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ABSTRACT

In 1998 and 1999, the Arkansas State Department of Education annual state census of deaf-blind children found none in a seven-county section of southeast Arkansas--a rural area that includes the Mississippi River delta region. A project investigated the idea that unique cultural characteristics of the region might prevent parents from identifying and receiving services for their children. Three focus group sessions were organized in Drew County, the central county of the region. Participants in two groups were African-American and Caucasian professional women and mothers who were long-term county residents, had professional and personal involvement with families, and were interested in a culturally sensitive approach to serving families. The third group consisted of residents of a low-income neighborhood. Focus group questions explored the various cultures in the county and their characteristics, culture-related attitudes about children with disabilities, cultural factors that might interfere with parents seeking services, cultural child-rearing practices, role of the extended family, and cross-cultural barriers to service provision and how they might be overcome. Short-term project outcomes include development of informational materials that reflect the region's basic cultural values and ethnic diversity and promotion of interagency networks and collaboration. Recommendations address the use of cultural information to facilitate communication and relationships with families. (Contains 13 references.) (SV)

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INCREASING SERVICES TO CHILDREN WHO ARE DEAFBLIND IN SOUTHEAST ARKANSAS: A STRATEGIC MODEL FOR IDENTIFYING CULTURAL INFLUENCES

ABSTRACT: This presentation addresses the problem of under-representation of children with deafblindness in the southeast quadrant of Arkansas. An investigation of the unique cultural characteristics of the region, conducted as a collaborative effort with the University of Arkansas at Little Rock and the Arkansas State Department of Education, revealed more effective identification and service strategies for families from diverse backgrounds. The process by which entry was gained to families in this region is presented in hopes of encouraging other program personnel to examine and revise current methods/materials for early intervention based on cultural insights.

Introduction to the population

Defining the general population of children who are deafblind is a complex task and requires an understanding of dual sensory impairment as a singular condition characterized by profound communication, concept development and orientation and mobility needs (McInnis, 1993). McInnis and Treffrey (1982) proposed that deafblindness presents a condition of composite disabilities in which "the deafblind child is not a blind child who can not hear, nor a deaf child who can not see" (p. iv). These children may exhibit extreme difficulties establishing interpersonal relationships, have a distorted perception of their world, and may lack the ability to interact with their environment in a meaningful way. This separation, or distance, of a child from the environment presents the unique early intervention requirements that are crucial to connecting these children to the world around them. Included in this population may be those children who are recognized as "at risk" for developing dual sensory impairments, especially those with particular syndromes and/or very low birth weights. The U.S. Department of Education defined deafblindness as:

concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness (Federal Register, 1999, p. 12422).

Individual states were required to adopt definitions of deafblindness that were consistent with the federal regulations; however, they were allowed flexibility in regard to terminology. The Arkansas Project for Children with Deafblindness specified these potential characteristics of this population:

1. a diagnosis of a degenerative disease that will affect both vision and hearing, such as Usher syndrome or CHARGE association
2. multiple disabilities due to generalized CNS dysfunction resulting in inconsistent responses to visual and auditory (functionally deafblind)
3. an additional learning and/or language disability (Census Information form, Arkansas State Department of Education, Special Education)

Based on the federal and state definitions, the Arkansas State Department of Education, Project for Children with Deafblindness, annually conducts the mandatory federal census of children birth to age 22. The 1999 census identified 121 children in this category. A seven-county section of southeast Arkansas, which included the Mississippi River delta region, was the most under-represented area of the state with no children who are deafblind being identified in the 1998 or 1999 census efforts. These statistics caused the Arkansas State Department of Education (SDE) to establish an objective for its current grant cycle (Oct. 1, 1999-Sept. 30, 2003) that targeted the under-represented and under-served southern quadrant of the state. Speculation about the cause

of under-representation led to a consideration of child find practices that more effectively reflected the unique cultural characteristics of this part of the state. For this purpose, a Community and University Partnership Grant was awarded by the University of Arkansas at Little Rock to determine if, and to what degree, the culture of the region may have contributed to the reporting deficit. If culture was discovered to be a contributing factor, public awareness and child find efforts would become more culturally responsive to families of the region.

Project Purpose and Procedure

The long-term goal of this project was to verify or adjust the cultural perceptions of the seven counties in the region and apply the information to early intervention practices for children who are deafblind. This strategic model followed this sequence: (a) target a central county for exploration, (b) verify information by triangulation methods, (c) modify child-find materials that reflect culture sensitivity, (d) change the approach to families, and (e) enhance personnel preparation that respond to diversity that is location-specific. If the model resulted in increased identification and service to this population of children, it would be used in other "pockets" of the state that are under-represented.

The underlying assumption was that children with dual sensory impairments exist in these areas, but were not being reported to the state agency responsible for providing specialized services. The research question was "What cultural influences of this rural region might impact the way families identify a child's needs and access services?" Due to the low incidence of deafblindness and the heterogeneous nature of the population (Chen & Haney, 1995), regarding these influences in child find efforts and intervention was a primary concern for state and national projects designed to service this population.

Project Development

Focus group interviews were utilized to obtain opinions and feedback on cultural issues from residents of Drew County, the centrally located county in this region. The purpose of the groups was to elicit responses of participants that reflected perceptions and emotions about personal and group culture that might not emerge in other forms of interviewing (Krueger, 1994). According to researchers with extensive experience using focus groups, this approach to qualitative research stimulates participants to state feelings and beliefs that they would not likely be expressed in a written survey or individual interview (Gall, Borg, & Gall, 1996). Thus, the group dynamics contributed to the responses obtained in the focus group session.

In a project planning meeting, the Advisory Council to the Arkansas SDE's Project for Children with Deafblindness discussed the perplexing under-representation of children who are deafblind in southeast Arkansas. The possible reasons that families and professionals fail to identify concurrent sensory impairments and/or receive early intervention services were of major concern. It was suspected that the unique cultural characteristics of the region prevent parents from identifying and receiving services for their children. The council determined that identifying specific cultural characteristics of the region, whether related to ethnicity, religion, or rural nature, was the first step toward modifying current methods of identification and intervention that reflect a family's cultural values.

A plan to investigate this question of cultural influence was constructed and three focus group sessions were organized in Drew County. Researchers have recommended that at least two focus groups are needed to fully understand the topic. The number may need to be adjusted based on the information gained in the previous groups (Vaughn, Schumm, and Sinagub, 1996). According to Krueger (1994), "several focus groups are often needed to gain a sense of how the questions are working, if they need to be revised, and the degree of convergence or divergence of the participants' comments" (p. 144). Krueger (1994) emphasized the importance of the researcher concentrating on the purpose of the study during the planning phase and considering those who will use the information at the study's conclusion; in this case, the "users" of the information referred to the Arkansas SDE. The Advisory Council worked in small groups to discuss the best methods for gaining entry into the

communities where sensitivity to cultural diversity is paramount. It was recommended that those who would be conducting the focus groups contact a local, well-respected and trusted professional or clergy to seek suggestions for potential group participants. The support and trust of a local person was necessary to lay the foundation of trust on which this project would progress.

Sample groups of participants for the first two groups were selected by the Drew County Department of Human Services (DHS) County Administrator and a University of Arkansas - Monticello faculty member. Their recommendations for potential participants were based on the following criteria: (a) long-term residency in Drew County, (b) professional and personal involvement with families, and (c) interest in a culturally sensitive approach to serving families in Drew County. Each potential participant was contacted initially by telephone and subsequently faxed or mailed a copy of a consent form, which provided a more comprehensive overview of the project. Individuals were asked to read about the study prior to the follow-up call within a few days to determine interest in participating in the study. Upon confirming interest, formal invitations were mailed and follow up telephone calls made to confirm attendance.

Organization of the focus group meetings included scheduling a time and place that was convenient to local participants. Monticello, approximately two hours from centrally located Little Rock, was selected as a convenient location. The Drew County DHS Administration offered the use of its conference room, which was a familiar location for most participants. The agenda slated two hours for the group meetings, including an incentive luncheon catered by a locally owned business.

Focus Group Meetings

Transportation was arranged for persons without means of attending the meetings. According to guidelines set forth for successful meetings of this type, seven to ten participants were recruited for each session (Krueger, 1994). Participation in each of the first two sessions was considerably lower than expected, averaging about 50% of those who had confirmed; however, valuable insights were obtained, and the notion that small groups afford more opportunity to share ideas was verified (Krueger, 1994). For example, when discussing the various cultures and the characteristics of those cultures represented in Drew County, a recurring response was related to the sense of pride in the region. Participants in both groups reiterated this pride, each adding a personal example of what it means to feel proud and protective of territory and heritage. The emphasis in the groups, composed of African-American and Caucasian professional women and mothers, was not placed on racial boundaries and conflicts, but on the indigenous pride of the people, regardless of ethnicity. This common perception of what made them unique motivated group members to speak freely within the group about the sensitive issues of childrearing practice and treatment of children with disabilities.

A Moderator (principal investigator of the project), Co-moderator (Educational Consultant for the SDE Deafblind Project), and respondents attended the focus group sessions. The meetings were conducted around a large table with a microphone in the center for recording responses. Although the Moderator made brief notes during the sessions, it was the responsibility of the Co-moderator to take extensive field notes of key points and notable quotes. The following vignette provides an example of "probing" for details:

- Moderator: What are the various cultures represented in Drew County?
- Respondent: There is a growing Hispanic population in the region. There is also a culture of just being from southeast Arkansas.
- Probe #1: What does "culture of southeast Arkansas" mean?
- Respondent: It's typically Southern here. There is a pride in the southeast. In fact, we have a saying, "You don't step on southeast Arkansas."
- Probe #2: Can you identify specific characteristics of this pride that would help me understand the people of this area better?

Respondent: This is our home. You can't come from somewhere else and take over here. If you are not from Drew County, it's like you are an outsider. We are cohesive and we don't trust outsiders.

Although questions were prepared (see Table 1 for sample questions), the natural expansion provided by probing encouraged participants to divulge more specific information. After the first two focus group meetings, questions were evaluated for appropriateness. Because the participants in these groups were primarily professionals, with the exception of two parents, the questions were deemed applicable to the study and comfortable for participants to answer. The questions planned for the third group, conducted in the neighborhood environment, targeted personal culture rather than large group culture and how it affects daily living with children in disadvantaged situations.

Table 1

Sample focus group questions

1. What are the various cultures represented in Drew County?
2. What are some characteristics of these cultures?
3. What different views about a child who is disabled may be related to culture?
4. What cultural factors of the region might be interfering with parents seeking assistance or acknowledging that the child is deafblind?
5. What are cultural practices within the community associated with childrearing?
6. What do you see is the role of the extended family?
7. What are barriers to someone from another culture working with families?
8. How can a service provider earn the trust of the family?
9. How can the people who provide services to children overcome cultural barriers?
10. How can churches and organizations help identify children with deafblindness?
11. When have you felt someone could have been more sensitive to your culture?
12. What advise would you give about the way we work with families?

The third focus group session followed a different format than the first two groups and targeted a neighborhood that survives below the poverty level. The results of the previous groups emphasized that transportation is a problem for these families, thus it was decided that a third group should be conducted in a way that allows easy access to parents. The Parent Coordinator for the Monticello School District, who provides volunteer homework assistance after school in this housing project, acted as liaison to this group of parents and organized a unique meeting. The district provided a school bus for the meeting to take place in "safe territory"... inside the bus. Recognizing that trust is vital to obtaining information, this approach was much more beneficial than attempting to meet in a conference room in a professional building.

Upon completion of the Drew County focus group interviews to obtain an ethnographic profile of the area, a multi-method strategy, or "triangulation" attempt, was made to verify the data and enhance the validity of the findings (Suter, 1998). To corroborate responses obtained during group sessions, follow-up letters were sent to persons who were confirmed to attend meetings but were unable to do so. They were asked to respond to a Likert-scale series of statements that checked their level of agreement about cultural values determined in the focus groups. For example, a question asked during the focus groups was, "What do you see as the role of the extended family?" A recurring response related to the role of the maternal grandmother. A corresponding statement to verify the response read "Maternal grandmothers are influential to families within my culture." Those who participated in the meetings also were asked to verify the statements for accuracy (from "strongly agree" to "strongly disagree") and discuss the issues with family and friends for additional opinions. A potential method for expanding the pool of respondents on these cultural questions would be to submit the statements to DHS County

Administrators in the surrounding counties. Results of the focus groups and triangulation efforts were analyzed to detect recurring themes, patterns or explanations for the reasons that parents, caregivers, and professionals in contact with these families fail to identify and receive subsequent early intervention for children who have dual sensory impairments.

Project Outcome

The networks that were established incidentally throughout the course of the project will remain intact and functioning, maintaining clear lines of communication between agencies, service providers, and parents. As the project continues to investigate cultural influences, the information obtained may result in several systemic changes, beginning with the Arkansas SDE's child-find methods and materials. Ongoing changes include informational materials development (i.e. brochures, public service announcements, posters) that address the characteristics identified as unique to Drew County residents. The annual Federal Deafblind Census conducted in March/April, 2000 and subsequent years will be the primary determinant of the project's effectiveness, thus deciding how the model's expansion might assist other areas of the state with similar problems of identification and service provision.

Using Cultural Information for System Change

Since ethnic minority groups compose a significant portion of rural populations and those in low socioeconomic categories (Helge, 1991; McLoyd, 1991), it is imperative that service providers explore cultural characteristics within a family. As a caution, it is valuable to remember that all families within a given culture are not the same and that cultural attributes vary from family to family (Turnbull & Turnbull, 1995). Traditions and values that are family-specific can not be generalized to other families within the larger culture. The isolation of rural cultures may result in sub-cultures and individual family cultures contributing more to the dynamics of the family than the larger cultural group (Helge, 1991). This project has confirmed that families were more affected by the economics of the rural culture than by the racial differences within the community. The participants in this research project emphasized that fierce pride in their community contributed to resistance to "outsiders" working with their children. They preferred that professionals show personal interest in families without meddling in private affairs when establishing the parent-professional team relationship.

Assimilating basic cultural information, such as acquired during this project, has been determined to facilitate communication, aid in establishing a working relationship with the family, and help the service provider develop a respect for the perceptions and values of the family unit. The process by which a practitioner (a) obtains the knowledge base, (b) discovers an individual family's degree of acculturation, (c) discusses differences with the family, and (d) adapts programming according to the value system of the family is the foundation of building effective parent-professional intervention (Kalyanpur & Harry, 1999), and is referred to as establishing a "posture of cultural reciprocity" (p.115). The procedures followed during the course of this project reinforced the investigator's understanding of minor cultural differences that affect how families respond to professionals. An openness to these differences proved to be the most valuable tool for developing trust with the participants.

When defining cultural characteristics, caution against stereotyping and perpetuating "culture-biased thinking" should be exercised at all cost (Turnbull & Turnbull, 1997). Lieberman (1989) emphasized the importance for the service provider to consider subsets and individual perceptions within the culture, in addition to understanding general characteristics of a specific culture. It should also be noted that a myopic attentiveness or single-minded focus on cultural differences might make it more difficult to locate the similarities between people. Analyzing one's own cultural perspective in the pursuit of self-awareness and subsequently communicating openly about culture-specific information has been determined to facilitate the formation of working relationships that might otherwise have been strained due to value differences (Chen, Brecken, & Chan, 1997). The process by which one becomes culturally sensitive will be ongoing throughout the course of service to the family.

Remembering that all families have strengths, and capitalizing on these strengths when developing programs, is the best way to ensure an effective collaboration between professionals and families.

Conclusion

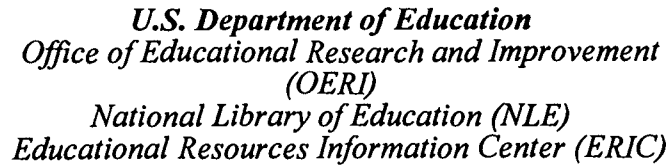
Short-term results of this project included the immediate revision in child-find efforts that considered the responses obtained in focus group activities. Informational materials were developed that considered basic values of the region, such as emphasizing the pride demonstrated in southeast Arkansas. Posters and brochures now feature pictures that reflect ethnic diversity, a simple but important consideration in the development of training curricula, informational mediums, and teaching materials used with children. Communication networks were established through this project that assist with the location of children with deafblindness. Isolation of resources and lack of communication between agencies was discovered to be a problem in remote areas of the state and efforts to improve the situation were implemented. Collaboration, the emphasis of this grant project, will be maintained long after the grant support is expired. The long-term results of the project will be application to other pockets of rural Arkansas that are under-represented on the deafblind census and envelop other cultures not heavily represented in southeast Arkansas.

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