

Early Intervention Services With American Indian Tribes in New Mexico

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Abstract

Typical approaches to early intervention services, as carried out in many parts of the United States, may not be practical or successful with traditional American Indian families and communities. New Mexico, home to 22 tribes (19 pueblos, Navajo, and 2 Apache tribes) with eight indigenous languages, has worked through its Part C Family Infant Toddler (FIT) Program to support services for all communities in ways that meet community and cultural norms. This has led to examination of service delivery approaches, community based services guided by local American Indian leadership, and scrutiny of early assessment and evaluation in a culturally appropriate manner, compatible with state and federal regulation. This overview of the early intervention system, its challenges and opportunities, shares features of early intervention programs serving New Mexico tribes, and speech-language services in the context of family-centered philosophy, and culturally competent service delivery.

Many changes have affected our perspective and practice of Early Intervention (EI) since Federal Public Law 99-457 first created a national system to support young children, from birth to the age of 3, with disabilities and their families in 1986. Developed as a “family-centered” service, EI consistently has worked to promote the child’s best opportunities for development, to lessen the effects of a disability or potential disability, and to maximize the child’s ability to be part of her “natural environment,” where typically developing children live, play, and learn. This is best accomplished in the context of the infant or toddler’s family and home, building on the relationships of the people closest to the child, who will be part of his world not only in the early years of development but for a lifetime.

As part of the Individuals with Disabilities Education Act (IDEA), and now The Individuals with Disabilities Education Improvement Act (IDEIA), EI, or “Part C” service, was constructed within educational law, working to address the unique aspects of early development and family support separate from a more traditional structure of public schooling and special education services. EI was a unique creation, blending early childhood development, special education and rehabilitative therapies, special family instruction, nutrition, service coordination, and other services delivered through a family-centered philosophy. It veers sharply from the confines of the school day or educationally necessary supports; rather it supports the family in supporting the child.

This has presented many challenges for the field over the years, not the least of which is the development and support of a work force that can take on the tasks associated with family-centered service in home and community locations. The home visiting approach requires a workforce trained in individual and family support, knowledge of diverse family needs, sensitivity to diverse cultures and family practices, and an ability to promote the child’s best

opportunities for development outside of a typical classroom or clinical therapeutic setting. While professional teachers and therapists bring skills needed in EI, they do not always bring the training and education needed in providing services in non-traditional settings (Peebles & Pedersen, 2005), of being a consultant to the parents who will carry lessons and approaches forward long after the teacher or therapist is no longer working with them (Buisse & Wesley, 2005), and of adapting to the unique cultural and linguistic context of each family's life (Harry, 2002).

Each state has identified a "lead agency" to design and coordinate its own EI service delivery system within IDEA Part C. New Mexico's EI system is carried out by over 30 individually contracted provider agencies serving specific geographic areas in the state. This has resulted in a formal network of providers, coordinated by the New Mexico Family Infant Toddler (FIT) Program of the Department of Health, lead agency for Part C in the state. While any of the contracted providers may serve American Indian children, the vast majority of that population resides in the northwestern quadrant of the state. Among the 22 tribes of New Mexico, there are eight spoken indigenous languages. Communities may have close physical proximity as in several of the pueblos, or may be located at great distances from each other. The vast Navajo Nation, for example, which sprawls across the four corners region of the United States (Arizona, Colorado, New Mexico and Utah), is similar in size to the state of West Virginia. There are less than 1,400 miles of paved road within the 26,000 on the Navajo Nation (Navajo Nation Profile, n.d) and over sixty percent of households do not have telephone service (Navajo Nation Economic Development, n.d.). Each tribal group is unique in size, location, needs, resources, language, and culture. Cultural and linguistic differences within and across each tribe require cultural sensitivity by providers.

Cultural Considerations

An understanding the cultural influences of communication, development and service delivery in early intervention is recommended (Hanson, Lynch & Wayman, 1990; Harry, 2002; Joe & Malach, 1992). From the perspective of early intervention services, Roberts and colleagues (1990) explained that cultural competence refers to "a program's ability to honor and respect those beliefs, interpersonal styles, attitudes, and behaviors" of both the families and staff who are providing services, and that competence implies "skills which help to translate beliefs, attitudes, and orientation into action and behavior" (p. 1). An example of cultural competence, according to this view, is helping families gain the services needed by honoring traditions within the tribes, acknowledging family choice and decision making, and respecting families' usage of both traditional and western (Euro-centric) views of disability and intervention (Roberts, Rule, & Innocenti, 1998). Respecting family decision making may mean that the services are delayed until the family has had a chance to seek traditional medicine. EI program services that support family preferences and choices are likely to effectively engage families in tribal communities. At times program policies may not be amenable to family situations. For example, a common Navajo practice is for a family to move to different homes in the summer and winter. When these homes are located in a different county or state, it can be cumbersome for both the EI program as well as families with disruption of continuity of services (Roberts, Jump, Gutshall, Morris, & Seanez, 1999). A coordinated system of supports and cultural understanding in EI is needed to respect family decisions for where services are delivered. Sensitivity to where and how families live, families' beliefs, and language needs is essential. When cultural and linguistic differences are respected, partnership can lead to shared problem-solving between staff and families as they face challenges in EI service delivery.

Challenges

Currently in New Mexico, American Indian children appear to be underserved through EI services (A. Gomm, personal communication, June 11, 2009). American Indian children

represent about fifteen percent of births in New Mexico, but only 10 percent of these children were served in EI last year (A. Erikson, personal communication, July 2, 2009). While the New Mexico EI program reaches out to all counties in the state, fewer American Indian children were enrolled in the program with Individualized Infant Family Service Plans (IFSPs), than might be expected. Difficulties in recruiting and retaining staff, distances and communication (as described above), and cultural connection with families have been cited as possible reasons for this difference (A. Gomm, June 11, 2009).

The importance of timely, consistent, and appropriate intervention is well documented in the professional literature (Ramey & Ramey, 1998). While outcomes for children are affected by a family's access to services, access also must be compatible with a family's values and culture (Hanson et al., 1990). Developing a work force with diverse skills of child development, special needs, intervention techniques, and cultural competence is a challenge. As a result, the issues of general workforce shortages are compounded by the need for interventionists that know and understand the unique cultural context of the families with which they work.

These challenges may be answered through the possibility of new and evolving models of EI services, supports, and approaches available to American Indian and other underserved families. There are American Indian communities in which EI is a strong and valued part of families' lives when services are needed. New Mexico's early intervention providers serving most of the American Indian communities have been part of the service delivery system for many years, becoming part of the communities in which they work in different ways.

The flexibility offered in New Mexico, through the individual contracts with independent EI provider agencies, may contribute to the emergence of new models and the success of veteran programs. These include communities that organize and develop their own services and achieve success in engaging families in EI services. An example of this is Laguna Pueblo, located 40 miles west of Albuquerque, NM, where EI services are part of larger early childhood efforts and under the guidance of the Laguna Department of Education. Early childhood programs were built with the intention of creating community collaboration across all services for young children and their families. This was the continuing guidance of tribal leadership and it has resulted in families responding positively by enrolling their children in a wide range of services (C. Riley, personal communication, August 20, 2009). Another New Mexico EI program serving American Indian children and families is the Native American Pueblo Parent Resources (NAPPR). While offering services by a diverse staff over many years, NAPPR has developed long term relationships with Native American communities. The success of NAPPR, however, largely may be attributed to the fact that, while not tribally connected, oversight is conducted by an all American Indian board of directors that actively provides guidance in program decision making (J. Larson, personal communication, July 2, 2009). The presence of American Indian leadership is consistent in these two examples of successful service delivery in EI. Clearly, there are pockets of success as well as communities and children that are underserved by EI in New Mexico.

Arcia, Keyes, Gallagher, and Herrick (1993) explored possible reasons for underutilization of services by families of young children with disabilities. While their research was conducted more than a decade ago, the same issues persist today. They noted that general public awareness campaigns may not be sufficient, and that such efforts need to be designed to target underserved minority populations. In addition, they recommend following a family's lead in defining family membership, supporting families in choosing assessments and services that make sense to them in the context of their lives and cultures, and remaining flexible in all aspects of service to the child and to the family.

Recommendations such as these, however, call for an appropriately trained workforce, prepared not only with skill in early development, assessment, and service delivery, but also with the ability to interact respectfully and successfully with diverse families and cultures

(Fenichel & Eggbeer, 1991). This is essential to providing EI services among American Indian populations. Difficulty in recruiting and retaining well-trained staff with skill in working with diverse cultures is an issue felt by New Mexico's EI providers (Peebles & Pedersen, 2005). One approach taken by the Indian Health Service, a division of the U.S. Public Health Service serving Indian populations, is the institution of loan repayment programs for physical, occupational, and speech therapists (for fiscal year 2009) to work in communities that are underserved. Extending this to EI service providers in New Mexico may help recruit and retain specialists and is an area currently being explored by the New Mexico Interagency Coordinating Council for EI. In addition, the New Mexico FIT Program has instituted reflective supervision as a way of supporting all EI providers, formalizing this requirement in state regulations for EI programs. As a tool, such supervision provides support to early interventionists and works to reduce isolation and address elements of practice in a supportive way (Fenichel & Eggbeer).

Other approaches to consider in ensuring that American Indian communities receive quality EI services must include training and recruitment of community members to provide the services families and young children need. This will require a long-term commitment of tribes, the EI system, and individuals working toward specialized degrees. In addition, programs serving tribal communities may consider co-treatment models where a tribal paraprofessional accompanies and supports the work of a non-Indian provider in delivering services together to families and children.

Practical Considerations in American Indian Populations

Typical elements of EI service provision across the United States may not be a good fit with American Indian populations in New Mexico and elsewhere. Some of these elements include approaches to effective public awareness campaigns and compliance with federal requirements and timelines which may not be compatible with local American Indian cultures and needs. The percentage of American Indian children receiving EI services in New Mexico appears to have gradually declined over the past several years (14% - 2004; 13% - 2005; 12% - 2006; 11% - 2007; 10% - 2008) (A. Ericson, personal communication, June 30, 2009). However, caution is essential when making assumptions from data, especially those representing small populations and small numbers of individuals (A. Ericson, personal communication, June 30, 2009).

There is a plethora of brochures, recruitment posters, and other visually engaging materials informing the public about EI services and their value in New Mexico. American Indian families frequently are depicted in New Mexico's public awareness campaigns. However, one must ask if those typical means of providing information are effective in engaging American Indian families in EI services. Traditional Native approaches to interaction have been those embedded in relationships, cultural common ground, and clan and family connections. It is, therefore, much more personal and developed over time than through public awareness campaigns.

Growing in Beauty (GIB), the Early Intervention service coordination program of the Navajo Nation, has developed an effective way of reaching out to and recruiting Navajo families whose children may be eligible for EI services. The GIB approach was created several years ago to support and enhance the work of state contracted EI providers serving Navajo children on and near the Navajo Nation. GIB established itself as an "interim service coordination" program, working as a bridge for families from their healthcare and community environments to the range of EI services, including speech therapy, offered by the state contracted providers. At this time, GIB does not provide direct EI services itself, but works in collaboration with local and state funded providers to link families to those services. Located at each of the Indian Health Service Units on the Navajo Nation, GIB employs a staff of interim service coordinators, frequently paraprofessionals, who follow up on referrals from health care providers, community services, and families themselves, connecting children and their families with appropriate EI

supports. GIB staff members are Navajo speakers, usually from the communities in which they work. They participate in a variety of early childhood networks in New Mexico, representing GIB and the needs of Navajo families on the Interagency Coordinating Council, local transition teams, training and technical assistance groups, and other organizations created to support children and families. Currently, one GIB staffer is housed at the Center for Development and Disability at the University of New Mexico (UNM), to help facilitate access to the UNM Hospital Neonatal Intensive Care Unit for families of newborns with significant health issues that require intensive care.

GIB is exploring opportunities to become a direct service provider for Navajo infants and toddlers on and near the Navajo Nation through a formal contract with New Mexico's FIT Program. Such an arrangement would require GIB to enlist staff beyond interim service coordinators to include therapists, developmental specialists, and other specialists who could provide the 16 services within EI. How this undertaking evolves will reflect the unique needs and leadership of the Navajo Nation, working within the requirements of the Part C system and also responding to cultural, social, and economic issues of the communities and families served.

Considerations in EI Service Delivery

Therapy services for American Indian infants and toddlers are family-centered, which entail identifying the family's concerns, setting goals, and choosing intervention strategies. Services need to be accessible, responsive, and to take into consideration informal supports, that is community-based and home-based. Services including speech-language therapy services need to make sense in the cultural context.

Cultural Considerations

Knowledge and skills with respect to American Indian culture and language differences are important considerations in service delivery (ASHA, 2004, 2005). It is beyond the scope of this article to discuss in depth cultural and linguistic considerations pertaining to communication development, communication styles, socialization patterns, cultural and linguistic expectations, language use, and child rearing practices by American Indian communities in NM. However, these topics are suggested for speech-language pathologists and other team members entering the pueblos or traveling to remote homes of Navajos and Apaches. Communication styles and language use of the family are considerations that impact whether an American Indian family has a successful experience with EI (Joe & Malach, 1992). Literature on communication and learning styles is available through the ASHA website (see www.asha.org/practice/readings). In addition, ASHA has provided guidelines for providing culturally and linguistically appropriate services to clients from racial/ethnic diverse communities and addresses cultural competence, language competencies of the clinician, cultural influences on language, speech, and hearing (ASHA, 2004). While the ASHA Code of Ethics requires cultural competence in service provision and recommends an understanding of one's own culture and the culture of those one serves, it warns against making assumptions about individuals based on their ethnicity, culture, language, or life experiences that could lead to inappropriate assessment, diagnosis, or intervention (ASHA, 2005).

Service Delivery in a Family-Centered Environment

New Mexico has adopted broad eligibility for children receiving EI services. Besides established condition and 25% developmental delay criteria, the state also recognizes biological/medical risk and environmental risk as eligibility categories in EI. The nuances of consideration for at-risk determination among American Indian children and families are beyond the scope of this article, but are important factors in eligibility determination and service provision.

Technical assistance documents developed in New Mexico provide guidance on conducting assessments, determining eligibility, and planning for intervention in family-centered care. The New Mexico FIT Program (2006) promotes guidelines on components of evaluation and assessment, informed clinical opinion, diagnostic evaluation, qualitative and quantitative approaches to evaluation and assessment, observation, and requirements for eligibility. The developmental evaluation helps to provide an opportunity to partner with families in obtaining information about the child's abilities, challenges, and interests. Information on what the child is able to do, what s/he is not yet able to do, and what might be helpful in maximizing participation in family and community life is necessary for developing family/child outcomes (NM FIT Program, 2002). In particular, information on natural learning opportunities experienced by the child that are supportive of developmental needs, and that need additional support, is essential for intervention planning and development of family/child outcomes.

Information Gathering

The developmental evaluation process relies on information gathering from various sources including the family. Effective communication and interaction skills, such as interviewing to gather information, are essential in approaching all families, including those from diverse communities (Jones & Thomas, 2009). Creating partnerships with American Indian families is based on trust and rapport, and necessary for gathering information and working with families in their homes. The ability to engage in respectful, reciprocal, and responsive interactions takes skill and knowledge (Barrera & Corso, 2002). In gathering information for assessment, ethnographic interviewing has been reported to be effective in facilitating rapport building and strengthening collaboration (Westby, 1990). Westby adapted ethnographic interviewing procedures to be used with families from diverse backgrounds, and this process has provided better understanding of family functioning including daily routines and activities for intervention planning. Hammer (1998) proposed the use of ethnography to learn about families from different cultural backgrounds where the goal was to see EI and family systems through the cultural lens of the family. The clinician gathers information using observation of interactions and communication, interviews, reports, and records, which then provides information on the family's culture, beliefs, and values. Ethnographic interviewing is therefore a useful tool that allows the speech-language pathologist and the EI team to learn how families live their lives and the activities that would best promote development in communication, feeding, and swallowing through the cultural lens of the family.

Team Assessments

In New Mexico, developmental assessments are supplemented by speech-language pathologist assessments (New Mexico FIT Program, 2006). For example, some EI programs serving American Indian families use the Infant-Toddler Developmental Assessment (IDA) (Provence, Erickson, & Vater, 1995) for developmental assessments, and supplement assessment of communication skills using standardized or criterion referenced tests administered by a speech-language pathologist. The IDA is "a comprehensive family-centered assessment process that addresses the interdependence of health, family, and social factors that influence a child's development" (Erikson, 2001, p. 20). Assessment teams also may use a variety of sources of information to become informed about a child's developmental status, including observation of the child's play, observation of parent-child interactions, and routine-based interviewing (McWilliam, 2001). Curriculum-based developmental assessment is also another means of documenting development, strengths and concerns. These sources help the assessment team members, including families, become informed about the child's developmental status and functional skills. This requires knowledge of typical development, appropriate training, previous experience with and knowledge of the child, previous experience with evaluation and assessment, sensitivity to cultural differences, and being able to share and include family perceptions (Shackelford, 2002).

The assessment of communication skills entails observation of the caregiver and child interactions. How young American Indian children are being socialized to play, interact, and speak are important considerations. Assessment of language includes observation of verbal and preverbal behaviors such as use of gestures, facial expressions, and other nonverbal behaviors. Language assessment also includes documentation of communicative functions and means used to express communicative intent, and how communicative intent is expressed provides information on strategies to support interaction and communication with the caregiver. Caregiver questionnaires, observation, and interviews are informal ways to inform the team members on the child's communication skills.

IFSP Planning/Consultation

The concept of natural learning environments has become central to EI service delivery (NM FIT Program, 2002). Nationally, there has been a focus on expanding and enhancing natural learning opportunities and this has led to opportunities to develop consultative approaches in early intervention. As team members and qualified providers, speech-language pathologists (SLPs) consult with other members of the team including family members and developmental specialists. Consultation is based on collaborative relationships, which impacts the degree to which child and family outcomes are achieved (Dinnebiel, Hale, & Rule, 1996). Collaboration between caregivers and SLPs often is necessary when the needs of children are complex, such as with feeding and swallowing. Fortunately, co-treatment is supported by EI programs. When documented on the IFSP that co-treatment or consultation with other providers will be used as a strategy, it is billable under Medicaid and the Department of Health. Consultation with families, developmental specialists and other team members to support development has emerged as an effective way to serve children with disabilities and their families, particularly in American Indian communities in New Mexico.

In summary, supporting families in their everyday routines and activities will enhance work with American Indian families. By being with the family, observing and communicating with them, SLPs and other team members can learn about the family's views on parenting, child rearing, and what matters to them in daily life. The early intervention services in New Mexico strive to improve services for American Indian children with disabilities, or at risk for delay and disability, and their families. Toward this goal, EI programs will continue to place families' goals, aspirations and concerns within the context of service delivery, making program priorities those same priorities identified not only by American Indian families, but families of all children.

Conclusion

Meeting established timelines for evaluation, IFSP development and services may be contrary to the cadence of lives and relationships among American Indian people. While providers feel the pressure of performance goals and indicators in their work, they also must learn to accommodate the family's culture and ultimate availability in desired services. There are ways both can be accommodated. Training and practice with appropriate record keeping and reporting, matched with recognition of the family's needs, beyond the immediate service needs of the child, help address the priorities of both family and reporting system. New Mexico's EI program has the means of doing this; with training, reinforcement and reassurance, service providers and therapists have been successful in meeting the family's needs as well as the system's need for accountability.

While research activities remain an area of sensitivity due to historical misperception of tribal life including cultural and linguistic practices, values, and beliefs, a greater understanding of the barriers to service and the reasons for success will help those of us who provide EI services a better idea of what we can do to best serve American Indian families and children. By asking careful questions, engaging American Indian communities in a dialogue

about what is working and why, along with what supports for their children and family should look like, we will be on a better path to support children from diverse American Indian communities. In New Mexico, local American Indian leadership has been critical to creating and maintaining successful EI services. GIB's anticipated experience in crafting Navajo services through a New Mexico EI contract will help us all further examine what works, what doesn't, and why. We also will better actualize the early promise of P.L. 99-457 in delivering family-centered services when American Indian communities begin to define that and weigh in by crafting and delivering these services in a manner that reflects community and family values, culture, and language.

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