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# Meeting the Nutrition and Feeding Needs of Children with Disabilities: A Training Model for Health and Education Personnel in the Outer Pacific

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*Infants and children with disabilities are at increased risk for problems with nutrition, feeding, and growth. Such problems are particularly acute in the U.S. Pacific jurisdictions where the overall health status is poor in comparison to U.S. national standards. As with many rural areas in the U.S., the U.S. Pacific jurisdictions lack adequate numbers of trained personnel to meet the feeding and nutrition needs of children with disabilities and their families. In order to address this need, a "nutrition mentoring" program was developed to train local health and education personnel in the U.S. Pacific region to provide nutrition and feeding supports to children with disabilities and their families. This article describes the training model and its implementation, as well as the benefits and challenges of implementing a similar program in rural areas of the U.S.*

Children with disabilities are at increased risk for undernutrition due to a myriad of emotional, physical, and social stresses that may include financial factors; chronic use of medications, complicated feeding problems, and delays in the development of feeding skills (American Dietetic Association, 1992). The undernutrition is reflected not only in poor growth and weight gain, but also in behavior. Undernourished children become inactive and apathetic. Their attention span and exploratory behaviors decrease, resulting in decreased interactions with the environment which, in turn, is thought to be responsible for the adverse effects of poor nutrition on cognitive development (Pollitt, 1994).

Feeding and nutrition problems for children with special needs are particularly acute in the U.S. Pacific jurisdictions, where the overall health and nutrition status is poor in comparison to U.S. national standards. Hepatitis B infection (and its serious neurological sequelae in young children) is a critical problem, with estimates of antigenemia ranging from 20% to 100% (Pacific Island Health Officer's Association, 1993). Other common causes of child morbidity in the Federated States of Micronesia (FSM) for children under 5 years of age include chronic otitis media, perinatal substance abuse, prematurity, anemia, vitamin A deficiency, and other forms of malnutrition, viral meningitis, child abuse, measles, and diarrhea. The most common developmental disabilities are cerebral palsy, achromatopsia, mental retardation, and visual and hearing impairments (blindness and deafness) (Pacific Island Health Officer's Association, 1993).

Furthermore, as with many rural areas in the U.S., the U.S. Pacific jurisdictions lack adequate numbers of trained personnel to meet the feeding and nutrition needs of children with disabilities and their families. Trained nutritionists and dietitians are rare, and when there is a local provider, it is unlikely they have experience or expertise in working with children with disabilities. Furthermore, the complex nature of feeding problems in children means that no one service provider can meet the needs of all children with disabilities, particularly with the geographical isolation of families on remote islands and atolls.

This article describes the efforts to develop a training program to address the need for feeding and nutrition services for children with special needs living in the remote Pacific Islands of the FSM. Though thousands of miles from

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the U.S. mainland, children with special needs and their families face many barriers that are similar to those living in rural areas of the U.S. mainland. The benefits and challenges of implementing the program are discussed, particularly as they relate to service provision in remote areas.

*The Federated States of Micronesia*

*Location.* The U.S. Pacific region stretches thousands of miles west of Hawaii. It is a vast archipelago of over 2100 volcanic islands and coral atolls that cover an area approximately the size of the continental United States. The islands were acquired by the U.S. following World War II and now operate as independent political entities. Compacts of Free Association with the U.S. Pacific jurisdictions provide financial aid in exchange for U.S. military access.

The FSM include four separate states: Pohnpei, Chuuk, Yap, and Kosrae, with a total population of approximately 127,377. Although the four states share a common history, there are significant differences in culture and language among the different states. Eight different languages are spoken in the FSM, with English as the common language (Stanley, 1992). The FSM is the least developed and most rural of all the U.S. Pacific island jurisdictions, with more than 75% of the population living in remote, rural settings. All the FSM states, with the exception of Kosrae, comprise a significant proportion of outer islanders who have limited and infrequent access to the capital centers. The cultural heterogeneity, compounded by the great distances from island to island, present formidable challenges to service delivery.

*Health status.* Nearly half the population of the FSM is under 15 years of age; 75% are under age 25. Infant mortality is 45.2 deaths per 1,000 births, with prematurity accounting for the greatest number of deaths. The sixth leading cause of infant death is nutritional disorders. Children also suffer from other disorders caused by poor nutritional practices, poor environmental sanitation, and substandard water quality. One of the most common problems of 3- to 5-year-old children is dental caries, which have a prevalence rate 3 to 5 times that of U.S. mainland children. This is due not only to the lack of adequate dental services, but also to poor nutrition and inadequate oral hygiene (University of Hawaii, 1989).

*Services for children with disabilities.* In the FSM, there are an estimated 3,300 students identified as having disabilities who are eligible for Part B services (Spencer & Hicks, 1995). (The FSM is not eligible for Part C funding). However, these numbers are believed to be an underestimate of the true population of children with disabilities, as many children are not identified, particularly those children living in the outlying villages and atolls (H. Ichiho, personal communication, November 6, 1995). Education departments in the FSM are currently providing services to about 2,000 of these students (Spencer & Hicks, 1995). There are 169 special education teachers serving children with disabilities in the FSM. Of these, only 63% have their associate degree and 31% have no degree (Spencer & Hicks, 1995).

Maternal and Child Health services to children with disabilities are equally limited. There are a few physicians, primarily on short-term contracts, and locally trained medical officers with experience working with children with special needs. The same is true for nurses, few of whom are baccalaureate-prepared. There are no physical therapists, occupational therapists, or speech pathologists in the FSM. While there are some persons who have received short-term training in nutrition, there are no fully trained registered dietitians or fully qualified nutritionists in the FSM who have training or experience with children with special needs (University of Hawaii, 1989).

## Methods

One recent effort to improve services for children with disabilities in the U.S. Pacific jurisdictions is the State Systems Development Initiatives (SSDI) Projects funded by the U.S. Department of Health and Human Services. Through the implementation of the SSDI Project in the FSM, a system of comprehensive identification, screening, assessment, and referral for children with special needs was developed. The SSDI Project included diagnostic and functional assessments, and intervention services for children with special needs in each of the four FSM states. Children with Special Health Needs (CSHN) Clinics were established in each state with a team of providers from the Department of Health and the Special Education Department.

The large numbers of malnourished children with disabilities referred to the CSHN clinic brought to the forefront the need for training in identifying and caring for children with feeding and nutrition problems. To meet this need, the SSDI consultant in the FSM (H. Ichiho) worked with an interdisciplinary team from the Hawaii University Affiliated Program (UAP) and the University of Southern California UAP to develop and implement a training model that would meet local needs. The members of the team represented the disciplines of nutrition, speech language pathology, physical therapy, psychology, medicine, public health, and special education. (Members of the team have degrees in more than one discipline.) Additional resources were provided by the Region IX Nutrition Mentoring Project funded by the Maternal and Child Health Bureau, U.S. Department of Health and Human Services.

*Core Principles of the Training Model*

The training team developed the training model based on the following core principles.

*Interdisciplinary training.* An interdisciplinary effort is necessary because of the complex nature of feeding and nutrition problems associated with children with disabilities. No one person or discipline has the knowledge or expertise to deal with the multitude of feeding and nutrition problems that can arise. Furthermore, given the limited resources and limited numbers of trained personnel available in the FSM, it is essential that providers from different agencies work collaboratively to meet the needs of these children and their families. Feeding and nutrition can not be seen as only a "health" issue. All providers working with children with disabilities must recognize nutrition and feeding services as an important part of their responsibilities.

*Local capacity building.* The FSM, like many other Pacific jurisdictions, frequently hires contract workers and consultants from the U.S. mainland to meet personnel shortages. While the short-term needs of some children may be met, the heavy reliance on contract workers and consultants is fraught with problems including the following: (a) contract workers and consultants are costly, typically charging anywhere from $200 to $500 a day, plus travel expenses; (b) hiring off-island does little to build local capacity to provide services on a long-term basis; and (c) the short-term nature of the contracts results in fragmented programs that lack continuity and consistency. Therefore, this project sought to identify and train local providers who would then have the knowledge and skills to train others.

*Locally-driven and culturally-appropriate practices.* Local providers must be involved in developing the training sessions, including identifying areas in which training is needed and training methods that are effective and culturally appropriate. Local experts must provide knowledge of local food habits and customs to assure that recommended strategies are in keeping with the cultural norms. If this does not occur, there is the danger of focusing training around foods that are not readily available or skills that are not valued or functional within the island culture (e.g., eating with a spoon or fork).

*Training activities combined with service delivery.* The dire need for services demands that training activities be conducted in such a way that children and their families also benefit. One method that has worked well in the Pacific has been to focus the training on individual children and their families. Children and families who are willing to participate in the training become the focus around which information is provided and skills demonstrated. Families of the children receive new and useful information, while participants gain experience in real-life contexts.

*Family-focused training practices.* The training activities must be sensitive to the needs of the child and family, and these activities must respect families as equal partners in the learning process. Arrangements must be made to assure that training sessions are conducted in a way that is comfortable for the family. This may include inviting other family members or close friends to the session, assigning a service provider who knows the family well to sit with the family and explain the process, or other accommodations that are consistent with the customs of the family. Given the many different languages spoken in the FSM, it is important that an interpreter be available for those families who wish to communicate in their spoken language.

*Functional skills in natural settings.* Training must reinforce the importance of integrating treatment strategies and recommendations into the child's and family's natural routines. Mealtime is a naturally-occurring event that provides opportunities to support not only feeding and nutrition interventions, but also communication, socialization, and motor skills. Providers must work together to integrate information from their various disciplines to develop program plans that can be implemented during the family's daily routines.

*Planning the Training*

Input regarding the content of training and the training methods was obtained from several different sources. The Maternal and Child Health (MCH) Program Manager in the FSM national government was consulted to assure that the training was consistent with the mission of MCH programs and viewed as an important facet of improving the existing service delivery system. Without administrative support, the training would be viewed as simply another activity, with little chance of making lasting changes in the system of services for children with disabilities and their family members. In addition, state special education coordinators from each state were contacted to inform them of the training and to secure their support for the involvement of their staff, particularly those with training and experience working with children with severe and multiple disabilities.

As communication with many of the FSM states by phone, fax, and e-mail is inconsistent and often unreliable, and because Pacific Island cultures prefer face-to-face meetings, a meeting in Honolulu was scheduled to coincide with an established annual conference to which many Pacific Islanders attend. The focus of the training was shared at this meeting. Participants identified their training needs and preferred methods of training. Dates for the training sessions and key providers to attend were identified. Based on this input, the training team developed their materials and activities.

*Developing the Curriculum*

*Competencies.* The curriculum was developed to address competencies in the areas of nutrition, feeding and oral motor development, communication development; dental concerns, and positioning and adaptations. The specific competencies are listed in Table 1.

*Training materials.* Written handouts were used which contained simple, succinct language supplemented by pictures and diagrams. Participants used the materials to refer to during and after the training sessions. While English is the common language in each state, it is the second language for the vast majority of people. Thus, having written materials to refer to assists the learning process. While videotapes were acknowledged to be useful at times, language barriers and lack of equipment to view the videotapes, particularly in the outlying villages where electricity is not universally available, make them impractical. Written handouts, on the other hand, can be easily copied and distributed.

*Training methods.* Several factors were considered in selecting the training methods. As noted above, English is the second language for the vast majority of Pacific Islanders. Therefore, training methods that encouraged active participation, rather than passive listening were used. In addition, Pacific Islanders place value on group harmony and mutual interdependence, rather than individual success and achievement. Therefore, small group discussion and problem-solving activities were used. In addition, there were other social, communication, and conversational mores that impacted the ways in which the training was conducted. Table 2 compares Western values with those of Pacific cultures, and provides examples of how these differences impacted the selection of training methods. Involving local providers in the planning helped assure that the teaching strategies and activities used were the most appropriate and effective for the participants in each state.

## Results

Providers in the states of Kosrae and Chuuk were trained during the first year of the project (1995-1996); providers in the states of Yap and Pohnpei were trained in the second year of the project (1996-1997). The decision to begin the training in Kosrae and Chuuk was made by the MCH program manager, who identified these two states as having the greatest number of children with nutrition problems and the fewest resources to address them.

*Training Schedule*

Training occurred over a 5-day period. As requested by each state, the training was divided into (a) general sessions providing basic information on feeding and nutrition that all community providers could attend, and (b) assessment/intervention sessions that focused on specific children and families. The latter training was limited to the key service providers from health and education who provide direct services to children with disabilities and their families on a regular basis. Local providers arranged the schedule to assure that there were no major conflicts with established meetings and that assessment/intervention sessions were held at times that would be convenient for the children and family members.

*Participants*

A total of 84 service providers participated in the training. The number of participants attending the training ranged from 11-36 providers in each of the four states. Participants included medical officers, nurses, special education teachers, related services assistants, Head Start teachers and coordinators, rehabilitation technicians, health assistants, and health educators.

*Pretest and Post-test Measures*

Pretest and post-test measures provided the most basic means of measuring the participant's acquisition of knowledge. In addition, the pretest measures provided information regarding topics that should be given more emphasis during the training session. The average percentage correct on the pretests by participants in the four states was 64% (range 51% - 75%). Following the completion of the training, the percentage correct averaged 88% (range 82% - 94%). A long-term evaluation of the effectiveness of the training in terms of impacts on the children and families served and changes in the system of services for children with special health needs is currently in progress.

*Children Served During the Training*

A total of 26 children and their families were involved in the training. The children ranged in age from 5 months to 16 years, with 19 (73%) of the children aged 0-5 years of age. Twenty-one (81%) of the children were diagnosed with cerebral palsy. All the children had problems related to feeding and nutrition as identified by their parents or service providers. Summaries of two children around whom the training was conducted are provided in the accompanying text boxes. They are representative of the types of problems and issues faced by children with disabilities and their families living in the FSM, and provide examples of how the core principles were actualized in the training.

Table 1
*Competencies of the Training Model*

Upon completion of the training, participations will:

*Nutrition*

1. Describe the importance of an interdisciplinary team approach to meet the nutritional needs of children with disabilities.
2. Describe the importance of nutrition to the child's growth and ability to learn.
3. Describe the importance of nutrition in preventing infections and illness.
4. Identify factors that place children with disabilities at risk for malnutrition.
5. Identify common nutrition problems in children with disabilities.
6. Take accurate height, weight, and head circumference measurements in children.
7. Use a growth chart to analyze a child's growth pattern.
8. Complete and analyze a 24-hour diet recall.
9. Identify key nutrients in local foods.
10. Identify ways to improve a child's diet using locally available foods.

*Feeding and Oral Motor Development*

11. Describe the basic stages of oral motor development in young children.
12. Identify oral motor problems frequently seen in children with disabilities.
13. Demonstrate ways to help children with oral motor problems to eat and drink more effectively including how to facilitate movements of the tongue, lips, and jaw.
14. Identify ways to change the texture and consistency of food and liquids to help children with oral motor problems eat more easily and safely.

*Communication Development*

15. Describe the basic concepts of communication and language development in young children.
16. Identify opportunities during feeding and mealtimes (as well as during other daily activities) to facilitate communication development (verbal and nonverbal) in young children.
17. Describe the relationship between the development of oral motor skills, and the development of feeding and expressive language.

*Dental Concerns*

18. Describe the importance of good oral health to promote good nutrition and speech.
19. Describe why children with disabilities are at risk for dental problems.
20. Describe ways to prevent baby bottle tooth decay.
21. Identify strategies to promote healthy teeth and gums.
22. Demonstrate ways to brush and clean the teeth of children with oral motor problems.

*Positioning and Adaptations*

23. Demonstrate ways to position and hold a child to help him/her eat and drink safely and comfortably.
24. Demonstrate ways to help comfortably move children into and out of positions.
25. Demonstrate ways to lift and carry children in ways that are safe and comfortable for the child and caregiver.
26. Use local materials to develop seating devices that will make meal times comfortable for the child and caregiver.
27. Adapt cups, plates, and eating utensils to promote self-feeding.

*Pelson: An example of the importance of involving local providers in the implementation of training to assure cultural-appropriateness.*

Pelson is a 5-year-old child with significant delays who consumed all his nourishment through a baby bottle in which coconut milk was combined with a variety of foods including rice, fish, and vegetables. After establishing that Pelson was adequately nourished (based on growth measurements and usual food intake information), the local health and education providers (with assistance from the consultation team) worked with the family to implement a program to encourage Pelson to eat without using the bottle.

It was not an easy task as Pelson resisted with yelling, crying, and throwing food. An unforeseen problem was the reaction of village members who believed that the family was hurting Pelson by withholding the bottle. The family, along with the local team, decided that a village meeting should be held, led by the coordinator of the local Head Start program (himself a village leader), to explain the importance of teaching Pelson to eat from other than the bottle and to assure them that he would not be harmed. With pressure from her fellow villagers diffused, and with continued support from the local health and education providers, the family was successful in withholding the bottle from Pelson. Follow-up reports indicated that approximately one-month later, he was finger-feeding (consistent with the cultural norm) and using a cup for liquids.

Functional assessments were conducted with each child and family, with particular attention to feeding and nutrition concerns. Participants worked with the training team to conduct the assessments and develop intervention plans, including the development of goals and objectives for their individualized educational programs. This included assessments of growth, nutritional status, diet, oral motor skills, gross and fine motor skills, and communication skills. Participants were able to observe and practice specific feeding techniques, as well as conduct diet recalls with the family members regarding their child's diet. Time was devoted at the end of each child's visit to summarize the assessments and intervention plans, and to reinforce key concepts and strategies. The training team wrote individual reports for each child for the hospital and school records; a copy was also provided to the child's family (with translation provided by the local providers).

*Delvin: An example of the need to combine training and services with an interdisciplinary focus.*

Delvin is a 4-year-old boy with cerebral palsy, spastic quadriplegia. A 24-hour dietary recall (completed during the training session) and growth measurements showed that he was undernourished and needed to consume greater quantities of high energy foods. Oral-motor involvement as well as difficulty in positioning Delvin made feeding a long and difficult process. The training session was used to introduce health and education staff to positioning and handling techniques, and ways to manage the tongue thrusting that interfered with his eating and drinking. In addition, a list of ways to increase the energy content of the food using local resources (e.g., coconut oil) was developed. Visits to the family home were scheduled by health and education providers to follow-up on recommendations. Health and education providers also committed to constructing a beanbag chair (using fabric and recycled Styrofoam pellets available from local businesses) to help with positioning in the home.

*Follow-up Training*

The geographical distance of the FSM from Hawaii and the U.S. mainland necessitated the development of several different strategies to support the participants to continue with their efforts to provide nutrition and feeding services to children with disabilities. First, when participants have been in Hawaii for other regional meetings, the project has arranged to have a separate meeting to discuss issues related to feeding and nutrition. The participants were asked to bring information about the children seen during the training such as growth measurements, progress in meeting specific goals and objectives, and any additional problems or concerns. Second, members of the training team who are traveling in the Pacific on other projects have followed up with the children and families seen during the initial training, and have worked with the service providers to continue to support the feeding and nutrition needs of the child. Third, plans are being made to support service providers to translate key written materials into their own languages for distribution to family members. Finally, intensive clinical training experiences in Hawaii are being developed for those participants who wish to gain additional training.

Table 2
*Cultural Values, Beliefs, and Practices: Implications for Training in the Pacific*

| Cultural Considerations | Western System | Pacific Cultures | Implications for Training |
|---|---|---|---|
| Achievement | Value is placed on individual success and achievement. | Value is placed on harmony and group. | Activities and instruction should focus on group achievement, rather than individual achievement. |
| Communication | Communication is direct. Asking questions and giving eye contact, show interest, attention, and respect. | Communication is indirect. Asking questions and giving eye contact are disrespectful. | Be aware of nonverbal communication that conveyus confusion/questions about information presented. |
| Conversational Styles | Silence during conversations is uncomfortable and implies lack of interest/knowledge. | Silence during conversation signifies time for thought. | Allow time for students to respond to questions; do not interpret silence as lack of interest/thought. |
| Social Orientation | Competition and aggressiveness are acceptable. | Value is placed on cooperation, nonconfrontation, and reconcilitation. | Use cooperative learning strategies, rather than competitive learning strategies. |
| Expression | Self-promotion and egocentrism are acceptable. | Modesty and self-effacing behaviors are valued. | Praise or reinforce the entire group rather than calling attention to the accomplishments of individuals. |
| Family Structure/ Support Networks | Individual autonomy is valued. | Extended family are significant sources of support. | Include extended family members in training. |
| Health Beliefs and Practices | Value is placed on a rational, scientific approach. | Traditional healers and methods may be used. | Respect traditional beliefs and and adapt recommended strategies so as not to interefere with beliefs. |

## Conclusions

### *Lessons Learned: Implications of the Training Model for Rural Communities*

Service providers in the FSM share many of the same challenges in meeting the feeding and nutrition needs of children with disabilities and their families as their counterparts in rural areas of the U.S. Their geographical isolation, lack of trained service providers, and limited resources make traditional inservice training approaches ineffective. The experience and knowledge gained in developing and implementing the training model in the FSM have provided valuable lessons for developing training models in rural areas. These include the following:

*Assure that the training is integrated into the larger system of services.* Targeting the training to meet goals that are consistent with the mission of key agencies is important to effect change in the overall service delivery system. The support of administrators is key not only to allow staff to participate in the training, but also to make changes in policies and procedures that will make lasting improvements in the services for children with disabilities.

*Facilitate a transdisciplinary approach to services.* Adequate nutrition is essential for life and should be the concern of all service providers. The absence of profes-

sionally-trained nutritionists and other service providers (e.g., physical and occupational therapists, speech pathologists) in the FSM, as well as in many rural areas of the U.S., makes it even more essential that all service providers have the basic knowledge and skills to identify and support children with disabilities who have feeding and nutrition problems.

*Involve community providers, consumers, and family members in planning and implementing the training.* Rather than assuming the role of "expert consultants," the training team collaborated with the local service providers in each state to plan the training. Local providers provided input on the desired training methods and content. They also selected the families to participate in the training and decided whom to invite to the training. They were critical in providing the training team with information about local diets, cooking methods, and food resources. They mentored the team to communicate and socialize in ways that were sensitive to cultural norms and customs. This collaborative model of training facilitated the "ownership" of the training by the local providers and made the training much more effective and culturally appropriate than would have been possible without their active involvement.

*Use locally-available resources.* Locally-available foods and supplies (e.g., children's cups) were used in the training, rather than bringing in supplies from Hawaii or the U.S. mainland. Demonstration with readily-available supplies is important so that local providers can implement recommendations without waiting for off-island supplies to arrive. This was particularly important for seating and positioning devices. Rather than relying on ready-made items purchased from U.S. mainland catalogues, participants were encouraged to use local materials and resources.

*Combine training with services.* Involving children with disabilities and their family members in the training provided important training opportunities for the participants, as well as much-needed services to the children. Participants observed training team members working with children and family members, thereby reinforcing family-centered practices. Participants were able to practice and apply their new skills to obtain immediate feedback from the training team. Since many of the child's current service providers participated in the training, this helped assure follow-through on the recommendations made by the participants and training team members.

*Provide follow-up training.* As with most inservice training efforts, questions arise following the completion of the training when participants return to their own settings and try to implement what they have learned. The geographical isolation of rural areas makes this a challenge. Given the inconsistent access to technology (e.g., e-mail), follow-up for this training effort has been limited to communication by phone, FAX, surface mail, and face-to-face meetings. For rural areas that have ready access to technology, we have found that sharing information via e-mail and videotapes is an efficient and effective way to provide follow-up training and technical assistance.

*Future Challenges*

The greatest challenge for training personnel in the remote islands of the Pacific region and similar rural areas is the limited local capacity to conduct training sessions where populations are small, where cultural and linguistic diversity exits, and where geographical distances from population centers are great. Long-range impacts are limited if the trainers do not work within the existing system of service delivery and do not provide follow up and technical assistance to assure that new skills are implemented and program improvements for children with disabilities and their family members occur. The project described has been successful in leveraging funds from other technical assistance providers and combining the training with other regional training efforts as one way to decrease the costs and provide follow-up training. However, many challenges remain to evaluate the effectiveness and appropriateness of outreach training and technical assistance models for rural and remote areas of the U.S. Some of the major issues addressed in the interdisciplinary approach implemented include (a) culturally-sensitive strategies with linguistic and resource adaptations; (b) mentorship of local providers; (c) problem solving around families and children with participants in training sessions; and (d) identification of key contact personnel in each locale for follow up. Barriers to meeting the needs of families and children with special needs and nutritional problems are formidable. Continued vigilance and consistent follow up using practices that were demonstrated in the present approach require collaboration and commitment, as well as a collective effort to identify all available resources in underserved rural areas. Those outside agencies who receive U.S. federal funds have a particular responsibility to maximize federal and local resources through mandated services in programs that include special education, Head Start, and Maternal and Child Health.

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