

- ◆ While every special education team must by law include parents and other family members as central team members, this is especially critical for students who are deafblind. Family members possess a unique understanding of their children's communication and learning abilities that educational teams must tap in order to complete appropriate assessments and to deliver appropriate educational services.
- ◆ The design of services and placement for students with deafblindness requires very thoughtful and personalized decision making. The goal of placement in the least restrictive environment (LRE) will only be realized when students have full access to the curriculum and educational environment in their own communication forms, engage in authentic interactions with both peers and professional personnel, and achieve according to the highest possible performance standards. Services must be well coordinated and implemented in a collaborative manner to meet the identified needs of students.
- ◆ It is important that state and local administrators work collaboratively and creatively with existing resources and develop new resources when necessary to expand state capacity and to ensure that students who are deafblind receive the specialized services necessary for equal access to education.

It is critical that the information contained in this publication be supplemented by training for state and local service providers to guide the development of services. Currently, representatives from state deaf-blind projects, Perkins School for the Blind, NCDB, NFADB, and NASDSE are working together to develop training modules on issues that must be addressed by state and local systems. There is a focus on building a pool of trainers who have expertise in the field and who are able to share their knowledge effectively. Over the next several months, all of the partner agencies in this project will work closely with the Department of Education's Office of Special Education and Rehabilitative Services and the field, to develop an implementation plan that will carry the message forward.

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## Home Visits with Families and Their Infants Who Are Deaf-Blind

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Families of infants and young children who are deaf-blind are likely to receive home visits from multiple service providers representing a variety of agencies. The main purpose of home-based early intervention is to help families promote the development of their children who have complex learning needs. To meet this goal, home visitors individualize home visits according to each family's priorities (Ridgley & O'Kelley, 2008), coach family members to use strategies that help their child learn and develop (Chen & Klein, 2008), and provide information and support (McWilliam & Scott, 2001).

Home visiting is a complex process that requires thoughtful planning and skilled practices to ensure effectiveness. According to a recent survey in California (Klein & Chen, 2008), early intervention professionals use a variety of strategies when making home visits, including providing information about learning strategies, child development, characteristics of disabilities, and resources; listening to family members and offering emotional support; working directly with children and demonstrating specific techniques and interventions; and coaching caregivers as they interact with their children. A survey of early interventionists in Australia revealed that similar strategies were used in serving families of young children with visual impairments and multiple disabilities (Chen, Griffin, & Mackevicius, 2009). In this article we describe important elements of these home-visiting practices and review research findings and current recommendations on conducting home visits with families and their infants who are deaf-blind.

## Promoting Learning and Development

A focused interview with mothers of infants with sensory impairments and additional disabilities revealed they felt that learning specific strategies to promote their children's development was the most helpful part of home visits (Klein & Chen, 2008). Similarly, parents of young children with visual impairments and additional disabilities identified "getting suggestions that fit the home environment" as most helpful (Chen et al., 2009). Effective teaching of these strategies to parents and other caregivers involve ensuring that professionals from different disciplines work together, making use of items already found in the home, embedding learning activities into everyday routines, and supporting infant-caregiver interactions.

**Interdisciplinary collaboration.** Professionals from different specialty areas should share their expertise with the family and with each other to effectively support an infant's learning within the context of family life. They should work together to identify effective strategies and use them consistently when interacting with the infant and family members. This is known as interdisciplinary teaming, and it is essential for high quality, coordinated services (Horn & Jones, 2004; Rapport, McWilliam, & Smith, 2004). For example, the intervention team for an infant with low muscle tone, moderate hearing loss, and total blindness may include service providers who are certified in the areas of hearing loss, visual impairment, occupational therapy, and physical therapy. The provider certified in hearing loss should help the family learn about the type and severity of their infant's hearing loss, available communication options and amplification devices, and ways to facilitate his or her listening skills. The service provider certified in visual impairment should share information about the infant's visual impairment and teach the family how to encourage the use of other senses and provide tactile input. The physical and/or occupational therapist should provide information on the infant's motor problems and skills, appropriate positioning and handling techniques, and strategies to encourage movement and physical development.

**Use of materials found in the home.** Current literature recommends using items and materials during home visits that families already have at home, instead of the "toy bag" containing toys and other items that many early interventionists have traditionally used when working directly

with infants. McWilliam (2007) has clearly articulated the following problems associated with the "toy bag" approach:

1. A professional toy bag sends the message that the family does not have useful items at home and that special materials are needed.
2. It gives the appearance that early intervention occurs only when the home visitor "works" with a child using specific toys.
3. It may lead families to incorrectly attribute their infant's progress solely to the time and effort of home visitors.

**Routine-based interventions.** Embedding interventions within everyday family routines takes advantage of natural learning opportunities to help children develop skills within the context of meaningful activities (Chen et al., 2009; Chen, Klein, & Haney, 2007; Dunst, Trivette, Humphries, Raab, & Roper, 2001). For example, one of the desired outcomes on the individualized family service plan (IFSP) for 34-month-old Henry is for him to walk independently. The home visitor asks his mother, Jen, to describe times when Henry seems motivated to walk. Jen tells her that Henry loves to eat and will often move toward his high chair. Together, Jen and the home visitor develop a routine for Jen to use at mealtimes that will help Henry achieve the goal of walking about 3 feet to his high chair. They place a dark, high-contrast mat under his high chair to help him see the chair better. When it is time to eat, Jen puts Henry's bib on him and says "time to eat" to cue Henry that it is time to find the high chair. When he reaches the high chair, she says "up, up, up" and touches his shoulders before putting him in the chair. Before feeding Henry, she touches his lips and does oral-motor stretches around his mouth as recommended by his occupational therapist. During the meal, she says "Henry, look! Find the spoon!" holds the spoon about 9 inches in front of his face, and waits for him to look at it before she moves it to his lips. She also says "take a bite" and waits to see if Henry opens his mouth. When the meal is finished, Jen says "all done," signs "finish," and waits for Henry to respond by putting his arms up to be removed from the high chair. By using the routine consistently, Jen is able to promote Henry's development by integrating strategies related to physical and occupational therapy, use of vision and hearing, and communication into a common everyday activity.

**Caregiver-infant interactions.** Home visitors should promote a family's confidence and competence in interacting with their child who is

deaf-blind and encourage a parent's or other caregiver's use of specific strategies to support these interactions (Chen et al., 2007). The caregiver-infant relationship is strengthened when the caregiver recognizes, interprets, and responds to an infant's communication efforts (Dunst & Kassow, 2004; Kassow & Dunst, 2004), but caregivers need assistance to recognize their infant's subtle and unique signals and to respond in a meaningful way. Thus, a significant focus of home visits should be to facilitate caregiver-infant interactions and promote the child's participation within the family routine (Chen & Klein, 2008; Keilty, 2008).

## Providing Information

When an infant has both visual impairment and hearing loss *and* other special needs, initial home visits usually involve sharing information about relevant medical issues, explaining the causes of the infant's sensory impairments, and helping the family to learn about their infant's particular visual, auditory, and communication needs. The home visitor may also provide information about agencies and professionals that conduct evaluations (e.g., audiological, ophthalmological, or physical therapy).

Most families of infants with combined visual impairment and hearing loss will be unfamiliar with the term *deaf-blind* and may not view the label as appropriate for their infant, particularly if he or she has some functional vision or residual hearing. Home visitors should explain the range of combined sensory impairments described by the term and how this relates to educational strategies, specialized services, and accommodations needed for a particular infant. Families should also become familiar with relevant resources such as state deaf-blind technical assistance projects, the National Consortium on Deaf-Blindness (NCDB; <http://nationaldb.org>), and the National Family Association for Deaf-Blind (NFADB; <http://www.nfadb.org>).

### *Use of functional vision and residual hearing.*

If the infant wears glasses or contact lenses or hearing aids, the family may need assistance to learn about the care and management of these devices, how to introduce them to the child, and how to help the child make sense of what he or she sees and hears. Families may also have questions about cochlear implants. Depending on the infant's sensory status, home visitors should help families create opportunities for their infants to move towards sounds (e.g., searching for a family member who is calling the child's name or locating a toy that makes a sound), to visually locate

preferred items and people (e.g., looking around the room for mother or searching for a favorite blanket), or to tactilely search for a favorite toy kept in a consistent place.

**Communication options.** Development of communication skills is a primary need for infants who are deaf-blind. Families may need encouragement to observe, interpret, and respond to their infant's communicative efforts. They will have questions about options in communication modes (e.g., combined oral/aural, total communication, or American Sign Language) and wonder if their child will be able to read print or Braille. Families may ask whether their child will learn to speak and will need assistance to develop and use concrete communication methods such as touch and object cues and adapted sign language. Home visitors with expertise in deaf-blindness should schedule joint visits with other service providers to share information and strategies and to develop consistent use of communication methods to encourage the infant's communication development.

## Supporting Families

Home-based early intervention services must be family-centered and tailored to each family's unique characteristics (e.g., beliefs, culture, language, composition, social-economic level, attitudes toward disability) and the infant's developmental needs. The home visitor should create ways to engage everyone who is involved in an infant's care. In a large extended family in which there are several caregivers, for example, the home visitor should ask who should be involved in home visits rather than make assumptions. If appropriate, siblings should participate in the visit and be invited to share their points-of-view about the infant's likes, dislikes, and strengths.

Information should be offered in a format that the family understands and prefers. Some individuals like print materials, while others prefer online resources or DVDs. If the family and home visitor do not share a common language, an interpreter familiar with terminology related to early intervention and the child's diagnoses should be used to translate discussions. However, a common language, while essential, is not all that is required to help families support their child's development. In a study of non-English-speaking Mexican-American mothers of infants with developmental delays, Perez (2000) found that even when home visitors were bilingual, they tended to work directly with children rather than modeling and coaching fami-

lies in ways to promote their children's communication development.

Home visitors should recognize that families are likely to experience a range of emotions associated with the birth or diagnosis of an infant with a disability. Feelings like shock, anger, and sadness have been associated with adapting to having a child with a disability (Anderregg, Vergason, & Smith, 1992; Moses, 1983). Home visitors should be sensitive, compassionate, active listeners and understand that each member of the family may experience different feelings at different times. These are natural feelings that serve a healing purpose (Gallagher, Flalka, Rhodes, & Arceneaux, 2002). Home visitors should also assist families to identify and obtain the kinds of informal support (e.g., extended family members, friends, or spiritual leaders) and formal help (e.g., parent mentors, mental health professionals, or family support groups) that are likely to be needed.

### Transition to Preschool

As a child approaches 3 years of age, families have questions about preschool options and concerns about moving away from home-based early intervention services. This transition is likely to be an emotional and anxious time for families as they leave the security of family-centered home visits and familiar service providers for unknown, child-centered preschool services. Home visitors should assist families to learn about the transition from the individualized family service plan (IFSP) process to the individualized education program (IEP) process, their rights under the Individuals with Disabilities Education Improvement Act (IDEA), advocating for their child, and what they can expect when their child goes to preschool.

### General Tips for Home Visiting

Although the nature and content of a home visit will vary according to each family's priorities and concerns, the age and needs of their child, and a variety of other factors (e.g., program policies or state requirements), service providers must be prepared to make the best use of the family's time. The following are general suggestions to guide home visits:

- ◆ Remember that you are in the family's home; be respectful, compassionate, and nonjudgmental.
- ◆ Explain that family involvement during home visits is essential.
- ◆ Be flexible, listen to the family, and follow their lead.
- ◆ Follow-up on issues raised during previous visits.
- ◆ Focus on the infant's and family's daily activities and interests and provide suggestions that fit into their routines.
- ◆ If the child wears a hearing aid or amplification device, check to make sure it is working.
- ◆ Discuss ways to promote the child's communication development.
- ◆ Consider recording videos of learning activities if the family is comfortable with this (viewing videos provides great opportunities for observation, learning, and discussion).
- ◆ Offer to make family-to-family connections if the family is interested in meeting other families of infants who are deaf-blind.
- ◆ Find enjoyment in learning together.

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## Just Say No to Drive-bys

Debra Garvue

I am tired of “drive-bys.” I’ve had enough. I am the mother of a 6-year-old deafblind daughter. Since entering the public school system, she has been bombarded with drive-bys. What are drive-bys? The term “drive-by” is my way of describing the school system’s solution to her education. A deafblind child is placed in a classroom full of children with multiple disabilities, where he or she is usually the only deafblind child in the room. Then the drive-bys begin. A vision teacher will drive by and spend 30 minutes with her, then a hearing teacher will drive by and spend 30 minutes with her, and on and on. My daughter’s day is fragmented by various therapists and their minute requirements.



My question is this, do drive-bys work? Is this the best a deafblind child can hope for? Wouldn't my daughter be better off in a room full of her peers with like disabilities? As I delve into these questions, please remember that these are the opinions of a mother, and a teacher with 15 years of experience.

There are schools for the deaf and schools for the blind. Where are the schools for the deafblind? This is a question that I have often asked. The public school system always gives the same answer—there aren't enough deafblind children to start a classroom of their own. Is that to say these children are insignificant? Even though they are few in number, do they not deserve the same consideration as other children? Many children who are deaf are immersed in language and communication all day. And many children who are visu-

