When family members collaborate with professionals, there is a recognition that (a) the family is the constant in the child's life, while services and professionals within the system are always in a state of flux (Parette, 1995;

Shelton, Jeppson, & Johnson, 1987); and (b) service recommendations are flexible, accessible, and responsive to family needs (Angelo, 1997; Bradley, Parette, & VanBiervliet, 1995; Parette & Brotherson, 1996; Shelton et al., 1987).

The involvement of families is particularly important with regard to assistive technology decision-making. When family members are involved in decision-making regarding assistive devices, there is a greater likelihood that they will perceive ownership of the interventions planned (Angelo, 1997; Beukelman & Mirenda, 1992; Parette & Angelo, 1996). Family participation can result in greater satisfaction with devices prescribed and increased parent-professional collaboration (Crais, 1991).

AAC Decision-Making and Family Involvement

Because many children with disabilities in early intervention and public school settings have communication disorders, augmentative and alternative communication (AAC) systems are frequently prescribed for children with disabilities and their families. An A/C system is an “integrated group of components, including the symbols, aids, strategies, and techniques used by individuals to enhance communication.” (American Speech-Language-Hearing Association, 1991, p. 10) Aids which are frequently used include low-tech (e.g., communication boards and notebooks) and high-tech (electronic) devices. Of particular importance are electronic AAC devices which use synthetic or digitized speech output, allowing children with disabilities to communicate with their family and individuals in school and community settings.

Historically, families have not been part of a collaborative process of identifying appropriate AAC devices for their children (Parette, 1996). When family members are not involved in AAC decision-making, important family issues may not be addressed, resulting in the prescription of inappropriate devices (Parette & Angelo, 1996; Parette & VanBiervliet, 1995). For example, if the commitment of family time required to implement an AAC device is not discussed with the family before the device is given to the child, there may be unwillingness for family members to commit time to learning to use the device if changes in family routines and stressors result. For some families, this can result in abandonment of recommended intervention strategies that incorporate use of the AAC device (Batavia et al., n.d.; Dillard, 1989; Phillips, n.d.). Abandonment may also occur when families become intensely committed to implementation of AAC devices. For example, families of children with severe disabilities may not have the necessary training to “teach” their children how to use the device, yet expend great amounts of time in attempting to help their children use the devices. When children are unsuccessful, family members can become frustrated and opt to abandon AAC devices for low-tech communication systems (e.g., eye-gaze boards) with which they are already comfortable. Professionals also have obligations to the family (e.g., provision of appropriate supports and training, providing information) to ensure that

abandonment does not occur. Abandonment of an assistive technology device may have potentially far-reaching implications including (a) an exacerbation of the effects of disability experienced by the child who could benefit from the device (Brody & Ruff, 1986), (b) excessive personal and financial costs for families (Lubosky, 1993), and (c) inefficient use of finite service system resources (Bradley et al., 1995).

AAC Decision-Making and Ethnic Sensitivity

The importance of learning about the value systems and lifestyles of persons from various ethnic groups is undisputed in our field (Barrera, 1993; Greenberg, 1992; Harry et al., 1995; Huer, 1994; Lynch & Hanson, 1992). Ethnicity exerts a strong influence on the way in which professionals behave toward family members when providing services, and in the manner that family members perceive and respond to these services (Misra, 1994). Without ethnic awareness, professionals cannot begin to appropriately serve children and families from various ethnic backgrounds (Hetzroni & Harris, 1996; Huer, 1997b).

However, it has been recognized that family members from various ethnic groups (e.g., African, Hispanic, and Asian Americans) are often less informed about and participate less in special education processes than family members from Euro American backgrounds (Bennett, 1988; Harry, 1992; Lynch & Stein, 1987). A lack of respect for ethnically diverse families can result in alienation of these family members from participation in such special education processes as AAC decision-making (Harry, 1992, Huer, in press; Parette, Brotherson, Hoge, & Hostetler, 1996). Inappropriate selection and/or abandonment of AAC devices may occur more frequently if ethnic factors are not considered during AAC decision-making processes (Parette, 1998).

While some professionals might argue that the field of special education is already quite sensitive to ethnic issues when providing intervention services, in practice there is still a significant gap between what is recognized as "best practice" and what is implemented in service systems, particularly in assistive technology decision-making processes (Parette & Hourcade, 1997). Ethnic understanding is typically accepted as being vital to an expanded view of AAC assessment processes that are family-centered, though recent surveys of states indicate that families of children with disabilities are more passive participants in AAC decision-making processes, and ethnic issues are less frequently considered than more traditional factors (Parette, 1995; Parette & Hourcade, 1996, 1997). This may be due to lack of referrals to knowledgeable professionals who understand the AAC decision-making process. Thus, growing professional recognition of the importance of ethnic sensitivity in AAC decision-making for children and families (Hetzroni & Harris, 1996; Parette, 1995; Soto, 1994; Soto, Huer, & Taylor, 1997) provides impetus for a closer examination of the role that ethnically diverse families desire to play in AAC decision-making, and what they expect of professionals. This does not overshadow the importance of self-determination and the active role of the child with a disability

in the process (Brown, Zager, Brown, & Price, 1998), but underscores the importance of providing families with a greater “voice” in such decision-making processes.

Related Literature: Professional Perceptions of Team AAC Decision-Making

Team participation in the development of child and family service plans has been widely discussed in the professional literature (cf Cramer, 1998; Fishbaugh, 1997). Team responsibilities for identifying specific intervention and related services, such as appropriate assistive technology devices and services, have also been described (Inge & Shepherd, 1995; Judge & Parette, 1998). With the recent passage of *The Individuals with Disabilities Act Amendments of 1997* (P.L. 105-17), the federal government asserted the importance of considering a child’s communication needs in stating that the team should consider “the communication needs of the child...[§300.346 (2)(iv)] and “whether the child requires assistive technology devices and services” [§300.346 (2)(v)]. Since assistive technology devices and services have become more frequently considered for children with disabilities during service plan development, greater attention has been directed toward individual team member responsibilities for identifying targeted assistive technology devices.

The literature has addressed both professional responsibilities (Mann & Lane, 1995) as well as family responsibilities (Angelo, 1997; Cramer, 1998; Judge & Parette, 1998) in assistive technology team processes. Current “best practices” in special education have moved towards more family-focused and family-centered team approaches (cf Baird & Peterson, 1997; Angelo, 1997), with emphases on diversity and cultural issues (see e.g., Harry, 1992; Makas, Marshall, & Wehman, 1997). Such sensitivity is an important consideration in assistive technology decision-making processes (see Huer, 1997b, 1997c; Parette, 1998).

Despite the philosophical acceptance of family-centered, culturally sensitive strategies, many professionals persist in employing “helping approaches” (McGonigel & Garland, 1988) when working with families to identify assistive technology devices and services. To “help” families professionals may still simply (a) have family members complete questionnaires that deal with family assistive technology needs and support networks (Bailey & Simeonsson, 1985; Trivette, Deal, & Dunst, 1986) or (b) rely on professional observations of devices parents have had success with in the home setting (Parette, Hourcade, & VanBierliet, 1993). In a survey of state practices, Parette (1995) found that many states presently involve families in more passive roles (e.g., information provider, trainer) during assistive technology assessment processes than in the active roles they may assume during IFSP and IEP service plan development activities. When teams rely on professional input as the primary source of information in the decision-making process, dissonance between the family’s and professionals’ priorities and insights may occur (Turnbull & Turnbull, 1985).

Teams and Augmentative and Alternative Communication

During team decision-making processes, augmentative and alternative communication (AAC) devices are often considered for children with mental retardation and other developmental disabilities. Historically, related services personnel such as speech/language pathologists have assumed primary responsibility on teams for identifying “appropriate” AAC devices for children with disabilities. As noted by Garshelis and McConnell (1993): “For many years professionals have determined goals for families with children who have handicaps based solely on their own assessments of family needs.” (p. 37)

Even in professional textbooks there is still an undertone suggesting the primary importance of professional insights and knowledge during team decision-making (see e.g., Harris, 1994). Interestingly, professional perspectives are often not shared by family members, particularly those from other cultures (Soto, Huer, & Taylor, 1997). However, many professionals continue to assume primary responsibility for AAC decision-making.

METHODS OF GATHERING INFORMATION

3

Sources of Information

Prior to developing the interactive CD-ROM between 1997-99, focus groups and structured interviews were conducted with families from a variety of cultures to understand their issues, their voice, regarding ACC decision making. Three additional sources of information were also used to identify and clarify critical AAC family and cultural impact issues. These included literature reviews, expert panel, and family advisory panel. Each of these sources informed the development of the family interview protocol and the analysis of family interview data.

Focus Groups and Structured Interviews

To provide families across cultures with a “voice”, or the opportunity to articulate their perceptions of their roles in AAC decision-making and expectations of professionals, focus groups (Bogden & Biklen, 1992; Brotherson, 1994; Glesne & Peshkin, 1992; Morgan, 1988) or structured interviews (Johnson & LaMontague, 1994; Patton, 1990) were conducted at five targeted sites nationally (California, New Mexico, Arkansas, Missouri, and Illinois) during the Fall of 1995 and Spring of 1996.

Focus groups or structured interviews were used to gain a holistic understanding of AAC assessment and prescriptive practices for children with disabilities and their families and to increase professional understanding of the diverse issues facing families and agencies serving them (Krueger, 1988). Families provided a “real life” understanding of the critical concerns, problems, ideas, and strategies that bear on the issue of AAC assessment and prescriptive practices.

Literature Reviews

An additional source of information used for protocol development and data analysis organization was comprehensive reviews of existing literature in each of the following areas: (a) impact of culture on service delivery to children with disabilities, (b) family-centered intervention, (c) team processes and decision-making, (d) assistive technology impact on children with disabilities, (e) family involvement in AAC assessment and prescriptive practices, and (f) multimedia training approaches. Literature reviews contributed to the development of a protocol of questions which were formally presented to participants. A comprehensive compilation of these literature reviews has been archived elsewhere (see <http://cstl.semo.edu/palette/homepage/database.pdf>).

Expert Panel

A panel of national authorities provided guidance and evaluative input during the initial phase of information-gathering by reviewing the knowledge base generated by literature reviews and Focus Groups and structured interviews. Expert Panel members included Drs. Sarah Blackstone (*Augmentative Communication News*), Dianne Angelo (Bloomsburg University of Pennsylvania), Corine Myers-Jennings (*Valdosta State University*), and Sharon Glennen (*Kennedy Krieger Institute*). On receipt of the CD-ROM *Concept Paper* and *CD-ROM Knowledge Base*, members were asked to examine the documents for content. Recommendations regarding the organization of the knowledge base and organization of the CD-ROM training materials were subsequently provided. The use of an Expert Panel was deemed to be a powerful strategy to insure that project activities and product development reflected current “best practices” in the field of AAC service delivery and cultural diversity issues.

Consumer Advisory Group

One person from each Focus Group site was invited to participate on a Consumer Advisory Group, thus ensuring that families had a “voice” in the process. Focus Group Moderators at each of the five participating sites identified potential Advisory Group members included families from Arkansas, Missouri, Illinois, and New Mexico. These individuals included family members of children across cultures who used AAC devices. Advisory Group members were provided with an honoraria for their evaluative contributions regarding the development of the knowledge base, interview data summaries, and initial design of the CD-ROM training materials.

Interview and Focus Group Participants

Speech-language pathologists at five arbitrarily targeted sites (i.e., California, New Mexico, Arkansas, Missouri, Illinois) were invited to participate as Focus Group Moderators during the 1995-1996 academic year. They included Dr. Mary Huer (*California State University-Fullerton*), Dr. Debbie Hoge (*Southern Illinois University-Edwardsville*), Dr. Sheela Stuart (*New Mexico State University*), Sheila Hostetler (*St. Louis Children's Hospital*), and Nancy Dunn (*Arkansas Easter Seal Society*). These professionals (a) had been identified by the American Speech-Language-Hearing Association as having national visibility/expertise in the area of AAC interventions with ethnic groups, or (b) were known to the principal investigator as having extensive experience in AAC decision-making with ethnic populations.

In the Fall, 1995, each of the moderators was trained by Dr. Mary Jane Brotherson, a faculty member at Iowa State University and national expert skilled in focus group/structured interview methodologies. Ethnic sensitivity issues were discussed during moderator training to increase awareness of specific strategies that might need to be employed at each site when working with families.

Moderators at each site invited participation of family members if they were: (a) parents or primary caregivers of children who had been evaluated for an AAC device, but had not yet received a device; (b) parents or primary caregivers having children who had already received an AAC device; (c) family members of children with disabilities, but who had not been identified as needing AAC devices; and (d) willing to be videotaped. Family members of various ethnic groups who had children with disabilities (but who had not been identified as needing AAC) were included to more fully understand the values and needs of families working with professionals during team decision-making. Participation of families with and without AAC devices were deemed to be important since the perceptions of family members often vary prior to and after receipt of assistive technology devices (Parette, Brotherson, Hoge et al., 1996). Ethnic diversity was ensured through representation of Native American, Hispanic, Asian, and African American families in the focus groups conducted in New Mexico and California. African American and European American family members from urban regions participated in focus groups and structured interviews conducted in Arkansas, Missouri, and Illinois.

Additional focus groups were held at some sites to include representatives of related services personnel (S/LPs, paraprofessionals) and vendors of AAC devices. This included professionals having regular and ongoing involvement in AAC assessment and prescriptive processes, and intervention, as well as, sales representatives or training coordinators for major AAC device manufacturers that provide training in the use of a specific device for families. The following section will report demographic data collected from both family members and professionals.

Demographics

A total of 88 individuals participated in all of the focus groups and structured interviews across the five national sites (California, $n=35$; Missouri, $n=23$; New Mexico, $n=12$; Arkansas, $n=9$; Illinois, $n=9$). Five different types of groups were represented across the five sites, including families of children with AAC devices ($n=21$; 23.9%); and families of children without AAC devices ($n=11$; 12.5%), multicultural ($n=19$; 21.6%), vendors ($n=6$; 6.8%); related service personnel ($n=31$; 35.2%). All families completed demographic information sheets prior to participation in focus groups/structured interviews.

Age

Participants across all groups ranged in age from 24-70 years, though most participants tended to be 40 or more years of age ($M=41.5$ yrs.).

Education

Educational levels of participants varied markedly, ranging from no education to 9 years of college, though participants tended to be better educated ($M=15.5$ yr.).

Marital Status

Most participants were married ($n=49$; 55.7%), though a substantial number had never been married ($n=17$; 19.3%). Only 9 participants reported being divorced (10.2%) and 8 indicated that they were separated (9.1%). Two of the participants reported being widowed (2.3%) and one indicated that they resided with a live-in partner (1.1%).

Ethnicity

Diversity in the participant pool was reflected in the spread of representation across cultural groups. Euro Americans represented a the largest single group ($n=40$; 45.5%), followed by African Americans ($n=15$; 17%), Asian Americans ($n=13$; 14.8%), Hispanic Americans ($n=9$; 10.2%); Native Americans ($n=7$; 8%); and other cultural groups ($n=4$; 4.5%).

Employment

A range of employment-related roles were reported by participants: part-time workers ($n=13$; 14.8%); full-time workers ($n=46$; 52.3%); homemakers ($n=10$; 11.4%); unemployed ($n=7$; 8%); part-time student ($n=2$; 2.3%); full-time student ($n=9$; 10.2%); and disability ($n=1$; 1.1%).

Socioeconomic Status

Reported income levels for participants were reported as follows: <\$4,999 ($n=16$; 18.2%); \$5,000-9,999 ($n=4$; 4.5%); \$10,000-14,999 ($n=5$; 5.7%); \$15,000-19,999 ($n=6$; 6.8%); \$20,000-39,999 ($n=12$; 13.6%); \$40,000-59,000 ($n=13$; 14.8%); >\$60,000 ($n=27$; 30.7%).

Professional Roles

Professionals who participated in focus groups ($n=47$), included 18 speech/language pathologists (43.9%), 6 vendors (14.6%), 1 physical therapist (6.3%), 1 occupational therapist (6.3%), and 15 paraprofessionals (36.6%).

Instrumentation

Protocol

Based on literature reviews which suggested potential areas of concern related to AAC decision-making, an interview protocol was developed for use with each focus group and structured family interview (see *Revised Focus Group Protocol and Instrumentation* at <http://cstl.semo.edu/parette/homepage/database.pdf>). Pre-identified probe questions were presented to groups and individuals at the five participating sites. Moderators were trained to be sensitive to issues that might emerge during discussions that deviated from the probe questions. Some focus groups and structured interviews went into more depth with issues specific to them; however, in most instances the interviews were guided by the broad probe questions.

AAC Impact Questionnaire

Prior to participation in each focus group or structured interview, project staff asked participants to complete a questionnaire that addressed child, family, and service system issues related to AAC decision-making. This questionnaire paralleled the broad probe questions posed to interview participants, providing an opportunity for triangulation of findings from analysis of transcripts. The questionnaire also allowed for open-ended elaboration on particular questions (see *Revised Focus Group Protocol and Instrumentation* at <http://cstl.semo.edu/parette/homepage/database.pdf>).

Data Collection

The focus groups and individual interviews were arranged and conducted by the project Moderators at each of the five national sites. The Moderators were aware of the need to be culturally sensitive and were responsive to the unique cultural needs of each interview. Moderators were asked to: conduct 1-2 hour interviews, audio tape the interviews for transcription, videotape the interviews

for additional data and CD-ROM production, ask participants to complete questionnaires, and secure consent forms.

Preparing for Data Collection

Each Moderator prepared in different ways to conduct the interviews. In several cases the researchers worked through community liaisons or advocates to develop trust and rapport to gain entrance into the community. In some cases an interpreter was used. Moderators were attentive to such cultural symbols as colors worn; in a large inner city colors could not be worn that were used by gang members, on a Navaho reservation, colors also had special meaning. Interviews were arranged that were at times and locations convenient for family members. In a Hispanic interview, many families took off work and viewed the interviews as an all day affair with special ethnic foods served. In an Asian community interview, family members desired a shorter interview that started on time and was focused on the task at hand. Researchers were respectful of the time, space and reciprocity issues for each cultural group. Many families received a small stipend or gift certificate for food.

Changes in Data Collection Process

Researchers balanced the need to maintain adequate research stability and integrity of protocol and procedures with respect for difference in family culture and comfort levels. It was a balance between gaining the family voice with the research agenda. Not all families were comfortable with focus groups. In these cases, individual interviews were conducted. In Euro American interviews, for example, family members were more comfortable with demographic and AAC questionnaires. In other families, they were fearful of "government" and were less comfortable with giving demographic information or completing questionnaires. For example, on a Navaho reservation one researcher spent several hours developing rapport and trust and was honored to be invited into a home for an interview. In this situation videotaping and extensive questionnaires were not appropriate. In some situations, researchers felt that questionnaires put a damper on participant willingness to speak; in these situations they reduced the amount of paperwork and began the interviews with giving families an opportunity to "tell their story." Interviews and focus groups ranged from 1-2 hours in length.

Data Analysis

Data analysis was continuous so that an emergent design could respond analytically to what was heard from subsequent interviews. Interviews were transcribed and content analyzed simultaneously as the issues and themes emerged from the family voices (Johnson & Montagne, 1992; Patton, 1990). Issues of credibility of data were addressed to enhance rigor of design

(Brotherson & Goldstein, 1992). Credibility addresses the issues of integrity and congruence between constructed realities of the families and those realities represented by the research team and attributed to the families (Guba, 1981). Three techniques were used which are described below: triangulation of data, member checks, and identification of themes.

Triangulation of Data

This involved bringing more than one source of data and more than one researcher's perspective to bear on understanding the issues and perspective of families. Focus group and individual interviews, questionnaire data, multiple researchers, a panel of nationally recognized experts in the field of A/C (recommended by the American Speech-Language-Hearing Association and having clinical and research backgrounds in A/C service delivery), a consumer advisory group of family members representing the various participating sites, and videotapes were used to corroborate data. The perspectives of eight researchers/moderators and assistant researchers were involved in conducting interviews and analyzing data. The questionnaire data supported the interview findings (Interview findings are archived at: <http://cstl.semo.edu/parette/homepage/database.pdf>).

Member Checks

This is a recurring process of presenting information and interpretations to family members for discussion in a process that draws the families into checking the credibility of research and ultimately its application. The consumer advisory group was used for member checks and gave feedback and reflection on the findings of the study (e.g., Does this summary reflect what you think was said? Do you have any additional comments?). Member checks resulted in clarifying several concepts into more family-centered perspectives.

Identification of Themes

Following established qualitative analysis procedures (LeCompte & Preissle, 1993; Patton, 1990; Tesch, 1990), project staff began by reading and rereading the transcripts to identify major themes or issues for families. Five levels of analysis were then performed:

- 1 A first researcher read transcripts. Major themes and issues in "synthesis statements" were written in the margins of transcripts.
- 2 A second and third researcher read the transcripts and validated the original "synthesis statements." These researchers could also add issues or identify additional themes. If there were any points of disagreement, they were discussed and transcripts reviewed until consensus was reached.
- 3 The "synthesis statements" were used to identify the *major themes* and issues for understanding AAC decision making from an ethnic perspective. Some of the initial issues that emerged were broad (e.g., time issues,

professional responsibilities, extended family involvement, support groups, transportation, training).

- 4 In an ongoing process, interviews were conducted, reread, and compared to the initial themes and issues observed so that continuous feedback could divide, merge, or create new themes in a “constant comparative method” (Glaser & Strauss, 1967). Issues were organized and integrated into three major themes that emerged.
- 5 Last, after reaching a point of saturation (no new themes or issues emerging), the themes and issues of AAC decision-making were presented to the consumer advisory group for feedback.

Themes for all Focus Groups and structured interviews are archived both on the CD and at <http://cstl.semo.edu/palette/homepage/database.pdf>.

Results from Family Focus Groups and Structured Interviews

The results are presented in three themes that were identified in the analysis of data. The three themes address the broader question of the study, *What do families of different ethnic backgrounds want professionals to know about AAC decision-making?* More specifically the themes answer three related questions: (a) *How do families want professionals to build family-professional partnerships?* (b) *How do families want professionals to demonstrate respect for family values and ethnicity?* and (c) *What can professionals do to help families learn how to use AAC devices?* The results are organized according to the three major themes identified.

Theme 1: *Building Family and Professional Partnerships*

Family and professional partnerships can enable families from different ethnic backgrounds and professionals to work together in pursuit of shared goals. Partnerships must be built on trust, and recognize the strengths and capabilities of each member of the partnership. Two major issues emerged for families regarding how they want professionals to build family and professional partnerships: communication and team decision-making.

Ethnicity can influence the content and process of communication. The communication issues raised in this study focused on the general need for clear, accurate, trustworthy, and straightforward communication. Many families spoke of the need for professionals to minimize jargon and be honest in their communication. If professionals are uncomfortable about using an AAC device or must learn how to use the device themselves, they should communicate this to family members. Many family members also wanted clear communication regarding such issues as ownership of AAC devices, repair periods, and waiting periods for initial receipt of devices. As one mother stated:

Yeah, when they first told me about it I had to fill out tons of paper work. It took about half of a school year for me to actually get it. First of all, I didn't know who was authorizing her to get it. This had to be authorized through somebody in special school district. I didn't know who to call to inquire about it, the teachers totally took control of the whole thing and took it away from me when she got it. It just arrived, the teacher told me about a week later that they had the Liberator (an electronic communication device) and I was really upset about that and I wanted the books and the Liberator right then and they told me no. It's gonna take us about a year to learn how to use it. We gotta keep it at school for about two or three weeks and learn how to use it. I was really upset about that. I had to call the company to find out how much it cost, who funded it, who funded my daughter for it. How did she even get it. You know it was a total breakdown from that point.

Families face a multitude of decisions when they have a child with disabilities. In team decision-making, families wanted to be key in providing information during the assessment process. Families wanted professionals to recognize that their child may refuse to participate in evaluations by new team members. They wanted professionals to establish rapport with their child prior to assessment and adapt procedures where necessary. Families indicated the importance of their role in evaluations and wanted professional to recognize their recommendations were based on short-term contact with the child, versus the lifetime contact of the family. Families discussed the importance of considering the opinions of the elder members and extended members of the family, of inviting them to the assessment. One African American mother stated:

A lot of times professionals are looking at the mother and father and not understanding that the parent is going back and asking their mothers or fathers what do you think about this. So there are a lot of people in the background who are in this discussion when the parent is going to be the person who will tell you the decision.

Families indicated they wanted information regarding the time lines of the AAC device assessment process and they hoped professionals were clear that insurance companies base decision on evaluation information provided by teams. Families did not want the AAC device to be taken away after the child had hands-on experiences and showed a preference and ability to use a device. They wanted the team to ensure that their child would have continued access to the AAC device from time of rental to actual delivery to the family. Families indicated they wanted professional recommendations to be based on objective, not subjective, experiences and they did not want the AAC device to be selected for use by many children in lieu of individualizing selection of a device to meet the needs of one child and family.

Theme 2: Respecting Family Values and Ethnicity

Respecting family values and ethnicity is key to becoming family-centered and ethnically competent. How do families want professionals to demonstrate respect for family values and ethnicity? Child specific issues and family systems issues emerged in this theme.

Child Specific Issues

Families wanted professionals to show sensitivity to the child specific issues of ethnicity and disability. They wanted professionals to show sensitivity to terminology when discussing their children and to see their child as a unique individual and not discuss their child in reference to a particular group of children. They wanted professionals to show greater sensitivity to the symbols used in communication devices, avoiding stereotyping of color and symbols. For example, the color black may be used to denote "wrong" or "bad." Family members from the Navaho wanted symbols and colors that were appropriate to their clan. The most important sensitivity issue discussed by family members was the issue of stigma. Families wanted professionals to be sensitive to the "double stigma" sometimes associated with being a member of a minority group and having a disability. Parents spoke of not wanting to draw "even greater negative attention" to their child. One mother shared, "How is the world going to perceive my child being an African American and also handicapped. That's like two negatives when you deal with a big society that doesn't look very positively upon African Americans."

This issue of stigma was closely tied to the need to have their children accepted into the community and accepted into peer groups. One mother stated:

Sometimes I think we forget to apply regular kid things to our kids. I mean people forget to do that. Think about a regular kid, they all, at certain ages want to be just like their friends. They want to wear the same kind of clothes; the same kind of tennis shoes. They want to talk the same, act the same. Our kids are not different, they want to fit in and be part of the gang.

Another mother shared:

I truly believe it goes back to the fact that even though she's in a wheelchair and she's strapped in and has problems with head control, that it is the device [an Alpha Talker, marketed by Prentke Romich Company] that makes her feel and appear different.

Family System Issues

The collectivist orientation of many minority families means that AAC decision making must consider and support the needs of extended family and siblings. Many parents spoke of how siblings were affected in both positive and negative ways that changed family interactions. One parent shared:

I can remember every cousin, every aunt, we all went over to my aunt's house when Walter got his wheelchair. That was our sole purpose for going over there - to see Walter in his wheelchair. So I think that would be the same thing if someone in my family got an augmentative device.

Families also wanted professionals to be sensitive to the demands, needs, routines and realities of family life. One parent stated her concern that she be involved in the decision making so that her knowledge of home and family routine could be considered:

One of my concerns in starting out was that they would listen to my ideas... so I could tell them the kinds of things that I felt Jennifer liked and didn't like and

the kinds of things that I felt would work at home and that we could manage at home.

Issues such as transportation of the device, space for the device, maintenance of the device were all important concerns for families. One parent said she had to purchase a bookcase to put all the materials, manuals and batteries into for safe keeping.

One mother shared her concerns:

I'm concerned it takes some learning and a definite level of maintenance to keep his device [an IBM compatible computer with Words Plus software] up and running, the switch has to be positioned correctly, the device has to be turned on for him, and hooked up for him, the battery pack needs to be charged, the batteries don't hold, he runs out of batteries, so there are definite concerns.

Another parent shared:

Gotta plug the wheelchair up every night. She reminds me every night. I cannot forget. If you forget it's inoperable the next day. That bugs me. It should at least be able to go two or three days without being plugged up.

Several parents also described the issue of transportation. One parent shared her concern:

The biggest concern I have right now is the weight of the device [Dynavox]... He couldn't have begun to even push the thing across the table, more or less carry it from room to room. We didn't even send it back and forth to school because it was so heavy. I was afraid. I just didn't do it.

Theme 3: *Helping Families to Use AAC Devices*

Another theme that emerged from the interviews was the great need families had for information and training on how to use the AAC device with their child and within their family. Families wanted more information regarding specific information on AAC devices including the range of devices available, critical features of devices, support from vendors, funding process, and warranties. Some families wanted the support information and training materials to be in Spanish or their native language. Other families discussed the need to be connected with other families or parent support groups to gain information and support. One parent shared:

I would do anything to get support from someone who's in my shoes. If I could have somebody to guide me and help me, boy I would have thought that was great. I would love to help somebody else along. Just helping other parents and telling other people what I've been through...

Parents needed information on the varying levels of support and information from vendors, and what to expect from vendors.

Families also wanted training on how to use specific AAC devices. They wanted this training for themselves and other extended family members. They wanted to watch other children using similar devices prior to purchase. They wanted to be provided hands on experiences for themselves and other children

and family members. They wanted this support prior to purchase and then again after purchase. They wanted professionals to show sensitivity to the family's need for repeated training sessions in order to learn to use the AAC device effectively. They also wanted professionals to show sensitivity to the inordinate amount of time families must wait to receive toll-free technical assistance callbacks from vendors. One parent shared that:

...the programming of it [Dynavox] was unbelievable. The rep says that technically we're supposed to get four hours of training and he still says that's not enough. Well, when he said that ... I thought I'm not prepared for this at all... Programming everything in is going to be totally overwhelming and will take lots and lots of time.

The three themes are further interpreted in the context of five general issue areas which are presented in Table 1.

General Information Form: Desired Services

Summary responses for the *General Information Form: Desired Services* are presented in Table 2. As can be seen, mean years of education varied between the two groups (Professionals=17.5 yrs.; Family Members=~10 yrs.). Differences existed between the two groups with regard to perceptions of types of services families would find helpful to assist them with AAC devices.

Almost 2/3 of the professional respondents indicated that *legal information* about AAC in schools would not be helpful, whereas approximately the same number of family members rated such information as needed. Professionals tended not to rate *assistance in helping families to be more active in the AAC process* as a need for families, while a majority of family respondents rated this highly. Professionals felt *liaisons* between the school and family were less important than did family members. While families felt that *parent training* in communication skills was very important, professionals seemed to be split on their perceptions. Both professionals and families tended to agree on the importance of having *information regarding the range of AAC devices* during AAC decision-making. Families also ranked information regarding *financial resources* for AAC devices much higher than professionals. Interestingly, ratings on the *need for lending programs* appeared to be mirror images: professionals did not view such services as important, while families felt such services were important. Professionals appeared to be split on the perceived importance of *networks of family members* who use AAC devices, while family members once again felt that such services would be very important. Most professionals felt *support groups* for families were not important, while most families perceived a need for these services. Professionals tended to be split (about 50%) with regard to the perceived need for *training in use and maintenance*, while 2/3 of family members believed such services were needed. Both professionals and family members tended not to feel that *siblings need assistance* in coping with stress. Both groups agreed that *other services* not identified on the form were needed.

AAC Impact Questionnaire

Presented in Table 3 are summary findings of completed *AAC Impact Questionnaires* for both professionals and family members. Professionals and family members appeared to agree that *families have AAC goals/expectations before receiving a device*. While there was disagreement among professionals whether *goals might change* after receipt of devices, families tended to feel that goals did not change. Both professionals and family members had concerns regarding *training*, either prior to, during, or after receipt of AAC devices. Both groups agreed that *positive effects of AAC training* were typically demonstrated. Professionals appeared to be split regarding whether there would be concerns if *no training were provided*, while families indicated strongly that such concerns would be present. Uncertainty across both groups was exhibited when asked if *positive effects* might be observed *in the absence of any AAC training*. Family members reported that *additional training* would have effects on their families, and that *time had to be taken daily* to help their children use or maintain devices. Both professionals and family members tended to agree that AAC devices *placed time demands* on families, though families felt that devices generally resulted in *changes in the home setting*. Professionals did not seem to think that such changes typically occurred. Most professionals did not feel that AAC devices had an *effect on a spouse or significant other*, while families reported that effects were observed. Professionals were split on whether families typically used AAC devices for *social purposes*, while family members all agreed that social use of these devices is generally exhibited. Most professionals reported that AAC devices did not *have an effect on how adults in the home feel about themselves*, while family members reported that such effects were apparent. Professionals were also split on whether children's use of AAC devices has an *effect on the ways that adults feel about others in the family*. More professionals than family members felt that devices did not have concerns about children's *usage of devices in community settings*. Interestingly, both family members and professionals appeared to agree that professionals generally *understood family needs* during the AAC decision-making process. They were also in agreement that professionals typically respected families as team members. Finally, both groups seemed to feel that *perceptions of professionals* were unchanged.

TABLE 1. ISSUES IN ACC: WHAT FAMILIES WANT OF PROFESSIONALS¹

<i>Issue Area</i>	<i>Families want professionals to:</i>
<i>Communication Style</i>	<ul style="list-style-type: none"> • Minimize use of jargon • Communicate discomfort with AAC devices • Communicate extent of involvement in learning to use AAC devices
<i>Specific Information Needs</i>	<ul style="list-style-type: none"> • Provide information regarding AAC devices • Communicate information regarding ownership • Allow family to observe others using devices prior to purchase • Communicate information regarding short-term AAC device alternatives
<i>Family Values</i>	<ul style="list-style-type: none"> • Be sensitive to family's expectations for child • Help identify immediate and future needs of child and family • Recognize that families have no background in parenting children with disabilities • Understand realities of family life, demands, and routines • Recognize that child and family experiences influence needs and priorities • Consider compact and easily transportable devices for smaller children • Examine child's home environment before prescribing devices • Show sensitivity to terminology used in discussing children • Recognize that child and family preferences for devices differ from those of professionals • Understand that children with similar symptoms are <i>unique individuals</i> and should not be discussed collectively as a group • Recognize child's need for "personal space" during AAC technology interventions

Teaming

- Recommend AAC devices based on objectivity
- Demonstrate comfort in using AAC devices
- Show sensitivity to and provide options for the child and family during repair intervals
- Recognize that professional recommendations are based on short-term contact with the child (versus the lifetime contact of the family)
- Consider age-appropriate recommendations
- Validate family concerns
- Include family members in meetings and ensure family ownership
- Ensure that new team members are familiar with past work of team
- Communicate their concerns regarding the child and AAC devices
- Acknowledge family members for their work in identifying resources
- Provide guidance for better decision-making
- Recognize that child may refuse to participate in evaluations by using a defense mechanism as a response to new team members
- Realize the importance of primary caregiver in development of child/team member rapport during evaluations
- Establish rapport with child prior to assessment
- Adapt child assessment procedures as needed
- Clearly understand that insurance companies base decisions on evaluation information provided by teams
- Provide information regarding time lines of AAC device assessment process
- Ensure continuous access to AAC device from time of rental to actual delivery
- Ensure that AAC device is not taken away after initial successful evaluation
- Ensure that AAC device is not selected for use by others in lieu of individualizing selection

Training

- Provide opportunities for hands-on experiences
- Demonstrate competence in using AAC devices
- Show sensitivity to inordinate amount of time families must wait to receive toll-free technical assistance callbacks
- Show sensitivity to family's needs for repeated training sessions to learn to use AAC device effectively
- Recognize that vendors provide varying levels and quality of family support
- Provide user-friendly, accessible training and support materials prior to purchase of AAC device and thereafter
- Create parent support groups for dissemination of information and training
- Ensure continuity of AAC programming across natural and community settings (e.g. ordering, receiving, learning to use)
- Provide instruction for appropriate use of ACC device to siblings in the family if device is intended for home usage
- Clearly communicate the extent to which professionals will train child and family (including siblings and extended family) to use the AAC device
- Teach families how to teach their children to use AAC devices

¹Note: Based on focus group discussions with families reported in: Parette, H. P., Brotherson, M. J., Hoge, D., & Hostetler, S. A. (1996, December). *Family-centered augmentative and alternative communication issues: Implications across cultures*. Paper presented to the International Early Childhood Conference on Children with Special Needs, Phoenix, AZ.

TABLE 2. PERCEIVED NEEDS FOR AAC DEVICES²

<i>Questionnaire Item</i>	<i>Professionals (n=32)</i>			<i>Families (n=32)</i>		
	<i>n Yes</i>	<i>n No</i>	<i>n Sometimes</i>	<i>n Yes</i>	<i>n No</i>	<i>n Sometimes</i>
Legal information about AAC in schools	20	12	0	10	21	0
Help in being active in educational process	18	14	0	9	22	0
Liaison between staff, parents, and agencies	22	10	0	13	18	0
Parent training in communication skills	17	15	0	6	25	0
Range of AAC devices available	20	12	0	17	14	0
Financial resources to buy AAC devices	17	15	0	3	28	0
Lending programs for AAC devices	24	8	0	7	24	0
Places to try AAC devices	23	9	0	10	21	0
Network of parents using AAC devices	19	13	0	9	22	0
Support group for parents	21	11	0	8	22	0
Training for use and maintenance	16	16	0	10	21	0
Strategies for coping with stress	13	9	0	17	14	0
Helping siblings cope with stress	25	7	0	20	11	0
Other desired services	28	4	0	30	1	0

²*AAC Impact Forms* for all Focus Group participants archived at: <http://cstl.semo.edu/palette/homepage/database.pdf>; VanBiervliet & Parette, 1999).

TABLE 3. AAC IMPACT QUESTIONNAIRE RESULTS³

<i>Questionnaire Item</i>	<i>Professionals (n=32)</i>			<i>Families (n=32)</i>		
	<i>n Yes</i>	<i>n No</i>	<i>n Sometimes</i>	<i>n Yes</i>	<i>n No</i>	<i>n Sometimes</i>
Family goals or expectations	2	16	0	0	20	2
Goals might change	9	7	2	0	18	3
Concerns about training	2	12	0	1	17	2
Positive effects of training	1	11	1	0	20	0
Concerns if no training received	6	5	1	3	15	2
Positive effects if no training received	5	2	0	7	7	4
Effects of additional training	5	2	0	1	16	4
Daily time spent by family members	4	14	0	0	17	3
Demands on family	7	9	2	0	16	3
Changes in home environment	14	4	0	1	11	7
Effects on other children in family	11	3	3	0	17	3
Effects on spouse/significant other	13	3	1	1	10	7
Use AAC device in social settings	5	8	5	0	10	9
Device changes feelings about self	11	6	1	1	11	8
Device changes feelings about family	15	0	3	3	7	7
Family concerns about social use	8	6	3	0	14	5
Device changes community feeling	11	3	2	4	10	5
Professionals understand family needs	0	12	5	1	8	11
Professionals respect families	0	15	2	0	11	9
Experiences with professionals change feelings about professionals	9	6	1	11	4	4

³ *AAC Impact Forms* for all Focus Group participants archived at: <http://cstl.semo.edu/parette/homepage/database.pdf>; VanBiervliet & Parette, 1999).

Family Findings: Discussion and Implications for Practice

Family members have been recognized as the most significant communication partners for children and credited with helping their children to achieve their communication potentials (Huer & Lloyd, 1990). Therefore, in the present study, investigators conducted conversations with various family members in order to collect information useful for service plan decision-making.

Numerous families “voiced” valuable perspectives regarding professionally prescribed AAC interventions. One important finding was the extent to which families across ethnic groups want to be involved in family-professional partnerships. In addition, the families were clear: they continue to request information, education, and training regarding AAC. Finally, and perhaps most importantly, the numerous, but differing conversations with the families provided mounting evidence of the impact of ethnicity on decision-making practices in AAC, and the resulting consequences. While many special educators acknowledge the importance of ethnic sensitivity in intervention processes, such sensitivity is not currently a widespread practice in assistive technology planning processes, particularly in AAC decision-making processes.

Families need to become a more integral part of the decision-making processes in order to reduce the degree of frustration with professionals, noncompliance with intervention strategies, and abandonment of AAC devices (Angelo, Jones, & Kokoska, 1995; Brinker, Seifer, & Sameroff, 1994; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Parette & Angelo, in press). Huer and Lloyd (1990) performed a content analysis of publications pertaining to 165 different AAC users. The results of their study indicated that the topic of frustration appeared more frequently than any other. The reasons for such frustration centered around consumers' interactions with professionals. Similarly, in the present study, families reported frustration with professional recommendations which are based on short-term contact with the child (versus the lifetime contact of the family). When families become frustrated with professionals, they do not wish to comply with their recommendations, communication begins to breakdown, and the devices are abandoned. Given the exploratory nature of this study, it must be noted that the five sites involved have similar funding resources within each state [i.e., *The Individuals with Disabilities Education Act* (IDEA), private insurance, Medicaid], though procedures and protocols for receiving devices and services using these funding systems can vary markedly. These differences could account for family frustrations rather than ethnic factors.

Regular meetings between educators and parents could eliminate some frustrations by providing opportunities for persons to communicate about problems and areas of personal discomfort. During such meetings, creative strategies might be developed to minimize problems and maximize available resources. An important objective of regular meetings is to acknowledge family members for the work they do with their children. Identifying the contributions

of all members of the team facilitates good team building and the establishment of partnerships.

The building of partnerships between families and professionals takes practice and time as roles and expectations constantly adjust and expand. Professionals have become familiar with their changing responsibilities, as a consequence of increased team building over the past few years. Huer (1997a) discussed four professional roles often observed in the practice of AAC: trainer/educator; expert/prescriptive; negotiator; and collaborator. It is not uncommon for parents to ask professionals to provide training on assistive technology as well as to prescribe the appropriate technology. In addition, "the AAC expert may take the role of collaborator and assist all parties in problem-solving and in establishing relationships for joint decision-making (Huer, 1997a, p. 341)."

Of the four roles described above, clearly the families in this study preferred the professional role of trainer/educator: *they wanted professionals to teach them how to use AAC devices*. They wanted instruction for themselves as well as for the siblings within the home, including repeated training sessions for all family members, if necessary.

In addition, parents wanted information about warranties, maintenance contracts, available features of each device, sources of funding, time lines, and toll-free support phone lines. But the role of trainer/educator is not limited to these responsibilities. Families must be helped to develop a working knowledge of many other aspects of the AAC process, including (a) the realities of existing funding mechanisms, (b) realistic expectations about support current systems (e.g., technical assistance lines are busy and heavily utilized, service personnel are busy, and maintenance costs of such supports are costly), and (c) the extent of their involvement and commitment of time to ensure successful AAC implementation.

Families often have high expectations for A/C devices, and may expect that once a device is provided to the child, communication will immediately result. Family members may be unprepared for the responsibilities of programming and learning to use devices, or for teaching their children how to use them effectively. Given the complexity of technology in the field of AAC, it is evident that not only do the families need continued information and training support, *but so do many professionals*. Toward this goal, personnel preparation programs that emphasize training in AAC are becoming available (Huer, 1993).

An important outcome of the present study was the collection of conversations pertaining to family values and ethnicity. Although family involvement is legally mandated in special education, it is recognized that families who are from communities that are ethnically diverse are often alienated from participation and not respected even when present (Huer, 1994; Huer, in press). If such practices continue to be the norm, how can family-centered intervention evolve with families who are not European American? Fortunately, the "voices" within this study provide some guiding principles for future practices with all families, as well as for families from communities that fall outside the mainstream.

How do families want professionals to interact with them? In general, the themes identified by families in this study, coupled with other sources of information, suggest practice patterns that have implications for AAC.

Recommendation 1

Professionals should understand that families have many demands placed upon them. Sources of these demands come from both outside and within the family unit. Such concerns may affect the family's ability or willingness to accept and implement AAC.

Recommendation 2

Professionals should realize that the presence of a disability in the family affects *all family members* within the immediate family. Extended family members may also be affected. The importance of AAC and its relationship to a child's disability may need to be understood by all family members.

Recommendation 3

Professionals should be aware that every child with a disability has unique needs. Similarly, each family member has individual expectations, traditions, values, and hopes for all interventions, including AAC.

Recommendation 4

Professionals should identify the child's communication needs in the home, school, and community. This requires more coordinated and comprehensive approaches than historically used.

Recommendation 5

Professionals should be able to recognize differences and strengths in families. This includes the communication styles of persons from varying ethnic backgrounds, and identifying the different priorities, preferences, and realities within each. Such an understanding will enhance family and professional relationships during AAC decision-making.

Recommendation 6

Professionals should spend time with each family member before discussing the AAC intervention. This serves to establish comfort, rapport, and trust.

Recommendation 7

Professionals should become competent in implementing ethnically sensitive action plans. These should use multi-language materials (including symbol

sets), and employ persons from non-dominant cultures, when necessary, to help design the AAC strategies.

In summary, conversations with a limited number of families have provided information related to three important topics: family-professional partnerships; education and training pertaining to AAC devices; and the interaction between family ethnicity and professional intervention. Since family involvement is known to be critical for successful AAC assessment and implementation, the “voices” of these families should provide valuable information that may guide future “team” decisions in AAC, and provide areas for future research.

Results from Professional Focus Groups

The results from the professional focus groups are presented in five themes that were identified in the analysis of data. The five themes address the broader question of the study, *What are professionally-held perceptions regarding the roles of professionals and family members in AAC decision making?* More specifically the themes answer five related questions: (a) *What are the communication styles needed by professionals and family members to build family-professional partnerships?* (b) *What is the responsibility of professionals to address family information needs?* (c) *What values should professionals and families acknowledge in working together on teams?* (d) *What teaming skills should professionals demonstrate in working with families?* and (e) *What do professionals and families want regarding AAC implementation and training?* The results are organized according to the five major themes identified.

Theme 1: *Communication Style*

Numerous authorities have noted that families of children with disabilities often lack the opportunity to communicate with professionals (Dunst & Paget, 1991; Munschenck & Foley, 1995; Nahmias, 1995). Professionals participating in focus groups agreed that two-way, open communication among team members was important for success in AAC decision-making. This process should ensure that families are both “heard” and “understood” (Simpson, 1996).

Since developing a collaborative relationship with families typically takes time, regular meetings may be necessary to ensure that effective communication occurs. As one related service professional who works with Native American children commented:

I think the team our weekly meeting that we have really had some rough waves. They're getting smoother. We're working through them. There are times when people don't agree. There are times when this isn't working. This is too hard, it's over her head and we need to go off in this direction. I think that's really necessary. Just the opportunity, if nothing else we are forced to sit down and talk about what are we doing and where are we going and what's

happening. I think that we could say yeah, let's get together but we've forced ourselves to set up a time weekly. I think that's made the difference.

Such regular meetings have unanticipated benefits for team members, such as providing an opportunity to share in daily progress, and to experience shared ownership in the AAC decision-making process.

Families may sometimes have preconceived notions regarding AAC devices that they deem to be desirable. They may feel that once a child has an AAC device, they will be able to communicate immediately (Parette, Brotherson, Hoge, & Hostetler, 1996). They may also feel that vendors should assume responsibilities for teaching families how to use AAC devices in the home, and to be available on demand by families in need of technical assistance. These preferences may be influenced by a variety of factors, and may be deemed to be unrealistic by professionals. As noted by one speech-language pathologist:

I think that the most important thing that a family can do when coming into say an evaluation for an AAC device with a professional is not to come in with a preconceived notion, and say things like, "I want you to prescribe this device for my child or we saw a Liberator in *Exceptional Parent* magazine and I think that would really be good for my child." It think that they need to come in with an open mind. Let us take a look at the child and discuss what they would like for their child to do, what their child needs to do, and look at all kinds of communication devices. Families should not walk in and say I would like this for my child and if you'll write a letter to a variety club they will buy it.

Professionals must afford families the opportunity to express themselves and to clearly communicate their perceived needs (Cobb & Reeve, 1991).

Theme 2: *Specific Information Needs*

It has long been recognized that both professionals and families have needs for information regarding assistive technology devices (cf Angelo, Jones, & Kokoska, 1995; Parette & VanBierliet, 1990). Families, in particular have needs for information about AAC devices, roles and responsibilities in assessment, team decision-making, funding, and other issues. Family-centered practice recognizes that the assessment process should result in the identification of the particular set of technology services most needed by the child *and* family (Parette & Brotherson, 1996). The specificity of child and family needs emerges through interviews and other information-gathering approaches with families, and through access to comprehensive information about supports and services that may be provided by professionals. The end product of the assessment process is a unique set of recommendations based on the family priorities for assistive technology.

Other families will want to be involved in AAC decision-making, yet they may not understand what is expected of them to effectively participate. One vendor having experiences working with families observed:

I think one thing that you hit on that's real important for us and what we've learned along this road is that involving parents from the beginning. One of the questions we always ask them is what do you want this device to do for your

child? What do you want them to be able to speak in every situation, communicate basic wants and needs as you were talking about. What are your goals for your child? Whether we think they are realistic or not to have this parent as a member of the team before we start an evaluation.

Some family members may have expectations regarding professional roles and responsibilities that may be perceived to be unrealistic. As one professional noted:

A lot a times they see the device as a fixer. That it's going to be an immediate repair for all of the issues that they've had to that point. I think that they underestimate the amount of long term effort that a device takes. That the procuring of the device appears to be their primary gusto; they normally see the long term that the initial purchase of the system. It's really just the beginning of the journey for communication.

Having professionals who are knowledgeable about assistive technology devices is highly desirable to many families (Parette & Angelo, 1998). When professionals do not have expertise in or information about assistive technology devices, this should be clearly communicated to family members. Such information may assist families in decision-making related to particular professionals that might potentially work with their child in the use of the assistive device.

Theme 3: *Values*

Values are laden with beliefs, convictions, and other strong persuasions through which professionals and family members structure their lives. As such, they are important considerations in team participation (Simpson, 1996). Professionals should understand the values of families to (a) build more collaborative relationships, (b) understand the extent of participation desired by the family, and (c) help the professional distinguish cultural differences from personal preferences or lack of understanding (Lynch & Hanson, 1992b). Professionals participating in the focus groups consistently stated the importance of valuing families in team participation, and acknowledged that dissonance occurs when values differ. For example, one physical therapist noted:

...family values are real important. Sometimes it's hard to step back from your values and say this is the most important thing to them. I think that's probably one of the hardest issues I have is what's most important to you, now let me tell you what's most important to me. Okay now how are we going to come to this middle ground?

Families from different cultural backgrounds may perceive the professional to be an expert, and defer their "voice" in AAC decision-making to professionals. When this occurs, valuable information can be lost during the decision-making processes. One focus group participant clearly summarized this theme identified by others in the various sites around the country:

I think too, one of my concerns is that we offer - they view us not that we view ourselves as the expert these people know everything about augmentative

communication. Therefore, the parents are at times less apt to project their own thoughts, feelings, about those things initially. They may feel we'll pick the best device and just go along, even if they are involved in the funding...We try as much as we can to give them a chance to look at different devices, talk about the capabilities of different devices, and what their child could and could not do with that device so they feel more informed and therefore more comfortable.

Participants in focus groups also recognized that fear of stigma associated with AAC devices is a value reflected in the behavior of many families from non-European backgrounds. For example, one speech/language pathologist commented on observations made while working on teams with African American family members:

I've also found in some of the clients that are African American that they are very concerned about how the child looks with the device, probably moreso than some of the other cultures that I've worked with. They're very concerned with its appropriateness and how it looks and that it's kept clean and that it's a...prestige presentation-- almost to the point where they would not have it as available because it had to be kept clean and it was hard to get and they didn't want anything to happen to it and very very protective of the device. In some cases the parents did not use it to its full potential even when the opportunities were there...if it were left at school by accident over night, or if there was a manual that needed to be borrowed or something like that they were very possessive of the device.

Recognition of *stigma* being associated with disability and assistive technology devices (Luborsky, 1993; Murphy, 1987) and AAC devices specifically (Parette et al., 1996; Smith-Lewis, 1992) has been reported in the professional literature previously. Professionals cannot dismiss such strong values held by families if family-centered practices are to be fully and effectively implemented in service settings. Failure to do may often result in "technology abandonment" (Batavia & Hammer, 1989), or failure to use the device to its optimal capability.

Focus group participants at various sites also observed that families may not fully understand the commitments expected by professionals to effectively implement AAC devices. As one therapist commented:

I... see basically two types of families. I see the ones that are totally surprised that someone would recommend an augmentative device; suggesting that there's some communication in that child and they're just not able to get it out. So I see those families that are totally surprised at the recommendation and then I see families that have their preconceived notions about what they think augmentative communication can do for their child. And sometimes that's right on target and sometimes they're at a point where they probably need a lot more information before they can truly see what the capabilities would be for the child with an augmentative device.

The concept of patience with AAC device implementation was also consistently identified by focus group participants. One speech-language pathologist noted:

The key word that I was thinking about was patience. One the family realized that while there was an immediate need and we all agreed yes it's immediate. This all takes time and even after you get the device it takes time to use it as we talked about it evolving. One family who really became frustrated was wanting things a lot quicker than they actually moved. We kept saying, "Well

we're working towards this but be patient." It's really hard to when you do have that immediate need.

Theme 4: *Teaming*

Teaming concerns identified by focus group participants addressed a variety of issue areas. A family-centered approach to assistive technology considers partnership building as a mechanism for empowering families to be involved in all aspects of assistive technology assessment and service delivery. The development of a feeling of partnership on AAC teams encourages shared responsibility and collaboration between the family and professional rather than client-professional relationships focused solely on the child:

I would say my one word would be *trust*. There has to be that level of trust on both sides of the table. The parents have to trust us to be out there looking for all of the devices, looking at all the opportunities of bringing the most current and up to date information we can to the table. We have to trust the parents when they say, "Hey my gut says this is what goes." We must say, "okay let's do it. Let's go with our gut and let's do it."

Funding was consistently identified as a priority need for team decision-making. Participants rated this as the most important issue confronting AAC teams, supporting previous reports in the professional literature (Behrmann, 1995; Derer, Posgrove, & Reith, 1996).

Partnerships are characterized by certain features that make them different from other types of cooperative endeavors (Judge & Parette, 1998). *First*, the AAC decision-making process must be flexible and consider the changing needs of the family. Professionals must provide all necessary information that will assist the family in evaluating different AAC options to enable informed decision-making regarding the selection and use of devices that are considered. However, the final decision regarding what devices appropriately match the needs of the child, what goals and interests should be pursued, and what courses of action will be taken to attain stated intentions rests *solely with the family*, assuming they are willing to accept this responsibility (see Parette, 1998 for an in-depth discussion of the influence of culture on such decision-making). Otherwise, lack of consensus may occur resulting in limited device use by the child and family (Allaire, Gressard, Blackman, & Hostler, 1991; Culp, Ambrosi, Berniger, & Mitchell, 1986) or abandonment of assistive devices (Batavia & Hammer, 1989; Culp, 1987) Even if the professional disagrees with the family's decision, parents still need the professional's encouragement after the decision has been made.

Second, partnerships developed between the family and professionals evolve from mutual trust, honesty, respect, open communication, and respect for cultural diversity (Judge & Parette, 1998). Honesty, trust, and commitment are the backbone of any effective helping relationship and are absolutely necessary for a partnership to be effective (Dunst & Paget, 1991). Professionals who enter into collaborative arrangements with families must give complete loyalty to the partnership, provide families with relevant,

accurate, and up-to-date information, and use effective communication skills so that trusting partnerships can be developed and enhanced. The professional must be able to confer confidence in the family and understand the responsibility of providing the necessary information so the family can make informed decisions regarding appropriate assistive technology services for their child. This is a very important step in creating an equal partnership and putting the parents on equal ground with the professional, assuming that the family desires equality in the relationship.

Third, partners recognize the benefits of a collaborative arrangement, and openly agree to pool their respective resources (e.g., knowledge, skills) and to work toward a mutually agreed-upon goal or interest (Judge & Parette, 1998). Both the parent and professional must discuss the assistive technology “joint venture” and then proceed to define the mutually agreed upon roles that will be used in the development of the partnership. This process is driven by family-identified needs, resources, routines, and values. The family is provided opportunities to evaluate the progress made at various times during the process and to renegotiate the mutually agreed-upon roles as well as the goals.

Partnerships in team decision-making benefit everyone involved, including the child (Dunst, Trivette, & Deal, 1994; Rosin, 1996). Building partnerships with parents and involving them purposefully and meaningfully at multiple levels within the assistive technology process, while providing them with options regarding their types and degrees of involvement, will facilitate the development of family-centered, culturally competent assistive technology services.

Theme 5: *Implementation and Training*

Once the team has decided on a particular AAC device, it must be implemented. Parent training was identified as a high priority need by focus group participants. Parent support groups were rated highly as a need for families, and some reports have indicated that such support groups are a preferred mechanism for the receipt of training (Battle, 1993; Parette et al., 1996), particularly for many non-European families who may distrust school personnel.

Professionals also reported that families must commit their time for AAC devices to be effectively implemented. When families committed time; more positive AAC outcomes were reportedly anticipated than if moderate or little commitment was made.

Professionals also acknowledged that the demands of AAC implementation result in varying degrees of family stress. Families were reported to frequently perceive professional recommendations as, “one more thing that I have to do.”

While the importance of family commitment to learning to use and implement AAC devices was identified as being important, it is less clear how training may

be effectively provided to family members representing diverse cultural and family value systems. Many families may distrust professionals and service systems based on past negative experiences (Harry, 1992; Roseberry-McKibbin, 1995), and prefer that other family members--those that have had successes with AAC previously--provide information and training regarding AAC implementation.

Training and implementation should also consider *critical periods for AAC intervention* when family receptiveness to the importance of the device is optimized. For Hispanic Americans, the *quincancera*, a celebration of the child's 15th birthday, frequently serves as a milestone to demonstrate the growing communication independence of a child, and marks a significant transition on the way to adulthood (Hourcade, Parette, & Huer, 1997). For other families, birthdays may function as a pivotal moment to reinforce the importance of family involvement in AAC implementation.

Family and professional partnerships can enable families from different cultures and professionals to work together in pursuit of shared goals. Partnerships must be built on trust, and recognize the strengths and capabilities of each member of the partnership. Two major issues have been identified by families regarding the role of professionals in building family and professional partnerships. These include *communication* and *team decision-making* (Parette, Brotherson, & Huer, in press)--issues which parallel perceptions of professionals participating in this study.

More specific findings identified from Focus Group proceedings are presented in *Table 4*.

TABLE 4. ISSUES IN ACC: IMPERATIVES FOR TEAM MEMBERS EXPRESSED BY PROFESSIONALS⁴

<i>Issue Area</i>	<i>Implications for Teams</i>
<i>Communication Style</i>	<p data-bbox="732 396 1149 424"><i>Families and Professionals should:</i></p> <ul data-bbox="732 434 1401 527" style="list-style-type: none"> • Maintain open lines of communication across settings • Be open-minded • Avoid assuming defensive postures <p data-bbox="732 548 992 575"><i>Professionals should:</i></p> <ul data-bbox="732 585 1284 611" style="list-style-type: none"> • Avoid jargon and gear language to listeners
<i>Specific Information Needs</i>	<p data-bbox="732 632 992 659"><i>Professionals should:</i></p> <ul data-bbox="732 669 1357 724" style="list-style-type: none"> • Communicate the role of the family in AAC device decision-making
<i>Values</i>	<p data-bbox="732 745 992 772"><i>Professionals should:</i></p> <ul data-bbox="732 783 1430 1073" style="list-style-type: none"> • Share a common value—wanting the child to learn—with the family • Value family insights • Value family members as team participants • Value insights of all persons who work with the child on a daily basis • Recognize that child/family bonds exist even in absence of regular contact • Recognize that families are limited by financial, educational, and physical constraints <p data-bbox="732 1094 932 1121"><i>Families should:</i></p> <ul data-bbox="732 1131 1401 1213" style="list-style-type: none"> • Accept reality of disabilities and children's limitations • Be patient and not demand rapid results after an AAC device has been implemented

Teaming*Professionals should:*

- Consider family needs to ensure appropriate selection of AAC devices
- Respect family needs, concerns, and priorities
- Recognize that families display varying degrees of willingness to participate in AAC device implementation across time (acculturation)
- Establish trust with family members
- Collaborate with family members and establish consensus
- Meet regularly with family members
- Celebrate positive daily changes resulting from AAC device implementation
- Recognize that *child factors* may have greater impact on success with AAC devices for some children than family commitment
- Recognize that evaluation process may have unjust elements—optimum devices may not be feasible due to funding constraints
- Clearly communicate expectations re: AAC devices
- Not have preconceived ideas re: AAC devices
- Clearly specify goals for the child
- Examine a range of AAC devices
- Be matched relative to their expertise with the demands of AAC devices
- Be aware that AAC device options are increasing in the midst of decreasing funding availability

Implementation and Training*Families want professionals to:*

- Provide support through family support groups
- Train family members in use of AAC devices in community settings
- Make loaner AAC devices available after evaluations
- Provide training targeting integration of AAC device into home

Professionals want families to:

- Commit time to AAC device implementation
- Understand that AAC device success corresponds to time commitment given by families

⁴Note: Based on focus group discussions with families reported in: Parette, H. P., Brotherson, M. J., Hoge, D., & Hostetler, S. A. (1996, December). *Family-centered augmentative and alternative communication issues: Implications across cultures*. Paper presented to the International Early Childhood Conference on Children with Special Needs, Phoenix, AZ.

Professional Findings: Discussion and Implications for Practice

Professionals participating in this limited, information-gathering study confirmed the importance of family involvement in AAC decision-making. However, their perceptions tended to less family-centered in light of current

best practice guidelines (Angelo, 1997; Lynch & Hanson, 1992a). Less discussion of cultural issues emerged in the conversations with professionals than was expected, even though the research protocol (see <http://cstl.semo.edu/palette/homepage/database.pdf>) provided a stimulus for cultural issues to be explored. This finding supported the report of Parette and Hourcade (1997), in which many states reported *less consideration* being given to family and cultural issues during assistive technology decision-making than more traditional factors (e.g., child characteristics, device features, service system concerns).

Professionals appeared to rank family needs for stress coping strategies as being *less important* than other needs. This is particularly interesting given the growing body of research which emphasizes the need to address family stressors during family-centered decision-making processes (see e.g., Hanson & Hanline, 1990; Sexton, Burrell, Thompson, & Sharpton, 1992). Increased levels of stress may be associated with (a) increased caregiving demands placed on families (Haddad, 1992; Harris, 1988), (b) time required for family members to provide intervention services (Brotherson & Goldstein, 1992), and (c) the introduction of assistive technology devices (McNaughton, 1990). With regard to AAC devices, it seems reasonable that consideration should be given to determining the potential impact of AAC prior to its delivery to and use by a family (Parette et al., 1996).

Families need to become a more integral part of the decision-making processes in order to reduce the degree of frustration with professionals, noncompliance with intervention strategies, and abandonment of AAC devices (Angelo et al., 1995; Parette & Angelo, 1996). Huer and Lloyd (1990) performed a content analysis of publications pertaining to 165 different AAC users. The results of their study indicated that the topic of frustration appeared more frequently than any other.

Regular meetings between professionals and family members would eliminate some of the frustration by providing opportunities for persons to communicate with each other about problems and areas of personal discomfort. During such meetings, creative strategies might be developed to minimize problems and maximize available resources. An important objective for regular meetings is to acknowledge family members for their work with the consumers. Identifying the contributions of all members of the team facilitates good team building and the establishment of partnerships.

The building of partnerships between families and professionals takes practice and time as roles and expectations constantly adjust and expand. Professionals have become familiar with their changing responsibilities, as a consequence of increased team building over the past few years. Huer (1997a) discussed four professional roles often observed in the practice of AAC: trainer/educator; expert/prescriptive; negotiator; and collaborator. It is not uncommon for parents to ask professionals to provide training on assistive technology as well as to prescribe the appropriate technology. In addition, "the AAC expert may take the role of collaborator and assist all parties in problem-

solving and in establishing relationships for joint decision-making.” (Huer, 1997a, p. 341)

How do families want professionals to interact with them? In general, the themes identified by families in this study suggest practice patterns that have implications for AAC. Of particular importance is for professionals to recognize the importance of the family ecosystem. While the idea of family systems is certainly not new (see e.g., Bronfenbrenner, 1979; Turnbull, Summers, & Brotherson, 1986), many professionals have yet to fully understand and accept the implications of such theories in their practice when working with families. Failure to acknowledge family priorities, resources, and concerns during decision-making—particularly internal and external demands—may result in ineffective decision-making and technology abandonment on the part of families. Professionals must acknowledge the cultural traditions, hopes, and value systems of families, and understand how these traditions and values influence the thinking and behavior of children and their families. To effectively accomplish this, efforts should be made to involve all family members—both immediate and extended—with whom the child with disabilities may be using the device. Such involvement will assist professionals to ensure that the range of AAC needs of the child across environmental contexts, and when interacting with particular individuals within those contexts, are accurately identified.

The foregoing findings and recommendations should provide direction for future AAC research and implementation efforts. Greater sensitivity to family and cultural issues may be anticipated when such planning is embedded in AAC decision-making approaches.

This section presents a brief review of literature related to multimedia and its relationship to AAC decision-making. Features of the CD-ROM are then described for the reader.

Interactive Multimedia

In addition to assessment and planning tools focusing on child and family outcomes, there is a need for more effective educational tools for children with disabilities, their families and the professionals who work with them. In order to be effective, these educational tools must focus on family issues, *including cultural perspectives*, that impact success. Interactive multimedia may be one educational technology for addressing these needs. No longer just a "buzz word," multimedia is firmly entrenched in our lives. The mix of sound, images, video, and interactivity with the audience has become a key ingredient of entertainment, business, and education. Multimedia incorporates graphic design, video techniques, print media, story writing, and audio production. Multimedia in the form of movies, television, and videotapes have been used for many years to transport audiences to places and events that they would not be able to experience otherwise.

While computer technology enables the display of images and sounds, it also increases user capability to control and individualize the learning experience. The user can select narration in alternative languages, select a personal onscreen guide, repeat an instructional segment, or skip irrelevant material. There have been rapid developments in the tools for creating high-quality multimedia so that programs can be created with only a modest investment in hardware and software. Considerable time and creativity, however, are still required for creating quality programs with the appropriate interactivity. Studies have shown that appropriately designed computer based instructional materials can reduce instructional time up to 50% (Ambron & Hooper, 1990) and be substantially more effective and less costly than conventional instruction (Department of Defense, 1990).

Interactive multimedia programs can be distributed in a wide variety of formats. Currently, the most common format is CD-ROM, which can hold up to 650 megabytes of information on a disk. The next generation of CDs are digital versatile disks, or DVDs, which hold from 4 to 8 times as much as a CD-ROM. Multimedia programs can also be distributed and played over a network or via the Internet. One of the primary limitations of multimedia use via the Internet is that multimedia requires the continuous transmission and processing of large amounts of data for smooth playback. With the availability of high-bandwidth transmission technologies such as Internet II, cable modems, digital broadcasting, digital subscriber line (DSL), and other communication technologies, multimedia will be more widely distributed via the Internet.

User-Related Design Factors

When interactive multimedia programs are designed, a number of user-related factors need to be considered. These factors include the characteristics, preferences, literacy, point of access, and the available technology resources of the potential users. Individual characteristics including age, sex, gender, disability, race, education, culture, and socioeconomic status influence the effectiveness of educational programs. It is extremely unlikely that any single program can be designed to meet the needs of all potential users. However, given the costs associated with developing, distributing, and using these programs, it is crucial to reach as much of the potential audience as possible. Situational examples used in the program should include persons that represent the spectrum of age, race, gender, culture, and socioeconomic background of your target audience.

Another important feature of successful interactive multimedia programs is the user's ability to tailor the presentation of information to meet his or her preferences, needs, and desires. Some of the features that can be included in an application to accommodate individual preferences are (a) a selection of topics to study, (b) a selection of electronic guides, (c) user-controlled pacing of information, and (d) the availability of additional or more detailed information on a topic. Other important program features include the ability to (a) review previous topics, (b) select the language, (c) easily skip or bypass components such as introductory instructions and credits, (d) easily backtrack or return to a previous point in the program, and, most important, (e) to quit or exit the program at any time.

Point of access and the technology resources that are available to the potential users are also important user-related factors in interactive multimedia programs. Point of access refers to where the user will interact with the program and technology resources refer to what equipment is required to access or playback the program. Multimedia developers must consider the playback resources the intended users currently have and what resources are likely to be available in the near future. These resources include the computer equipment, operating system software, run-time software, and network connectivity.

In order to increase access to multimedia programs by persons with widely differing backgrounds, interests, learning styles, abilities, and disabilities, developers need to incorporate the concepts of universal design into their programs (Brewer, Dardailler, & Vanderheiden, 1998; Center for Applied Special Technology, 1998a; Center for Universal Design, 2000; VanBiervliet, 1994). For educational programs, universal design can be viewed as providing multiple representations of content, providing multiple options for expression and control, and providing multiple options for engagement and motivation (Center for Applied Special Technology, 1998b). Providing multiple representations of content involves providing essential information in redundant formats such as an auditory narration accompanied by text and images. Multimedia applications need to be designed so that individuals who cannot easily use a mouse or keyboard can use alternative input devices with minimum fatigue and minimal errors. Another example of providing options for expression and control involves providing various options for users to test their knowledge. For example, in addition to traditional multiple choice questions, the program could include questions presented in a challenging game format, essay writing, or an interactive exploration of three-dimensional objects. Options for engagement include providing content in multiple learning styles, such as guided and exploratory styles, and providing multiple levels of depth or detail on topics. The overall design of the visual appearance and interactivity of the multimedia application also impacts the user's motivation and engagement levels. Although multimedia programs that utilize universal design approaches can and should be visually attractive, function should always take precedence over form. For example, some designers create small, multi-function navigation controls. These controls may be visually attractive, however, larger fixed buttons might be easier to use and require less fine motor control to operate.

A final issue regarding access in interactive multimedia that is even overlooked in much of the universal design literature concerns the use of color. Eight to 12% of all European American males, but very few females or males of other origin, have some form of color vision deficiency or color blindness. When designing applications, developers should avoid color as the only cue for something and should only use color in combination with some other visual feature such as size or font style change (Oakley, n.d.; Wilson, 1996). Also, developers should avoid giving instructions, such as "Click on the red button", that refer to objects only by color.

Families Culture and AAC

The primary product of this project was a new interactive multimedia educational tool designed for AAC planning from a family perspective. The *Families, Cultures and AAC* (VanBiervliet & Parette, 1999) CD focuses on family and cultural issues related to augmentative and alternative communication (AAC) devices, though it has potential broad implications for a wide range of assistive technology devices. The program's content is based on participation in AAC planning and implementation processes from a family

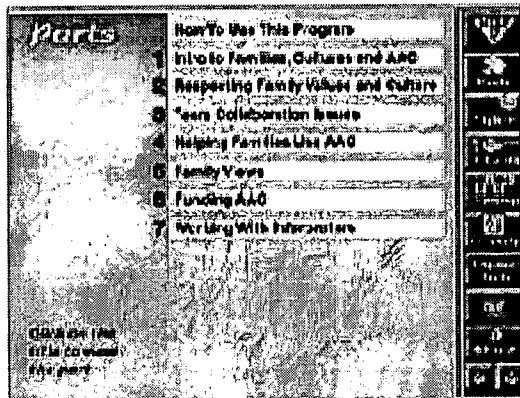
perspective. Particular emphasis is placed on cultural considerations. Content was derived from a knowledge base that was initially created using both families (i.e., Advisory Board, focus groups, and structured interviews) and professionals (i.e., expert panel, focus groups). The program is designed to be used by professionals, families, students and others involved in AAC decision-making.

Unique features have been built into the CD which are not often found in other information and training multimedia products. Figure 1 presents a number of key components of the CD. The CD can be used in many ways: as (a) a tutor, (b) a decision-making tool when working on teams, (c) learning games, (d) an encyclopedia on AAC, and (e) a research tool. This program contains video vignettes of family members from five different cultural groups who express their thoughts and feelings about aspects of the assistive technology decision-making process. Interactive games are also available to provide alternative means of accessing information and to reinforce concepts and content presented. The program incorporates Universal Design features including information redundancy, multiple strategies for expression and control, and multiple options for engagement and motivation. In addition, the program represents one of the first multimedia programs in special education that provides for bi-lingual access. Narration and essential program features are provided in English and Spanish - a simple click of a button switches language modes.

The CD also includes research materials that may be of interest to personnel in higher education and clinical settings (see <http://cstl.semo.edu/palette/homepage/database.pdf>). These include focus group transcripts, an AAC knowledge base, instruments used in collecting data from families and related service personnel, and a concept paper.

Inherent in the distribution of the above described CD is an evaluation instrument that is being made available via printed and on-line formats (see <http://cstl.semo.edu/palette/homepage/word/revform.rtf>). The evaluation tool (VanBiervliet, 2000) will provide information necessary for future upgrades, and requests users to evaluate the CD from the perspectives of a student, family member, and professional. It examines 10 different dimensions of the CD design and content, including (a) usability, (b) visual appearance, (c) consistency, (d) error tolerance, (e) navigation, (f) feedback, (g) user control, (h) redundant formats, (i) content accuracy, and (j) engaging styles. Such evaluative information is essential for future upgrades that respond to user concerns over time.

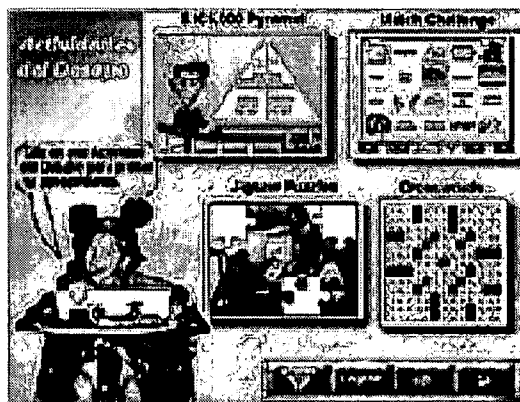
FIGURE 1. SELECTED COMPONENTS OF CD.



Content is organized into eight chapters or Parts.

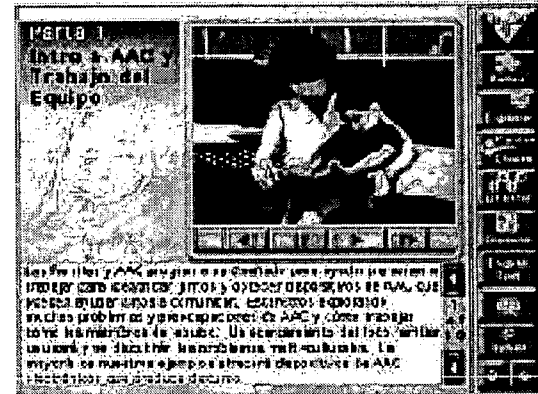


Information is presented in innovative animated formats.

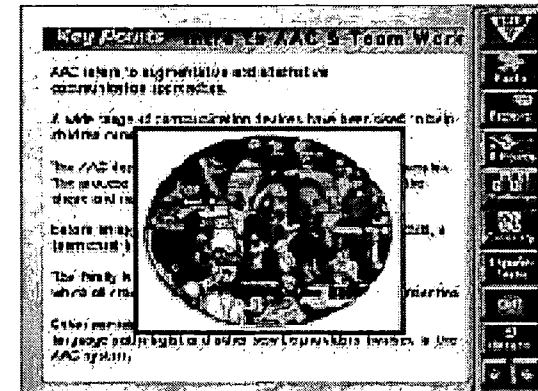


Challenge activities present opportunities to review and test your knowledge in game formats.

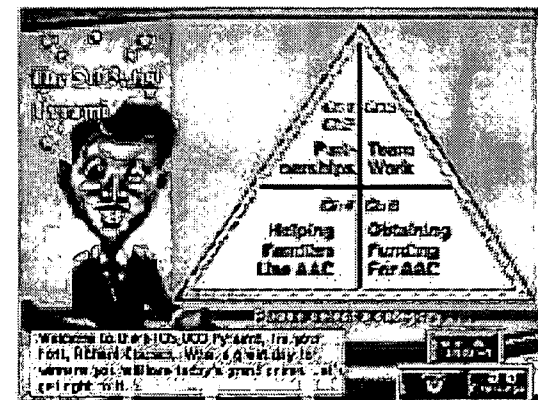
Families, Cultures and AAC Augmentative and Alternative Communication



Digital videos can be easily controlled by the user. Audio narration is synched with text in English or Spanish.



A multimedia Glossary, Topic Index, and Key Points are available for review and supplementary information.



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REFERENCES & PROJECT DISSEMINATION

6

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