

**Module: Family-Centered Practices
for Infants and Toddlers With Visual Impairments**

Session 1: Building Reliable Alliances

Handout B

**Position Statement, Division on Visual Impairments, Council for
Exceptional Children, October 19, 2003, Family-Centered Practices for
Young Children With Visual Impairments**

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Introduction

Legislation and research affirm the importance of early intervention for young children with disabilities as well as early intervention that is family centered. Family-centered practices are based on collaborations between families and professionals that not only facilitate the optimal development of the child but also address the concerns and priorities of families. Family-centered practices are characterized by

- focusing on the strengths of families while respecting and honoring diversity.
- empowering families to make their own decisions about resources and services.
- viewing the family holistically.
- collaborating with families and other members of the early intervention team.

This position paper outlines basic principles that should be addressed in the implementation of early intervention and preschool services for infants and young children with visual impairments (birth to six years). Although children with visual impairments represent a small group within the population of children with disabilities, they have diverse and unique needs that result from challenges in accessing the visual environment. To meet the legal mandate for appropriate support for infants and young children with visual impairments and their families, this paper will describe issues and supports that must be addressed in order to provide basic services.

Developmental Needs

The impact of visual impairment on development begins at birth. The mutual eye gaze observed between infants and their parents facilitates attachment between them. Indeed, some psychologists (Schore, 1994) have theorized that this eye gaze actually stimulates brain development in infants. Very young infants and their caregivers typically spend considerable time gazing and smiling at each other and also imitating each other. Later, eye

gaze is used to establish joint reference to objects of interest. When vision is impaired, attachment and communication between parents and infant present a challenge. Because strong attachment between infant and parents is related to developmental outcome, early intervention that is focused on strengthening attachment between infants with visual impairment and their caregivers and family is recommended. Typically, very early intervention for infants with visual impairments and their families is directed to helping caregivers interpret communicative cues of their infants while also helping them use appropriate communication cues that may not be as dependent on intact vision.

Infants and young children with visual impairments have the same needs as all children, as well as some unique developmental needs. Vision is the primary organizing and integrative sense for the sighted child; the remaining senses, particularly the tactile and auditory, become more important for the child with a visual impairment. Unless specific intervention, particularly in maximizing efficient use of all senses and in symbolic operations and concept development, is introduced, many young children with visual impairments will not be able to form accurate concepts of the world around them. Children with visual impairments require specific interventions designed to promote optimal use of vision and all senses, including the use of environmental adaptations and optical devices. In order to assure that young children with visual impairments use all sensory input as effectively as possible to maximize learning and facilitate development, professionals must collaborate with families to facilitate their understanding of their children's unique strengths and challenges.

Many infants and young children with visual impairments have different perceptions of the world than children with normal vision. Concepts are built on perceptions, of the objects and events in the world, that result from information processed by our senses. Consequently, an understanding of the world that results from information obtained primarily through tactile, auditory, olfactory, and kinesthetic information, rather than vision, must be different. Vision is particularly important for information about objects, people, and events at a distance. Although hearing does provide some information about distance, it typically does not provide the stable and consistent information provided by vision. Thus, development in all areas, including cognitive, social-emotional, communicative, and motor development, as well as the development of daily living skills, may be quite different for children with visual impairments. These differences in development, combined with lack of access to the visual environment, must be considered and addressed through early intervention that

- addresses family concerns and priorities.
- assesses and maximizes the unique sensory capabilities and preferences of each child.
- adapts environments to make them accessible and to maximize effective use of all senses.
- provides appropriate experiential learning opportunities that facilitate development in all domains.
- facilitates the acquisition of emergent literacy skills for potential braille and print readers.
- facilitates engagement, independence, and the development of social relationships.

Children with multiple disabilities often have needs that are even more distinctive than those of children with visual impairment as a single disability. When visual impairment is compounded by other disabilities, professionals with expertise in other areas, such as augmentative communication or assistive technology, will be required, as well as those who

understand positioning and handling and other special needs such as deafblindness. Regardless of the extent and types of disabilities, close collaboration among all specialists, the family, and qualified professionals with knowledge of the impact of a visual impairment on development and learning is essential.

A visual impairment has an immediate and lasting impact on the child and the family. Parents, siblings, and extended family members may experience considerable stress at the time of diagnosis and throughout their lives unless they receive the specialized supports required to meet their unique needs. As mandated, the strengths, needs, and concerns of families must be addressed in developing and implementing the individualized family service plan (IFSP). A family-centered approach can facilitate the identification of family concerns and priorities and effective strategies for responding to those concerns and priorities on an individual basis for each child and family. From the time the visual impairment is identified, the family and child should have ongoing, individualized support and services. Initially, the primary focus should be on the establishment of attachment between parent and child. Through continuous close collaboration, professionals and families can facilitate the child's optimal development while also addressing the concerns and priorities of families.

Recommended Practices

When vision is impaired, it is more difficult for children to acquire efficient, holistic, and simultaneous information about people, objects, and the environment. This inability to obtain detailed information through a single glance affects all areas of development—even the most basic concepts can be altered. Children with visual impairments have access to efficient learning about the world only when primary caregivers, family members, and professionals consciously and consistently provide experiences that make maximum use of all senses. For most children with visual impairments, systematic learning does not occur incidentally or spontaneously.

Intervention and educational services may be provided in a variety of settings—the home, childcare centers, community-based preschools, specialized class placements, residential schools for the blind, or in any combination of these settings. Although the Individuals With Disabilities Education Act (IDEA) of 1997, Part C, specifies that early intervention be provided in natural environments with nondisabled peers, that same document also calls for support that addresses family concerns and priorities as well as needs identified during a multidisciplinary assessment. Family strengths and priorities as well as the results of the multidisciplinary assessment are used as a basis for developing outcomes for the IFSP and identifying the settings in which early intervention takes place. IDEA guidelines specify that the rationale for providing supports and services in settings other than those with nondisabled peers must be described in the IFSP, suggesting that there are instances in which the early intervention team may determine that specialized settings may be appropriate. Because of the unique needs of children with visual impairments and their families, it is important that an array of service and support options be provided. Regardless of the setting, practices should include:

- recognition of and respect for the family as the most influential factor in the child's growth and development.

- immediate comprehensive support for families that includes information, assurance, hope, and confidence, and that facilitates the development of strong relationships between the child and family.
- comprehensive supports and services, based upon the collaborative development of an individualized family service plan (IFSP) for infants and toddlers and an individualized education plan (IEP) for preschoolers, that consider families' culture, values, strengths, concerns, and priorities.
- supports and services that are individually designed to meet the global and specific needs of each child and family.
- facilitation of cognitive, social-emotional, communicative, sensory, and motor development, as well as the development of daily living skills and orientation and mobility skills through appropriate experiential learning within daily routines in order to promote engagement, independence, and the development of social relationships.
- assessment of the unique sensory capabilities and preferences of the child in order to identify appropriate environmental adaptations and intervention strategies, including the use of low-vision devices that promote accessibility and effective use of all senses.
- facilitation of emergent literacy skills based on the child's sensory preferences and individual learning style, including emergent literacy for potential braille and print readers.
- provision of services by specialists who are appropriately trained to enhance the development and early learning of infants and young children with visual impairments, including assessment, intervention and education planning, and the development or modification of developmentally and functionally appropriate support and services.
- coordination with the medical community as partners in the provision of comprehensive services for children with visual impairments and their families.
- provision of ongoing in-service and professional development for all staff as well as families.

These recommended practices apply to supports and services for all infants and young children with visual impairments and their families, including those with additional disabilities.

Competencies and Functions of Personnel

Understanding the impact of vision loss on development and the subsequent impact of a child with visual impairment on the family is a complex and ongoing process that demands a variety of special skills and knowledge. In addition to the specialized professional competencies of teachers of infants and young children with visual impairments, deaf-blind specialists, and certified orientation and mobility specialists, the numerous service providers, such as family counselors, speech and language pathologists, social workers, physical therapists, occupational therapists, medical and health-care workers, and others, require additional competencies and collaborative skills to provide effective and efficient services.

Service Providers

All service providers for the child and family should have knowledge of typical and atypical infant and early childhood development including visual development. In addition, they should receive ongoing professional training that includes:

- ability to screen for and identify risk factors or behavioral indicators of potential visual impairments.
- knowledge and understanding of the impact of a visual impairment on early childhood development and behavior and on the child, family, and social environment.
- knowledge and understanding of the impact of visual impairments in combination with additional exceptionalities.

Support Personnel

Additionally, support personnel should demonstrate the ability to adapt their specialized training to meet the unique needs of infants and young children with visual impairments and their families and be supported in these efforts through collaborative program planning with professionals trained in the area of visual impairments.

Primary Service Provider

The primary service provider should have the following additional competencies:

1. Skill and sensitivity in working collaboratively and in partnership with families and other team members through effective communication and the use of family-centered practices to share information and jointly plan and implement supports and services that will enhance the child's overall development and address the family's priorities.
2. Ability to assess functional vision and use of all senses in order to plan effective strategies for facilitating optimal use of vision and all senses and to adapt environments to make them accessible.
3. Ability to adapt and use a variety of assessment strategies to accurately identify the child's strengths and current levels of functioning and the family's strengths, concerns, and priorities, particularly as they relate the child's visual impairment.
4. Ability to create, coordinate, implement, and continuously evaluate intervention and education plans in order to meet the strengths and needs of the child and the family, including use of support personnel and community resources.
5. Ability to work effectively as a team member.
6. Ability to make appropriate referrals to other professionals, e.g., low-vision clinicians or certified orientation and mobility specialists.
7. Ability to function as a service coordinator or case manager if designated.
8. Ability to translate appropriate research into practice.
9. Ability to access appropriate resources such as assistive technology in order to provide appropriate intervention for infants and young children with visual impairments and their families while also helping caregivers acquire life-long advocacy skills that will enable them to access appropriate supports throughout the child's life.

Because many infants and young children with visual impairments have additional disabilities, service personnel must have an understanding of the impact of combinations of disabilities on individual children and their development. This knowledge can assist them in providing support to families that will help them understand their children's unique needs. Additional competencies may be required of professional personnel when providing support to children and families from diverse geographic, cultural, and economic communities.

Position

Infants and young children with visual impairments and their families require appropriate early intervention support and services. Childhood blindness or visual impairment has an impact on the entire family system. Support should begin as soon as a vision problem is diagnosed in order to assist the family and help it facilitate the child's optimal development.

Infants and young children with visual impairments and their families have a right to qualified early interventionists, teachers, and specialists. Individuals specifically trained to provide early intervention and educational services to children with visual impairments include a) teachers of students with visual impairments, b) certified orientation and mobility specialists, and c) deaf-blind specialists.

Infants and young children with visual impairments and their families have a right to appropriate specialized supports and services. The following components should be integrated into intervention and education plans and services to promote optimal development and independence for each child:

1. development of attachment and meaningful social relationships and communication skills (listening, turn-taking, personal expression, nonverbal communication, emergent literacy) when vision is impaired.
2. assessment of sensory capabilities and preferences in order to facilitate the effective use of all senses, including the use of low-vision devices if appropriate.
3. adaptation of environments, toys, and learning materials to make them more accessible.
4. use of compensatory skills to accommodate for vision loss (e.g., strategies for accomplishing tasks using touch rather than vision, learning to use all senses as effectively as possible).
5. cognitive development opportunities that are experience based and designed to teach concepts that are acquired primarily through vision (basic concepts, problem-solving skills).
6. facilitation of emergent literacy including literacy for potential Braille and print readers through collaboration with families and other professionals.
7. gross and fine motor development (as well as the development of physical control and stamina) with special attention to prerequisite skills required for age-appropriate orientation and mobility and braille and print reading and writing if appropriate.
8. age-appropriate orientation and mobility instruction (self-directed, independent movement in the environment).
9. instruction in daily living skills typically acquired through incidental visual learning that must be taught using hands-on, step-by-step procedures to young children with visual impairments in order for them to function independently within natural environments (e.g., self-care skills, ability to do household and classroom chores).

10. comprehensive family support that includes emotional support and access to information and resources that will help families become life-long advocates for their children.
11. thorough understanding of medical and visual conditions and their implications for early intervention and education.
12. recreational opportunities that enhance creativity and enjoyment.

Reference

Schore, A.N. (1994). *Affect regulation and the origin of the self: The neurobiology of emotional development*. Hillsdale, NJ: Lawrence Erlbaum Associates, Inc.

The following individuals were participants of the XIVth International Seminar on Preschool Blind held in Raleigh, NC, in May 1990 that drafted the original DVH Statement of Position, Family-Focused Services for Infants and Young Children with Visual Handicaps, ratified in Atlanta, GA on April 3, 1991.

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