

NEWS EXCHANGE



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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

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What Is Maddie Going to Be When She Grows Up?

Debra Garvue

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Deaf-Blind Perspectives

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When you learn that your child is deaf-blind, you become consumed by many concerns. Once I

accepted and understood my daughter's diagnosis, I still had many questions: not just questions about her current needs like "What can she see?," "Who is a good therapist?," or "When will her IEP meeting be?," but also questions about her future. The most basic and gut wrenching question I

had was this: "What is my child going to be when she grows up?"

I found this question hard. I had watched my older daughter flourish. When she was little and played with a doctor's set, I dreamed of her becoming a doctor. When she tried

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Special points of interest:

- THE AAHBEI SOUTH-EAST REGIONAL CONFERENCE WILL NOT BE HELD THIS YEAR.
- AAHBEI NEWSLETTER WILL BE ONLINE ONLY. GO TO THE WEBSITE TO DOWNLOAD YOUR COPY: WWW.AAHBEI.ORG

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“FAMILIES ARE FORCED TO FIND WAYS TO DO MORE WITH LESS, TO MAKE DO WITH WHAT THEY HAVE, WHETHER IT BE MONEY, TIME OR EVEN HOPE.”



Tom Clark
Founder of AAHBEI, SKI-HI Institute, and HOPE Inc.
1930-2010

AAHBEI NEWS EXCHANGE

President's Message

Dear AAHBEI Friends and Colleagues,

While pondering all the news to share with you about AAHBEI, I learned of the death of Tom Clark. Tom was the mastermind and

creator of the SKI-HI Institute, HOPE, and many home intervention programs providing early language education to families of children with sensory needs. If you are reading this newsletter, you have been touched in some way by the amazing gifts of Tom.

He was a small man but he lived large, touching all who had the honor to be in his presence. Tom had enough energy and enthusiasm to motivate an army of bright, talented professionals, which is his legacy. He was once likened to the little-engine-that-could. What a perfect description for this terrific man!

Tom taught us about early intervention and serving families in natural environments long before these terms became known and as a result, countless families have been touched in countless ways, finding the true potential of their children. The American Association for Home-Based Early Interventionists (AAHBEI) exists because of the vision of Tom Clark. He will be greatly missed, but he lives on as each of us provides excellent support to the families we touch.

AAHBEI has felt the effects of the current economy. But with the passion that Tom has instilled in us, we persevere. We have made and continue to make changes in our organization due to the challenging economic times. Your input is appreciated, as AAHBEI has a newly appointed executive committee and we are in the process of filling some of the governing board positions which have become

vacant.

Here are some of the changes you'll see:

- ◆ Updated website to better meet the needs of membership
- ◆ Valuable newsletter sharing articles, information and upcoming activities
- ◆ *AAHBEI Speakers Bureau*, a partnership with Part C agencies which will allow us to encourage and provide quality training on a variety of topics to the professionals working in the field of early intervention

We look forward to entering the new decade with fresh ideas and with an enthusiasm that will keep Tom Clark's legacy alive.

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Home Visits (continued from page 1)

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

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Home Visits (continued from page 2)

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 involves 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



CURRENT LITERATURE RECOMMENDS USING ITEMS AND MATERIALS DURING HOME VISITS THAT FAMILIES ALREADY HAVE AT HOME.



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Home Visits (continued from page 3)



HOME VISITORS SHOULD PROMOTE A FAMILY'S CONFIDENCE AND COMPETENCE IN INTERACTING WITH THEIR CHILD WHO IS DEAF-BLIND.



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

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Maddie (continued from page 1)

to argue her way out of punishments, I thought to myself, "Wow, she would make a great lawyer!" But the basic parenting rules I knew didn't seem to apply to Maddie. I couldn't find her case in any parent book. Dr. Spock had no advice for me.

Maddie was born with Leber's Congenital Amaurosis. Generally this genetic disorder affects eyesight only. However, in addition to her vision loss, Maddie was born with bilateral profound sensorineural hearing loss, severe hypotonic (floppy) muscles, a seizure disorder, and sleep apnea. She only has light perception and can see some hand movements if they are made within one or two inches of her eyes. She is in a wheelchair and, because of her weak muscles, has a feeding tube and requires oxygen at night. At 9 months of age, Maddie received a cochlear implant and loves hearing with it.

Given all of Maddie's disabilities, I still can't help asking myself, "What will she be when she grows up?" It is like a nagging ball of worry in the pit of my stomach. The question haunts me! Will my child grow up to be something, or will she be an eternal companion whom I care for and who never leaves her mark on society?



Recently during a very difficult time, I had an epiphany, one of those rare moments when a light shone down and I knew the answer to that question. Maddie had recently been hospitalized for about ten weeks. She was on a ventilator for eight of those weeks, and for awhile it was touch and go. I watched her struggle to survive. When she was about a week into her struggle, I developed a website to let friends and family members keep track of her condition, and I was blown away by how many hits it received. It seemed as if everyone was reaching out to Maddie and my family. Friends and family members shared

Maddie's site with people they knew, and soon we were receiving hugs and cards from people I had never met. It was inspiring to know how many people were touched by her fight to live.

This led me to wonder, to contemplate deeply, how many lives has Maddie touched? Therapists? Teachers? Doctors? Nurses? Friends? Family? The list is endless. And I realized that I already know what my child will be when she grows up, because she is already it. She has chosen her profession and is practicing it now, and I know that she is already making a mark on society. She is changing the way

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Home Visits (continued from page 4)



INFORMATION SHOULD BE OFFERED IN A FORMAT THAT THE FAMILY UNDERSTANDS AND PREFERS.



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 families 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

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Home Visits (continued from page 6)

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.

References

Available upon request.



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.

Maddie (continued from page 5)

people think and function in their daily lives. She has inspired me to leave my job as an educator and enter the field of deaf-blindness

with the hope that I can make a difference. What is she? Why, she went into the family business. She is a teacher.

To read Maddie's journal, go to:
www.caringbridge.org/visit/maddiegarvue

Families and providers working together in natural environments for young children with special needs.

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We're on the Web:
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AAHBEI provides leadership in a transdisciplinary forum involving families, providers, teachers, administrators, and advocates where best practices about working together in natural environments for young children with special needs can be shared, discussed, supported, and promoted.

Conferences

10th National Early Childhood Inclusion Institute: Chapel Hill, North Carolina

May 17-19, 2010

More information can be found here: <http://www.nectac.org/~meetings/inclusionmtg2010/mtghomepage.asp>

NAEYC Institute for Early Childhood Professional Development

Phoenix, Arizona

June 6-9, 2010

More information can be found here: http://www.naeyc.org/institute/?utm_source=TACSEI+%26+CSEFEL+Updates&utm_campaign=d76519c618-TACSEI+and+CSEFEL+Updates_12.2009&utm_medium=email

Georgia Sensory Assistance Project, Summer Institute Strategies for Sensory Motor

Level Learners: Sensory Learning Kit, Calendar Systems and Active Learning Environments
June 23-25, 2010
<http://education.gsu.edu/georgia/deafblindproj/tng2001.html>

The 2nd Biennial Weekend For Families and Professionals of Individuals with Combined Hearing and Vision Loss

July 16-18, 2010
Kingsport, Tennessee

<http://treds-deafblindproject.com/>

AER International Conference

July 20 - 25, 2010

• Where: Statehouse Convention Center & The Peabody Little Rock Little Rock, Arkansas
• Sponsored by: AER (Association for Education and Rehabilitation of the Blind and

Visually Impaired)

• To Register: www.aerbvi.org

DEC: Division of Early Childhood: THE 26TH ANNUAL INTERNATIONAL CONFERENCE ON YOUNG CHILDREN WITH SPECIAL NEEDS & THEIR FAMILIES

October 14-17, 2010
Kansas City, Missouri

NAEYC Annual Conference
Anaheim, California
November 3-6, 2010

The Early Intervention and Preschool Conference

November 17-19, 2010
Montgomery, Alabama
<http://ucpconference.org>

Zero to Three's 25th National Training Institute National Center for Infants, Toddlers and Families

December 8-11, 2010
<http://www.zttntconference.org/>