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ABSTRACT

This manual documents key program development strategies and inservice training topics provided by the Model Demonstration Early Intervention Network Project. This project focused on building the capacity of early intervention programs to serve infants who are deaf-blind and their families. The first section covers program development and includes information on "program self reviews," mentorship and collegial support in early intervention teams, and the art of collaboration. The identification of infants who are deaf-blind is addressed in the second section along with strategies for gathering information. The third section includes information on functional vision assessment and interventions, tests used to diagnose visual impairments in infants, and clinical vision assessment for infants with severe and multiple disabilities. Section 4 describes hearing loss, assessments, and interventions and audiological tests for infants with multiple disabilities. Gross motor development in infants with multiple disabilities and medications and medical interventions are reviewed in section 5. The sixth section provides strategies for beginning communication, vignettes describing four infants who are deaf-blind, and the rationale for an integrated therapy model. Transition to preschool is highlighted in the last section. Blank forms are attached for self reviews and disability identification. (Each section includes references.) (CR)

Effective Practices In Early Intervention

Infants whose multiple disabilities include both vision & hearing loss

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California State University, Northridge

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Introduction

Program Development

Identification

Vision

Hearing

Motor & Health

Strategies

Transition

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Introduction

Introduction to the Project

The Model Demonstration Early Intervention Network serving Infants who are Deaf-Blind and their Families was a three year project of California State University, Northridge funded by the U.S. Department of Education from October 1, 1993 to February 28, 1997. The project focused on building the capacity of early intervention programs to serve infants who are deaf-blind and their families. To this end, project goals involved identifying and developing effective early intervention practices with infants whose multiple disabilities include both vision and hearing loss and their families. Project goals were accomplished through a series of activities: family/professional focus group meetings, program self reviews, program development plans, interdisciplinary focus group meetings, a supervisory focus group meeting, workshops, follow up consultation, and the development of videos and this manual. Over 16 early intervention programs participated in at least one component of the project. The following programs were involved in major components in all three years of the project:

- ► Off to a Good Start Program, Blind Babies Foundation, San Francisco
- ► Preschool Program, Blind Children's Learning Center, Santa Ana
- ► Infant-Family Program, Foundation for the Junior Blind, Los Angeles
- ► Infant Deaf and Hard of Hearing Program, Los Angeles County Office of Education
- ► Deaf and Hard of Hearing Infant Program, Los Angeles Unified School District
- ► PIVIT (Parents and Infants with Visual Impairment Together), Los Angeles Unified School District
- ► Early Start Program, Marin County Office of Education, San Rafael
- ► Infant Program, West End Selpa Early Start, San Bernardino County Office of Education, Ontario
- ► Deaf Special Needs Program, San Diego Unified School District

The project conducted program self reviews and family/professional focus group meetings to identify primary program needs and to reveal effective practices. The program self reviews involved committees of administrators, direct service personnel, and families. These reviews were facilitated and recorded by the project through a family/professional team of consultants or staff of California Deaf-Blind Services. The family/professional focus group meetings were composed of teams of direct service providers and parents of children who are deaf-blind. A total of 15 family representatives and 15 professionals participated in these meetings plus three educational specialist/family specialist teams from California Deaf-Blind Services who assisted project staff in facilitating and recording group input.

Program self reviews and focus group meetings revealed a primary need for inservice training and materials on beginning communication strategies, audiological assessment and interventions, and vision tests and interventions for infants. In general, family members wanted materials that could help staff work with their infants more effectively. Both professionals and family members requested strategies for beginning communication particularly with infants who have significant motor and cognitive delays in addition to vision and hearing loss. Early intervention personnel requested information not only for beginning professionals, but also for those with significant training and experience in vision impairment or hearing loss, particularly on recent developments in audiological and vision tests for infants. For this reason, the manual provides chapters on clinical assessments to assist early interventionists in understanding audiological and vision tests and reports, as well as chapters on functional vision and hearing screenings and interventions. The project addressed identified training needs through a series of workshops, onsite consultation, and the development of videos. This manual documents the training topics, effective practices, and key strategies developed and identified by the project process.

Videotapes developed by the project

What can baby hear? Auditory Tests and Interventions for Infants with Multiple Disabilities (27 minutes). Paul H. Brookes Publishing, P.O. Box 10624, Baltimore, MD 21285. Identifies the importance of early identification of hearing loss particularly in infants with severe and multiple disabilities. A pediatric audiologist demonstrates selected audiological tests (Behavioral Observation Audiometry, Visual Reinforcement Audiometry, Auditory Brainstem Response, Otoacoustic Emissions) for infants (under 24 months). Shows an early interventionist obtaining functional hearing information with an infant who has both vision and hearing loss through structured observation in the home and parent interview. The mothers and early interventionists of three other infants with different types of hearing loss discuss their infants' listening and communication skills. Shows selected strategies in a total communication early intervention program and emphasizes the consistent use of hearing aids. Includes a booklet.

Making the Most of Early Communication (34 minutes). AFB Press, American Foundation for the Blind, Eleven Penn Plaza, New York, NY 10001. Emphasizes the importance of making use of the child's available senses, using familiar routines and turntaking games, and using systematic and direct instruction for encouraging communication. Shows various communication strategies (oral and total communication, touch and object cues) with a variety of infants, toddlers, and preschoolers with multiple disabilities/vision and hearing loss at home and in preschool activities. Children from five different programs are shown. Includes a booklet.

What can baby see? Vision Tests and Interventions for Infants with Multiple Disabilities (30 minutes). AFB Press, American Foundation for the Blind, Eleven Penn Plaza, New York, NY 10001. Identifies the importance of early identification of visual impairment in infants with severe and multiple disabilities. A pediatric optometrist demonstrates five common vision tests (checking ocular health, Cover-Uncover Test; Pupillary Response, Retinoscopy, Preferential Looking/Teller Cards, and the Visual Evoked Potential). Shows an early interventionist obtaining functional vision information with two infants who have both visual impairment and hearing loss through structured observation in the home and parent interview. Parents share their feelings about their infants' disabilities. Provides examples of selected interventions used in an infant program. Includes a booklet.

Vision Tests for Infants (20 minutes). AFB Press, American Foundation for the Blind, Eleven Penn Plaza, New York, NY 10001. A pediatric optometrist demonstrates a comprehensive battery of vision tests that are appropriate for infants under 12 months of age. These tests include: Versions, Hirshberg, Krimsky, Unilateral and Alternating Cover, and Base out Prism (fixation and eye alignment tests); Pupillary Response; Vestibular Ocular Reflex; Retinoscopy; Contrast Sensitivity, Color Vision, Depth Perception, Visual Field, and Visual Acuity (behavioral tests); Visual Evoked Potential and Electroretinography (Electrophysiological tests); and checking ocular health. Includes a booklet.

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Effective Practices in Early Intervention: Infants whose Multiple Disabilities include both Vision and Hearing Loss is the result of the collective effort of many individuals and agencies. This manual documents the key program development strategies and inservice training topics provided by the Model Demonstration Early Intervention Network Project. In particular, I appreciate the contributions of each author and the thoughtful feedback of each person who reviewed the manuscripts. My special thanks to the project secretary, Suzanne Hendley for coordinating the complexity of requisitions, paperwork, logistics, and communication involved in the project; and to the student assistants for their expertise on computers: Helen Saporito who began the documentation process and Anise Azizad who completed it. The manual would not have been ready by the designated time without their ability to work on an evolving product which involved many revisions, quick turnarounds, and short timelines. Thanks to Donna Kaptain for her design and layout magic in changing a stack of ordinary manuscript pages into an attractive and inviting product. I also appreciate the assistance and contributions of the educational specialists and the family specialists of California Deaf-Blind Services who collaborated on various components of the project. Finally and most of all, special appreciation goes to all the early intervention program staff and families who contributed to an exciting and dynamic learning process for us all.

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PROGRAM Development

Program Self Review: A Program Development Process

by

Deborah Chen

Mentorship & Collegial Support: Enhancing the Early Intervention Team

by

Pamela Haag Schachter

The Art of Collaboration

by

Pamela Haag Schachter

Program Self Review: A Program Development Process

by Deborah Chen

Program challenges

Providing early intervention services to infants with multiple disabilities is challenging and complicated work. Program administrators and direct service providers are often inundated with critical tasks that need immediate attention. Administrators deal with the blunt realities of program management, funding issues; numbers of families being served; eligibility criteria; policies and procedures; personnel training, retention, and supervision; staff shortages, unmet needs, and the quality of services to families. Direct service personnel are engaged with complicated and emotional tasks involved in working with infants and families, teaming with other professionals, accessing resources for families, and other everyday professional responsibilities. Amid this whirlwind of service provision there is little time to reflect on past actions, evaluate current practices, or plan the future course. Early intervention programs must ask and answer three simple but significant questions: What are we doing? How are we doing it? What do we need to do?

Making time

The primary goal of the Early Intervention Model Demonstration Network was to identify, develop, and demonstrate effective early intervention services to infants and toddlers who are deaf-blind and their families. To meet this goal, the project developed a *Program Self Review* document and process to assist programs in identifying service strengths, effective practices, and areas that needed to be developed. The *Program Self Review* provided an opportunity for program administrators, direct service personnel, and family representatives to ask and share answers to: What are we doing? How are we doing it? What do we need to do?

In the first and second years of the project, completion of the *Program Self Review* resulted in the following outcomes for each participating program:

- A time for program administrators, direct service providers, and family representatives to share accomplishments, perspectives, and priorities.
- Identification of effective practices.
- Identification of priorities for program development.

- Development of a *Program Development Plan* which identified specific program objectives, outcomes, and resources (at a follow up meeting with project staff and the program administrator).
- Development of a *Technical Assistance Plan* to address the *Program Development Plan*. The *Technical Assistance Plan* identified specific strategies for the program to address objectives and match intended outcomes. These included onsite consultation and follow up by project staff or consultants on specific content or skill areas; staff and family support and training activities; tailor made workshops; and access to local, regional, state, and national resources.
- Implementation of the *Technical Assistance Plan*.

During the second and third years of the project:

- The *Program Development* and *Technical Assistance Plans* were reviewed, updated, and evaluated by the program administrator and project staff. Revised Plans were implemented.
- Personnel from participating early intervention programs contributed to project videos, manual, and materials.
- Successful strategies and effective practices were documented and disseminated.

Development of the Program Self Review

The project developed the *Program Self Review* document in response to P.L. 99–457, Part H and based on a review of the current literature on effective practices in early intervention. This review included selected program checklists such as *DEC recommended practices: Indicators of quality in programs for infants and young children with special needs and their families* (1993), *Brass tacks: A self-rating of family-centered practices in early intervention* (1991), *Family-centered program rating scale* (1991), and *Programs guidelines for individuals who are deaf-blind* (1990).

The *Program Self Review* document and process was field-tested with five early intervention programs involved in the project. Each meeting ranged between five and 13 participants (parents, direct service personnel, administrator) plus a facilitator/recorder team provided by the project. The process provided both program evaluation and program development opportunities by strengthening family/professional collaboration, by revealing effective practices, and by identifying program development needs. In this way, the project assisted programs in building their capacity to serve infants who are deaf-blind and their families.

Identifying quality indicators

The *Program Self Review* process facilitated the identification of quality indicators of early intervention programs serving infants who are deaf-blind and their families. First, quality indicators of early intervention programs were identified from an extensive review of effective practices in early intervention literature including the *DEC recommended practices: Indicators of quality in programs for infants and young children with special needs and their families* (1993). Next, this generic list of quality indicators was reviewed by program administrators, direct service personnel, and family representatives. In this way, specific program indicators were added to reflect the unique learning needs of infants who are deaf-blind as well as the concerns and priorities and their families.

The review and validation process of the list of quality indicators occurred during the *Program Self Reviews* conducted in five early intervention programs and during a series of six focus group meetings across the three year project. Two family/professional focus group meetings were held in southern California and one in northern California in 1994–1995. These meetings were composed of early intervention personnel and parents of children who are deaf-blind (two to nine years old). California does not have specialized certification in the deaf-blind area. Infants who are deaf-blind may be served in a variety of early intervention programs. Therefore, early intervention personnel represented teachers of infants with visual impairment, teachers of deaf and hard of hearing infants, teachers of infants with severe disabilities, program administrators, and school psychologists.

Three other focus group meetings were held in 1995–1996. One meeting involved program administrators and direct service personnel, and two others involved direct service early intervention personnel from the primary disciplines (early childhood special education, visual impairment, hearing loss, orientation and mobility, occupational therapy, and physical therapy) working with infants with multiple disabilities/vision and hearing loss.

Program evaluation and development

What are we doing? How are we doing? What do we need to do? To answer these three questions, visualize a feedback loop which begins with a program philosophy that is reflected in goals and objectives, which leads to services, and is put into practice through activities and strategies. The *Program Self Review* assists early intervention programs in monitoring whether the program is on "track" (given its philosophy and goals), determines when and how "track switches" (i.e., changes in services and strategies) need to occur, and provides linkage for the feedback loop (from program philosophy to intervention strategies). Clearly, it is most essential for an early intervention pro-

Quality indicators

High quality programs serving infants who are deaf-blind and their families have the following characteristics:

- A clearly articulated program philosophy which guides program goals and practices
- Strong administrative support
- Flexible program options and funding model
- Planned program evaluation linked to program goals, practices, and development
- Mechanisms for family/professional collaboration in decision-making, program development, and program evaluation activities
- Qualified personnel (at all levels including early interventionists, specialized consultants, and administrators)
- Opportunities for family, professional, and program development
- Individualized services based on family concerns, priorities and resources
- Services that are culturally responsive
- Services that are coordinated with other agencies
- Services that reflect an interdisciplinary or transdisciplinary team approach in program planning and implementation
- Services that are provided in natural environments
- Specific interventions that address the infant's learning needs
- Specific interventions that increase the infant's access to sensory information
- Individualized communication options for infants and toddlers
- Activity-based interventions with systematic and direct instruction occurring within the context of predictable, natural routines
- Objectives and interventions from various disciplines that are infused within the infant's daily routine
- Interventions that support the infant/caregiver relationship
- Transition support to preschool programs for families and children

gram to be guided by a well thought-out philosophy and explicit goals.

Program philosophy

Guiding principles, values, and beliefs about how children learn and how early intervention should support families in promoting their infant's development.

Goals/objectives

Statements of what the program will provide or accomplish and that reflect the program beliefs and principles.

Program services

Types of services to infants and families that are linked to program goals and reflect program beliefs and principles.

Activities/strategies

Specific intervention techniques (used in delivering services) that are linked to program goals and reflect program principles and beliefs.

A sample from the Parents and Visually Impaired Infants Project

The program feedback loop process is illustrated in the following selected samples from the main components of the PAVII Project (Chen, Friedman & Calvello, 1990). This example focuses on one of the program's guiding principles, i.e., the role of the parent in the infant's development. It is presented to demonstrate the need for a clearly articulated program philosophy to guide program goals, components, and activities.

Program philosophy

A caregiver's ability to observe, interpret, and respond contingently to infant behavior is most important in promoting early social and communicative development. The home is the most natural environment for early intervention.

A significant caregiver is a primary teacher for all children under three years of age. Infants learn about the physical and social environment through interaction with a caregiver. Infants with visual impairment and their families benefit from supported interactions in developmentally-appropriate activities.

Goals/objectives

- ► To develop, implement, and evaluate an early intervention model for infants with visual impairment and their families.
- ► To develop and field test early intervention materials .

Program services

- Home visits
- Supported inclusion at community play group for infants and parents
- Parent education meetings
- Parent support group
- Family Fun Events
- Transition supports

Activities/strategies

Program staff assumed a coaching role with families in providing early intervention services. The *Parent Assessment of Needs* was used to assist parents in identifying specific intervention goals for their infants that fit within the family routine. The *Parent Observation Protocol* was used to implement a microteaching process whereby parents identified a daily activity (e.g., feeding, play, bathing), viewed a videotape of their interaction with their infants in this situation, and identified strategies to support the infant's participation. These strategies were documented in *Learning together: A parent guide to socially-based routines for visually impaired infants.*

Program Self Review for early intervention programs

Serving infants who are deaf-blind and their families

Purpose

The *Program Self Review* is both a document and a process for assisting early intervention programs in developing and providing quality services for infants (birth to three years) who are deaf-blind and their families. The *Program Self Review* document is designed for early intervention programs to identify:

- Quality indicators of early intervention services for infants who are deaf-blind and their families;
- Program practices that are very effective;
- Program practices that need to be developed further; and
- Priorities for program development.

The *Program Self Review* is a systematic process for planning and implementing directed program change in order to meet the philosophy, goals, and program and personnel standards required under

P.L.99–457, Part H. It is a non-judgmental process of reflection. It enables program staff and family representatives to examine the types and quality of services being provided in order to identify priority areas for program development. The *Program Self Review* is **not** an external evaluation tool or a mechanism for resolving in overall programmatic concerns or issues.

The *Program Self Review* may be conducted annually. The process assists early intervention programs in three ways: (a) by highlighting accomplishments of the previous year, (b) by evaluating current practices and services, (c) by identifying organization, personnel, and program goals for the future.

Key players

The *Program Self Review* should be conducted by a representative committee of program administrators, direct service personnel, and family members. It is most important that these key players are represented. The wider the representation on the committee, the richer the process, and the more valuable the outcome. The *Program Self Review* will be severely limited if only an administrator and early intervention professionals attend. Efforts should be made to identify a time, place, and other considerations that will encourage participation by families, paraprofessional service providers, specialized consultants, and other team members as appropriate.

Specific administrative tasks

- Identify who should be involved on the *Program Self Review* committee to provide broad representation of program personnel and families.
- Identify the time and resources needed to encourage participation and to complete the process.
- Finalize committee membership and logistical arrangements.
- Distribute the *Initial Program Self Review* document if this is the first review (see *Forms* section of this manual). If this process has been conducted previously, distribute *Annual Program Self Review* and the summary from the last review (see *Forms* section of this manual). Committee members should receive the necessary documents at least two weeks before the meeting in order to complete them before coming together.
- Identify a meeting facilitator/recorder team and how input will be recorded and distributed, e.g., recording on chart paper, sending a copy of meeting notes to committee members, and sharing accomplishments and priorities with board members, all personnel, and in the program newsletter to families. Some programs may

prefer to engage the assistance of an external facilitator/recorder team who have the skills to keep the committee focused and to encourage input from all members. It is important to view the *Program Self Review* process as a valuable opportunity to share information, perspectives, and priorities. It is most essential to provide a supportive environment that will foster open communication among participants.

Tasks of committee members

- Review and complete the relevant sections of the *Program Self Review* document before the scheduled meeting. At the meeting, committee members will use their written notes to answer the questions and share information with the group.
- Participate in identifying accomplishments and program changes at the meeting.
- Participate in identifying Program Development priorities based on the *Program Self Review* process. The group will need to determine how to select priorities, i.e., reach consensus on what are the most important goals and how many can be addressed during the next year, given available time and resources.

Directions for completing the Program Self Review

In preparation for the meeting, please review this document and complete the sections which relate to your knowledge of the program (as indicated). If you are both a program administrator and direct service provider, the total form should take about one hour to complete. If you are either an administrator, direct service staff, or family member, your selected sections will take 15 to 30 minutes to complete. The time periods indicated on the document refer to the time allotted for reporting and discussion at the meeting. About three hours is required for the *Initial Program Self Review* and less time for subsequent reviews.

As you complete the identified sections, please do so from this perspective: *Families are equal members in and can take part in all aspects of early intervention systems. This includes participation in all aspects of their child's care and all levels of decision making* (DEC 1993:26). Also consider the quality indicators of early intervention services to infants who are deaf-blind and their families.

Bring completed forms to the meeting. Participants will be asked to report on relevant sections using their notes. Note that a certain amount of time is allocated for the discussion of each section. The meeting facilitator will be responsible for keeping the group on task and the recorder will record the discussion and answers on chart paper.

Benefits of a Program Self Review

The *Program Self Review* provides a framework for program development based on recommended practices in early intervention. Through the *Program Self Review* process, family representatives, direct service staff, consultants, and administrators can share program strengths and identify program needs from their perspectives. The process strengthens both the identity of the program and collaboration with families. It provides early intervention programs with a unique program development opportunity.

References

California Department of Education (1990). *Program guidelines for individuals who are deaf-blind.* Sacramento, CA: California Department of Education.

Division for Early Childhood (1993). *DEC recommended practices: Indicators of quality in programs for infants and young children with special needs and their families.* Reston, VA: Council for Exceptional Children.

Murphy, D.L., Lee I.M., Turbiville, V., Turnbull, A.P., Summers J.A. (1991). *Family-centered program rating scale.* The University of Kansas, Beach Center on Families and Disability.

McWilliam, P.J., & Winton, P. (1991). *Brass tacks: A self-rating of family-centered practices in early intervention.* The University of North Carolina at Chapel Hill, Frank Porter Graham Child Development Center.

Curricular resources (to assist with the Program Self Review)

Available from AFB Press, American Foundation for the Blind, Eleven Penn Plaza, New York, NY 10001:

Chen, D. (1997). *What can baby see? Vision tests and interventions for infants with multiple disabilities* [Video and booklet]. New York: AFB Press.

Chen, D. & Schachter, P. (1997). *Making the most of early communication* [Video and booklet]. New York: AFB Press.

Chen, D., & Orel-Bixler, D.A. (1997). *Vision tests for infants* [Video and booklet]. New York: AFB Press.

Ferrell, K.A. (1985). *Reach out and teach: Materials for parents of visually handicapped and multihandicapped young children.* Parent Handbook and Reach Book.

Huebner, K.M., Prickett, J.G., Rafalowski T.W., & Joffee, E. (1995). *Hand in hand. Essentials of communication and orientation and mobility for your students who are deaf-blind (Vol. 1).* New York: AFB Press.

Available from the American Printing House for the Blind, P.O. Box 6085, 1839 Frankfort Avenue, Louisville, KY:

Chen, D., Friedman, C.T., & Calvello, G. (1990). *Parents and visually impaired infants.* Louisville, KY: American Printing House for the Blind.

Curricular resources, continued

Lueck Hall A., Chen, D., & Kekelis, L. (in press). *Developmental guidelines for infants with visual impairments. A manual for early intervention.*

Available from Paul H. Brookes Publishing, P.O. Box 10624, Baltimore, MD 21285:

Bricker, D. (1993). *AEPS measurement for birth to three years (Vol. 1).*

Bricker, D., & Woods Cripe, J.J. (1992). *An activity-based approach to early intervention.*

Chen, D. (1997). *What can baby hear? Audiological tests and interventions for infants with multiple disabilities* [video and booklet].

Woods Cripe, J., Sientz, K., Bricker, D. (1993). *AEPS curriculum for birth to three years (Vol 2).*

Available from HOPE Inc. 809 North 800 East, Logan UT 84322-1900:

Alsop, L. (Ed.), (1992). *A resource manual for understanding and interacting with infants, toddlers, and preschool age children with deaf-blindness.*

Clark, T., & Watkins, S. (Ed.), (1985). *The SKI*HI model: Programming for hearing impaired infants through home intervention.*

Morgan, E.C. (Ed.), (1994). *Resources for family centered intervention for infants, toddlers, and preschoolers who are visually impaired.* VIISA Project (Vols. 1 & 2).

Watkins, S. (Ed.). (1989). *The INSITE model. A model of home intervention for infant, toddler, and preschool aged multihandicapped sensory impaired children.* (Vols. 1 & 2). Logan, UT: Hope Inc.

Other Publishers:

Furuno, S., et al. (1985). *Hawaii Early Learning Profile (HELP) activity guide.* VORT Corporation, P.O. Box 60880-P, Palo Alto, CA 94306.

Freeman, P. (1985). *The deaf/blind baby: A programme of care.* William Heineman Medical Books, 23 Bedford Square, London, WC1B 3HH, England.

McInnes, J.M., & Treffry, J.A. (1982). *Deaf-blind infants and children: A developmental guide.* University of Toronto Press, 5201 Dufferin, North York, Ontario, M3H 5T8 Canada.

Mentorship & Collegial Support: Enhancing the Early Intervention Team

by Pamela Haag Schachter

Early intervention teams are extremely varied in their composition and functioning. Whatever the service delivery model, funding source, program philosophy or professional backgrounds, all teams face the challenge of defining and creating leadership, supervision, mentorship and collegial support within their own group. While official functions of leadership, supervision and staff development may be determined by an outside structure, such as the school district or state agency, informal structures exist within every team as well. Although this is true of most workplaces, early interventionists face the added challenge of defining their "workplace" as everywhere from their cars, to a family's home, to a school or clinic setting.

Traditional approaches to staff development, such as lecture based in-service training, are neither effective or time efficient for the early interventionist (Trohanis, 1994). A variety of approaches must be used in order to help early interventionists gain professional knowledge and skills. This paper will review key components of mentorship and collegial support, from both a business and education perspective; identify the implications for developing mentorship in early intervention programs; review the characteristics of an early intervention team and recommend and provide examples of effective practices for supporting the professional development of early intervention team members.

Mentorship in business settings

A mentorship is defined as an involved working relationship between a senior (mentor) and junior (protégé) member in an organization (Chao, Walz & Gardner, 1991). The mentor, through experience and power in the organization, is able to advise, counsel, coach and promote the career of the protégé. The protégé trusts the mentor to provide wise counsel.

Chao, Walz and Gardner (1991) studied the differences between formal and informal mentor relationships. Informal mentorships typically grow out of friendships, while formal mentorships are characterized by assignment from a third party in the organization. The formal relationship, beginning without the benefit of a friendship, may require a longer introductory period to allow the participants to get to know one another and may be hampered by the mentor not viewing the protégé as worthy of additional time and support. Chao, Walz and

Gardner found that, in all cases, the average scores for informal protégés were higher than for formal protégés on measures of socialization, career functions and intrinsic satisfaction. They hypothesized that informal mentors are more likely to help socialize the protégé, assisting him/her in learning about the job, people, policies, and the culture. Informally mentored relationships may have more influence on aspects of work such as responsibility, autonomy and feelings of accomplishment.

Mentorship

Mentors provide for their protégés...

A CAREER function that relates directly to career advancement,

and,

A PSYCHOSOCIAL FUNCTION that is more concerned with the protégé's self-image and competence.

Kram, 1983

Mentorship in educational settings

A variety of factors influences the success of mentor teacher relationships (Kling & Brookhart, 1991), including characteristics of the mentor and protégé. In particular, compatibility, similar values, similar commitment levels, trust, openness, acceptance and caring are cited as important components. Trust in the mentor facilitates a willingness for the protégé to engage in the risk-taking behaviors necessary for professional growth. Mentors and protégés must be aware of the goals of the mentor relationship in order to have clear communication. The relationship must have reciprocal commitment from both partners. The mentor must be willing to allow the protégé to take risks. Some mentors and protégés report that it is helpful if they teach the same subject or grade, especially if highly technical information is involved.

The administrator plays a critical role in supporting a mentoring relationship (Kling & Brookhart, 1991). The administrator needs to facilitate release time for mentor and protégé to observe each other's teaching, observe other teachers together, and attend conferences. Administrators and supervisors often see the mentor as an assistant supervisor. It is critical to the mentor relationship that the mentor not be involved in any aspect of supervision or evaluation of the protégé's job performance and that the confidentiality of the relationship be respected at all times.

A case teaching approach is useful for facilitating mentor-protégé conversations about teaching (Carter, 1988). Case study serves as a tool to reveal the depth and breadth of teaching knowledge. Mentor teachers who have functional understanding of classroom processes can impart their knowledge through the language "in use" by practitioners.

The Case Method of Instruction (CMI) is proposed by McWilliam (1992) as an effective pre- and in-service training method in early intervention. It emphasizes problem solving and group decision making, helping interventionists to bridge the gap between theory and practice. Trainees are provided with cases that reflect the complexity and challenge of early intervention. As in real life, there is no one correct answer to the cases presented. In-service interventionists may be drawn into a training through the use of CMI as they see the immediate relevance of the training content. One drawback to this method is the availability of relatively few high quality cases for study (McWilliam, 1992).

Essential features of effective supervision and mentorship in early intervention are reflection, collaboration and regularity (Fenichel, 1992). Reflection involves the protégé stepping back from the immediate, intense, "hands on" experience of intervention and entering into dialogue with the mentor. From this dialogue the protégé should have a clearer vision of the work in progress. Collaboration is described as "having a friend on a difficult journey," and thereby not having to navigate unknown territory alone. Collaborative relationships have shared power, clear mutual expectations, and open communication. Regularity refers to the critical need to allocate regular time for the mentor relationship to occur. The nature of early intervention work (limited funding, complicated family situations, urgency of children's needs, paperwork), does not lend itself to taking time out for mentorship. The availability of a regular meeting time is critical to the success of the process.

The process of "teachers coaching teachers" builds a community of teachers who engage in the study of their craft and develop a shared language and common set of understandings necessary for collegial study (Showers, 1985). Coaching provides a structure for the essential follow up to training that is necessary in order to acquire new teaching skills and strategies. The process of coaching is a cyclical extension of initial training. Early sessions provide opportunities for checking performance against expert models of behavior. Teachers must give each other feedback which is accurate, specific, and nonevaluative. As skills develop, the coaching moves into a more complex phase, i.e., mutual examination of the application of the new strategies learned. Showers reports that coaching has two major effects: it facilitates transfer of training and it creates of norms of collegiality and exploration. Transfer of training is facilitated because through coaching, strategies are usually practiced more frequently, used more appropriately, retained longer, and better explained to the students in the class.

Implications for mentorship in the early intervention team

Mentor relationships in business settings are said to focus on assisting the protégé to adjust to the corporate culture, to fit in socially. In educational settings, the focus is described as acquisition of new skills or information. Individuals who choose to work in early intervention generally do so because they like young children, enjoy helping relationships, and hold values that promote this kind of work. They fit easily into the culture of the organization, but may not come with the knowledge and skills necessary to provide effective intervention. Mentorship may be an effective tool for helping interventionists to develop these skills.

Program administrators play a key role in the development of an effective mentorship program. The administrator must encourage staff to form mentor relationships for their professional development. On a fiscal level, staff will need release time and financial support to cover travel and phone expenses. In the role of job supervisor, the program administrator can help a protégé define areas in need of professional development. This will help the protégé identify a mentor who has the skills that she wishes to acquire. Mentors may be found in other early intervention programs, at universities, hospitals or elsewhere in the professional community. It is generally advisable to choose a mentor who is within driving distance of the protégé, unless financial support can be found for travel expenses. Mentor relationships may focus on virtually any of the skills required of an early interventionist: understanding specific disabilities, working with families, home visiting skills, group teaching skills, transition, assessment, intervention techniques, and so on.

All parties must be clear on the nature of the relationship and the roles of mentor and protégé. The mentor does not replace the administrator as the protégé's job supervisor. The relationship is supportive of the protégé's job, but is separate from it. The mentor and protégé must be clear on the protégé's reasons for requesting to enter the relationship and they must write attainable goals for the relationship. The mentor and protégé may choose to observe each other at work, address specific intervention problems, attend workshops, or discuss intervention strategies. A wide variety of activities will help the protégé to achieve her goals. The mentor and protégé enter into the relationship voluntarily and unless specified in advance, the mentor receives no financial compensation. The mentor must define the limits of her time and availability to the protégé.

Informal mentor relationships that grow out of a friendship have the advantage of the mentor and protégé knowing each other well. They have the risk of being more socially focused and less skill focused. In formal mentor relationships it may take longer for the participants to get to know each other. However, formal mentorships have greater potential for the protégé to acquire new skills and knowledge if the mentor was selected because she has the specific skills the protégé needs. The protégé must feel comfortable with the mentor so that a relationship of trust and respect may develop. Successful mentor relationships have an affective component as well as a focus on specific content.

Unique challenges to the early intervention team

Members of early intervention teams are unique in many ways. They are likely to have widely varied educational backgrounds. Individuals with high school diplomas, many with bachelor's and master's degrees, and even some with doctoral degrees may work on the same team. Individual experiences in early intervention will vary as well. Some individuals may be new to working with infants and toddlers, having experience with older children with disabilities, while others may come from a child development background and have experience with young children who are developing typically.

Research has shown that specialized training and education are the best predictors of effective early intervention, not experience alone (Kontos & File, 1992). However, professional competencies and personnel standards for early intervention did not exist before P.L. 99–457. A recent survey of California personnel preparation programs across 11 disciplines, including special educators, revealed little training content specific to infants and toddlers (Hanson & Lovett, 1992). These results highlight the need for specialized inservice as well as preservice training for early interventionists.

A study

Home-based early interventionists in North Carolina, found an annual turnover rate for...

Professional staff	19%
Program Administrators	12%

This compares favorably with an annual turnover rate for...

Child Care Workers	42%

Palsha, Bailey, Vandiviere & Munn, 1990

Another important characteristic of the early intervention team is staff turnover and job satisfaction. When surveyed on the factors that influence job satisfaction, early interventionists indicate that salary, promotion and retirement benefits are very important (Kontos & File, 1992). Early interventionists are likely to be underpaid when compared to public school teachers with similar educational levels. They are also more likely to receive inexpensive benefits such as release time for conferences and less likely to receive medical insurance, pension plans, and other financial benefits (Kontos & File, 1992). Additionally, opportunities for career advancement, reduced caseloads, and less paperwork were indicated as factors that add to job satisfaction and help to retain trained interventionists.

Early interventionists have a deep desire to improve the quality of life of the infants and families with whom they work. They face many challenges in doing so. The infants and toddlers may have complex, difficult, or even terminal conditions. Families are often under a great deal of stress and depend on the early interventionist for help with solutions to problems and to serve as an emotional outlet for them. Early interventionists providing home-based services often work alone and may be isolated from their colleagues for several days at a time. Driving on congested freeways, in dangerous urban areas, or along lonely rural roads also adds to the stress of providing early intervention services.

Administration of early intervention programs is as varied as the individuals who work in them. Programs based in school districts or county offices of education may be supervised by a principal or area administrator who may or may not have an early intervention or special education background. These individuals are often responsible for a great many service areas and may not be directly involved in the day to day supervision of services. Often a lead or mentor teacher assumes this role, either by formal designation or by staff choosing to turn to this individual for support and direction. Nurses, therapists, and psychologists who work on these teams are often hired and supervised by an entirely different administrator, which may result in confusing messages and expectations.

Private, not-for-profit programs face many administrative challenges as well. The program director, responsible for day-to-day supervision of the program is often chosen from the early intervention team because of his/her exemplary work. These individuals, while highly skilled with children and families, may not have any training in administration or supervision. Budget constraints may also press a program director into serving a caseload of children as well as serving in an administrative role. This leaves the program director with little opportunity to provide supervision to other team members. Supervision may also be provided by the executive director of the not-for-profit organization. Other programs run by the organization may serve older children with disabilities, serve young children who are typically developing, provide counseling or offer many other human services. The executive director may not have any personal experience in early intervention.

Most early intervention administrators have developed their skills through "on the job" training, without the benefit of formal training as an administrator. The early intervention administrator is asked to supervise a team of individuals from a variety of disciplines. The administrator must receive training beyond her own discipline to be prepared to assume a leadership role. Nationally, very few programs are available to train early intervention administrators (Johnson, Kilgo, Cook, Hammitte, Beauchamp & Finn, 1992). A well trained leader with effective management skills will improve the quality of services provided.

Specialists and consultants working on early intervention teams are often hired on a part-time or as-needed basis. These team members are rarely able to participate in all team meetings or in-service opportunities. It is difficult for them to benefit from the input and support of other team members or to share their expertise fully with the team. Training programs for professionals from disciplines other than education are least likely to include competencies specifically relating to infants (Hanson & Lovett, 1992).

Effective practices

Successful early intervention teams—that is, those that provide the necessary support and information to their members so that they can effectively do their jobs—must first define the leadership roles in their team. There is no one set model for leadership. Different individuals may provide leadership in different situations. It is most important that someone, formally or informally designated, provides leadership in the area of development. The leader of the team need not be able to provide all information or support, but should be a starting point in guiding a team member to find answers.

Different individuals provide leadership in different situations

TO WHOM do staff turn when they need information and support?

and,

TO WHOM do they turn for assistance in coping with the emotional stress of their job?

and,

FROM WHOM do they seek assistance with babies who have unique or complex conditions?

Early intervention teams also face the challenge of frequent turnover of staff. In addition to orienting new staff to program paperwork and policies it is important that the new team members' intervention knowledge, skills and interests are also assessed and that an appropriate professional development plan is developed.

Support and information should be offered in a variety of formats. In a formal mentor program, a team leader may help pair a protégé and mentor who are willing to make a long term commitment to work together. The mentor and protégé may or may not work in the same program. A technical assistance project or university faculty member may be of assistance in finding a mentor with specific expertise. The protégé and mentor may work together in person and by telephone. The mentor and protégé may need assistance to write objectives and choose training activities. This option is especially helpful for protégés who often work in isolation from other professionals.

Peer coaching is another powerful development tool. Team members may choose a peer from their own or a nearby program with whom to engage in a course of study. The peer team attends formal trainings and visits and observes other early intervention programs. Team leaders may assist the peer team with determining objectives and activities and with the peer coaching process itself.

Supervision by a designated team leader is another important piece in the staff development puzzle. Supervision which provides for an opportunity to reflect on work in progress and to collaboratively problem solve is most likely to be helpful to the early interventionist. Finally, it is equally important to recognize that program leaders, supervisors and administrators may need assistance and training in order to effectively use the staff development tools described in this chapter.

Examples of mentorship and peer coaching in early intervention

Peer coaching was used successfully by two home-based early intervention teachers, Susan and Clara, who work for the same agency. Susan and Clara serve children between birth and three who have vision problems and other disabilities. The teachers attended an in-service training on how to screen the infants they serve for hearing loss. Susan and Clara were both excited bout the information they received, as they had concerns about the hearing status of many of the babies they served. Neither felt entirely confident in her ability to implement all the procedures and forms that the training covered. Susan and Clara felt that they could work together to practice the skills and provide feedback to each other.

The main obstacle that Susan and Clara identified was that their schedules did not provide time for them to see children or meet with families together, something they felt would be necessary to observe and provide feedback to each other. They agreed that they could meet with each other to plan and give feedback over coffee after their weekly staff meetings. Susan and Clara approached the program director and requested four half days that each of them could be released from regular home visits so that one could attend an afternoon or morning of visits with the other. Although staffing patterns for the agency meant that the visits would be missed that could not be made up, the administrator felt that the time would be well invested in Susan and Clara's professional development and that the children would ultimately benefit.

Susan and Clara wrote a detailed plan for their peer coaching time, including the work that each would do individually (such as review medical records or informal observations), what would occur doing joint visits (such as family interviews or screening a baby with the HEAR kit) and when they would meet to discuss their observations and give each other feedback. Susan and Clara became confident in their skills in functional hearing screening and were able to use the procedures independently, although they still confer with each other informally about a child who challenges them.

Mentorship was used by another home-based agency serving children from birth to three who have vision loss. Some of the children have multiple disabilities in addition to their vision loss. The teachers working in the program are very skilled in working with infants with vision loss, but training in multiple disabilities is not consistent. Patricia, a very skilled and experienced member of the staff, was recruited by the program director to serve as a mentor to Joyce, a newly hired teacher. Joyce, while trained and experienced as a teacher of the visually impaired, had not worked with infants and toddlers with multiple disabilities. Although eager to have the opportunity to serve as a mentor, Patricia was initially concerned about how the time she would spend with Joyce might impact her own workload. The program director asked Patricia to design how she could best spend time with Joyce, while taking the least time away from her babies and their families. As an additional challenge, Patricia and Joyce would be serving two adjacent, but very large, counties. Their daily visits would involve driving many miles between visits.

The solution involved Patricia spending one day a month with Joyce, conducting home visits together. Joyce and Patricia chose different days each month, so that Patricia missed visits with different children each time. One week before the joint visits, Patricia and Joyce would schedule a one hour phone time to discuss the issues of concern to Joyce and to allow Patricia to prepare materials or suggestions for the visits. The phone meeting was then repeated one to two weeks after the visits to discuss follow up questions or analyze how Patricia's suggestions were working for Joyce. The phone meetings were creatively scheduled, with both teachers sometimes at home, the office, or even a public telephone. Using the telephone to prepare and debrief from the visits was an effective use of time that allowed this mentor-protégé relationship to flourish. Although originally planned for a six-month period, Joyce and Patricia continued to have formal phone meetings for over a year.

Conclusion

Early intervention teams serve infants, toddlers and families with wide ranging and complex needs. It is an ongoing challenge to find effective methods for training and supporting staff in their important and complicated work. As staff needs are identified, interventionists and administrators must collaborate to plan how to meet them. Just as we assess, write objectives and plan very specific intervention activities for children and families, we must do so for our own professional development. Early interventionists, a very creative and resourceful group of problem solvers, will create solutions to their own training needs when given the opportunity, encouragement and means to do so.

References

Carter, K. (1988). Using cases to frame mentor-novice conversations about teaching. *Theory into Practice*, 215-222.

Chao, G.T., Walz, P.M. & Gardner, P.D. (1991). *A comparison of informal mentoring relationships and formal mentorship programs*. Michigan State University (ERIC Document Reproduction Service No. ED 333784).

Fenichel, E. (1992). *Learning through supervision and mentorship*. Arlington, VA: Zero to Three/National Center for Clinical Infant Programs.

Hanson, M.J. & Lovett, D. (1992). Personnel preparation for early intervention: A cross disciplinary survey. *Journal of Early Intervention*, 16, 123-135.

Johnson, L.J., Kilgo, J., Cook, M.J., Hammitte, D.J., Beauchamp, K. & Finn, D. (1992). The skills needed by early intervention administrators/supervisors: A study across six states. *Journal of Early Intervention*, 16, 136-145.

Kling, R.E. & Brookhart, D.A. (1991). *Mentoring: A review of related literature*. Colorado State University (ERIC Document Reproduction Service No. ED 346095).

Kontos, S. & File, N. (1992). Conditions of employment, job satisfaction, and job commitment among early intervention personnel. *Journal of Early Intervention*, 16, 155-165.

Kram, K.E. (1983). Phases of the mentor relationship. *Academy of Management Review*, 26, 608-625.

McWilliam, P.J., (1992). The case method of instruction: Teaching Application and problem solving skills to early interventionists. *Journal of Early Intervention*, 16, 360-373.

Palsha, S.A., Bailey, D.B., Vandiviere, P. & Munn, D. (1990). A study of employed stability and turnover in home-based early intervention. *Journal of Early Intervention*, 14, 342-351.

Showers, B. (1985). Teachers coaching teachers. *Educational Leadership*, 42(7), 43-48.

Trohanis, P.L. (1994). Planning for successful inservice education for local early childhood programs. *Topics in Early Childhood Special Education*, 14, 311-332.

The Art of Collaboration

by Pamela Haag Schachter

Part H of the Individuals with Disabilities Education Act (IDEA) identifies collaboration as an effective practice. The law recommends that states establish early intervention service delivery systems that are more collaborative and less hierarchical (Cook, Tessier & Klein, 1992). The development of a meaningful Individualized Family Serivce PLan (IFSP) requires collaboration between the family and professionals involved in the care of the child. Professional teams must collaborate in order to provide comprehensive and coordinated services to a child and family.

As basic as these concepts may appear, there are many roadblocks to providing seamless, comprehensive and coordinated early intervention services. Infants with multiple disabilities, including vision and hearing loss, may be receiving services from a variety of agencies. An infant may transition from one program to another. An infant's "team" may be a group of unrelated professionals who have never all gathered together in a room at the same time. They may work for agencies that have different agendas, philosophies and funding sources. Likewise, individual service providers have different personalities, training and approaches. In an ideal world, these differences could be used by the team to design intervention that best meets the needs of the infant and family in question. Unfortunately, these differences often become stumbling blocks to an infant and family receiving the comprehensive and coordinated services that the law prescribes as best practice.

Additionally, barriers to collaboration between agencies reduce the capacity of a community's service delivery system. Interagency collaboration has the potential to reduce costs of service delivery, increase opportunities for staff development, improve the overall quality of intervention services and increase the variety of service models available. This chapter will provide examples of interagency collaboration in the early intervention system and discuss practices that help facilitate collaborative relationships among early intervention service agencies.

Learning on the job

The following stories are taken from my experiences as an early intervention teacher, administrator and technical assistance provider. In retrospect, it is easy to see how collaboration between agencies benefited the children and their families. When embroiled in the situations, though, it was very difficult to see the problems so clearly. Still, I firmly believed that through the collaborative relationships mandated by P.L. 99–457 I could help create a more effective early intervention system in my community.

One-on-one

Collaboration slowly brought about a mutually beneficial relationship between my early intervention program and the large, urban school district that many of our toddlers graduated to for preschool services. For many years, the transition at age three from our early intervention program to the school district's preschool programs was an adversarial battle. We encouraged our families to fight for the least restrictive placement possible and for all of the related services they wanted for their children. These activities were based on our belief that advocacy was a central part of the services we provided. We felt that the school district's assessments were unfair and biased, rarely showing anything but the child's deficits. We believed that our children were being sent to unnecessarily segregated classrooms at special education centers, often far from their homes. In our advocacy efforts, we had thoroughly angered and frustrated the administrators, psychologists, therapists and teachers who where receiving our graduates. IEP meetings were viewed routinely as battlegrounds where our philosophical battles were fought and the family's needs ignored.

Collaboration began to enter our relationship as I served, alongside the school district's preschool program coordinator, on the local Interagency Coordinating Council. I was amazed to find myself often agreeing with the viewpoints Linda offered. A friendly relationship evolved at meetings, leading eventually to a few lunches together between meetings. As we got to know each other, personally and professionally, many misconceptions about each other began to dissolve. I had expected that we would agree on nothing, but was amazed to begin to view Linda as a caring professional who shared many of my beliefs and ideals. I learned a great deal about the enormous bureaucratic system that Linda worked in and how she felt it hampered her ability to do what she felt was best for children. Likewise, I told her about the constraints of working in a small not-for-profit organization that was often fighting for its very existence.

As trust developed, we agreed on mutual goals to improve the transition process between our programs. I presented training to the school district's preschool assessment team, and Linda spoke to our early intervention team, helping its members to understand how a large school district operates. We shared with each other the stumbling blocks to change within our own organizations. We identified key people in our organizations whose opinions or attitudes needed to change.

Over time we helped to create a vastly smoother transition for our graduating families. Assessments came to be shared and respected between our programs. Further assessment needed by the school district was done at our center or the child's home and in collaboration with the early intervention teacher. Families were shown a wider range of placement options and were supported by the school district team if they chose Head Start or another general education preschool option. The early intervention teachers showed greater respect for the knowledge, skills, and dedication of the school district staff and transmitted those feelings to families as they guided them through the transition process. IEP meetings came to be seen as an opportunity to share information and be supportive of the family as they made choices about their child's preschool education.

These changes took place without any formal interagency agreements. They took place because of trust and an emerging openness to learning about the strengths and constraints of each of the systems involved. Each of us faced colleagues who scoffed at our suggestions that we would benefit from hearing more from the other agency. The willingness of Linda and myself to take risks, personal and professional, made collaboration possible. This collaboration saved money by reducing duplicative assessment. Both agencies reduced the amount of time needed to plan each transition, and families benefited by having the sending and receiving agencies working together to help them choose a preschool program for their child.

Creating a team

Infants and toddlers with complex medical, developmental and sensory needs require a high level of interagency collaboration in order to receive coordinated services. In my position as a technical assistance provider I met eight month-old Lupita and her family. The Sanchez family's life was centered in Lupita's bedroom, where her suction machine, oxygen, nebulizer, feeding pump and apnea monitor were set up and in frequent use. Lupita's two year-old brother's toys were there, and the couch where Mrs. Sanchez slept at night, so that she would immediately hear Lupita if she needed suctioning. I sat in Lupita's bedroom and listened as Mr. and Mrs. Sanchez told me the story of Lupita's traumatic birth and severe deprivation of oxygen as she was born. Mrs. Sanchez's tears displayed the grief she was still struggling with as she told me that the doctors had said Lupita could not see or hear and would never know her mother.

I inquired naively about what services Lupita and the family were receiving and Mrs. Sanchez answered by handing me an inch thick pile of business cards. I began to sort the cards, to try to understand who was doing what and when they came to the house. Mrs. Sanchez didn't know why all of these people were coming, or when to expect them. She didn't know what to expect that they could do for Lupita and clearly had no idea of any goals or objectives that might have been written in an IFSP.

Following our first home visit, I began to call the professionals who were visiting Lupita. They included a visiting nurse from the family's health insurer, a nurse sent to provide occasional respite care, an occupational therapist, an early intervention teacher specializing in infants with vision loss and multiple disabilities, two different general early interventionists, a teacher in the area of visual impairment and a teacher of the deaf. Not one of these professionals was aware that all of the others were also visiting Lupita and her family.

I contacted the service coordinator assigned to the Sanchez family and tried to tactfully explain that, despite all the services, the family's urgent needs were not being met. Mrs. Sanchez did not know what to expect intervention could do for Lupita, how she could be involved in her daughter's treatment, or how to get the increased respite care that she so desperately needed. As I spoke to many of the professionals involved, I was overwhelmed by the lack of coordination between them and their seeming indifference. Each believed that as long as he or she was seeing Lupita and working in the assigned developmental area or body part, then all was well. Defensiveness played a part, and my questions about the services being provided were taken as a condemnation. My own frustration grew as I struggled to convince the service coordinator that Lupita's services were totally uncoordinated and had not even begun to address her unique needs as a child with dual sensory impairments. We allowed our own agendas to interfere with appropriate service delivery.

Eventually, the service coordinator and I agreed to call a meeting of all of Lupita's service providers. Choosing a date and time was difficult, and a few providers did not attend. The meeting began with introductions, clarifying the role of each provider, his/her service and schedule. We began to debate the relative value of each service, a process that was only reinforcing territorialism and fragmented services. Finally, the administrator who was hosting the meeting turned to Mrs. Sanchez and asked her what she thought would help Lupita and the family. It was an important turning point.

Mrs. Sanchez explained her urgent need for sleep and time with her two year old son. She expressed concern about her ability to communicate with her daughter, asked how to help her move her arms and legs and wondered aloud if she could see anything. The professionals in the room began to respond in a compassionate and professional manner, some suggesting that their services were a duplication, or could be done on a consultant basis. The infant teacher of the deaf asked to increase her services, as did the teacher in the area of visual impairment. The service coordinator pledged to increase respite services, asking Mrs. Sanchez how many hours a month she thought she needed. Paperwork began a referral for physical therapy consultation. Future team meetings were scheduled as everyone agreed that Lupita's complex needs required a coordinated approach.

Sharing space

As the director of a university-based early intervention program, I was approached with the news that the dean had given one of our classrooms to a Head Start Program for its use and that our infant class would have to vacate the space. Very much in need of the classroom, I launched into a variety of diplomatic efforts to keep Head Start out and my infants in the classroom.

After several months it became apparent that this approach was ineffective and I had to try a new tact. A meeting was scheduled with the Head Start Director and Special Needs Coordinator and myself. I approached the meeting planning to convince Head Start that we needed the classroom more than they did. I was shocked to learn for the first time that day that Head Start planned to only have an afternoon class, while our infant class met in the morning. The compromise of sharing the classroom was obvious, and our relationship began to evolve from adversarial to mutually cooperative.

I moved a morning toddler class to the room in question, so the physical space and equipment would be easier to share with Head Start's four and five year olds. The teachers met and began to re-design the room and decide what furniture, toys and supplies would be mutually or exclusively used. Upon learning that a Head Start class would soon be located in the same space as our program, two parents of graduating students from our toddler class applied to have their children attend the Head Start class.

While the teachers grumbled about the need to move tables and chairs at the beginning and end of each day, positive changes occurred as well. When they had time, the teachers of both classes stayed to observe the other. The Head Start teachers were eager to learn more about teaching young children with disabilities. The early intervention teachers were fascinated to watch typically developing children at play and learn more about the routines and skills needed in a typical classroom.

Eventually, the two programs wrote an application for federal funding for Head Start classes for toddlers. The application was funded and a fully integrated toddler class, run collaboratively by both programs, opened. Out of a relationship that began for reasons of self preservation came a better program than either program operated individually. The collaborative efforts that eventually took place were delayed for many reasons. One of the biggest barriers was that we perceived each other as adversaries vying for the classroom, without ever speaking to each other. It was an important lesson about going directly to the people involved and exploring the problem together. Through mutual concessions each program eventually offered better services to a wider variety of young children with better trained staff.

Skills for collaboration

Collaboration requires an investment in and commitment to teamwork. As difficult as teamwork may be within an agency, it faces even greater challenges between agencies. Teamwork in human service professions requires, at a minimum, effective communication skills in order to accurately share information; an interest in collaborative service delivery; skills at conflict resolution and mutual support (Garner, 1994). Teamwork may be impeded by individuals or agencies with highly specialized skills which focus on a very narrow part of the child and are not interested in a whole child approach (Garner, 1994). Additionally, team members need to define their roles on the team, how the team is structured and who, if anyone, has final authority over decisions that are made (Garner, 1994).

Effective teams share many characteristics. They must have a clear understanding of their objectives. Team members must be competent; that is, they must have the technical skills required for their job roles and the personal skills to work collaboratively with others. A collaborative climate where there is a deep level of trust , a desire for excellence and strong leadership are also key characteristics of effective teams (Garner, 1994).

Interagency collaboration in early intervention may come about through work on formal teams, such as the Interagency Coordinating Councils, but it is just as likely to occur through informal relationships that grow from the identification of a mutual need or problem. Teams may be large, or they can begin with a relationship between just two individuals. Whatever their size and however they came together, collaborative teams will benefit from clearly examining the critical issues facing the members. Each participant must acknowledge that individual actions and decisions are affected by the mission and philosophy of the agency. Individual philosophies may conflict with institutional ones. Becoming aware of your own philosophy and that of your partners in collaboration is critical. Acknowledging that you have different beliefs about how children learn, where they should learn, the role of families, and so on, will help you find solutions to problems that are acceptable to all parties. Similarly, understanding the critical issues your partners face in the day to day functioning of their services is vital as well. Problems with funding, personnel, governmental regulations and boards of directors can strongly affect an individual's positions and ability to compromise. It is equally important to understand how these factors influence your own actions and those of your partners in collaboration.

Partners in collaboration also must define what kind of relationships they can (by law or direction of superiors) and want to engage in. Running a program together is a wonderful idea, but reaching agreement on the financial and operational details will depend on a careful understanding of the constraints faced.

Collaborative professional relationships, like personal relationships, take time and require an ongoing commitment to effective communication skills. Partners must communicate their expectations, boundaries and how much time and energy they are prepared to commit to the relationship. All parties can then operate more effectively with this information out in the open.

The Harvard Negotiation Project studied how individuals and groups can more effectively negotiate agreements that are mutually satisfying to all parties. The project emphasized that in order to deal with differences, they must first be brought out in the open. The image of a good relationship may be temporarily satisfying, but it is counterproductive to ignore differences. By acknowledging areas of disagreement we can balance reason and emotion and look for solutions that are mutually acceptable (Fisher & Brown, 1988).

Bargaining pits one position against another and makes compromises appear as weakness. This strategy, as experienced by many car buyers, seldom leads to an outcome that is mutually satisfying. Principled negotiations, as described by Fisher and Ury (1981), suggest that separating the people and the problems, focusing on interests as opposed to positions, generating a wide variety of possibilities before deciding what to do and seeking a result that meets an objective standard will lead to a solution that makes all parties feel as if they have won.

Children and families are the true winners when professionals in the early intervention system are able to collaborate. Beyond discussion of collaboration, we must roll up our sleeves and engage in the hard work of self examination and openness to the ideas of our colleagues. The art of collaboration is an ongoing and necessary cornerstone of early intervention.

References

Cook, R.E., Tessier, A. & Klein, M.D. (1992). *Adapting early childhood curricula for children with special needs*, 3rd ed. Macmillan Publishing Co., New York, NY.

Fisher, R. & Brown, S., (1988). *Getting together: Building a relationship that gets to Yes*. Houghton Mifflin Co., Boston, MA.

Fisher, R. & Ury, W. (1981). *Getting to yes: Negotiating agreement without giving in*. Houghton Mifflin Co., Boston, MA.

Garner, H.G. (1994). Critical Issues in teamwork. In H.G. Garner and F.P. Orelove (Eds.), *Team work in human services: Models and applications across the life span* (pp. 1-15). Butterworth-Heinemann, Newton, MA.

Identification

Identifying Infants who are Deaf-Blind

by

Deborah Chen

Strategies for Gathering Information

by

Pamela Haag Schachter

Identifying Infants who are Deaf-Blind

by Deborah Chen

The term "deaf-blind" indicates that an infant has impairments in both significant avenues for learning—vision and hearing. Fortunately, the majority of these children have either some vision or hearing (Fredericks & Baldwin, 1987). Infants who are deaf-blind include babies with mild-to-profound vision and hearing losses, those with cortical visual impairment and/or central auditory processing disorders, those who are hard of hearing and blind, those who are low vision and deaf, those who are totally blind and have a profound hearing loss, infants who are hard of hearing and low vision, and those with medical needs, severe developmental delays and other physical disabilities (Chen, 1993, Chen & Haney, 1995; Michael & Paul, 1991). There are no data on the distribution of characteristics in infants who are deaf-blind. Data are available on the school age populations from Outlette (1984) as reported by Federicks and Baldwin (1987). In the population of children and youth identified as "deaf-blind," 6.1% were deaf and blind, 3.4% were deaf with a severe visual impairment, 48% were blind and had a severe hearing loss, and 42.4% had a severe hearing loss and severe visual impairment. These statistics indicate that almost 94% of the deaf-blind population have some functional vision or hearing. More recent data in the 1990s (Edwards, Goehl, & Gordon, n.d.) also indicate that a majority of the deaf-blind population (birth to 21 years) have some usable vision or hearing.

Under P.L. 99–457 Part H, infants (birth to 36 months) are eligible for early intervention services if they meet the following eligibility: (a)have developmental delays in one or more of five developmental areas (cognitive development, physical and motor development, including vision and hearing, communication development, social emotional development, or adaptive development), (b) have established risk (physical or mental) conditions that have a high probability of resulting in a developmental delay in one of the five areas of development, or (c) are at high risk for substantial developmental delay unless early interventions services are provided. Thus infants may be eligible for deaf-blind services if they are under 36 months and: (a)have developmental delays in vision and hearing, (b) have a diagnosed physical or mental condition that has a high probability of resulting in developmental delays in vision and hearing; or (c) are at risk for having substantial developmental delays in vision and hearing if early intervention services are not provided (Office of Federal Regulations, 1995, pp.157-158). Public recognition that the term deaf-blind includes a wide range of vision and hearing loss is a critical step towards (a) early identification of infants with both vision and hearing loss, and (b) the provision of appropriate early intervention services.

High risk factors associated with hearing loss or visual impairment in very young children

HIGH RISK FACTORS ASSOCIATED WITH HEARING LOSS

Family history

Prenatal exposure to maternal infections (toxoplasmosis, syphilis, rubella, cytomegalovirus, herpes)

Prematurity

Hypoxia

Cleft lip and palate

Craniofacial anomalies (malformations of pinna, ear canal, absent philtrum, low hairline)

Hyperbilirubinemia level requiring transfusion

APGAR score of 3 or less at 5 minutes after birth

Prolonged use of ototoxic medications

Prolonged medical ventilation (>10 days)

Certain syndromes (e.g., CHARGE, Down, Fetal Alcohol, Goldenhar, Hurler, Norrie, Refsum, Trisomy 13, Waardenburg)

Childhood infections (baterial meningitis, mumps, measles)

Head trauma

Cerebral palsy

Certain neurodegenerative disorders (e.g., neurofibromatosis, Tay-Sach, Niemann-Pick disease)

Joint Committee on Infant Hearing, 1991; Northern & Downs, 1991

HIGH RISK FACTORS ASSOCIATED WITH VISUAL IMPAIRMENT

Family history

Prenatal exposure to maternal infections (toxoplasmosis, syphilis, rubella, cytomegalovirus, herpes, chicken pox, HIV)

Abnormal prenatal brain development

Prematurity

Hypoxia

Certain syndromes (e.g., CHARGE, cri du chat, Down, Fetal Alcohol, Goldenhar, Hurler, Lowe, Marfan, Norrie, Refsum, Trisomy 13)

Other congenital ophthalmological syndromes (optic nerve hypoplasia, Leber's)

Bacterial meningitis

Head trauma

Cerebral palsy

Certain neurodegenerative disorders (e.g.,neurofibromatosis, Tay Sachs)

Northern & Downs, 1991; Teplin, 1995

Early identification

The combination of a vision and hearing loss will have a profound effect on an infant's development. Moreover, many infants with both vision and hearing loss have other disabilities. When a baby has obvious disabilities or meets certain high risk criteria (e.g., severe multiple disabilities, congenital facial anomalies, and congenital infections), vision and hearing tests may be conducted. However, even if a vision and/or hearing impairment is identified, the infant may not receive appropriate early intervention services related to the sensory impairments in a timely fashion. How quickly an infant receives these services often depends on the resources of the local medical and educational systems and the ability of the family to advocate for services within these systems (Chen, 1997a; Chen, 1997b).

Early interventionists working with infants with disabilities must be aware of the high risk factors and signs associated with vision and/or hearing loss (as shown in the charts). Newborns who demonstrate these risk factors should receive an audiological evaluation as early as possible (Kile & Beauchaine, 1991; Kramer & Williams, 1993; Mauk, Barringer & Mauk, 1995). Moreover, universal infant screening for hearing loss has been recommended nationally (Mauk, Barringer, & Mauk, 1995; National Institutes of Health, 1993). Similarly, both the National Academy of Ophthalmology and the National Academy of Optometry have recommended a comprehensive visual examination for all infants (see the chapter on *Clinical Vision Assessments*).

Many high risk factors are associated with *both* a visual impairment and hearing loss. In most cases, visual impairment is identified first, so the hearing of these infants must be tested and monitored closely. Early interventionists should review medical reports carefully, obtain detailed observations from parents, and conduct their own observations of the infant's responses to visual and auditory stimuli (see the chapter on *Strategies for Gathering Information*).

Incidence of combined visual impairment and hearing loss with other disabilities

There are more than 70 syndromes in which hearing and vision loss are likely to occur together (Regenbogen & Coscas, 1985). Some of these syndromes are rare and others are more common (e.g., CHARGE association, Down syndrome, Fetal Alcohol syndrome).

Other factors that may occur during the prenatal and neonatal periods place a baby at risk for vision and hearing loss and other disabilities. The numbers of infants with visual impairment, hearing loss, and other disabilities have increased because of advances in medical technology and the ability to sustain premature infants with very low birthweight (Lueng & Hollins, 1989; Hayes & Northern 1996; Northern

High risk signs of a hearing loss or visual impairment in very young children

HIGH RISK SIGNS OF HEARING LOSS

ATYPICAL APPEARANCE OF THE FACE OR EARS:

Cleft lip and palate

Malformations of the head or neck

Malformations of the ears including lack of opening at ear canal (atresia)

Frequent earaches or ear infections (otitis media)

Discharge from the ears

ATYPICAL LISTENING BEHAVIORS:

Has few or inconsistent responses to sounds

Does not seem to listen

Does not respond to caregivers calling his name

Shows a preference for certain types of sounds

ATYPICAL VOCAL DEVELOPMENT:

Has limited vocalizations

Has abnormalities in voice, intonation, or articulation

Shows a delay in language development

OTHER BEHAVIORS:

Pulls on ears or puts hands over ears

Breathes through mouth

Cocks head to one side

Chen, 1990; Gatty, 1996; Fewell, 1983; Joint Committee on Infant Hearing, 1991

HIGH RISK SIGNS OF VISUAL IMPAIRMENT

ATYPICAL APPEARANCE OF THE EYES:

Drooping eyelid which obscures the pupil

Obvious abnormalities in the shape or structure of eyes

Absence of a clear, black pupil

Persistent redness of conjunctiva (normally white)

Persistent tearing without crying

High sensitivity to bright light indicated by squinting, closing eyes, or turning head away

UNUSUAL EYE MOVEMENTS:

Jerky eye movements (nystagmus)

Absence of eyes moving together or sustained eye turn after 4 to 6 months of age

UNUSUAL GAZE OR HEAD POSITIONS:

Tilts or turns head in certain positions when looking at an object

Holds object close to eyes

Averts gaze or seems to be looking beside, under, or above the object of focus

ABSENCE OF VISUALLY DIRECTED BEHAVIORS:

Eye contact by 3 months

Visual fixation or following by 3 months

Accurate reaching for objects by 6 months

Calvello, 1990; Fewell, 1983; Teplin, 1995

& Downs, 1991;Trief et al., 1989).These premature babies are at risk for hearing loss, retinopathy of prematurity, and cortical visual impairment (Ferrell et al. 1990; Hayes & Northern, 1996; Northern & Downs, 1991). Additionally, infants who have certain congenital infections including toxoplasmosis, syphilis, rubella, cytomegalovirus, and herpes or who have cerebral palsy are likely to have a hearing loss and/or visual impairment and other disabilities. Research has found that 40 to 70 percent of preschoolers with visual impairment have other disabilities (Bishop, 1991; Dietz & Ferrell, 1993; Hyvarinen, 1988; Kirchner, 1989). While other studies suggest that 40 to 90 percent of children with severe or profound disabilities have visual impairments (Cress et al., 1981; Jacobson & Janicki, 1985). Up to one third of children with multiple disabilities have a hearing loss (Sobsey & Wolf-Schein, 1991). Given these statistics, it is imperative that infants with multiple disabilities receive early hearing tests and vision evaluations and appropriate early intervention services.

Effects of hearing loss

The effects of a hearing loss on an infant with other disabilities will depend on the infant's developmental skills, the severity and configuration of the hearing loss, and access to appropriate interventions. If a hearing loss is not identified and treated, it will have severe effects on the communication development of any infant (Nozza, 1994).

Early interventionists should assist families in obtaining information about their infant's hearing loss and in understanding the implications of the hearing loss. Parents are often confused by medical and educational definitions. They may think "hearing impaired" or "deaf" means totally deaf. Early interventionists should discuss the definitions for various categories including types and degrees of hearing loss, hard of hearing, deaf, hearing impaired (Northern & Downs, 1991).

Types of hearing loss

Hearing loss is identified according to the location of the damage or problem in the ear and auditory system and may be classified as conductive, sensorineural, mixed, and progressive losses, and central auditory processing disorders (Flexer, 1994; Hayes & Northern, 1996; Northern & Downs, 1991).

A **conductive hearing loss** occurs when problems in the outer and/or middle ear prevents sound conduction to the inner ear. These problems include an absence of closure of the ear canal (atresia), an abnormally small ear canal (stenosis), a perforated ear drum, middle ear infections (otitis media) or excessive wax. Middle ear infections are the most common cause of conductive hearing loss in young children. Medical intervention is required to treat most conductive hearing losses and surgery may be warranted. Recommendations for amplification will depend on the cause of the conductive loss, for example, infants with atresia will benefit from a bone conduction aid.

A **sensorineural hearing loss** occurs when the inner ear or cochlea is damaged permanently. Medical intervention or surgery cannot remediate the hearing loss. Cochlear implants are not used with infants under 24 months and those with additional disabilities (Hayes & Northern, 1996).

A **mixed hearing loss** occurs when there is both a conductive and sensorineural loss. Once the audiologist determines the type of hearing loss and recommends interventions, a physician should identify the causes and make recommendations for treatment.

A **progressive hearing loss** is characterized by a hearing loss becoming more severe over time. This infant will need to be monitored closely by the physician, audiologist, and early interventionist. Families will need additional support to cope with their infant's progressive loss of hearing.

A **central auditory processing disorder** indicates the infant does not have a conductive or sensorineural loss but cannot understand and interpret sound. This problem may occur in causes of neurological damage and head trauma. This is difficult to diagnose in a preverbal child (Northern & Downs, 1991). Infants with developmental delays may not attend to sounds although they pass hearing tests. They require specific interventions such as using contextual cues, focusing their attention, and encouraging their listening skills (Kile, Schaffmeyer, Kuba, 1994).

Degree of hearing loss

The loudness or intensity of sound is measured in decibels (dB). Early interventionists and families must understand that the decibel has a logarithmic and not a linear scale. If sound A is 10 dB and sound B is 20 dB then sound B is 10 times louder than sound A. If sound C is 30 dB then it is 10 x 10 = 100 times louder than sound A (Flexer, 1994). Therefore, if infant A has a 10 dB HL (normal hearing) and Infant B has a slight hearing loss of 20 dB HL then infant B can hear 10 times less well than infant A. If Infant C has a mild hearing loss of 30 dB HL then this infant can hear 100 times less well than infant A. Thus frequent middle ear infections can result in slight to mild hearing loss that will decrease the infant's ability to hear and understand sound.

Zero decibel hearing level (0 dB HL) represents the softest sound heard by a normally hearing person and does not indicate an absence of sound. A whisper has a loudness level of about 25–30 dB, conversational speech in a quiet place is about 45–50 dB, the noise of a dishwasher is about 75 dB, the sound of a food blender is about 90 dB, a rock band may be more than 110 dB HL, and the sound of a jet at take off may be 120 dB (Berg, 1993; Northern & Downs, 1991).

The severity of a hearing loss is expressed by hearing level (HL) measured in decibels (dB) and may be classified as slight or minimal, mild, moderate, moderate to severe, severe, and profound (Northern & Downs, 1991).

Slight or minimal hearing loss (16–25 dB) Although not considered a problem for older children who have developed speech, even a slight or minimal hearing loss can have a detrimental impact on the communication development of infants, particularly those with other disabilities.

Mild hearing loss (26–40 dB) The infant may hear only louder-voiced speech sounds (eg. "ah," "oo," "m") and will miss consonant sounds. Without amplification, an infant may miss 25 to 50% of speech depending on the configuration of the hearing loss, how close the infant is to the speaker, and the noise level of the environment. A mild or unilateral hearing loss can hinder the infant's understanding of speech.

Moderate to severe hearing loss (41–70 dB) The infant may miss most familiar words in normal conversational speech. Without amplification 50 to 100% of speech may be missed. A hearing impaired child with no other disabilities may understand familiar words and conversation if the speaker is less than five feet away. The classifications of moderate (41–55 dB) and moderate to severe (56–70 dB) hearing losses were combined in this paragraph.

Severe hearing loss (71–90 dB) The infant will not hear normal conversational speech or most other sounds except very intense ones, e.g., car horn when close to a car. Without amplification, this infant cannot understand speech. With amplification and appropriate intervention, depending on the configuration of the hearing loss, some infants with severe hearing loss may be able to understand speech.

Profound loss (more than 91 dB) The infant hears no speech or other sounds. However, some infants benefit from amplification depending on the individual situation. Amplification might enable this child to be aware of intense environmental sounds especially those that signal danger such as car horns and sirens.

Common terms associated with hearing loss

Hearing impairment includes a range of hearing loss from minimal (15–25 dB HL) to profound (>90 dB HL).

Hard of hearing indicates a hearing loss under 70 dB HL in the better ear.

Deaf indicates a loss that is greater than 70 dB HL in the better ear.

Effects of visual impairment

Similarly, the influence of a visual impairment on an infant's learning and development will depend on the type and degree of vision loss, the infant's other disabilities, and whether these needs are identified and appropriate interventions are provided.

Early interventionists should assist families in obtaining information about their infant's diagnosis and in understanding the implications of a given type of visual impairment. Families may be overwhelmed by medical terminology and educational definitions. Understanding the significant difference between legally blind and totally blind may require careful explanation.

Common types of visual impairment

Visual impairment may be caused by defects in the eye or in

Intervention tips for engaging infants with hearing loss and other disabilities

- Use animated facial expressions to engage the infant's visual attention
- Use gestures to assist communication
- Position the infant so he/she can see the speaker's face
- Imitate the infant's vocalizations to develop vocal turntaking
- Expand on the infant's vocalizations
- Develop turntaking games and play routines to develop a sense of predictability and control
- Speak close to the infant's ear when the hearing aid is not being worn
- Use exaggerated intonation to get the infant's auditory attention
- Use short, repetitive phrases to build the infant's language
- Put words to the infant's action to expand the infant's communication
- Place the baby on the speaker's chest to feel vibrations
- Place the baby's hand on the speaker's lips or cheek to call attention to sounds
- Dance or move with the baby in rhythm to song/music
- Pat the baby's back or arm in rhythm with intonation and syllables of spoken words
- Adapt signs so the infant can attend to them

Chen, 1996 and see chapters on *Hearing Loss* and *Beginning Communication* in this manual the brain. However, the majority of infants with visual impairment have some functional vision (Buncic, 1987) or vision that is useful in everyday situations. Families and early interventionists should discuss the infant's diagnosis and visual impairment with the infant's ophthalmologist or optometrist in order to determine appropriate intervention strategies for encouraging the infant's use of available vision. There are many types of vision impairment that affect the clarity and completeness of the visual image (e.g, decrease in visual acuity, visual field restriction, loss in contrast sensitivity, deficits in color vision, and oculomotor problems). This section will focus just on two types of visual impairment that are common in infants with multiple disabilities.

Ocular visual impairment: Refractive errors

The visual process involves light rays entering the eye and projecting a clear visual image on retina which is interpreted by the brain. Abnormalities in the eye will interfere with the projection of a clear or complete visual image on the retina and may result in reduced visual acuity or the ability to discriminate visual detail. Refractive errors are the most common cause of visual acuity loss and occur when there are problems in how the light rays are bent or refracted by the eye and which result in a blurry visual image on the retina (Bailey & Hall, 1990; Teplin, 1995). Myopia or nearsightedness, hyperopia or farsightedness, and astigmatism are common refractive errors. Myopia occurs when the light rays converge before they reach the retina because the eyeball is too long or the refractive surfaces of the eye (cornea, lens) are too strong. Near objects will be clear but distant objects will be blurred. Hyperopia or farsightedness occurs when the eyeball is too short or the refractive surfaces are too weak and the light rays focus behind the retina. In this case, looking at near objects will be more difficult than focusing on distant objects. Astigmatism results when the shape and curvature of the cornea prevents clear vision. These refractive errors can be improved by corrective lenses. In general, infants who are near sighted or myopic can usually see more clearly if they are close to the visual information, if objects or pictures are made larger, if colors are used to provide high contrast, if lighting is used to enhance visual stimuli, and if visual distractions and glare are reduced (Levack, 1994).

Cortical visual impairment

Compared to infants with refractive errors, infants with cortical visual impairment (CVI) receive a clear visual image but have difficulty interpreting it (Teplin, 1995). Cortical visual impairment cannot be improved by corrective lenses. This diagnosis is associated with medical conditions that indicate neurological damage, these include anoxia, hydrocephalus, congenital brain malformations, traumatic brain injury, meningitis or encephalitis (Teplin, 1995). An infant may have poor visual response despite a normal pupillary response and good ocular health. Results of a MRI and information on how the infant functions visually is needed for diagnosing cortical visual impairment (see chapter on *Clinical Vision Assessments*). Most infants with cortical visual impairment have some functional vision although their visual skills are extremely variable. Their visual skills are influenced by such variables as health, medications, lighting and contrast, complexity and familiarity of the visual information (Jan & Groenveld, 1993). Infants with cortical visual impairment seem to benefit from different interventions than those with low vision due to ocular impairments. They seem to be confused and overstimulated by simultaneous multisensory experiences and visual clutter (Baker-Nobles & Rutherford, 1995). Some infants with cortical visual impairment seem to look away from objects before reaching for them, may be using their peripheral vision (Blind Babies Foundation, in press).

Intervention tips for engaging infants with visual impairment (especially CVI) and other disabilities

- ▶ Encourage visual attention by presenting one object at a time
- ▶ Use color and familiar objects to assist in recognition and identification
- ▶ Help the infant to touch and handle objects to assist in recognition
- ▶ Encourage the infant to work on one skill at a time, for example, it may be tiring and difficult for an infant with multiple disabilities to handle an object, look at it, and work on head control all at the same time.
- ▶ Identify and use the infant's preferences, e.g., for toys, activities, people
- ▶ Identify and build on the infant's preferences for visual stimuli, e.g, for certain movements, bright colors, geometric patterns, different shapes, or certain sizes of objects.
- ▶ Identify and use the infant's visual abilities, e.g., lighting conditions, viewing distances, and visual fields
- ▶ Build anticipation and a sense of control through familiar routines and repetition of activities
- ▶ Modify the environment to reduce distractions—background noise and visual clutter

Blind Babies Foundation, in press; Crossman, 1992; Jan et al., 1987; Hyvarinen, 1988; Levack, 1994; Steendam, 1989

Common terms associated with vision loss

The following common definitions (Bailey & Hall, 1990; Lueck Hall, Chen & Kekelis, in press; Levack, 1994; Teplin, 1995) should be discussed with families of infants with visual impairment, as appropriate.

Cortical visual impairment indicates that an infant may receive a clear visual image but have difficulty processing and interpreting visual information. Corrective lenses will not improve this infant's vision unless there is also a refractive error.

Visual impairment indicates vision loss and includes the range from totally blind to a slight vision loss. Although certain types of visual impairments may be improved by corrective lenses, they cannot be corrected to a normal vision level. The specific type of visual impairment may affect the infant's ability to see clearly, to view the full visual field, to understand what is seen, to discriminate between colors, to make out shapes of objects, to see movement without discriminating detail, or to locate the source of light or see light sources.

Low vision indicates some useful vision for routine tasks and includes the range of vision loss from mild to severe.

Legally blind indicates visual acuity of 20/200 or less in the better eye with correction (i.e., the visually impaired child sees at 20 feet what a normally sighted child can see at 200 feet. Refer to chapter on *Clinical Visual Assessments* for developmentally appropriate visual acuity measures during the first two years) or a visual field of 20 degrees or less. Visual loss may range to total blindness. Eligibility for educational services based on a visual impairment usually requires 20/70 or less in the better eye with correction.

Functionally blind the infant has the ability to distinguish light from dark (LP or light perception) but is unable to locate the direction of the light source.

Totally blind the infant has no usable vision (NLP: no light perception).

Effects of combined hearing loss and visual impairment

The following four hypothetical and simplified combinations of vision and hearing loss (see the chart on the following page) are intended to highlight the significant interventions that will be needed to support an infant's development.

I. Central auditory processing disorder and cortical visual impairment

This infant has difficulty understanding what is seen and heard. He will require systematic and structured intervention in order to make sense of the confusing sounds and sights. This infant will need time to process input and will benefit from opportunities to touch and handle objects and from alternative modes of communication. Simultaneous use of multisensory sensory stimulation should be used with caution. The infant's health and behavioral state will influence his ability to use sensory input.

II. Mild hearing loss and low vision

This infant has mild impairments in both vision and hearing and should be able to learn through visual and auditory channels. *With* appropriate early intervention (i.e., amplification and corrective lenses if prescribed and simple environmental modifications) and *without* additional disabilities, this infant should be able to acquire speech and other developmental skills at age level.

III. Moderate to severe hearing loss and legally blind

This infant has functional hearing and vision. However, adaptations are needed to help the infant perceive sounds and sights, e.g., he may need to be "closer" to the object, speaker, visual target, or sound source by moving closer or using amplification and magnification as appropriate. An alternative communication system (touch cues, object cues, gestures, signs) should be used as appropriate to support spoken communication input.

Combination of visual and hearing loss included under deaf-blind

			Normal Hearing* 0–25dB	Central Auditory Disorder	Slight Loss 15–25dB	Mild Loss 26–40dB	Moderate Loss 41–55dB	Moderate to Severe Loss 56–70db	Severe Loss 71–90db	Profound Loss 91dB or more
		Normal Vision*								
		Cortical Visual Impairment		I						
	Low Vision	Acuity <20/70 corrected				II				
Legally Blind		Acuity <20/200 corr. or Peripheral Field <20°						III		
		Form Perception								
		Functionally Blind**								
		Totally Blind***								IV

*20/20 Older children & adults; 20/800–20/100 one month old infants; 20/100– 2/20 12 month old infants

**Light Perception

***No Light Perception

IV. Profound hearing loss and totally blind

In this rare condition, the infant requires one-to-one support during interactions and to support his learning through tactile exploration. An alternative communication system must be developed.

Early intervention responsibilities

Early interventionists should support the infant and family in obtaining appropriate ophthalmological/optometric evaluations and audiological tests and follow up. They should obtain information about the family's observations and concerns, and make observations of an infant's use of available vision and hearing to supplement clinical assessments and guide interventions (for information about functional hearing and vision screenings see Chen, 1990; Calvello, 1990; and the chapters on *Hearing Loss*, *Functional Vision Assessment* and the *Forms* section in this manual). It is important to discuss the infant's diagnoses and recommendations for interventions with the infant's eye care specialist, audiologist, and family. Early interventionists working with infants who have multiple disabilities have many concerns regarding the identification of a vision or hearing loss. They wonder how parents will react to the "bad news" or another diagnosis, whether glasses or a hearing aid will be overwhelming to the infant of family, whether it is worth the effort involved in encouraging the infant to wear the glasses and/or hearing aids. Some early interventionists have reported that glasses or hearing aids were not recommended because "the infant is not yet sitting up," "the baby is too disabled," "the infant may be confused or overstimulated by the sensory stimulation," or "the family might have difficulty with managing this equipment." Certainly the particular situation of an infant with severe and multiple disabilities and the family will determine how much benefit the baby will obtain from glasses and hearing aids. However, the family in collaboration with the early interventionist, audiologist, and ophthalmologist or optometrist should discuss options and decide on the best course of action (Chen, 1997a; 1997b).

Once a visual impairment and/or a hearing loss is identified in an infant with other disabilities, the early interventionist must collaborate with other professionals in providing systematic interventions to support the family in promoting infant's development (Chen & Dote-Kwan, in press; and see the chapter *From Interdisciplinary to Transdisciplinary Interventions*). If the infant has available vision and/or hearing, the early interventionist should encourage the infant to use these senses through magnification and amplification as appropriate, through other intervention strategies, environmental modifications, and activity adaptations. Intervention strategies may include using real, colorful, and meaningful objects within natural contexts; encouraging the infant to look, listen, and touch as appropriate; reducing sensory "noise" to allow the infant to attend to critical features; and adding words/symbols/or cues to actions. Moreover, interventions focused on stimulating these infants to use their vision and hearing should occur in natural home situations that are developmentally-appropriate for infants (Chen, 1996; Chen & Dote-Kwan, in press; Dote-Kwan & Chen 1995; Ferrell & Muir, 1996).

Early interventionists should identify factors that influenced each infant's ability to receive and understand sensory input, such as internal (health, energy level, other disabilities) as well as environmental factors (lighting, distractions, type of stimuli, speed, frequency and mode of presentation). These variables should be taken into account when developing, implementing, and evaluating interventions.

The interaction of visual impairment *and* hearing loss complicates the usual process of early learning and requires specific interventions. Further, the occurrence of vision and hearing loss with other disabilities presents additional learning needs. Similarly, the presence of a visual impairment *or* hearing loss with other disabilities must not be ignored and appropriate interventions must be provided. Early interventionists working with infants whose multiple disabilities include vision and hearing loss and their families play a critical role in a dynamic, challenging, and exciting area of special education.

References

Bailey, I. L., & Hall, L. (1990). *Visual impairment. An overview.* New York: American Foundation for the Blind.

Baker-Nobles, L. (1995). Understanding cortical visual impairment in children. *American Journal of Occupational Therapy,* 49, 899-903.

Berg, F.S. (1993). *Acoustics and sound systems in schools.* San Diego: Singular Publishing Group.

Blind Babies Foundation (in press). *Visual diagnosis fact sheet: Cortical visual impairment.* San Francisco, CA: Blind Babies Foundation.

Bishop, V.E. (1991). Preschool visually impaired children: A demographic study. *Journal of Visual Impairment & Blindness,* 85(2), 69-74.

Buncic, J.R. (1987). The blind child. *Pediatric Clinics of North America,* 34,1403-1414.

Calvello, G.(1990). *Identifying visual impairments in infants. In D.Chen, C.T. Friedman, & G. Calvello. Parents and visually impaired infants.* Louisville, KY: American Printing House for the Blind.

Chen, D. (1990). Functional hearing screening. In D.Chen, C.T. Friedman, & G. Calvello, *Parents and visually impaired infants.* Louisville, KY: American Printing House for the Blind.

Chen, D. (1993). *Early intervention.* Presentation. In J.W. Reiman & P.A. Johnson (Eds.), Proceedings from the National Symposium of Children and Youth who are Deaf-Blind (pp. 37-44). Monmouth, OR: Teaching Research Publications.

Chen, D., & Haney, M. (1995). An early intervention model for infants who are deaf-blind. *Journal of Visual Impairment and Blindness,* 89, 213-221.

Chen, D. (1996). Parent-infant communication: Early intervention for very young children with visual impairment or hearing loss. *Infants and Young Children,* 9(1), 1-12.

Chen, D. (1997a). *What can baby hear? Audiological tests and interventions for infants with multiple disabilities* [Video and booklet]. Baltimore, MD: Paul H. Brookes.

Chen, D. (1997b). *What can baby see? Vision tests and interventions for infants with multiple disabilities* [Video and booklet]. New York: AFB Press.

Chen, D., & Dote-Kwan, J. (in press). Early intervention services for young children with visual impairments and other disabilities and their families. In S. Sacks & R. Silberman (Eds.), *Educating students with visual impairments and other disabilities.* Baltimore, MD: Paul H. Brookes.

Cress, P. , Spellman, C.R., DeBriere, T.J., Sizemore, A.C., Northam, J.K., & Johnson, J.L. (1981). Vision screening for persons with severe handicaps. *Journal of the Association for the Severely Handicapped,* 6, 41-50.

Crossman, H.L. (1992). *Cortical visual impairment presentation, assessment and management* (Monograph Series No. 3). North Rocks, Australia: The Royal New South Wales Institute for Deaf and Blind Children.

Deitz, S., & Ferrell, K.A. (1993). *Early services for young children with visual impairment: From diagnosis to comprehensive services.* Infants and Young Children, 6(1) 68-76.

Dote-Kwan, J., & Chen, D. (1995). Learners with visual impairment and blindness. In M.C. Wang, M.C. Reynolds & H.J. Walberg (Eds.), *Handbook of special education: Research and practice* (2nd.ed.) (pp. 205-228). London, England: Elsevier Science Press.

Edwards, L.E., Goehl, K.S., Gordon, L.A. (n.d.) *Profiles: Individuals with deafblindness.* Terra Haute, IN: Indiana State University, Blumberg Center for Interdisciplinary Studies in Special Education, Indiana Deaf-Blind Services Project.

Ferrell, K.A., Trief, E., Dietz, S.J., Bonner, M.A., Cruz, D., Ford, E., & Stratton, J.M. (1990). Visually impaired infants research consortium (VIIRC): First year results. *Journal of Visual Impairment & Blindness,* 84(8), 404-410.

Ferrell, K.A., & Muir, D.W. (1996). A call to end vision stimulation training. *Journal of Visual Impairment & Blindness,* 90, 364-366.

Fewell, R.R. (1983). Working with sensorily impaired children. In S.G. Garwood (Ed.)., *Educating young handicapped children. A developmental approach* (2nd ed., pp. 235- 280).

Flexer, C. (1994). *Facilitating hearing and listening in young children.* San Diego: Singular Publishing.

Fredericks, H.D.B. & Baldwin, V.L. (1987). Individuals with sensory impairments: Who are they? How are they educated? In L. Goetz, D. Guess, & K. Stremel-Campbell (Eds.), *Innovative program design for individuals with dual sensory impairments* (pp. 3-12). Baltimore, MD: Paul H. Brookes.

Gatty, C.G. (1996). Early intervention and management of hearing in infants and toddlers. *Infants and Young Children,* 9(1), 1-13.

Hall Lueck, A., Chen, D., & Kekelis, L. (in press). *Developmental guidelines for infants with visual impairment (birth to 24 months): A manual for early intervention.* Louisville, KY: American Printing House for the Blind.

References, continued

Hayes, D. & Northern, J.L. (1996). *Infants and hearing*. San Diego, CA: Singular.

Hoon, Jr., A.H. (1991). Visual impairments in children with developmental disabilities. In A.J. Capute & P.J. Accardo (Eds.), *Developmental disabilities in infancy and childhood* (pp. 395-410). Baltimore, MD: Paul H. Brookes.

Hyvarinen, L. (1988). *Vision in children: Normal and abnormal*. Meaford, Ont. Canada: The Canadian Deaf-Blind and Rubella Association.

Jacobson, J.W., & Janicki, M.P. (1985). Functional and health status characteristics of persons with severe handicaps in New York State. *Journal of The Association for Person with Severe Handicaps*, 10(1), 51-60.

Jan, J.E., & Groenveld, M. (1993) Visual behaviors and adaptations associated with cortical and ocular impairment in children. *Journal of Visual Impairment & Blindness*, 87(4), 101-105.

Jan, J.E., Groenveld, M., Sykanda, A.M., Hoyt, C.S. (1987). Behavioral characteristics of children with permanent cortical visual impairment. *Developmental Medicine and Child Neurology*, 29, 571-576.

Joint Committee on Infant Hearing. (1991). 1990 Position statement. *ASHA*, 33, 3-6.

Kile, J.E., Schaffmeyer, M.J., & Kuba J. (1994). From assessment to management in infant and toddlers with unusual auditory behavior. *Infant-Toddler Intervention*, 4, 299-318.

Kile, J.E. & Beauchaine, K.L. (1991). Identification, assessment, and management of hearing impairment in infants and toddlers. *Infant-Toddler Intervention*,1, 61-81.

Kirchner, C. (1989). National estimates of prevalence and demographics of children with visual impairments. In. M.C. Wang, M.C. Reynolds, & H.L. Walberg, (Eds.), *Handbook of special education: Research and practice. Volume 3, Low incidence conditions* (pp. 135-153). Oxford: Pergamon Press.

Kramer, S.J., & Williams, D.R. (1993). The hearing-impaired infant and toddler: Identification, assessment, and intervention. *Infants and Young Children*, 6(1), 35-49.

Levack, N. (1994). *Low vision: A resource guide with adaptations for students with visual impairments* (2nd. ed.). Austin, TX: Texas State School for the Blind.

Leung, E.H.L., & Hollins, M. (1989). The blind child. In M. Hollins (Ed.), *Understanding blindness* (pp. 139-170). Hillsdale, N.J: Lawrence Erlbaum.

Mauk, G.W., D.G. Barringer, & Mauk, P.O. (1995). Seizing the moment, setting the stage and serving the future: Towards collaborative models of early identification and early intervention services for children born with hearing loss and their families. Part 1: Early identification of hearing loss. *Infant-Toddler Intervention*, 5, 367-394.

Michael, M.,& Paul, P. (1991). Early interventions for infants with deaf-blindness. *Exceptional Children*, 57, 200-210.

National Institutes of Health (NIH). (1993). *NIH consensus statement: Early identification of hearing impairment in infants and young children*, 11(1), 1-25.

Northern, J.L., & Downs, M.P. (1991). *Hearing in children*. Baltimore, MD: Williams & Wilkins.

Nozza, R.J. (1994). The effects of mild hearing loss on infant auditory function. *Infant-Toddler Intervention*, 4, 285-298.

Regenbogen, L.S., & Coscas, G.J. (1985). *Oculo-auditory syndromes*. New York: Masson Publishing.

Office of Federal Regulations. (1995). *Title 34 (revised)* 34 CFR, Part 307, Subpart A, 307.4(c) 2 (ii) . Washington DC: U.S. Government Printing Office.

Outlette, S. (1984). Deaf blind population estimates. In D. Watson, S. Barrett, & R. Brown (Eds.), *A model service delivery system for deaf-blind persons*. Little Rock: University of Arkansas.

Sobsey, D., & Wolf-Schein, E.G. (1991). Sensory impairments. In F.P. Orelove & D. Sobsey, (Eds.), *Educating children with multiple disabilities: A transdisciplinary approach* (2nd ed.). (pp. 119-154). Baltimore, MD: Paul H. Brookes.

Steendam, M. (1989). *Cortical visual impairment in children*. Enfields, Australia: Royal Blind Society of N.S.W.

Teplin, S. W. (1995). Visual impairment in infants and young children. *Infants and Young Children*, 8(1), 18-51.

Trief, E., Duckman, R., Morse, A.R., & Silberman, R.K. (1989). Retinopathy of prematurity. *Journal of Visual Impairment & Blindness*, 83(10), 500-504.

Strategies for Gathering Information

by Pamela Haag Schachter

The first step in the identification of an infant or toddler suspected of having vision and hearing loss is to gather all relevant information on the child's medical, developmental, hearing and vision status. The key to success is to do this through a comprehensive approach, accessing all available sources of information. The early interventionist must take on an inquisitive and assertive role in assembling all relevant pieces of information about the infant/toddler. The purposes of this information gathering process are to develop an appropriate course of assessment, establish baseline data, refer to specialists for their assessments and follow up on the results of those assessments. This process is essential for the development of an individualized and appropriate intervention plan. Infants and toddlers with multiple disabilities/vision and hearing loss must have every opportunity to use available vision or hearing. This is a fundamental goal of early intervention services. It is necessary to carefully explain to caregivers why it is so important for you to see the infant's medical and developmental records. This may ease their concerns about releasing information to you. If the caregivers do not release all records to you, you must respect their wishes.

The key to success is a comprehensive approach...

► Do not assume,

► Review all records,

and,

► Summarize

Do not assume

Do not assume that someone else has gathered, read or interpreted the medical, developmental, visual or audiological reports that may exist for the infant/toddler. In many service delivery systems, decisions regarding eligibility for services may be made without receiving or scrutinizing all records or asking all questions that are necessary in order to plan an appropriate intervention program. Eligibility may be readily determined for a child based on a genetic condition and comprehensive records may never be requested. Nurses and psychologists may be looking for other information when reviewing records. Early interventionists bring a unique perspective to the process and must become familiar with the infant/toddler's complete history. Use the "Infant Medical Summary" (in the *Forms* section of this manual) to review with the family all professionals who have ever seen their infant/toddler, including hospitals, doctors, clinics, audiologists, thera-

Infant Medical Summary

Infant's Name Hope Jones

DOB 10/4/93 C.A. 1-11 as of 9/20/95 (today's date)

Adjusted Age N.A. (if applicable)

FAMILY INFORMATION

Mother's Name Emma Jones

Father's Name Roberto Jones

Other Primary Caregiver Babysitter, live-in, Amalia

Siblings Sister, Anna, 10, brothers, Roberto 8, Edwardo 5

Others in Home

Languages Spoken in Home Spanish and English

Other family information that is relevant to the infant's medical needs:
Both parents work full time, most care is provided by Amalia.

SERVICE PROVIDERS Private and Public Agencies
(i.e.: Department of Health, Local Educational Agency, Regional Centers, etc.)

Name of Agency Harbor Regional Center

Address

Phone

[✓ Public] or Private (circle one)

Service Coordinator Leticia Gonzales

Brief description of services receiving:
Service coordination, in-home early intervention teacher, O.T., 2x/week.

HEALTH INSURANCE

How is infant's health care paid for? (cash, insurance, Medicaid, etc.)
Insurance

Name of insurer or public agency? Kaiser Permanente

Contact Person

Phone

Identification #

Type of coverage: (fee for service, PPO, HMO, etc.) HMO

Deductible/Co-Payments family is responsible for $10 per visit

Family concerns regarding paying for Infant's health care:
None at this time. Mother works full time, in part, to receive health insurance benefits.

pists, etc. Determine whether or not you have complete records from each of these sources. Obtain necessary authorizations and request any records you do not have.

Review all records

Review all records obtained and summarize your findings. Read the records carefully, looking for conditions that are known to have a high incidence of developmental, visual or auditory impairment. Note the causes of frequent doctor visits or hospitalizations, look for recurrent middle ear infections, respiratory or feeding difficulties. Note results of screenings for antibodies that may indicate that the mother had an infection during pregnancy that may effect vision and/or hearing. Consider the possibility of seemingly unrelated medical problems being related. Note the problems that appear to be resolved and those that are still ongoing. Read hospital records carefully to see if vision (through a Visual Evoked Potential, VEP) or hearing (through an Auditory

Summary of medical history

INFANT'S NAME Hope Jones **DOB** 10/4/93

(Obtained from reports and records reviewed.)

DIAGNOSIS Trisomy 4-p Ventral-septal heart defect Cerebral palsy Nearsighted Asthma	MEDICATIONS Phenobarbitol Proventil Rynatan
HOSPITALIZATIONS For pneumonia, 1/94, 9/94, 2/95, 4/95 and 7/95. 2-3 days at a time.	SURGERIES Tubes placed in both ears 11/94.
EQUIPMENT PRESCRIBED Nebulizer for breathing treatments. Rifton feeder seat Bilateral hand splints. Glasses.	PRECAUTIONS Listen and watch for respiratory distress (wheezing, nails or lips having blue tinge).
VISION STATUS & DATE OF LAST TEST Vision evaluation and retinoscopy, 10/94 Glasses prescribed very nearsighted.	HEARING STATUS & DATE OF LAST TEST Abnormal tympanograms, had tubes placed. Scheduled for hearing test (ABR).

Summary of all professionals involved in the infant's care

INFANT'S NAME Hope Jones **DOB** 10/4/93

HOSPITAL/DOCTOR/THERAPIST/EDUCATOR	AGENCY	PHONE	DATES SEEN
Dr. Bell, Pediatrician	Kaiser Permanente	310-555-6248	Since birth
Dr. Bowden, Pulmonologist	Kaiser Permanente	310-555-8781	1/94 ⟹
Ms. Booth, Genetic Counselor	Kaiser Permanente	310-555-8259	11/93, 1/94
Alice Watkins, OT	Harbor Regional Center	310-555-8525	3/94 ⟹
Denise Yakamoto, Teacher	Harbor Regional Center	310-555-1074	6/94 ⟹
Dr. Baum, Opthalmologist	Kaiser Permanente	310-555-0305	Since birth ⟹
Dr. Nelson, ENT	Kaiser Permanente	310-555-1144	4/94 ⟹
Dr. Raska, Cardiologist	Kaiser Permanente	310-555-1207	Since birth

Brainstem Response, ABR) were tested during a hospitalization or clinic visit. Use a medical dictionary and consult a colleague with a medical background to help you decipher unfamiliar terminology.

Summarize

Summarize your developmental concerns. Note both the more obvious presenting problems and the questions you may now have after reviewing all records on the child.

Gathering information about the child's hearing loss

When you have unanswered questions about the status of an infant/toddler's hearing, use the "Functional Hearing Screening for the Family" (in the *Forms* section of this manual) to provide some answers and directions for follow-up. This form is intended to be used as an interview tool with the infant/toddler's primary caregiver(s). If the infant spends a great deal of time in more than one environment (such as home and a babysitter) it may be helpful to interview both caregivers to determine if different information is provided. The form is intended as an outline and early interventionists are encouraged to ask additional questions that may expand on information or draw out answers that are difficult to obtain. Skillful interviewing will increase the amount and quality of information obtained. Families should be interviewed in the language they are most comfortable using. Obtain the services of a competent interpreter when necessary.

Refer to the "Interviewer's Directions" (in the *Forms* section of this manual) for information on the significance of answers to the questions. If the interview does not lead to the conclusion that the infant/toddler hears well, it is appropriate to conduct a functional hearing assessment (see *Hearing Loss, Assessments, and*

Summary of developmental concerns

INFANT'S NAME Hope Jones DOB 10/4/93

(Note known areas of concern as well as those that you have questions about as a result of information from medical records.)

GROSS MOTOR Holds head up briefly Sits with full support Rolls from stomach to back	FINE MOTOR Hands tightly fisted. Retains objects if placed in hand. Brings hands to mouth, and eyes.
COMMUNICATION Cries to express displeasure. Smiles when sees mom, dad, siblings. Laughs when hears music placed right by ears.	COGNITION Recognizes familiar people. Not interested in objects other than loud music. Does not attempt to follow dropped object.
EATING Eats mashed food fed by others. Drinks from bottle. Gaining weight well.	SOCIAL/BEHAVIOR Enjoys family members, likes rough-housing with dad. Concerned about hands in mouth and rubbing glasses off.
SLEEP PATTERNS Sleeps about 9pm-4am Awake from about 4am-6am Sleeps again from 6am-9am (exhausting for mom)	OTHER

Functional hearing screening

Questions for the family

Interviewer Form

CHILD'S NAME Hope Jones

DOB October 14, 1994

DATE RECORDS REVIEWED December 05, 1995

MEDICAL AND HEALTH INFORMATION

1. What have you been told by medical professionals about your baby's hearing?

   70% hearing loss. Had a hearing test, should be getting a hearing aid.

2. Has your baby had an ear infection? How frequently?

   Don't know if she has had one.

3. Is your infant often congested? Having frequent colds?

   Not very congested. Had lots of fevers until about 8 months old, was given antibiotics. Very healthy lately.

OBSERVATIONS (Note: If parents are unable to answer these questions you will need to help structure observations of the infant's responses to sound and to model how to observe for the parent.)

4. What is your impression of the infant's hearing?

   Hears loud noises, not soft sounds. Stops sucking pacifier, starts or stops hand and leg movements. Hope doesn't seem to understand any specific words.

5. What sounds seem to get your baby's attention? How does your baby respond to these sounds?

   When her sister screams. Dad's voice. Turning the T.V. on.

6. What does your baby do when you call his/her name?

   Dad—gets excited, moves arms and legs, up to 4 feet away.

   Mom—less response, closer, calls her "Ohpee," seems to get a better response.

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Interventions for Infants with Multiple Disabilities) and to refer the child for an audiological evaluation. Many health care and service agencies will require documentation of the need for an audiological exam. Using the information gathered in the family interview, you can provide the necessary justification. Assertiveness and strong advocacy skills may be required to obtain the necessary tests for an infant/toddler. This is an important role of the early interventionist.

Another important role of the early interventionist is to help the family to understand the need for another test. They may have concerns if sedation is involved. Ultimately, they may fear learning that something else is wrong with their child. The interventionist must respect the fears of the family, while educating them about the importance of the early identification of hearing loss.

Once obtained, interpreting audiological records and gathering useful information from them may pose a challenge to the early interventionist. Use the "Questions to Ask the Infant's Audiologist" form to review all audiological reports (see the *Forms* section of this manual). To assist an infant/toddler to make the most use of his hearing, you must understand what kind of test was administered and what it measured (see *Audiological Tests for Infants with Multiple Disabilities*).

Functional hearing screening

Interviewer Form

Questions for the family

Continued from page 55

CHILD'S NAME Hope Jones

7. How does the baby react to sudden loud noises (dog barking, honking car horn, vacuum cleaner)?

   Sometimes laughs when the door slams or someone drops something. Parents think she likes hearing the noise and maybe feels vibrations.

8. Does your baby seem to respond differently to your vocalizations when the radio or television is on?

   If the room is very noisy, Hope doesn't seem to hear very much.

9. Does your baby enjoy toys that "talk" or make noise?

   Hope has a wind-up tape player, she likes to put her head against it. Likes toys with sounds and bright lights together.

10. Does your baby enjoy you talking or "when you talk," cooing or singing to him/her?

    Especially likes Dad's singing and playing tickle games with her. Doesn't react to Mom's singing.

Most importantly, you must determine whether the audiologist feels that the best possible measure of the infant/toddler's hearing was obtained and interpreted in light of the complex health needs or multiple disabilities of the child. The early interventionist's role is to work collaboratively with the audiologist, sharing knowledge of the infant/toddler's unique behaviors and traits to ensure that the best possible hearing test is obtained.

The early interventionist may be of valuable assistance to the audiologist by reporting functional hearing observations and by being available to assist the family with the use of amplification devices. An audiologist may be hesitant to prescribe amplification for an infant/toddler with multiple disabilities. The early interventionist may play a critical role in working with the audiologist to determine whether the infant/toddler will benefit from an amplification device. Families who are unfamiliar with hearing loss and amplification devices will benefit from the early interventionist's active role in their use and the necessary follow up care.

If after careful review of an audiological report you cannot answer the family's and your questions, do not hesitate to call the audiologist to discuss the report. Audiological testing is useless if the infant/toddler's family and teachers cannot make use of the information provided. An experienced pediatric audiologist will be happy to explain testing procedures and results to you and the family.

Gathering information about the child's vision loss

When you have unanswered questions about the status of an infant/toddler's vision, use the "Functional Vision Screening for the Family" to provide some answers and directions for follow-up (see the *Forms* section of this manual). This form is intended to be used as an interview tool with the infant/toddler's primary caregiver(s). If the infant spends a great deal of time in more than one environment (such as home and a babysitter) it may be helpful to interview both caregivers to determine if different information is provided. The form is intended as an outline and early interventionists are encouraged to ask additional questions that may expand on information or draw out answers that are difficult to obtain. Skillful interviewing will increase the amount and quality of information obtained. Families should be interviewed in the language they are most comfortable using. Obtain the services of a competent interpreter when necessary.

Refer to the Interviewer's Sheet for information on the significance of answers to the questions. If the interview does not lead to the conclusion that the infant/toddler sees well, it is appropriate to conduct a functional vision assessment (see *Functional Vision Assessment and*

Questions to ask the Infant's Audiologist

CHILD'S NAME Hope Jones

AGE 2 years

DATE RECORDS REVIEWED December 12, 1995

1. What kinds of hearing tests were conducted?
   1. ABR—Auditory Brainstem Response
   2. Behavioral Observations in sound field
2. What were the test results?
   1. Severe bilateral hearing loss
   2. Moderate to severe hearing loss in better ear
3. How did the test go—how was the baby during the testing situation? How reliable are the results?
   1. Very reliable, sedated easily
   2. On mom's lap, some fussing, definite responses to louder sounds, eye widening, stopped movement
4. What do results mean in terms of the baby's benefit from amplification?
   Ability to understand speech will likely be severely impaired.
5. With this hearing loss would this baby benefit from amplification?
   Yes.
6. What can we expect this baby to hear?
   Unaided: loud sounds, door slamming, car honking
   Aided: Uncertain. Likely to hear environmental sounds, some speech.
7. Are more tests needed? When? What kind?
   Yes, after Hope is comfortably wearing her hearing aids most of the day, we should repeat behavioral observations with the hearing aids.
8. When should this baby be retested? (If questions remain about baby's hearing, s/he should be seen at least once annually to see if hearing has changed or if aid is appropriate and setting of aid is appropriate.)
   3–4 months, when adjusted to wearing aids.

Continued on page 59

Interventions) and to refer the child for an ophthalmological evaluation. Many health care and service agencies will require documentation of the need for an ophthalmological exam. Using the information gathered in the family interview, you can provide the necessary justification. Assertiveness and strong advocacy skills may be required to obtain the necessary tests for an infant/toddler. This is an important role of the early interventionist.

Another important role of the early interventionist is to help the family to understand the need for another test. They may have concerns if sedation is involved. Ultimately, they may fear learning that something else is wrong with their child. The interventionist must respect the fears of the family, while educating them about the importance of the early identification of vision loss.

Once obtained, interpreting ophthalmological records and gathering useful information from them may pose a challenge to the early interventionist. Use the "Questions to Ask the Infant's Ophthalmologist or Optometrist" form to review all vision evaluation reports (see the *Forms* section of this manual). To assist an infant/toddler to make the most use of his vision, you must understand what kind of test was administered and what it measured (see *Clinical Vision Assessments for Infants with Severe and Multiple Disabilities*).

Most importantly, you must determine whether the clinician feels that the best possible measure of the infant/toddler's vision was obtained and interpreted in light of the complex health needs or multiple disabilities of the child. The early interventionist's role is to work collab-

Questions to ask the Infant's Audiologist

Continued from page 58

CHILD'S NAME Hope Jones

9. How can I help prepare this child for further testing?
   Assist family with hearing aid use. Auditory training to establish consistent responses to voices and environmental sounds.
10. Can I participate in further testing?
    Yes, please schedule next exam with family.
11. [If present at the exam.] Can the parents and I listen through headphones to what the baby is hearing to help us better understand the baby's hearing loss?
    At next exam.
12. When does the baby need new ear molds made? (If wearing aids.)
    Will be checked at next evaluation in 3–4 months.

You should be able to answer questions #1–7 from an audiological report. If the written report does not provide this information, you will need to discuss the results with the audiologist.

Functional vision screening

Interviewer Form

Questions for the family

CHILD'S NAME Hope Jones

AGE 2 years

DATE RECORDS REVIEWED November 12, 1995

MEDICAL AND HEALTH INFORMATION

1. What have you been told by medical professionals about your baby's vision?
   Needs glasses, can't see anything far away.
2. Have you noticed if one of your baby's eyes turns inward, outward, upward or downward? If so, when does this occur?
   No.
3. Do your infant's eyes look normal?
   Yes.
4. Does anyone in your family have a vision problem? Amblyopia or "lazy eye"? Far/nearsightedness/astigmatism? Color blindness?
   Older sister (8) wore a patch for lazy eye, now wears glasses.

OBSERVATIONS (Note: If parents are unable to answer these questions you will need to help structure observations of the infant's responses to visual stimuli and to model how to observe for the parent.)

5. What is your impression of your infant's vision?
   Sometimes looks at Mom or Dad or siblings, may look at noisy toys—otherwise, doesn't seem to see.
6. What does you baby like to look at?
   Noisy toys held close, brightly colored.
7. What does your baby do when you're about 8–12 inches away and look at him/her?
   If mom catches her eye—Hope will look back at her, occasionally she smiles.
8. Does your infant use both eyes to look at objects or your face when close to him/her (about 4 inches away)?
   Yes.
9. Does your baby use both eyes to follow a moving object that crosses from the one side of the body to the other (e.g.: from left to right)?
   Can only follow object briefly—can't cross midline.

Continued on page 61

oratively with the ophthalmologist or optometrist, sharing knowledge of the infant/toddler's unique behaviors and traits to ensure the most accurate measure possible is obtained of the child's vision.

The early interventionist may be of valuable assistance to the ophthalmologist or optometrist by reporting functional vision observations and by being available to assist the family with the use of corrective lenses. A clinician may be hesitant to prescribe glasses for an infant/toddler with multiple disabilities. The early interventionist may play a critical role in working with the clinician to determine whether the infant/toddler will benefit from corrective lenses. Families who are unfamiliar with vision loss and corrective lenses will benefit from the early interventionist's active role in their use and the necessary follow up care.

If after careful review of an vision evaluation report you cannot answer the family's and your questions, do not hesitate to call the clinician to discuss the report. Vision testing is useless if the infant/toddler's family and teachers cannot make use of the information provided. An experienced pediatric ophthalmologist or optometrist will be happy to explain testing procedures and results to you and the family.

Functional vision screening

Interviewer Form

Questions for the family

Continued from page 60

CHILD'S NAME Hope Jones

10. Does your baby swipe at, reach for, and grasp colorful objects that are close to him/her? If so, please explain.
Does not use hands independently —holds toys that are placed in her hands.

11. Does your baby seem to respond to your face or brightly colored toys? If so, how far away, or how close, and in what positions are they noticed?
Usually notices Mom's face when being held, about 6–8 inches away. Toys noticed up close and when shaken or moved.

12. How does your baby respond if many toys are presented at the same time (e.g.: several toys on a quilt during playtime)? Will he/she notice a favorite toy?
Looks at whatever is closest to her. Doesn't seem to have a favorite.

13. What toys does your baby prefer? Toys that make sounds? Toys that are bright and colorful? Shiny toys?
Loves toys with loud sounds—bright and colorful.

Questions to ask the Infant's Ophthalmologist or Optometrist

CHILD'S NAME Hope Jones

AGE 2 years

DATE RECORDS REVIEWED November 12, 1995

1. What kinds of vision tests were conducted?
   1. Retinoscopy
   2. Cover Uncover test
   3. Teller Acuity
2. What were the test(s) results?
   1. Refractive error—extremely nearsighted, approximately 20/400
   2. Slight astigmatism in right eye
3. How did the test go—how was the baby during the testing situation? How reliable are the results?
   1. Very agitated and crying while held by Mom
   2. Reliability is moderate to good
4. What do results mean in terms of the baby's ability to see clearly?
   Won't see much past 12" without correction.
5. With this vision loss would this baby benefit from glasses or contact lenses?
   Yes. Glasses will be prescribed. Put on wearing schedule until tolerated at all times.
6. What can we expect this baby to see with and without lenses?
   Without glasses: up to 12" from face.
   With glasses: should see up to 10' away.
7. Are more tests needed? When? What kind?
   Reassess in office in 6 months with glasses.
8. When should this baby be retested? (If questions remain about baby's vision he or she should be seen at least once a year to see if vision has changed or if glasses or contact lenses have been prescribed and to see if the strength and fit of glasses/contract lenses is appropriate.)
   Six months—check glasses.
   See if Hope can participate in further tests

Continued on page 63

Keys to effective family interviews

At the heart of gathering useful information about a child's health and developmental needs is the family interview. In early intervention, family interviews are used extensively to incorporate the family's needs, concerns and priorities into the Individualized Family Service Plan. In order to be a useful tool, the interview must be conducted in a manner that is as sensitive as possible to the family's cultural context. Culture refers to the family's ethnic, religious or racial background, it implies that each family has its own unique characteristics which must be accommodated by the interviewer.

Dennis and Giangreco (1996) conducted a survey of professionals in special education who are themselves members of ethnic minority groups. Respondents discouraged professionals from making generalizations about large groups of people for fear of reinforcing or creating stereotypes. Recommended instead was an approach that is sensitive to the individual family culture, including the meaning of family, the roles of family members and their expectations of each other. Additionally, it was recommended that professionals appreciate the environment in which a family may live. Safety and stability in the home and school environment may be overriding concerns. Culture will have an impact on how a family views the role of children—and

Questions to ask the Infant's Ophthalmologist or Optometrist

Continued from page 62

CHILD'S NAME Hope Jones

9. How can I help prepare this child for further testing? (For example, for acuity tests which require a matching or verbal response, or tests performed at distances beyond 16 inches.)
   Assist family to establish glasses wearing. Increase Hope's tolerance to handling and strangers.

10. Can I participate in further testing? (Recognition acuity tests.)
    Yes, please come to next exam with family.

11. [If present at the exam.] Can the parents and I look at the Forced Preferential Looking Cards from the point of view of the tester? Of the baby? To better understand the baby's vision loss?
    Yes, at 6 months re-check.

12. If the baby is wearing contact lenses or glasses, when does he/she need to be checked for a new prescription?
    Will assess in 6 months.

You should be able to answer questions #1–7 from a complete vision report. If the written report does not provide this information, you will need to discuss the results with the optometrist or ophthalmologist.

the role of children with disabilities—within the family structure. Families may be hesitant to participate actively in their child's educational planning because they hold educators in high esteem and feel that they should defer to them at all times. The professional culture—one of forms, deadlines and meetings—must be introduced and taught to families if they are unfamiliar with it.

Working together with families, the early interventionist can gain deeper understanding of the cultural factors that motivate attitudes and actions of both the interventionist and the families. Through careful self reflection and mutual respect, the early interventionist and family can share information that ultimately provides the greatest benefit possible to the child.

Recommendations for conducting family interviews that are culturally sensitive

APPRECIATE the uniqueness in each family,

BE AWARE of the influence of your role as a professional,

ACKNOWLEDGE your own cultural biases,

SEEK new understandings and knowledge of cultures,

and,

LEARN along with families.

Dennis & Giangreco, 1996

References

Dennis, R. & Giangreco, D. (1996). Creating conversation: Reflections on cultural sensitivity in family interviewing. *Exceptional Children,* 103-116.

Vision

Functional Vision Assessment & Interventions

by

Irene L. Topor

An Easy Guide to Tests Used to Diagnose Visual Impairments in Infants

by

Dorothy Bridge

Clinical Vision Assessments for Infants with Severe & Multiple Disabilities

by

Deborah Orel-Bixler

Functional Vision Assessment & Interventions

by Irene L. Topor

Much of what we learn happens as we watch what others do around us. Hearing, taste, touch, and smell all provide important information about the world, but none of these can compete with the visual sense. Vision helps people gain information in a manner that is both quick and efficient. Infants who are deaf-blind including those with significant developmental delays and who may have other disabilities including severe motor or neurological impairments may still use their vision to learn. These infants learn by exploring, interacting with people and things, repeating experiences so that they can be remembered and by being expected to learn. Early interventionists serving infants who are deaf-blind can assist parents to learn about how their children use vision to learn about the world even if small amounts of vision are available. Parents can help their infants use vision more efficiently by making environmental adaptations and/or modifications where their children commonly engage in routine activities throughout a typical day. These adaptations may include changes in illumination, color/contrast within the activity, changing the distance/angle or position at which a toy or food item is placed before the child or simply adding verbal cues which may encourage visual attention toward the task being completed.

How to perform a functional vision assessment with infants who are deaf-blind

(Birth through 36 months of age)

Parents often are the first ones to detect if their child has a visual problem. If an infant normally notices mother's face when she is being held in mother's left arm but not the right one, typically overreaches or underreaches for objects, or brings things very close to the face to look at, parents will comment or ask questions about these behaviors. A functional vision assessment should start with the early interventionist asking the parents questions about how they believe their infant who is deaf-blind is using vision.

Questions to ask parents

Q. What has your eye doctor told you about your child's vision?
A clinical examination from a pediatric ophthalmologist or optometrist will provide information to the parents about the child's physical ability to see. Sometimes, parents are not always sure what their child's eye condition is and may need some assistance in obtaining more information about it and the implications for working

with their infant to encourage use of vision. Though it may not be possible to physically change the eye and the visual system, it may be possible to "correct" a child's vision as determined by the child's eye doctor. The correction may be achieved through surgery, medication, a "patch" program, and/or corrective lenses (glasses or contact). Correction of refractive errors (nearsightedness, farsightedness and/or astigmatism) becomes very important for the infant who is deaf-blind who will be involved in an intervention program which stresses the encouragement and use of vision throughout a routine day.

Q. Is your child taking any medications? What medical issues should we know about that would affect your child's learning to use vision?

Anti-seizure medications may have an affect on how the child uses vision to do tasks. Sometimes children who are taking high doses of anti-seizure medications don't appear to use vision very well because they are tired, sleep often, and visual attentiveness does not occur on a frequent basis. This information is important because you may ask the parent to defer giving the medications one time before you observe the infant in a typical routine. If you see differences in how the infant uses vision as compared to what the parent has described to you, discuss the effects the medication may have on the way the child uses vision. Help the parent to understand that their expectations for their child's use of vision immediately following a dose of anti-seizure medication may result in differences in how their child uses vision (e.g., less attentive, less reactive to a color previously responsive to, areas of vision seen are not used as functionally as they had been in the past to complete routine tasks, etc.).

Q. What kinds of things do you think your child sees and in what activities does your child use vision to complete the activity(ies)?

Ask whether or not their child appears to notice if the room lights are on or off. Is their child interested in watching television? What pictures capture their child's attention? What picture books are interesting to their child (e.g., pop-out illustrations, brightly colored drawings with little or no visual clutter, pictures of animals and/or other familiar people, objects or events)? What are their child's favorite toys and color preferences for any of the above mentioned materials and objects?

Q. Does your child recognize people when they first enter a room when no auditory cue is given (e.g., person signals presence by calling out child's name)? How far away is the person when the child visually recognizes his/her presence?

After asking this question, parents often think about other ways their child uses vision to localize, fixate, track, scan, and shift gaze at distances beyond six feet. (e.g., "My child appears to see his own image in a mirror when at the physical therapist's but when close to the mirror, doesn't appear to 'know' that the reflection is of himself.")

Q. Does your child look out the windows of your car when you take him on an outing?
Parents notice their child using vision when taking a car ride to go to the grocery store, visit a relative or friend, or running a routine errand. Parents often comment that they hadn't realized that their son noticed the "golden arches" or seemed visually aware of a bright red landmark (red gas station emblem) at turn made routinely on a route to the nearest grocery store. Information pertaining to this question also gives interventionists more insight as to how a child uses distant vision to gain information about the environment.

Q. Have you noticed your child squinting when playing in the bright sunlight or does s/he turn away from bright lights coming in windows or from lamps?
Answers to these questions give us information about a child's sensitivity to light (a condition called "photophobia"). We can assist parents in understanding how to easily adapt a situation that may be potentially uncomfortable for a child because of glare that causes discomfort and/or interference with performing a task visually.

Q. Some children with a visual impairment hold their hand near or against their eyes in unusual ways. For example, some children wave a hand in front of one or both eyes; others press against an eye. Have you noticed your child doing this and if so, when do you most often see this behavior?
The first step would be to teach the parents how to observe the child and specifically note when s/he is hand gazing and/or eye pressing throughout a routine day. Is the pattern consistent or does the child hand gaze/eye press when in an uncomfortable or unfamiliar situation? If the child appears to benefit from using vision when more light is present as is indicated by these behaviors that are not usually related to a routine, increased illumination may be a way to modify an environment to enhance visual functioning during a routine activity.

Q. Does your child appear to tilt her head in an unusual way to look at things?
A head tilt may mean that the child has a field loss. Eccentric viewing or finding the null point of nystagmus helps the child to use vision more efficiently to complete a task. Parents may need to be taught that it's fine for their child to tilt the head if, during a routine he needs to tilt his head to see something more easily.

Q. Is your child more hesitant to explore or move about unfamiliar places when in open spaces, or when on stairs? Please describe.

If the child moves more freely in familiar places, he may need to be taught to use vision when experiencing an unfamiliar environment. Vision is a learned process and for those children with a diagnosed visual impairment, instruction in how to use vision in new, unfamiliar environments will be necessary to assure that they do not miss incidental information which may be obvious to the caregiver or other children who may not have a visual impairment.

Q. How does your child locate things he drops on the floor? Please give an example. Does the child use vision to locate lost objects? How?

Parents can give interventionists information about how a child uses vision to problem solve, scan and use eye and hand together to complete an activity. If vision is not routinely used to complete a daily activity where something needs to be retrieved, environmental strategies and adaptations may need to be tried to improve the child's use of vision.

Q. Describe your child's coloring/drawing skills (if applicable). Obtain a sample, if possible. How does your child use vision to perform these tasks? Does the child experiment with many colors? Does the child choose to color/draw on much space or are colors limited to certain areas on the page (e.g., right/left corner/center of the page, upper/lower areas of the page, etc.)?

Parent report will give interventionists insight as to how child uses near vision for eye/hand task. Also, if parents have been hesitant to expose their child to this type of task, interventionists can determine if parents need assistance in finding ways to set up a situation so that their child can experience more eye/hand coordination near tasks in the fine motor area. Interventionists should also discover whether or not a history of color blindness exists in the family. If the father or brother of the mother has a history of color blindness, the child may be at risk for also having the same type of color blindness in addition to the primary visual condition. Special considerations may be needed in adaptations of toys (use bright, warm colors; limit the greens and blues) and/or environmental conditions. The process of discovering which colors are most discernible for the child who may be experiencing a color perception deficit is on-going. Records can be kept to determine if a pattern exists for which colors are most discernible and which colors are least attractive to the child.

For children with eyeglasses/contact lenses/patching program

Q. Does your child wear her glasses all the time? If not, why not?

Q. Does your child move his glasses forward on the nose or look over the glasses?

Q. How long has your child had her present pair of glasses/contact lenses?

Q. Does your child wear her patch the prescribed length of time recommended by your eye care specialist?
Parents often wonder whether or not glasses are helpful to their children. If a child does not appear to benefit from wearing glasses, parents are sometimes hesitant to require her to wear them. Patch programs are also sometimes difficult for children to tolerate if there are large differences in the ability to see between the right and left eyes. If the child is required to use the weaker eye for up to four hours a day, the child may attempt to remove the patch. Parents feel guilty when they are continually having to replace the patch on their child's eye. Some may eventually stop a patch program entirely because of the adverse reactions it causes the child. Interventions for parents include asking them where they would feel most comfortable reinforcing their child's "patch on" behavior for short periods of time throughout a routine day. The parent's goal would be (with support) to gradually assist the child to wear the patch for the prescribed amount of time as set forth by the eye care specialist to increase the visual function of the weaker eye over time.

For many children, there are benefits to wearing correction (glasses/contact lenses), even if the child is deaf-blind. Though a child may not have 20/20 vision with correction, affording the child an opportunity to see with best correction is desirable under conditions where tasks need to be performed using the visual sense. If a child does not choose to wear glasses consistently, several reasons should be checked before deciding that the child should stop wearing the corrective lenses.

Check the fit of the glasses/contact lenses. Are they too tight? For example, do the glass frames rub against the nose or behind the ears causing red marks? Are the contact lenses causing corneal abrasions? Do the glasses slide down the nose of the child? Do the contact lenses appear to be moving about the eye(s), e.g., lodged above the upper or lower eye lids? If any of the answers to these questions are "yes," an optician experienced in fitting children with glasses and/or contact lenses should be consulted to improve the fit.

DAILY ROUTINES & FACTORS AFFECTING USE OF VISION

(Sample sheet)

ASSESSMENT AREA Kitchen

LIGHTING Natural lighting occurring through window on east side of house, curtains are drawn to inhibit light from fully illuminating room; overhead incandescent light fixture with two 40-watt cool white bulbs are overhead, ten feet above eye level.

ACTIVITY Eating breakfast

VISUAL AIDS None

(e.g., slant board, magnification, colored filters, etc.)

STEPS IN ACTIVITY	CHILD'S ACTION*	FACTORS AFFECTING USE OF VISION	TEACHING STRATEGIES AND ADAPTATIONS
Child is seated in high chair, ready and motivated to eat	+	Support for neck, trunk, and head needed as prerequisite for looking	
Child fixates on mom and food, shifts gaze as mom places cracker on high chair tray	+	Distance and position mom is in when she places cracker on tray	
Child reaches for pieces of cracker on tray	–	Color/contrast of cracker upon background of high chair tray	Change color background; adjust lighting
When offered a spoonful of oatmeal, child opens mouth and eats cereal	+	Size, color of spoon, color/contrast of oatmeal against spoon, angle at which mom presents spoon	
Child is offered bottle, reaches for it and begins to drink liquid	–	Color and size of bottle, position and distance of mom, when offering bottle, illumination	Try different colored and sized bottles; present within different visual field

***CHILD'S ACTION: + INDEPENDENT – NEEDED HELP * INCONSISTENT**

NOTE: Child is within the birth to 12 months of age range

Is the prescription of the glasses and/or contact lenses correct? Ask the ophthalmologist's technician or optician to recheck the prescription, assuring that the correct prescription has been placed in the right and left eye(s). Busy labs may inadvertently switch the prescription or mistakenly prescribe someone else's prescription for a child.

Q. After the interventionist has comfortably gathered all the information pertaining to the above questions, she must then ask the parents about their daily schedules. Simply say, "describe your child's indoor and outdoor activities including travel skills" (include weekend schedule if different from daily schedule).

Q. Of the activities in your child's schedule, what would you like to focus on to enhance his use of vision more efficiently (domestic, community, recreation/leisure)?

What types of communication systems does your child use?

- ○ Verbal (sounds and words)
- ○ Sign language
- ○ Picture/communication boards
- ○ Gestures/touch cues
- ○ Objects/textures
- ○ Other_______________

What to do after the functional vision assessment: Interventions, strategies and considerations

What is the best way to help a child understand what is seen?

An analysis of a family's chosen routine activities is performed. The factors that affect use of vision within these activities is completed. Interventionists can then share information with parents that educates them about how vision is learned. The information will be useful to them as they modify their attempts to work with their children. Encourage consistency of instruction in the vision area throughout their routine day. Remember, some children may be able to detect that something is present (e.g., see a shape or a bright color), but have no idea what they are seeing. When children are looking at something, parents should not assume that their child will automatically understand what it is. Understanding what we see is a process that occurs over time as we grow from an infant to a young child. The experience of *learning what is seen* requires interaction. A parent can guide learning by making sure that the child is an active participant in daily routines and is able to make use of what is seen. They will need encouragement to reach out, explore, and manipulate items seen. If the child can hear, telling the child what the child is experiencing can help make meaningful connections. For instance, a child may not be able to see the features of an object clearly. However if a parent is consistent in using words, presenting activities, and supporting a child, the child may learn to pair what can be seen with the words the parent uses to describe meaningful objects and activities. For example, a family turtle may only be detected as movement at a certain height off the floor. Yet if the child touches this "movement" and interacts with this "movement," the visual detection of this "movement" can become recognized as the family turtle. The child may not be able to clearly see the turtle, but can still "recognize" the turtle.

The important aspects of teaching a child to use available vision are consistency, repeating information and using a positive approach while providing many regular opportunities to encourage use of vision. Make life visually functional, meaningful, and enjoyable. For instance, if a child picks a snack from two different choices and one is preferred to the other, the child may be motivated to learn what differentiates the two snack options. A parent can assist the child to get what he wants by making sure the two snacks look different in shape, size or color, (e.g., a red apple versus a box of animal crackers), or by placing them on two different colored plates.

What are the visual behaviors parents and interventionists need to enhance with infants who are deaf-blind?

There are six visual behaviors that caregivers need to foster and promote with their children.

LOCALIZING Searching for an object or a person against a background

FIXATING Focusing directly on an object or a person

SCANNING Systematically examining an area from a display of three objects, pictures, people, or events

TRACKING Following the movement of an object, person or event

SHIFTING GAZE Looking back and forth from one object or person to another

EYE-HAND COORDINATION Reaching out to touch something or pick up an object

Each of these visual behaviors is considered a voluntary skill and is important in the development of vision.

When is the best time to teach a child to use vision?

It is best to teach during the normal routine of the day's activities. Since we are constantly making use of visual information, the best time to help a child learn to use vision is whenever a need naturally arises.

Some activities that children engage in may not *require* the use of vision (e.g., taking a bath, listening to music, getting a massage). Other activities may not *require* vision, but are made easier or more enjoyable with vision (e.g., watching cartoons, looking at a family member's face when engaging in play, picking out a favorite cereal at the grocery store). If a child seems to be having difficulty in an activity and if use of vision could help participation, then the parent may want to offer ways to make what is seen more visible or encourage his child to look.

Although special times may be set aside to work on using vision, it is just as important that children receive assistance to see and make use of visual information throughout the activities in a typical day. The instruction that fits naturally into the child's life and is provided when and where it is needed will be most beneficial, motivating and reinforcing.

Learning to use vision: A developmental process for the young child

Like all skills, developing vision has to be learned, and just as we achieve some skills before others, vision use also tends to happen in a certain order. It begins with an interest in light, then people attract our attention and finally, objects become more of a focus. When children do start to fix their attention, they usually start with stationary targets. Then they try and follow movement. Children's awareness usually begins with interest in large simple items that are nearby and later children seek out more detail and complexity, as well as examine what's beyond their immediate reach. Initially, children show preference for what is familiar and later they develop interest in what's new or different. Think about what motivates a particular child. How children presently try to use their vision can often provide clues on where to start teaching next.

When a child has a cortical visual impairment, acquiring visual skills in a normal progression within routine activities may be difficult. Though the eye examination of children with cortical visual impairment is often normal if there is no accompanying optic nerve atrophy, dystrophy or hypoplasia, the visual function of children who are cortically visually impaired is highly variable, with a markedly short attention span. These children may light gaze and display a sensitivity to light. Jan & Groenveld (1993) note that children with cortical visual impairment appear to use peripheral vision (side vision) when reaching for an object. Colors, especially red and yellow, are very attractive for children with cortical visual impairment. The authors also suggest that colors, when used with form, facilitate the perception of forms by persons with cortical visual impairment.

Children who are cortically visually impaired tend to test well when given the Forced Preferential Looking Test. A visual acuity of "20/150," both eyes, raises hopes of parents and doubts by early interventionists who wonder how a child could obtain a visual acuity in the low vision range, yet function as though he does not see a favorite toy or mom's face even when the toy or face are presented within an 8–12 inch range from the face. The explanation may be that the face or toy are "too much" to look at for the child with cortical visual impairment. The forced preferential looking lines are evaluating "resolution" acuity or the ability of the child to distinguish lines from "no lines." The gradients on the Teller Acuity System cards have been placed on the gray cards to capture the visual attention and fixation of many children. A wide-eyed look or look and then look away behavior (averted gaze) of the child with cortical visual impairment when he sees patterned lines on the card give caregivers clues that potentially this child has vision to use. Environmental adaptations (color/contrast, illumination, distance considerations) may have to be implemented to best facilitate the child's use of vision within his daily routine activities. To encourage a child to keep looking at Mom's face or a brightly colored toy, one might adapt by revealing only portions of Mom's face or one colored part of the toy to increase visual interest.

Modifying the environment: Suggestions and considerations

(Brennan, et al., 1992)

Lighting Quantity, type, direction, and position of illumination are critical to visual performance. Some children are light sensitive and may experience pain and discomfort from bright or direct light or glare. Other children need more lighting to see optimally.

Experiment with different light sources Gooseneck lamps, including those with full spectrum lighting can be directed on tasks and positioned to avoid glare.

Full spectrum lighting combines the red/orange spectrum with the blue spectrum to make the illumination more calming to children.

Color and Contrast Another way to make it easier for a child to see is to increase the contrast between the object the child is working with and its background, and to reduce the number of items around the object. The child who is deaf-blind may need a more exaggerated difference between an object and its background for visibility. Black and white provide a good contrast, but sometimes routine activities involve objects that are not black or white. The material, dycem, a non-slip background used often by occupational therapists, has worked well when creating a contrast between a child's finger foods on a high chair tray and the background. Dycem is made in red and bright blue. When crackers, cheerios, etc. are placed upon a blue dycem background, the ability to localize, fixate and reach and grasp for small food items has remarkably improved for many children who have a vision impairment. It will always be important to experiment with sizes and color of objects, e.g., different colored cups and spoons, placing clothing choices on different colored backgrounds to increased visual choice making behavior.

Highlighting light switches with a contrasting color to the walls or a band of tape outlining the switchplate helps the child who is deaf-blind distinguish where the light switch is on the wall. Indicate toy storage area in the child's room by placing a contrastive piece of carpet in front of the child's toy area so he knows where to locate toys to make choices.

Another consideration one must make when adapting the environment is to position the child so that he does not maintain an asymmetrical tonic reflex. The key to proper positioning is first to consult the physical therapist for suggestions about how to position the child so he is supported within the trunk/neck and head areas. With proper support, the child has the best opportunity to use vision. Second, discuss with the parents what equipment is available to them to create a situation where the child is in a supported position to encourage looking behaviors. If the equipment available is used easily within a routine activity and vision is a skill that can be encouraged within this activity, continue to work with the physical and/or occupational therapists to monitor head/neck and trunk stability and use of vision as the child engages in and completes the routine task.

Size and Distance Children who are deaf-blind may not see detail well at a distance or an object may be too small to see well. Moving closer to an object will make it more visible.

For example, a child can move closer to a television. Even with corrective lenses, moving closer to an object make the detail of the object more easily seen. If possible, one can also increase the size of the object. Place pictures, designs and wall hangings in the child's bedroom at eye level for the child.

Time Accuracy and speed of performing an activity decreases when a child has a visual impairment. According to Brennan, et al. (1992), detecting, recognizing, and then acting upon an object require more time for the child who has a visual impairment and can be especially difficult and time consuming the for the child with multiple impairments (e.g., deaf-blind). Physical demands of prolonged seeing may cause eye fatigue and reduce the child's speed, accuracy and attention. More time should be given to the child who is deaf-blind to locate and discriminate an object.

In summary

Many opportunities arise throughout a routine day to encourage children to look. Looking and discovering the world through vision can be fun. Parents and other caregivers can be enthusiastic about what there is to see in the world. provide interesting things to look at and plenty of time to explore. Look for typical times and places to practice using different vision skills. Looking, finding, following, shifting attention between objects, and picking up or pointing can all happen during daily routines and activities. Professionals can give input about corrective lenses or adaptations as well as special training and can help parents in their efforts to achieve greater independence for their children. Whatever a child learns to see depends on how positive caregivers are about the attempts the child makes to learn to use vision. Children can gain valuable information if they are encouraged to look on a regular basis.

References and resources

Bishop, V. (1988). Making choices in functional vision evaluations: "noodles, needles and haystacks." *Journal of Visual Impairment and Blindness*, 82, 94-98.

Brennan, V. et al. (1992). *Suggestions for modifying the home and school environment. Hand-book for parents and teachers of children with dual sensory impairments.* Watertown, MA: Low Vision Services, Perkins School for the Blind.

Downing, J. & Bailey, B. (1993). *Helping young children with visual impairments make use of their vision.* Indiana Blumberg Center for Interdisciplinary Studies in Special Education, Indiana State University.

Goetz, L. & Gee, K (1987). Functional vision programming. A model for teaching visual behaviors in natural context. In L. Goetz, D. Guess and K. Stremel-Campbell (eds.), *Innovative program design for individuals with dual sensory impairment* (pp. 77-98). Baltimore, MD: Paul H. Brookes Co.

Hall, A., Orel-Bixler, D.A., & Haegerstrom-Portnay, G. (1991). Special visual assessment techniques for multiply handicapped persons. *Journal of Visual Impairment and Blindness*. 85, 23-28.

Hanson, M. (1989). *Beyond tracking.* Bridgeview, Illinois: Vision Unlimited.

Jan, J. E., Groenveld, M., Sykanda, A.M., & Hoyt, C. (1987). Behavioural characteristics of children with permanent cortical visual impairment. *Developmental Medicine & Child Neurology.* 25, 755-762.

Jan, J. E. & Groenveld, M. (1993). Visual behaviors and adaptations associated with cortical and ocular impairment in children. *Journal of Visual Impairment and Blindness*, 87, 101-105.

Levack, N. (1991). *Low Vision—A resource guide with adaptations for students with visual impairments.* Austin, TX: Texas State School for the Blind.

Topor, I. (with L. Penny Rosenblum) (1994). What's functional about a functional vision assessment? *Indiana Deaf-Blind Services Project Information Updates*, 5, Blumberg Center for Interdisciplinary Studies in Special Education, Indiana State University, Terre Haute: Indiana.

An Easy Guide to Tests Used to Diagnose Visual Impairments in Infants

by Dorothy Bridge

Children are very often screened by the pediatrician. In the pediatrician's office the child is checked for pupillary response and tracking by using a flashlight. The child is often examined with an indirect ophthalmoscope. With this tool the child can be screened for abnormalities of the eye such as congenital cataracts. The indirect ophthalmoscope screens for problems of the eye that are visible by looking through the dilated pupil with the indirect ophthalmoscope.

Ophthalmology office visit

Eyes are checked first without drops. Visual responsiveness, construction and dilation of the pupil, symmetry of the eyes, tracking patterns, ocular motor control are checked.

Cycloplegic examination

Ophthalmologists usually use two different drops to do this examination: The first drop is to numb the eye, second drop is to both dilate the pupil and freeze the focus of the eye. An infant's eye has the ability to focus or compensate for a refractive error of up to eight diopters. If a cycloplegic drop is not used to dilate the pupil, then the physician will get a false reading concerning a possible refractive error—this is very important because this is what allows the physician to know if a baby (or a child under seven years) needs glasses.

Ophthalmologists are often asked how glasses are prescribed when the child cannot say when a picture is clear. The eye is supposed to be very round. If it is not, glasses are prescribed to round out the eye. It is the initial screening that could detect children's eye conditions such as: retinopathy of prematurity, cataracts, optic nerve hy-

The Cycloplegic Examination

This process allows the ophthalmologist...

TO CHECK the health of the eye. A dilated pupil will allow the doctor to look at the internal structures of the eye such as the retina, macula, fundus, optic nerve

and,

TO DETERMINE if there is a refractive error.

popasia, optic nerve atrophy, retinoblastoma, retinal colobomas, retinal detachment, refractive error, shaken baby retinas, and infectious retinal disease.

Most visual disabilities can be diagnosed with the pediatric ophthalmologist's office visit. When the baby is not visually responsive but doesn't appear to have any of the structural abnormalities that are visible by looking through the ophthalmoscope then more sophisticated tests may be suggested.

ERG or Electroretinogram

The ERG is often used when the baby has poor vision or is visually unresponsive but the physician cannot detect a cause for the poor vision. Electroretinography detects the electrical activity of the retina when the eye is exposed to light. This test measures the responsiveness of the rods (day and night vision) and cones (color and detail vision). Electroretinography is not typically considered useful before the age of six months because of false readings.

Procedure

Typically performed under anesthesia. The entire exam takes approximately two hours. For the first part of the test, the eyes need to be dark adapted. This means the child's eyes are dilated with drops and then the parents and the child sit in a dark room for approximately an hour. Depending on the clinic, the child will either take an oral sedative (chloral hydrate), or will be fully anesthetized in order to run the test. Next, a corneal contact lens with an electrode in it is placed in both eyes. This lens has wires running out of the top of it to another electrode which is placed on the forehead. A large machine is positioned over the baby's head and lights are flashed directly into the baby's eyes. The electrodes send messages to a computer which records the electrical activity of the rods and cones. In an eye with normal retina there will be a printout that looks like the peaks and valleys of a mountain range. When the rods and cones are not functioning properly, the printout of activity may be flattened line. Sometimes the rods and/or cones do not function but to the naked eye the retina looks normal. Diagnosis such as Leber's Amaurosis, Cone Dystrophy, Rod Cone Dystrophy are a few of the childhood eye conditions that can be ruled out with an ERG. Retinal eye conditions may give information about whether or not the eye condition is genetic.

Ultrasonography

Ultrasonography is used frequently when the child has an opacity which doesn't allow the physician to look into the back of the eye. Looking in the back of the eye allows the doctor to see abnormalities of the internal structures of the eye. With external eye opacities such as cataracts, or scleralized corneas, an ultrasound can give the physician information concerning the development of the retina, and the viterous. It is helpful in determining possible complications when removing cataracts, transplanting corneas, and attaching retinas.

Procedure

An orbital ultrasound is much like that of an ultrasound during pregnancy. It is a procedure which is done in the physician's office. A viscose lotion is applied to the eyelid. This lotion makes the eyelid very slippery so that when the sound probe is slid slowly over the eyelid, the technician or doctor gets a visual image of the internal structures of the eye. The images are displayed on a screen and can be put into print also so that parents are able to see how their child's eye has been formed. Detached retinas, colobomas, persistent hypoplastic viterous, might be abnormalities that an orbital ultrasound would detect.

Magnetic Resonance Imaging (MRI)

There are many reasons ophthalmologists might recommend an MRI. Since the eye is often considered a part of the forebrain structure, when the eye is improperly formed, there may be implications for abnormalities of the brain. Also, when there has been neurological trauma during pregnancy, the birthing process, as a result of infection or trauma, and MRI might be recommended to determine how the visual pathways and the visual cortex of the brain are affected. MRIs are very important for ruling out neurological problems as well as for determining whether or not the visual areas of the brain are working.

Procedure

The MRI is performed under anesthesia as the child has to be perfectly still while the camera is taking pictures of the brain. It is often done under the supervision of a radiologist. The radiologist reads the results of the test to the doctor who in turn translates the information to the parents. From the MRI, the doctor can relay information about cortical visual impairment, optic nerve problems, risk factors related to optic nerve problems, and abnormalities of the brain which may have developed when the eye was being formed.

Tonometry

This test is traditionally done in the physician's office. It is a test which measures intraocular pressure of the eye. It is a relatively routine test and it is done on most children who present with eye conditions. The intraocular pressure is normally in the range of 10–20mm HG. If a child shows signs of having high pressure, this is considered to be glaucoma.

Procedure

First, numbing drops are put in the eyes so that the test can be administered. A tonometer is placed on the cornea (front part of the eye) and an electronic recording device measures the intraocular pressure. If the pressure is moderately high, a child might begin treatment for glaucoma with drops. If the pressure is dramatically high, surgery might be indicated in order to release pressure from the inside of the globe of the eye. When glaucoma is present frequent pressure checks are recommended. When a child is particularly traumatized by this office procedure, it is not unusual to anesthetize the child and perform the test as an exam under anesthesia. It is not uncommon to have elevated pressures from the child being so upset by the test (i.e., screaming) that intraocular pressures is raised, but this would be a false reading. Close supervision of glaucoma is very critical as corneal, nerve and retinal damage can occur as a result of elevated pressures.

Clinical Vision Assessments for Infants with Severe and Multiple Disabilities

by Deborah Orel-Bixler

Until about 25 years ago, it was thought that infants could see very little. Textbooks for ophthalmologists in 1960 stated that infants could see light and dark but could not see patterns. Over the past 20 years, vision development has been studied intensively by developmental and experimental psychologists and vision care practitioners. It is now known that the visual system of infants is relatively mature at birth and undergoes rapid development in the early postnatal years.

Development of the visual system

Of all the human organs, the eye is the most fully developed at birth. Formation of the eye begins at 22 days of fetal life and develops from an outpouching of the developing brain. By six weeks after conception, the ocular structures and differentiation of the brain are fairly well developed. Therefore, teratogenic factors (drug abuse, infection, medications) occurring in the first trimester of pregnancy often result in ocular defects.

The eye of the newborn is two-thirds of the adult size. It undergoes its most rapid growth during the first year of life and finally reaches the adult length and size by adolescence. At birth, the anterior structures of the eye (cornea, lens, iris) are more developed than the posterior structures (retina). Within the retina, the photoreceptors consisting of rods (responsible for night vision) and cones (responsible for day vision, detail vision, color vision) are all present at birth but are immature in size and spacing. The inner layers of the retina differentiate further after birth. In particular, the fovea (central area of the retina specialized for acute vision) is very immature and develops later than the peripheral retina. The optic nerve, which conveys information from the eye to the brain, is relatively full size at birth. Myelination of this visual pathway to speed the neural connection rate is not complete until age two years. The lateral geniculate nucleus (a midbrain relay station) has the full complement of neurons present at birth but they enlarge and establish more connections to other neurons with age. The visual cortex of the brain has all the neurons of one's lifetime present at birth, but these migrate to superficial layers of the brain and increase in their neural connections.

The anatomical and physiological developments of the visual system are accompanied by a rapid improvement in visual capabilities. Most aspects of vision function reach adult levels during the first year of life. Visual fixation by the newborn is evident at birth and accurate fixation is achieved by six to nine weeks. The newborn's eye movements change from saccadic or steplike, fixational movements to smooth pursuit eye movements by two to three months of age (Aslin, 1987). Optokinetic nystagmus (OKN) and the vestibular ocular reflex (VOR) are involuntary eye movements important for providing stability of visual images on the eye when objects in the world move (OKN) or the infant moves (VOR). OKN is present at birth but immature until three months of age. The newborn is unable to suppress the VOR (reflexive eye movements induced by spinning) until two months of age. Accommodation, the ability to focus the intraocular lens of the eye for near viewing, is present at birth but inaccurate until two to three months of age (Banks, 1980). Fortunately, the small pupils of the neonate permit a relatively large depth of focus or range over which visual objects remain clear without focusing effort. The average refractive error of newborns is hyperopic (far-sighted) due to the strong optics of the eye and short axial length with an incidence of astigmatism from 15 to 30% (Fulton, Dobson, & Salem, 1980). The prevalence of hyperopia and astigmatism decrease with age (Abrahamson, Fabian & Sjostrand, 1988). The refractive error in the majority of infants disappears by 9 to 12 months (Baldwin 1990).

Visual capabilities improve rapidly during the first year of life. **Contrast sensitivity**, the ability to detect brightness differences or subtle shades of gray, for large objects is adultlike by 10 weeks of age (Norcia, Hamer & Tyler, 1990). Infants have measurable **color discrimination** as early as two weeks of age although they need more saturated (brighter) colors and larger target areas than adults. **Color vision** improves over the first three months of life (Brown, 1990). **Visual acuity**, the ability to discern fine details, reaches adult levels by six to eight months of age (Norcia & Tyler, 1985). **Stereopsis**, the ability to discern fine depth or 3-D vision, has a rapid onset at three months of age and reaches near adult levels in most infants by six months of age (Birch et al., 1982). The extent of the peripheral **visual field** of infants increases rapidly after two months of age. By one year of age, the upper visual field reaches adult size but the lateral and lower visual fields are still smaller than the adult size (Mohn & van Hof-van Duin, 1986).

Early identification

Certainly, any hindrance to these normal visual developmental processes should be detected early and remedied. Vision screening at birth and during the first six months of life is important. Unfortunately, primary care physicians usually limit their visual assessment to ocular media clarity which does not detect strabismus (eyeturns) and amblyopia (unilateral loss of vision) (Campbell & Charney, 1991). For this reason, the current recommendation by both the American Academy of Optometry and the American Academy of Ophthalmology is for a complete eye examination to be conducted with all infants at six to eight months of age followed by another exam at two and one half years of age. The basic components of a vision examination include the history, evaluation of eye alignment and binocularity, determination of refractive error (focus of the eyes), quantification of visual capabilities including visual acuity, color vision, contrast sensitivity, depth perception and visual fields, and an assessment of the health of the eyes.

The infant with severe or multiple disabilities is at greater risk for vision disorders. There is a high prevalence of visual impairment in the multidisabled population (Edwards, Price & Weisskopf, 1972; Harcourt 1974; Jan, Freeman & Scott, 1977, Landau & Berson, 1971; Orel-Bixler, Haegerstrom-Portnoy, & Hall, 1989) as listed in Table 1. Several studies have indicated that children with more severe disabling conditions have more severe vision problems (Landau & Berson, 1971; Mohn & van Hof vanDuin, 1986).

Table 1. Prevalence of vision problems in several studies of children with disabilities

	REFRACTIVE ERROR	STRABISMUS	OTHER
Nondisabled	15–20%	2–4%	n/a
Cerebral palsy	21–76%	15–60%	1–25%
Mental retardation	52%	16–40%	21%
Down syndrome	42–73%	23–44%	33%
Fragile X syndrome	29%	13%	9%

Wesson & Maino, 1995

Children with cerebral palsy who have a refractive error are three times more likely to be far-sighted than near-sighted. In addition, other ocular anomalies are associated with cerebral palsy including: nystagmus 12%, optic atrophy 8%, visual field defect 5.6%, cortical visual impairment 3.6%, cataract 2.2%, fundus anomaly 6.1%, microphthalmos 5.9%, and corneal opacity 2.2% (Wesson & Maino, 1995).

It is important to detect these problems early in order to provide proper intervention. Those conditions which are noncorrectable through medical or optical means must be understood so that appropriate vision rehabilitation and educational programs can be implemented. The examination techniques for infants with severe or multiple disabilities are the same as infants without disabilities but may require some modification of the testing procedure. The history taking in particular requires careful review of several aspects of the infant's pre- and post-natal course. Information gathered from the parents or guardians of the child include the reason for the examination, signs and symptoms including family and doctor observations, the family history of vision or medical problems, and the child's pre-, peri- and post-natal course or complications.

Aspects of the vision examination

History

Chief complaint or reason for the examination

The first question concerns the chief complaint or reason for the eye examination in order to clarify the nature of the presenting problem. Most often, parents, grandparents or family members are concerned about the infant's visual inattention. The baby is not making eye contact, does not respond to familiar faces or does not fixate and follow objects with their eyes. The early presence of nystagmus (repetitive, usually rapid, and involuntary movements or rotation of the eyes) or wandering eye movements usually prompts an early vision assessment. A difficult prenatal or neonatal course such as prematurity are indications for an early eye examination. First, parents want to know what their infant can "see" and then they want to know if anything can be done, i.e., treatment or intervention strategies.

There are several ocular conditions that result in poor vision and lead to visual inattention in infants. These include: 1) opacities of the ocular media including bilateral cataracts or corneal opacities associated with congenital glaucoma; 2) disorders of the retina including achromatopsia, congenital stationary night blindness, Leber's congenital amaurosis, albinism, retinal degenerations associated with rare syndromes and metabolic disorders, retinopathy of prematurity, vitreous hemorrhage, macular lesions; 3) optic nerve disorders including optic nerve hypoplasia and optic nerve atrophy; and 4) disorders of the brain including cortical visual impairment. All of these conditions can be diagnosed with a vision examination, but not all of these conditions present with obvious signs to the parents other than visual inattention.

Signs and symptoms

The signs during infancy that a parent may recognize and that may indicate a serious vision threatening problem are listed in Table 2. These signs should prompt a visit to the child's physician (Teplin, 1995) and eye care professional.

The specific behaviors of an infant that suggest poor vision may include staring at lights, nystagmus, eye poking, failure to smile, or disinterest in the visual environment. The apparent vision difficulty may be present only under specific conditions such as dim or bright illumination. The child may become upset when a night light is turned off or when taken out into bright sunlight. If the infant has older siblings, parents can compare the younger child's development to the older child's achievement of visual milestones. Often the open ended question "How well does your baby see?" elicits recall of these specific behaviors of concern.

Table 2

Signs during infancy that may indicate a serious vision threatening problem

- ▶ Lack of eye contact by 3 months
- ▶ Lack of visual fixation or following by 3 months
- ▶ Lack of accurate reaching for objects by 6 months
- ▶ Persistent lack of the eyes moving in concert or the sustained crossing of one eye after about 4 months
- ▶ Frequent horizontal or vertical jerky eye movements (nystagmus)
- ▶ Lack of a clear black pupil (haziness of the cornea, a whitish appearance inside the pupil or a significant asymmetry in the usual "red eye" appearance in a flash photograph)
- ▶ Persistent tearing when the infant is not crying
- ▶ Significant sensitivity to bright light (photophobia)
- ▶ Persistent redness of the normally white conjunctiva
- ▶ Drooping of an eyelid sufficient to obscure the pupil
- ▶ Any asymmetry of pupil size
- ▶ Any obvious abnormalities of the shape or structure of the eyes (keyhole pupil)

Teplin, 1995

Patient medical history

The etiology of childhood visual impairment can be categorized into pre-, peri- and post-natal factors (Table 3). Up to two-thirds of all cases of visual impairment in children can be attributed to prenatal factors and of these, genetic causes account for 50% of the cases. Inheritance patterns include dominant, recessive and x-linked traits. Careful inquiry into the family history of systemic and ocular disorders aids in the diagnosis of the disorder, in particular whether any family members have poor vision, ocular abnormalities or inheritable conditions that affect the eyes. Inquiries about pre-natal factors include complications or problems during the pregnancy, delivery or shortly afterwards. The clinician may need to make specific inquiries regarding the frequency of prenatal examinations, maternal drug history including usage of alcohol, tobacco, caffeine and anticonvulsants and maternal health aspects such as anemia, diabetes, blood pressure, and infection. Inquiries about perinatal factors include the delivery, whether it was pre- post or at term; vaginal or cesarean; the duration of labor and whether there was any evidence of fetal distress i.e. meconium staining or fetal heart rate monitoring. Inquiries about post-natal factors include the neonatal period, birth weight, Apgar scores, any difficulty feeding and jaundice in the newborn.

The trend in childhood visual impairment is that less are attributed to environmental causes and more are caused by pre- and perinatal factors. Overall, genetics is the predominate cause of visual impairment. Fortunately, our knowledge of the gene locus for eye disease is increasing with advancing technology (Elston, 1990).

Table 3

Etiology of childhood visual impairment

PRENATAL FACTORS

- Genetic
- Other: Infection, Pre-eclampsia

PERINATAL FACTORS

- Prematurity
- Complications of delivery (neonatal asphyxia)
- Infection (meningitis and ophthalmia neonatorum)

POST-NATAL FACTORS

- Trauma (non-accidental injury)
- Infection
- Raised intracranial pressure and tumors

Elston, 1990

Developmental history of the child

The doctor must determine whether the infant who is visually impaired has a generalized delay in development or a systemic syndrome with poor vision being only one manifestation (Isenberg, 1994). While specific questions about early milestones can be asked, often just asking the open ended question "do you or your child's pediatrician have any concerns about the child's health and general development?" addresses the specific areas of concern.

Developmental delay exists when the infant or child does not reach developmental milestones at the expected age with allowance for the broad variation in normal children (see Illingworth, 1978; Shalowitz & Gorski, 1990; Simeonsson & Sharp, 1992 for indicators of developmental delay). The cause of the developmental delay can include prenatal factors, such as maternal drug abuse leading to intrauterine growth retardation, but also includes postnatal factors such as a drug-abusing mother's ongoing difficulties which impairs her ability to nourish and nurture her baby through each developmental stage (First & Palfrey, 1994). Seventy percent of infants with congenital visual impairment have additional major disabilities (Robinson, 1977). In another report, 68 of 100 children with visual impairment were at the 75th percentile level of development or less for their age (Zinkin, 1979).

The motor development of infants with visual impairment is not markedly different from a normally sighted infant in the first few months of life. Postural milestones such as independent sitting and standing can be achieved within expectations for sighted infants

Table 4

Percentage of associated disabilities in 576 congenitally blind individuals (1945 to 1984)

ASSOCIATED DISABILITIES	AVERAGE
None	36.1%
Mental retardation	37.1%
Cerebral palsy	15.6%
Epilepsy	13.3%
Hearing loss	13.7%
Heart defect	11.8%
No information	21.5%

Robinson, Jan, & Kinnis, 1987

(Fraiberg, 1977). There are, however, qualitative differences in motor development. It has been reported that the baby who is blind sits in a "frozen attitude" (Sonksen, 1983) with a delay in acquisition of self-initiated mobility. Even blind infants will "look" at their hands by bringing them to the face by 16 weeks, however, reaching out is delayed beyond the three to four month age norm (Reynell & Zinkin, 1975). By seven months, sighted infants localize with their eyes a part of the body which has been touched, whereas infants who are blind may take up to two years to do this (Sonkson, 1983). In general, the baby who is blind is slow to localize sounds by reaching out to touch them but instead tends to "go motionless" in response to sound. In the area of language development, the acquisition of babbling is the same in both sighted and visually impaired infants. There are mixed findings as to whether the 10–20 word vocabulary is achieved at the same age (Warren, 1994).

A complete vision examination with specialized tests can answer some questions about the visual capabilities of the infant. Other diagnostic tests (MRI, ERG, genetic work-up, etc.) can answer questions about etiology of the visual disorder. With an accurate diagnosis the prognosis can be given with some certainty in most disorders except for cortical visual impairment.

During the taking of the history, the astute clinician makes observations of the infant or child's interactions with their parent and environment as they play. The vision examination for infants and children is best approached as an extension of this play. It is best to avoid shining bright lights into an infant's eyes as the first interaction. An adequate supply of noisy and quiet toys (including the examiner's face) are usually all that is required to engage and maintain the visual interest of the infant.

Confrontation tests

The first battery of tests in the vision examination are confrontation tests that assess the fixation and eye movement behavior of the infant.

Versions

This test is an observation of the infant's eye movements as the infant fixates and follows a toy which is moved in front of the eyes in different fields of gaze. The toy is moved from midline (straight ahead) to the extreme right and left along a horizontal path, up and down along a vertical path, and moved into the upper right, upper left, lower right and lower left quadrants. The clinician looks for any restriction of eye movement since both eyes should move in concert and to the same extent. This tests for the function of the six extra ocular eye muscles in various directions of gaze and gives information about the function of the cranial nerves III, IV and XI and supranuclear control of eye movements.

Hirschberg test

The Hirschberg test is an objective measure to detect the presence of an eyeturn (strabismus). It is based on evaluating the symmetry of images from a penlight reflected on the cornea in both eyes. The light reflexes from the penlight should be centered in each eye or slightly nasal (towards the nose) when the penlight is held straight ahead and each eye fixates with the fovea. If the reflex in one eye is decentered with respect to the other, then the eye with the decentered reflex may have a strabismus. For example, if the reflex in the right eye is displaced nasally (towards the nose), that implies that the eye is exotropia (turned outwards). Conversely, if the image of the penlight in the right eye is displaced temporally (toward the ear) compared to the left eye, that implies that the right eye is esotropic (turned inwards).

A strabismus is a misalignment of the eyes resulting in a failure to achieve or maintain binocular vision when both eyes are viewing. Strabismus is defined in terms of frequency (constant or intermittent occurrence); laterality (occurring in one eye only, unilateral, or alternating between the two eyes); direction (esotropia or inward eyeturn, exotropia or outward eyeturn, hypertropia or upward eyeturn and hypotropia or downward eyeturn), and concomitancy (whether the eyeturn remains the same or varies in different directions of gaze). An accommodative esotropia is an inward eyeturn that increase in magnitude when the focusing effort for near viewing is exerted. Accommodative esotropia is usually accompanied by a hyperopic (farsighted) refractive error. Hyperopic refractive errors may be overcome by focusing effort to provide clear vision. In infants with accommodative esotropia, the amount of hyperopia is too large to allow clear vision and aligned eyes simultaneously. Corrective lenses to correct the hyperopia is usually sufficient to eliminate the eyeturn.

Monocular fixation

The evaluation of the light reflex from a penlight on the cornea in each eye tests for monocular fixation by noting whether infant's fixation on the penlight target is central or eccentric, steady or unsteady, and maintained or non-maintained. During this test, one eye is occluded (covered) and the fixation of the uncovered eye on a penlight is recorded. If the light reflex is centrally located on the infant's cornea, then fixation is assumed to be with the fovea and is recorded as C for central fixation. Next, the penlight is slowly moved and the infant's ability to follow the light is observed. If the eye maintains alignment with the penlight, then fixation and following is recorded as S for steady. Whether the eye can maintain fixation is observed when the occluder is removed from the other eye. If the previously fixating eye continues to fixate the penlight, then fixation is recorded as M for maintained. If all the above conditions are met, CSM fixation is recorded in the chart as an abbreviation for central, steady and maintained fixation.

When a unilateral strabismus is present, the deviating eye often does not maintain fixation as the preferred eye is uncovered. Infants with a strabismus or decreased vision in one eye often do not show central fixation. Eccentric fixation occurs when viewing with non-foveal part of the retina. Infants with macula lesions from colobomas, toxoplasmosis scars, or dragging of the macula region with retinopathy of prematurity may show eccentric fixation. Since visual acuity is maximal at the fovea, any eccentric fixation implies reduced vision. It is important to note that visual acuity loss is not always accompanied by eccentric fixation, therefore, central fixation does not imply normal visual acuity.

Unsteady fixation occurs with nystagmus. Nystagmus is a repetitive, usually rapid, and involuntary movement or rotation of the eye. The movement is either oscillatory or with slow and fast phases in alternate directions. Quantification of nystagmus is important in terms of amplitude (the extent of the eye excursion), frequency (the rate of the side to side movement), manifest or latent (whether the nystagmus is present when both eyes are open, i.e. manifest, or only elicited when one eye is covered, i.e., latent). The presence of a null point (position of eyes where nystagmus is dampened or minimal) should be noted. Often the infant adopts a head turn or eyeturn for which the nystagmus is minimal or absent. If the nystagmus diminishes as the infant converges their eyes for near fixation, this should be noted.

Sensory nystagmus in infancy occurs with bilateral disruption of central vision if the visual defect is congenital or acquired during the first two years of life (Cogan, 1956). In congenital nystagmus, the onset of nystagmus occurs usually between eight and 12 weeks of age (Jan et al., 1986). Acquired nystagmus appears about one month after vision loss and only develops when the visual loss occurs prior to two years of age if damage occurs to the ocular or anterior visual pathway structures. If central vision can be restored, the nystagmus may disappear. With longer delays in visual rehabilitation, the nystagmus becomes irreversible. The presence of roving eye movements indicates severely reduced vision, usually worse than 20/200. There have been reports that jerky nystagmus implies vision between 20/70 to 20/200. However, the absence of nystagmus does not imply good vision, particularly since nystagmus is absent in cortical visual impairment.

While the presence or absence of nystagmus alone cannot predict visual function, others have reported that nystagmus can be used to ascertain the age at onset of visual loss (Jan et al, 1986). Slow, large amplitude nystagmus accompanies vision loss in the first six months of life. Vision loss acquired under one year of age is generally followed by nystagmus within four weeks whereas vision loss after one year of age does not cause nystagmus. Roving nystagmus gradually disappeared between two and 12 months of age in most children who developed useful vision (Jan et al, 1986). The notable exception to the above is that in cortical visual impairment, no nystagmus develops despite the subnormal vision from birth.

Cover test

The unilateral cover test, also known as the cover-uncover test, involves an observation of the infant's fixation as the other eye is covered to test for presence of strabismus. After the attention of the infant is attracted with a small noisy toy, an occluder or cover paddle is introduced briefly over the right eye while the left eye is observed for any movement or refixation. The cover is removed and the process is repeated by covering the left eye and observing the fixation of the right eye. In each instance, the fixation of the uncovered eye should remain steady and no movement should be elicited. When an esotropia (inward eyeturn) is present, the deviating eye moves outward when the other eye is covered. When an exotropia (outward eyeturn) is present, the deviating eye moves inwards as the cover is introduced in front of the nondeviating eye. The cover-uncover test is repeated several times to determine whether strabismus exists, which eye has the strabismus, and whether it is constant or intermittent.

The alternate cover test is an observation of the infant's fixation when each eye is alternately covered. The alternate cover test assesses the eye posture when the eyes are not permitted to be used together. The occluder is placed over the right eye and is quickly moved to the left eye and back. The movement of the right eye is observed. The test is repeated with the cover over the left eye and quickly moved to the right eye and back. Any inward movement of the eye when it is uncovered indicates tendency for the eyes to assume an outward posture (exophoria) when they are not actively being used together. Any outward movement of the eyes with uncovering indicates an inward posture to the eyes (esophoria).

The magnitude of an eyeturn can be quantified with a prism, a wedge of glass that moves the visual image on the retina. The magnitude of the eyeturn is expressed in prism diopters. Eyeturns exceeding 20 prism diopters will be cosmetically noticeable to laypersons. Medical records may include the following abbreviations: RET for a constant right esotropia, LXT for a constant left exotropia, RH(T) for an intermittent, right hypertropia, XP for exophoria, and EP for esophoria.

The infant or child may assume a head posture to minimize or even mask the presence of a strabismus. Observation of the head posture of an infant or child may provide insight as to which eye muscle is affected. Head turns to the right or left implies a problem with the horizontal eye muscles, a chin up or down posture implies problems with the vertical eye muscles, and a head tilt to the left or right shoulder implies a problem with the oblique eye muscles.

Base out prism test

This test is an observation of the infant's eye movements when a base out prism is introduced in front of each eye alternately. The base out prism moves the image of the object viewed through that eye causing temporary diplopia (double vision). If the innate ability to see singly is intact, the eye behind the prism reflexively moves to place the image again on the fovea and achieve clear, single vision. If an eyeturn is present, the eye behind the prism makes no attempt to refixate. Small amounts of an eyeturn (microtropia) can be detected with this test.

Pupillary responses

The observation of the pupil response to illumination tests for integrity of the visual pathway. Pupillary testing has four components: the response to direct illumination (shining a light into the eye and observing the pupillary constriction), consensual illumination (shining a light into one eye and observing the pupil response in the other eye), the swinging flashlight test (shining a light into one eye for a few seconds then rapidly moving the light to the other eye) and the near reflex (observation of constriction of the pupil as fixation and focus is shifted from distance to near).

Pupillary responses to direct illumination are present at birth in full-term infants and premature infants at 30 weeks gestation age. Consensual pupillary responses are present at birth (Isenberg, 1994). A totally blind eye from ocular or optic nerve disease usually has no pupil reaction to light. If only one eye is blind, the affected eye has no pupil response to a direct illumination but when the light is shifted to the unaffected eye, both pupils constrict. When one or both eyes have visual impairment associated with optic nerve disease, the swinging flashlight test indicates one eye as being more affected than the other. The pupillary light reaction is sluggish in infants with congenital retinal disorders. The pupillary light reaction is usually normal in infants with cortical visual impairment.

Determination of refractive error

Determination of the focusing error of the eye is achieved objectively with an instrument called a retinoscope in the procedure called retinoscopy. During retinoscopy, the examiner evaluates the movement of a light reflex generated in the child's eye. If the eye is hyperopic (far-sighted), the observed reflex in the eye moves "with" the movement of the examiner's light. If the eye is myopic (near-sighted) the light reflex is observed to move "against" the movement of the examiner's light. Spectacle lenses of different powers are held in front of the eye to "neutralize" the light movement. The lens power at neutrality, minus the working distance of the examiner, yields the prescription for glasses. The presence of astigmatism is detected by comparison of the light reflex in the eye in two orthogonal directions (i.e. vertically and horizontally). No subjective response from the infant is necessary to determine refractive error and to prescribe corrective lenses.

Estimates of refractive error are determined before testing of visual function so that an approximate correction can be used. The final prescription for glasses, however, is determined with the use of eyes drops that temporarily relax accommodation (the focusing ability) of the infant. The medication is used after all functional vision tests have been completed and preceding the ocular health evaluation.

In a study of 1000 fullterm newborn infants, hyperopia was present in 43.9%, myopia in 16.7%, and astigmatism in 35% (Cook & Glassock, 1951). In premature infants, the average refractive error is myopic (Dobson et al, 1981). Premature infants with retinopathy of prematurity (ROP) have a higher incidence of myopia (25%) compared to 13% in infants without ROP. The incidence of high myopia (greater than 5.00 diopters) is 6.5% infants with ROP but only 1% in infants without ROP. Increasing severity of ROP and low birth weight were strong predictors of myopia (Quinn et al, 1990). The prevalence of significant refractive error in infants and children with severe and multiple disabilities ranges from 21 to 76% (Edwards et al., 1972; Harcourt, 1974; Jan, Freeman & Scott, 1977; Landau & Berson, 1971; Orel-Bixler, Haegerstrom-Portnoy & Hall, 1989; Wesson & Maino, 1995).

Visual fields

Although rigorous standard visual field testing is not possible in infants and young children, useful information can be obtained from measurement of confrontation visual fields. In dim room illumination, the examiner faces the infant or child and attracts attention with a penlight toy. The central penlight is extinguished and another examiner, hiding behind the infant, introduces another penlight toy silently from the far periphery in the lateral (left and right), superior (upper), and inferior (lower) visual fields of the infant. The infant's refixation to the peripheral penlight toy provides an estimate of the extent of the visual field. An infant with full visual fields will make a rapid head movement or eye movement towards the peripheral target. Significant visual field loss or hemianopias can be detected with this confrontation technique. Qualitative differences in the infant or child's response to the peripheral penlight from one field to the other should be verified with repeat testing. After one year of age, normally sighted infants have a full visual field. The developmental process of visual field is currently being studied. Attention and cooperation difficulties restrict the testing of an infant's visual field.

Children with cerebral palsy or poor head and eye motor control may need additional time to respond so the peripheral target should be moved in slowly. Sometimes other responses, such as smiling by the child when the peripheral target is seen, can suffice to indicate seeing of the target rather than relying on a head or eye movement. Although the measurement of visual fields by this technique are crude, the field losses are likely to be functionally significant. Infants with hemianopias may be startled when objects or persons suddenly appear in their visual field without warning. Placement of educational materials to maximize visual attending may be determined from the assessment of visual fields.

Assessment of ocular health

Gross inspection of the infant's eyes and surrounding structures can be obtained using penlights but the magnification provided by more sophisticated instruments is preferred.

Hand-held slitlamp

A biomicroscope (slit-lamp) is used to evaluate the anterior(front) structures of the eye including an evaluation of the clarity of the ocular media (cornea and lens). It is particularly important in evaluating infants with nystagmus and possible albinism. In ocular albinism, transillumination defects of the iris can be seen with retroillumination (light reflected back from the fundus shines through areas of pigment loss in the iris as a red glow). The slitlamp affords a magnified view for the evaluation of corneal opacities and cataracts.

Direct and indirect ophthalmoscopes

Different instruments are used to evaluate the posterior (back) structures of the eyes; the optic discs, retina, macula or fovea and retinal vasculature. Evaluation of the posterior ocular structures generally requires pupillary dilation. These instruments provide different magnified views. The binocular indirect ophthalmoscope (BIO) provides for stereoscopic (3-D) high resolution views into the child's eye. Advantages of the BIO include the stereopsis, large field of view, minimal peripheral distortion, and the ability to evaluate the extreme peripheral retina which is important in evaluating retinopathy of prematurity (Fingeret,Casser & Woodcome, 1990) Views with the BIO are relatively independent of a child's refractive error or moderate media opacification. The examiner is able to maintain a comfortable evaluation distance (arm's length) from the infant and is able to hold a fixation target for the eye not presently being evaluated. The infant may nurse or feed on bottle during the evaluation which increases cooperation. The disadvantages of BIO include the lower magnification than direct ophthalmoscopy with loss of fine detail and moderate glare or discomfort for the child due to the brightness of the light source. The examiner needs to steady the hand holding the condensing lens on the child which may be difficult in children who are sensitive to touch.

The direct ophthalmoscope produces a magnified, well-detailed image of the retina. It can be used through non-dilated pupils and is less bright thereby increasing the infant's comfort. Media opacities degrade the view and allow an estimate of the extent of the child's visual compromise (Fingeret et al., 1990). The primary disadvantage is the very close working distance of examiner to infant (cheek to cheek), lack of stereopsis, dependence on refractive error for clarity and magnification, and the small field of view. Dilation of the pupils is necessary for the best view.

An assessment of ocular health is easiest to obtain when the infant is comfortable nursing or being bottle fed. Singing by the examiner may have a calming effect. An examination with sedation or anesthesia may be necessary if an adequate evaluation cannot be obtained but is indicated by the patient history and other examination findings.

Hand-held tonometer

This device is used to measure the intraocular pressures (IOP) of each eye which is important in the diagnosis of glaucoma. Measuring intraocular pressure is not a routine part of the eye examination of the infant or toddler since IOP measures are difficult and often unreliable (American Academy of Ophthalmology, 1992). Intraocular pressure should be assessed in rare instances when glaucoma is suspected due to other ocular signs (corneal edema, increased corneal diameter, myopia) or other risk factors for glaucoma are present. Most often in the infant and toddler population, measurement of IOP requires testing under sedation or anesthesia.

Assessment of visual capabilities for birth to two-year olds

Visual acuity tests

Visual acuity is a threshold measure of the eye's ability to detect fine detail or fine resolution. Visual acuity is expressed in 20/20 notation which is defined as the test distance divided by the letter size for which the detail in the visual target subtends one minute of arc at the eye.

Indirect tests of visual acuity

In routine clinical applications, indirect tests to make assumptions about visual acuity are primarily used in the birth to two-year age group. For example, when a constant strabismus is present in one eye, visual acuity is presumed to be reduced in the strabismic eye. When the eyeturn alternates between eyes, visual acuity is likely to be equal in both eyes. However, actual measures of acuity and fixation preference do not show a strong association. For the child with severe or multiple disabilities, inferences about visual function based on the presence of strabismus are not accurate.

For an infant with suspected low vision, the presence of involuntary eye movements; optokinetic nystagmus (OKN) and the vestibular ocular reflex (VOR), may be used to infer visual function. Optokinetic nystagmus (OKN) is an involuntary eye movement elicited by motion in the environment. In clinical testing, black and white stripes on a rotating cylinder elicit slow following eye movements at the same rate as the movement of the stripes followed by a fast saccadic eye movement in the opposite direction. An OKN response indicates that some pattern vision is present but a lack of response has uncertain significance. In VOR testing, the infant's fixation is evaluated after inducing the vestibular ocular nystagmus (a horizontal nystagmus induced by spinning). The infant is held at arm's length in front of the examiner and after several rotations the spinning is discontinued and the examiner assesses the infant's eye movements. There are normally only one or two beats of nystagmus after the spinning has stopped. There is prolonged nystagmus in infants with severe vision impairment or severe cerebellar disease.

The above indirect tests of visual function are only qualitative assessments of visual function. Quantitative measurement of visual acuity has been made possible with two techniques; preferential looking and the visual evoked potential (see Teller & Movshon, 1987 for a review).

Preferential looking

In the preferential looking (PL) technique, grating targets (black and white stripes) are presented with a gray square of equal luminance on a gray background. The infant's fixation is observed through a peephole on the stimulus card. The smallest stripe width which the infant reliably fixates is judged to be the estimate of visual acuity.

Early laboratory studies with preferential looking used rigorous psychophysical testing protocols and two-alternative forced-choice paradigms to assure that the infant's performance was better than predicted by chance alone. Laboratory studies reported that a single acuity estimate required an average of approximately 15 minutes of test time and 60 trials which made it impractical for the clinical setting. Recently, a more rapid procedure, the acuity card procedure, has been developed specifically for applications within the clinical setting.

In the acuity card procedure (McDonald, Ankrum, Preston, Sebris & Dobson, 1986; McDonald, Sebris, Mohn, Teller & Dobson, 1986), the tester's task on each trial is to judge, based on the quality and consistency of the infant's looking behavior, whether the infant can resolve that grating. When the stripes are wide and easily seen, the infant's looking behavior is clearly in the direction of the grating, then only two presentations of the grating are needed. As the infant's acuity limit is approached, the looking behavior becomes less consistent and the tester may need to show the grating cards several times to determine whether the infant is consistently looking at the grating. The tester uses the overall looking behavior of the infant on a small number of presentations to judge whether the grating was visible to the infant. Grating patterns are expressed in terms of spatial frequency or the number of cycles (light and dark bar pairs) of the grating per degree of visual angle. The acuity estimate is given in cycles/degree. Conversion of grating acuity (c/deg) to Snellen notation is achieved by using the conversion that a grating with 30 cycles/degree is equivalent to one minute of arc of visual angle or 20/20. It is important to note that this mathematical translation of grating acuity into Snellen notation is not appropriate in some eye disorders with accompanying low vision. The ideal way to report an infant's visual acuity with PL techniques is to reference it to age-matched norms.

The development of grating acuity during the first few years of life has been investigated by several groups using forced-choice preferential looking (FPL) techniques (Dobson & Teller, 1978), FPL acuity cards (McDonald et al., 1986a; McDonald et al., 1986b) and the acuity card procedure (Mayer et al. 1995). There is general agreement across studies that PL grating acuity develops from approximately one cycle/degree at one month of age and improves to six cycles/degree by six months of age with little measurable improvement from six to 12 months. Preferential looking grating acuity does not reach adult levels until approximately three years of age (Mayer et al, 1996). In premature infants, acuity development is predictable from post-term (corrected) age rather than from postnatal age (Getz, Dobson, & Luna, 1992). For example, if an infant is born four weeks prematurely and is tested at 20 weeks postnatally, their acuity data should be compared to the normative data of a 16 week old rather than the 20 week old at least during the first year of life.

The advantages of the acuity card procedure is the portability of the testing cards and flexibility in testing, the examiner can interact with the infant in between presentations to maintain interest. In children with eyeturns or nystagmus for which horizontal eye position is difficult to judge, the test cards can be rotated so that vertical head and eye movements are generated. The disadvantages of PL techniques include bias of the tester, the lack of durability of cards such that smudges can be more interesting than the gratings, and edge or brightness artifacts of the fine grating targets that could lead to an overestimation of acuity. A major disadvantage of PL techniques is that one cannot conclude that a grating that is not preferentially fixated is not resolvable to an infant. Therefore, a PL derived acuity probably represents a conservative measure of visual threshold measures. There have been some reports that PL grating acuities underestimate the vision loss compared to optotypes. Currently, there is no "conversion factor" for PL grating acuity to optotype. The PL measure is compared to age-matched norms. If the measure for a three month old falls outside the normal range, that infant would be diagnosed as visually impaired but a numerical value for acuity would not be given.

Successful application of PL acuity techniques have been reported for several clinical populations including infants and children with congenital cataracts and aphakia (Mauer, Lewis & Brent, 1989), retinopathy of prematurity (Dobson et al, 1990), Leber's congenital amaurosis (Mayer, Fulton & Hansen, 1985), and infants with neurologic impairment and multiple disabilities (Bane & Birch, 1992; Mohn & van Hof-van Duin, 1986).

Visual Evoked Potential (VEP)

The visual evoked potential (VEP) is an electrical signal generated in the occipital region of the cortex in response to visual stimulation (Sokol, 1976). To measure visual acuity, the VEP is recorded while the infant watches grating patterns presented on a television monitor. The VEP is recorded through five recording sensors which are attached to the infant's scalp with a water-soluble paste. The VEP signals are amplified and computer analyzed. In the sweep VEP technique, twenty different stripe sizes are displayed on a video monitor during each 10 second recording trial. The amplitude (magnitude) of the VEP decreases progressively as the stripe width decreases. Visual acuity is determined from an extrapolation of the amplitude of the VEP versus the size of the stripe (Norcia & Tyler, 1985).

In pediatric applications, VEP testing is usually performed in a darkened room to provide minimum distraction. Attention to the video monitor is achieved by dangling small fixation toys on the video screen and speaking or singing to the infant or child being tested. A pause/resume remote control is used by the examiner to start and stop the VEP recording during fixation lapses. Electrical artifacts caused by excessive movements of the subject can be eliminated with appropriate data analysis techniques. With the skill of the examiner and rapid recording paradigms, such as the sweep VEP technique, sedation or general anesthesia is unnecessary.

As determined with the visual evoked potential, visual acuity develops rapidly during the first year of life and adult levels of grating acuity are reached as early as six months to eight months of age (Norcia & Tyler, 1985; Orel-Bixler & Norcia, 1987). The rate for acuity development is much more rapid with the VEP compared to behavioral measures with preferential looking (PL) techniques (Table 5). The sweep VEP technique had relatively small test-retest variability and a narrower standard deviation range in comparison to PL techniques (Hamer, Tyler & Hsu-Winges, 1989). The 99% confidence limits and interocular differences (differences in acuity between eyes) for the sweep VEP were two to four times smaller than PL measures.

Table 5

Mean expected monocular grating acuity values

AGE (MOS)	VEP C/DEG	PL C/DEG	20/20 NOTATION VEP	20/20 NOTATION PL
1	5	0.94	20/120	20/638
2.5	7.8	2.16	20/77	20/278
4	12	2.68	20/50	20/224
6	18	5.65	20/33	20/106
9	23	6.79	20/26	20/88
12	25	6.42	20/24	20/93
18		8.59		20/70
24		9.57		20/62

VEP grating acuity data from *Norcia & Tyler, 1985* and monocular grating acuity with the acuity card procedure from *Mayer et al, 1996.*

Likewise, monocular VEP grating acuities were higher than PL acuity by a factor ranging from two to ten. Therefore, the sweep VEP technique may have higher sensitivity to detect visual acuity deficits in infants as compared to PL techniques.

VEP in clinical populations

The VEP has been shown to be a sensitive indicator of early acuity losses in studies of infants with strabismus (Day, Orel-Bixler & Norcia, 1988). The VEP has been used to monitor changes in the vision of the amblyopic and fellow eye during patching therapy (Odom, Hoyt & Marg, 1981) and to record the post-operative acuity in infants with congenital cataract after early surgical intervention (Beller et al, 1981). Several studies reported that the VEP measure of visual function can be useful in the clinical management of nonverbal patients including; children with multiple disabilities (Mackie, McCulloch &

Saunders, 1995; Orel-Bixler et al, 1989;), a diverse group of pediatric ophthalmology patients (Gottlob et al, 1990), and children with visual impairment (Bane & Birch, 1992).

Validation studies using the sweep VEP reported good correlations between VEP grating acuity and optotype (Snellen) acuity in normal adults and children (Orel-Bixler, 1989) and in children with various visual disorders including strabismus and amblyopia (Gottlob et al, 1990; Orel-Bixler, 1989). Sweep VEP grating and optotype acuities were well correlated in amblyopia, in spite of substantial absolute differences between the two measures in patients with significant amblyopia (Orel-Bixler, 1989). There was good agreement between VEP and optotype acuity in observers with optotype acuity better than 20/60, however, an increasing discrepancy accompanied poorer acuity. A discrepancy by a factor of 2.5 was found with grating measures giving better acuity than optotypes. Thus a measured grating acuity of 6 cycles/degree, which is mathematically equivalent to 20/100 grating acuity, is expected to yield an optotype acuity of approximately 20/250. Several other studies have indicated that visual acuities measured with grating targets are higher than those measured with optotypes in amblyopic observers (Selenow et al., 1986) and pediatric patients with significant ocular structural anomalies (Mayer, Fulton & Rodier, 1984). A better prediction of optotype acuity from the VEP grating acuity can be made by taking this systematic overestimation into account.

VEP studies with Cortical Visual Impairment

Cortical visual impairment (CVI) is a loss of vision secondary to damage to the geniculostriate pathways and is characterized by reduced vision, absence of optokinetic nystagmus (OKN) with normal ocular examination findings and intact pupillary light responses (Barnett, Manson & Wilner, 1970). Cortical visual impairment results from hypoxic insults, meningitis, encephalitis, metabolic disturbances, head trauma, or hydrocephalus. The recovery of vision is often protracted and only partial although, in some cases, recovery may be complete and rapid. For this reason cortical visual impairment rather than cortical blindness is the more appropriate terminology (Whiting et al 1985). The most common cause of CVI is generalized cerebral hypoxia at the striate, parietal and premotor regions as well as vascular lesions of the striate cortex.

Several studies have evaluated VEP responses to flashes of light rather than gratings in cortical visual impairment. The findings are variable probably due to the inherent difficulty in interpreting flash VEPs and the larger variations in waveform and amplitude than pattern VEPs. The studies were often limited to single case reports or small population studies of patients with cortical blindness and have reported both normal and abnormal flash VEP responses or VEP responses that improved with time (Aduchi-Usami, 1991). Recently, the VEP has been used to determine visual prognosis following perinatal asphyxia (McCulloch, Taylor & Whyte, 1991). In this study, flash VEPs were recorded from 25 asphyxiated infants. Sixteen infants had normal or only transient abnormalities of the VEP and with follow-up all these infants developed normal vision. The remaining nine infants who had abnormal flash VEPs never developed normal vision. The VEP findings in cortical visual impairment remain controversial since subjective measures of visual function cannot be determined for comparison to the VEP measures and the lesions that cause CVI are not often localized exclusively to the striate cortex (Aduchi-Usami, 1991).

There are several clinical applications of visual evoked potentials in the pediatric population. The VEP is non-invasive, requires some expertise, but can be applied to a population that cannot communicate or cooperate for standard assessment of visual function. As summarized in a review by Taylor and McCulloch (1992) the major applications of VEPs in pediatric patients has been to quantify visual impairment with measures of visual acuity or contrast sensitivity or by quantifying flash or pattern VEP abnormalities. Early detection of visual impairment allows referral to early intervention programs. The flash VEP may help establish the prognosis for visual recovery for specific pediatric disorders including perinatal asphyxia in full-term

Table 6

Comparison of vision tests for infants

METHOD	PROCEDURE	ADVANTAGES	DISADVANTAGES
Qualitative tests			
Fixation & following	Assess fixation CSM	Practical	Lacks precision
VOR test Optokinetic nystagmus Fixation preference	Assess involuntary eye movements		No acuity estimate
Quantitative tests			
Preferential Looking techniques (PL)	Observe fixation preference with acuity card procedure	Portability	Limited durability
		Ease of use	Tester bias
		Accessibility	Requires cooperation
			Grating acuity measure
Visual Evoked Potential (VEP)	Record the electrical response generated in the visual cortex of the brain following visual stimulation	Objective test	Requires technician
		Expect higher acuity than PL, smaller interocular differences and smaller standard deviation	Cost Testing duration
		Repeated measurement	Grating acuity measure

neonates and acute-onset cortical blindness and in some cases, contribute to the differential diagnosis. The VEP can help monitor patients who are at risk for visual complications either from diseases (i.e. hydrocephalus) or as a complication of therapeutic intervention (i.e. neurosurgery) to help detect and avoid long-term sequelae of such therapies on the developing nervous system. VEPs have become an indispensable tool in pediatric ophthalmology and neurology and will probably play an increasingly important role in the future, primarily due to the difficulty in assessing visual system function in young or medically fragile children and the VEPs sensitivity to subclinical damage in this aspect of the central nervous system (Taylor & McCulloch, 1992).

Other vision functions assessed with PL and VEP techniques

Contrast sensitivity

Contrast sensitivity is the ability to detect brightness differences or subtle shades of gray. This ability is used to detect real-world spatial targets under a variety of luminance conditions. Some visual anomalies are revealed only under low or moderate contrast conditions. A wide range of vision disorders affect contrast sensitivity but spare visual acuity. Contrast sensitivity tests have been applied clinically in diagnosing such vision disorders as glaucoma, amblyopia, and optic neuropathies (Regan, 1988). Contrast sensitivity can predict performance in everyday tasks such as reading (Rubin & Legge, 1989) and mobility (Marron & Bailey, 1982).

The development of contrast sensitivity has been studied with the VEP. The contrast sensitivity for coarse targets for a 10 week-old was only a factor of two lower than for adults (Norcia et al, 1990). Preferential looking measures of contrast sensitivity with grating targets (Adams & Courage, 1996) and Happy face targets (Fisher, Orel-Bixler & Bailey, 1995), show a slower rate of development than VEP studies; adultlike values are not reached until one to two years of age in most children.

Color vision

Visual evoked potential studies indicate that infants as young as two weeks of age have the functional pathway needed to relay color discrimination information from the eyes to the brain (Allen, Banks & Norcia, 1993). These findings do not imply that neonates have mature color vision since behavioral measures of color discrimination show later development (Adams, Mauer & Davis, 1986). Unfortunately routine clinical assessment of color vision in infants under two years of age is not currently possible (Pease & Allen, 1988) but the development of behavioral tests for color vision are in progress which use face targets in a preferential looking paradigm to access color vision in infants (Ventocilla, Orel-Bixler & Haegerstrom-Portnoy, 1995).

The risk for inherited color vision problems can be explored through an assessment of family history. Congenital red-green color vision deficiencies are inherited in an X-linked manner and occur in eight to 10 percent of the male population in the U.S. and less than 0.05 percent of the female population (Krill, 1977). Information about the family history of color vision problems can infer the probability for an inherited color vision defect. Since the color vision defect is carried on the X-chromosome, the mother is a carrier if her father has the defect and there is a 50 percent chance that each son will have the color defect. Fathers with color vision defects cannot pass the defect onto their sons, but all daughters are carriers. For a female to have an inherited red/green defect, both her father and her maternal grandfather must have a color vision defect. Blue-yellow color vision defects occur in up to 0.007 percent of the population and most frequently accompany eye disease (Krill, 1977). A recent report suggested that premature infants with significant retinopathy of prematurity have blue-yellow color vision defects (Dobson, 1995). Acquired color vision defects (red/green or blue/yellow defects) can occur with optic nerve disorder, retinal disorders and with central nervous system pathology.

It is important to measure color vision since many educational materials for reading and math are color coded. Changes in color vision can precede a loss in visual acuity or visual fields and may serve as an early warning signal to the presence of disease.

Other diagnostic tests

Electroretinogram (ERG) The ERG is a measure of the bioelectrical response generated in the retina of the eye in response to stimulation by light (Fishman & Sokol, 1990). The ERG is recorded with a contact lens electrode under both light (photopic) and dark adapted (scotopic) viewing conditions using single and multiple (flicker) flash presentations. The amplitude (size of the response) and latency (time for the response to occur) of the ERG components are compared to normative data. In general, the interpretation of electrophysiological responses depends upon comparisons to age-matched norms. It may be difficult to interpret the results when an infant has clinically abnormal vision yet a recordable ERG. Often serial testing will be necessary for a conclusive diagnosis (Fulton, Hartmann & Hansen, 1989).

The ERG is valuable in the differential diagnosis of vision disorders in infants and children whose common presenting feature is reduced vision and nystagmus. Infants with Leber's congenital amaurosis, achromatopsia, albinism and congenital stationary night blindness will each have nystagmus but the ERG can differentially diagnose the disorder. The photopic and scotopic ERG is extinguished in Leber's congenital amaurosis. The flicker and single flash photopic ERG is absent in achromatopsia and these infants have no color vision. In all forms of albinism, including oculocutaneous albinism, the scotopic ERG is supernormal. In congenital stationary night blindness, the b-wave is absent in the scotopic ERG. Abnormal ERG findings may precede any ocular health changes in retinitis pigmentosa and cone-rod dystrophies.

The ERG is not necessary in other disorders which cause nystagmus and vision impairment in infants when abnormal findings are present on the ocular health examination. For example, nystagmus and visual impairment in infancy may be associated with ocular abnormalities or media opacities. These include bilateral congenital cataracts or corneal opacities, macular scarring, vitreous hemorrhage, and retinopathy of prematurity. Similarly, optic nerve hypoplasia and optic nerve atrophy are accompanied by vision impairment and nystagmus but with careful examination, the anomalies of the optic disc are detectable. Fundus signs and nystagmus are absent in infants with vision impairment due to cortical visual impairment and delayed visual maturation. In suspected cortical visual impairment, delayed visual maturation, and optic nerve anomalies little information is gained from an ERG, but rather a referral for visual evoked potential (VEP) testing and neuroimaging would be recommended.

Neuroimaging The introduction of x-ray computed tomography (CT) in 1972 began a new era in imaging technology and provided a safer and more sensitive way to image soft tissue and bone far superior to the previous techniques of plain x-rays of the orbits and skull (McCrary, 1991). CT can provide images of fine anatomical details of the orbit, oculomotor nerves and muscles, and the central nervous system. Magnetic Resonance Imaging (MR imaging) uses nuclear magnetic resonance (NMR) to produce tomographic images (Kamholtz, Abrahams, 1992). Available since the early 1980s, MR imaging is now accepted as the most sensitive and among the most specific, diagnostic imaging tools available for most neuro-ophthalmic applications (McCrary, 1991).

Neuroimaging studies are indicated in the work-up of a child who may be blind when the diagnosis is still uncertain after a careful history, clinical examination and electrophysiologic testing have been performed (Fulton, Hansen & Lambert, 1994). Computed tomography is the preferred imaging technique for diagnosis of complex ocular trauma and suspected non-accidental injury due to its excellent imaging of the orbit and bony anatomy (Zimmerman & Bilanuik, 1994). Calcium deposits within intracranial and intraorbital masses, particularly retinoblastoma, are readily detected with CT (McCrary, 1991). As recommended by Brodsky, Baker and Hamed (1996), neuroimaging studies are indicated in: 1) infants with congenital nystagmus and optic nerve hypoplasia to look for central nervous system anomalies; 2) infants or children with congenital nystagmus and optic atrophy to rule out hydrocephalus or a congenital suprasellar tumor; and 3) infants or children with an uncertain diagnosis of congenital nystagmus and the possibility of spasmus nutans exists to rule out chiasmal gliomas or other suprasellar tumors.

SAMPLE REPORT #1

Special Visual Assessment Clinic for the Handicapped

SCHOOL OF OPTOMETRY BERKELEY, CALIFORNIA 94720

PATIENT Kevin

AGE 2 years, 9 months

HISTORY

Kevin has been diagnosed with cerebral palsy and cortical visual impairment associated with birth asphyxia and cerebral hemorrhages. His mother had pre-eclampsia and seizures resulting in a coma during her pregnancy. Kevin's maternal grandmother reported that he was injured in an automobile accident in when he was 8 months old and had surgery for a hematoma 5 months after the accident. Kevin reportedly has had stomach problems since birth and takes Peptobismol as needed. He receives physical and speech therapy.

REASON FOR EXAMINATION To provide information about visual functioning.

REFRACTIVE STATUS

CURRENT SPECTACLES None

RETINOSCOPY WITH CYCLOPLEGIA Right Eye: +4.25 -3.00 x 180. Left Eye: +4.75 -3.25 x 180

BINOCULAR STATUS A very large, alternating exotropia was noted (Kevin's eyes turn outwards alternately). Kevin's eyes were often in up gaze. He did not reliably fixate on objects. No restrictions of eye movements were noted on versions (he can move his eyes in all directions).

OCULAR HEALTH Normal direct, consensual and accommodative pupil responses were present in each eye. Clear ocular media, maculae, and fundii were noted in each eye. The optic nerves appeared normal in size and color. The retinal periphery was unremarkable. Kevin's ocular health appeared normal which is consistent with his diagnosis of cortical visual impairment.

VISUAL ACUITY Kevin was able to detect a penlight but did not appear to detect a black and white striped doll moved silently and directly in front of his face. No formal behavioral tests of vision could be done due to Kevin's lack of fixation and lack of a visual response.

SWEEP VISUAL EVOKED POTENTIAL

Both eyes viewing at 50 cm with current Rx: 1.25 cy/deg or predicted optotype acuity 20/1515

In persons with low vision, the VEP grating acuity measure is higher than the acuity for letters or symbols. A conversion factor is used to "predict" the letter acuity from the grating acuity measure and this predicted optotype acuity measure should be used in guidelines for educational materials. The VEP acuity findings are quite discrepant from the behavioral estimates of Kevin's vision. Although the VEP indicates that information is

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Neuroimaging is not usually indicated in children with retinal disorders unless there are other neurologic abnormalities or developmental delays (Fulton et al, 1994). For example, the ERG is severely reduced in the retinal disorder Leber's congenital amaurosis which may later be accompanied by optic atrophy. Other causes of optic atrophy show a normal ERG. Generally, neuroimaging studies are warranted in all infants with optic atrophy or optic nerve hypoplasia (Brodsky et al, 1996). Optic nerve atrophy is a clinical sign but not a diagnosis. Children at any age exhibiting nystagmus and optic atrophy should have a CT or MRI scan to rule out associated conditions.

Neuroimaging is valuable in revealing the structural abnormalities of the central nervous system and is also critical to the diagnosis of cortical visual impairment in infants and children. However, the findings with neuroimaging cannot predict visual function or visual potential. In a study of 30 infants with CVI, all but two infants had abnormalities in the neuroimaging studies. None of the abnormalities demonstrated with neuroimaging correlated with the degree of visual recovery in these infants except for abnormalities of the optic radiations (Lambert, Hoyt, Jan, Barkovich & Flodmark, 1987). Areas that appear non-functioning with MRI and CT may have some residual function. There is a case report of a 20 month old with absence of the occipital and parietal lobes confirmed by neuroimaging who could none the less use vision to reach for small objects (Summers & MacDonald, 1990). Neuro-imaging has many applications for the diagnosis of visual system syndromes but also gives useful information for prognostic and genetic counseling.

Consultation

The final aspect of the vision examination is a discussion of the examination findings with the parents or guardians in laypersons' terms. The discussion should include a treatment or intervention plan, follow-up schedule, prognosis, discussion of rehabilitation services and consultation with other medical professionals if necessary.

When the diagnosis includes visual impairment, the parents want to know what the infant can see. Many people equate vision impairment with no light perception, so the clinician needs explain how much the child can use the vision he has. Often a demonstration of the vision impairment can be simulated with blurring lenses (to simulate nearsightedness and astigmatism) or by showing the letter size required at the visual acuity threshold. Visual field losses can be demonstrated by having the parent look through field restricting cardboard tubes. A brief summary report given at the time of the examination should be followed by a more detailed report (see samples). Parents will want to know if anything can be done regarding treatment or intervention. They may inquire as to what the future holds and about educational options for their child. Finally, they will want to know what to do next. The clinician should provide informa-

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being relayed to the visual cortex, it cannot tell us exactly what Kevin perceives. Based on measures from other children with cortical visual impairment who have been able to complete both VEP and behavioral acuity tasks, the predicted acuity measure from the VEP should represent an upper boundary on Kevin's visual function and his behavioral responses the lower boundary.

BEHAVIORAL IMPRESSIONS Kevin is non-verbal and non-mobile and was carried into the examination by his grandmother. She reported that he sees lights, can track her fingers when she moves them and responds to her speech. Kevin had stomach distress during the examination and when it was most severe, his eyes rolled upwards and he did not respond. He was able to lift his head and push up on his arms when he laid on the floor.

SUMMARY AND RECOMMENDATIONS Kevin has a moderate hyperopic refractive error (far-sighted) with significant astigmatism. He has an alternating outward eyeturn and poor fixation. Kevin has significant visual impairment due to cortical visual impairment and his ocular health appears normal. We cannot be certain that glasses to correct his refractive error will have any benefit visually due to his severe visual impairment. However, since this refractive error would decrease the vision abilities of a normally sighted child, we have recommended glasses for fulltime wear.

Kevin did not respond visually to the acuity targets in order to obtain a behavioral measure of his visual acuity or an assessment of his visual fields. Objective measures with the VEP indicated pattern vision (20/1515) but it is severely reduced from normal (by a factor of 75). Educational materials, pictures and toys should be large, with high contrast, primary colors (rather than pastels) and should be outlined with thick marking pens. To make it easier for Kevin to locate toys and objects, the contrast should be enhanced between the object and its background. For example, place dark colored toys on a light colored mat or vice versa. These objects should be paired with auditory or tactile cues since hearing is his strength. The objects should be at least 4 inches if viewed at 1 ft, and 8 inches in height if viewed at 2 feet. Kevin's education should emphasize auditory, tactile and olfactory learning.

Kevin is legally blind and qualifies for educational services for children with visual impairment. He should be evaluated for educational services for his visual impairment and multiple disabilities. We would like to re-evaluate Kevin's vision after he has worn his glasses for about 6 months.

General recommendations for educational materials for children with cortical visual impairment are summarized below:

1) Use high contrast and primary colors
   Present visual objects and toys which are high in contrast and cue with color whenever possible. For example, when Kevin is eating, place light colored cereal and milk in a dark colored bowl. Place dark colored food, such as raisins on a light placemat to increase the contrast. Concrete steps or light colored stairs can be painted with a dark wide line of non-slippery paint on the edges.

2) Use all senses; add verbal and tactile clues to visual presentations

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tion about available resources such as: early intervention programs, educational services from a teacher certified in the area of visual impairment, and services from orientation and mobility specialists.

Early identification of visual impairment is important. The earlier the identification of causative factors for vision impairment, the better the prognosis for any therapeutic interventions. The visual system of the infant is still developing, and reversal of amblyogenic factors may prevent the occurrence of visual deficit before it becomes embedded. Parents can provide toys and visual stimulation to match the infant's visual abilities and participate actively in enabling their infant's optimal visual development.

References

Abrahamsson, M., Fabian, G., & Sjostrand, J. (1988). Changes in astigmatism between the ages of 1 and 4 years: A longitudinal study. *British Journal of Ophthalmology*, 72, 145-150.

Adams, R.J., & Courage, M.L. (1996). Monocular contrast sensitivity in 3- to 36-month-old human infants. *Optometry & Vision Science*, 73, 546-551.

Adams, R.J., Mauer, D., & Davis, M. (1986). Newborns' discrimination of chromatic from achromatic stimuli. *Journal of Experimental Child Psychology*, 41, 267-281.

Aduchi-Usami, E. (1991). Visually evoked cortical potentials in cortical blindness. In J.R. Heckenlively & G.B. Arden GB (Eds.), *Principles and practice of clinical electrophysiology of vision* (pp.578-580). St. Louis: Mosby Year Book Inc.

Allen, D., Banks, M.S., & Norcia, A.M. (1993). Does chromatic sensitivity develop more slowly than luminance sensitivity? *Vision Research*, 33, 2553-2562.

American Academy of Ophthalmology (1992). *Preferred practice pattern: Comprehensive pediatric eye evaluation*. San Francisco: AAO.

Aslin, R.N. (1987). Motor aspects of visual development in infancy. In P. Salapatek & L. Cohen (Eds.), *Handbook of infant perception* (Vol 1, pp.43-113). New York: Academic Press.

Baldwin, W.R. (1990). Refractive status of infants and children. In A. Rosenbloom, M. Morgan (Eds). *Principles and practice of pediatric optometry*. (pp. 104-152). Philadelphia: JB Lippincott.

Bane, M.C., & Birch, E.E. (1992). VEP acuity, FPL acuity, and visual behavior of visually impaired children. *Journal of Pediatric Ophthalmology and Strabismus*, 29, 202-209.

Banks, M.S. (1980). The development of visual accommodation during early infancy. *Child Development*, 51, 646-666.

Barnett, A.B., Manson, J.I., & Wilner, E. (1970). Acute cerebral blindness in children. *Neurology*, 20, 1147.

Beller, R., Hoyt, C.S., & Marg, E. (1981). Good visual function after neo-natal surgery for congenital monocular cataracts. *American Journal of Ophthalmology*, 91, 559-565.

Birch, E.E., Gwiazada, J., & Held, R. (1982). Stereoacuity development for crossed and uncrossed disparities in human infants. *Vision Research*, 22, 507-513.

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Present objects which Kevin can feel, smell and see. For example, when eating, place an apple, banana and orange on the table and let him choose which he would like to eat. Ask him to feel, smell and look at the fruit before choosing. Tell him the names of the three fruits before and during the presentation.

3) Simplify the environment and eliminate crowding
Present only a few objects at a time with spacing between objects. Objects placed closely together may "blend" together for children with cortical visual impairment and, because of the "crowding" together the objects in the middle may be difficult to see or may disappear.

4) Use repetition and constancy
Often it takes repetition and constancy of objects being presented for the child to "see" them. Use familiar objects or symbols. Repeat presentation of the same objects on many occasions.

5) Use movement
Often children with cortical visual impairment "see" better when they are moving or things around them are moving. Choose toys which move. As Kevin begins to scoot and crawl, encourage him to explore. Try moving objects back and forth to increase their visual interest. Remember to tell him what the objects are and let him feel, smell and taste them when it is appropriate.

Brodsky, M.C., Baker, R.S., & Hamed, L.M. (1996). *In Pediatric neuro-ophthalmology* (pp. 302-465). New York: Springer-Verlag.

Brown, A.M. (1990). Development of visual sensitivity to light and color vision in human infants: A critical review. *Vision Research*, 30, 1159-1188.

Campbell, L.R., & Charney, E. (1991). Factors associated with delay in diagnosis of childhood amblyopia. *Pediatrics*, 87, 178-185.

Cogan, D.G. (1956). *Neurology of the ocular muscles*. Springfield, Il: Charles C. Thomas.

Day, S.H., Orel-Bixler, D.A., & Norcia, A.M. (1988). Abnormal acuity development in infantile esotropia. *Investigative Ophthalmology & Visual Science*, 29, 327-329.

Dobson, V., Quinn, G.E., Biglan, A.W., Tung, B., Flynn, J.T., & Palmer, E.A. (1990). Acuity card assessment of visual function in the cryotherapy for retinopathy of prematurity study. *Investigative Ophthalmology & Visual Science*, 31, 1702-1708.

Dobson, V., & Teller, D.Y. (1978). Visual acuity in human infants: a review and comparison of behavioral and electrophysiological studies. *Vision Research*, 18, 1469-1483.

Dobson, V., Fulton, A.B., Manning, K., Salem,D., & Peterson, R.A. (1981). Cycloplegic refractions of premature infants. *American Journal of Ophthalmology*, 91, 490-495.

Edwards, W.C., Price, W.D., & Weisskopf, B. (1972). Ocular findings in developmentally handicapped children. *Journal of Pediatric Ophthalmology*, 9, 162-167.

Elston, J. (1990). Epidemiology of visual handicap in childhood. In D.Taylor (Ed.), *Pediatric Ophthalmology* (pp.3-6). Boston: Blackwell Scientific.

Fingeret, M., Casser, L., & Woodcome, H.T. (1990). *Altas of primary eyecare procedures*. Norwalk, CT: Appleton & Lange.

First, L.R., & Palfrey, J.S. (1994). The infant or young child with developmental delay. *New England Journal of Medicine*, 330, 478-483.

Fisher, S., Orel-Bixler, D., & Bailey, I. (1995). Mr. Happy contrast sensitivity: A behavioral test for infants and children. *Optometry & Vision Science*, 72, 204 (abs).

Fishman, G.A.& Sokol, S. (1990). Electrophysiologic testing in disorders of the retina, optic nerve, and visual pathway. *Ophthalmology Monographs*, 2, American Academy of Ophthalmology.

Fraiberg, S. (1977). *Insights from the Blind*. London, England: Souvenir Press.

Fulton, A.B., Dobson, V., Salem, D., Mar, C., Peterson, R.A., & Hansen, R.M. (1980). Cycloplegic refractions in infants and young children. *American Journal of Ophthalmology*, 90, 239-247.

Fulton, A.B., Hansen, R.M., & Lambert, S.R. (1994). Workup of the possibly blind child. In S.J.Isenberg (Ed.), *The eye in infancy* (pp.547-560). St.Louis, MO: Mosby-Year Book.

Fulton, A.B., Hartmann, E.E, & Hansen, R.M. Electrophysiological testing techniques for children. *Doc Ophthalmology*, 71, 341-354.

Getz, L., Dobson, V., & Luna, B. (1992). Grating acuity development in two-week to three-year-old children born prior to term. *Clinical Vision Science*, 7, 251-256.

SAMPLE REPORT #2

Infant and Toddler's Clinic

SCHOOL OF OPTOMETRY BERKELEY, CALIFORNIA 94720

PATIENT Aaron

AGE 4 months

HISTORY
Aaron has been diagnosed with familial exudative vitreoretinopathy as reported by Dr. X. The macula of the right eye is involved in the retinal fold. The macula of the left eye appeared completely flattened at his follow-up evaluation when he was 3 months old. Aaron has also been examined by Dr. Y but results of the examination were not available for our review. Aaron was born fullterm with a birthweight of 9 lb. 7 oz. There is no family history of visual impairment. He receives services from Ms. Z, a counselor with an early intervention program, Off to a Good Start program of Blind Babies Foundation.

REASON FOR EXAMINATION To provide information about visual functioning.

REFRACTIVE STATUS

RETINOSCOPY WITH CYCLOPLEGIA Right Eye: unable to judge reflex due to retinal fold.
Left Eye: -6.25-3.50 x 090

PRESCRIPTION WRITTEN Right eye: plano. Left eye: -4.75 -2.50 x 090

BINOCULAR STATUS
A variable, right esotropia was noted (inward eyeturn). Aaron appeared to fixate on a penlight and the television monitor during VEP testing with the left eye. No fixation response was noted with the right eye. No nystagmus was noted.

OCULAR HEALTH The right eye corneal diameter appears about 1 mm smaller than the left eye. Aaron has been diagnosed with familial exudative vitreoretinopathy involving the right eye more than the left. The right eye has a severe retinal fold which includes the macula. The macula of the left eye appeared flat to the disc margin. Temporal lens opacities were noted in each eye but the lenses appeared clear along the visual axis.

VISUAL ACUITY MEASURES
Sweep Visual Evoked Potential grating acuity measure
Both eyes viewing at 50 cm: 1.4 cycles/degree or "predicted" optotype acuity 20/1350

Left eye viewing at 50 cm with -8 DS lens: 3.5 c/deg or "predicted" optotype acuity 20/520

The visual evoked potential uses black and white gratings (stripes) as the target to measure visual acuity (the ability to see fine details). In persons with low vision, grating acuity consistently overestimates visual acuity as compared to the acuity obtained when measured using letters or symbols. Therefore, a conversion factor is used to "predict" the

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Gottlob, I., Fendick, M.G., Guo, S., Zubcov, A.A., Odom, J.V., & Reinecke, R.D. (1990). Visual acuity measurements by swept spatial frequency visual-evoked-cortical potentials (VECPs): Clinical application in children with various visual disorders. *Journal of Pediatric Ophthalmology and Strabismus*, 27, 40-47.

Hamer, R.D., Norcia, A,M., Tyler, C.W., & Hsu-Winges, C. (1989). The development of monocular and binocular VEP acuity. *Vision Research*, 29, 397-408.

Harcourt, B. (1974). Strabismus affecting children with multiple disabilities. *British Journal of Ophthalmology*, 58, 272-280.

Illingworth, R.S. (1978). Child development. In J.O.Forfar & G.C. Arneil (Eds.), *Textbook of pediatrics*. Edinburgh, Scotland: Churchill Livingstone.

Isenberg, S.J. (1994). Workup of common differential diagnostic problems. In S.J. Isenberg (Ed.), *The eye in infancy* (pp.73-86). St. Louis, MO: Mosby-Year Book.

Jan, J.E., Farrell, K., Wong, P.K., & McCormick, A.Q. (1986). Eye and head movements of visually impaired children. *Developmental Medicine and Child Neurology*, 28, 285-293.

Jan, J.E., Freeman, R.D., & Scott, E.P. (1977). *Visual impairment in children and adolescents*. New York: Grune and Stratton.

Kamholtz, R.G., & Abrahams, J.J. (1992). Magnetic resonance imaging of the orbits and extraorbital visual system. In T.J. Walsh (Ed.), *Neuro-ophthalmology: Clinical signs and symptoms* (pp.277-322). Philadelphia,PA: Lea & Febiger.

Krill, A.E. (1977). Congenital color vision defects. In A.E. Krill & D.B. Archer (Eds.), *Krill's Hereditary Retinal and Choroidal Diseases, vol II. Clinical characteristics* (p.355). Hagerstown, MD: Harper & Row.

Lambert, S.R., Hoyt, C.S., Jan, J.E., Barkovich, J., & Flodmark, O. (1987). Visual recovery from hypoxic cortical blindness during childhood. Computed tomographic and magnetic resonance imaging predictors. *Archives of Ophthalmology*, 105, 1371-1377.

Landau, L., & Berson, D. (1971). Cerebral palsy and mental retardation: Ocular findings. *Journal of Pediatric Ophthalmology*, 8, 245-248.

Mackie, R.T., McCulloch, D.L., & Saunders, K.J. (1995). Comparison of visual assessment tests in multiply handicapped children. *Eye*, 9, 136-141.

Marron, J.A, & Bailey, I.L. (1982). Visual factors and orientation-mobility performance. *American Journal of Optometry and Physiological Optics*, 59, 413-426.

Mauer, D., Lewis, T.l., & Brent, H.P. (1989). The effects of deprivation on human visual development: Studies of children treated for cataracts. In F.J. Morrision, C.E. Lord, & D.P. Keating (Eds.), *Applied developmental psychology, vol 3. Psychological development in infancy.* New York: Academic Press.

Mayer, D.L., Beiser, A.S., Warner, A.F., Pratt, E.M., Raye, K.N., & Lang, J.M. (1995). Monocular acuity norms for the Teller Acuity Cards between ages one month and four years. *Investigative Ophthalmology and Visual Science*, 36, 671-685.

Mayer, D.L., Fulton, A.B. & Rodier, D. (1984). Grating and recognition acuities of pediatric patients. *Ophthalmology*, 91, 947-953.

Mayer, D.L., Fulton, A.B., & Hansen, R.M. (1985). Visual acuity of infants and children with retinal degenerations. *Ophthalmic Paediatrics and Genetics*, 5, 51-56.

McCrary, J.A. (1991). Magnetic resonance imaging applications in ophthalmology. International Ophthalmology Clinics, *Neuro-Ophthalmology*, 31, 101-115.

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letter acuity from the grating acuity measure. This predicted acuity measure should be used in guidelines for educational materials. The VEP indicates pattern detection. During the VEP testing, Aaron appeared to fixate on the television monitor. He often stopped sucking on his bottle when the grating pattern appeared and resumed sucking when the gratings disappeared at the end of the 10 second trial.

CONTRAST SENSITIVITY

Sweep VEP contrast sensitivity: 11.3% Michelson contrast without spectacle correction, 4.5% Michelson contrast with a -8 DS lens held in front of the left eye. Normal values are 0.5% indicating that Aaron's ability to detect subtle shades of gray is reduced by a factor of 10 from normal.

SUMMARY AND RECOMMENDATIONS

Aaron has familial exudative vitreoretinopathy affecting the right eye more than the left. The right eye has a severe retinal fold involving the macula. The macula in the left eye appears flat. The refractive error of the right eye could not be determined due to the retinal fold along the visual axis. The refractive error of the left showed significant myopia with astigmatism. The myopia decreased significantly after cycloplegia indicating an accommodative (focusing) response was present before cycloplegia. With this amount of myopia, objects further than 5 inches from Aaron's eyes will be out of focus. Although his vision is reduced due to the FEVR, such a large amount of optical defocus may also affect his vision. We have recommended a trial period of glasses with follow-up. The prescription written purposely undercorrects his myopia to place his eyes in focus for objects within arm's reach (closer than 50 cm or 20 inches).

Aaron's visual acuity (ability to see details) as measured with the VEP was 20/1350 without spectacle correction. With a -8 DS trial lens held in front of the left eye, the VEP measure of acuity was 20/520. This improvement with spectacle correction is not surprising since his eyes are in focus for 5 inches or closer without glasses and the VEP monitor was placed at 20 inches for testing. His contrast sensitivity (ability to detect brightness differences) was reduced by a factor of 10 from normal as measured with the VEP. The VEP indicates than Aaron has pattern vision and observations of his fixation during the VEP testing also suggest that he has pattern vision.

To make it easier for Aaron to locate toys and objects, the contrast should be enhanced between the object and its background. For example, place dark colored toys on a light colored mat or vice versa. These objects should be paired with auditory or tactile cues since hearing is his strength.

Aaron is legally blind and qualifies for educational services to children with visual impairment including services from a teacher certified in the area of visual impairment. He should continue services with Off to a Good Start, an early intervention program.

We would like to re-evaluate Aaron's vision after he has worn his glasses for two months. He should continue to receive regular eye examinations.

McCulloch, D.L., Taylor, M.J., & Whyte, H.E. (1991). Visual evoked potentials and visual prognosis following perinatal asphyxia. *Archives of Ophthalmology*, 109, 229-233.

McDonald, M., Ankrum, C., Preston, K., Sebris, S.L., & Dobson, V. (1986). Monocular and binocular acuity estimation in 18- to 36-month-olds: Acuity card results. *American Journal of Optometry & Physiological Optics*, 63, 181-186.

McDonald, M., Sebris, S.L., Mohn, G., Teller, D.Y., & Dobson, V. (1986). Monocular acuity in normal infants: The acuity card procedure. *American Journal Optometry & Physiological Optics*, 63, 127-134.

Mohn, G., & van Hof-van Duin, J. (1986). Preferential looking in normal and neurologically abnormal infants and pediatric patients. *Documenta Ophthalmologica Proceedings Series*, 45, 64-69.

Mohn, G., & van Hof-van Duin J. (1986). Development of the binocular and monocular visual fields of human infants during the first year of life. *Clinical Vision Science*, 1, 51.

Norcia, A.M., Hamer, R.D., & Tyler, C.W. (1990). Development of contrast sensitivity in the infant. *Vision Research*, 30, 1475.

Norcia, A.M., & Tyler, C.W. (1985). Spatial frequency sweep VEP: visual acuity during the first year of life. *Vision Research*, 25, 1399-1408.

Odom, J.V., Hoyt, C.S., & Marg, E. (1981). Effect of natural deprivation and unilateral eye patching on visual acuity of infants and children: evoked potential measurements. *Archives of Ophthalmology*, 99, 1412-1416.

Orel-Bixler, D.A., Haegerstrom-Portnoy, G. & Hall, A. (1989). Visual assessment of the multiply handicapped patient. *Optometry & Vision Science*, 69, 530-536.

Orel-Bixler, D.A., Norcia, A.M. (1987). Differential growth of acuity for steady-state pattern reversal and transient pattern onset-offset VEPs. *Clinical Vision Science*, 2, 1-9.

Orel-Bixler, D.A. (1989). *Subjective and visual evoked potential measures of acuity in normal and amblyopic adults and children*. Unpublished doctoral dissertation. University of California at Berkeley.

Pease, P., & Allen, J. (1988). A new test for screening color vision: Concurrent validity and utility. *American Journal of Optometry & Physiological Optics*, 65, 729-738.

Quinn, E.A., et al. (1990). Development of myopia in infants with birth weights less than 1251 grams. The cryotherapy for retinopathy of prematurity cooperative group. *Ophthalmology*, 99, 329-340.

Regan, D. (1988). Low contrast visual acuity test for pediatric use. *Canadian Journal of Ophthalmology*, 23, 224-227.

Reynell, J., & Zinkin, P. (1975). New perspectives for the developmental assessment of young children with severe visual handicap. *Child: Care, Health, & Development*, 1, 61-69.

Robinson, G.C., Jan, J.E., & Kinnis, C. (1987). Congenital ocular blindness in children 1945 to 1984. *American Journal of Diseases of Children*, 147, 1321-1324.

Rubin, G.S., & Legge, G.E. (1985). Psychophysics of reading. VI-The role of contrast in low vision. *Vision Research*, 29, 79-91.

Rutstein, R.P., Wesson, M.D., Gotlieb, S., & Biasini, F.J. (1986). Clinical comparison of the visual parameters in infants with intrauterine growth retardation vs. infants with normal birth weight. *American Journal of Optometry & Physiological Optics*, 63, 697-701.

Selenow, A., Cuiffreda, K.J., Mozlin, R. & Rumpf, D. (1986). Prognostic value of laser interferometric visual acuity in amblyopia therapy. *Investigative Ophthalmology & Vision Science*, 27, 273-277.

Shalowitz, M.U., & Gorski, P.A. (1990). Developmental assessment in the first year of life. In J.A. Stockman, III (Ed.), *Difficult diagnosis in pediatrics* (pp. 3-14). Philadelphia,PA: W.B. Saunders.

Simeonsson, R.J., & Sharp, M.C. (1992). Developmental delays. In R.A. Hoekelman, S.B. Friedman, N.M. Nelson & H.M. Seidel (Eds.), *Primary pediatric care* (2nd ed., pp. 867-870). St. Louis,MO: Mosby-Year Book.

Sokol, S. (1976). Visually evoked potentials: Theory, techniques, and clinical applications. *Survey of Ophthalmology*, 21, 18-44.

Sonksen, P. (1983). Vision and early development. In K. Wybar & D. Taylor (Eds.), *Paediatric Ophthalmology* (pp.85-95). New York: Dekker.

Summers, C.G., & MacDonald, J.T. (1990). Vision despite tomographic absence of occipital cortex. *Survey of Ophthalmology*, 35, 188-190.

Taylor, M.J., & McCulloch, D.L. (1992). Visual evoked potentials in infants and children. *Journal of Clinical Neurophysiology*, 9, 357-372.

Teller, D.Y. & Movshon, J.A. (1987). Visual development. *Vision Research*, 26, 1483-1506.

Teplin, S.W. (1995). Visual impairment in infants and young children. *Infants and Young Children*, 8(1), 18-51.

Ventocilla, M., Orel-Bixler, D.A., & Haegerstrom-Portnoy, G. (1995). Pediatric color vision screening: AO HRR vs. Mr. Color. *Optometry & Vision Science*, 72, 203 (abs).

von Noorden, GK. (1975). Ocular motor effects on vision: Clinical aspects. In G. Lennerstrand & P. Bach-y-Rita (Eds.), *Basic mechanisms of ocular motility and their clinical implications* (pp.417-423). Oxford, England: Pergamon.

Warren, D.H. (1994). *Blindness and children. An individual differences approach.* New York: Cambridge University Press.

Wesson, M.D., & Maino, D.M. (1995). Oculovisual findings in children with Down syndrome, cerebral palsy, and mental retardation without specific etiology. In D.M. Maino (Ed.), *Diagnosis and Management of Special Populations* (pp.17-54). St Louis, MO: Mosby Year Book.

Whiting, S., Jan, J.E., Wong, P.K.H., Flormark, O., Farrell, K., & McCormick, A.Q. (1985). Permanent cortical visual impairment in children. *Developmental Medicine & Child Neurology*, 27, 730-739.

Zimmerman, R.A., & Bilaniuk, L.T. (1994). Pediatric head trauma. *Neuroimaging Clinics of North America*, 4, 349-366.

Zinkin, P. (1979). The effect of visual handicap on early development. In *Visual Handicap in Children* (Vol. 16, pp. 132-138). London, England: Spastics International Medical Publications.

Hearing

Hearing Loss, Assessments, & Interventions for Infants with Multiple Disabilities

by

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Audiological Tests for Infants with Multiple Disabilities

by

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Hearing Loss, Assessments & Interventions for Infants with Multiple Disabilities

by Edith P. Bosworth & Vicky Maley

Hearing is defined by Funk & Wagnalls Standard Desk Dictionary as, "to perceive sound by means of the ear" and "to be informed or made aware." The act of hearing or perceiving sound is invisible. There is no physical, observable sign of whether or not the ear is working. The ability to hear is only observable by bodily actions such as a startle, head turn, following a command, or a spoken response. Therefore, when an infant has a hearing loss it often goes undetected until around eighteen months of age when a child usually begins to talk. Often, if a parent becomes concerned about their child's hearing before this age, they are reassured by well-meaning relatives or doctors. They are told there is a wide range of development or that the child is just "being stubborn" when he does not respond when called. They are told to wait and are reminded that a close relative was a "late talker." Parents are often given the impression, especially if it is their first child, that they are just "over concerned" parents who are worrying unnecessarily.

A diagnosis of deaf or hard of hearing in infancy is referred to in this chapter as elusive because the process of assessing an infant's hearing acuity can be complicated and a final diagnosis can be "elusive." This is especially true with the infant born with multiple disabilities or deaf blindness (Goetz, Utley, Gee, Baldwin, & Sailor, 1981). It is often the most difficult sense to evaluate and frequently the last disability to be identified (McGinnes & Treffry, 1982). Formal audiological assessments can indicate an infant's sensitivity to auditory stimulation or sound. However, the tests cannot give information about the infant's ability to integrate or process the auditory stimulation to make it meaningful. In other words, the assessments can test an infant's ability to hear but they cannot give information about how well he will *use* the hearing he has or how much ability he has to become "informed and made aware."

This chapter will provide...

INFORMATION about how the hearing system works and what can go wrong,

INFORMATION about informal or functional hearing assessments,

TYPES & FUNCTIONS of hearing aids,

and,

PRACTICAL, DEVELOPMENTALLY APPROPRIATE intervention strategies which can fit into a family's daily routine.

Warning signs of possible hearing loss in infants

A parent's instinct is usually correct. If a parent has questions or doubts about their infant's hearing, or if a parent often feels their baby is "being stubborn" or "ignoring them," they should have the child's hearing tested as soon as possible.

Some questions to consider

DOES THE BABY...

...jump or startle primarily when s/he hears a loud noise?

...feel comforted or show excitement by the sound of your voice?

...awake from a light sleep when you talk to her/him?

...use a variety of intonation patterns when s/he is not crying?

...turn or know you are coming when you call her/his name?

...wake up when the phone/door bell rings or the dog barks?

...enjoy your talking, cooing or singing to her/him?

...enjoy toys that make noise or talk?

...enjoy music from the television, radio or stereo?

...stop being fussy when you say you have a bottle, cookie, or something s/he wants something without seeing it first?

...say a few words and understand much of what you say if s/he is near two years of age?

If the answer to two or more of these questions is "No," the child's hearing should be checked immediately.

How the hearing system works

The hearing system consists of four areas including the outer ear, middle ear, inner ear, brainstem and the auditory section of the brain (Goetz et al., 1981; Watkins, 1989).

The outer ear consists of the auricle or fleshy ear flap and ear lobe, and the auditory canal, a passageway from the auricle to the eardrum.

The middle ear consists of the eardrum or tympanic membrane, three small bones which have scientific names and "common" names that indicate their shape, i.e., the malleus (hammer) the incus (anvil) and the stapes (stirrup). The middle ear also contains the oval window, a membrane similar to the eardrum except that it separates the middle ear from the inner ear. The middle ear cavity is filled with air and the pressure of the air is controlled by the Eustachian tube which leads from the middle ear into the back of the throat (pharynx).

The inner ear consists of the semicircular canal, the organ of equilibrium or balance; the cochlea, a spiral tube containing hair-like nerves which are an essential part of the hearing system; and the auditory nerve, a part of the brainstem leading to the auditory section of the brain.

How we hear

In order for sound to occur there must be a sound source which starts a vibration, a medium to carry the vibration, and a receiver of the vibration. The movement of the sound source (vocal cords) causes the medium (air molecules) to move, which carries the sound in waves into the ear (receiver). The frequency of the movement or vibration determines the pitch of the sound. A fast vibration creates a high pitched sound, and a slow vibration creates a low pitched sound (Clark & Watkins, 1985).

Hearing occurs when air waves are channeled into the auditory canal where they cause the eardrum to vibrate. The three bones of the middle ear are attached to the eardrum, to each other as well as to the oval window, so each of these parts of the ear also vibrate. The movement of the oval window creates movement of the fluid in the cochlea, causing the hair cells or nerves to move similar to the way seaweed moves in the ocean. The movement pattern of the nerves is carried through the auditory nerve to the auditory center of the brain where it is interpreted as sound or speech (Clark & Watkins, 1985).

Problems within each area of the hearing system

There are four basic types of hearing loss determined by where the problem(s) occur (Clark & Watkins, 1985; Goetz et al., 1981; Martin, 1991).

Conductive hearing loss

A conductive hearing loss occurs when there is a problem with the structure of the outer or middle ear or when an infection exists in these areas.

A conductive hearing loss is created because the vibration needed for sound to occur cannot be conducted through the hearing system when one of these problems is present. The hearing loss is more prevalent in the lower frequencies (low pitched sounds) and can usually be corrected through medication or surgery.

Sensorineural hearing loss

A sensorineural hearing loss is one which results when the nerves of the cochlea are damaged or missing.

A sensorineural hearing loss is created because the vibration needed for sound to occur cannot travel through the damaged nerves or neurals of the hearing system. A sensorineural hearing loss cannot be treated by medical or surgical techniques except for the use of cochlear implants. The hearing loss is usually more prevalent in the higher frequencies (higher pitched sounds).

Some of the causes of a conductive hearing loss are...

- A missing or malformed auricle
- Auditory canal plugged by wax or by a growth of skin over the opening
- A hole in the ear drum
- Fluid and/or infection in the middle ear (otitis media)
- A broken, unattached or diseased middle ear bone
- Specific syndromes
- Heredity (otosclerosis)

Mixed hearing loss

A mixed hearing loss is one that involves both a conductive and sensorineural problem. The conductive loss should be treated with medical or surgical techniques. A hearing aid will usually be prescribed for the sensorineural loss.

Central auditory disorders

In rare cases a hearing loss is caused by problems in the auditory nerve of the brainstem or in the part of the brain that recognizes or processes sound to make it meaningful. The child may have "normal auditory sensitivity" but may not be able to use or process sound meaningfully (Goetz et al., 1981; Martin, 1991). Educational and language interventions are thought to be more appropriate for this type of disorder (Goetz et al., 1981; Robbins, 1964).

It is important for parents to try to determine the etiology or cause of their child's hearing loss when possible. Some of the causes of hearing impairment may also cause physical, neurological and/or developmental disorders. The implications for medical treatment and educational programming can best be determined by knowing the

Some of the causes of a sensorineural hearing loss are...

- Heredity
- Meningitis
- Ototoxic drugs
- Rh factor
- Maternal viral infections and sexually transmitted diseases (STD)
- Specific syndromes
- Loud noises

cause of the hearing loss. Sometimes, even with genetic counseling, the cause of a sensorineural hearing loss cannot be determined. In these situations families should be encouraged to proceed with the best medical and educational program that can be developed using available information (Bailey & Wolery, 1989).

Some of the causes of auditory processing problems are...

- A tumor or lesions on the brainstem or brain
- Brain atrophy or damage as a result of:
  Ototoxic drugs
  Maternal viral infections
  Anoxia
  Rh incompatibility
  Prematurity
  Birth trauma
  Encephalopathic diseases

The age of onset of the hearing loss

A congenital hearing loss is one which occurred before birth. An acquired hearing loss is one which developed after birth. When planning a developmental or educational program for an infant it is extremely important to know the "age of onset" of the hearing loss. The infant's communication program should be based on whether the age of onset of the hearing loss was before the child had acquired speech and language "pre-linguistic" or after being exposed to and/or developing some language "post-linguistic" (Bailey & Wolery, 1989).

How hearing is assessed

The assessment of an infant's hearing should be thought of as a process. Several assessments should be completed over a period of six months or a year when trying to determine an infants ability to respond to or process sound. Very seldom does one test give all of the needed information. Parents should be informed about the complete process and should be made aware of exactly what information each test will provide. An informed parent will have more realistic expectations and can make choices about which tests are needed by their child and which ones can be eliminated or scheduled at a later time. Understanding the process also minimizes the chance that a family will expect too much from one test and therefore be frustrated and disappointed when other tests are scheduled.

The assessment of an infant's hearing is sometimes delayed because the infant who is inattentive is thought to be hyperactive, experiencing behavioral problems, or "spoiled." Infants born with multiple disabilities have often undergone long or numerous hospitalizations or have life threatening conditions that demand immediate attention. In these situations the hearing loss may go undetected (Goetz et al., 1981; McGinnes & Treffry, 1982).

Medical tests

An examination of the ear by an otolaryngologist or otologist must be completed for the purpose of establishing the medical characteristics of an individual's hearing (Bailey & Wolery, 1989). The otolaryngologist, usually referred to as an ear, nose and throat (ENT) doctor, looks at the physical characteristics of the ear to determine whether all of the parts of the ear are present and are formed normally. In part, this examination concerns the existence of the ear flap or auricle, the ear canal, the ear drum, to some extent the bones of the middle ear, and whether or not there is fluid or infection in the middle ear cavity (congestion caused by a cold or allergies).

If the ENT finds fluid and/or infection in the middle ear, a decongestant is usually prescribed. Once the middle ear is free of fluid, if a hearing loss is still suspected, the ENT should refer the family to an audiologist.

Functional hearing assessment

It is important to know about the formal methods of audiological assessment, which are needed, when, how and what each one tests. However, it is also necessary to understand the importance of a functional hearing assessment. A functional hearing assessment is an informal, on-going assessment which takes place in the child's natural environment, usually his home, to determine how an infant responds to and uses sound with and without hearing aids, if the child is aided (Chen, 1990; Clark & Watkins, 1985; Michael & Paul, 1991). A functional hearing assessment is a way to learn to recognize the child's "specific behavioral responses" to sound, which may often be subtle (Bailey & Wolery, 1989; Goetz et al., 1981). The primary care provider is usually the best source of information in this type of assessment. Familiar toys, activities, and environmental sounds that are typically a part of the child's daily experiences are used (Clark & Watkins, 1985; Goetz et al., 1981; Michael & Paul, 1991).

What to look for or what kind of responses to expect, depend upon a variety of issues including...

- The infant's gestation age
- The maturation of the nervous system (especially in premature infants)
- The child's state of arousal
- The medical condition or etiology of the child's disabilities
- The visual, motor and cognitive skill development of the child.

The functional hearing assessment and the understanding of what an infant can hear and how he uses hearing must be observed over a period of time, by someone who knows the child well, and within the environment that is most natural and comfortable for the child. Also, the person observing the child must understand what to look for.

The following three areas of sound which should be used during a functional screening (Chen, 1990; Goetz et al., 1981; Michael & Paul, 1991):

ENVIRONMENTAL SOUNDS Television, vacuum, dog barking, doorbell

SOUND TOYS Familiar and developmentally appropriate toys

SPEECH A familiar person's voice; use name of child or name of favorite object; babble/imitate child using a variety of intonation patterns

One of the best ways to test an infant who has some vision and who you suspect of having a mild to moderate/severe hearing loss is to talk to him when he is in a light sleep.

An inconsistency of responses to the same sounds at different presentations may indicate that the child becomes easily saturated when stimulated or has an immature nervous system.

A functional assessment should include...

- ► Getting to know the infant's natural behaviors before starting the assessment
- ► Observing the infant's environment
- ► Establishing rapport with the infant by holding, rocking, or playing for several minutes
- ► Presenting contrived sounds in a quiet environment
- ► Symmetrical positioning of the infant for the most complete, reliable and easily observable response behaviors
- ► Asking parents/caregivers and other professionals about their observations of the child's auditory behaviors and sharing any information you may have

Chen, 1990; Clark & Watkins, 1985; Goetz et al., 1981

Questions for parents

- ► What does the baby do when you call his name? Does he change his activity; show excitement; become fussy; stop crying?
- ► What sounds does he seem to notice around the house?
- ► What does the baby do when loud noises are made (dog barking, honking car horn, vacuum cleaner)? Does he turn his head towards sounds, stop what he is doing, tense his body?

- Does your baby increase his/her movement or open his/her eyes when in a light sleep and you talk to him/her (without touching the crib)?
- Does you baby enjoy toys that talk or make noise? Are they too loud or is no sound heard?
- Does he enjoy making noise (banging a spoon, kicking the high-chair while seated, etc.)?
- Is there a difference in what your child seems to hear when the radio or television is on?
- What sounds does he make when he is not crying (i.e.: cooing, squealing, lip smacking, babbling, saying one syllable repeatedly)?
- Does he use his voice to get attention, to show anxiousness or excitement?
- What does he do if you imitate some of his sounds?
- Does your baby enjoy you talking, cooing or singing to him/her?
- When does your child seem most likely to hear sound?
- What have you been told by medical professionals about your child's hearing?
- Has your baby had an ear infection? How frequently?
- Is your child often congested? Having frequent colds?
- What is your impression of your child's hearing?

The importance of using amplification

There are many important reasons for a child with a hearing loss, especially a child with multiple disabilities or deaf-blindness, to wear a hearing aid. People think primarily of using hearing as a way to learn speech and language and a parent may question why the child should wear a hearing aid if it may not create the ability for the child to learn to talk. Increasing the child's ability to hear gross (non-speech) sounds through the use of hearing aids is important for the following reasons (Clark & Watkins, 1989; Freeman, 1985; McGinnes & Treffry, 1982; Michael & Paul, 1991):

PSYCHOLOGICAL Sounds give a sense of being a part of the world, it imparts a sense of stability and security; thus improving the quality of experience with the world and decreasing the feeling of isolation.

PHYSICAL Sound gives a sense of distance, balance.

SOCIAL/EMOTIONAL Access to sound can decrease feelings of isolation that can lead to withdrawal, frustration and behavior problems.

COGNITIVE Associating sound with the source increases cognitive development and a better understanding of experiences through other senses.

SAFETY Some specific sounds are warning signals of danger.

Types of amplification

Hearing aids come in many forms (Clark & Watkins, 1985; Goetz et al., 1981; Martin, 1991; Michael & Paul, 1991). Body aids are worn in a harness strapped to the child's body with wires leading up to and attached to a part of the earmold. There are hearing aids which fit behind the ear (ear level aids) and also in the ear. The in-the-ear-aids are appropriate for a mild-to-moderate hearing loss as they are limited in the amount of amplification they can achieve and also in the level of technology which can be built into them.

The screening procedure should include the following procedures

- ► Present sound source out of view of infant
- ► Present sound within view of infant
- ► Present sound for two seconds continuously
- ► Present sound within 24 to 36 inches of infant's ear
- ► Present a variety of pitches, durations and intensities of sound
- ► Observe infant's behaviors before, during and after sound presentations

Chen, 1990

There are bone conduction aids which consist of a head band with the vibrator placed on the mastoid bone. The bone conduction aids are used for hearing problems caused by the absence or blockage of the external auditory canal, or some other problem in the outer or middle ear.

Tactile hearing aids create a vibration on the chest or wrist where they are worn. Tactile aids are prescribed for profound hearing loss. They give the wearer information about the loudness and duration of the sound.

Personal auditory trainers or FM Systems are very advanced and highly technical hearing aids which include a microphone worn by the adult caretaker of the child. The personal trainers have the advantage of always keeping the adult's voice (through the microphone) within six inches of the child's ear which is the best distance for clarity of speech.

What hearing aids can do

Hearing aids can assist in making better use of usable hearing; they can make sounds louder, however the clarity of speech sounds may not necessarily be improved (Robbins, 1964). Bone conduction hearing aids can by-pass the ear canal, eardrum and ossicles of the middle ear. Sound is carried directly through the cochlea to the auditory nerve. Hearing aids can improve the ability to use hearing as a distance sense and can assist in increasing the child's ability to benefit from other sensory stimuli such as vision, and touch (Clark & Watkins, 1985; McGinnes & Treffry, 1982; Michael & Paul, 1991; Robbins, 1964). They also assist in auditory training.

What hearing aids cannot do

Hearing aids cannot replace hearing that does not exist nor can they create normal hearing. They cannot amplify sound without some distortions. Hearing aids cannot provide instantaneous or automatic understanding of speech (Clark & Watkins, 1985; McGinnes & Treffry, 1982; Michael & Paul, 1991).

Issues involved with the fitting of hearing aids

The initial fitting of the child's hearing aid(s) is a time for close observation of the child's reaction to amplification. Early amplification is at first "diagnostic." As stated earlier, determining a young child's or infant's hearing acuity is difficult; thus, making it critical to observe the child's reaction to amplification over time (Clark & Watkins, 1985; McGinnes & Treffry, 1982; Michael & Paul, 1991; Robbins, 1964). It may take several visits to the audiologist and/or hearing aid dispenser to "fine tune" the hearing aid(s). It is at this time that the audiologist's and hearing aid dispenser's experience, patience and perseverance are most needed. It is important to watch for the following:

GOOD EARMOLD FIT Not too large as to cause discomfort inside the ear, and not too small as to allow sound to leak out (feedback); young children outgrow their earmolds and will need to be replaced a minimum of twice a year (Clark & Watkins, 1985).

EARMOLD MATERIAL Most earmolds are made of latex which some children cannot tolerate, the inside of the ear may become red or itchy; this problem is usually solved by using hypoallergenic material.

PE TUBES Should be checked periodically to see they are in place and that the earmold canal is not too long as to be touching them (it would cause discomfort).

CHRONIC EAR INFECTIONS The child cannot wear his hearing aids during this time due to middle ear discomfort and/or discharge.

LENGTH OF TUBING Not too long so that the hearing aid will not remain behind the ear, or too short as to pull down on the ear and cause discomfort (Clark & Watkins, 1985).

SIZE OF HEARING AID Ask for "child-size" aids to better fit the size of the child's ear; an "adult-size" aid will be difficult to maintain behind the ear.

TONE CONTROL AND POWER OUTPUT Pitch and power are set according to the best information the audiologist is able to derive from formal hearing assessment; the goal is to achieve an appropriate balance; improper amplification may either be too little to be of any help or too much as to cause discomfort; this is especially a problem with a child who has a mixed loss (conductive and sensorineural) or a sloping loss (Clark & Watkins, 1985).

FUNDING Obtaining Medicare approval or other medical services approval is frequently a long wait.

Issues involved in hearing aid wear for infants

The child will sense the parents reaction to the hearing aid and, if negative, will react in the same way. Parents/caregivers should try to keep a pleasant expression on their face when putting the aids on the child. The parent should have some way of listening to the hearing aid to be sure it is working correctly and to check the working condition of the battery (Watkins, 1989). Many children with multiple disabilities do not easily adjust to amplification and the wearing of hearing aids. They need a consistent routine that will help them to tolerate, accept and use the hearing aids. The wear time of the aids should begin with short intervals and be increased slowly until the infant wears the aids all waking hours (Clark & Watkins, 1985; McGinnes & Treffry, 1982). A "wear-time" plan should be developed to take advantage of naturally occurring enjoyable activities when the parent can be present, such as the reading of a favorite story or playing with a favorite toy. The parent should remove the aids at the end of the activity if necessary (Clark & Watkins, 1985). The toddler should be taught to adjust and put the aids on as soon as it is practical to do so (Clark & Watkins, 1985; Goetz et al., 1981; McGinnes & Treffry, 1982).

Parent/caregivers should observe the infant closely in noisy and quiet environments when aids are first placed to determine the appropriate volume setting of the aid.

The volume setting of the aids needs to be readjusted with each extreme change in the loudness level of the environment. When the child is not wearing the aids, they should be placed in an area out of reach of the child. The hearing aids should also be out of reach of animals because the scent of the earmolds attracts animals, especially dogs, who will chew and destroy them.

The "hearing age" of an infant/toddler with a severe to profound hearing loss should be counted from the first day of wearing the aids "all waking hours." The child's speech skills will depend on abilities and motivation but adult expectations of the child should be based on this "hearing age."

Auditory training

Children who experience hearing loss need to be encouraged or "trained" to use their residual or existing hearing. Auditory training involves planned interventions to help the child learn to make better use of residual hearing. It goes beyond simple exposure to sound but rather is a process to help the child learn to respond appropriately to sounds in the environment and to speech of significant caregivers (Clark & Watkins, 1985; Goetz et al., 1981; Martin, 1991; Robbins, 1964).

Auditory training activities should take infants and toddlers through all stages of auditory development. Auditory training should begin at the current auditory response level demonstrated by the child. The better the ability of the parent and professional to recognize and respond to the infant's natural listening behaviors, the more likely the auditory training activities will be at the appropriate skill and interest level of the child. Planning for auditory training activities should involve parents or primary caregivers, the use of natural and meaningful environments, and age-appropriate activities based on the functional developmental sequence of auditory responses as observed in infants without disabilities (Goetz, et al., 1981; Michael & Paul, 1991). Parents have the

The hierarchy of infant responses to sound include...

AWARENESS/REFLEXIVE The infant's responses are unintentional

ATTENTION/ALERTING The infant demonstrates curiosity about sound and its source

LOCALIZATION The infant/toddler demonstrates the ability to turn to or locate the source of a sound

DISCRIMINATION The infant/toddler demonstrates recognition of differences between sounds

RECOGNITION The infant/toddler demonstrates the ability to recognize and obtain meaning from sound as well as to attach meaning to sound or a combination of sounds

COMPREHENSION The infant demonstrates the ability to maintain and recall past auditory experience, sustaining linguistic association and transferring learned patterns to new situations.

Chen, 1990; Clark & Watkins, 1985; Goetz et al., 1981; Martin, 1991; Robbins, 1964 best opportunities to observe the skills and interests of their child. Parents and professionals should work together to develop activities best suited to the individual child.

Activities for infants need to be planned for the whole child to include as many areas as possible: thinking (cognitive); movement (motor); gesturing and vocalizing/talking (communication); playing and interacting with people (social); and dressing/bathroom behaviors (self-help). In addition, each of the five sense areas of seeing, hearing, feeling, smelling and tasting also need to be used whenever possible within planned activities (Paul & Michael, 1991; Watkins, 1989).

Most of the areas listed above occur during the natural daily routine. For example, saying and waving good-bye appears to be a communication skill, but speaking involves mouth or oral-motor movements, waving involves a hand/arm or gross motor movement and understanding when it is appropriate to say good-bye is a thinking skill and shows social awareness. If possible, visits with the family should be scheduled at different times during the day so that a variety of activities from the daily routine can be incorporated into auditory training activities. Auditory experiences occur while the child/family is in the car, grocery store, on walks, at meals and during play time, and so on.

Intervention strategies for auditory response and developmental age levels

The direct service provider should know...

...the skills the child does independently,

...the skills the child does with support, adaptation, and assistance

...the type of adaptation and assistance needed

and,

...the skills the child does not have.

Bailey & Wolery, 1989

"Incidental learning" (Clark & Watkins, 1985) is a term used to describe the learning which occurs when a child is not being directly taught something. For example, a child may be playing with toys in one corner of the room and overhear family members discussing the items needed from the grocery store. The family is not aware that the child was listening and is surprised when they arrive at the store and the child points to an item which was discussed earlier.

Deaf and hard of hearing children, children with multiple disabilities and hearing loss, or children who are deaf-blind, do not have the advantage of incidental learning or of "overhearing" information. Most information available to them is taught or experienced directly. Families need to be aware of assisting their infants in the understanding of the most common daily activities. The repeated activities of all family members should be described to the child at the appropriate language level whether or not the child is directly involved in the activity.

Auditory training activities are important for all hard of hearing and deaf infants with multiple disabilities. Naturally occurring situations and experiences easily lend themselves to teaching real-life applications of auditory skills and listening behaviors. For profoundly deaf infants, infants with multiple disabilities, and deaf-blind infants who may not hear speech sounds, the parent/professional may choose to use Total Communication (a combination of oral, aural and sign language) along with object and touch cues and other augmentative communication systems in all instances where speech is mentioned in the following activities (Clark & Watkins, 1989; Goetz et al., 1981; McInnes & Treffry, 1982; Watkins, 1989):

AWARENESS/REFLEXIVE RESPONSE LEVEL The infant's responses are unintentional

Infants listen and observe in order to make sense of the world around them for approximately 12 to 18 months before they begin to try to put the sounds/experiences they have been involved with into meaningful words and actions. This listening/observing time is very important to their overall development and families should provide every opportunity for infants to experience the world around them. The infant should have a standard daily routine which provides him with many repetitions of the same sounds, sights, and comfortable feelings. During his waking hours he should be placed as near the normal activities of the family as is safe for him. Family members should hold and touch him, and talk to him using a firm, clear voice and the "motherese" techniques of a) repetitions, b) questions, c) words, phrases, and short sentences, and d) imitation of the infant's sounds.

ATTENTION/ALERTING The infant demonstrates curiosity about sound and its source

A child who is hard of hearing or deaf and with other developmental delays, should be given extra help with understanding what sound is and which sound goes with which experience. Family members should make a game of calling attention to the sound source of natural activities and repeating the game whenever possible when the sound occurs naturally. An example of this would be to touch the child's ear and say "Listen, listen, mom is going to make some juice now." A child 12 months or older may be allowed to help push the blender button to mix the frozen juice. The mother should continue to talk about what is happening and also allow the child to participate as much as possible. The family should talk about the feel, smell, taste, and touch of the experience. The often repeated dialogue for the "making juice" activity might be: "Mom is going to make some juice now. Want to help me? The can is cold. Feel it. Brrr. Pour it into the blender. Let's add water. Help Mommy push. Push hard. Oh! that is loud. Listen. Loud! Look, Gary we made orange juice. Want some juice? Feel the cold glass. Oh, the juice is cold. Have a drink. Umm good juice."

In the beginning the child is not expected to know the meaning of the signs (if sign language is used) or words. We all learned words by being spoken to in a language that we did not at first understand. The meaning of language comes with the repetition of the signs or words attached to the meaningful sights, sounds, smells and touch of the ever expanding experiences of the daily routine.

LOCALIZATION The infant/toddler demonstrates the ability to turn to or locate the source of a sound

The familiar voices of family members and caretakers are some of the best sounds to use to encourage development of the infant's localizing skills. Family members should call the infant's name and then pause and say her name again before touching her, to give her a chance to turn to the sound of the voice. For a child who is walking, parents could sit on the floor and take turns calling the child's name to give her the experience of listening and the reward of trying her new walking skill to reach the appropriate parent. As the infant's localizing skills increase, the parent's could stand, call from another room, and call in whispered, loud and soft voices to increase listening skills in a variety of situations. Family members can also expand the localizing experience by placing noise making toys in different locations and helping the child find them.

DISCRIMINATION The infant/toddler demonstrates recognition of differences between sounds

If the infant's aided hearing level is within the range of speech sounds, the different voices of family members will be the most meaningful sounds to the child. Family members should talk to the infant as frequently as possible, making sure the infant with multiple disabilities has a method of identifying the speaker. Methods of identification may be having the infant touch the person's hair, glasses or some identifying feature of the speaker.

Sounds of the infant's favorite toys can also be used in discrimination activities. The infant could be given an opportunity to listen to two (or more) toy sounds in order to choose the one with which to play.

RECOGNITION The infant/toddler demonstrates the ability to recognize and obtain meaning from sound as well as to attach meaning to sound or a combination of sounds

An activity that will call attention to sound and its meaning and also can be increased developmentally with the skills of the child is the game of "Stop and Go." For a very young infant or an infant with multiple disabilities, one family member would hold the child and say or use tactile cues or signs for, "Go." At the "Go" command, another person would turn music on and the person holding the child would walk or dance until "Stop" is indicated. The dancing or walking stops when the music stops. As the child gets older the parent could hold the child's hand and then walk or dance and stop on command. Later the child and adult could take turns indicating "Stop" and "Go." It is always fun and reinforcing for a child to control an adults' behavior. If the adult walks, dances, or pulls the child in a wagon as the child gives commands, the child will willingly use her voice. This game can also be used for language expansion as the child matures. The stop and go command could be expanded into "Stop—walking, dancing, the music, pulling the wagon," and so on.

Another activity which can progress as the child's skills increase, is stacking blocks. Each time a block is placed, the adult should say an appropriate word such as "Up." The word should be repeated with each block. When the blocks are knocked down, a word such as "Down" or "Fall down" should be used. As the child matures, the language can be expanded into such phrases or sentences as the "The blocks go up!" "The blocks fall down!" *Children learn best during play and when there is no pressure to say or pronounce the word correctly.*

COMPREHENSION The infant demonstrates the ability to maintain and recall past auditory experience, sustaining linguistic association and transferring learned patterns to new situations

There are many natural repetitions of daily activities and all of these can be used to encourage the child's looking, listening and communications skills. When feeding the child the parent should repeat the same phrases such as "Ready to eat?" "Open." "M-m-m-m tastes good." "The cereal is all gone." Family members should comment on the sound, feel, taste, color, temperature of the activity whenever it is appropriate. For example when opening the door, "Oh, it's hot outside." If the adult has a sensory experience such as the loud sound of traffic or the radio, or the heat or coldness of the weather or air conditioning, then the child is most likely experiencing the same thing but with no words to understand the experience. The words are more meaningful if spoken when the experience is happening. This is also true of emotional experiences. If a child is laughing or crying, the parent should, while playing with or comforting the child, use the language which best describes the behavior such as "laughing, happy, silly, funny, crying, sad, hurt, angry." After many repetitions of calling attention to the sounds and language of natural experiences, the child will begin to demonstrate an understanding and anticipation of her environment by using the correct behavior, word, or sign.

References

The information in this chapter is based on the authors' experiences as teachers of infants and young children with hearing loss and other disabilities, as persons with hearing impairment, and a review of the following references.

Bailey, D. B., & Wolery, M. (1989). *Assessing Infants and Preschoolers with handicaps.* Columbus, Ohio: Merrill Publishing Co.

Chen, D. (1990). *Parents And Visually Impaired Infants: Functional Hearing Screening.* Louisville, KY: American Printing House for the Blind.

Clark, T. C. & Watkins, S. (1985). *The SKI*HI Model: Programming for Hearing Impaired Infants Through Home Intervention (4th ed.).* Logan, UT: HOPE Inc.

Goetz, L., Utley, B., Gee, K., Baldwin, M., & Sailor, W. (1981). *Auditory assessment and program manual for severely handicapped deaf-blind students.* Seattle, WA: TASH.

Michael, M., & Paul., P. (1991). Early intervention for infants with deaf-blindness. *Exceptional Children, 57*, 200-209.

Freeman, P. (1985). *The deaf-blind baby: A programmme of care.* London, England: Heinneman Medical Books.

Funk & Wagnalls standard desk dictionary (1986). Library of Congress. USA: Funk & Wagnalls Publishing Co., Inc.

Martin, F. (1991). *Introduction to audiology (4th ed.).* Englewood Cliffs, NJ: Prentice-Hall.

McInnes, J. M. & Treffry, J. A. (1982). *Deaf-blind infants and children: A developmental guide.* Toronto, Canada: University of Toronto Press.

Robbins, N. (1964). *Auditory training program in the Perkins deaf-blind department.* Watertown, MA: Perkins School for the Blind.

Watkins, S. (1989). *The INSITE Model: A model of home intervention for infant, toddler, and preschool aged multihandicapped sensory impaired children.* Logan, UT: HOPE, Inc.

Audiological Tests for Infants with Multiple Disabilities

by Carolina Abdala

Hearing assessment

Audiogram

The *audiogram* is the basic graph describing a person's hearing. It is a plot of pitch or *frequency* by loudness or *level*. It basically tells us how loud a sound has to be at each frequency before a person hears it. Figure 1 shows an illustration of an audiogram for a normal hearing individual. Frequency in Hertz (Hz) is plotted on the horizontal axis of the audiogram so as we look across the audiogram, frequency goes from low to high. 250–2000 Hz are generally considered low frequencies while 3000–8000 are considered high frequencies. On the vertical axis, the level of the sound is plotted in decibels (dB). An audiologist is a hearing professional who records the audiogram in addition to conducting many other diagnostic and therapeutic procedures related to the auditory system. An audiologist must have a Masters degree in Communicative Disorders or Speech and Hearing Science and is required to complete a supervised clinical fellowship year before working independently.

To fill out or obtain a complete audiogram, hearing *thresholds* are determined for various frequencies. A *pure tone* (a tone that sounds like a whistle or flute and has only one frequency) is initially presented at a given frequency, from 250 Hz to 8000 Hz, at a moderate-loud level and the child tells you, "I hear it," raises her hand or pushes a button to let you know she can hear the sound. If the child does not hear it, the level of the tone is raised until it is audible to the child. When the child does hear the tone, its level is lowered again until she can no longer hear it and then increased slightly until the sound is barely audible. This is called bracketing the threshold. The standard method for bracketing a persons response includes lowering the tone 10 dB and raising it 5 dB, although techniques do vary. The tone is presented around threshold several times until the child hears and responds to the tone about 50% of the time. This level is called a threshold. Hearing thresholds are obtained for

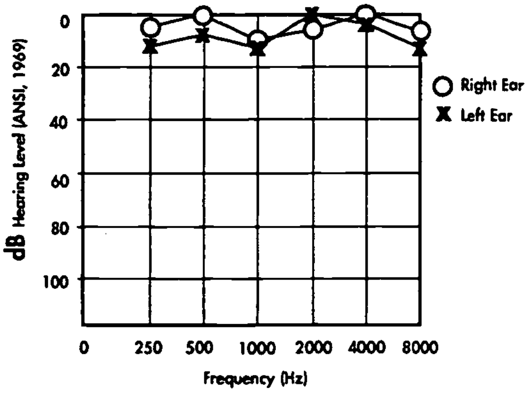


Figure 1. **Pure Tone Audiogram Normal Hearing**

all of the audiometric frequencies (250 Hz to 8000 Hz). Therefore, by recording an audiogram, we evaluate hearing in the low-, mid- and high-frequency ranges.

As an example, if a person just hears a 1000 Hz sound 50% of the time at 5 dB HL, the audiologist will find 1000 Hz along the horizontal axis, and find 5 dB along the vertical axis, then make a O (right ear) or an X (left) symbol where these two values intersect. The 0 dB value on the audiogram is not the absence of sound. It represents the average level at which most normal-hearing young adults will have thresholds at the various audiometric frequencies (ANSI 1969). Of course people with normal hearing will vary in their exact threshold. For this reason, 10 to 15 dB HL is usually considered normal.

It is very important to recognize that the audiometric procedures and the results described above are conducted in the ideal test condition when a cooperative adult or child is able to behaviorally indicate when a low-level sound is heard. They are important to understand because of the concepts they introduce such as "threshold," "frequency" and intensity or level. These tasks require concentration, certain cognitive level, motivation, physical integrity to press a button or raise your hand and the speech and language ability to say, "I hear it."

As we will see throughout this chapter, *pediatric* audiology often involves less than ideal testing conditions and requires modified techniques. Pediatric audiology with multiply involved children with pervasive developmental delays requires even more creative and adaptive procedures than standard pediatric audiology. Regardless of the population tested, the goal of all audiometric testing applied to infants and children is to achieve early identification of hearing loss so as to initiate early intervention. Hearing loss present during the first three years of life can be a severe obstacle to language acquisition and consequently, to psychosocial and educational development (Menyuk, 1977; Osberger, 1986).

Hearing loss

In children, a mild loss is present when hearing thresholds (plotted on an audiogram) are in the range of 15 to 30 or 35 dB HL; a moderate loss is classified as 35 to 50 dB HL and a moderate- severe loss ranges from 55–70 dB HL and a severe loss from 70 to 85 or 90 dB HL. If hearing thresholds are beyond 85 or 90 dB HL, the hearing loss is considered profound. People who are called "deaf" typically have thresholds at least in the severe to profound range.

There are two basic types of hearing loss; conductive hearing loss (CHL) which involves the pathway that conducts or transmits sound to the inner ear such as the ear canal and middle ear and, sensorineural hearing loss (SNHL) which involves damage to the inner ear or nerve fibers of the auditory nerve. CHL can often be medically treated while SNHL cannot be reversed, although rehabilitation with appropriate amplification is possible. In order to determine whether a loss is a CHL or SNHL, thresholds on the audiogram are obtained using two types of *transducers* or sound generators. *Air-conduction* thresholds are determined through a conventional earphone or through an insert phone placed in the ear canal. Most people are familiar with an earphone. An insert phone is a newer device that is coupled to the ear with a tiny foam tip connected to a flexible tubing. It fits comfortably at the entrance of the ear canal. Many clinics have replaced their old, bulky earphones with insert phones. Sound field testing is another way to present air-conducted signals. *Sound field* testing involves sounds presented through speakers inside the test booth. Sound field testing stimulates both ears and therefore, cannot provide information about ear specific results.

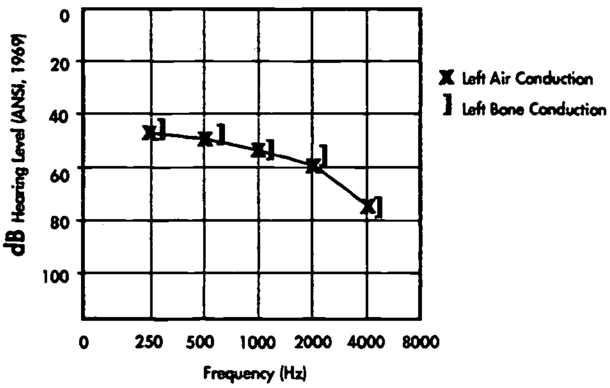


Figure 2. **Pure Tone Audiogram**
Moderate to moderate-severe SNHL

Bone-conduction thresholds are determined by placing a small vibrator on the mastoid (bone that protrudes slightly just behind the ear). Sound is transmitted through the vibration of bone thus the term, bone conduction. Air conduction testing is influenced by anything in the ear canal or middle ear whereas bone conduction testing bypasses the entire conductive pathway and directly stimulates the cochlea by vibrating the bones of the skull. This vibration stimulates the fluids in the cochlea and initiates the process of coding the sound so the brain can interpret it.

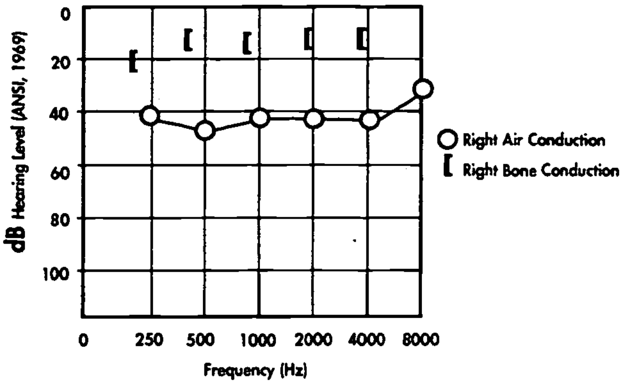


Figure 3. **Pure Tone Audiogram**
Mild Conductive Hearing Loss

If hearing loss is present, and air and bone conduction thresholds are the same or within 5–10 dB of each other, the hearing loss is SNHL and damage in the cochlea or nerve exists (Figure 2). If the bone conduction thresholds are much better than the air conduction thresholds, the loss is conductive (Figure 3). For example, if air-conduction thresholds indicate a mild level of hearing loss (45 dB HL) and bone-conduction thresholds appear normal (0 dB HL), this allows us to speculate that something is wrong with the outer or middle ear but the cochlea is working perfectly well once sound gets through. Recall that a CHL indicates that something in the outer or middle ear is interfering with the transmission of sound into the inner ear.

Immittance tests

Immittance or *Impedance* tests can be considered along with air and bone-conduction thresholds to determine if a conductive loss is present. Impedance tests include a tympanogram and acoustic reflexes. These tests are physiologic tests of middle ear function and will not be discussed further in this manual. Immittance tests determine: 1) how the eardrum or *tympanic membrane* is moving by recording a tympanogram, and 2) whether the middle ear muscle reflex is functioning by measuring an acoustic reflex threshold. A *type A* tympanogram is normal and the descriptors "flat" and "negative" are used to describe an abnormal tympanogram. Acoustic reflexes are absent when the hearing loss is moderate or greater. Both immittance tests, along with an air- and bone-conduction audiogram, aid in distinguishing a conductive from a sensorineural hearing loss.

Therefore, by obtaining audiogram thresholds by both air and bone conduction, it is possible to evaluate all three components of the ear to some extent: the outer ear (pinna and ear canal), the middle ear (tympanic membrane, middle ear bones or *ossicles*) and the inner ear or *cochlea*. A full audiological evaluation usually includes air- and bone-conduction thresholds. In addition, for older children, whenever possible speech testing is conducted. Speech testing can give an indication of the level at which speech is detected (a speech reception threshold or speech awareness threshold) and how well speech is discriminated or perceived (speech discrimination scores).

A pure tone audiogram is usually obtained using an *audiometer* which is a calibrated instrument that is able to present tones of specified level and frequency through earphones or speakers. The audiologist is behind the audiometer in the control booth and the child is seated in the test booth. There is usually a window between the tester and child. The test booth is a sound-treated room which significantly dampens outside noise and maintains an ideal acoustic test environment.

Pediatric audiology

Behavioral observation audiometry

An audiogram, such as the one described above and shown in Figure 1, can be recorded in ideal testing situations. However, when we are dealing with infants, it is often not possible to obtain a full audiogram using conventional techniques. *Behavioral Observation Audiometry* (BOA) is typically used for infants ranging in age from 0 to 5–6 months old. BOA is simply an observation technique with no conditioning, training or reinforcement provided to the infant (Northern and Downs, 1991). Various sounds are presented though a speaker, generally, rather than an earphone, including, bands of noise (like radio static), tones that change frequency slightly or *warble* and noise makers such as a rattle or bell. A variety of noise-makers and sounds are presented in an effort to assess both low- and high-frequency hearing. If the child is a slow or poor responder, the audiologist may use the parent's voice or a favorite toy from home to elicit a response. Once the sound is presented, the audiologist watches for a time-locked response. That is, the infant must respond within a given time after the sound in order for it to be considered a response. If an infant began sucking a pacifier 30 seconds after the presentation of a sound, it would be inappropriate to consider this a response. However, if an infant began to suck within one or two seconds of the sound, this may be considered a response.

Infants with multiple disabilities or any neurological impairment causing a generalized slowness of responding may need more time to respond. This can be detected by the astute audiologist in the first few moments of a test session. Also, parents and caregivers can provide valuable information about an infant's typical response time and pattern and, in this way, help the audiologist adapt the testing paradigm appropriately.

Typical BOA responses include eye-widening, sucking or cessation of sucking if the infant is sucking before the sound is presented, startle response with whole body movement and arms flung outward, crying or cessation of crying, blinking and arousal from sleep (Northern & Downs, 1991). A speech awareness threshold (SAT) is an important indicator of hearing. The SAT simply indicates that the infant responded (using any of the above-mentioned behaviors) when the tester spoke to them through the speakers in the test booth. BOA is highly dependent upon the audiologists experience and skill at observing auditory behavior.

Using BOA, even at the youngest ages, some very valuable information can be obtained. If the infant startles appropriately at 65 dB HL, has a SAT of 40 dB HL, responds to both low- and high-frequency at moderate sound levels and the parent reports normal responding and interest in sound at home, it is likely that the infant has normal hearing in at least one ear (no ear-specific testing is done with speaker presentation of sound). Follow-up testing with Visual Reinforcement Audiometry when the child is older is still recommended, however, with normal, reliable BOA, a profound hearing loss in both ears (deafness) can be ruled out. This is critical information for both audiologist and parents.

Auditory thresholds and ear-specific information cannot be established with BOA. In addition, there is no way to differentiate between a CHL or SNHL with BOA because a stimulator (earphone or bone vi-

REPORT #1

PATIENT Bobby

BIRTHDATE 10/17/94

AGE 9 mos

BACKGROUND

Bobby is a nine month old male who presents with a severe to profound hearing loss of unknown type at this time. He was referred by Ms. Smith at the Regional Center in Los Angeles and was originally seen at the CARE Center on 7/10/95 for an audiological evaluation. He currently wears binaural Phonak hearing aids he obtained at 6 months of age. He was seen today to confirm soundfield thresholds obtained on his initial visit.

Per report, Bobby has Moebius Syndrome, a congenital facial diplegia. Additionally, he has had "traphorapy," an eye surgery due to visual impairment. An MRI revealed lack of brainstem development. He receive physical and occupational therapy two times a week at Casa Colina in Pomona. He is currently producing long vowels. Prenatal and birth history are unremarkable. The mother reports that Bobby's twin sister does not have Moebius Syndrome or any other medical conditions.

AUDIOLOGICAL EVALUATIONS

On 7/10/95, soundfield testing utilizing Behavioral Observation Audiometry (BOA) revealed a bilateral severe to profound hearing loss. Speech awareness threshold (SAT) was 65 dB HL. Eye-widening and partial localization to sound were both observed consistently in response to both low- and high-frequency bands of noise presented between 70 and 80 dB HL. Immittance testing revealed normal tympanograms in both ears and absent ipsilateral acoustic reflexes.

Bobby was fit with hearing aids and on 7/28/95 (today's test), aided soundfield testing using BOA was conducted. Aided BOA revealed responses at 55 dB HL with 500 Hz tones and 65 dB HL with 1000 Hz tones. Accepted responses included eye widening and attempts to localize sound with head turns in the soundfield. Bobby fatigued before more frequencies could be tested. Aided SAT was 40 to 45 dB HL.

IMPRESSIONS AND RECOMMENDATIONS

Bobby appears to receive good benefit from amplification. The exact extent of this benefit is difficult to assess due to the lack of muscle tone in his head and neck and his, inability to perform more specific and reliable audiometry tests such as visual reinforcement audiometry (VRA). The following recommendations are made at this time:

1) Gradually increase hearing aid use with the ultimate goal of full time use (two hours per day as a beginning target goal)

2) Return in three months to obtain further audiological information.

Please do not hesitate to contact us if you have any questions or if we could be of further assistance.

brator) is not used on or around the ears; speakers are used to present sound. Consequently, limited information is obtained. However, as previously mentioned, with a good BOA test, sufficient information may be obtained to guide future management decisions and eliminate or confirm any urgency to continue diagnostic testing.

Although the general age guideline for BOA with normally-developing infants is from 0 to six months, in cases where an infant is very delayed or unable to be conditioned for more advanced techniques, it may be necessary to perform an adaptation of BOA. A one-year old or 18 month old, for example, may be observed for any response to sound: The reflexive behavior of the early months such as a full body startle may be gone, however, sounds can be presented and observation conducted in order to detect any response that is time-locked to the sound. This is a variation of BOA and may be used in the absence of any more appropriate technique.

If BOA results are abnormal or poor in reliability, further testing should be done. If the child is not old enough for other behavioral tests such as visual reinforcement audiometry, a physiologic test of hearing such as the *auditory brainstem response* or *otoacoustic emissions* should be considered, particularly if there is parental or care giver concern about hearing. If the test is ambiguous because of poor reliability, but neither parent or care giver are concerned about hearing because the child shows normal auditory behavior at home, a decision may be made to wait until the child is old enough for conditioned audiometry. By six months of age most normally developing infants can be tested with visual reinforcement techniques. Whether a child is followed up immediately with further testing, or whether the audiologist decides to wait until a more complex and reliable test can be done, is unique to each situation and the many factors involved.

An example is provided of an audiological report describing a hearing test using BOA on a hypothetical child named Bobby (Report #1). In this case, BOA was used with and without hearing aids on to confirm the usefulness of the hearing aids. The test should report results clearly and give directions as to further testing or observation. If any ambiguity is present, it is appropriate to call the audiologists and discuss the case further.

Visual reinforcement audiometry

Visual Reinforcement Audiometry (VRA) is conducted with normally-developing infants ranging from age six months to approximately two years (Thompson, Wilson & Moore, 1979; Thompson & Wilson, 1984). It is different from BOA in many ways. During VRA, a head-turn response is trained or conditioned to be a reliable indicator of whether an infant hears a sound. Recall that BOA requires no conditioning or teaching, simply observation. VRA is a much more reliable test than BOA.

To perform VRA, initially, a high-level sound is presented through a speaker. The infant turns towards the sound, and a small animated animal in a plexi-glass box under the speaker is turned on and marches or plays drums as a reward. At the beginning of the test, the infant may turn his/her head in response to the sound and have no idea that an animal will light up. However, once the child reliably associates a headturn with the musical bunny or monkey, he/she is conditioned or trained. The audiologist can then, present a sound and withhold the animal reward until after a headturn is made.

As soon as the audiologist sees and reinforces several reliable headturns towards a loud sound, the level of the sound is lowered methodically in order to find the lowest sound at which the infant will reliably respond. This is the infants VRA threshold, however, it is not an ear-specific threshold. Because speakers are used, it is unclear whether there is a unilateral (one ear only) hearing loss. If there is a difference in hearing between ears, it is possible to determine hearing in the better ear only with soundfield VRA. In some cases, earphones are used to conduct VRA. It is important to read the notes on the audiogram to ascertain whether speakers or earphones were used. Speaker presentation is typically designated a *sound field* response (SF) on a VRA audiogram.

VRA is conducted with tones of different frequency, with noise-bands (like static) centered at certain frequencies, or even with voice/speech. The most interesting and complex sound is presented first in order to capture the infants attention. At the University of Washington, where this technique was developed and refined, a noise band centered around the speech frequencies (500–2000 Hz) is initially presented (Thompson & Wilson, 1984). In this way, even if no other information is obtained, the audiologist gets an indication of hearing in a critical frequency range. Following this noise-band, a high-frequency warble tone or noise band is presented. If a threshold is obtained at this frequency, the audiologist now has an indication of both low-mid frequency hearing and high-frequency hearing. Although this is not the same as having a pure tone audiogram threshold from 250 Hz–8000 Hz, it does give an indication of hearing across our frequency range. In this way, it is less likely that a high-frequency or low-frequency loss will be missed. The infant will only give a limited number of responses before habituating to VRA (habituation is when the child loses interest and stops responding); therefore, it is critical to choose stimuli wisely. An average VRA procedure may last one hour with a "play" break in between.

Most typically-developing children, are able to condition for VRA testing sometime between five and nine months of age. However, children who are delayed, may not be able to give a headturn or cognitively understand the concept of pairing a sound with a reward. When a child is unable to give a full headturn because of physical constraints such as low muscle tone, cerebral palsy or insufficient head control, adapted versions of VRA may be used. If a partial head turn is consistent, it too can be trained as the appropriate response. Even consistent eye movement toward the sound source can be conditioned. However, a *consistent* behavior must be associated with hearing in order to condition the response appropriately. If during one trial an eye movement is accepted and during another trial, pulling at the ear is considered a response, the test becomes similar to BOA since observation of any and all responses time-locked to the stimulus is accepted as an indication of hearing.

If a child is visually impaired, the visual reinforcement task must be modified somewhat. Many children with visual impairments are attracted to light and a light may replace the animated toy as a reinforcer. If, however, the child has no light perception, visual reinforcement provided with this technique is useless and an alternative technique must be found. The clinician may try a reward that is not visual such as a tactile reward of some kind to condition a response. The key to success with conventional VRA is that the animated, lighted animals motivate the child as a reward and that the child is able to physically make a head turn toward the source of the sound. When either of these conditions are not present, VRA is not a useful tool. In cases of multiple and severe disabilities that impair headturning or light perception, it is probably most useful to consider a physiologic test of hearing.

If a child is physically able to make a full head turn spontaneously but cannot be reliability trained to do so, the VRA test is also inappropriate. This may be observed in a child who is severely cognitively delayed. It is necessary for the child to conceptually pair the sound and the visual reward in order for VRA to be successful. Many children with cognitive delays will be able to do this task although at a later chronological age then their typically-developing peers. A child with Down syndrome for example, may be 18 months old before he/she is able to understand the task. VRA may remain an appropriate test procedure for this child up through eight or nine years of age or throughout their lifetime if they are unable to move onto a play *audiometry* task. Typically developing children become bored with the VRA task and reward between two and three years of age.

VRA results begin to resemble an audiogram if they are reliable and complete. That is, VRA thresholds are established at certain frequencies or within certain frequency ranges, and can be plotted on an audiogram. It is critical to look closely at a VRA audiogram when interpreting it. *If it says sound field (or SF), it means that the sounds were presented from a speaker and are not specific to any one ear.* If it designates right and left ear results, it may be that earphones were used to obtain frequency-specific thresholds. An audiogram will usually have a designated reliability rating as well. Poor and fair reliability ratings given by an audiologist should be suspect and will almost always be followed up with recommendations for further testing. Good and excellent ratings suggest that the test was reliable and that the tester has confidence in his/her results.

Two audiological reports of VRA audiometry with two-year old Fred (Report #2a and #2b) are included. These reports represent two sequential attempts to obtain reliable results with VRA information on a difficult to test child. Report #3 describes a VRA hearing test for Karen, a 16 month old child with hearing loss. Note that the report describing Karen's test, was conducted using insert-earphones rather than speaker presentation. As previously mentioned, the report should be self-explanatory and give appropriate direction as to future assessment.

REPORT #2a

PATIENT Fred Chan TEST DATE 7/10/94

BIRTHDATE 8/18/92

AGE 23 mos

BACKGROUND

Fred was seen on the above date for an audiological evaluation. He was accompanied by his mother who expressed concern regarding his speech and language development. She reported that Fred cannot follow direction and only uses the words, "No," "Go" and "Mama." Medical history was unremarkable. Fred was the product of a full term pregnancy and birth.

AUDIOLOGICAL EVALUATION

Fred was evaluated using Visual Reinforcement Audiometry (VRA) in the sound field. Consistent head turn responses were observed at a screening level of 20 dB HL from 250–4000 Hz. Speech detection responses were obtained at 10 dB HL. Tympanograms were within normal limits. Acoustic reflex thresholds could not be measured this date due to excessive movement.

SUMMARY

Results are consistent with hearing sensitivity within the rang of normal for at least the better ear. Fred's speech and language development should not be affected by his hearing ability.

RECOMMENDATIONS

1) Return for a speech and language evaluation

2) Return for an audiological evaluation in 6 months. We will attempt to obtain individual ear responses under earphones at that time.

VROCA/TROCA

Finally, there are two alternative forms of testing for older infants/toddlers who are not yet mature enough for the more sophisticated *play audiometry* task. These are used infrequently but it is a good idea to be familiar with them in case they are mentioned in a hearing report. TROCA or *tangible reinforcement operant conditioned audiometry* and VROCA or *visual reinforcement operant conditioned audiometry* involve operant conditioning. They are typically lever push paradigms where the child ideally wears headphones and manipulates the reward him/herself by pushing a button when the sound is heard and getting a edible treat or a visual toy reinforcer if the response is correct. More recently, a computer keyboard or mouse is used to replace the lever and the computer screen provides a visual reinforcement.

Play audiometry

Somewhere between 18 months and two and one half years is a transition period, when children may either be able to give true audiometric thresholds through play activity or may require continued use of VRA, or a combination of the two techniques. This depends on emotional, cognitive and physical maturity of each child. Typically developing two to three year olds are particularly challenging because they are often "between" techniques. Four and five year olds may be able to perform play audiometry however, maintaining their focus and attention on the task remains challenging. Beyond about five years of age in typically-developing children, the task of obtaining an audiogram becomes easier and can be comparable to testing an adult.

Play audiometry involves a task such as throwing a block in a tub or inserting a wooden peg in a pegboard when a sound is heard. Other tasks can be used, such as putting a puzzle piece in or moving a game piece. Whichever task is used, it must never be so interesting that the child loses interest in the real task of listening for sound and begins to play the game without waiting for the sound! Play audiometry is conducted using earphones or insert phones and therefore yields ear-specific thresholds.

The task requires several skills that younger children do not possess. It is necessary to have concentration (listening intently for very low-level near threshold sounds); patience (waiting for the tone between presentations for several seconds or more), motivation (wanting to please the tester or parent); cooperation (willingness to accept earphones or insert phones for ear-specific information), and some degree of autonomy (the ability to accomplish a task independently without mom/dads help or presence in some cases).

The play audiogram is filled out in the same way a full adult audiogram is filled out; that is, a threshold is attempted at each frequency by varying sound level up and down. The initial sound level is high, so that the response is trained easily and the tester is certain that the initial sounds are heard. The child will need guidance at first and may need the audiologist or assistant (sometimes the parent will act as an assistant) to hold the block at the earphone until the sound is presented than guide it into the bucket. After several guided trials, the audiologist steps back and allows the child to do the same independently when the sound is heard. The audiologist gives praise for each correct response. It is critical that the time interval vary between trials so as to catch the child who plops the block in methodically every five seconds.

REPORT #2B

PATIENT Fred Chan

TEST DATE 1/12/95

BIRTHDATE 8/18/92

AGE 2 years, 5 mos.

BACKGROUND

Fred was seen on the above date for an audiological evaluation. He was accompanied by his mother. Previous audiological evaluation (7/94) was consistent with hearing sensitivity within normal limits at least in the better ear. No ear-specific results were obtained in the first evaluation. Mother stated that Fred has recently been diagnosed with autism. Medical history is significant for otitis media.

AUDIOLOGICAL EVALUATION

Fred was evaluated in the sound field using Visual Reinforcement Audiometry (VRA) techniques. Fred would not accept earphones this date. Responses to speech stimuli were within normal limits for at least the better ear. We were unable to fully assess responses to pure tones as Fred began to cry and cover his ears upon presentation of test stimuli. Head turn responses were seen at 50 dB HL for 500 and 2000 Hz. Testing was discontinued due to the patient's distress.

IMPRESSIONS

We could not rule out a hearing loss at this date, however, previous audiological evaluation suggested hearing sensitivity within the range of normal in at least the better ear.

RECOMMENDATIONS

1) Fred's mother will practice listening to various sounds with Fred under earphones at home.

2) Fred should return in 6 months to attempt audiological evaluation retest under earphones.

REPORT #3

PATIENT Karen Garcia TEST DATE 8/6/95

BIRTHDATE 4/5/94

AGE 16 mos.

BACKGROUND

Karen was referred to the CARE Center for audiological evaluation by Smith Hospital. She was recently diagnosed with significant hearing loss as determined by ABR results. Her mother reports that hearing gloss was suspected by age 13 months and ABR was first performed at that time, showing no response bilaterally, but Karen has a history of middle ear infection and had fluid in both ears when this test was performed. Karen had PE tubes inserted in both ears and the ABR was then repeated by Lester Johnson on August 22. These results also indicated a profound level of hearing loss bilaterally.

Karen's parents report no family history of hearing loss. Karen's motor development is delayed: at 16 months, she is now able to sit alone but does not stand alone. She is scheduled for an evaluation of her motoric function through their local regional center. Her parents report that she did babble for a period of time but stopped doing so at about 9 months of age and that she now communicates her needs by pointing and vocalizing.

AUDIOLOGICAL EVALUATION

Karen was tested behaviorally under insert ear phones using visual reinforcement audiometry (VRA). Clear head turns to voice and pure tone stimuli were consistent and reliable. In her left ear, responses to voice were seen at 100 dB HL. Questionable head turns were seen at 105 dB HL at 250 Hz and at 115 dB HL at 500 Hz, and a repeatable and reliable response was seen at 120 dB HL at 1000 Hz. In her right ear, responses to voice were seen at 85 dB HL and response to tones ranged from 95 dB HL to 120 dB HL between 500 and 4000 Hz, with best thresholds being at 1000 and 2000 Hz. There was no response at 250 Hz.

Otoscopic examination revealed the presence of PE tubes in both ears. An examination by a physician indicates that these tubes are open and functional bilaterally.

IMPRESSIONS AND RECOMMENDATIONS

Karen has a bilateral sensorineural hearing loss of profound degree, with better thresholds in the right ear. There is no evidence of middle ear dysfunction.

Karen should be fit with hearing aids as soon as possible: to this end, ear impressions were taken and the earmolds will be sent directly to the parents so that they will have them for the hearing aid evaluation scheduled in September.

Information regarding various support facilities and educational facilities was given to Mr. and Ms. Garcia, including John Tracy Clinic and TRIPOD. They will contact their local school district regarding early intervention programs available to them.

Thank you for the opportunity to see this nice family. Please do not hesitate to contact us if you have any questions or if we can be of further assistance.

Different children need different amounts of training for this task. Sometimes a child will attempt the task one session and be unsuccessful because of poor concentration or anxiety or other factor. The audiologist may notice this quickly and use the remainder of the session for practice, making the test appear fun and self-motivating. This child may then be sent home with instructions for the parents to practice the "wait, listen and put the block in the bucket" task then come back another time for continued testing.

REPORT #4

PATIENT Billy Gee

BIRTHDATE 10/16/92

AGE 2 years, 3 mos.

BACKGROUND

Billy was seen on January 20, 1995 for an audiological evaluation. He was referred to the CARE Center by Children's Institute International because of a language delay. Children's Institute is a foster care service Center that places children with appropriate care givers and houses children during transitional periods. Bill's developmental and medical histories were not available, although it was noted that he has a history of anemia.

AUDIOLOGICAL EVALUATION

Billy was tested under earphones and via bone vibrator using play audiometry. He was conditioned to put a wooden block into a bucket each time he heard a sound. Test reliability was considered good. Billy gave consistent and reliable responses throughout the test session.

A speech awareness threshold was obtained at 15 dB HL in the right ear and at 5 dB HL in the left ear. Air conduction thresholds were present between 20 and 30 dB HL in the right ear and between 15 and 30 dB HL in the left ear for the frequencies of 500, 1000, 2000 and 4000 Hz. Bone conduction testing revealed thresholds between 0 and 10 dB HL at these same frequencies for at least the better ear.

Tympanometry indicated abnormal middle ear function bilaterally, with flat tympanograms and no ipsilateral acoustic reflexes.

IMPRESSIONS AND RECOMMENDATIONS

Air conduction results indicate a mild bilateral hearing loss. Bone conduction results, as well as tympanometry indicate that the loss in conductive in nature. It is recommended that Billy be seen by a physician for a medical evaluation in order to determine a proper course of treatment and that he return to the CARE Center for a repeat audiological evaluation after treatment to see if the problem has been remediated. Because there is concern about Billy's language, development, it is also recommended that he be evaluated by a speech-language pathologist.

Please do not hesitate to contact me if you have any further questions or we can be of further assistance.

Often, even if a child learns the task the first day and provides reliable thresholds, he may not have sufficient attention span for all the frequencies to be tested in each ear. Therefore, the audiologist must be very wise in her choice of frequencies to test. Sometimes you will see a play audiogram with only 4000 Hz and 1000 Hz information in each ear. This may mean that the tester chose a low- and a high-frequency sound to present to each ear first before seeking detailed information in each ear. These partial audiograms are helpful but should always be followed up with a full hearing test at all frequencies as the child's attention and ability matures.

An audiometric report of a two and one half year old child (Billy, Report #4) is included describing an audiogram obtained through play audiometry. After reading this section, the terminology used to describe the hearing in this report should be understandable.

Age appropriateness for specific tests

Although each test has a designated age range for typically-developing children, a child who has multiple disabilities and a chronological age of 10 or 12 years old may not be able to perform standard audiometry. This child often does well with play audiometry, VROCA, TROCA or even VRA. Because these tasks are simple and entertaining, offer immediate reinforcement and follow a simple conditioning paradigm, they may be much more effective in testing a 10 year old child with Down syndrome, for example, than a conventional audiometric paradigm. Likewise, a child with attention deficit disorder may be more motivated by play audiometry than conventional audiometry even though chronological age suggests otherwise.

The key to successful pediatric audiology is that the child's developmental abilities, not simply their chronological age, be considered before choosing a test technique. If you, as an early interventionist, are familiar with a given child and his/her limitations/abilities and see that he/she is being given tests involving physical or cognitive tasks beyond their ability, it is important to call the audiologist and discuss this concern. An audiologist has experience and knowledge of the auditory system and effective testing paradigms while the child's therapist or teacher knows the child's cognitive and physical capacity. Consequently a team approach for testing difficult to evaluate, multiply involved children is ideal.

The standard for audiological testing is a behavioral response to sound. Consequently, all of the above techniques may be utilized at various times to appropriately evaluate a child's auditory system. There are cases, however, when a behavioral response cannot be obtained and more objective, physiologic techniques to evaluate the auditory system must be employed.

Physiological tests of hearing

There are many reasons why an infant or child may not be able to respond behaviorally to sound in a reliable manner. First of all, BOA can be a difficult test to interpret because it is simply observation and it is highly dependent on the experience of the tester. The infant may give responses to sound but may not give responses that a particular audiologist considers consistent and reliable. BOA alone, is not generally considered a highly reliable indicator of hearing so some audiologists may not feel comfortable with the results, even if they are consistent. Therefore, if an infant is less than six months old, BOA is ambiguous or borderline normal and the caregivers express a concern about hearing, physiologic tests may be performed.

An older infant (more than six months) being tested with VRA may habituate to the sounds too quickly and stop turning his/her head, resulting in an incomplete test. A child who is visually impaired may be too old for BOA, unstimulated by VRA and too young for play audiometry. A child with cognitive delays might find the tasks too complex or demanding. There are many, many reasons why a newborn, young infant child or child with multiple disabilities of any age may not be able to provide behavioral indications of hearing. It is in these cases, that the audiologist, utilizes physiologic, objective tests of hearing.

It is critical to understand that neither of the two tests described below are actually "hearing tests." Hearing is typically measured as a volitional response indicating that the sound has been detected by the child or infant. The auditory brainstem response (ABR) and otoacoustic emissions (OAE) do not involve a volitional response by the child. They are not true hearing measures, however, they are useful to us because they *correlate with hearing* in a systematic way and consequently we are able to make some predictive statements about hearing based on results of these tests.

Auditory brainstem response

The Auditory brainstem response or ABR measures how the auditory nerve and brainstem auditory pathways are conducting sound toward the brain. It does not evaluate any auditory structures beyond the brainstem such as the cortex (i.e. brain). Other terms used for this test are *BSER* (Brainstem Evoked Response) or *BAER* (Brainstem Auditory Evoked Response). These terms are often used by physicians but the accepted terminology in audiology and hearing science is ABR.

ABR procedure

The ABR is used for either auditory/hearing evaluation or for neurological evaluation. We will focus, here, on auditory application. An ABR can be done on a patient of any age and including preparation time, duration of the test may range from one and one half to two and one half hours. In order to record the ABR, the patient must be very, very still. It is nearly impossible to test most infants and children with the ABR unless they are sleeping. An adult or older, cooperative child, however, may lie quietly and be tested without sleeping. When patients are between three months and four or five years of age, they are usually given a mild sedative such as *chloral hydrate* to help them sleep. Beyond four or five years, the test is often conducted during natural, unsedated, sleep. Especially in cases where the child will not be sedated, the evaluation is scheduled for a time that coincides with naptime and the parent is instructed to sleep deprive the child the night before. Sleep deprivation maximizes the likelihood that the child will sleep and the test will be conducted It helps prevent the need for repeated test sessions to evaluate hearing.

Often with children who are developmentally delayed or multiply disabled, chloral hydrate is not successful as a sedative. A paradoxical effect has been observed in these children. The chloral hydrate may cause a hyperactive effect so that the child never sleeps or even calms down enough for the test. Sometimes, if a child has serious respiratory or other medical problems, a physician may consider it too risky to administer sedatives. There are some optional medications for sleep and this should be discussed with the physician prior to the test date. The reason sleep and/or stillness is so important for ABR testing is because muscle movement and activity interferes greatly with detecting the tiny little neural responses being generated by the human auditory system.

The ABR is recorded by applying non-invasive surface *electrodes* on strategic spots on the head. Although this word sounds threatening to many parents, an electrode is simply a measuring device that detects neural activity below the skin—it does not send any electrical activity to the child. Many clinics use disposable electrodes that are nothing more than stickers composed of the appropriate metal for detecting electrical energy and coated with a conductive gel. Other clinics use "cup" electrodes which are small concave metal circles that are filled with a conductive gel and taped to the skin's surface. Before applying either type of electrode, the skin is cleaned with gauze and a special paste. This procedure is not painful and insures good contact between the electrode and the skin. The contact is crucial because the neural activity that must be detected lies below the skin in the auditory nerve and brainstem pathways.

Once the electrodes are in place, a earphone is put over the ear or an insert phone is placed in the ear canal and rapid click-like sounds are presented. The electrodes detect, and the ABR equipment records, several thousands of the tiny neural firings of the auditory nerve and brainstem as they traverse the auditory pathway towards the brain. Although the ABR is typically evoked with air-conduction, it can also be recorded with bone-conduction stimulation. Fewer clinics perform this variation of the ABR although it provides valuable information in cases where middle ear dysfunction is suspected.

The click sounds used to record an ABR do not offer frequency-specific information because they contain energy at a broad range of frequencies. They normally reflect hearing in the *mid- and high frequency areas* (2000–6000 Hz). In cases where an estimation of the audiogram must be made based on the ABR only, it is helpful to obtain *frequency-specific* information by using a low-frequency *tone-burst* (a very short-duration tone) instead of just a click. Typically a low-frequency tone-burst such as 500 Hz tone bursts will be used to obtain frequency-specific information after a ABR click threshold has been obtained. If an audiologist obtains a click ABR threshold and an ABR threshold for low-frequency tonebursts, she will have an indication of both low- and high-frequency hearing. This is useful information upon which to base intervention strategies until behavioral responses can be obtained. In children with multiple disabilities, who will not be able to provide behavioral indication of hearing during their lifespan, the ABR is relied upon heavily to fit hearing aids or other assistive listening devices. In these instances, it is especially important to obtain ABRs with both the click and low-frequency tones. Not all clinics are able to perform frequency-specific ABR testing, so it is important to review this with the audiologist/clinic prior to making an appointment.

ABR analysis

The ABR is displayed on a computer monitor as a series of waveforms that the audiologist can analyze and interpret (Figure 4). ABR waveforms are judged in several ways and the following terms are often included in ABR reports:

ABR ABSENCE/PRESENCE If the cochlea is not functioning, that is, a child is deaf, the clicks presented to elicit the ABR will not stimulate the cochlea.

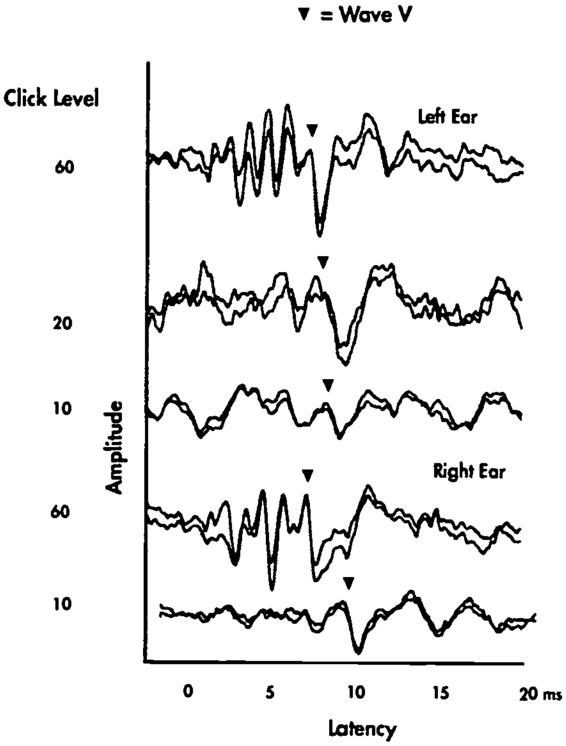


Figure 4. **ABR Waveforms for a Normal Hearing Child**

If the cochlea is not stimulated, the nerve fibers will not be stimulated and an ABR will not be detected even at high click levels. This is a *flat* or *absent* ABR.

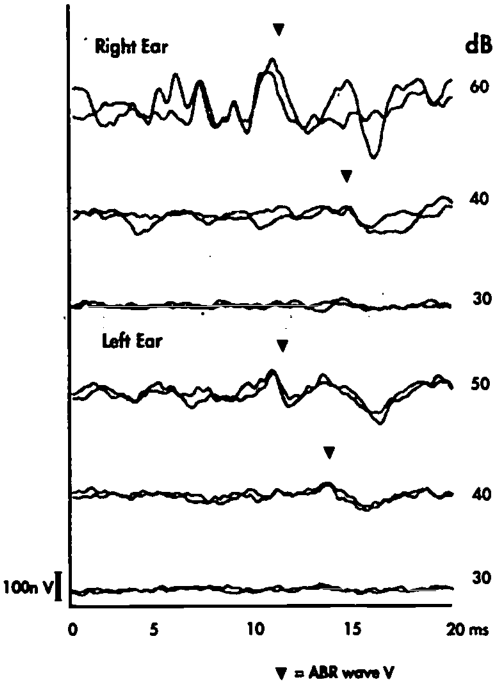


Figure 5. **ABR Waveforms with Mild Sensorineural Hearing Loss**

ABR THRESHOLD This refers to the last level at which an ABR is reliably detected (Figure 5 shows the results of a child with ABR thresholds of 40 dB HL in each ear). It gives an indication of the degree of hearing loss present. In normally hearing individuals, the ABR click threshold is present at 0–20 dB HL (like the example in Figure 4).

If more frequency-specific information is desired, a tone-pip should be presented to obtain ABR threshold in the low-frequency range. In our clinic at the CARE Center, we perform a click-evoked ABR followed by a 500 Hz tone-pip evoked ABR. The 500 Hz tone-pip threshold is typically present at 20–40 dB HL.

LATENCY This refers to the typical time, between click presentation and the appearance of the ABR waveform. "Delayed latency" can mean hearing loss or neurological problems.

PEAK AMPLITUDE Amplitude refers to how big each peak is. It is not used as commonly as latency to judge an ABR because it is fairly variable.

MORPHOLOGY Morphology refers to waveform shape and how typical looking they are. Typically two ABR waveforms are collected at the same click level to check how well they replicate one another. When a audiological report states, "Good morphology" it means the waveforms replicate well and look typical and are not contaminated by too much body noise.

When evaluating an ABR test, the audiologist always uses age-appropriate standards or norms through approximately 18–24 months of age. This is done because the infant ABR is typically delayed and more poorly defined than the adult ABR. This is normal. Beyond, two years of age, ABR latency, morphology and amplitude are typically adultlike (Salamy & McKean, 1976).

REPORT #5

PATIENT Susie Jones

TEST DATE 8/22/95

BIRTHDATE 7/24/92

BRIEF HISTORY

Susie was referred for auditory brainstem response and otoacoustic emissions testing by the John Tracy Clinic. A soundfield audiogram performed at John Tracy Clinic suggested normal hearing. However, Susie's mother reports that she is generally unresponsive to sound and at age 3, she has no oral language. She points to objects she wants or directs her mother toward them. Ms. Jones began to be concerned about Susie's language development about 8 months ago. Around that time, the family moved and Susie suffered an apparently mild head injury; her mother stated that she had no concussion or fracture according to the attending physician and no x-rays were taken. A few months prior to this time, she was beginning to use a few words like "mama" and "bye bye" but she stopped speaking about one year ago. She was seen recently by a developmental psychologist who found her to have a severe communication delay.

Susie has a history of frequent ear infections during the winter months which have been treated with antibiotics. According to Ms. Jones, Susie's physical development has been normal. She states that Susie's behavior is becoming a problem; she bites when angry and bangs her head when frustrated.

AUDIOLOGICAL EVALUATION

Auditory Brainstem Response (ABR): Susie was sedated with chloral hydrate and slept quietly throughout testing. Active electrodes were placed on the vertex, C7 and ipsilateral mastoid with a ground on the contralateral mastoid.

Click ABR: Activity was filtered from 100 to 3000 Hz (12 dB/octave). Responses were elicited with 100 us pulses sent to ER-3 insert earphones to produce rarefaction click stimuli presented at 25/sec. Averaging was performed on a Neuroscan evoked potential computer system. Each response was averaged for 6144 accepted sweeps or until Fsp value (statistical techniqiue used to detect the presence of a true response) reached 2.25, corresponding to a 95% confidence level.

Toneburst ABR: Activity was filtered from 30 to 1000 Hz. Short duration 500 Hz tones were presented at a rate of 25/sec with ipsilateral notched noise 20 dB below the signal level. Averaging was continued until noise reached 20 nv or until the response was visually detected by the clinician.

OTOACOUSTIC EMISSIONS

Transient otoacoustic emissions (TEOAE) were measured in response to click stimuli of 87 dB SPL. Distortion product otoacoustic emissions (DPOAE) were measured with 70 dB SPL equilevel stimuli.

RESULTS

ABRs to click stimuli are clearly identifiable at 10 dB HL in both ears. Responses to 500

Continued on page 157

Hearing screening & the ABR

The ABR has proven to be very useful for hearing screening of premature infants and other infants at risk for hearing loss (Folsom, 1990). An ABR screening test is much shorter than a full diagnostic test described above. If an infant has "passed" an ABR screening at birth, this indicates that they had a present ABR with appropriate latency at either 30 or 40 dB HL (these are typical screening levels). By screening at these levels, the ABR identifies the great majority of hearing losses in neonates. The very few losses that might slip by unidentified (false negatives), would be mild SNHL or conductive losses. In general, if a neonate has had a "pass" in their ABR screening at birth, there is no high risk for hearing loss and the caregiver reports responsiveness to sound at home, there may be no need to conduct a full diagnostic ABR at a later time. However, if the child has risk for a progressive

REPORT #5

Continued from page 156

PATIENT Susie Jones

TEST DATE 8/22/95

BIRTHDATE 7/24/92

Hz tone burst stimuli were present at 30 dB HL in both ears as well.

TEOAEs were present in the right ear, though not robust, but were absent in the left ear. DPOAEs were also present in the right and absent in the left ear. Emissions are expected to be absent in the presence of hearing loss greater than 35–45 dB, or where middle ear dysfunction is present, even if hearing is within normal limits.

Impedance testing revealed negative middle ear pressure in the left ear and normal pressure in the right ear. Acoustic reflexes were normal in the right and either absent or weak in the left ear.

SUMMARY/IMPRESSIONS

Results of today's evaluation are consistent with normal hearing sensitivity in both ears. There is no evidence of hearing loss that could be handicapping to speech and language development. The absent otoacoustic emissions in the left ear are consistent with negative middle ear pressure in this ear. Susie was referred to an otolaryngologist for treatment.

A speech/language evaluation was scheduled at the CARE Center. Ms. Jones was referred back to their developmental psychologist for follow-up. A behavioral audiologic evaluation should be scheduled following the speech/language evaluation, to determine frequency-specific thresholds and to observe Susie's responsiveness to auditory stimuli. Otoacoustic emission testing should be repeated when Susie's middle ear pressure is normal bilaterally.

Thank you for referring this patient to the Children's Auditory Research and Evaluation Center of the House Ear Institute. Please do not hesitate to contact me if you have any questions or if I can be of further assistance.

hearing loss (one that gets worse over time), or shows inappropriate/absent responses to sound in the home, it may be necessary to perform a full diagnostic ABR to search for hearing thresholds, even if the screening ABR at birth indicated a "pass."

Unfortunately newborn hearing screening is not routinely performed in all hospitals in the U.S. If a hospital has a hearing screening program, it is often only applied to infants who have a high risk factor for hearing loss (ASHA, 1989). High risk factors include things like facial deformities, family history of hearing loss, and administration of ototoxic drugs. Consequently, an early interventionist should obtain hospital records of hearing screening rather than rely on parental report only. Often the parents are not certain of whether a hearing test was done in the hospital prior to discharge.

Infants & children with neurological impairments

In infrequent cases where a child is multiply involved and has neurological dysfunction, the ABR may be difficult to obtain. If the neurological system is so impaired that many neural fibers of the hearing nerve cannot fire in a time-coordinated fashion, an ABR cannot be detected. Before assuming that hearing loss is present due to an absent ABR, one would need to take neurological dysfunction into consideration. Demyelination disease, such as multiple sclerosis, for example, can affect ABR morphology and latency adversely in some cases. Although latency and morphology abnormalities are often indicative of hearing loss, in this case, they would simply be consistent with multiple sclerosis. Consequently, it is critical to consider all of the child's problems when evaluating the abnormality or normalcy of the ABR. Some non-auditory problems may affect the ABR negatively and this needs to be taken into consideration before diagnosing hearing loss based on the results of this test.

The disadvantages involved with the ABR are minimal, especially relative to the information gained. Administering sedation involves a small risk and there are a few children that show an allergic reaction to the conductive gel or paste. There are no other known risks. Most audiological clinics routinely perform this test, however, some clinics provide specific expertise with the ABR and offer frequency-specific testing and bone-conduction ABR if necessary. Other clinics may perform only a routine simple version of the test. Also, some clinics specialize in pediatric assessment and may have more experience and expertise with children who have multiple disabilities, and are difficult to test. It is important to consider these factors when recommending an evaluation for a young child.

Finally, although the ABR is an excellent auditory test, careful audiologists recommend follow-up behavioral testing even after a normal ABR and definitely after an abnormal ABR. It is important to remember that our gold-standard of hearing involves a behavioral response confirming that sounds are being heard by the child. Even after an ABR has been obtained, it is important to strive for this goal. In some children with multiple disabilities, this will not be possible. Thus, the ABR may be the only indicator of normal hearing or hearing loss. As mentioned previously, in these cases, the ABR results will be relied upon heavily to fit hearing aids and/or other assistive listening devices.

Summary

In summary, the ABR requires no volitional response from the child yet gives an indication of hearing status in a non-invasive fashion by evaluating the conduction of sound through the hearing nerve and hearing pathways in the brainstem. It is often recommended in cases where an estimation of hearing threshold is necessary yet the child is unable or unwilling to provide behavioral indices of his/her hearing. Since its discovery and application in the early 1970s the ABR has served as an invaluable tool for estimating the audiogram. It is a safe test and has been used clinically for over 20 years.

An example of an ABR report is included (Report #5) to illustrate how results are typically reported. (This report also includes OAE results). Report format will vary from clinic to clinic. The reports, however, should be clear and concise containing a case history section, results, diagnostic impressions and recommendations section. If there is any ambiguity in an audiological report, it is important to call the audiologist and ask for clarification. After reading a report, an individual should be clear about the test results, what they mean and what the next course of action should be.

Otoacoustic emissions

Otoacoustic Emissions (OAEs) represent the most recently developed physiological test to assess hearing. Unlike the ABR, OAEs assess only cochlear or inner ear function. The hearing nerve or brainstem are not involved at all in the testing.

In order to understand OAEs, it is important to understand a little bit about how the cochlea works. For many years, the cochlea was thought to be a passive system that received sound and coded it, sent it on up the system to the brain. We now know believe that the cochlea is an active participant in the coding of sound. A signal comes in, it vibrates the delicate *basilar membrane* in the cochlea and then the cochlea activates its own energy source and *amplifies* the movement of the basilar membrane. During this amplification, some of the energy that is generated escapes, somewhat like a leakage. This escaped energy travels in reverse, back through the middle ear and toward the ear canal. If a sensitive microphone is put into the ear canal, this energy can be recorded. They are called otoacoustic emissions (Kemp, 1978). Bascially all normal-functioning inner ears produce these sounds.

There are two types of clinically applied evoked emissions: 1) transient or click-evoked OAEs, and 2) distortion product OAEs. Both of these OAEs tell us something about the ear. They are different primarily because we use different types of sound to evoke them and because they are different in the frequencies they represent when they are measured. Figure 6 and 7 display typical, normal TEOAE results and Figure 8 displays normal DPOAE results. The report included with these graphs should always interpret the results for you.

OAEs & hearing loss

Both TEOAEs and DPOAEs are related to hearing loss. When hearing loss exceeds about 35–45 dB (a mild loss), the cochlear amplifier is no longer functional and OAEs are not present. Consequently, OAEs can be a reliable indicator of hearing loss only if it is greater than mild in nature. A person can have a mild hearing loss and still have OAEs, however, they are usually smaller in amplitude and fairly sparse.

OAE analysis

At this point in audiology and hearing science, both TEOAEs and DPOAEs basically give us present/absent categorical information only. When OAEs are present, hearing is either normal (from 0 to 15 dB HL on the audiogram), or a mild hearing loss may be present (up to 40 dB HL on the audiogram). When OAEs are absent, a moderate through profound hearing loss may be pre-

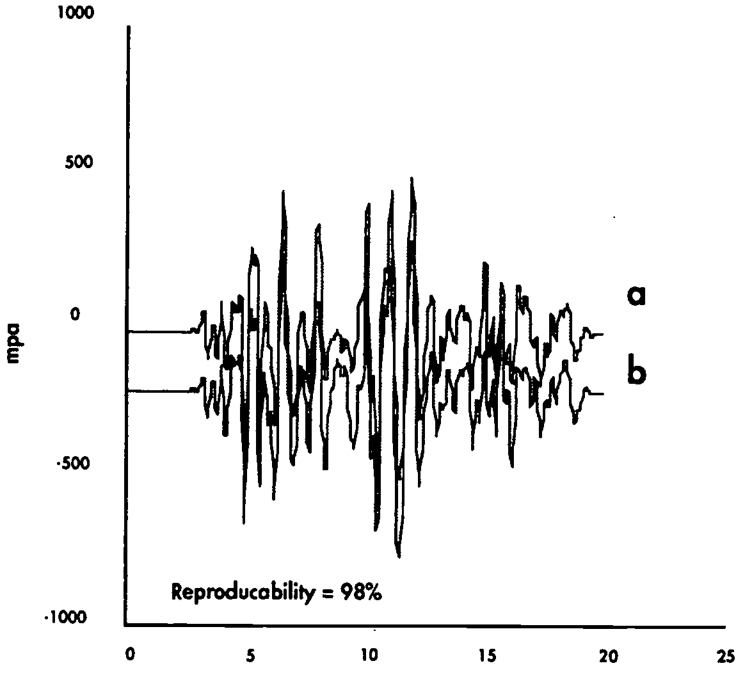


Figure 6. TEOAE Time Waveform

sent. They do not discriminate among degree of hearing loss or provide information about the configuration of hearing loss (i.e. high-frequency versus flat hearing loss). Consequently, if OAEs are absent, it simply indicates that hearing loss is present without yielding any information about the degree of hearing loss. When they are absent, it is usually necessary to conduct an ABR as follow up or a behavioral test if the child is able.

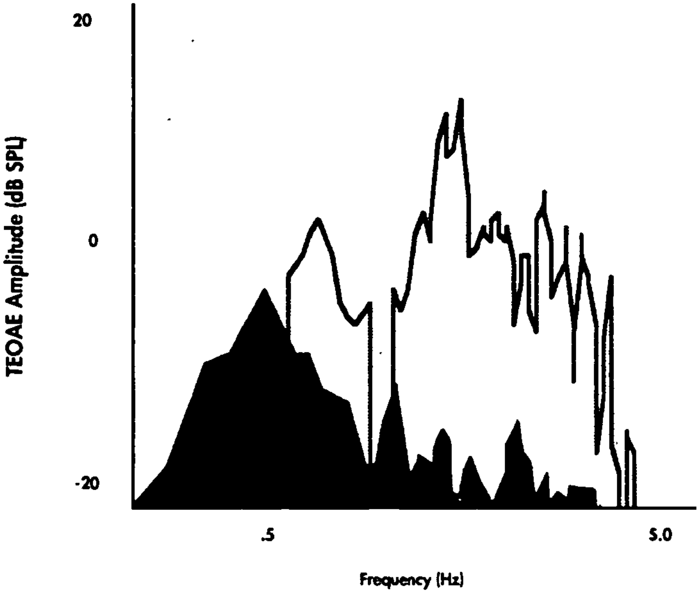


Figure 7. TEOAE Noise (block region) and Response (white region) for a Normal Hearing Child

Because OAE results are categorical (i.e. they are evaluated as being absent or present), they cannot estimate thresholds like the ABR can. If a person is interested in getting *threshold* information on an infant or child who cannot cooperate with behavioral measures, an ABR will provide this information, not OAEs. However, if someone wants to rule out hearing loss or deafness as a factor in learning disability or attention deficit disorder or autistic-like behavior, a normal OAE may provide this information quickly and effectively. A combination of ABR and OAE provide the most comprehensive evaluation since the ABR focuses on hearing nerve and brainstem conduction and OAEs focus on cochlear function.

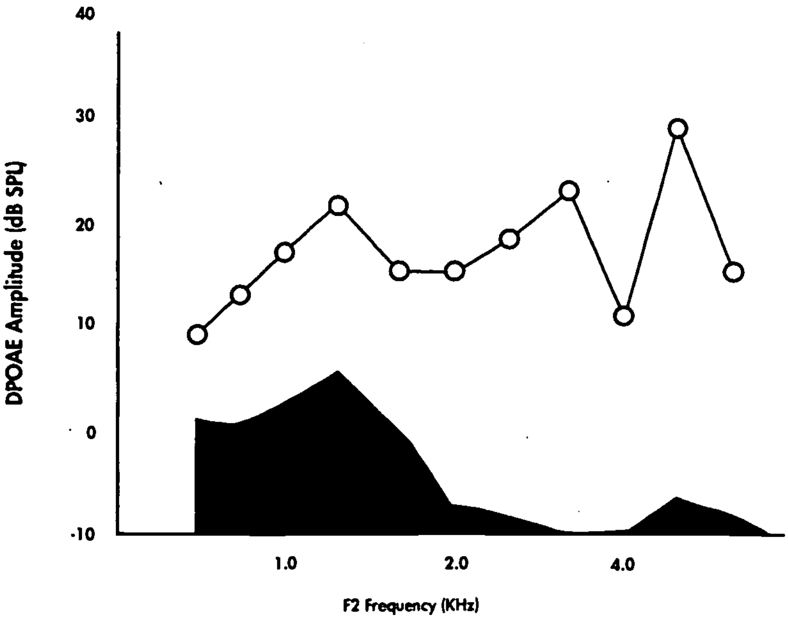


Figure 8. DP-Gram Generated from Distortion Product Otoacoustic Emissions for a Normal Hearing Child

Advantages of OAE testing

Although there are many limitations to OAE results (as discussed above), there are some very practical advantages as well. There are no electrodes to be applied, and the test itself may often be conducted in just 5–10 minutes. The speed of testing is a critical factor with children who are very young, babies in natural sleep, or lightly sedated children. Also, OAEs are completely non-invasive, require no skin preparation and cause no discomfort to the child.

OAEs are becoming a popular tool for screening the hearing of newborns in hospitals prior to discharge. The minimal test time makes OAEs attractive in the application. OAEs can answer some preliminary questions about hearing and often eliminate the need for extensive testing. For example, if they are present, robust and clearly normal, and the parent or interventionist does not have a real concern about hearing and auditory function, it may not be necessary to perform an ABR. This can save thousands of tests a year. Whether the OAE test is: 1) normal and eliminates need for further testing, or 2) ambiguous and necessitates further testing to define the problem, it is a time-effective procedure because the test because it can be done so quickly.

Middle ear problems

There is one critical factor that must be evaluated when making diagnostic decisions based on OAEs. The middle ear must be clear of fluid and/or infection for OAEs to be detected. Recall that the sound emitted from the ear travels backwards from the inner ear, through the middle ear and out into the ear canal. If the middle ear has an infection and fluid, the sound is absorbed by this and becomes so soft that it is no longer detectable in the ear canal. If there is a middle ear infection and OAEs are not present, it is impossible for the audiologist to know whether the OAE is truly being generated by the ear but unable to be measured due to the middle ear condition, or if it is not generated by the inner ear due to sensorineural hearing loss. OAEs must be measured when the middle ear is free of disease and fluid.

Auditory neuropathy

There is a rare auditory condition called an *auditory neuropathy* (Sininger et al., 1995) that must be mentioned as an exception to some of the general statements made above. In infrequent cases, we see children or infants that have present OAEs and absent ABRs. This condition may be more prevalent in children with multiple problems. The present OAEs, with no further information, would lead the clinician to believe that the ear was "hearing" and processing sound normally. Once the ABR is done, and it is evident that no response can be detected, it is clear that there is dysfunction in the auditory system.

In most cases of auditory neuropathy, there are accompanying complaints by the parent or teacher that the child is not functioning well in school, doesn't attend, doesn't hear, or hears sometimes better than others. If an audiogram has been obtained, often the thresholds fluctuate over time and speech discrimination scores are much poorer than one would expect based on the audiogram thresholds. Auditory neuropathy indicates that a person is neurally deaf. Even if the cochlea receives sound input normally, the brainstem or nerve cannot send the information upward to the brain effectively so it can interpret it as speech or other meaningful sound. This child is deaf in a very different way than other deaf children. This combination of findings is being seen more and more as clinics are obtaining OAE units and conducting both ABRs and OAEs on the same patients. Research is currently being conducted into its etiology and into rehabilitation for individuals who present with these symptoms.

Conclusion

In conclusion, the ideal tool for defining our hearing at all frequencies of importance is the audiogram. However, in young children, the audiogram or approximations of the audiogram must be obtained with creative behavioral techniques ranging from BOA to play audiometry. In many cases, even these unique and creative techniques, do not produce reliable results. In these cases, more objective physiologic tests such as the ABR and/or OAEs must be applied to assess auditory function. The ABR can estimate hearing thresholds at various frequencies while OAEs can rule out significant hearing loss when they are present but do not yield threshold information. The audiologist must be versatile and creative in applying the appropriate test battery for each individual child. As the child matures, the long-term goal is always to obtain an accurate behavioral reflection of their hearing. In this way, audiologists will be able to tackle the goal of aural rehabilitation and education in the most precise and appropriate manner.

References

American National Standards Institute (1969). *American national standard specifications for audiometers* (ANSI S3.6-1969). New York.

ASHA (1989). Guidelines: Audiologic screening of newborn infants who are at risk for hearing impairment, *ASHA*, 31, 89-92.

Folsom, R. (1990). Identification of hearing loss in infants using auditory brainstem response: Strategies and program choices. *Seminars in Hearing*, 11, 333-341.

Kemp, D. (1978). Stimulated acoustic emissions from within the human auditory system. *Journal of the Acoustical Society America*, 64, 1386-1391.

Menyuk, P. (1977). Cognition and Language. *Volta Review*, 78, 250-257.

Northern, J. & Downs, M. (1991). *Hearing in Children*. Baltimore, M.D: Williams & Wilkins.

Osberger, M. (1986). Language and learning skills of hearing-impaired students. *ASHA Monograph*, 23.

Salamy, A. & McKean, C. (1976). Postnatal development of human brain stem potentials during the first year of life. *Electroencephalography and Clinical Neurophysiology*, 40, 418-426.

Sininger, Y., Hood, L., Starr, A., Berlin, C., & Picton, T. (1995). Hearing loss due to auditory neuropathy. *Audiology Today*, 7, 10-13.

Thompson, G., Wilson, W. & Moore, J. (1979). Application of visual reinforcement audiometry (VRA) to low-functioning children. *Journal of Speech and Hearing Disorders*, 44, 80-90.

Thompson, G. & Wilson, W. (1984). Application of VRA. *Seminars in Hearing*, 5, 85-99.

Resource

Flexer, C (1994). *Facilitating hearing and listening in young children*. San Diego, CA: Singular Publishing Group.

MOTOR & Health

Gross Motor Development in Infants with Multiple Disabilities

by

Rita Snell

Understanding Medications & Medical Interventions

by

Beverly Simkin

Gross Motor Development in Infants with Multiple Disabilities

by Rita Snell

Typical development

A typical infant tends to follow a known developmental progression that starts at birth. As the infant grows and his central nervous system matures, the gross motor skills develop in a head to foot progression (Gesell, 1940). First, at about two months of age, the infant will learn to hold his head up in attempt to look at the world around him. As he begins to notice light and sounds, the curious infant will look from side to side, developing strength and coordination in the neck and upper back muscles. At three to four months an infant will often roll over for the first time while desperately trying to reach for a favorite toy that is just beyond reach. Around six months of age, when placed in a sitting position, the infant keeps himself balanced by propping himself up with both arms. Within a month or two, he is able to get into and out of the sitting position without any help, and use both hands to explore a toy. On the floor he can scoot across the room on his tummy, and later get up on his hands and knees to crawl. Generally by a year of age, the infant has figured out how to pull up to stand, cruise along the furniture, and maybe even attempt a few steps alone, until he is finally walking, climbing, and getting into everything (McGraw, 1943; Gesell, 1945).

Effects of disabilities

When an infant is developmentally delayed or neurologically impaired, these motor skills are often delayed, and do not develop easily. Gross motor skills occur in a typical sequence. However, these skills can only occur as the infant develops the balance, coordination and postural control needed to move his body about in space (Shumway-Cook & Woollacott, 1985). An infant's desire to reach out and explore his surroundings is the primary motivator that eventually leads to gross motor development. When an infant's disabilities interfere with what he is able to see and hear, or impair his overall motor functioning, then an infant will not follow the developmental sequence as we know it (Teplin, 1983).

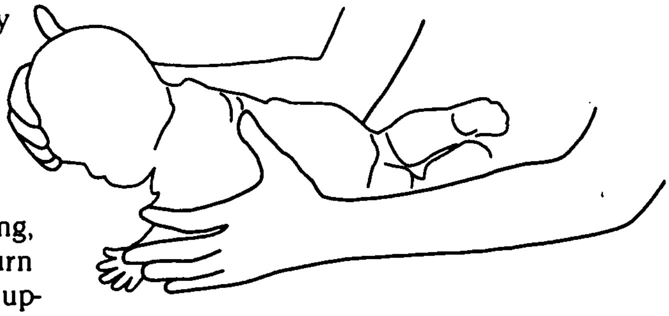
As a parent or early interventionist of a special needs infant, you may already be working with a physical or occupational therapist. Starting with a detailed assessment of your baby, they have probably established a specific program for you to follow. If so, please consider any precautions or specific instructions they have suggested. The activities presented in this chapter are general ways in which you can interact with your infant, while encouraging progress in gross motor development. Although each developmental level builds on a previously developed skill, the infant experiments with many movements at the same time, which are preparing him for higher levels of activity (Gesell, 1940). Playing with your infant and making it possible for him to explore his surroundings is very helpful for the baby's development. The extent to which each infant will progress depends on the type of impairment and the amount of neurological damage that is present.

In this chapter, I will cover the various gross motor skills from head control through walking. First, we will examine how these skills occur in normal development, then we can look at ways to adapt the environment as well as our interactions with an infant who has multiple disabilities to encourage these developmental skills. Each of these activities will allow the infant to experience normal movement to increase the likelihood that typical movement patterns will develop.

In each of the following areas, I have provided a variety of ways to play with your infant, and facilitate developmental milestones. Since infants are motivated initially through their senses, you can choose the most appropriate activity that meets the auditory, visual or physical needs of each infant.

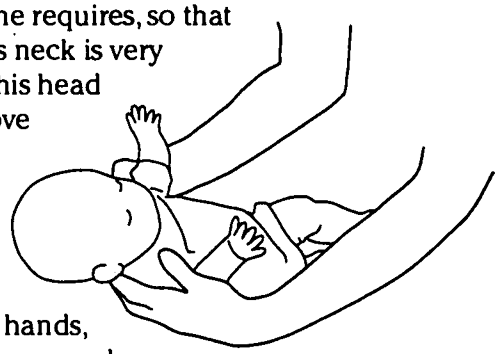
Head control

Head control is the first movement that a baby achieves, and is necessary to attain other movement skills such as sitting, crawling, and walking (Illingworth, 1983). Head control requires strength and coordination of the muscles which flex (bend) and extend (straighten) the neck. Infants are born with a flexion pattern throughout their neck and bodies, and will develop extension by repeatedly attempting to lift their head and turn it from side to side. A baby will develop head control in three major positions; prone (on tummy), supine (on back), and in sitting, as the infant learns to raise, turn and maintain his head in the upright position. A baby is generally motivated to turn his head in attempt to see an object, or to locate a near by sound. A newborn can distinguish colors, focus on a human face, and follow the movement of the face across his visual field (Miranda, Hack, & Fantz, 1977). When a child has a visual and hearing impairment, there are other ways to encourage head control and exploration.



Place baby on floor, lying on his back or stomach

An important way to develop head control in an infant is in the pull-to-sit position. Place the baby on his back, either on the floor in front of you, or on your lap. Place both of your hands behind his shoulders, providing only as much support as he requires, so that his head does not drop back. If the baby's neck is very weak, you can place your hands behind his head rather than his shoulders initially, and move your hands down to his shoulders as his head control improves. Slowly raise him up towards you, as you bring him from the supine to the sitting position. As his neck and trunk muscles get stronger, you can do this activity by holding the baby's hands, and gently pulling him up into sitting. This can only be done when the infant shows the ability to bring his own head forward, and uses his shoulders to help you pull him up into sitting.



Shake a rattle, or place a musical toy to each side, encouraging head turning.

Use flashlight or brightly colored object to encourage baby's eyes to focus in midline, then slowly move light from side to side, allowing the infant opportunity to turn head as he follows the light.

Gently stroke side of baby's cheek with your fingers, and with a variety of soft textures (plush toys, washcloth) to encourage head turning to each side.

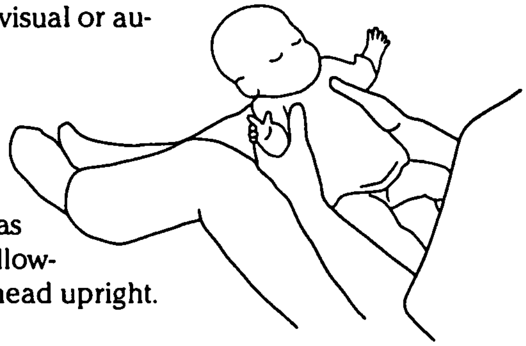
Approach and talk to your baby from both sides to encourage turning in both directions. If an infant has the tendency to look toward one side, make an effort to feed and play with your baby primarily from the opposite side.

Position yourself directly in front of baby, and use your voice, a musical toy, or brightly colored object to encourage him to raise head up.

If your infant shows no ability to raise head up or turn from side to side, place your hand gently on his forehead, and move him through these positions while providing visual or auditory stimulation.

Head control in sitting

Have infant sitting on your lap, facing you. With your hands behind his shoulders, gently move him from side to side, as well as forward and back. Move slowly, allowing him time to respond by keeping his head upright.



Playing in front of a mirror is a perfect way to work on head control. Sit on floor in front of mirror, with baby positioned on your lap, facing the mirror. Gently rock him side to side, and forward and back, allowing him opportunity to maintain head upright.

Rolling

The ability to roll smoothly from back to stomach, or stomach to back requires some degree of head control, and a rotation movement that occurs along the trunk of the body, between the hips and the shoulders. Rolling is the first movement that allows a baby to change his position, and usually develops between four and five months of age (Caplan, 1978). An infant with abnormal muscle tone may have difficulty with this movement. Spasticity can cause stiffness through the trunk, interfering with a coordinated rolling movement. A baby who is weak or floppy may not be able to begin the movement, as rolling requires enough strength to move against gravity.

As with head control, a baby is generally motivated to roll when an object of interest is off to one side, and he is determined to get to it. An infant with visual and auditory impairments can be encouraged to roll by providing him with brightly colored objects, musical toys, or your voice introduced from the side. If a baby is physically unable to roll, you can help him roll so he can experience this pattern of movement. A child who is visually impaired generally prefers being on his back, and will often learn to roll from his stomach to his back to avoid being on his stomach (Fraiberg, 1971). It is important for these infants to spend some time on their stomach, however, as many skills are developed when a child plays in this position. The prone position allows the baby to develop weight shift to each side, weight bearing through both arms and shoulders as he begins to prop on his forearms (Hanson & Harris, 1986), and trunk rotation as the baby reaches for a toy in front of him.

Rolling from stomach to back

Place infant on the floor, lying on his stomach

While baby is on his stomach, be sure his head is turned toward one side. Slightly tuck his opposite shoulder under him. Place a rattle or brightly colored toy in front of baby, where he can easily see it. Slowly raise it above where he is lying, encouraging him to follow it while turning his head, and shifting his weight over towards the tucked shoulder. The baby will then be in a position to roll over onto his back as he continues to follow the toy. If he stops following the toy or sound, bring it back to where he can easily see or hear it, and continue again from there. If baby gets stuck anywhere along the way, gently grasp the baby's top leg and help him to complete the rolling movement. Switch off doing this to both sides.

If the baby displays abnormal muscle tone, spasticity may interfere with rolling from stomach to back. You can physically assist the infant with rolling to help teach him this movement. Place the baby on his stomach, and as he looks toward one side, you can tuck his opposite arm slightly under him. Gently grasp the leg on the side toward where he is facing, holding near the hip and the knee. Bend that leg up slightly, and help him to roll over onto his back. This can be repeated to both sides.

If a visually impaired infant does not like the prone position, you can use pillows and wedge shapes to help him prop in that position, so that he can develop head and trunk control in his extensor muscles.

Rolling from back to stomach

Place infant on the floor, lying on his back

Present a rattle or brightly colored toy in front of baby. As he focuses on the toy, move it off to one side, and slightly above the level of his head. As baby follows the object, he will be encouraged to roll toward his side, facing the toy. If baby is unable to complete the movement, gently grasp his leg on the side opposite the toy, and assist him to roll onto his side, then over to his stomach.

Place brightly colored or musical toy to one side, and slightly above the level of baby's head. Gently grasp baby's leg on side opposite toy, and rotate that leg across baby's body, moving him onto his side. Assist infant to reach up toward toy, and continue to roll him onto his side, then over to his stomach, as he completes the rolling movement.

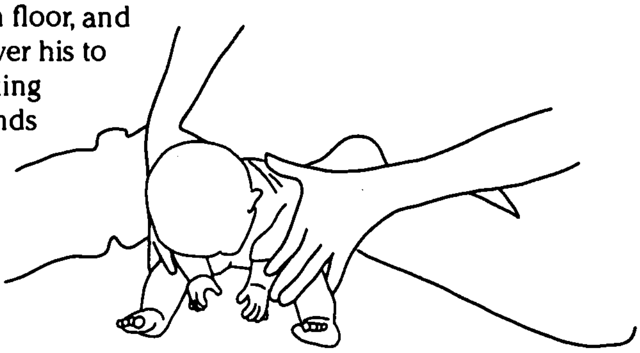
If baby cannot see or hear a toy, you can place him on his back, and gently move him through this position so that he can repeatedly experience this rolling movement.

Sitting

The ability to maintain a sitting position requires a baby to have developed equilibrium reactions and protective responses in the forward, backward, and side to side directions (Bobath & Bobath, 1964). If a baby has difficulty with maintaining balance, his equilibrium reactions can often be improved by playing with him in the sitting position, and challenging his balance in all directions. If a baby has muscle tightness in his legs, or weakness in his neck or trunk muscles, sitting will be more difficult for the baby. Initially a baby sits by propping forward with both hands in front of him. As his balance and upright posture improve, he maintains the sitting position by placing a hand to one side or the other as needed to keep himself sitting upright. Eventually the baby can hold himself in a good sitting position without the use of his hands for balance.

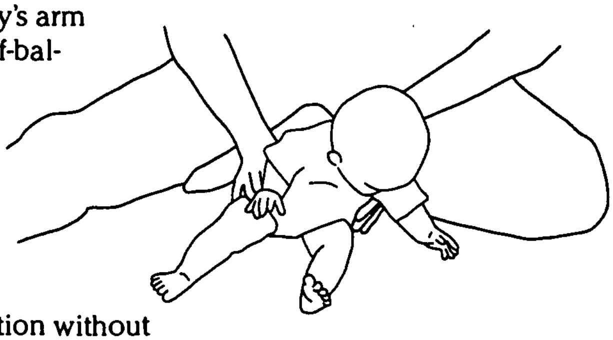
Developing the sitting position

Place baby on the floor in a sitting position, and seat yourself behind him to provide support as needed. Place toy or familiar object on floor in front of infant to encourage him to prop forward on both hands. If baby cannot put both hands on the floor, you can help by placing both of his hands on floor, and gently placing your hands over his to give him the sensation of taking some weight through his hands and arms. While your hands are still over his, rock him forward over his hands several times to help facilitate this propping position.



Once the infant can prop forward, you can begin to encourage side to side balance. Place a toy or familiar object off to one side, and slightly in front of the baby. Assist him to support his weight on the hand near the toy, as he reaches with the opposite hand. As you switch sides with this activity, the baby will have the opportunity to develop weight bearing and protective responses to each side.

If the infant falls to the side while in the sitting position, you can teach him to use his hands for balance. Start by placing one of his hands out to the side. Gently shift him off balance to that side, so that he needs to use that arm to maintain sitting balance. Switch off doing this to both sides. As the baby's arm supports his weight in this off-balance position, he will be learning how his arms can support him. The baby will begin responding by putting his arms out automatically as he leans to one side, until eventually he can maintain the sitting position without the use of his arms.



The visually impaired infant generally develops sitting around the same time as a sighted infant. It is common for them to be slower learning to get in and out of the sitting position. Try to provide a reason for the baby to get out of sitting, such as a musical toy just out of his reach.

There are many opportunities throughout the day to practice sitting with your infant. Each time you change a diaper or dress your infant, encourage her/him to assist in coming to sit by rolling toward one side, and pushing up into sitting with that arm.

Pull to stand, cruising and walking

Once an infant develops strength, coordination, and balance to move about freely on the floor, he will begin to pull up to stand and discover ways to explore things that were previously out of his reach (Bly, 1980). As a baby pulls to his feet and stands, he gains further strength and control in his trunk and leg muscles. Soon he develops enough strength and balance to "cruise" along furniture, as he sidesteps to reach a new destination. This sidestepping teaches the weight shift your baby will need to take steps forward in walking.

When an infant has increased muscle tone, the stiffness through the legs and possibly the trunk may interfere with pulling to stand, and maintaining the upright position. Often the spasticity will make both legs move stiffly together and cause the baby to weight bear up on his toes. When this happens, the baby will benefit from activities that encourage the legs to work separately, and help maintain the feet flat on the floor. Adaptive equipment is sometimes needed to assist your baby with walking, such as special braces or a walker. These would be recommended by your therapist or orthopedist, and they will be able to instruct you in the proper use of any adaptive equipment that is necessary.

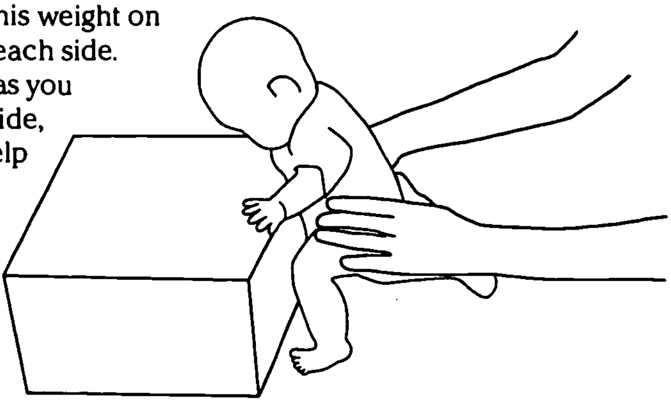
A visually impaired infant will often be delayed in walking, as he may feel insecure in the upright position. Very little of his body is supported once he is up on his feet, and he may prefer being on the floor until closer to 18 months of age (Fraiberg, 1971). Once he does show some interest in walking, he will need to be encouraged to move toward musical or noisy objects, or a familiar voice that is slightly out of his reach. It is also normal for the visually impaired infant to keep his feet further apart for a longer time, as he is understandably more unsure of himself without the visual input, and this will allow him to feel more balanced and secure during the first few months of walking.

Pull to stand

Once your baby gets around well on the floor, he will probably begin to play in the "tall kneel" position, where he is up on both knees, and usually holding onto a surface such as a couch or low table. If your infant is unable to assume this position, you can place him in this kneeling position, where he can support himself against a couch or low table or chair. Position yourself behind him, with your hands at his hips. Gently shift him over to one side, which places most of his weight on that leg, and very little weight on the opposite leg. This will allow him to pick up the leg he is not weight bearing on, and bring it up, so that he is in a half kneel position. From here, he can pull himself all the way up to stand, or you can assist him up into a standing position by keeping your hands at his hips, and shifting his weight slightly forward over his feet, and upward.

Position yourself seated on the floor, near a low table or couch. Place baby on your lap, facing away from you. Place a toy of interest, or a snack on the low table, and with your hands at his hips, shift his weight forward over his feet, and help him to assume the standing position. As he develops more strength and trunk control, allow him to do more of the work in pulling up to a standing position.

Once your baby is in the standing position, you can help improve his standing balance by gently shifting his weight from side to side, and encouraging him to support his weight on each leg, as you rock him to each side. Place your hands at his hips as you shift his weight from side to side, so that his arms are free to help him balance.



Cruising

Once in the standing position at a couch or low table, you can help encourage cruising, or sidestepping by placing a toy of interest or a snack a short distance out of baby's reach. With your hands at his hips, shift baby's weight off the leg nearest the toy, allowing him time to take a step with that leg. Now shift his weight over that leg, so he can take a step with the opposite leg, which will bring the legs together again. As you repeat this, he will be able to side step to one side. You can then repeat this in the other direction, to strengthen the muscles of both legs.

To help strengthen your baby's trunk and hip muscles so that he is able to cruise along furniture, have him stand on your lap while you are sitting on the couch or a chair. Hold both of your baby's hands, and gently move your legs up and down, one at a time, so that he will be shifting his weight from one side to the other. If he needs more support, place your hands at his hips to do this activity.

Walking

Have baby push a small chair, box, or push toy with a handle that is made for this purpose. Stand behind your infant, and give support with your hands at his hips, as you move the object just a few inches in front of your baby. Allow him the time to shift his weight forward, and take a step, as he moves toward the object he is pushing. Repeat this, continuing to move object just a few steps at a time, so baby has a chance to balance himself as he moves forward over alternating legs.

Position yourself on the floor behind baby while he is in a standing position. Place your hands at his hips, so that his arms are free to help him balance. Move yourself along behind your baby as you help him shift his weight from one leg to the other, allowing him to move forward in a walking pattern. As his balance and upright posture improve, offer him less support.

Try to make walking a purposeful activity for your baby, and encourage him to be up on his feet as you need to move from one room to another. When it is bath time, for example, assist him into an upright position, and use the technique described above to help him weight shift, and take steps forward into the bathroom.

Summary

All the play activities discussed here are presented in a way to help you understand normal development and movement patterns that your infant can benefit from. Once you understand the various ways to help your baby, you can begin to incorporate these ideas into everyday play that will be fun for both you and your baby. Most of the activities can be done on your lap as you sit on the floor or the couch, or even across your chest as you play on the floor with your infant. Just carrying your baby from room to room during the day can be an opportunity to help your baby develop head control if you provide only the support he needs, and allow him to assist with holding his head and trunk upright. If he tends to look primarily to one side, carry him in a way that he must look to the opposite side to see you.

Having your infant stand on your lap, supported at the shoulders or hips, or even standing him next to you while you sit on the couch is a great opportunity to encourage upright posture, weight shift, and equilibrium in standing.

Introducing toys and food from different sides encourages head control and trunk rotation that is needed in all of your baby's motor skills.

Dressing is an excellent opportunity to work on balance and weight shift if you have your baby stand to put on his pants, and sitting at the edge of the couch or your lap to put on his shoes and socks.

Gross motor development is an important area to develop in your infant, as it will allow him the opportunity to be mobile, and to interact with his surroundings. It is exciting to see the changes in your baby's overall growth and learning as he gains control over his movement and his motor abilities.

References

Bly, L. (1980). *The components of normal movement during the first year of life*. Chapel Hill, NC: University of North Carolina.

Bobath, K. & Bobath, B. (1964). The facilitation of normal postural reactions and movements in the treatment of cerebral palsy. *Physiotherapy*, 50, 246-252.

Caplan, F. (1978). *The first twelve months of life*. New York: Bantam Books.

Fraiberg, S. (1971). Intervention in infancy: A program for blind infants. *Journal of the American Academy of Child Psychiatry*, 10, 381-405.

Gesell, A. (1940). *The first five years of life*. New York: Harper.

Gesell, A. (1945). *The embryology of behavior.* New York: Harper.

Hanson, M.J. & Harris, S.R. (1986). *Teaching the young child with motor delays*. Austin, TX.

Illingworth, R.S. (1983). *The development of the infant and young child: normal and abnormal*. New York: Churchill Livingstone, Inc.

McGraw, M.B. (1943). *Neuromuscular maturation of the human infant*. New York: Hafner.

Miranda, S.B., Hack, M., Frantz, R.L. (1977). Neonatal pattern vision: A predictor of future mental performance? *Journal of Pediatrics*, 91, 642-647.

Shumway-Cook, A. & Woollacott, M.H. (1985). The growth of stability: Postural control from a developmental perspective. *Journal of Motor Behavior*, 17, 131-147.

Teplin, S.W. (1983). Development of blind infants and children with retrolental fibroplasia: Implications for physicians. *Pediatrics*, 71, 6-12.

Resources

Batshaw, M.L. & Y.M. Perret (1988). *Children with handicaps; a medical primer.* Baltimore, London. Paul Brooks Publishing.

Boehme, R. (1990). *Approach to treatment of the baby*. Tucson, AZ: Therapy Skill Builders.

Brown, C.C. & A.W. Gottfried (Eds.) (1985). *Play interactions: The role of toys and parental involvement in children's development*. Skillman, NJ: Johnson and Johnson Baby Products.

Diamant, R.B. (1989). *Positioning for play; home activities for parents of young children*. Tucson, AZ: Therapy Skill Builders.

Finnie, N. (1975). *Handling the young cerebral palsied child at home*. New York: E.P. Dutton and Company, Inc.

Hagstrom, J. and J. Morrill (1981). *Games babies play and more games babies play.* New York: Pocket Books.

Jaeger, D.L. (1987). *Home program instruction sheets for infants and young children*. Tucson, AZ: Therapy Skill Builders.

Parks, S. (1988). *HELP...at home. Activity sheets for parents*. Palo Alto, CA: VORT Corporation.

Understanding Medications & Medical Interventions

by Beverly Simkin

The birth of a child who has a disability is a difficult and stressful time for a family. It is a time when parents must grieve the loss of the "perfect" baby that they had anticipated and deal with the medical and emotional complexities of the situation (Batshaw, 1991).

When the infant is finally discharged home from the hospital, the parents are generally overwhelmed with the "special care" that their baby needs. Besides feeding and infant care, medications, treatments and special equipment become part of the daily routine. Parents must learn to cope with dependency on medical and paraprofessional personnel for advise and intervention.

This chapter covers issues frequently encountered by Early Interventionists (EI) during home visits and/or center based sessions by offering clarification of common medical concerns and interventions. It is a collection of practical information that can be shared with families and team members to enhance the understanding of health related issues.

Medication

It may be necessary for an infant to receive medication for an injury, illness or medical condition. Medication must be given as prescribed by the infant's doctor. The EI and the parent(s) should observe the infant's response to the medicine once it is given. It is important to note if the medicine is effective: is it doing what it is supposed to do? The infant's doctor should be contacted immediately if the infant shows any side effects or adverse reactions. Parents should be reminded to give all the medication that is prescribed for their infant. Even as the infant's condition begins to improve, some therapies require a full treatment plan before lasting results can be achieved. Never change the dose and/or frequency of any medication an infant is receiving without consulting a physician.

Possible questions/concerns for the family

What are the side effects of the medicine that my baby is taking? Generally, most medications are taken without any problems. Occasionally, a drug may cause a rash or upset stomach which would be considered an adverse side effect. It is important to read the medication insert that is provided with the medicine from the pharmacy or pharmacist. It would be appropriate to call the pharmacist or physician with any questions or concerns about the drug. Many phar-

Common medications used in the home

Type of Medication	Indication for Usage	Schedule of Administration and Comments
Analgesics *Tylenol* *Motrin*	Given for pain.	To be given at regular intervals to maintain a constant level of pain control.
Antibiotics *Ammoxicillin* *Ceclor* *Pediazole* *Bactrim*	Given for bacterial infections such as ear infections, conjunctivitis or tonsillitis.	To be given at regular intervals throughout the day and usually 10–14 days in duration. Improvement in the child's condition is generally noted in 2–3 days but for lasting results all medication must be taken.
Anti convulsants (Seizure medication) *Phenobarbitol* *Depakane* *Tegretol*	Given for seizures or seizure-like activity.	They are often given in combination with each other and in fluctuating doses until the optimum level of seizure control is achieved. An initial loading dose of the drug(s) is prescribed to achieve a blood level that will produce seizure control without sleepiness, then, a lower maintenance dose will be prescribed for ongoing use. It is important to remember that sensory systems may be affected adversely when these drugs are used like worsening already poor vision or dulling skin sensations to textures and temperature.
Antihistamines *Benadryl*	Given for allergies and allergic reactions.	To be used for temporary or long term use until the irritant source is identified and removed. They often cause drowsiness or sleepiness that may interfere with typical activity level for the infant.

Continued on page 180

Common medications used in the home

Continued from 178

Type of Medication	Indication for Usage	Schedule of Administration and Comments
Antipiuretics *Tylenol*	Given for fever.	They are used at regular intervals to keep the fever down. They may also be used with cooling measures (tepid bath) to bring down a high fever.
Decongestants *Triminic* *Dimatapp*	Given to relieve congestion in the nose and chest.	They are given at regular intervals (short and long term) to keep air passages clear. They generally do not cause drowsiness or sleepiness but may cause excitability and difficulty sleeping.
Expectorant *Robitussin* *Robitussin DM*	Given to help thin secretions so they may be easily coughed up.	They are given when ever needed but usually just at night. They are used along with decongestants as therapy for congestion.
Ophthalmic medication	Antibiotic eye drops or cream are given for eye infections.	They are prescribed to be given at regular intervals (eye drops or cream) throughout the day for approximately 5 days or until the infection is gone.
	Dilators are used for eye exams.	They are given by the eye doctor or nurse prior to examination of the internal eye structures. Although eye drops used during an examination are generally safe, respiratory distress can be an adverse side effect if these drops drain into the sinuses.
Prophylaxsis medication (antibiotics and decongestants)	Given to maintain a constant drug level in the body to deter any infection from recurring in the infant.	To be given once daily either in the morning or at night. It is to be used following a full course of drug therapy and after a long history of recurrent infections like sinusitis or ear infections.

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macies have a "hot line" for medication questions at their disposal.

Can I give his/her medication with food?
All dispensed medication must be labeled with easy-to-read instruction including: patient's name, dose, method administration, frequency of administration, storage requirements and any special instructions. Medications such as analgesics and antibiotics need to be taken with food since they can upset the stomach, while other medications absorb better if the stomach is empty. It is very important to read the "medicine bottle" instructions prior to administration of medicine to infants and children. Medication instructions can also be requested in Spanish for Spanish speaking families. The request for Spanish instructions should be made at the time the prescription is dropped off to is be filled. Requests can also be made for the medication to be placed in two bottles for an emergency pack or supplies for child care.

What do I do if I spill or lose the medicine for my baby?
Just call the pharmacy where the prescription was filled and explain the circumstances. Generally, extra medicine will be provided (for an additional charge) so that the course of therapy can be completed.

Medication precautions

DO...

...keep all medication out of reach of children.

...give medicine at the times prescribed by the doctor.

...store medication as indicated by the pharmacist and/or company.

...give medicine at the times prescribed by the doctor.

...keep an extra bottle of medicine in emergency supplies. If it is a prescription, check the expiration date periodically.

...measure liquid medicine in a measuring spoon or medicine syringe for accuracy. Do not use tableware.

...ask your pharmacist for child protective caps on all bottles of medicine.

DON'T...

...mix the medicine in a full bottle of milk or juice. The infant may not finish the whole bottle and will not get the required dosage.

...mix medicine with favorite food. The child will associate medicine with it and will stop eating it.

...give medicine that is expired as it will have decreased effectiveness or no effect on the problem. Do check the expiration date!

...give medication that is prescribed to someone else. This is dangerous and foolish.

Sedation

Many exams and procedures require the infant to be completely still, so that the procedure can be completed quickly and safely. Since *all* children have difficulties remaining immobile, it is necessary to sedate them.

Sedation of infants and children can be achieved by giving medication orally or rectally, by injection or intravenous therapy. Medication taken by mouth or rectally needs time to be absorbed through the intestinal tract before it reaches the blood stream and can be effective.This process can take up to one hour before the infant falls asleep.Medication given by injection or intravenous therapy (IV) acts much faster since it is administered directly into the muscle or blood stream. Medication given this way will usually be effective in 10–20 minutes (Physicians' Desk Reference, 1995).

The type of medication that an infant will receive depends on the level of sedation required for the procedure, the age of the child, the setting or location where the procedure will take place and the physician's preference (Lovejoy, 1987). Some procedures require the infant to be completely immobile while other procedures require him/her to be sleepy or tired. Depending on the level of sedation, the infant may need to be monitored until awake and alert before going home.

General anesthesia is the strongest form of sedation. This type of sedation is often necessary to reduce the risks of injury during a procedure or medical exam (Lovejoy, 1987). General anesthesia provides complete sedation in a controlled setting at which time the infant is monitored very closely. It is available only in an operating room setting where it is administered by a anesthesiologist or nurse anaethetist. It is given through a mask over the face and is often preceded by an injection to make the infant tired or sleepy.

When an infant requires general anesthesia, the anesthesiologist or nurse anaethetist will meet with the parents in advance to discuss the scheduled procedure. He/she will ask questions about the infant that may have been asked before and will want to know if the infant has any allergies to foods or medications. The parent(s) may be asked to sign a consent for the general anesthesia separate from the procedural consent, since the doctor/nurse practitioner who administers the anesthesia is different from the one doing the procedure.

Possible questions/concerns for the family

How long will it take before my baby wakes up? (This is an important question for the parent(s) to ask the doctor in charge.) The level of sedation required for the procedure, the drug used and the baby's ability to excrete that drug from his/her body will determine how long it will take for the baby to wake up. Regardless of the type of sedation received, it usually takes a day for a baby to be back to his/her usual level of activity.

Can the baby still eat if he/she has to be sedated?
In most cases when food must be restricted prior to medication or procedure, the infant is scheduled for the first morning appointment. This way the infant does not have to wait very long without eating (since he/she usually does not need a bottle at night). If the infant is scheduled for a surgical procedure where general anesthesia is necessary he/she must have nothing to eat at least 6–8 hours prior to this event. Sometimes the combination of food and the anesthesia may cause the infant to throw-up, so it is best that the stomach remain empty to avoid aspiration of the stomach contents should the baby vomit.

After the procedure is completed the baby should not be fed until he/she is completely awake to avoid complications of aspiration of food. *A sleepy baby will have trouble swallowing* and may choke and gag on a bottle of milk or juice.

Can my baby still be sedated and have the procedure if he/she has a cold?
It is up to the doctor to determine if the baby is stable enough to undergo the procedure prescribed. It will also depend on the imminent need for the infant's health and well being. Many physicians will have the parent(s) follow up with their pediatrician/care provider to determine the infant's health status prior to any procedure that requires sedation. If there are still health or medical issues related to the infant's status, a phone call to the doctor in charge may help clarify the situation. It is the doctor's responsibility (not the early interventionist) to provide information to the parents to alleviate fears. "Informed Consent" is a law that requires physicians to explain in full, all aspects of any medical procedure prior to the medical intervention.

Seizures

Seizures are caused by abnormal and excessive electrical discharge from neurons in the brain. Resulting behaviors may include loss of consciousness and muscle spasms (clonic-tonic) a dazed look, staring, or twitching (Batshaw, 1991; Lovejoy,1989). There are many types of seizures that are a result of numerous medical and/or neurological diagnoses including prematurity, infections, trauma, and hypoxia.

It is important to notice and record events leading up to, during and after a seizure, along with any other information that may be related to the event (e.g. duration, frequency). If you notice an episode during an intervention session you should collect this data to share with parents so they may follow up with their infant's doctor.

When a seizure occurs *remain calm* and keep the infant safe from harm. You may need to position the infant on his/her side to prevent aspiration of secretions. Do not restrain the baby's body movements and call for help if you feel you need it!

Long term management is directed at prevention of seizures and promotion of normal development of the infant/child (See Medications: Anti-convulsants).

Febrile seizures occur in up to five percent of children during childhood (Chow,1979). Generally these seizures are associated with a rapid rise in an infant's temperature due to illness or immunization. Febrile seizures are characterized as lasting less than five minutes, having a single occurrence and causing no changes in brain wave patterns (i.e. EEG). Parents should notify their physician immediately to determine appropriate follow up care. Children who show recurrent signs of febrile seizures may be given a daily prophylactic dose of an anticonvulsant to prevent further episodes.

Seizure precautions

DO...

...remove hard and dangerous objects from the area

...lower the child to the ground, if possible,

and,

...attempt to lay the child on his or her side with the hips elevated and the head turned to the side.

DON'T...

...place any object between the child's teeth

...restrain the child in any way

...pour liquids into the child's mouth; he or she may inhale the liquid and begin to choke,

or,

...attempt to ensure that the child does not swallow his/her tongue. It is impossible for that to happen.

Electroencephalogram (EEG)

An EEG is sometimes indicated to provide a more complex evaluation of the nervous system, to rule out or confirm a seizure disorder and to provide baseline information for future use. This procedure is performed by attaching very small electrodes to the scalp of the infant with tape. The electrodes are prepared with a white paste to the tip prior to placing them on the scalp. The paste improves the conduction of electrical impulses through the electrodes and up the wires which are attached to a computer to record the brain's electrical impulse patterns (Batshaw, 1991).

The infant must be completely still and is sedated to achieve a sleep state for best results. Movement by the infant will disturb the brain's wave patterns and furnish unclear results. The exam takes approximately one hour once the infant is asleep and is repeated in intervals of six months to a year or as necessary.

Types of seizures

GENERALIZED SEIZURES Seizure activity that occurs throughout the entire brain

TYPE	SYMPTOMS	DURATION/OCCURRENCE	POST SEIZURE ACTIVITY/IMPLICATIONS
Tonic-Clonic Seizures (Grand Mal Seizures)	Loss of consciousness; body become rigid begins rhythmic jerking and shaking.	Lasts 30 seconds to 5 minutes.	Relaxed, disoriented, lethargic or sleepy.
Absence Seizures (Petite Mal Seizures)	Looks vacantly into space, blinking, loss of awareness momentarily.	Occurs during late childhood and adolescence. Can happen over 100 times daily.	Not associated with falling or injury. Not followed by sleepiness or fatigue. Can interfere with alertness and learning.
Myoclonic Seizures (Infantile Spasms)	Sudden startle-like episodes. Body flexes or extends.	May be as brief as a second and occur in clusters of 8–10 frequently throughout the day.	Begin at 3–6 months of age and are difficult to control. These cases often have a poor prognosis.

PARTIAL SEIZURES Limited to a part, or "focus" in, one side of the brain

Occipital Lobe Focus	Visual disturbances	Lasts 2–3 minutes.	In "Simple" Partial seizures there is no loss of consciousness.
Frontal Lobe Focus	Muscle twitching	Lasts 2–3 minutes.	Complex partial seizures are associated with loss of consciousness and are often difficult to control.
Temporal Lobe Focus "Psychomotor" Seizures	Mental distortions or hallucinations, heightened sensory experiences, repetitive fine-motor actions.	Lasts 2–3 minutes.	

Lovejoy, 1987

Possible questions/concerns of the family

Will the seizures go away when my baby takes the medication?
Seizure disorders are generally a chronic, ongoing problem for infants and children who have them. Medication can help reduce the symptoms of the disease but usually does not eliminate it (the disease). Situations that are stressful to the infant may cause a flare up of seizures. A rapid growth spurts may demand frequent changes in medication doses and impact the anti-seizure therapy.

My baby is always sleepy. Can I decrease the medication?
Sleepiness may be an indication that the infant may be receiving more medication than he/she requires. It is important to notify the physician and discuss the infant's behavior if he/she is unusually sleepy or lethargic. Changes in medication should only be determined by a physician. Guidelines on how to make simple adjustments in the medication (if the situation permits) are usually given by the physician at the time of medical intervention.

If my doctor tells me over the phone to increase/decrease medications,is it safe?
Physicians are trained to give advice and orders over the phone. It is a very common practice for physicians to provide information concerning changes in medications and/or dosages. It is vital to observe the infant's behaviors after a medication alteration and report to the doctor any changes (positive or negative) that occur.

Related problems or illness

Ear infections

Otitis Externa (Swimmer's Ear)

This is a painful infection of the external auditory canal. It causes pain upon movement of the ear, swelling and possible discharge. Ear drops are generally prescribed to relieve pain and cure the infection (Lovejoy, 1987; Mitchell & Eiger, 1994).

Serious Otitis Media (Fluid in the middle ear)

This is a condition in which there is an accumulation of fluid in the middle ear. It can be caused by allergy, colds, ear infections or changes in altitudes or pressure. It may continue for weeks or months following and ear infection and cause a sensation of fullness in the ear. It can cause a decrease in functional hearing ability. Fluid in the middle ear decreases the motility of the ear drum and is detected during visual inspection of the drum or tympanometry (Lovejoy, 1987; Mitchell & Eiger, 1994).

Suppurative Otitis Media (Middle ear infection)

A bacterial infection of the middle ear that is very common in infants and children. It causes severe pain and needs prompt attention. The position of the infant/child's eustachian tube, which is shorter and more horizontal than an adult's leads to the higher incidence of this problem with this age group. The infant may show signs of nasal congestion, ear pulling, irritability and/or fever. Oral antibiotics are generally prescribed for 7–10 days along with a follow-up ear recheck at the end of the drug therapy (Lovejoy, 1987; Mitchell & Eiger, 1994).

Many infants and children have an occasional ear ache or ear infection that is cleared up with drug therapy. They usually do not have significant, long lasting effects on the infant/child's hearing. However, middle ear fluid may linger for many weeks following an ear infection and needs to be monitored by the physician.

Chronic Otitis Media is a condition in which infants and children are plagued continuously with recurrent middle ear infections following repeated courses of antibiotic treatment. Infants and children who have six or more ear infections a year are considered to have this problem. This condition can significantly impact the infant/child's hearing and language acquisition and the patient should be referred to a Ear-Nose & Throat (ENT) Specialist for consultation and evaluation. Early identification of a hearing loss through regular hearing screenings is extremely important. It is also recommended that hearing testing be done prior to six months of age for all children who are premature, developmentally and/or multiply disabled as they are at a higher risk for a hearing loss (Batshaw, 1991; Lovejoy, 1987).

Universal precautions for home visits

WASH YOUR HANDS before and after each visit.

USE A DISINFECTANT SOLUTION to wash all toys that the infant has touched or mouthed after each visit.

IF YOU WIPE the infant's nose during a visit, use plenty of tissues and wash your hands right away.

DO NOT VISIT an infant's home if you have a cold! Many of the infants that you serve are medically fragile and are more susceptible to infection.

Lovejoy, 1987

If antibiotics and decongestants are ineffective for chronic or serious otitis media, the doctor may recommend a procedure that is called *myrigotomy with vent tubes* to combat the problem. In this procedure, a very small hole is placed in the ear drum and the middle ear fluid is drained. Next a very small vent tube is placed into the ear canal and pushed down the ear canal until it reaches the ear drum. The vent tube is then nudged into the ear drum where it is left to stay. The ear drum eventually adheres to the vent tubes to secure them in place. This allows pressure on both sides of the ear drum to equalize and allows accumulated fluid to drain as necessary. This is a very delicate procedure and requires the infant to be completely immobile, therefore, general anesthesia is required. The procedure takes approximately fifteen minutes once the infant is surgically prepared (Lovejoy, 1987; Spock & Rothenberg 1992).

Following the placement of "tubes," it is important for the parent(s) to adhere to the directions for the care and the maintenance of the vent tubes. There has been controversy on the care of vent tubes, keeping canals dry vs no restrictions (Lovejoy, 1987; Chow, 1979). It is important to ask the parent what they have been told to do by the physician and follow the parent's instructions.

Universal precautions for center-based program

WASH YOUR HANDS before the program begins and when your hands become "dirty" from activities or infants secretions.

IF YOU CHANGE a child's diaper use good hand washing technique and protective gloves. Dispose of the diaper properly as your program has indicated.

WASH ALL TOYS that the infant has touched or mouthed with a disinfectant solution when an activity is completed before other children use them.

IF YOU WIPE the infant's nose, use plenty of tissues and wash your hands right away.

IF YOU HAVE A COLD it may be best to stay home until you are feeling better. If you must work, refrain from interaction with the children since you could be contogious. Many of the infants that you serve are medically fragile and are more susceptible to infection.

Lovejoy, 1987

Possible questions/concerns for the family

Why does my baby have to take medicine all the time?
Antibiotics and decongestants are the first line of treatment for ear infections. They are relatively safe and generally effective for this problem. Some infants may need many courses of different drug combinations until the condition is cleared and will then be placed on prophylaxis antibiotic therapy to stop a recurrence. Ultimately, some may need surgery and the placement of vent tubes.

What effect does ear infections have on my baby's ability to hear?
Fluid trapped in the middle ear (infected or not) will cause a conductive hearing loss. This means that the infant will not be hearing certain sounds or words or that they may be distorted and unclear. If this condition is ignored, it can severely impact a child's communica-

tion and language development. *It is important to follow-up on ear exams and hearing tests to determine the effectiveness of medical treatment and hearing ability.* If middle ear fluid is chronic, a consultation with an ear specialist would be important.

Nutritional supplementation

Some infants will have difficulties eating enough food to sustain normal growth due to neurological and/or oral tactile defensiveness (does not like things or food textures in or near the mouth or face) problems (Batshaw, 1991). As a temporary measure, a thin tube is passed through the nasal opening down to the stomach which is called a naso (nose)- gastric(stomach) tube. When a child has significant difficulty getting enough nutrition by mouth, a gastrointestinal tube (G tube) is placed through the abdominal wall directly into the stomach (Batshaw, 1991). Liquids as well as semi-solid supplements can be given through either of these tubes by gravity (also known as gavage feeding). The G tube can be for supplemental feedings only, or may be the avenue for total nutritional support. A G tube is not a treatment that should restrict activity or positioning of an infant. Most infants learn to discriminate which positions are most comfortable and generally let their caregivers know how to position them.

You may encounter an infant that uses a feeding/Kangaroo pump. This is a machine that gives the nutritional supplement at regular amounts and over a predetermined period of time, at regular times during the day and night, or only at night. It is up to the infant's doctor to determine the rate and the amount of supplement to be given. This amount is based on a formula growth rate in relation to caloric intake.

Possible questions/concerns for the family

How long will my baby be on a G tube?
The length of time an infant will need a G tube depends on his/her nutritional needs and ability to take food by mouth. It will be up to the physician and/or medical team to determine the duration in which a G tube will stay in place.

How can I bathe my baby?
Once the G tube has been in place and the doctor allows bathing, the infant can be bathed in the regular manner. In general, infants prefer tub baths but the shower is fine if that is the infant's normal routine. Remember to dry the area around the tube well as it can become irritated if moisture is allowed to accumulate there. If the area around the tube should become reddened and irritated or "weepy," it is important to contact the physician to determine the appropriate care.

How will he learn to eat?

When a child has been using a G tube for a significant amount of time for his nutritional needs, he often becomes used to eating through the tube and no longer has the need or desire to eat by mouth. Also, when a child is fed by a G tube his feedings are usually scheduled and the child does not have the opportunity to experience hunger. Another problem that may be encountered is the fact that an infant may not have the oral motor skills necessary for sucking or eating or may be oral tactile defensive (does not like things or food textures in or near the mouth or face).

Once the child is out of danger for weight loss and his nutritional status is no longer a threat to his well being, the therapeutic focus can turn to getting the child to eat by mouth again. This can be a long and difficult process to teach a child to eat again by mouth and takes the combined efforts of the medical team, intervention team and family for this process to be successful.

It is important to remember to encourage infants to place approved appropriate infant items in their mouths (i.e., pacifier, wash cloth, toy) whenever possible, especially if they are receiving feedings through a G tube. Also, if approved by

Special equipment

OXYGEN Comes in green tanks of varying sizes or in a liquid form sometimes called a "Lindy Walker." It should never be used in the presence of an open flame such as a lit cigarette, stove or fireplace. It is administered through nasal prongs for continuous use or by mask for temporary therapy. Some children may outgrow the need for even intermittent therapy and eventually only require oxygen during an illness.

SUCTION EQUIPMENT It is a portable unit that can be plugged into the wall or run on battery. A supply of suction catheters (long thin tubing) are used and can be passed through the nose, mouth or tracheostomy down to the lungs, depending on the needs of the infant. Parent(s) are instructed on operation and care of the equipment for use in the home.

RESPIRATORY TREATMENT MACHINES (PulmonAid) These are machines that administer medication directly into the lungs under positive pressure. Respiratory medicine is placed in a chamber that is attached to the tubing that is connected to both the machine and the infants mask. When the machine is turned on, air is pushed through the tubing and medicine chamber forcing the medicine out (like a mist) into the infants mask. The oxygen mask is then placed over the face of the infant so he/she can inhale the medicine during the natural rhythm of breathing. The mask remains in place until the medicine in the drug chamber is completely gone. The benefit to this mode of treatment is that the medicine can be placed directly in the area where it is needed. When respiratory medicine is given in this way, the medicine has virtually no adverse side effects.

the physician, give the infant small amounts of food or formula by mouth prior to or during a G tube feeding to associate feeding with food in the mouth and not just through the tube.

What happens if the tube falls out?

Before your infant is discharged from the hospital you will be instructed on the care and maintenance of the G tube. Instructions include how to reinsert the G tube if it should fall out. It is important to insert the new tube as quickly as possible so the opening to the stomach will not close. Go straight to your physician or medical center for immediate follow-up care.

Tips for parents

OBTAIN COPIES of all medical records for each child.

PLACE IN A BINDER and organize according to medical specialities (i.e. pediatrics general care, orthopedist, ENT).

HAVE A LIST of child's physicians and their phone numbers close to the phone.

HAVE A LIST of current medications (including amount and the reason for usage) close at hand. Make sure to revise the list regularly.

HAVE A LIST of emergency contacts and procedures for by the phone.

MAKE A PHONE LIST of all individuals and professionals (including names addresses, phone numbers, and what they do) and place it in your binder.

KEEP TRACK of phone calls by keeping a phone log so you can remember who you called, when you called and for what purpose you called them.

Respiratory infections

Respiratory tract infections are the most common cause of illness in infants and children. They include symptoms of cough, respiratory difficulties, rhinorrhea (runny nose) and sore throat. The causative agent is generally a virus and most infections are treated symptomatically with fluids, humidification and medication (Brazelton, 1983; Leach, 1995, Lovejoy 1987).

It is important for an early interventionist to use "good" judgment and universal precautions when confronted with an infant who has an upper respiratory infection (URI). If the infant has an active URI and is producing lots of discharge, it is probably a good idea to postpone your visit until another time. Since it is hard to determine whether an infant is "coming down with something or not," it is important to *always* follow universal precautions with every infant or child that you visit.

Severe acute and chronic respiratory conditions (eg. asthma) often require special equipment for their treatment. They may require oxygen, suction equipment, or respiratory treatment machines

(Batshaw, 1991). It is necessary to know what precautions (if any) are required.

Possible questions/concerns for the family

How will I be able to provide all of these therapies for my baby? I'm not a nurse!

Before an infant is discharged from the hospital, instructions on required infant care are always given. The hospital staff encourage parents and family members to practice the infant's care before leaving

Glossary

ADVERSE SIDE EFFECTS Unfavorable condition(s) that may occur with use of medications or treatments.
ANALGESIC Medicine given for pain.
ANTIBIOTIC Medicine given for bacterial infections.
ANTICONVULSENT Medicine given to control seizures.
ANTIHISTAMINE Medicine given to reduce symptoms of allergy and allergic reactions.
ANTIPIURETIC Medicine given to reduce fever.
ASPIRATION Act of breathing into the lungs.
BASELINE A basis serving as a measurement of comparative studies/tests.
CONGESTION Nasal "stuffiness" or chest congestion related to a cough.
DECONGESTANT Medicine given to relieve congestion in the nose and chest.
DISABILITY Physical, neurological or genetic disorder that prevents or restricts typical development.
DOSAGE Amount of medicine to be given.
EXCRETE Discharge waste material from blood, tissue or organs.
EXPIRATION Date printed on the medication label to indicate when the medicine is no longer "good" to use.
HUMIDIFICATION Adding extra moisture to the air through warm or cold mist.
HYPOXIA Lack of oxygen.
IMMOBILE Unmoving.
INJECTION "shot."
INTERMITTENT Occurring at different times (may or may not be scheduled).
INTRAVENOUS Therapy medicine, fluid and/or nutritional supplements given thraugh a thin plastic tubing directly into the vein.
LOADING DOSE the initial dose of a drug, usually larger than the routine dose.
MONITORED Watched or supervised carefully by an individual who is appropriately qualified.
NEUROLOGICAL Related to the brain.
NEURONS Brain cells.
OPHTHALMIC Related to the eye.
ORALLY By mouth.
PARAPROFESSIONAL Professionals that are part of the "medical team" to help support the infant and parents (i.e., Social Workers, Respiratory Therapists, Discharge Planners).
PREMATURITY An infant born before term.
PROPHYLAXSIS Medicine or treatment given to reduce the chances of recurrence of illness or disease.
RECTALLY Relating to the rectum.
RECURRENCE Happens again.
RESPIRATORY Related to the lungs.
ROUTE OF ADMINISTRATION How the medicine is given (i.e. orally, rectally).
TRACHEOTOMY A surgical opening in the trachea made in the neck to provide an open airway.
TYMPANOMETRY Exam to measure movement of the ear drum.
UNIVERSAL Precautions using precautions to stop the spread of germs from one individual to another.
VISUALIZATION To make visible.

the hospital so caregivers will feel comfortable and confident in their ability to care for the baby.

How can my three year old attend the center-based program if he needs oxygen, suctioning or respiratory therapy?
It will be up to the medical team, intervention team and family to determine the stability of the toddler to attend programs outside the home. Although all equipment is portable, it may be too overwhelming to travel with an infant who is medically fragile. Home programming may continue or alternative (often creative) methods of transportation can be developed to get the infant to and from the agency.

Should my toddler attend the center-based program if he seems to get sick?
Many toddlers, when exposed to a center-based preschool environment, tend to get sick more often. Illness occurs when the toddler is exposed to new sets of "germs" from the other children. Eventually the toddler builds up a resistance to these "germs" and seems healthier and will become sick less often. In certain circumstances a physician may recommend a toddler to stay at home during specific times of the year when illness is more frequent or recommend further immunizations.

References

Batshaw, M. (1991). *Your child has a disability.* Boston, MA: Little, Brown and Company.

Brazelton, B. (1983). *Infants and mothers.* New York: Bantam Doubleday Dell Publishing Group Inc.

Chow, M. (1979). *Handbook of pediatric primary care.* New York: John Wiley and Sons.

Leach, P. (1995). *Your baby & child—From birth to age five.* New York: Alfred A. Knopf.

Lovejoy, F. (1987). *The new child health encyclopedia: the complete guide for parents.* New York, New York: Bantam Doubleday Dell Publishing.

Mitchell, M. and Eiger, M. (1994). *The pill book guide to children's medications.* New York: Bantam Books.

Physicians' Desk Reference, (49th edition). (1995). Oradell, NJ: Medical Economics Data Production Co.

Spock, B. & Rothenberg, M. (1992). *Dr. Spock's baby and child care.* New York: Pocket Books.

Strategies

Beginning Communication

by

Deborah Chen

Infant Vignettes: Jose

by

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From Interdisciplinary to Transdisciplinary Interventions

by

Deborah Chen

Beginning Communication

by Deborah Chen

Communication is fundamental to all social interactions and learning experiences. Therefore encouraging communication should be a primary focus of early intervention with infants whose multiple disabilities include both vision and hearing loss. This chapter will discuss practical strategies for beginning communication with these infants within the context of daily activities.

Infants are natural communicators. However, when infants have multiple disabilities with both vision and hearing loss, their early communications may be difficult to recognize and they may not respond in expected ways. The first strategy for encouraging communication is to find out how the infant communicates and what he is communicating about.

Identify and interpret the infant's behavior as communicative

Careful observation is a most important intervention skill. Caregivers and early interventionists should observe the infant's responses and behaviors in a variety of natural and structured situations.

The second strategy is for significant people to respond to and expand the infant's communication behaviors and opportunities. Procedures involve identifying situations that motivate communication, building turntaking routines, and selecting communication options. These consistent and systematic learning experiences will promote the infant's understanding about the purpose and power of communication.

How does the infant express

- Interest ?
- Disinterest?
- Preference?
- Dislike?
- Availability for interaction?
- A need to take a break from interaction?
- Hunger, fatigue, boredom?

Create communication opportunities

Most of us communicate more in situations that are familiar, with people we like, and on topics that are interesting. We can apply these simple observations to create communication opportunities with infants who are deaf-blind.

Identify the infant's preferences

Ask caregivers to make a list of the infant's favorite objects, people, and activities and make your own observations of what the infant prefers. These preferences will reveal situations that are familiar, people that are liked, and topics that are interesting to the infant. They should provide the basis for meaningful and motivating interventions.

Develop turntaking routines

Turntaking simply requires responding in some way to the infant's behaviors and then supporting another response from the baby. This creates a foundation for developing conversation. There are many natural opportunities for turntaking games in daily caregiving situations, for example, playing tickle tummy, peek-a-boo, and imitating sounds or movements. Little games can occur when dressing, feeding, and bathing the baby (Chen & Haney, 1995). Turntaking routines with infants may be developed as game-based or imitation-based, action-based, or reference-based exchanges (Chen, 1996).

Imitation-based routines involves repeating the baby's sounds or actions on objects. When the infant is engaged in making sounds (e.g., "bah, bah, bah") or movements (patting the high chair tray), wait for a break in his vocalizations or actions and imitate his sounds and/or actions to encourage turntaking. Once the infant is making the sound or action consistently, change your turn slightly (e.g., from saying "bah, bah, bah" to "baaahhh," or from patting the high tray to patting a toy on the tray).

Game-based routines involve predictable tactile or movement games that the infant likes (e.g., "blow-on-tummy," or "blanket swing"). Once the infant recognizes the game, delay the next step (e.g., blow on the infant's tummy and then stop) wait for the infant to react in some way, then respond to his vocalizations or movements by blowing on the tummy again). When the infant realizes that he can get you to play the game, show him how to say "let's play" (e.g., by pulling up on his shirt to request "blow-on-tummy"). The blanket swing game is outlined below as an example of interrupting a routine.

Imitation-based and game-based routines are helpful for engaging an unresponsive infant. Imitation of the baby's sounds and action should be changed slowly to include different sounds, actions, objects, and words to fit the infant's development. Object play in imitation-based and game-based routines helps to differentiate between infant and caregiver turns and supports a transition to action-based routines.

Action-based routines involve turntaking and joint attention to specific objects. Simple activities, such as, pouring water out of a cup at bathtime, taking toys out of a basket, and putting blocks into a bottle, invite an infant to act on an object. The significant person may take a turn in different ways that supports the infant's actions, e.g., by filling the cup for the infant to pour, or by pouring some water on the infant's tummy and then filling the cup for the infant; by commenting on, or acting on the toys the infant takes out of the basket; by giving the infant a block to put in the bottle; or by putting a block in the bottle. Simple language input and related sounds should mark the actions in these routines, e.g., "On your tummy" or "ooohh" when pouring the water, or "all gone" when the infant empties the cup, or " Block" when handing the infant a block for the tub, or "Ah boom" when the infant puts a block in the tub."

Reference-based routines involve turntaking, joint attention to specific topics, and a focus on symbolic language input. The adult provides labels to help the infant develop specific language concepts for a variety of objects, for example, identifying body parts, looking at books, and playing with dolls and other symbolic toys. The infant's focus is engaged when the adult uses exaggerated intonation, makes the sign on the object, or makes the sign on the baby's body as appropriate.

These routines are supported by the concept of progressively matched turntaking (MacDonald & Gillette, 1986) and similar interventions (Manolson, 1984). The adult engages the infant in turntaking by imitating what the infant does and then adding a bit more. For example:

- ► If the infant does not communicate intentionally, then imitate the baby's actions and sounds.
- ► If the infant uses gestures and sounds that represent words, then imitate the infant's behaviors and provide the words.
- ► If the infant uses words, then provide the standard form of the word and add a bit more information.

Interrupting a routine

Once the infant is familiar with a preferred turntaking game, use an interruption strategy to elicit a request from the infant.

- ► Select a favorite activity, e.g. the infant loves being swung in a blanket.
- ► Create a need for the infant to communicate, e.g., stop moving the blanket and hold it still.
- ► Wait and observe what the infant does, e.g., wiggles body.
- ► Interpret the infant's behavior as communicative, e.g., "I want more swing."
- ► Add words to the infant's behaviors, e.g., MORE SWING.

- ► Respond to the infant's communication by continuing the activity as requested.

Communication input and output

An important strategy for encouraging communication with infants who are deaf-blind is to differentiate between communication input and communication output. From the infant's perspective, input is receptive communication or what another person is conveying to him; while output is expressive communication or what the infant wants to communicate. This is an important distinction because the methods used for input and output may need to be different to fit the infant's understanding and abilities. The following outlines are intended to assist early interventionists and families in determining (a) the method of communication input that is *most likely to be understood by their infant*, and (b) the communication output that their infant will *produce the most easily*. These methods are not mutually exclusive, more than one method can be used for one message, and a variety of methods may be used for different messages.

Communication input

Ways to send messages to the infant

TOUCH CUES (a tactile signal) The infant must be aware of tactile input.

OBJECT CUES (object or part of an object used in an activity or associated with a person) The infant must be aware of tactile input; he will receive more information if he can handle the object.

GESTURES (natural body movements) The infant must be aware of tactile and kinesthetic input; he will receive more information if he has some vision.

VOCALIZATIONS (vocal sounds) The infant must have some hearing and be aware of sounds.

3D TANGIBLE SYMBOLS (objects or part of objects that represent activities, may be used on communication boards) The infant must have made an association between the three dimensional referent and what it represents; he will receive more information if he has some visual, motor, and tactile discrimination.

PICTURES (a two dimensional form of a tangible symbol) The infant must make an association between the two dimensional illustration and what it represents, so he needs visual discrimination.

SIGNS The infant must make an association between the movements of the sign and what the sign represents; so he will receive more information if he has some vision and/or tactile and kinesthetic discrimination.

SPEECH The infant must make an association between how the word sounds and what it represents, so he needs some hearing to discriminate between sounds.

Communication input is enhanced when the infant can make use of available senses through amplification, corrective lenses, magnification, and other sensory cues that provide pertinent information. In addition, input must be comprehensible: (a) it must match the infant's abilities, (b) the infant should be able to differentiate it from the background noise and visual clutter of the environment, and (c) he must be able to associate it with the message it conveys.

Alternative communication methods

As outlined in the previous section, there are many alternative methods for communicating with young children who are deaf-blind including: touch cues, object cues, tangible symbols, pictures, and signs (Chen, 1995a; 1995b; Rowland, Schweigert & Prickett, 1995). This section will focus on touch cues, object cues, and adapted signs as selected options for beginning communication with infants whose multiple disabilities include vision and hearing loss.

Touch cues are tactile signals made on the infant's body that are used to communicate a specific message during everyday situations. They are very useful for communicating with infants with multiple disabilities who do not seem to understand signs or speech. For example, tugging on the infant's diaper means "I'm going to change your diaper." Touch cues should be paired with specific words in order to support the infant's attention to and understanding of the spoken word. Touch cues must be presented in a consistent and systematic manner on a

Communication output

Ways the infant sends messages

BODY MOVEMENTS (generalized movements or actions) The infant must be able to make movements. At first these movements may be unintentional communicative behaviors (e.g., indicating preference or dislike) that can be shaped into gestures.

OBJECT CUES (object or part of an object used in an activity or associated with a person) The infant must recognize objects and associate them with specific activities or people. This recognition is facilitated by some vision and/or motor abilities.

GESTURES (natural body movements that have specific meanings) The infant must associate certain body movements with particular activities; he must have some motor abilities; he will have a larger repertoire of gestures if he has some vision.

VOCALIZATIONS (vocal sounds) He must have some hearing and be aware of sounds.

3D TANGIBLE SYMBOLS (objects or part of objects that represent activities, may be used on communication boards) He must have made an association between the three dimensional referent and what it represents; he will receive more information if he has some visual, motor, and tactile discrimination.

PICTURES (a two dimensional form of a tangible symbol) He must have made an association between the two dimensional illustration and what it represents, he so needs visual discrimination.

SIGNS He must have motor abilities to produce signs and have made an association between the movements of the sign and what the sign represents; he will receive more information if he has some vision and/or tactile and kinesthetic discrimination.

SPEECH He must have the oral-motor skills to produce speech and have made an association between how the word sounds and what it represents, so he needs some hearing to discriminate between sounds.

Identifying input options

COMMUNICATION METHODS	REQUIREMENTS					COGNITIVE		
x = essential √ = optional	VISION	HEARING	MOTOR	TACTILE	KINESTHETIC	AWARENESS	RECOGNITION	DISCRIMINATION
Body Movements				x		x		
Object Cues			√	x		x		
Gestures	√			x	x	x		
Vocalizations		x				x		
Tangible Symbols	√		√	√				x
Pictures	x							x
Signs	√			√	√			x
Speech		x						x

specific part on the infant's body if they are to become meaningful. For example, the infant will not begin to anticipate "getting diaper changed" if sometimes she receives a pat on the bottom and other times she feels a tug on her diaper. Moreover, the infant's preference for and response to particular types of tactile stimulation must be considered. Infants are more likely to prefer a touch cue that is a firm touch or deep pressure than a light tickling stroke. Certain types of touch on specific body areas may trigger aversive or reflexive move-

Identifying output options

COMMUNICATION METHODS	REQUIREMENTS					COGNITIVE		
x = essential √ = optional	VISION	HEARING	MOTOR	TACTILE	KINESTHETIC	AWARENESS	RECOGNITION	DISCRIMINATION
Body Movements			x					
Object Cues	√		√				x	
Gestures	√		x				x	
Vocalizations		x	√			x		
Tangible Symbols	√		√	√				x
Pictures	x							x
Signs	√		x	√	√			x
Speech		x May be aided	x Oral Motor					x

ments in infants who are medically fragile or neurologically impaired (Chen, 1995a). It is important to collaborate with the infant's family and other team members including the physical or occupational therapist to determine the most appropriate type and placement of touch cues for a particular baby.

Early interventionists and caregivers should begin by identifying daily situations in which a few touch cues can be used easily and will help the infant understand what is about to happen. Discuss these cues with everyone who interacts with the baby so they can be used consistently within familiar and unfamiliar activities.

Object cues are actual objects used in activities with the infant. First, object cues inform the baby about what is to happen next, i.e., a bottle indicates mealtime. The baby must use the object during the activity, i.e., drink from the bottle, to understand what the object cue represents. Once the infant associates certain objects with particular activities, object cues may be used to offer a choice. Initially, the infant will indicate a choice through interest or disinterest when one object is offered. When the infant recognizes more than one object cue, he can be given a choice of two objects. Begin with a preferred object (e.g., bottle) and a disliked one (e.g., apple slice) to develop an understanding of choice-making.

Touch cues

FORM

- Specific signals on the infant's body
- Consistent and systematic
- Individualized

INPUT FUNCTIONS

- Provide information to the infant, e.g., grasp under both arms of the baby: "Up, we go."
- Provide comfort, e.g., stroke baby's back: "There, there, tired baby."
- Offer praise, e.g, pat baby's chest: "Yeah. Big boy."
- Requests action, e.g., touch baby's mouth: "Take a bite."

Object cues

FORM

- Real objects
- Part of real object
- Miniatures of objects (not appropriate for most infants with multiple disabilities or who are blind)

INPUT FUNCTIONS

- Provides information to the infant, e.g., giving the infant a diaper: "Let's change your diaper."
- Provides the infant with a choice, e.g, giving the baby a piece of a blanket or a bottle: "Want to swing or want a drink?"

OUTPUT FUNCTIONS

- Infant can indicate preference, e.g. infant grabs blanket that adult offers: "I wanna swing."
- Infant can make requests, e.g., infant gives empty bottle to adult: "I wanna drink."

Object cues should be selected and presented from the baby's perspective and experience. For example, placing a bottle in the baby's hand may not elicit recognition of this object if this infant does not hold his bottle. However, the infant may respond to the feel of the nipple on his lips. Similarly, a cup should not be used as an object cue for "Have a drink" if the infant drinks from a bottle. Once the infant associates the actual object with the activity (e.g., blanket = blanket swing), a part of the object may be paired with the actual object as a cue. In this way, the actual object may be faded gradually and the smaller object cue (e.g., a piece of a blanket = blanket swing) may be used instead. Object cues should be presented consistently in natural situations and familiar activities for them to become meaningful.

Identifying familiar people Object cues can be used to help the infant recognize familiar people. Infants who are deaf-blind may discriminate people by obvious distinctive characteristics (, e.g., long hair, beard, glasses, ring) and how they smell. It is important to recognize that infants will associate certain smells with comfort and preferred people and other smells with disliked situations or people. For example, an infant may alert and brighten because her father (who just finished a cigarette) walks into the room. Similarly, an infant may become upset when the nurse approaches her because she associates the smell of antiseptic with discomfort. These observations provide information about the infant's development and may be used to add touch or object identification cues. For example, helping the infant touch his father's mustache or the nurse's glasses.

Encouraging gestures The baby's movements in an activity or action on an object can be used to develop gestures. For example, the spoken or signed word for swing will not be readily understood by an infant who is deaf-blind. However, the infant's natural action of bouncing his upper body while on the swing may be used as a gesture that he will recognize more easily. The gesture must be based on the infant's perspective, for example, a pushing gesture with the hands would not as easily understood by the infant. This strategy encourages gestures and the infant's active participation in everyday activities as essential learning experiences.

Identify key daily activities

- Preferred
- Disliked
- Person involved in specific activity
- Distinctive feature of person
- Objects associated with activity
- Objects used in activity
- Distinctive feature of object
- Infant's actions on selected objects or in familiar activities

Moreover, conventional gestures should be used as appropriate, i.e., to indicate agreement (nod head), disagreement or refusal (shake head), directing attention or making a request (pointing or tapping an object).

Identify sign adaptations

- ► Proximity to the infant—viewing distance
- ► Rate or speed of sign input
- ► Amount and size of sign movements
- ► Position and placement of the hands (figure/ground, tactile sensitivity, visual field)

Adapting signs When an infant has both hearing and vision loss, signs need to be made so that the infant can receive them. If the infant has low vision, signs must be produced within his visual field, at an optimal viewing distance, and at an appropriate pace. It is also important for the signer to wear clothing that provides a high contrast and solid background for the signs to be seen easily, e.g., a shirt in a solid color that provides a strong contrast with skin color. Depending on the infant's developmental level and other learning needs, the rate of signing may need to be slowed down, the number of words may need to be limited, and the hand movements may need to be made smaller to allow the infant the time to process the visual input. When the infant is totally blind, other sign adaptations will be required, i.e., coactive and interactive signing (Watkins, 1985). This infant will need physical guidance to make the sign (coactive signing) and should be encouraged to feel the signer's movements (interactive signing). For an infant, coactive signing should be used to prompt the infant to communicate (output). Care must be taken to help the infant distinguish between when someone is communicating with him (input) and when someone is asking him to communicate (output). The infant may be confused by the variety of "transition" movements that accompany taking and positioning his hands for coactive signing. The same transition

Strategies for introducing signs

- ► Make the sign on the infant's body (input)
- ► Use physical guidance to help the baby make the sign—coactive signing (output)
- ► Help the infant make the sign on your body (output)
- ► Use tactile modelling by placing the baby's hands on yours to feel the sign movements—interactive signing (input)
- ► Make the sign on the object, i.e. sign BOTTLE on infant's shoe while the baby is looking at or handling his bottle (input)
- ► Match the number of movements of the sign with the number of syllables in the word, e.g., MAMA (input)

Chen, 1995a; Watkins, 1985

movements should be used consistently (e.g., touch the back of the infant's hand and then grasp them) and the signs movements should be made distinctly (Chen, 1995a).

First signs Begin by asking the family to make a list of words that are most important for communicating with their baby. Develop a list of vocabulary with family and other team members, decide on the signs to be used for these words, identify any adaptations that are needed, and use selected signs consistently across activities. When first learning signs, infants with multiple disabilities are more likely to produce signs that represent preferred objects (BLANKET), favorite activities(BOUNCING), and familiar people (MAMA); that are used for daily routines (EAT, BATH); that are easy to produce, touch the body, and have symmetrical movements (MORE, COOKIE, MAMA); and that look like or feel like what they represent (EAT, WASH, DOWN). Select signs that meet all four of these criteria to provide the infant with a quick understanding of the power of signs (Chen, Friedman, & Calvello, 1990).

Selecting communication options

Early interventionists and families wonder where to begin in encouraging communication with infants who are deaf-blind. Many of these infants benefit from a specific focus on communication input rather than being bombarded with every possible communication method as one time. Close your eyes and consider how confused you would be if someone spoke to you in an unfamiliar language, while he held your hands and moved them, and then put an unfamiliar object in your hand.

Imagine the experience of an infant exposed to a haphazard approach to communication. The purpose of this section is to demonstrate how to build on the infant's abilities and interests in developing communication interventions that fit into the family's routine of preferred activities. The process is not meant to restrict the communication options for a particular infant but rather to emphasize systematic and consistent use of selected methods that are the most likely to produce results. In addition, the early interventionist must do her home work in preparation for her home visits. She has a professional responsibility to develop the skills and competencies necessary for making professional recommendations and for balancing these recommendations with the family's priorities, values, and concerns.

Thumb nail sketch: Maria

Maria is 18 months old. She has a diagnosis of retinopathy of prematurity, hypotonia, and a moderate hearing loss due to bilateral atresia. She has just received bone conduction aids but pulls them off. Maria is totally blind. She makes some babbling sounds, drinks from a bottle on her own, and is beginning to scoot around on the floor. Her father plays a vigorous "airplane" game that makes her laugh. Maria begins to move her arms and legs and makes sounds when her father picks her up. She is very quiet when her mother sits and holds her in a rocking chair for a lullaby before nap and bedtime.

Home work for the homevisit

Maria's family has told the early interventionist that they are very concerned about Maria's communication development. In preparation for a home visit, the early interventionist completes the *Communication Options Worksheet* based on her familiarity with Maria. She notes that signs will need to be adapted because Maria is totally blind and that Maria has functional hearing although encouraging her to wear her bone conduction aids will require some effort. She decides to discuss with the family the communication options of using speech, adapted signs, and object cues to provide communication input; and to encourage Maria to communicate through vocalizations, object cues, and gestures or signs.

Working together

At the home visit, the early interventionist notes that Maria loves "rough" and tumble games with her father and the rocking chair—lullaby time with her mother. She asks whether Maria wears her hear-

Communication options worksheet
Model demonstration project

NAME Maria (18 months) DATE June 09, 1995

		COMMUNICATION OPTIONS	
CHILD'S STRENGTHS AND NEEDS		INPUT	OUTPUT
Vision	Totally blind	Adapted signs	Sign
Hearing	Moderate hearing loss, unaided	Vocal	Vocalizations
Motor	Low tone, rolls, sits, arms and legs move, bangs, holds bottle, removes hearing aid	Interactive and coactive signs, objects	Body movements Gestures
Tactile	Now tolerates holding	Touch cues	Objects
Responses to Movement	Loves movement games		
Cognitive Level			
• Awareness			
• Recognition			
• Discrimination	Objects, people, activities		
	Selected Options	Adapted signs	Vocalizations
	To discuss	Speech	Signs/gestures
	with family	Objects	Objects

ing aids during those activities. Maria's parents indicate that she fusses and pulls them off. The early interventionist suggests that the lullaby-rocking chair activity might be a motivating time for Maria to wear her hearing aids. Maria's mother says she will put them on when they sit in the rocking chair and take them off when she puts Maria in her crib. The early interventionist explains the interrupted routine strategy to the parents. Together they develop a strategy for the rocking-chair song time and the "airplane" game. To play the "airplane" game, Maria's father lies on the floor and holds her parallel over his body. He moves her up and down and side to side while he makes funny noises. He agrees to add the words "Up," "Down" with exaggerated intonation to coincide with those movements when he plays the airplane game. He will pause when he holds her up, wait for a reaction, and respond to her sounds and movements as communication by continuing the movement game. Before she leaves, the early interventionist checks Maria's bone conduction aids to make sure they are working and to see that the headband fits Maria comfortably.

Rocking chair song

1. Sing "Row, row, row your boat gently down the stream, merrily..." and pause. Stop singing and rocking.
2. Wait and watch for Maria's response.
3. Verbalize her response (e.g., if she makes a movement or sound, say "You want more singing, more rocking," and help her to make the MORE sign).
4. Continue the rocking chair song.

Thumbnail sketch: Huey

Huey is 30 months old. He has a diagnosis of cortical visual impairment, a bilateral severe to profound hearing loss and is nonambulatory because of spastic cerebral palsy. He has been in foster placement for the past six months with the Woo family, is now receiving homevisits from an early intervention program and has begun to transition into center-based services. He prefers to be left alone and doesn't liked to be held or touched. His foster mother reports that he eats pureed foods and drinks from a bottle. She is concerned about his self injurious behaviors (biting his hand in the calloused area) and his fussing and crying episodes.

Homework for the homevisit

From her own initial observations of Huey and information gathered from Mrs. Woo, the early interventionist decided to complete the *Communication Options Worksheet*. She discussed the form with the speech and language specialist at the center to determine where to begin with Huey's communication. Huey does not seem to respond to any sounds and does not have a hearing aid. The early interventionist made a note to discuss this with Mrs. Woo and to contact his audiologist to ask whether Huey might benefit from a hearing aid. Although Huey might learn signs, his present sensitivity to touch and level of visual attention does not support a sole focus on signs. The early interventionist decided to discuss communication options with Mrs. Woo, to explain the systematic use of object and touch cues as communication input for Huey, and to suggest the use of object cues for his expressive communication.

Working together

At the home visit, Mrs. Woo is very interested to learn about object and touch cues. She had wondered about Huey's communication since he did not make any sounds except for fussing and crying. She does not know any sign language and although she is bilingual, the

Communication options worksheet

Model demonstration project

NAME Huey (30 months) DATE June 09, 1995

		COMMUNICATION OPTIONS	
CHILD'S STRENGTHS AND NEEDS		INPUT	OUTPUT
Vision	Low vision	Sign possible Object/pictures	Picture communication board (adapted) Objects with attention to visual characteristics
Hearing	Profoundly deaf	Vocal limited	Non-vocal
Motor	Non-ambulatory, fluctuating muscle tone, not sitting independently, moves arm	Limit coactive signing	Generalized body movements to interpret and shape to gestures Orientation to people/objects
Tactile	Does not like to touch anything but hard objects Does not like to be held	Limit coactive signing Object cues possible Tactile cues possible	Objects that are solid (spoon vs. teddy bear)
Responses to Movement	Screams when picked up, and bites hand	Do not use movement as gestures	
Cognitive Level			
•Awareness		Pictures: not yet	
•Recognition		Objects: beginning	
•Discrimination			
	Selected Options To discuss with family	Object cues	Body language
		Tactile cues	Objects

family speaks Chinese at home. The early interventionist offers to teach Mrs. Woo the single word signs that she could use with Huey during everyday activities. Over the next few weeks, both the early interventionist and Mrs Woo observe Huey during his everyday activities. They discover that he expresses interest by breathing noisily and seems to enjoy being in the bath. Mrs. Woo says he is was very cooperative during bath time and that she tends to wash him slowly because she feels this is "their special time." She observes that he fusses and cries when she picks him up quickly or must compete a caregiving task rapidly. She wonders whether he is startled or confused by quick movements and rapid interactions and is becoming very concerned about his handbiting behavior.

Components of daily routines

- ▶ Getting ready
- ▶ Beginning the activity
- ▶ Supporting participation
- ▶ Ending the activity

When she returns to her office, the early interventionist discusses Mrs. Woo's concern about Huey's behavior with the program psychologist. He suggests the *Motivation Assessment Scale* (Durand & Crimmins, 1992) to identify the function of Huey's hand biting behavior. At the next home visit, Mrs. Woo and the early interventionist complete the *Motivation Assessment Scale*. They discover that Huey bites his hand when he is left alone, that he seems fairly calm, and seems to like biting on his hand. They decide to decrease the time that Huey spends alone, to increase opportunities for Huey to interact with different family members, to identify other sensory activities that he seems to enjoy, and to pick him up and move him slowly so that he has time to adjust to the change. They plan also to consult with the occupational therapist at the program regarding activities that will motivate Huey to use his hands in other stimulating ways.

The following week, the early interventionist introduces the *Routine Analysis* form to analyze the bath routine and to build opportunities for intervention objectives. She asks Mrs. Woo about the bath routine, where and when each step takes place. They brainstorm on the variety of input that Huey might accept. Through the process, Mrs. Woo discovers that Huey anticipates bathtime because of all the natural cues associated with the activity. She agrees to encourage Huey to use his hands in a variety of ways and to provide communication input when possible. The early interventionist demonstrates each of the cues that they selected and offers to make a late home visit during Huey's bathtime to help Mrs. Woo with this goal. The early interventionist stresses that Mrs. Woo should try out the *Bath Time Routine Analysis* with Huey and settle on a sequence of input that was natural and comfortable for them both. She emphasizes that it may not be possible to use all the identified object cues, touch cues, and signs during every bath. In addition, she encourages Mrs. Woo to continue to talk to Huey while she uses the selected communication options.

Develop predictable routines

A critical component of creating communication opportunities is developing predictable routines. Every activity has a beginning, middle, and end. These are natural steps for preparing the baby for the beginning of an activity, involving him actively in the activity, and marking the end of the activity by using alternative communication methods. This sequence was demonstrated in Huey's bath routine analysis.

Routine analysis

NAME Huey
DATE June 06, 1995
ACTIVITY Bath

STEPS IN ROUTINE	NATURAL CUES	CHILD BEHAVIORS TO ENCOURAGE	INPUT
1. Going to the bathroom	After dinner Being in the bathroom Smell and feel of air	Put hand in washcloth mitt	Object cue: washcloth mitt
2. Getting undressed	Change of temperature Skin contact with air On towel or rug	Relaxed, not fighting Move limbs out of clothes	Touch cue: for removing clothing
3. Getting into the tub	Water & temperature Foam cutout that supports head & body Feeling of tub	Cooperate	Sign: WASH (on body) Object cue: tub
4. Washing	Soap Washcloth mitt Pouring water	Rub hands together Coactively rub body with mitt Play tickle game	Object cue: liquid soap in hand Object cue: pour water over leg or hand
5. Rinsing	Pouring water	Playful anticipation	Object cue: pour water over leg or hand
6. Getting out of the tub	Picked up and out of the tub	Keep head erect	Touch cue: for pick up
7. Drying off	Towel Lotion on limbs Desitin on bottom	Cooperate Reaching for lotion/hand Touch lotion	Object cue: towel, lotion bottle
8. Getting dressed	Diaper PJs on	Cooperate Push hand & foot through clothes	Object cue: diaper Co-active sign: ALL DONE

Key strategies for encouraging communication with infants who a deaf-blind

- Interpret infant cues and identify communicative behaviors
- Encourage the infant's use of functional vision
- Encourage the infant's use of available hearing
- Create opportunities for communication
- Develop predictable routines
- Identify motivating situations that create a need for the infant to communicate
- Select communication options (touch cues, object cues, adapted signs)
- Develop enjoyable turntaking games within the context of everyday situations
- Have fun!

Consistent sequences provide the infant with predictability, promote his sense of control over events, and support his active participation. Moreover, the use of daily routines will (a) enhance the family's involvement in intervention strategies, (b) promote the infant's understanding of and response to significant natural cues, and (c) provide frequent and repetitive opportunities for the infant to learn important and meaningful skills.

The complexity of communication input should fit the infant's developmental and cognitive levels. Communication about what the infant is doing should coincide with the infant's actions and focus on the most critical aspects of the activity. Providing too much or too complicated input will result in a decrease in interaction on the infant's part. On the other hand, providing too little input will not engage the infant. Similarly, expecting communication output that is far beyond the infant's current ability will limit the infant's immediate possibilities of independent expressive communication; while expecting too little communication from the infant will not encourage communication development. There is a fine and delicate balance in creating the most appropriate beginning communication interventions for each infant who is deaf-blind.

References

Chen, D. (1995a). Understanding and developing communication. In D. Chen & J. Dote-Kwan, *Starting points: Instructional practices for young children whose disabilities include visual impairment* (pp. 57-72) Los Angeles: Blind Childrens Center.

Chen, D. (1995b). The beginnings of communication: Early childhood. In K.M. Huebner, J.G. Prickett, T. Rafalowski Welsh., & E. Joffee (Eds.), *Hand in hand. Essentials of communication and orientation and mobility for your students who are deaf-blind* (pp.185-218). New York: AFB Press.

Chen, D. (1996). Parent-infant communication: Early intervention for very young children with visual impairment or hearing loss. *Infants and Young Children,* 9(2), 1-12.

Chen, D., Friedman, C.T., & Calvello. (1990). *Learning together: A guide to socially-based routines for visually impaired infants.* Louisville, KY: American Printing House for the Blind.

Chen, D. & Haney, M. (1995). An early intervention model for infants who are deaf-blind. *Journal of Visual Impairment & Blindness*, 89, 213-221.

Chen, D., & Schachter, P. (in press). *Making the most of early communication* [Video and booklet]. New York: AFB Press.

Durand, V.M., & Crimmins, D. (1992). *Motivation assessment scale.* Topeka, KS: Monaco Associates.

MacDonald, J.D., & Gilette, Y. (1986). Communicating with persons with severe handicaps: Roles of parents and professionals. *Journal of the Association for Persons with Severe Handicaps,* 11, 255-265.

Manolson, A. (1984). *It takes two to talk.* Toronto, Canada: Hanen Early Language Resource Centre.

Rowland, C., Schweigert, P.D., & Prickett, J.G. (1995). Communication systems, devices, and modes. In K.M. Huebner, J.G. Prickett, T. Rafalowski Welsh., & E. Joffee (Eds.), *Hand in hand. Essentials of communication and orientation and mobility for your students who are deaf-blind* (pp.219-260). New York: AFB Press.

Watkins, S. (1985). *Developing sign communication with the multi-handicapped sensory impaired child.* Logan, UT: SKI*HI Institute.

Infant Vignettes

Jose

by Pamela Haag Schachter, Kathy Goodspeed & Patty Salcedo

Jose, a small, cuddly 17 month old toddler is attending the center-based early intervention program in his community for children with visual impairments. Born at 26 weeks , Jose is completely blind in his left eye and has light perception in his right eye due to Retinopathy of Prematurity, Stage V. An Auditory Brainstem Response (ABR) test, completed while Jose was hospitalized following his birth, revealed a mild to moderate hearing loss in his right ear. Jose battled many other complications of extreme prematurity, and though his health has stabilized he has just been diagnosed with a seizure disorder, about which mother is quite concerned.

Jose is very active, enjoying rolling, rocking on all fours and sitting independently. He reaches for toys and people and searches actively for objects while lying on his stomach. Jose has a very soft cry, which is thought to be due to vocal cord damage from when he was intubated as newborn. He will play reciprocal movement games with adults; he makes raspberry sounds, kicks his legs and is beginning to imitate the sign "MORE" through coactive signing. Jose likes light and will roll toward windows and other strong light sources. He responds to his name being called within five feet and cries when the neighbor's loud air conditioner turns on. Jose prefers toys that are musical. Jose often sits in chairs with his head turned completely to the right, with his left ear facing outward. Jose likes other people and has a very easygoing personality. He loves tickling, gentle roughhousing, and swinging. He does not like to touch objects. Jose eats pureed baby food and is very resistant to changes in taste or texture.

Model demonstration project **ACTION PLAN**

CHILD'S NAME Jose **PROGRAM** Early Intervention ABC
SERVICE COORDINATOR/ PRIMARY SERVICE PROVIDER Paula **DATE** 12/1/96

QUESTION/CONCERN	ACTION	WHO	WHEN	STATUS
How much can Jose hear? Should his hearing be retested? Does he need a hearing aid?	Functional observations at home and school. Teacher to use HEAR Kit. Report to Developmental Services for referral for further testing, if indicated.	Mother and teacher.	Within one month.	
Is phenobarbitol the best medication to control his seizures?	Mother to request referral to neurologist from pediatrician.	Mother	Winthin two months.	
Is Jose taking the right amount of medicine?	If necessary, teacher will help to request referral from Developmental Services.			

Jose's mother, Alicia, told his teacher, Paula, that her current priorities are to stabilize Jose's seizures and to carry her current pregnancy to full term. She is also concerned that Jose is not talking yet. Paula shared the team's concerns about Jose's hearing. These issues were recorded on an Action Plan.

Alicia agreed to observe at home to determine the circumstances in which Jose seemed to hear her and those when he did not. Paula decided to conduct a functional hearing screening at school using the HEAR Kit. They agreed to meet in a month to compare observations and write a summary of their findings. If indicated, they will use the information to request a formal hearing test for Jose. Additionally, Alicia agreed to call the pediatrician and request a referral to a neurologist. If she has difficulty obtaining a referral, the teacher will help her request funding from the Department of Developmental Services.

At a subsequent meeting with Maria, the speech therapist, Alicia discussed her concern that Jose is not talking yet. Maria explained that encouraging Jose's communication through gesture, signs and objects will help his development of language and hopefully speech. Together, they completed the Communication Options Worksheet to identify appropriate ways of communicating with Jose at this time.

Analysis of the form revealed that Jose could possibly use spoken words, tactile (co-active) signs, object cues or touch cues to receive information and sounds, signs and gestures or objects to express him-

Communication options worksheet

CHILD'S NAME Jose **DATE** December 1, 1996

		COMMUNICATION OPTIONS	
CHILD'S STRENGTHS AND NEEDS		**INPUT**	**OUTPUT**
Vision	Light perception, right eye only		
Hearing	Mild-moderate loss in right ear	Loud, clear sounds and speech	Speech (unknown damage to vocal cords)
Motor	Good fine motor, emerging mobility skills	Tactile signs, object cues	Signs, object cues
Tactile	Orally defensive, tolerates new textures if not forced	Touch cues, tactile signs object cues	Signs, object cues
Responses to Movement	Loves swinging, gentle rough-housing	Touch cues, tactile signs gestures	Signs, gestures
Cognitive Level			
• Awareness			
• Recognition			
• Discrimination	People, toys, foods		
	Selected Options	Voice-with reduced background noise and close proximity	Sounds
	to be discussed with family	Object cues	Signs and gestures
		Coactive signs	Object cues

self. The team developed communication strategies to be used at school. Alicia agreed that she would like to try similar strategies at home after Jose began using them at school and she had given birth to her next baby.

The team decided to use a variety of strategies to help Jose understand what is happening around him and express his wants and needs. Object cues were selected, to be paired with words, to help Jose anticipate what will happen next in his day. Jose has the motor skills to pick up and handle the objects and is not likely to be afraid to explore to familiar objects. Moreover, objects can be understood tactilely and do not require any vision. The teacher built a daily activities system for Jose on a low table next to the cubbys at the entrance to his toddler classroom. Cardboard boxes were glued together, and a coffee can was chosen for a "finished" box. Jose smiles when he hears things drop into the can and he feels the vibration. The list of objects chosen and their meaning is attached. Jose will be carried or encouraged to roll to his activities box before the start of each new activity. He will be helped to feel the outside of the box and to retrieve the object. Jose also will be helped to carry the object with him to the activity and return it to the finished box when the activity is done.

Routine analysis

INFANT Jose **ACTIVITY** Snack **DATE** December 1, 1996

STEPS IN ROUTINE	NATURAL CUES	CHILD BEHAVIORS TO ENCOURAGE	INPUT
Get spoon from activities after box	After diaper change, handwashing, hungry tummy ="snack time"	Feel empty box, feel next box with spoon in it	Physical and verbal prompting SNACK TIME
Sit in feeder seat at snack table	Feel chair, table = "sit down"	Climb into chair	Say and coactively sign TIME TO EAT
Put on bib	Feel bib	Reach for bib, lean forward to have bib put on	Physical and verbal prompting "Bib on"
Choose snack from 2 foods	Two foods being offered	Reach and feel and smell both foods, choose one	Physical and verbal prompting "What do you want?"
Eat food	Food presented	Reach for spoon, open mouth	Tap cheek with spoon "Take a bite"
Request more	Feeding stops	Signs MORE, vocalizes, reaches	Say and coactively sign WANT MORE?
Drink juice	Food finished	Reach for cup, open mouth	Help him feel cup, Say and coactively sign DRINK
Request more	Drinking stops	Sign MORE, vocalize, reach	Say and coactively sign WANT MORE?
Clean up from snack	Food finished, full tummy = "time to clean up"	Pull off bib, reach for washcloth	Say and coactively sign FINISHED
Take spoon to finished box	Bib off, face washed, seat belt off	Hold spoon, put onto finished box	Say and coactively sign FINISHED

In addition, the team decided to target six signs that Jose could use to tell people what he wants and to understand that others want to tell him something. The words chosen were MORE, UP, EAT, DRINK, FINISHED and MUSIC. The team believed that these were words that would be motivating to Jose to use to obtain desired objects and activities or to signal his need to end an activity. All signs and object cues would always be paired with clear vocal cues directed to Jose's better ear. His sounds and vocal play would also be reinforced. An analysis of Jose's snack routine was completed to determine how to maximize communication opportunities within this activity. The Routine Analysis was shared with Alicia, who agreed that she would like to try something similar at home a few months after the new baby has been born.

Although questions remain unanswered about Jose's hearing, the team was able to develop effective strategies to promote communication development. Those strategies will be revised as the child grows and develops, new medical data are received, and functional assessments are completed.

Summary of developmental concerns

INFANT'S NAME Jose **DOB** 17 months

(Note known areas of concern as well as those that you have questions about as a result of information from medical records.)

GROSS MOTOR
Rolls to brother
Sits alone
Rocks on all fours

FINE MOTOR
Reaches for toys, people
When on tummy, searches for objects

COMMUNICATION
Makes raspberries
—in a reciprocal game
Very soft cry
Responds to verbal cues/ sign for ready
Beginning to imitate sign MORE

COGNITION
Anticipates familiar activities
Knows familiar people
Has prefrences for certain toys
Is begining to participate in turn taking games

EATING
Fed baby food, does not like textures or variety

SOCIAL/BEHAVIOR
Likes others, very easy going

SLEEP PATTERNS
OK

OTHER

INFANT'S NAME Jose **AGE** 17 months
PROGRAM ABC Early Intervention Program
SERVICE PROVIDER Paula

Describe the infant's response to different sensory information.

SOUNDS
Mild—mod loss in 1 ear. Likes TV, music, repsonds to name within 5 feet. Startles to door being closed

VISUAL STIMULI
Light perception—moves toward light.

TACTILE INPUT
Cuddles, likes tickling, gentle rough housing, orally defensive, defensive to new materials, decreasing with brushing.

MOVEMENT
Likes swing, movement games.

INFANT'S STRENGTHS
Social—very attractive, interactive. Independent play at high quality and duration.

INFANT'S PREFERENCES AND INTERESTS
Interested in exploring , interacting with toys and people, self motivated.

FAMILY RESOURCES
Mother very attached to Jose. Attends support group.

FAMILY'S PRIORITIES AND CONCERNS
Seizure control. Nutrition—doesn't eat well. Wants 5 days/week of school. Frequent ear infections/medical.

YOUR CONCERNS ABOUT THE INFANT'S NEEDS
Increase in services. Communication development. Referral to neurologist for seizures.

Darin

by Pamela Haag Schachter & Judith Harris

Darin is a 32 month old toddler who has been receiving early intervention services at home since he was nine months old. Darin and his three brothers live with their aunt, Lucille and her three teenage children. Darin was seven months old when he and his brothers came to live with Lucille. Lucille is attending school and managing a very busy and loving household. A central part of the work of the household is caring for Darin, who has multiple disabilities.

Darin was prenatally exposed to cocaine and marijuana. He had meningitis at three months and head trauma and meningitis again at seven months. As a result, Darin has a profound hearing loss, a cortical visual impairment, cerebral palsy and a controlled seizure disorder. The most difficult aspect of caring for Darin is that he prefers to be left alone, lying on his back or in his bed. He cries and thrashes his arms and legs when held or touched. His family has worked very lovingly and consistently to help him tolerate being touched, and moved. Darin has progressed to cuddling with his aunt and tolerating an entire hour session with his early intervention teacher, Jennifer.

Most intervention with Darin has been focused on helping him tolerate being touched and positioned. Jennifer has worked primarily with Darin in her lap, using a firm touch and gradually increasing the

Model demonstration project **ACTION PLAN**

CHILD'S NAME Darin **PROGRAM** In-Home Early Intervention

SERVICE COORDINATOR/ PRIMARY SERVICE PROVIDER Jennifer **DATE** 12/1/96

QUESTION/CONCERN	ACTION	WHO	WHEN	STATUS
Darin hates his wheelchair. We need to help him tolerate sitting in it, at least to ride the bus to preschool in a few months.	Have the PT check the fit, Darin has grown a lot in the last few months. Begin a wheelchair use schedule, increasing time by a few minutes a day during favorite activity.	Lucille, PT, Jennifer	After next week's PT session.	
Lucille is very busy because of school and family demands. The school district needs her to bring Darin in for assessment and she needs to visit possible placements for Darin.	Ask district for a late afternoon meeting to plan all upcoming appointments. Encourage assessment at home when possible. Schedule classroom visits during Lucille's upcoming semester break.	Jennifer	Make appointment within 1 week	
Darin has a very hard time staying calm and tolerating people working with him. How can we help him tolerate things more easily?	Communication assessment needs to be done so we can better tell Darin what is happening and help him express himself other than by screaming.	Jennifer & Lucille	Meet together to begin next week	
Darin's hearing has not been evaluated since he was hospitalized at 7 months. He needs to be tested to see if he could benefit from hearing aids.	Request pediatrician to write referral. Lucille to schedule during her next break between classes.	Lucille	Within 3 months	

amount of time he is held. Jennifer has found that Darin is very interested in toys with lights. He follows them visually if they move and has begun to reach for them. Using a variety of interesting lighted toys has helped to distract Darin and increase the amount of time he will tolerate being held. Darin eats in a high chair with a seatbelt and foam pieces at his sides to keep him supported. He has a custom-fit wheelchair, but because he begins to cry and thrash around as soon as he is placed in it, he has spent very little time in the chair. When placed on the floor or a bed, Darin will immediately roll to his back. He can scoot on his back from place to place, usually moving until he is trapped by a large piece of furniture. When left alone, Darin plays with his hands and feet and sucks on both. When he is very frustrated, Darin will chew on his wrist where a thick callous has developed.

Summary of medical history

INFANT'S NAME Darin **AGE** 32 mos

(Obtained from reports and records reviewed.)

DIAGNOSIS Cerebral palsy, cortical visual impairment, hydrocephalus, profound hearing loss, prenatal cocaine and marijuana exposure, meningitis at 3 & 7 months, head trauma at 7 months, seizure disorder.	MEDICATIONS For seizures
HOSPITALIZATIONS 3 & 7 months.	SURGERIES
EQUIPMENT PRESCRIBED Wheelchair	PRECAUTIONS Seizures (controlled)
VISION STATUS & DATE OF LAST TEST 8/7/93 VEP Delay in conduction and central pathways between retina and visual cortex.	HEARING STATUS & DATE OF LAST TEST ABR 11/4/92: profound hearing loss. Recurrent otitis media.

Communication options worksheet

CHILD'S NAME Darin **DATE** May 5, 1996

CHILD'S STRENGTHS AND NEEDS		COMMUNICATION OPTIONS INPUT	OUTPUT
Vision	Light perception, beginning to see well lit objects	Object cues	Object cues
Hearing	No observable responses to sound		Vocalizations
Motor	Can reach and grasp, scoots on back	Object cues	Object cues, body movements, natural gestures
Tactile	Beginning to hold hard objects when placed, hates soft objects or touches	Firm touch cues, limited object cues	
Responses to Movement	Startles easily, likes rough-housing	Touch and movement cues after he knows you are there	
Cognitive Level			
• Awareness	Objects, own hands		
• Recognition	Bottle, Aunt		
• Discrimination			
	Selected Options	Touch cues, well lit object cues, voice paired with the above	Gestures, body language, choice between 2 objects

Darin loves to eat and drink. He drinks from a bottle which he has begun to track, usually reach for, and hold himself. He eats large amounts of soft mashed foods fed to him by spoon.

Lucille and Jennifer met to discuss Darin's progress. Lucille began by sharing with Jennifer her frustration that the school district has been asking her to bring Darin in for assessment appointments at times that she is in school. Lucille also said she was worried about Darin's resistance to using his wheelchair which she knows he will need in preschool. Jennifer began to note the concerns in an Action Plan. Together, she and Lucille discussed what they could do about each problem. Though Darin's irritability has improved since he was a baby, Lucille was worried about how he will handle new teachers and a new school. Finally, Jennifer mentioned her concern that Darin might be able to benefit from hearing aids and encouraged Lucille to consider a trial period of using them if they were prescribed. Jennifer described how Darin might get a lot of pleasure from hearing noise and possibly people's voices.

Jennifer and Lucille met again the following week to complete a Communication Options worksheet for Darin. Lucille felt very frustrated, because whenever she had tried to help Darin sign EAT and DRINK he screamed, pulled away and bit his hand. The communication options worksheet showed that at this time coactive signs would not be a good choice for telling Darin what is going to be done to him. Darin resists having his hands held for any length of time. Lucille and Jennifer agreed that a few firm touch cues, made on bony parts

Routine analysis

INFANT Darin   ACTIVITY Snack   DATE May 5, 1996

STEPS IN ROUTINE	NATURAL CUES	CHILD BEHAVIORS TO ENCOURAGE	INPUT
Take Darin to high chair	Hungry	Flexed when picked up	"Time to eat." Firm touch to shoulder to start, touch cue for "up."
Put a bib on	Sitting in high chair	Lean forward toward bib	Touch cue around back of neck for "bib."
Choose food or drink	Bottle and food are presented	Fixate on objects, reach for one	Show objects, place on light box to illuminate, prompt to reach from elbow.
Repeat as opportunities for choices occur			
Ask for more	Bottle empty or plate empty	Make noises, looking at bottle or plate, touch bottle or plate	Touch cue using bottle and plate "Want more?" Try to pick up on and reinforce subtle communication other than crying.
Finished eating	Tummy full = food gone	Look away, push plate or bottle away, change in vocalizations	"You're finished," remove plate, take out of high chair
Clean up	Out of chair, food on face	Allows bib to be removed, face wiped	Touch cue around back of neck for "bib," touch washcloth to hands, then wipe face quickly and firmly.

of Darin's body would be a good way to tell him that he is about to be touched, picked up, dressed, and so on. They hope that as Darin learns to anticipate what is about to happen, he may not get as upset, even if he really does not like the activity.

Lucille and Jennifer discussed how frustrating it must be for Darin to never be able to make a choice about what he wants to do. When he is unhappy, Lucille tries many different ways to please him. An Intervention Plan was developed to clarify ways that Darin could express himself by making a choice. Jennifer suggested taking advantage of Darin's newly emerging visual skills and willingness to briefly hold objects and use a few object cues with Darin. They chose objects to represent "eat," "drink," "toys with lights," "bed" and "lying on the floor." The objects will be given to Darin to see and touch before doing the activity and at times when he can make a choice of activities. The objects will be presented with extra lighting, either sitting on the light box, or under the light of a large floor lamp in the family's living room. Objects were chosen for their bright colors and black

Summary of developmental concerns

INFANT'S NAME Darin **AGE** 32 months

(Note known areas of concern as well as those that you have questions about as a result of information from medical records.)

GROSS MOTOR
Fairly good head control. Doesn't sit independently. Roll to light box, prefers supine.

FINE MOTOR
Reaches for bottle, lights. Beginning to search for objects. Exploring textured ball.

COMMUNICATION
Smiles and vocalizes. Expressive body movement. Chews on hands, feet when bored or frustrated. Whining (new) versus crying. Responds to touch cues.

COGNITION
Beginning social smile. Beginning to look in mirror.

EATING
Eats chopped food when fed. Drinks from bottle he holds.

SOCIAL/BEHAVIOR
Prefers to be left alone. Kicks, hits, wiggles to get away. Beginning to cuddle aunt.

SLEEP PATTERNS
OK

OTHER

Model demonstration project

Intervention Plan

CHILD'S NAME Darin **PROGRAM** In-Home E. I. **DATE** 4/6/96

DESIRED OUTCOME Darin will indicate his choice of preferred foods, toys, and activities.

OBSTACLES
Sees lights, beginning to focus on objects. Profoundly deaf. Doesn't like to hold things. Cries and thrashes to get away from things he doesn't want, no way to say what he does want.

STRENGTHS
Loves to look at light, beginning to fixate on bottle. Loves to eat. Family very motivated to find a way for Darin to express himself.

STRATEGIES
1. Begin with choices about eating and drinking since he loves them most.
2. Light up the objects and encourage Darin to reach for them.
3. Teach all the children in the house to help Darin make choices so he gets lots of chances to practice.

INTERVENTION PLAN
Place bottle and plate on the light box and encourage Darin to reach for one. Begin to offer choices other than food when he is reaching consistently. Choose a few objects to represent major activities of the day and use them consistently before he does the activity. Later offer the objects for a choice of activities.

tape was added to his bottle in a criss-cross pattern to increase its visual appeal. Jennifer completed a Routine Analysis of Darin's feeding times (one of his favorite activities) to help Lucille see all the opportunities for communication during meals and snacks.

Darin's transition to preschool still lies ahead, with a great deal of uncertainty as to how ready he will be for the many changes. Lucille feels that she has taken as much control of the process as she can and that the work she and Jennifer are doing in the area of communication will help Darin's preschool program be able to better communicate with him.

INFANT'S NAME Darin **AGE** 32 months
PROGRAM In Home Early Intervention
SERVICE PROVIDER Jennifer

Describe the infant's response to different sensory information.

SOUNDS
No response.

VISUAL STIMULI
Likes light, shiny, bright, moving objects. Tracks bottle, people.

TACTILE INPUT
Tolerating more, easily over stimulated.

MOVEMENT
Tolerating more, easily over stimulated.

INFANT'S STRENGTHS
Increasing use of vision. Eats very well, likes food.

INFANT'S PREFERENCES AND INTERESTS
Eating. Family members, over other people. Light.

FAMILY RESOURCES
Large family, lots of sibs. Aunt is very committed.

FAMILY'S PRIORITIES AND CONCERNS
Communication. Sitting independantly.

YOUR CONCERNS ABOUT THE INFANT'S NEEDS
Could he benefit from hearing aids? Transition to preschool. Continue to develop tolerance for people. Make most of visual skills.

Sara

by Pamela Haag Schachter & Kathy Cardinal

Sara, a 34 month-old toddler who has a diagnosis of Trisomy 13, is about to make the transition from home-based early intervention services to preschool special education services. Sara's development is extremely delayed and she has vision and hearing losses along with several unresolved health issues. The most serious of these are her uncontrolled seizures, recurrent pneumonia, scoliosis and frequent choking due to reflux.

Sara lives with her parents, Mr. and Mrs. Smith, and her older sister, Emily, who enjoy the support of a large and caring extended family. Sara's mother cares for her daughters full time. Sara's many medical, therapy and educational appointments require careful scheduling and effort to ensure time for Emily's after-school activities and play dates. The Smiths are active in their church and find a great deal of personal support there. Mr. Smith's job provides medical insurance that covers most of the costs of Sara's care. Unfortunately, the insurance coverage for physical therapy and in-home nursing are about to run out. The Smiths are aware that they must apply to state agencies to have these services continue after insurance funding ends.

As Sara's third birthday approaches, her family's stress level increases. Aside from the practical concerns of paying for nursing and therapy, finding an appropriate preschool placement for their daughter, and getting to know and trust new service providers, the Smiths fear that Sara will die. Mr. and Mrs. Smith were told when Sara was born that most babies with Trisomy 13 do not live very long. Each decision about medical care, educational services, and basic parenting is colored by this information. They are very concerned that attending preschool will expose Sara to many more infections, one of which could prove fatal.

Sara's county early intervention team met with her parents to write an Action Plan to address the many

INFANT'S NAME Sara **DOB** 34 months
PROGRAM County Intervention Program
SERVICE PROVIDER Georgeanne

Describe the infant's response to different sensory information.

SOUNDS
Vocalizes to sound source, orients to spoken name. Inhibits to "no" or "stop."

VISUAL STIMULI
Tracks people 10 ft., aware of sister, tracks horizonatlly, attends to illuminated objects, very poor lower vision, central best, does use perpheral vision.

TACTILE INPUT
Likes to mouth toys. Will hold, transfer toys.

MOVEMENT
Rolls from one room to another, prop on elbows when prone, no head control when upright.

INFANT'S STRENGTHS
Social awareness, wants to be with others—distinguishes familiar and unfamiliar people. Plays peek-a-boo, social smile, responds to simple commands.

INFANT'S PREFERENCES AND INTERESTS
Likes people, music. Bright objects on dark surfaces—at eye level.

FAMILY RESOURCES
Mother advocates for her. Extended family. Church, strong religious beliefs, private insurance (about to run out).

FAMILY'S PRIORITIES AND CONCERNS
Seizures control (worse when upright). Overall health and safety. Therapy: nursing funding running out from insurance, need to replace with state funding.

YOUR CONCERNS ABOUT THE INFANT'S NEEDS
Not currently receiving educational services. Needs audiological follow up. Needs a wheelchair.

Model demonstration project

ACTION PLAN School Priority List

CHILD'S NAME Sara **PROGRAM** County Early Intervention
SERVICE COORDINATOR Karen **DATE** April 5, 1996
PRIMARY SERVICE PROVIDER Georgeanne

QUESTION/CONCERN	ACTION	WHO	WHEN	STATUS
Sara needs a follow-up audiological exam to determine if she could benefit from hearing aids.	On hold for now. Issue will be mentioned to new service providers for follow-up in 3-6 mos.			
Sara needs a wheelchair for transportation to preschool, to have an appropriate chair to sit in at school and to transport her in when she is too heavy for her parents to carry.	Family will ask pediatrician about a wheelchair in their letter about attending school. Service Coordinator will assist family to request chair from health insurance.	Parents, service coordinator	Within 6 weeks	
Sara takes her glasses off, but seems to see better with them on.	With mother's consent, Teacher (VI) will call eye doctor to discuss use of glasses. Is prescription accurate? Plan wearing schedule with mother, consider new style of frame for greater comfort and to be harder to take off.	Teacher certified in visual impairment.	Within 4 weeks	

practical issues and personal concerns that the Smiths are facing. The team included her parents, her early intervention teacher, the school nurse, the teacher of children with visual impairments, the physical therapist and the Developmental Services coordinator. Although all of the team members have been working with Sara for at least a year, they had never all met together to discuss Sara before this meeting.

At the meeting each person expressed concerns about the upcoming changes in Sara's intervention services. Each question or major area of concern was listed on the Action Plan, along

Summary of developmental concerns

INFANT'S NAME Sara **DOB** 34 months

(Note known areas of concern as well as those that you have questions about as a result of information from medical records.)

GROSS MOTOR Can roll from place to place. No head control upright.	FINE MOTOR Brings objects to mouth. Prefers bright objects on dark surfaces, at eye level. Grasps objects and can transfer.
COMMUNICATION Coos to vocal interaction Has social smile Lifts arms in anticipation of being picked up.	COGNITION Responds to simple commands. Plays peek-a-boo. Distinguishes familiar versus unfamilair people. Beginning to search for object/person out of view.
EATING Eats chopped food. Can get spoon to mouth. Gnaws on cookies. Holds cup, drinks propped in a semi recline in lap.	SOCIAL/BEHAVIOR Enjoys others, especially children.
SLEEP PATTERNS Frequently snores, restless in sleep.	OTHER Not going to school. Health or family concerns?

Model demonstration project

ACTION PLAN Family Priority List

CHILD'S NAME Sara **PROGRAM** County Early Intervention
SERVICE COORDINATOR Karen **DATE** April 5, 1996
PRIMARY SERVICE PROVIDER Georgeanne

QUESTION/CONCERN	ACTION	WHO	WHEN	STATUS
Sara's seizures are only partially controlled. They are worse when she sits upright. Can they be better controlled? Can she go to school and not sit upright?	Parents and school nurse will write detailed description of current seizure activity and concerns. Nurse will accompany family on a neurologist appointment, sending the observations and concerns to the doctor in advance.	Family and school nurse.	Within 6 weeks.	
Sara does not tolerate her body brace (for scoliosis) which she is supposed to wear when sitting up.	PT will thoroughly check fit of brace at next home visit. Teacher and mother will write a wearing schedule to gradually increase Sara's time and tolerance.	PT, mother, and Teacher.	Within 2 weeks.	
Can Sara safely go to preschool? Concerns include: catching infections from others, choking and increased seizures.	Parent and school nurse will write a letter to Sara's pediatrician outlining concerns. Invite doctor to reply in writing and/or to participate in IEP meeting. School nurse to accompany on an office visit.	Family and School Nurse	Within 6 weeks	
Physical therapy and in-home nursing services funding runs out in 2 months, need to replace it with services funded by state.	Mother will request letter of end of services from insurance company. Service Coordinator will initiate paperwork for new funding. Mother to follow up with forms and meetings.	Mother and Regional Center Service Coordinator	Within 1 week	

with the action(s) to be taken to begin addressing the question or concern, the person(s) responsible, and the time frame for action. The team acknowledged that the action plan lists many more questions than could typically be addressed at one time. Due to Sara's imminent transition, and the acknowledgment that the family may have difficulty getting to all the items, the team divided the concerns into lists of family priorities and school priorities. This was done to acknowledge that the family may have difficulty getting to all the items on the lists. Although there are many tasks to accomplish, everyone on the team agreed that the entire process was less overwhelming once it was written as an Action Plan.

At a subsequent meeting between the early intervention teacher and the Smiths, an Intervention Plan was also written. Using a top-down approach, the teacher and parents identified their desired outcome, i.e. for Sara to receive preschool services in the least restrictive environment possible, while maintaining the best possible health. They identified the obstacles and strengths that would affect reaching the desired outcome. They generated a list of strategies they would use to help them identify the best possible educational placement for Sara. The actual intervention plan, was completed after Sara's IEP meeting was held and the Smiths had had an opportunity to use the strategies they had generated to make the best possible choice of preschool placement for Sara. The Smith's felt that had they not used this planning process, they would have only noted the obstacles to Sara attending school. Identifying her strengths encouraged them to identify an appropriate school placement and to take some risks so that Sara might benefit from being around other children.

Model demonstration project

Intervention Plan

CHILD'S NAME Sara **PROGRAM** County Early Intervention **DATE** April 5, 1996

DESIRED OUTCOME Sara will receive preschool services in the least restrictive environment possible, while maintaining the best possible health.

OBSTACLES
Seizures not well controlled, difficulty sitting upright, no wheelchair, chokes easily, gets very sick when catches colds.

STRENGTHS
Sara enjoys new people. She likes to watch other children playing. Explores the environment by rolling. Using residual vision and hearing to gain information. Parents are very committed to her education.

STRATEGIES
1. Consult physicians to help to evaluate risk to Sara in attending preschool.
2. Observe all possible classrooms for Sara to try to find one that has the most desired features (proximity to home, nurse on site, experienced staff, etc.).
3. Consider flexible options such as attending school in fall and spring and having home-based services in winter when Sara gets sick the most.
4. Consider non-school opportunities for Sara to play with peers if she receives home-based education (such as story hour at the library, play group, etc.)
5. Entire team to meet again in two months to discuss possible placements and write the intervention plan below.

INTERVENTION PLAN
Sara will attend preschool special education class at Longfellow school 3 days a week. This class was chosen because there is a nurse on-site every day. Mother will transport Sara to school until she has a wheelchair and parents are comfortable having Sara ride in it on the bus. Mother will stay in the classroom with Sara for the first month to help the staff recognize her seizures and feed her in the safest manner possible. Sara will receive in-home preschool services from December to March, or earlier at the direction of her physician. Plan will be re-evaluated in 6 months or earlier if needed.

Henry

by Pamela Haag Schachter & Dorothy Bridge

Henry is the child of immigrant parents of Chinese descent. Mr. and Mrs. Li are both college educated and work in the computer industry. Henry's premature birth at 27 weeks came as a great surprise. Henry was hospitalized for the first 6 months of his life. He came home from the hospital with oxygen and a heart monitor and diagnoses of Retinopathy of Prematurity (Stage 3 in one eye, Stage 4 in the other) and a suspected moderate-to-severe hearing loss. Mr. Li's mother, living with the family, provided Henry's daytime care, as Mrs. Li returned to work when Henry came home from the hospital.

Early intervention services began immediately. An occupational therapist came to the house once a week and Margaret, a teacher of children with visual impairments visited twice a month. The initial intervention challenge was communication. Grandmother Li speaks no English, and the interventionists speak no Cantonese. This problem was resolved by evening phone calls and written notes left for the parents. This solution caused a great deal of stress for Mrs. Li as it put her in the position of telling her mother-in-law how to care for Henry. The family had had no previous experience with children who were as fragile as Henry, in their home country he would never have been released from the hospital. In this family, the grandmother is expected to be the expert on child rearing. Henry's health problems and disabilities forced a renegotiation of many family roles. Grandmother Li worked very hard to care for Henry and to learn to handle monitors, oxygen, feeding techniques and a hearing aid. Henry had a very poor appetite and fell asleep during feedings from the effort of eating. Grandmother Li worked tirelessly to feed Henry, and through her efforts Henry is now an enthusiastic eater.

Summary of developmental concerns

INFANT'S NAME Henry DOB 4/30/93

(Note known areas of concern as well as those that you have questions about as a result of information from medical records.)

GROSS MOTOR Beginning to sit with arms to balance. Crawls on tummy.	FINE MOTOR Scribbles w/crayons. Feeds self. Operates tape player. Puts together simple puzzles.
COMMUNICATION Uses 2-3 word phrases in Cantonese. Follows 1 step directions and uses singlewords in English.	COGNITION Plays reciprocal games. Enjoys puzzles. Scribbles. Knows colors, counts. Pretend play e.g. "tea party."
EATING Loves it. All textures, temperatures, flavors. Drinks from cup. Feeds self. Secured in high chair for stability.	SOCIAL/BEHAVIOR Prefers family, likes early interventionist. Likes hugging, holding. Fearful of unfamiliar environments.
SLEEP PATTERNS No Problem.	OTHER

Mr. and Mrs. Li struggled with their own roles in parenting a fragile baby. Not being Henry's primary caregivers, they had to work even harder to be comfortable holding, feeding, changing and nurturing their son. They required a great deal of encouragement to ask questions about Henry's problems. Mr. and Mrs. Li had had no previous experience with people with disabilities and needed time and support to be comfortable talking about Henry's multiple disabilities. Henry's lengthy hospitalization increased the already large financial pressure felt by his parents.

When Henry was 13 months old additional hearing testing, both electrophysiological (Auditory Brainstem Response) and behavioral observations, determined that he had only a moderate hearing loss in one ear. The pediatric audiologist did not recommend a hearing aid and provided the interventionists and family with specific techniques to teach Henry to attend to speech. At this time, Henry was being cared for by his aunt, a very child-centered and bilingual (English-Cantonese) caregiver. The audiologist's recommendations included having Henry feel the speaker's throat, finding toys that make a variety of pitches and sounds, exaggerating the inflection in words, facing Henry when talking to him, and giving him enough time to respond. Finally, the audiologist suggested picking one language, either English or Cantonese to use with Henry during this initial period of teaching him to listen. Since all family members could not comfortably speak English, Cantonese was chosen.

INFANT'S NAME Henry DOB 4/30/93
PROGRAM ABC Early Intervention Program
SERVICE PROVIDER Mary Jones

Describe the infant's response to different sensory information.

SOUNDS
Loves auditory tape. Listens to adult speaking.

VISUAL STIMULI
2-3" working distance close—sees 12' across living room. Uses upper field—familiar environment best.

TACTILE INPUT

MOVEMENT

INFANT'S STRENGTHS
Language developing rapidly. Loves to play with toys.

INFANT'S PREFERENCES AND INTERESTS
Play—pretend tea party, scribbles, puzzles, etc. Social.

FAMILY RESOURCES
Strong extended family.

FAMILY'S PRIORITIES AND CONCERNS
Adapting culturally, grandmother caring for him. Primary language Cantonese.

YOUR CONCERNS ABOUT THE INFANT'S NEEDS
Motor—finally getting therapy. Transition to preschool—transition to more English/help him to not be overwhelmed by environment and shut down. Getting him to wear glasses.

Henry's language skills have continued to grow, especially given his early prognosis. At 35 months Henry now speaks in two to three word sentences in Cantonese. Henry loves to tell people what to do, demand food, and have tea parties. In English, which was reintroduced at 18 months, Henry uses single words.

Henry's vision has remained fairly stable. Glasses were prescribed for his nearsightedness, but he refuses to wear them, preferring to bring objects two to three inches from his eyes. At home, in a very familiar environment, Henry is able to see up to 12 feet away, under best conditions. His visual field is restricted, and he depends on movement and auditory cues to help him gain information about objects.

Henry's gross motor skills have been the slowest of all his developmental areas to progress. After a year of pleading from his early interventionist and family, his pediatrician made a referral for medical evaluation of his motor skills. Subsequently, Henry was diagnosed as having cerebral palsy. His sitting balance has improved since he began receiving physical therapy. This newest diagnosis has been the hardest for Mr. and Mrs. Li to deal with emotionally. Presently, Henry's inability to walk is the most overt sign that "something is wrong." The entire Li family have worked very hard to help Henry thrive, learn and develop new skills. The success of their past efforts is encouraging them to participate actively in therapy and to search for an appropriate preschool for him.

Summary of medical history

INFANT'S NAME Henry **DOB** 4/30/93

(Obtained from reports and records reviewed.)

DIAGNOSIS 27 Weeks Premature ROP. Moderate Hearing Loss CP	MEDICATIONS None
HOSPITALIZATIONS Released at 6 months age Pneumonia at 10 months	SURGERIES Heart Surgery
EQUIPMENT PRESCRIBED Oxygen and Apnea monitor no longer used after 18 months. Hearing Aid: prescribed 2/94 not recommended 5/95. Glasses: Won't wear.	PRECAUTIONS Typical mobile baby strategies. Oxygen, apnea monitor: discontinued.
VISION STATUS & DATE OF LAST TEST ROP: stage 3 left eye stage 4 right eye 20/80: acuity 20 degrees visual field	HEARING STATUS & DATE OF LAST TEST 2 failed ALGO tests 2/94: ABR, Behavioral 4/94: Mod loss. No need for HA. Unilateral loss.

From Interdisciplinary to Transdisciplinary Interventions

by Deborah Chen

Rationale for an integrated therapy model

P.L. 99–457 requires interagency and interdisciplinary coordination among various agencies and specialists serving infants with disabilities and their families at the state, local community, and program levels (Harbin & McNulty, 1990; Lowenthal, 1992; Woodruff & McGonigel, 1988). Given the complicated needs of infants who are deaf-blind, effective coordination is a substantial challenge to providing early intervention services to these infants and their families. How can we meet the multiple needs of an infant with significant disabilities in a way that reflects a coordinated team approach?

Early intervention literature describes three different models for teaming: multidisciplinary, interdisciplinary, and transdisciplinary (McCollum & Hughes, 1988; Woodruff & McGonigel, 1988). In the traditional multidisciplinary model, professionals from different disciplines conduct individual assessments and develop and implement separate interventions. In the interdisciplinary model, professionals share their individual assessment results, develop interventions jointly, and implement individual discipline-specific interventions. In the transdisciplinary model, professionals from different disciplines serve on a team to conduct joint assessments and share expertise and roles in developing and implementing interventions. Families are active members of this team and interventions are integrated within the family's context. Further, role release is at the heart of the transdisciplinary model. Role release involves the willingness to share information about discipline specific practices to assist team members in implementing interventions (Orelove & Sobsey, 1987). A survey of 10 early childhood special education programs reported that the team model varied in each program depending on available staff and the program functions. Multidisciplinary teams were used frequently for conducting assessments, interdisciplinary teams were common for implementing interventions, while the transdisciplinary teams were least common (McCollum & Hughes, 1988). The challenges of limited resources, skeptical attitudes, and old practices hinder a widespread implementation of a true transdisciplinary model (Chen, 1992).

Research examining the early childhood special education services of different disciplines (early childhood special education, occupational therapy, special therapy, and speech and language therapy) in center-based settings has identified a continuum of consultative models which may be appropriate for different situations (McWilliam, 1995). However, this research also reported that therapists advocated an increased use of an integrated therapy model approach. This model increases opportunities for sharing knowledge and skills among primary service providers, specialized consultants, and families, by integrating discipline specific objectives and interventions within naturally occurring opportunities (Hill, Dobson-Burk & Smith, 1989; McWilliam, 1995; Rainforth & Salisbury, 1988). Moreover, the integrated therapy model supports the focus on meaningful outcomes by building on the strengths and interests of the young child in creating motivating interventions (Brown & Lehr, 1993; Campbell, 1992; Chen, 1995).

Model Demonstration Project
Interdisciplinary Focus Group
INPUT SUMMARY

Unique interventions provided to infants and toddlers with multiple disabilities (vision and hearing loss) by teachers trained in early childhood special education (ECSE).

1. Service coordination on behalf of family
2. Referral to other services and professionals
3. Work on parent, child, sibling, extended family, peer interactions
4. Facilitation of services for families
5. Advocate for families
6. Provide family emotional support
7. Work as members of transdiscipinary team
8. Conduct developmental assessment of all areas of development
9. Encourage play skills: attention, reaching/grasping, cause and effect, localizing sounds, responding visually
10. Encourage communication skills: touch cues, tactile cues, signing
11. Assist families to read child's cues
12. Frequency of visits: once per week or more
13. Encourage self-help skills
14. Determine child's learning style (pacing, cues, amount of input)
15. Help child to recognize familiar people
16. Help parents to add interventions into their daily routine
17. Develop predictable routines for intervention with child

Interdisciplinary focus group process

The project provided a mechanism to address the challenges of developing an integrated therapy model for infants who are deaf-blind by facilitating two all day interdisciplinary focus group meetings. The main purpose was: (a) to identify the unique and shared interventions provided by different disciplines serving infants with multiple disabilities/vision and hearing loss, and (b) to identify strategies for developing an coordinated approach for providing meaningful transdisciplinary interventions within an infant's daily routine.

Model Demonstration Project
Interdisciplinary Focus Group
INPUT SUMMARY

Unique interventions provided to infants and toddlers with multiple disabilities (vision and hearing loss) by teachers certified in the area of deaf and hard-of-hearing (DHH).

1. Facilitate language development
    - Communication Methods: ASL, SEE signs, oral/Aural, cued speech
    - Speech services for Hard-of-Hearing/Deaf
    - Family awareness as it relates to deafness and language development.
2. Explain behaviors due to lack of language as result of hearing loss
3. Assess
    - Functional hearing
    - Language (receptive/expressive)
4. Access local resources (DHH) for individuals with hearing loss and their families
5. Provide awareness of cultural aspects of Deaf Culture
6. Explain of audiogram as it relates to speech development expectations
7. Provide educational implications/life implications of a hearing loss
8. Assist with and explain assistive technology

Although there is great variation in the service models, all the early intervention programs involved in the project provided home-based services. Some also provided center-based services. The majority of infants who are deaf-blind in these programs were served by a primary early interventionist (an early childhood special educator, a teacher credentialed in hearing impairment or a teacher credentialed in visual impairment). Depending on their learning needs and their primary service provider, these infants also received services from specialized consultants, most frequently, occupational therapists, physical therapists, teachers credentialed in hearing impairment or visual impairment, and orientation and mobility specialists. For this reason, focus group participants represented these disciplines.

Model Demonstration Project
Interdisciplinary Focus Group
INPUT SUMMARY

Unique interventions provided to infants and toddlers with multiple disabilities (vision and hearing loss) by teachers certified with the area of visual impairment (VI).

1. Provide information of impact of vision loss on specific domains, e.g.: how vision loss affects cognition, gross motor, language, etc.
2. Conduct assessments across developmental domains (gathering medical history)
3. Conduct functional low vision assessment
   - Interpret eye report to IFSP
   - Interpret other medical information as relates to vision
4. Act as liaison with eye care specialist
5. Support development of positive caregiver/child relationship
   - ID infant cues
   - Facilitation of caregiver ability to interpret and respond to infant cues
6. Increase visual functioning (if applicable)
   - Visual enhancement of environment (positioning and arrangement of environment (i.e.: play area) to promote using vision: contrast and lighting)
   - Visual skill training (tracking, fixation, scanning)
   - Visual motor skill training
   - Use of optical and non-optical aids
7. Encourage development/Increase compensatory skills (tactual, auditory—awareness and discrimination
8. Promote Braille literacy through ID resources (Twin Vision Books), labeling environment, reading to children, etc.

9a. Determine primary learning media (visual, auditory, or tactual) and secondary learning media.

9b. Facilitate social skills (i.e.: parallel interactive play, symbolic play)

10. Provide resources on eye conditions on development, general parenting issues, networking with other parents, parent education and support (emotional and respite)

In preparation for the first focus group meeting, participants received a worksheet asking them to answer questions from the perspective of providing direct services to infants whose multiple disabilities include vision and hearing loss:

- ► Identify the roles of your discipline in an early intervention program.
- ► What services do you provide?

Model Demonstration Project
Interdisciplinary Focus Group
INPUT SUMMARY

Unique interventions provided to infants and toddlers with multiple disabilities (vision and hearing loss) by orientation and mobility specialists (O&M).

1. Defining spatial parameters—Environmental analysis and arrangements to facilitate:
   - Awareness of self and environmental and interrelationships
   - Concept development (spatial and other)
   - Motor development
   - Utilizing available sensory information for orientation
2. Promote use of residual vision for O&M/movement
3. Work with families— how to facilitate environmental awareness, how to facilitate curiosity. (Exploration, movement and concept development. Increasing awareness of space and cognitive mapping.)
4. Establish routines to promote orientation and environmental awareness.
5. Practice use of motor skills in home environment and natural environment.
6. Experiential learning opportunities
   - "Where am I and what does it mean to be here?"
   - "Why should I be anywhere different?"
   - Motivation for movement.
   - Provide safe/secure opportunities for movement.
   - Contextual learning.
   - Predictability

- What do you view as the specific or unique services provided by your discipline?
- What training does your discipline require in order to provide these services to infants with multiple disabilities?
- What professional competencies are needed in order for your discipline to work effectively with infants whose multiple disabilities include vision and hearing loss?

Model Demonstration Project
Interdisciplinary Focus Group
INPUT SUMMARY

Unique interventions provided to infants and toddlers with multiple disabilities (vision and hearing loss) by occupational therapists (OT) and physical therapists (PT).

1. Neuro-Developmental Treatment techniques to facilitate normal movement patterns (Relative to neurological status/tone)
2. Feeding therapy
3. Oral, motor, sensory: assessment and intervention
4. Assessing sensory processing -> sensory integration therapy
5. Addressing sensory defensiveness/tactile
6. Vestibular/proprioceptive stimulation (balance/movement activities)
7. Handling skills to facilitate optimal vision use
8. Developmentally appropriate play activities (age appropriate play and play positions)
9. Adaptive equipment for play, positioning, feeding and classroom
10. Splinting and bracing
11. Range of motion/muscle testing
12. Instruction/parent education for motor activities
13. Sensory processing versus sensory play
14. Individual intervention (in center based)

- What strategies have you used to integrate your discipline specific objectives across an infant's daily routine?
- What strategies have you used to develop an effective team approach in serving an infant whose multiple disabilities include vision and hearing loss?

Model Demonstration Project
Interdisciplinary Focus Group

INPUT SUMMARY

Shared interventions of teachers (ECSE) provided to infants and toddlers with multiple disabilities (vision and hearing loss)

INTERVENTION (all include parent education)	**DISCIPLINE(S)**
Develop communication skills (cues, signs, localizing and responding to sounds)	DHH
Visual/tactile cues, communication, reaching/grasping, responding visually to stimuli, positioning child to use optimal vision, educating families of visual abilities of child and how it impacts development.	VI
Facilitate appropriate positioning, educate parents in abilities/limitations, fine/gross motor movements/use, feeding/oral motor skills, balance, play skills, and mobility	OT/PT O&M Nutritionist Speech and language therapist

At the meeting, participants met in small groups of three to five individuals representing the same discipline. In small groups, they shared individual perspectives and created a brainstorm list that reflected group consensus.

Each small group shared their list with the large group and participants identified similarities and differences across the disciplines. Participants received a typed copy representing the perspectives of their discipline to review and edit as necessary.

In preparation for the second focus group meeting, participants were sent articles and materials regarding the interdisciplinary and transdisciplinary team approaches, the integrated therapy model (Hill et.

al., 1989; McWilliam, 1995; Rainforth & Salisbury, 1988), and professional standards/personnel competencies for each discipline. At the second focus group meeting there were two activities to address an integrated therapy approach. First, participants were grouped with colleagues of the same discipline. Each person received a copy of four different vignettes and an individual input sheet on which to note the infant's strengths and two key discipline specific objectives. As a discipline-specific team, the small group shared their individual perspectives and decided on recommended objectives. Each discipline-specific team shared their recommendations for each infant with the large group.

Model Demonstration Project
Interdisciplinary Focus Group

INPUT SUMMARY

Shared interventions of teachers (DHH) provided to infants and toddlers with multiple disabilities (vision and hearing loss).

INTERVENTION (all include parent education)	**DISCIPLINE(S)**
Vision	VH
Children with vision problems	O&M Consultant
Understanding Atypical Behaviors	
1. Biting	Behavior Specialist
2. Autistic tendencies	ECSE
3. Physical defensiveness	ECSE, OT
Physical Development	
1. CP	OT/PT
2. Gross and fine motor	
Speech	OT Speech Therapist
Medical coordination of services	Nurse Support
Medical interventions	

Next, four transdisciplinary teams were created to develop a Routine Analysis of an activity and to infuse discipline-specific objectives within the daily routine on an Objectives within Routines Matrix. Each team shared with the large group.

Model Demonstration Project
Interdisciplinary Focus Group

INPUT SUMMARY

Shared interventions of teachers (VI) provided to infants and toddlers with multiple disabilities (vision and hearing loss).

INTERVENTION (all include parent education)	**DISCIPLINE(S)**
Assessment across domains	ECSE OT/PT DHH Speech/Language
Vision assessment	O&M (training in infancy and multiple disabilities)
Support positive relationships (Caregiver/Infant)	ECSE
Increase visual functioning	O&M
Increase compensatory skills	O&M
Primary learning media	OT/PT O&M DHH ECSE
Secondary learning media	ECSE O&M

Participants in the focus group process identified certain requirements for an effective transdisciplinary team approach. First, professionals need to know their "own stuff," i.e., have competencies in discipline professional skills so that they can be blended with other disciplines. At the same time, professionals need to realize when additional expertise is needed

Model Demonstration Project
Interdisciplinary Focus Group

INPUT SUMMARY

Shared interventions of **O&M** specialits provided to infants and toddlers with multiple disabilities (vision and hearing loss).

INTERVENTION (all include parent education)	**DISCIPLINE(S)**
Facilitating use of functional vision	VI
Motor Development	OT/PT
Matching daily activities to proper and natural environment	ECSE, VI, DHH
Use real objects Allow response time Make life fun	DHH ECSE O&M OT/PT

and where to access help. Next, there has to be a process for sharing information, planning, and implementing meaningful interventions. This goal can be achieved by establishing ground rules for the process and maintaining communication among team members including sharing reports, resources, and progress. Specific strategies involve round table interagency meetings, shared staff meetings, joint home visits, family interviews, ecological inventories, arena assessment for program planning, family-driven goals, and infusing objectives within daily routines. Most of all, participants wanted additional time and opportunities for sharing information, for receiving and providing cross disciplinary training, and for developing true collaboration with families.

Model Demonstration Project
Interdisciplinary Focus Group

INPUT SUMMARY

Shared interventions of **OTs** and **PTs** provided to infants and toddlers with multiple disabilities (vision and hearing loss).

INTERVENTION (all include parent education)	**DISCIPLINE(S)**
Ambulation	OT/PT ECSE O&M
Handling/Positioning	All educators: home and center based. O&M OT/PT
Feeding/ADL	All educators: center-based OT/PT Speech
Fine Motor Play	All educators VI DHH ECSE O&M

Focus group

The intervention objectives, strategies, and practices highlighted in this chapter were developed through an interdisciplinary focus group process. Participants represented the disciplines of early childhood special education (ECSE), hearing impairment (DHH—deaf and hard of hearing), visual impairment (VI), orientation and mobility (O&M), occupational therapy (OT) and physical therapy (PT). Focus group members represented professionals with a range of experiences serving infants whose multiple disabilities include vision and hearing loss and were willing to share their perspectives in two all day focus group meetings. Their suggestions do not reflect a comprehensive approach but rather the initial efforts of infusing discipline specific interventions within the natural routines of infants who are deaf-blind.

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References

Brown, F., & Lehr, D.H. (1993). Making activities meaningful for students with severe multiple disabilities. *Teaching Exceptional Children*, 25, 12-16.

Campbell, P.H. (1991). Evaluation and assessment in early intervention for infants and toddlers. *Journal of Early Intervention*, 151, 36-45.

Chen, D. (1992). Early intervention. In J.W. Reiman & O.A. Johnson (Eds.), *Proceedings from the national symposium on children and youth who are deaf-blind* (pp. 37-44). Monmouth, OR: Teaching Research Publications.

Chen, D. (1995). Guiding principles for instruction and program development. In D. Chen & J. Dote-Kwan, *Starting points. Instructional practices for young children whose multiple disabilities include visual impairment* (pp. 15-28). Blind Childrens Center: Los Angeles.

Harbin, G., & McNulty, B. (1990). Policy implementation: Perspectives on service coordination and interagency coordination. In S. Meisels, & A. Shonoff (Eds.), *Handbook of early intervention* (pp. 700-721). New York: Cambridge University Press.

Hill, E. W., Dobson-Burk, B., Smith, B.A. (1989). Orientation and mobility for infants who are visually impaired. *RE:view*, 21(2), 47-60.

Lowenthal, B. (1992). Interagency collaboration in early intervention: Rationale, barriers and implications. *Infant-Toddler Intervention*, (2), 103-112.

McWilliam, R.A. (1995). Integration of therapy and consultative special education a continuum in early intervention. *Infants and Young Children*, 7(4), 29-38.

McCollum, J.A., & Hughes, M. (1988). Staffing patterns and team models in infancy programs. In J.B. Jordan, J.J. Gallagher, P.L. Hutinger, & M.B. Karnes (Eds.), *Early childhood special education: Birth to three* (pp.129-146). Reston, VA: Council for Exceptional Children.

Orelove, F.P., & Sobsey, D. (1987). *Educating children with multiple disabilities: A transdisciplinary approach*. Baltimore: Paul H. Brookes.

Rainforth, B., Salisbury, C.L. (1988). Functional home programs: A model for therapists. *Topics in Early Childhood Special Education*, (7)4, 33-45.

Woodruff, G., & McGonigel, M. (1988). Early intervention team approaches: The transdisciplinary team. In J.B. Jordan, J.J. Gallagher, P.L. Hutinger, & M.B. Karnes (Eds.), *Early childhood special education: Birth to three* (pp. 163-181). Restan, VA: Council for Exceptional Children.

VIGNETTE #1

Recommended objectives form

Discipline ECSE Lisa is 9 months old. She is diagnosed as having CHARGE Association. Lisa has bilateral colobomae, a heart defect, mental and growth retardation, and a moderate sensorineural hearing loss. She is very hypotonic and has a cleft lip and palate. She has been diagnosed as a failure-to-thrive and is fed by a G tube. Despite her complex medical needs, she is alert and responsive to familiar people and can grasp her rattle and other toys. She receives home-based intervention.	**STRENGTHS** Alert and responsive to familiar people Grasps her rattle Some hearing
OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Develop cues to recognize familiar people	ID how family identifies themselves to child. Help develop identification cues
Encourage hand use and transfer of objects	Encourage grasp and transfer of toys to other hand during play
Encourage hand to mouth coordination	Use varied textured rattle. Put food on the rattle

Discipline DHH Lisa is 9 months old. She is diagnosed as having CHARGE Association. Lisa has bilateral colobomae, a heart defect, mental and growth retardation, and a moderate sensorineural hearing loss. She is very hypotonic and has a cleft lip and palate. She has been diagnosed as a failure-to-thrive and is fed by a G tube. Despite her complex medical needs, she is alert and responsive to familiar people and can grasp her rattle and other toys. She receives home-based intervention.	**STRENGTHS** Alert Responsive to people Able to grasp things Moderate loss as opposed to profound loss Receiving intervention early
OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Name people in her environment. Develop a communication system	Determine how much she can see. Devise communication (name signs, names) depending on vision/motor abilities. Be very specific.
Name activities so she can begin to predict what's coming up.	Use object cues, touch cues, signs and vocal cues as deemed appropriate due to her abilities.
Obtain hearing aid	Have DHH consultant go with family to hearing aid dealer and to audiologist.
Obtain: Oral motor assessment; Assessment of vision.	Call in an OT. Call in a VI consultant.
Recognize attending and listening behaviors.	Observe during familiar and unfamiliar situations. Evaluate background noise.

Discipline VI Lisa is 9 months old. She is diagnosed as having CHARGE Association. Lisa has bilateral colobomae, a heart defect, mental and growth retardation, and a moderate sensorineural hearing loss. She is very hypotonic and has a cleft lip and palate. She has been diagnosed as a failure-to-thrive and is fed by a G tube. Despite her complex medical needs, she is alert and responsive to familiar people and can grasp her rattle and other toys. She receives home-based intervention.	**STRENGTHS** Alert Grasp Responsive to familiar people
OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Encourage visual fixation, localization following of a familiar person.	Conduct functional low vision assessment: Viewing distance Lighting requirements; Visual field.
Encourage reaching for objects and people to promote eye-hand coordination.	Combine visual with auditory input. Provide contrasting light to enhance beloved people.
Promote head control to use vision.	Support sitting device to play with handing toys. Use familiar person's face as a social motivator to bring head into position.
Encourage visual searching for toy to hold and play with.	Facilitate usable vision for localization by arranging toys/play objects with predictable placement which would encourage emerging motor skills. Use high contrast with lighting.

VIGNETTE #1, CONTINUED

Recommended objectives form

Discipline **O&M**

Lisa is 9 months old. She is diagnosed as having CHARGE Association. Lisa has bilateral colobomae, a heart defect, mental and growth retardation, and a moderate sensorineural hearing loss. She is very hypotonic and has a cleft lip and palate. She has been diagnosed as a failure-to-thrive and is fed by a G tube. Despite her complex medical needs, she is alert and responsive to familiar people and can grasp her rattle and other toys. She receives home-based intervention.

STRENGTHS

Alert and responsive
Some form of grasp
Recognizes familiar people

OBJECTIVES AND RECOMMENDATIONS	STRATEGIES
Encourage looking for toys.	Use vision, hearing, other environment clues. Arrange objects in predictable placements and encourage evolving motor skills.
Facilitate awareness/use of residual vision.	Use bright yellow, slow moving targets, watch for light sensitivity, contrast.
Develop motor skills as needed (i.e.: head control).	Encourage use of vision to promote head control. Position with support needed to use arms, vision, interact with environment. Use familiar face as social motivator. Participate in daily activities (help bathe) with family.

Discipline OT/PT

Lisa is 9 months old. She is diagnosed as having CHARGE Association. Lisa has bilateral colobomae, a heart defect, mental and growth retardation, and a moderate sensorineural hearing loss. She is very hypotonic and has a cleft lip and palate. She has been diagnosed as a failure-to-thrive and is fed by a G tube. Despite her complex medical needs, she is alert and responsive to familiar people and can grasp her rattle and other toys. She receives home-based intervention.

STRENGTHS

Alert and responsive to environment
Can grasp toys
Some vision
Some hearing

OBJECTIVES AND RECOMMENDATIONS	STRATEGIES
Explore possibility of oral feeding. Long term goal to eat by mouth.	Evaluate, provide oral motor activities, cleft palate repair. Help family obtain follow-up for repair to cleft palate.
Improve motor control (general motor skills).	Handling/positioning, tolerance, and strengthening activities. Develop hand use. Home program.
Evaluate for splinting and adaptive equipment.	Obtain necessary equipment.
Promote fine motor, play and body exploration skills.	Develop home program. Instruct parents on play activities, develop hand manipulation skills.
Assess for sensory needs.	Provide vestibular stimulation and proprioceptive input.

VIGNETTE #2

Recommended objectives form

Discipline ECSE

Maria receives home-based intervention. She is 18 months old. She has a diagnosis of Retinopathy of Prematurity, hypotonia, and a bilateral moderate hearing loss due to atresia. However, she pulls off her hearing aids. Maria is totally blind, makes some babbling sounds, and drinks from a bottle without help Her father plays a vigorous "airplane" game that makes her laugh. Maria begins to move her arms and legs and make sounds when her father picks her up. Maria is very quiet when her mother sits and holds her in a rocking chair for their lullaby before nap and bedtime. Maria eats soft food . She will grasp rattles and other easy to hold toys for a few seconds. Maria scoots on her bottom and can roll.

STRENGTHS

Some hearing
Babbling
Drinking from bottle
Enjoys play
Laughs
Recognizes dad and game they play
Enjoys movement
Grasping/holding toy
Eats soft food
Scooting
Rolls

OBJECTIVES AND RECOMMENDATIONS	STRATEGIES
Maria will keep hearing aid on.	Put hearing aids on and then family member will engage in a desirable activity with child (sing lullabies, play airplane game).
Maria will engage in turn taking babbling game.	When Maria makes sound, adult will imitate then wait for child's response.
Maria will ask for "more."	Shape movement of arms into sign for MORE. Hand over hand model of MORE.
Maria will tolerate food with increased texture.	Add crumbled graham crackers to applesauce.

VIGNETTE #2, CONTINUED

Recommended objectives form

Discipline DHH

Maria receives home-based intervention. She is 18 months old. She has a diagnosis of Retinopathy of Prematurity, hypotonia, and a bilateral moderate hearing loss due to atresia. However, she pulls off her hearing aids. Maria is totally blind, makes some babbling sounds, and drinks from a bottle without help Her father plays a vigorous "airplane" game that makes her laugh. Maria begins to move her arms and legs and make sounds when her father picks her up. Maria is very quiet when her mother sits and holds her in a rocking chair for their lullaby before nap and bedtime. Maria eats soft food . She will grasp rattles and other easy to hold toys for a few seconds. Maria scoots on her bottom and can roll.

STRENGTHS

Making some sounds
Drinks from bottle by herself
Recognizes parent
Showing communication intent
Likes touch (comforted)
Can grasp objects
Trying to be mobile

OBJECTIVES AND RECOMMENDATIONS	STRATEGIES
To wear hearing aids consistently.	Increase length of time of amplification. Wear aids in stimulating situation (when singing the lullaby). Different head bands.
To develop communication.	Presymbolic communication. Increase babbling. Labels for family members. Use family routine to add labels.

Discipline VI

Maria receives home-based intervention. She is 18 months old. She has a diagnosis of Retinopathy of Prematurity, hypotonia, and a bilateral moderate hearing loss due to atresia. However, she pulls off her hearing aids. Maria is totally blind, makes some babbling sounds, and drinks from a bottle without help Her father plays a vigorous "airplane" game that makes her laugh. Maria begins to move her arms and legs and make sounds when her father picks her up. Maria is very quiet when her mother sits and holds her in a rocking chair for their lullaby before nap and bedtime. Maria eats soft food . She will grasp rattles and other easy to hold toys for a few seconds. Maria scoots on her bottom and can roll.

STRENGTHS

Drinks from a bottle without help
Anticipates favorite activities
Attempting to focus listening skills
Eats soft food
Grasps rattles
Scoots
Babbling

OBJECTIVES AND RECOMMENDATIONS	STRATEGIES
Independent finger-feeding.	Provide foods she likes in small helpings. Use a shallow bowl or tray. Use highchair—consistently.
Encourage beginning word "baba" "dada."	Use shaping strategies to encourage vocalization. Pair sounds with favorite activities or events.
Encourage hand use and playing with objects.	Provide a variety of different sound toys for Maria to grasp and shake. Develop turntaking games.

Discipline O&M

Maria receives home-based intervention. She is 18 months old. She has a diagnosis of Retinopathy of Prematurity, hypotonia, and a bilateral moderate hearing loss due to atresia. However, she pulls off her hearing aids. Maria is totally blind, makes some babbling sounds, and drinks from a bottle without help Her father plays a vigorous "airplane" game that makes her laugh. Maria begins to move her arms and legs and make sounds when her father picks her up. Maria is very quiet when her mother sits and holds her in a rocking chair for their lullaby before nap and bedtime. Maria eats soft food . She will grasp rattles and other easy to hold toys for a few seconds. Maria scoots on her bottom and can roll.

STRENGTHS

Some grasp
Social
Knows simple game
Differentiates behavior for parents

OBJECTIVES AND RECOMMENDATIONS	STRATEGIES
Develop environment concepts. Encourage body awareness.	Set up environment opportunities and situations to encourage exploration and interaction. Massage in predictable way, labeling body parts ("I'm gonna get your toes." etc.).
Encourage motor development.	Sensory-motor stimulation. Activities to develop tone. Play on pillows so she can kneel. Use inner tube to help with balance. Motor games.
Facilitate concept development —spatial, cause & effect, etc.	Participate as much as possible in feeding and other activities (i.e.: reach with spoon to bowl, help find rub washcloth over body in bath).
Feed in high chair to promote environmental awareness	Serve food in bowl, not jar. Encourage messy food play.
Promote awareness of space with home environment used for mapping (all rooms in the house.	Use furniture in house as tactile map. Use people/family as motivators for movement.

VIGNETTE #2, CONTINUED

Recommended objectives form

Discipline OT/PT Maria receives home-based intervention. She is 18 months old. She has a diagnosis of Retinopathy of Prematurity, hypotonia, and a bilateral moderate hearing loss due to atresia. However, she pulls off her hearing aids. Maria is totally blind, makes some babbling sounds, and drinks from a bottle without help Her father plays a vigorous "airplane" game that makes her laugh. Maria begins to move her arms and legs and make sounds when her father picks her up. Maria is very quiet when her mother sits and holds her in a rocking chair for their lullaby before nap and bedtime. Maria eats soft food . She will grasp rattles and other easy to hold toys for a few seconds. Maria scoots on her bottom and can roll.	**STRENGTHS** Has some hearing Some language, beginning vocalization Socially aware (responsive to family members) Feeder (pureed foods), holds bottle Some play skills Developing mobility skills (grasps toys)
OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Improve motor control (prone, creeping, transitional movements).	Developmental handling to promote motor skills. Transitional activities, creeping.
Improve play skills.	Use hearing for motivation for play skills.
Assess sensory needs.	Provide tactile stimulation, and vestibular proprioceptive input.
Work on oral, motor, and self-feeding skills.	Train parents and educators on feeding techniques, texture progression, chewing.

VIGNETTE #3

Recommended objectives form

Discipline ECSE Tony is 24 months old. He is diagnosed as having a severe visual impairment (cataracts have been removed but he responds to light and tracks brightly colored objects, but he does not seem to recognize familiar people or toys). He has just begun to crawl with encouragement. He has low tone. Tony does not make any sounds. He does not respond consistently to sounds, although sometimes he smiles to certain loud and exaggerated vocalizations. He is usually congested and his parents report that he is prone to ear infections and seems to catch whatever is going around. He may have a hearing loss but has not had an audiological as yet. He attends a center based program and receives home visits.	**STRENGTHS** Responds to light Tracking bright objects Crawl Smiles/responds to loud sounds
OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Obtain audiological test for child	Refer mom to audiologist. Educate family to importance/process of assessment. Address resources to attain test (go with family to visit).
Encourage recognition of familiar people.	Help family to make up or use existing touch cue for each member when they approach child. Face with flashlight during games. Use loud exaggerated voice.
Encourage recognition of familiar toys.	Provide toys with loud sounds, and use tactile cues, visual cues.

Discipline DHH

Tony is 24 months old. He is diagnosed as having a severe visual impairment (cataracts have been removed but he responds to light and tracks brightly colored objects, but he does not seem to recognize familiar people or toys). He has just begun to crawl with encouragement. He has low tone. Tony does not make any sounds. He does not respond consistently to sounds, although sometimes he smiles to certain loud and exaggerated vocalizations. He is usually congested and his parents report that he is prone to ear infections and seems to catch whatever is going around. He may have a hearing loss but has not had an audiological as yet. He attends a center based program and receives home visits.

STRENGTHS
Crawls
Aware of sounds
Responds to people
Has EI services
Tracks lights and colors

OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Obtain audiological and otological evaluations	Refer to an ENT. Obtain Tympanogram & hearing test.
Obtain functional visual assessment.	VH Consultant
Obtain Physical Therapy Assessment.	OT/PT
Encourage response to familiar people or toys.	Light on faces/objects. High contrast, use lighted video, big and shiny earrings.
Encourage communication and order in his life.	Get a sense of his environment and routine. Find ways to develop labels.
Obtain extra support for family.	Contact Family Resource Center (FRC).

Discipline VI

Tony is 24 months old. He is diagnosed as having a severe visual impairment (cataracts have been removed but he responds to light and tracks brightly colored objects, but he does not seem to recognize familiar people or toys). He has just begun to crawl with encouragement. He has low tone. Tony does not make any sounds. He does not respond consistently to sounds, although sometimes he smiles to certain loud and exaggerated vocalizations. He is usually congested and his parents report that he is prone to ear infections and seems to catch whatever is going around. He may have a hearing loss but has not had an audiological as yet. He attends a center based program and receives home visits.

STRENGTHS
Tracks colored objects
Responds to light
Crawl (beginning)
Responds with smile to loud and exaggerated vocalizations

OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Refer for audiological.	Consult with appropriate resources/specialists.
Encourage response to familiar people, toys, and objects.	Use high contrast, lighted visor, Christmas light earrings, add lights to faces, match with auditory cues.

Discipline O&M

Tony is 24 months old. He is diagnosed as having a severe visual impairment (cataracts have been removed but he responds to light and tracks brightly colored objects, but he does not seem to recognize familiar people or toys). He has just begun to crawl with encouragement. He has low tone. Tony does not make any sounds. He does not respond consistently to sounds, although sometimes he smiles to certain loud and exaggerated vocalizations. He is usually congested and his parents report that he is prone to ear infections and seems to catch whatever is going around. He may have a hearing loss but has not had an audiological as yet. He attends a center based program and receives home visits.

STRENGTHS
Crawling
Visually responds to light/tracks

OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Facilitate visual awareness of environment and functional vision skills.	Use bright and contrasting colored objects: toys, dishes, washcloths, etc.
Facilitate motor development.	Have him use motor skills (e.g.: crawling) for functional purposes (e.g.: crawl to dinner table versus being carried). Give opportunities to practice developing and evolving skills.
Facilitate sensory awareness and orientation.	Explore new and semi-familiar environments and interact with them.
Get audiological work-up.	Get appointment and transportation.

VIGNETTE #3, CONTINUED

Recommended objectives form

Discipline OT/PT	**STRENGTHS**
Tony is 24 months old. He is diagnosed as having a severe visual impairment (cataracts have been removed but he responds to light and tracks brightly colored objects, but he does not seem to recognize familiar people or toys). He has just begun to crawl with encouragement. He has low tone. Tony does not make any sounds. He does not respond consistently to sounds, although sometimes he smiles to certain loud and exaggerated vocalizations. He is usually congested and his parents report that he is prone to ear infections and seems to catch whatever is going around. He may have a hearing loss but has not had an audiological as yet. He attends a center based program and receives home visits.	Some light perception, tracking Some mobility
OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Address hearing deficit, language delay and medical concerns.	Referral for medical follow-up and audiological evaluation.
Improve motor skills, mobility and transitional skills (creeping -> pull to stand -> ambulatory).	Developmental and positioning activities. Family/classroom education.
Evaluate play, adaptive daily living skills, fine motor.	Appropriate activities provided for areas of weakness.
Improve muscle tone and stability.	Use proprioceptive and vestibular activities.
Improve balance and upright mobility.	Work on equilibrium and transitional skills.

VIGNETTE #4

Recommended objectives form

Discipline ECSE	**STRENGTHS**
Huey is 30 months old. He has a diagnosis of cortical visual impairment, seizures, a bilateral severe to profound hearing loss and is nonambulatory because of spastic cerebral palsy. He prefers to be left alone and doesn't like to be held or touched. His foster mother reports that he eats pureed foods and drinks from a bottle held by another. She is concerned about his self injurious behavior (biting his hand in the callous area) and his fussing and crying episodes. He has a home visit program and is transitioning to a center based program.	Eats by mouth Drinks from bottle Showing preference for interaction (being left alone)
OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Huey will learn to anticipate daily events with assistance of tactile/object cues.	Work with families to establish cues.
Determine when self-injurious behavior is worst and what occurs prior to the behavior.	Colaborate with behavior specialist. Use Scale "Motivation Assessment." Collaborate with behavior specialist. .
Review medical history (does crying = seizures?)	Consult with nurse/physician regarding medical issues.
Begins to tolerate holding during eating.	Collaborate with PT/OT

Discipline VI	**STRENGTHS**
Huey is 30 months old. He has a diagnosis of cortical visual impairment, seizures, a bilateral severe to profound hearing loss, and is nonambulatory because of spastic cerebral palsy. He prefers to be left alone and doesn't like to be held or touched. His foster mother reports that he eats pureed foods and drinks from a bottle held by another. She is concerned about his self injurious behavior (biting his hand in the callous area) and his fussing and crying episodes. He has a home visit program and is transitioning to a center based program.	Pureed foods. Drinks from a bottle.
OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Identify preferred activity or objects.	ID blanket swinging, music, vestibular activity, hammock.
Identify something else to replace the biting (i.e.: massage, vesibular activity).	Substitute object -> teething ring, put different food on the hand (peanut butter, jam, chocolate). Pacifier.
Identify how Huey uses his vision and his visual preferences.	Observe during familiar activities. Use brightly colored bottle and spoon during feeding.

Discipline O&M Huey is 30 months old. He has a diagnosis of cortical visual impairment, seizures, a bilateral severe to profound hearing loss and is nonambulatory because of spastic cerebral palsy. He prefers to be left alone and doesn't like to be held or touched. His foster mother reports that he eats pureed foods and drinks from a bottle held by another. She is concerned about his self injurious behavior (biting his hand in the callous area) and his fussing and crying episodes. He has a home visit program and is transitioning to a center based program.	**STRENGTHS** Can move arms Some body awareness Some communication
OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Increase social tolerance.	Predictable, controllable routines and cues.
Increase tolerance of being handled.	Reduce tone, tactile defensiveness. Sensory integration activities.
Encourage independent and meaningful movement.	Set up environment opportunities, situation to positively interact with objects/people in environment.
Establish patterns with primary caregiver which will promote social connectedness with caregivers. For example through body awareness activities.	Encourage massage and sensory integration activities.
Encourage recognition of consistent others in Huey's world.	Encourage touch cues for foster mom/family, home visitor and center based people.
Daily routines will be broken down to controllable consistent activities that allow Huey to show awareness of environment and activities related to places.	Encourage diaper change routine, bath routine, environment experience activities.

Discipline OT/PT Huey is 30 months old. He has a diagnosis of cortical visual impairment, seizures, a bilateral severe to profound hearing loss and is nonambulatory because of spastic cerebral palsy. He prefers to be left alone and doesn't like to be held or touched. His foster mother reports that he eats pureed foods and drinks from a bottle held by another. She is concerned about his self injurious behavior (biting his hand in the callous area) and his fussing and crying episodes. He has a home visit program and is transitioning to a center based program.	**STRENGTHS** Eats pureed foods; Drinks from bottle Limited vision (variable) Communicating (fussying/crying) Willing to be touched Concerned foster mother Eats
OBJECTIVES AND RECOMMENDATIONS	**STRATEGIES**
Increase motor control. (OP/PT Assessment)	Splinting/adaptive equipment needs, orientation to gravity (deep pressure). Neuro-developmental activities. Positioning for function/feeding.
Address feeding skills.	Introduce textures in food. Self-feeding activities. Progress to cup drinking.
Evaluate and address sensory needs. Break down sensory defensiveness.	Replace self-stimulation behaviors with functional activities (brushing, appropriate chew toys, mouthing). Small steps in massage and touch. *Parent/teacher education re: sensory overload, tactile, handling, swaddling.*
Address social responsiveness.	Tolerate handling, firm touch, swaddling
Functional Vision Assessment	VI consultant. Determine what/how he sees

Routine analysis

INFANT Lisa (#1) **ACTIVITY** Play with Mobile (cradle gym) **DATE** March 02, 1996

STEPS IN ROUTINE	NATURAL CUES	INFANT BEHAVIORS TO ENCOURAGE	INPUT AND ADAPTIVE STRATEGIES	AREA *(Discipline)*
For example: Preparing for the activity, marking the beginning, middle and end of activity, and transition to another.	*For example: Characteristics of the environment, what adult does to engage the infant's attention and participation.*	*For example: Ways the infant can indicate anticipation and participate actively.*	*For example: Ways to provide appropriate communication input, may include: speech, sign, touch cues and object cues or handling and positioning, ways to encourage functional vision and hand use.*	DHH ECSE VI O&M OT/PT
1. Put baby on floor on fuzzy blanket (supine)	Have her touch blanket before/as she lies down.	Anticipates lying down, cooing.	Touch her hand to blanket, give verbal information ("blanket")	
2. Place mobile over Lisa. Put objects on it.	Guide her arm to show her mobile exists and where it is.	Cooperates with reaching for mobile	Placement of objects with visual and motor needs to be considered	
3. She interacts with objects on mobile.	Sound of rattle, feel and sight of objects	Reaches, grasps, interacts with objects, cooing, mouthing, bring objects to mouth.	Place mouthable objects on mobile (elastic cord) Black/white objects, bright colors, moving, auditory, tactile toys.	
4. Baby and adult (together) remove mobile. *Future goal	Adult helps her to push mobile away (guides hand to do it).	Helps push mobile away or visually tracks movement of mobile away.	Verbal input Have her use object to see its function, give verbal input. "All done!"	

Objectives within routines matrix

INFANT Lisa (#1) **DATE** March 02, 1996

	ROUTINES			
OBJECTIVES	G-TUBE FEEDING	BATHING	FAMILY TIME/ LEISURE	DIAPERING
OT: To develop hand use.	Hold object.	Splash water.	Handle toys.	Touch diaper.
OT: To develop oral motor skills.	Place pacifier in mouth and stroke lips.		Pacifier and toys to mouth.	
ECSE: To respond to individual family members.	*Each family member will develop unique cues to tell her who is doing activity with her.*			
DHH :To localize to sound.	Call her name before doing things. Tune into mother's voice.		Say "Turn TV on" before doing it.	Say "Lisa" before diaper.
O&M/VI: Develop use of functional vision.	*Present object in direct visual field, time to focus/attend, then use object.*			
	Direct her visual attention to mother.	Track movement of washcloth.	Play and toys: locate visually.	Visually attend, track movements.

Objectives within routines matrix

INFANT Maria (#2) **DATE** March 02, 1996

	ROUTINES			
OBJECTIVES	**DRESSED**	**MEALS**	**PLAY**	**BED**
DHH: To develop communication for what is about to happen.	Touch cue and/or coactive sign.	Touch cue with bowl.	Touch cue with play item.	Sound of lullabye or mom sitting on rocking chair.
VI: To increase use of hands.	Coactive signing.	Holding and/or carrying bowl.	Grasping and/or carrying toy.	
OT/PT: To improve motor control.		Improve motor control by using positioning or type chair.	Improve motor control by using positioning or type chair.	
ECSE: To indicate that she wants to continue an activity.		Body movement or saying "more."	Body movement or saying "more."	Rocking stops child indicates wants more.

Objectives within routines matrix

INFANT Tony (#3) **DATE** March 02, 1996

	ROUTINES			
OBJECTIVES	**(PLAY) BATH**	**BED**	**MEALS**	**DIAPER CHANGE**
DHH: To recognize and respond to his name.	"Tony want bath?"	Add name to all statements.	"Tony..."	"Tony..."
OT/PT: To get into and maintain appropriate position.	Help him transition into tub.	Climb or help get into bed.	Place in supported sitting position.	Help him to sit (transition).
ECSE: To recognize familiar people.	Use ID cues for caregivers.	Establish bedtime routine. Good-night to family members.	Have family members assigned to seats.	Use ID cues for caregivers.
O&M: To know where he is and what is expected of him there.	Find his toys in container.	Holds his special blanket from foot of bed.	Search on tray for favorite food.	Throws away own diaper.
VI: To visually attend to the object and reach for it.	Place in his hand consistently, divert his attention towards it.	Coactive activity to turn on light.	Encourage finger feeding.	

Transition

Off to Preschool! A Parent's Perspective

by

Jackie Kenley

Planning Transitions to Preschool

by

Lavada Minor

Educating Young Children with Severe & Multiple Disabilities in Typical Preschool Settings

by

June Downing

Off to Preschool! A Parent's Perspective

by Jackie Kenley

We are a family of five including two parents and three children. Laura is the third child in our family. She was born into our family in 1985. At the writing of this, she is nine years old. Laura has an older brother and an older sister, who are very devoted to her. Laura has an adorable smile, blond hair, blue eyes and can give wonderful hugs! While all of us are unique, Laura's uniqueness includes a profound hearing loss, low vision, hypotonia (low muscle tone), and an extensive heart defect. Laura has CHARGE Association.

Due to Laura's multi-sensory impairment, her development has been very delayed. She is also small for her age. She is in the fifth percentile on the growth charts and still only weighs forty-seven pounds. As a baby and young child, her slow growth and development were not quite as noticeable although she kept her "baby look" for a long time!

Early intervention

Help with Laura's development began shortly after she arrived home from the hospital at fourteen days old. She was seen by a home counselor from Blind Babies and later began having physical therapy at home through Easter Seals Society. As she grew older, she was a part of the PAVII Project (Parents and Visually Impaired Infants), receiving home visits and being part of a weekly play group in a community setting. To address Laura's deafness and communication needs, she attended San Francisco Hearing and Speech Center accompanied by her Mom and older sister. Mom and Sister began learning sign language and how to work with hearing aids and we all had a comfortable time being together with our new little sister. During this time, it was Mom's responsibility to get Laura to and from programs and therapies.

Preschool programs

At age three, the program plan changes for children with disabilities! Children are under the auspices of the School District to which they are assigned. This meant that we would want to visit programs that were available for our daughter within our district. We asked the Program Director for Special Education to give us the names of school sites which might be appropriate for Laura. We then visited these programs during class time and spoke with the teachers in the various classrooms. We also visited the state school in our area and I would suggest visiting private schools that might be appropriate. An Individual Education Program is established for the child by the school district, the child's family and teacher/therapists. At Laura's first I.E.P. meeting there was a room full of people and the whole thing seemed quite overwhelming after our comfortable, family-oriented infant programs. It seems the I.E.P. meeting was divided into two camps...those who knew Laura's needs and wanted to be sure that these needs would all be addressed and those who were trying to understand her needs and find a program that fit her within the district...an awesome task! After a long meeting and many words written into her I.E.P., there were also the words "door to door transportation required." That sounded fine on paper, however, the reality for the parent of a deaf/blind child can be somewhat frightening!

Laura's assigned preschool was actually within walking distance of our home. She was assigned to a classroom for children with severe disabilities with a teacher who had some experience with children who are visually impaired and a small student/adult ratio. I had been encouraged by members of the Local Community Advisory Council on Disabilities to have Laura take the bus. Since Laura did not walk very well at this time, my only options were to drive her myself or have her take the bus. Why should this be any problem for a mom who had already sent two children to school on the bus for years? Well first of all, those two children had not gone to school at age three on a bus! They could both communicate, walk well, and did not require a car seat when they started riding the bus!

The bus ride

For some reason, I only vaguely remember the first day I put Laura on the big yellow school bus. I do recall the bus seemed very large pulling up to the front of our home. Laura required a back pack, a sturdy car seat, and we had to get her to the bus which was not such an easy task. She did begin her public school career in the spring which meant her brother and sister already had their transportation schedules in tact. I also recall the routine of first taking her car seat and back pack out to the front sidewalk and then going in the house for Laura. She was unable to walk to the bus at that time so I carried her out to the bus and up the stairs after handing the bus driver her car seat. Thank heaven for that sturdy little Fischer-Price car seat which gave Laura a secure seat and protected her head with its sides. I am sure the bus drivers and class room staff were not crazy about dealing with that car seat as it was somewhat cumbersome and heavy, however, it gave me and I believe Laura some peace knowing it was protecting her. Laura's Physical Therapist was insistent on this type of protection for our little girl for several years and I am glad we persisted.

No one informed the garbage collectors that we had a little girl who was deaf-blind at our house nor that I put her car seat on the sidewalk while I went into the house to get her. So one morning two years into Laura's program, the car seat was being smashed by some big machine on the garbage truck as I came back out the door with Laura. The garbage collectors were certainly alarmed by my hysteria but alas could do nothing to unsmash the car seat!

At that point, we moved on to a lighter half-seat type car seat and today Laura rides with a harness that is bolted to the bus seat and she is also belted in. It took some haggling with the transportation department, who sometimes feel a harness is not necessary. However, several bus drivers had been distressed at Laura's ways of amusing herself on the bus by leaning off the seat, head towards the floor and giggling over the sensory input she gets in that position.

One driver was in an accident with the kids on the bus and told me how thankful he was that Laura had been seated with her harness on at the time of the accident. It is worth the hassles with transportation to have your child safe and for the parents to have peace of mind!

Your child has a right to door to door transportation and it is important for the child to be safe and comfortable, and for you to have peace of mind about the transportation to school. Laura has been riding the school bus for six years now and I encourage you to "hang in there" and be a strong advocate for the transportation needs of your child. We have had several bus drivers who have been real encouragers for our family and Laura and I truly appreciate their role in Laura's growth and development...and I have told them so! It isn't always easy for some of us to be thankful and pleasant at 7:45 A.M. or on a busy afternoon but "thank you" and "have a good day!" are a boost to all of us, perhaps especially to the Special Ed bus drivers.

Here are some things that have helped our family with sending Laura off to school.

Selecting a preschool program

- ► Ask your school district for possible placement sites for your child. Visit the site and present classroom at the site. Remember sites, teachers, and programs can change, especially during the summer months.
- ► Visit the site, if possible with someone you have worked with in your child's infant program. This person might be able to make suggestions and give opinions about the programs suitability for your child.
- ► Once your child is in a classroom, visit the class and get a feeling as to whether this is the optimal placement for your child. Maintain communication with the teacher through visits, phone calls and notes.

You have the right to change your child's placement if this is not the optimal environment to meet the child's Individual Education Program goals.

- Give strong consideration as to whether your child with multiple disabilities needs a one-on-one para-professional (if needed, with signing skills) to interpret what's going on in the classroom and to keep your child involved. Every parent I have discussed this with has had difficulty asking for the one-on-one and every parent who has accomplished this wishes they had done it sooner!
- Ask for team meetings. So many people are working with your child and everyone should know what the other person is doing.

Transportation

- Introduce the child to the driver: "This is Laura, she doesn't hear you but she can see you. She communicates through sign language."
- Introduce yourself to the driver: "I am Laura's Mom, Jackie, will you be our new driver?"
- Help your child understand the concept of steps—getting up the bus steps—by working on indoor steps with a railing or in physical therapy sessions. What a great accomplishment for a child with depth perception problems!
- Be firm about your child's needs. Laura required a car seat for years. (Some districts will even provide a car seat.) She now requires a harness. This has often meant my phoning the district numerous times and having transportation personnel in front of our home to make sure she had a harness.
- Know the bus numbers for your child and keep them near your telephone. Also, call the bus company if the bus is not present twenty minutes (or sooner) than the time you were given for its arrival. Most buses have direct communication through radio with the bus line switchboard.
- Let the bus company know if your child is not attending school that day. This message will be radioed to the driver. Give the bus company twenty to thirty minutes time before your pick up time to notify the driver. This is most appreciated by drivers.
- In the beginning of your child's transportation journey, if you need to, take the bus! or follow it in your car! You will not be the first parent to do this!

Planning Transitions to Preschool

by Lavada Minor

A transition is a change from one service or program to another. Families of infants and toddlers with dual sensory impairments (vision and hearing), including multiple disabilities, are likely to experience more transitions than families of other children. One major transition families of toddlers with disabilities face is moving from home or center-based to preschool programs. This change involves not only different settings such as regular or special preschool programs, but also changes from the Individual Family Service Plan (IFSP) to the Individualized Education Plan (IEP), and from family focused to child focused services. This chapter will discuss important considerations when transitioning toddlers with dual sensory impairments and other multiple disabilities from home and center-based infant programs to preschool programs.

Federal law requires a formal and planned transition process for toddlers with disabilities. Part H of the Individuals with Disabilities Education Amendment (IDEA) of 1986 (P.L.99–457) requires that children with disabilities from birth to three receive early intervention services to address their special needs. It also mandates the development of an Individual Family Service Plan (IFSP) for families and their children with disabilities. The IFSP is a formal document which states the child's current level of development, goals, outcomes, needs, as well as the strengths and needs of family (Coleman, 1993). Developing the IFSP consists of input from the family as they identify their concerns, priorities, and resources. Transition steps to special education preschool services should be included in the IFSP when appropriate.

Although planned transitions to preschools are required by federal laws, special planning is needed to assist parents during this process. Transitions may occur for reasons other than the child's age, these may include the child's developmental needs, a newly identified diagnosis or family relocation. Transition to preschool may occur when families are facing other stressful events related to their child's multiple disabilities or their daily lives.

> *Eric is a 28 month old little boy who was born with cortical visual impairment. At 24 months of age, his parents informed their new early interventionist that their son did not seem to respond to speech. The early interventionist and the parents made careful observations of Eric's responses to voices and toy sounds. His lack of response supported the early interventionist's recommendation for an audiological evaluation. Eric was later diagnosed by an audiologist with a severe bi-lateral hearing loss. He was fitted with his first pair of hearing aids by the time he was 33 months.*

> *At the same time, Eric's maternal grandmother passed away. When Eric turned three years old, he started a center-based program for preschoolers with hearing impairments and other disabilities. His program receives consultant services from a teacher certified in the area of visual impairments. His early interventionist no longer visits his home and he rides to the center on the school bus. Eric's mother welcomed the idea of him attending a center-based program three days a week. However, encountering a new diagnosis, changing of services, and managing the wearing of his hearing aids in a short period of time was very stressful for her.*

Transitioning to new programs may change the types of services the family receives and the level of parent involvement. During home visits with their early interventionist, parents have opportunities to observe and participate in the services provided to their child. Parents also benefit from ongoing communication with their service provider which may support the development of close and trusting relationships. These relationships may end when the child transitions to a preschool program because special education services are usually provided outside of the home.

Transition brings a whole new set of roles and responsibilities from the initial stages of planning until the child is actually enrolled and attending the new program. Ample time is required in order to provide a smooth and successful transition from one program to another. The transition process should begin at least six months before the actual transition date to allow the school district or other receiving agencies sufficient time to prepare for a child with a low incidence disability and other unique learning needs. Practical considerations, as well as state or agency policies, may dictate transition timelines. The best time to start the transition process should be determined by the individual child's needs and family's situations.

A carefully planned transition is important to the family, child, and service providers because: 1) it will prevent interruptions in services; 2) it will provide parents with an opportunity to participate as equal partners in the transition process; 3) it will facilitate the adjustment of the child and family to the new program; and 4) it will eliminate the duplication of tests and planning meetings when the child is receiving services multiple services (Conn-Powers, Ross-Allen, Holburn, 1990). Planning a transition takes time, communication, patience, and sensitivity to the needs and emotions of the family and their child. Planning in advance will minimize the stress caused by changes the family will experience, reduce fears of the unknown, help families to build new relationships with staff and become involved in the new program, support the child during the transition process and help him or her adapt to the new environment (Smith, 1993).

Stages in the transition process

The initial stages of the transition process should include five major steps: 1) developing a planning team; 2) setting goals and identifying problems; 3) defining roles; 4) developing a written transition planning procedure (Conn-Powers, Ross-Allen, & Holburn, 1990); and 5) following-up and evaluation of the child's adaptation to the new program and the transition process (Smith, 1993).

Developing a planning team

Developing a planning team is one of the most crucial components of a carefully planned transition. Toddlers who have visual and hearing impairments with other disabilities require services from many specialists. This may complicate the organization of a planning team. Team members may consist of the parent, friends, relatives, a representative from the receiving school district, current service providers such as the occupational therapist, physical therapist, orientation and mobility specialist, members from the State Deaf Blind Project, a teacher certified in the area of deaf and hard of hearing and a teacher certified in the area of vision impairment.

The initial planning meetings may not include a representative from the receiving school if one has not yet been identified. There will be many issues to discuss about the child's skills, developmental needs, eligibility criteria and the type of programs to consider (i.e. inclusive setting, special day classroom & day class.) Establishing a planning team provides opportunities for everyone involved with the child to express their concerns and opinions on transition needs or potential concerns. The most optimal setting for the child must be based on his or her individual needs.

Some questions that the team should address at this point may be:

How long will the child remain in his current program?

When are the services to be terminated and started somewhere else?

What are the family's preferences for future services?

Is there another family with a similar child who can share their transition experience to preschool with the current family?

When will the changes take place?

Smith, 1993

When children with multiple disabilities and dual sensory impairments are placed in inclusive settings, there must be adequate supports in order for the child to be successful. For example, preschoolers with low vision and hearing loss will need learning environments which are well structured and consistent so that they will know what to expect from their classroom and its routine. Environmental adaptations may include providing color contrast at meal time (i.e., red Jell-O served in a white or yellow dish), shelves and materials labeled in Braille, or placing the child closer to the teacher as she reads the group a story.

Setting goals and identifying challenges

Once the team has been established and the child's current abilities and needs have been identified, the group can begin to develop goals and identify possible challenges and solutions. Problems may arise because of the different types of demands that may be placed on the child and family such as location, transportation, and increased class size. Families may select a program which may not have staff members trained to work with children with multiple disabilities. Families moving from a home-based program to a center-based program will be confronted with a different structure, curriculum, activities, and other children with varying disabilities or non-disabled peers. Parents may have questions about the philosophy or the practices of the new program, hours of the new program's operation, transportation safety, differences in the needs of other children in the program, and the teacher's ability to use their child's equipment safely (Hains, Rosenkoetter, & Fowler, 1991; Smith, 1993).

Staff members from the sending program may also have concerns such as the adjustment of the child and family, continuity of services, and the child's ability to handle the demands of the new setting (Smith, 1993). Different approaches can be taken to help prepare the family, child and receiving agency for the transition. Each team member has a role to play in a carefully planned transition.

The role of the sending program

The sending program will play a vital role in preparing the family for the transition because of an established relationship with the child and family. The sending program can also discuss with parents how their participation in the future program may differ from their current program. Preschool settings are usually more structured and child-focused than early intervention programs. The team can discuss the differences in the new program and suggest ways the parent can remain involved. Information for parents should include:

Gathering information

- ► Information about the new program (i.e., contact person, telephone numbers, and population of children attending the program)
- ► Copies of recent reports and evaluations

- Information about services available to children who are dual sensory impaired. Parents have many questions such as:
  - What kinds of specialized services will the child receive at the new program?
  - How frequently will the services be available to the child?
  - Will the services be provided directly through center staff or through consultation?
  - Will the services be provided within the classroom setting or in pull out programs?

Classroom environment

Information about the new program's ability and willingness to include the child in a typical preschool program. Some questions to consider are:

- Does the program have special materials that the child might need?
- Is the program flexible and willing to make important adaptations to include the new child and meet his/her visual and auditory needs?
- How much extra help is available in the classroom?
- What is the teacher/child ratio?

Becoming involved

- Strategies to facilitate parental involvement, i.e., researching appropriate settings in the community, introducing their child to peers, volunteering at different times of the routine (recess, class time, and special activities)
- Strategies to maintain regular communication with the teacher i.e., communication book, telephone calls, message boards, and notes sent in the child's backpack

The sending program should also share relevant information about the child with the receiving agency in order to assist with the family's transition to the new program.

Suggested information and materials for the receiving agency should include

- A contact person and telephone number from the sending agency to maintain contact and provide assistance as needed
- Information about the child that will help the new program understand the child's previous services and his ways of communicating and interacting with his environment. This information may include the following:

- Background information
- Medical history
- Formal evaluations/assessment results
- Previous IFSP
- Individual programming needs
- Specialized equipment needs, including all forms of assistive technology
- Video tapes or photos to demonstrate details about specific strategies, how the child communicates with others, positions for play, table activities or meal times; use of adaptive equipment such as wheel chairs or braces, and orientation and mobility lessons; or the child's use of special equipment
- Communication systems used with the child in his previous settings
- Adaptations and supports provided to support the child's play (i.e., materials used to keep toys within the child's reach, adaptive utensils).

Preparing the child

The parent and early interventionist from the sending agency should visit the proposed classroom, meet with the receiving teacher and inquire about the curriculum, routine, and activities. If the receiving teacher is not designated, the sending teacher could visit the program, review the curriculum, and observe activities taking place. This will provide some information about the types of expectations and skills that should be focused on in the current program to help the child participate in the new program.

The demands placed on the child will depend on his abilities and the expectation of the new program. Children moving from an infant program to a preschool program will be expected to participate actively as they become familiar with the new environment and its routine. These expectations may be particularly challenging for those children with dual sensory impairment.

Another change that may be particularly challenging for the child and the family is the expectation for the child to travel alone to school and attend class without family members. New encounters with peers, unknown adults, and different environmental feedback may be overwhelming for some preschool children when they are away from the family. Many of these stressors can be addressed in advance to help the child become familiar with his new experiences and environments. For example, an object such as a new stuffed animal backpack could be used to indicate to the child that he will be going to his new school. He will wear the backpack when the early interventionist and parent visits the new program with the child if appropriate. The child could be introduced to the classroom by the orientation and mobility (O&M) instructor while the other children are outdoors. This strategy would reduce environmental noises so that the child could make the most of his visual and auditory abilities. The child could be shown where his backpack will be kept and placed there during his first visit. The O&M instructor could next introduce the child to the playground and to the other children. Later they can all return indoors as a group.

The backpack may be used as an object cue in the calendar box (at home or infant program) to signify when the child will be going to preschool. Other objects that may be used to prepare the child for the transition include: providing the child with a familiar object from home such as a toy; a cassette recording of familiar music, environmental sounds or voices of family members; or a family member's personal belonging such as a piece of clothing. Objects and materials from the new program could possibly be used in the home.

The role of the parent

Parents will respond differently according to the needs of their family. It is not uncommon for parents to express excitement about their new found personal time. However, they may also experience feelings of guilt. In some families, changes may be difficult as they consider issues such as transportation, their child's specialized equipment, or complications around feeding or breathing needs (Hains et al. 1991). Aside from these concerns, parents must also face the responsibility of selecting the most appropriate program for their child, negotiating a new schedule, finding new services, educating personnel about their child's special needs, and preparing their child and family for the change (Hains et al. 1988.) Transitions may bring about additional changes that may include the following: the use of an orthopedic walker, adaptive mobility devices, braces, FM systems, special education buses arriving at their home, new terminology for the parent, new service providers and a multitude of other changes. While transitions cannot be eliminated, parents can be better prepared through collaboration with and support from the planning team.

Some ways parents may help prepare the child:

- ► Visiting the new program with their child
- ► Arranging visits to the new program with the early interventionist; Helping the child become familiar with the new teachers, classroom and the school

- Arranging after-school activities or visits with children from the new program
- Riding on the bus to the new school with their child (Hains, Fowler, & Chandler, 1988).

The role of the receiving program

The receiving program and staff members may be anxious when a child with multiple disabilities transitions into their setting. Their experiences may be limited to nondisabled children or children with mild disabilities. The environment, staff, volunteers, and children will be prepared for the new child if the transition is planned carefully (Smith, 1993). Some suggestions for the receiving program are:

- Make arrangements to meet the family and child before the child begins
- Identify parent's concerns and plan together for the change
- Provide pictures, brochures, tours, time for observation for the family or previous service providers
- Identify physical barriers that may impede the child's access
- Conduct environmental analysis to determine modifications for children with visual and hearing needs
- Identify and supply special materials and equipment needed (adaptive seating, eating utensils, colorful and musical toys, trikes)
- Arrange the classroom environment so that children feel safe to explore and socialize
- Adapt the environment to reduce the noise level by using shelves as dividers, chair tips to reduce the noise of moving chairs, adding carpet to bare floors and using foam place mats for hammering or construction activities
- Provide appropriate lighting throughout classroom
- Prepare volunteers, parents and classmates about the new student (i.e. pictures, introducing new equipment before the child arrives)
- Provide the staff information about the child's specific diagnosis and needs
- Obtain strategies used in previous program
- Clearly define the role of aides and para-professionals as they *assist* with the child
- Provide inservice training and information on young children with dual sensory impairment

- Provide support to classroom staff from specialized consultants
- Access technical assistance from the State Deaf-Blind Services Project for consultation as needed
- Evaluate the child's adaptation to the new program and participation in classroom activities

Developing written transition planning procedures

Once the challenge and goals have been identified, the team is ready to assign responsibilities to its members. Specific activities, strategies, and responsibilities must be agreed upon with time lines established in writing. Written transition planning procedures help to keep the group focused and on task. Each member has responsibilities identified in writing and everyone knows what is expected. A written plan also provides a more simplified understanding of the program's transition procedures and policies. In cases where a team member will no longer be available, the written plan will assist in maintaining continuity and limiting disruptions. Through developing its own transition plan, the team will be able to identify its unique needs and concerns (Conn-Powers et. al, 1990).

Follow-up and evaluation

The final step in the transition process is to follow-up on the family's and child's adjustments to their new program and to evaluate the process. This can be planned during the final IFSP meeting before the transfer occurs. However, funding realities may limit follow up activities. Some questions to consider are:

- How is the child adjusting to the new program?
- How does the family feel about the new program? Is it a good match?
- Are there any problems with which the family needs additional help?
- Does the receiving teacher need additional information and training?
- Does the program need more consultation or direct services from someone trained with children with dual sensory impairment such as the State Deaf-Blind Services?
- Are transition goals being met?

Follow-up procedures allow for an evaluation of the effectiveness of the transition process. Was the planned transition effective? What was the impact on the child? Which things worked well and which ones needed improvement? This feedback can be useful in future transition plans for the family's next change and the professionals' future participation in the transition process. Parents should also be encouraged to visit the new program after their child has enrolled to provide feedback and assist with the child's adjustment. Providing these parents with adequate support, information, and guidance will help them deal with the challenges associated with transitioning children with dual sensory impairment and multiple disabilities into preschool programs.

Transitioning from early intervention programs to preschool programs involves many changes that are stressful and confusing for families. Planning transitions carefully is necessary to provide everyone involved in the transition process adequate time to share information, obtain special materials and equipment, learn new skills, and become familiar with the unfamiliar.

References

Coleman, J.G., (1993). *The early intervention dictionary: A multidisciplinary guide to terminology.* Rockville, Maryland: Woodbine House.

Conn-Powers, M.C., Ross-Allen, J., & Holburn, S., (1990). Transition of young children into the elementary education mainstream. *Topics in Early Childhood Special Education*, 9(4), 91-105.

Hains, A., Rosenkoetter, S., & Fowler, S., (1991). Transition planning with families in early intervention programs. *Infants and Young Children*, 3(4), 38-47.

Hains, A., Fowler, S., & Chandler, L., (1988). Planning school transitions: Family and professional collaboration. *Journal of the Division for Early Childhood.* 12, 108-115.

Smith, D., (1993). *Passport for change: Transition planning. Hints and helps for families with infants and toddlers.*

Resources

Chen, D., & McCann, M.E., (1993). *Selecting a program: A guide for parents of infants and preschoolers with visual impairments.* Blind Children's Center. Los Angeles, CA. 1(800)222–3567 or (213)664–2153.

Winton, P.J., Turnbull, A.P., & Blacher, J.B. (1984). *Selecting a preschool: A guide for parents with handicapped children.* Baltimore, MD: University Park Press.

Educating Young Children with Severe & Multiple Disabilities in Typical Preschool Settings

by June Downing

Children typically learn a great deal from one another. They learn to play, share, interact, gain attention, request assistance when needed and express themselves. Though children learn a lot from their parents and other significant adults, interactions with other children generally aid the learning process. Children learn by watching and listening to their siblings and children they play with.

Children who have severe and multiple disabilities (especially when a visual loss is present) are at a distinct disadvantage when it comes to vicarious learning (McInnes & Treffry, 1982). These children may not be able to obtain information from a distance, physically act on that information if physically impaired or talk about what they have access to if delayed communicatively. When these students are placed together to learn and separated from nondisabled youngsters, their disabilities may become exacerbated as learning becomes more difficult due to the lack of appropriate role models and interactive playmates. Children will have much less frequent contact and interactions with effective communication partners and less frequent interactions with various objects if they can't see well, hear well, or move easily. Opportunities to learn from one another may be greatly reduced.

Bringing young children of diverse strengths and abilities together creates many quality opportunities for all children to grow and develop. Children learn at a young age that everyone is different and has unique qualities. They learn not to be afraid of differences. They learn to interact in different ways that are most effective for different individuals. They learn that all children are to be valued and respected. Early interactions with young children of different races, gender, cultural backgrounds and abilities will help to lay a solid positive foundation for later life experiences. These benefits have been clearly documented (see Buysse, 1993; Demchak & Drinkwater, 1992).

Since everyone will be learning somewhat differently from each other, teaching staff will need information pertaining to different learning styles and needs. Adaptations will be necessary to ensure that children receive as much information as possible and use that information most effectively. Given the appropriate supports, all children can benefit from learning together.

Choosing an appropriate preschool program

Presently, the majority of preschool programs specifically designed to accommodate young children with disabilities are found in separate facilities for these children (Odom, McConnell, & Chandler, 1993). However, this does not mean that typical preschool programs cannot meet the needs of children having disabilities, even severe disabilities. Their special needs can be met in typical preschool settings, just as they are met in homes, grocery stores, parks, churches, restaurants, etc. The special support needed is provided to the child, versus taking the child to a special support in a special place.

When deciding on a preschool program (for any child), certain factors should be considered. The following list of indicators is not exhaustive and all indicators do not have to be present for the program to be high quality. However, both parents and teachers may wish to use such guidelines when considering an appropriate preschool program for their child with special needs.

Beginning steps

Introduce child to staff

Parents play a critical role in helping their child get a good start in a new preschool program. Instead of focusing on their child's disabilities, parents can help staff understand their child's strengths, abilities, likes and dislikes. By highlighting how their child is like other children without disabilities, parents can help preschool staff feel less hesitant and more confident in their abilities to meet the child's needs. Teachers can find out from parents how the child learns best and communicates most effectively. Teachers also need to learn what motivates the child to learn. Sharing such critical information with teaching staff not only assists teachers to be most effective with a given child, but also reduces the need to elaborate on the areas in which the child has limitations. For example, when a parent informs a teacher that his three year old child communicates by smiling, reaching for objects, making "happy" sounds, crying, grimacing, and grinding teeth, the teacher does not need to hear about all the communication skills that the child has *not* mastered. The focus is on what the child can do, not on the child's limitations.

Identify basic needs

If the child does have significant disabilities, it is important that preschool staff obtain specific information to ensure the child's safety, health, and learning potential. Parents should share information regarding the child's medical needs (allergies, medication, respiration) and basic physical needs (nutritional intake, toileting schedule, physical positioning) just as they would with any care provider. Parents are in the best position to show staff how to lift, carry and position their child, though this information also should be reinforced by physical and occupational therapists. Information about the child could be written out and kept in various places at the preschool (e.g., in child's back and forth journal, with the child's IEP, on the refrigerator where meals are kept, in the bathroom) to remind staff of necessary precautions.

Indicators of quality programs for young children with disabilities

Stated program philosophy that all children are to be valued and respected for what they bring to school

Stated program philosophy on the positive ways children will be treated

Stated program philosophy of active family involvement in all aspects of the program

Open, warm, nurturing, flexible and qualified staff

Effective staff training program

Staff to pupil ratio which supports all students and permits IFSP or IEP objectives to be met

Majority of students who do not have disabilities

Play emphasized as a major avenue for learning

Structure that is apparent with specific routines and rules in evidence, but flexibility also in evidence and children encouraged to make individual choices

Toys that are accessible to encourage both independence and interactive play

Environment that is clean, safe and fun with sufficient age-appropriate, multisensory materials to stimulate learning and facilitate interactions

Children encouraged to interact

Collaborative teaming in evidence

Support services available as needed (e.g., orientation and mobility, speech and language, physical therapy)

Equipment to facilitate participation in activities

Transition planning to prepare children for future learning environments

Help peers understand

The research that has focused on inclusive educational practices for young children with disabilities has made it clear that just physical placement with nondisabled peers is insufficient if the goal is truly one of inclusion (Guralnick & Groom, 1987, 1988; Hill & Rabe, 1992). Young children with no disabilities need encouragement and sometimes specific instruction on ways to interact with their classmates who have disabilities. When a child cannot see or hear, move efficiently, or speak, children may have concerns and questions that need to be addressed. Both parents and teachers can share with the children what a particular child likes to do, doesn't like to do, what their family is like, if there are any pets, etc. The focus is on the similarities among children, not on differences. Person first language is always used to help children focus on the person, not the disability (e.g., the little girl who doesn't see, vs. the blind child).

During introductory sessions of this nature, children are encouraged to recognize how they are all alike. Any questions they might have are answered matter-of-factly and at a level that young children can understand. Young children (ages 3–5) do notice differences among individuals and may use those differences to avoid classmates, preferring to play with those similar to themselves (Diamond, 1994). Therefore, children are encouraged to openly discuss issues around differences that they might perceive (e.g., clear physical differences in size or ability, mannerisms, lack of speech). Adults can facilitate the discussion of differences in a very factual manner, highlighting how everyone is different from everyone else in some ways and how important those differences are. Besides learning how they are like their classmate who has a disability, children will also need to know how to interact. Learning ways to interact with a child with disabilities is particularly important when that child has a sensory and/or physical impairment

Guidelines for helping teachers deal with childrens' comments or reactions to a child with disabilities in the classroom

- Always respond to a child's question even if embarrassing
- Always respond in a positive and practical way (e.g., "What's wrong with him?" "Nothing is wrong, he just can't use his eyes, so he uses his hands and ears instead.")
- Provide information in small, easily understood amounts (don't go into too much detail)
- Use descriptive words that relate to the children's own experiences (e.g., "When you wear mittens it's very hard to pick up things. That's what it's like for Jenny without mittens.")
- Watch how a child acts around a child with disabilities and be ready to intercede (e.g., "Does it bother you that Jason waves his arms a lot and makes that sound? It's not what you do, is it? Maybe Jason is trying to tell us something. What could it be?") [pp. 140-141]
- Let all children explore any special equipment, materials, and toys so they can feel comfortable around certain adaptations

Rab & Wood, 1995

that can interfere with interactions. Children need specific guidance and encouragement for their efforts at interaction (Fad, Ross, & Boston, 1995; Strain & Odom, 1986). Children need to know simple ways of greeting their classmate and saying goodbye, asking them questions, and understanding their responses. They need to be able to interpret the child's unique sounds, body language, facial expressions, and movements in such a way that makes sense and they can relate to their own means of communication. Children need to be shown how to use their voices (especially with children who can't see), use touch cues, and use objects to interact. Gaining experience using a child's augmentative and alternative communication device also is necessary to help children feel comfortable interacting. Becoming comfortable with alternative means to communicate helps create the awareness that the child can effectively communicate albeit not through speech.

Finally, children need to understand what it means when a child can't hear, see, move, or speak well. They do not need to know technical terms, just what to expect from that child, so they can adjust their interactions accordingly. For instance, they need to learn to put objects (e.g., toys, bowls) in the hands of a child who is blind or perhaps physically disabled versus holding them at a distance. They need to learn to tell a child who is blind when they are leaving and going elsewhere. They need to learn to gain the visual attention of a child who is deaf or has a severe hearing impairment before trying to share information. They need to learn to bring items close to a child who has a severe physical disability, and to talk to a child who is blind while they are playing. Learning these skills occurs over time and as children are encouraged to learn and play together. Information is provided as children either express the interest and/or demonstrate a need to improve interaction skills.

Educating everyone together: Adaptations

To make sure that everyone is benefiting from an inclusive preschool program, adaptations to accommodate unique learning styles and needs will be essential (Downing, 1996; Gee, 1995). Adaptations to include children with severe and multiple disabilities in typical preschools can occur in several ways. Modifications can involve the following: environmental adaptations (both physical and social), participation adaptations, material adaptations, instructional adaptations, and outcome adaptations. Each of these general types of adaptations will be described in greater detail for children who have sensory impairments, and those who have physical disabilities. The overall intent of adaptations is to help make learning together as effective and efficient as possible (Rosenberg, Clark, Filer, Hupp, & Finkler, 1992). Of course, the necessary adaptations will be determined by the individual student's strengths and needs.

Checklist of possible modifications to enhance the learning environment of typical preschool settings for young children with severe and multiple disabilities

PHYSICAL ENVIRONMENT

Play items are easily accessible—in view and within reach.

Area is safe and accessible, making it easy to get around.

Lighting is sufficient and adjustable to accommodate individual needs. Glare is reduced.

Excessive sound is absorbed through the use of carpets, rugs, curtains, acoustic tile, and sound absorbent room dividers.

Toys are brightly colored, interesting, have sound, vibration and movement, and are easy to handle.

Toys encourage interactive play.

Areas are clearly organized for different lessons with clear demarcation and landmarks.

Furniture can be adapted to meet the individual needs of children (e.g., proper height at table, feet on floor).

Cubbies are accessible to each child and labeled so that each child can find his or her name (color coded, brailled, textured, large print name).

SOCIAL ENVIRONMENT

Toys are used that encourage interactive play such as blocks and toy animals.

Children are encouraged to sit together and play together.

Children are not grouped by ability.

Adults facilitate and support interactions, but do not interrupt or interfere.

Social interaction skills are specifically taught.

Children with no disabilities are taught both how to communicate with the child who has a disability and how to interpret that child's communication modes.

Staff is positive, supportive, and follows the lead of the child when possible.

PERSONAL ADAPTATIONS

Individual children have the optical and/or auditory aids that they need (e.g., glasses, hearing aids), and staff know how to help the child make the best use of these aids.

Individual children have the positioning equipment they need to participate in different activities and staff know how and when to use this equipment.

Materials are adapted for individual use (e.g., switches added, dowels added, tactual materials added for art projects).

Augmentative communication devices are available at all times for children who need them.

Staff know communicative methods appropriate for each child (e.g., sign, object symbols, gestures).

Staff know how to recognize, interpret, and respond to each child's communicative attempts, and know how to encourage communicative interactions.

Environmental adaptations

Children with visual impairments

For children with visual impairments, perhaps the most important adaptation of the physical environment is the *lighting*. Depending on the visual impairment, a child will need solid lighting on the work or play area, but not light that creates a glare or shines in the child's eyes. Therefore, not only is the type of light important, but the child's position with regard to that light source.

Many children with visual impairments will wear glasses to correct as much as possible for their particular visual impairment. The vision specialist or ophthalmologist can assist the teaching staff understand the benefits of the glasses, need for their use and care. Such information is usually no more complex or different from any young child who wears glasses, but has no visual impairment when corrected. However, teachers need to understand whether the glasses are correcting for near or distant vision. A child may try to take off glasses when looking at things up close if near vision is quite functional *without* glasses. Forcing the child to keep glasses on for all activities may be unnecessary and serve to frustrate the child.

When children have very limited or no vision, the environment must be structured so that it is easy and safe to move around to encourage the child's exploration. Children will need to be taught specific routes to get to frequented places. The orientation and mobility specialist can provide direct instruction as well as teach staff ways to help the child practice these skills. Items (toys, books, tapes, etc.) should be kept in specific places to accommodate the child's ability to follow directions and obtain desired items. Shelves and drawers can be color coded and/or tactually coded to assist the child find certain items (e.g., personal cubby, coat hook). Tactile markers can be the brailled word, brailled child's name, a design made by dried glue dots or puff paints, or textures (sandpaper, velvet, foam rubber). The only real restrictions are that the tactile cue should be something the child feels comfortable touching (not aversive) and can easily discriminate from other tactile cues.

Children with hearing loss

The physical environment for young children with some functional hearing needs to accommodate that remaining hearing. The acoustics of a given environment need to be checked to ensure that everything has been done to enhance the transmission of sound (Prickett, & Welch, 1995). Curtains and rugs can be added to bare walls and floors to absorb extraneous sounds, and keep noise levels down. Dividers can be used to create quiet areas for all children when needed. Ambient sounds such as air conditioning, fans, or radio should be monitored so that they do not distract the child or make it more difficult for the child to hear the teacher or peers. Similar to adjusting the environment for children with visual impairments, the position of the child who has a hearing impairment can be quite critical. This child needs to be close to the teacher and other peers, so that verbal information can be most readily received and the child has close visual contact to aid in understanding that information.

Equipment may be needed that will increase and highlight auditory information. An FM (frequency modulated) system may be used to block background noise and increase the volume of the teacher's voice. Most children with hearing impairments will benefit from amplification devices such as hearing aids to improve reception of auditory information. The audiologist or hearing specialist can provide valuable information on hearing aids, their use, settings, and care. As with glasses, this information is not very complex and can be readily acquired.

Children with physical disabilities

The child with severe physical disabilities will have a more difficult time maneuvering in space, so the best environmental adaptations should address the need for accessibility. Ramps must be used to bypass steps, bathrooms must accommodate children in wheelchairs and those who need to be changed, and there must be sufficient space to encourage the child to move around using a wheelchair or walker. Items need to be easily accessible so that the child can either obtain them independently or partially participate in obtaining them. The child with difficulty controlling his or her movements should have sufficient room to play with toys without having to worry about knocking things over. In general the learning environment should be laid out so that it is safe for the child to move as freely as possible.

Often the child with physical disabilities will be unable to engage in activities without the aid of positioning equipment. Positioning equipment provides the child with a comfortable and functional position and also provides passive therapy by maintaining proper posture and position of the body (Campbell, 1993). Positioning equipment enhances participation by supporting young children in various positions that resemble those of other young children. In other words, if children are sitting on the floor, the child with a physical disability also will need to be on the floor and physically supported so that arms and hands are free to engage in the activity. When children stand to paint or sing, this child may need to be positioned in a standing table, prone or supine stander. The positioning equipment necessary will depend on the activity, how others engage in the activity and the child's physical abilities and needs. Equipment can be commercially available or handmade. A physical therapist can recommend appropriate equipment and can teach preschool staff about the use and care of the equipment.

Resources available for physical accommodations

Initially the physical accommodations required for children having physical disabilities may seem overwhelming for a typical preschool program. Since it is a legal requirement (PL 99–457) to make the necessary accommodations for an individual child (at least for a child three years or older), preschools offering a program for a child can receive some financial assistance through the state department of education. In addition nonprofit, advocacy organizations such as United Cerebral Palsy, Easter Seals, March of Dimes, Lions Foundation, and the American Foundation for the Blind, can provide some equipment and materials for the child to use. These agencies may also provide training for staff in the use of the equipment.

Social environment

Regardless of the disability, children will need support to learn to effectively interact. At this young age, all children will need help to learn the social skills needed to engage in cooperative play and make friends (Hoffman & Wundram, 1984; Martin, Brady, & Williams, 1991; Wolf & Fine, 1996). Teachers can facilitate interactions by encouraging children to play together and by ensuring that toys are interactive versus solitary in nature. Children can be given toys to share versus each having their own. Instead of having children spend the majority of their time playing individually with puzzles, painting at easels, or reading books, teachers can ensure that children spend substantial time in imaginative play with dolls, dollhouses, toy cars, building materials, and sand or water tables. Opportunities to target social interactive skills are much more prevalent in these types of activities than in those activities that have the child playing alone.

Children with disabilities will need to be positioned physically close to their classmates without disabilities, especially those having physical disabilities and unable to move easily on their own. Teachers will need to be alert to the physical position of children and ensure that the child with the disability is supported in a similar position. Teachers will also need to make certain that in their efforts to support children, that they avoid physically interfering with child to child interactions. For instance, during circle time a child with physical and multiple disabilities is positioned on the floor at one end of the circle, and a teaching assistant sits between this child and the other children who do not have disabilities. This position automatically blocks the child's access to classmates and prevents him from observing their behavior.

As discussed earlier, children will need specific and practical information on how best to interact with a given child. Then throughout each day teachers can do a great deal to encourage children to share toys, food, and art materials, ask each other questions, show each other what they're doing, help each other, look out for each other, and say nice things to each other. For children who cannot speak, teachers must make sure that children understand and can adequately interpret facial expressions, body language, vocalizations, and their use of alternative and augmentative communication systems. While the teacher may initially suggest ways in which children can interact, the goal will be to slowly fade support so that children naturally respond to one another (Luetke-Stahlman, 1994). For example, during block play the teacher encourages Christopher to pick up and hand blocks to Jeremy so he can build a tower. Christopher is three years old and has severe physical disabilities, a cognitive impairment, and is profoundly deaf. He is learning to hold his head up, look at people when they touch him or visually obtain his attention, and handle items. Though Jeremy could build a tower on his own, depending on Christopher to supply him with the blocks creates a social interaction that is of value to both children. At present the teacher must provide considerable support for Christopher to respond to Jeremy's physical and gestural request to get a block, grab a block, an extend it to Jeremy. The goal is to fade this support as Christopher develops the necessary skills.

Material adaptations

Children with visual impairments

Since most teachers use visual information while teaching, especially at the preschool level, adaptations with regard to teaching materials will be most obvious for children having severe visual impairments. Children who have functional vision will need to be encouraged to use that vision by enhancing the visual characteristics of materials (Bailey & Downing, 1994). Considerable information is available on this subject (Downing, & Bailey, 1990; Jan & Groenveld, 1993; Levack, 1994). In general, bright colors (especially yellow, orange, and red) can be added to items (if not naturally available on toys). Reflective tape can be added as well to draw the child's attention to such objects as a cassette tape, spoon, cup, cubby, and shoes. Using a flashlight to highlight items to draw the child's visual attention and encourage both looking and reaching also is an option. However, flashlights should not be used to shine in the child's eyes. Maintaining high contrast between the information (whether picture or object) and background information is critical. Keeping a solid pale color as background behind relevant information can help the child discern the appropriate item or picture.

For the child with insufficient vision to detect things visually, the use of objects for tactual exploration is recommended. The objects should be used in whatever activity they represent and should be the actual item, not a miniaturization (Downing & Eichinger, 1990). For instance, a 3" plastic tree toy should not be used to represent a real tree. It would be more meaningful to let the child tactually explore and smell a real tree or a branch from a real tree. This way the child can obtain accurate information related to size, shape, texture, scent and if pertinent, any auditory information, and will not handle information that is misleading. For items too large to bring to the child, teachers will need to determine what parts of the item would provide the most relevant and meaningful information. For example, allowing the child to see an eagle could be difficult. Obtaining a taxidermist's re-creation of a live eagle would be a good start, or showing the child feathers, and nest, and hearing the tape of an eagle's cry would be appropriate. Even when a child has some functional vision, making use of other information sources, such as hearing, touch, and smell is important.

Key points to remember with children who are visually impaired/blind

- ► Access to toys that are colorful, interesting to touch and have sound and/or vibration
- ► Cose physical proximity to others (teachers and classmates)
- ► Safe, predictable environment in which to explore
- ► Structured environment and routines
- ► Sufficient lighting on task/play area
- ► Clear, verbal directions, and physical prompts as needed
- ► Tactual materials to replace visual activities (e.g., textured collage vs. drawing)
- ► Emphasis on active and interactive play
- ► Good contrast when providing visual information (e.g., foreground information clear from background)
- ► Concrete, real items to introduce concepts
- ► Exposure to brailled and/or large print (e.g., labels on items in room, books)

Material adaptations that keep materials close to the child and within easy reach are easy to make and very helpful to the child. Toys that roll or move around can have a string attached so that the child does not lose control over where the item has gone (e.g., balls, toy cars). A tray can be used to contain a child's toys so that they will be easy to find and manipulate during play (e.g., marbles, blocks, small plastic dolls).

One activity that may pose some difficulties for children with sensory impairments is the critical activity of reading. At this age young children typically sit around their teacher and listen to a story being told. They look at colorful pictures that add to the information and interest of the story. Having a severe visual impairment that interferes with the ability to perceive pictures can diminish the enjoyment of this important activity. In addition children with an intellectual disability may not be able to understand the story through verbal means alone. To replace the missing visual information from the book's pictures, a child with a severe visual impairment (especially when other disabilities are present) may resort to self-stimulatory behaviors such as rocking or hand flapping. To reduce the need for such behaviors and to increase understanding of the story, the child who is unable to see the pictures needs to handle and explore real items directly related to the story (if at all possible). Sometimes this is quite easy to arrange (e.g., a story about a balloon). Other times it is much more difficult (e.g., a story about bears). When real or related items cannot be obtained, the child may need to handle an unrelated small item (e.g., onyx piece, rubberband, leather piece) to provide some form of additional stimulation while listening. Of course telling stories that particularly relate to the child's life experiences (e.g., a trip to Disneyland, a visit to the beach, pets) will help maintain the child's attention and promote greater understanding.

Finally, when activities require the child to create what is typically a visual product (coloring, drawing, painting), adaptations must be used to make this meaningful for the child with no vision. A child can create tactual designs by using a dull, but pointed instrument (e.g., tip of a ball point pen) on a piece of paper placed over a plastic mesh screen. The child does not have to create the same image as his or her sighted peers, but should be encouraged to experiment with this art form instead. Using colors (as in crayoning and painting) to create designs could be bypassed by using different textures and materials (e.g., cotton, felt, sandpaper, pipecleaners, feathers, rubber pieces) and gluing them in a creative manner to a heavy piece of paper. These adaptations allow the child to participate fully, though the final product may look different.

Children with hearing impairments

Materials will probably not need to be adapted as much for the child who can see, but has limited to no functional hearing. This child will rely on visual information to a large extent, which necessitates that visual information be readily available. At the preschool age, ensuring the use and availability of visual information should not be overly difficult. However, when the activity involves sound (e.g., singing and music), special adaptations may need to be made. One simple adaptation is to add light to replace the sound. For example, if musical chairs is being played, a light is turned on with the music and goes off when the music stops. For music, the child can feel the vibrations of certain instruments (guitar, piano, drum) and/or play a rhythm instrument or clap hands with the teacher as a model. The teacher may wish to increase the volume or increase the bass to aid in the child either feeling the vibrations or actually hearing the music.

Children with physical disabilities

Children having a severe physical disability could require certain adaptations to access materials they can see and hear. Of course if these children also have vision and auditory impairments, then the adaptations mentioned previously will be relevant as well. Children may need help grasping crayons, paint brushes, glue bottles, or holding any object. The major adaptation required is to make the item easier to grasp and handle. This may mean enlarging the area that the child is to grasp. Though commercial devices can be obtained to aid a child's ability to grasp, very simple and inexpensive aids can be made with common materials. Tape, cloth or playdough can be wrapped around a crayon, paintbrush or felt tip marker. Pencil grips and sponge curlers can also be used to aid a child's grasp on a thin handle. If a child is hypotonic (low muscle tone) and does not have the strength to maintain a grasp, a special mitt or mitten with a wrist velcro strap can be worn by the child to hold items. Utensils that glide on paper are easier for the child to handle than those requiring a more specific grasp. Stamp pad designs can be on rollers and pushed vs grasped and stamped. Wide roller pens may be easier to use than crayons, scissors (from craft and sewing stores) that can be pushed across paper to cut it, rather than scissors that require the traditional open and close movements also are recommended.

Dowels can be added to items that are hard to handle (e.g., small toy cars, paper dolls, small farm animals), so that the child can more easily manipulate them during play. If turning pages in a book is difficult, "page fluffers" can be added. These are tongue depressers that extend out from each page and separate the pages with a small piece of foam rubber glued to them. These can be glued to each page as a permanent adaptation or paper clipped to each page as it is being read.

Slant boards can be used to bring material closer to a child and at a more accessible angle. This adaptation also is helpful for children with low vision. Magnetic boards also can be helpful for children with physical disabilities and visual impairments. Keeping paper from bunching or slipping away is another issue. Papers can be taped down, or Dycem (or any nonslip material) can be placed under the paper.

Assistive technology in all of its myriad forms has been very helpful in increasing the level of participation possible for a child with physical disabilities (Flippo, Inge, & Barcus, 1995). Simple switch devices allow children to turn on toys, lights, music, and essentially, anything that is either electrical or battery operated. The child uses whatever movement is under the greatest control (e.g., head, arm, knee, foot, chin) to activate the switch. For example, when children are listening to music that tells them what action to engage in, the child who has very severe physical disabilities and cannot perform the various movements, still participates by turning on and off the music as directed by the teacher. Physical therapists can help determine the movements allowing the child the greatest control and can help teaching staff acquire the necessary equipment and teach the child to make use of it. Teachers need to determine the number of opportunities throughout each activity that can be used to include a child in activities that could be difficult without switch adaptations.

As young children gain greater access to computers and software programs for learning and for play, high technological adaptations allow the child with limited use of hands to participate as well. Many adaptations exist that bypass the traditional keyboard on a computer, making access to interesting software programs much easier. Using these devices, children can use simple movements to activate programs. Touch windows allow the child more direct access to information on the screen; joysticks allow easier movement of the cursor; and adapted keyboards (e.g., IntelliKeys™, Key Largo™) remove the need to understand traditional commands of the keyboard. In addition, software programs exist that promote fun ways of learning cause and effect, and control. Software programs have characters that are colorful, have sounds, and make interesting movements on the screen. Learning the use of the computer using such adaptations helps develop a firm foundation for later computer use, which can have a significant and positive impact on the adult with severe physical disabilities.

Augmentative communication devices (both simple and complex) allow the child who is unable to speak, to communicate with others. Considerable information exists on the development and use of augmentative communication devices (Baumgart, Johnson, & Helmstetter, 1990; Mirenda, & Mathy-Laikko, 1989; Tanchak, & Sawyer, 1995; Van Tatenhove, 1993). A speech and language pathologist in collaboration with other members of the team, especially the parents, can assist in the development and/or procurement of the appropriate devices for a given child.

Instructional adaptations

Children with visual impairments

With limited or no visual information to rely on, young children with visual impairments will need to have some adaptive instructional techniques. In general, teachers will need to be very verbally specific and use language that has meaning for the child (both at the child's level of understanding and relates to the child's experiential background). Vague directions like, "go over there," accompanied by a point or "start at Center 1 by the red sign" will not suffice. Rather, directions like, "go the the carpet area where we listen to stories" provides the child with much more concrete and useable information.

The teacher also needs to make sure that the child has information that can be seen or felt that adds to the verbal information being given. Often teachers request children to "look at" them, to "watch" what they are doing, and to do the same. The technique of visual demonstration is very common in most classrooms at any age. A child unable to perform this basic skill in order to obtain the desired information will be at a serious disadvantage. The teacher will need to accommodate for this loss by providing tactual demonstrations (modelling under the child's hands) so that the child can follow directions for a given project in a tactual manner. Such a technique also encourages the child to actively make use of his or her hands, which is vital for present and future learning. For a child with some visual abilities, demonstrating the upcoming task very close to this child will be necessary. Finally, the teacher needs to allow sufficient time for the child to acquire, process, and act on the available information, whether visual, verbal, or tactual. Loss of vision requires a child to piece together bits of information and formulate them into a meaningful whole. This process is not easy and takes time to be effective. The teacher should be aware of how much quicker and easier it is to take the whole and disassemble it into its various pieces, versus taking individual pieces and trying to assemble them into a whole. The difficulty of this task becomes even more apparent when the final product cannot be visualized.

Reinforcing the child's efforts to learn is one obvious element of teaching at any age. The child with a severe visual impairment may be hesitant to try new things for fear of encountering an unfamiliar and uncomfortable environment. This child may appear afraid to touch things or to move toward them. The learning that arises from natural exploration and watching others do things is lost, or greatly diminished. Yet, to learn, this child needs to explore, using remaining modes of information input (hearing, touch, kinesthetics). A current emphasis within early childhood is a program of intervention that is child-centered, play-based, and very active (Tompkins, 1991). The teacher needs to make the learning environment as safe and stimulating as possible, while praising all efforts that the child shows to engage in active learning. Alerting the child verbally to what he or she is about to come in contact with helps the child anticipate a certain texture, temperature, or size prior to actually coming in direct contact. Whereas vision prepares the child at a distance for upcoming contact, and provides a myriad of cues that help the child anticipate what is to be touched, the lack of vision greatly reduces this anticipation. This inability to give oneself some advance warning before things enter one's personal space can contribute to a child's reluctance to actively engage in exploration. Therefore, verbal cues that give some information and make the item sound interesting can encourage the child to explore. For example, when students are looking at a sea shell and passing it around, the teacher can prepare the child with limited or no vision by saying things like: "Doesn't the shell feel cool?"; "Do you feel where the shell has some smooth spots and some rougher ones?"; "Can you put your finger in the hole?" These verbal cues tend to take the fear out of touching something new, while giving the child some cues as to what to expect and do with the shell when he or she gets a turn at holding it.

Children with hearing loss

Instructional strategies for children with hearing losses will rely on the sense of vision. Obviously, there is a need to interact with the child using the child's natural language. For a child who is deaf, the natural language could well be American Sign Language (ASL). In this case, the child would require at least one teacher who was fluent in this language mode. Teachers could team teach in such a situation, so that all students could benefit from the situation. The preschool teacher with no knowledge of ASL could still interact with the child who is hearing impaired by being more visually expressive, ensuring she had the child's visual attention, making good use of facial expressions, natural gestures, pointing, getting close to the child, and using touch cues when appropriate. Using objects and pictures as well as any acquired signs can help to clarify intent. Visually modelling what is expected several times before having the child perform the activity helps with understanding. If this child also has a visual impairment, modelling within the child's visual range will be very important.

Key points to remember with children who are deaf/hard of hearing

- ▶ Lots of visually interesting stimulation
- ▶ Close proximity to others
- ▶ Acoustically sound environments—acoustic tile, acoustic dividers, carpet
- ▶ Emphasis on active and interactive play
- ▶ Easy visual access to person who is speaking
- ▶ Use of FM systems, auditory trainers as appropriate
- ▶ Access to multiple modes of communication (e.g., manual sign, pictorial books, gestures, facial expressions)

For those children who have some hearing, every effort should be made to use this source of information. Children can learn to respond to the tone of words spoken even if they can't clearly perceive the actual word. They can be encouraged to use their voice in different ways to gain the attention of others. Their attention can be directed to environmental sounds that add information such as music being played, the loud squeak of playground equipment, the sound when something is dropped, etc. Children need to learn what creates such sounds and how to use that information in a purposeful way. For instance, if a child can hear a fire alarm, he or she needs to understand what that sound is and what action is required. The teacher should use words that refer to hearing and listening (e.g., "listen, Heather is making sounds like a lion"). This type of verbal prompt paired with a gestural cue (e.g., pointing to your ear) can help cue the child to listen (Flexer, 1994).

Children with physical disabilities

Instructional strategies for children who have difficulty moving their bodies and handling objects will probably involve the use of increased time to allow the child to demonstrate the desired behavior. Of course if the child also has sensory impairments, then the strategies suggested above should also be considered. When the child is unable to learn by doing (performing all steps of the activity), then information must be received via other input sources (visual, auditory, tactual). Checking comprehension of the child will require the teacher to look for an alternative way for the child to respond. For example, when a child cannot point to the correct color or say the correct color, choices of color can be offered and the child asked to look at the correct color. The teacher must provide these opportunities for the child to demonstrate understanding. Without such ongoing opportunities to demonstrate learning throughout each day, the child may become very passive and uninvolved.

Making sure the child is in the most comfortable and appropriate physical position for a given activity is a prerequisite before any instruction can begin. The physical therapist can monitor this, making suggestions that will most benefit the child.

As with all children, making activities fun and interesting is critical. At the preschool level in particular, learning should occur naturally during typical play activities versus overly structured and teacher-directed drills (Carta, 1995). The importance of play to a child's development, especially when the child has intellectual disabilities has been well documented (Greenspan, 1992; Linder, 1993; Rogers, 1988). Play is the young child's work and holds many opportunities for all children to learn valuable lifelong skills.

Participation adaptations

Children with visual impairments

How children with visual impairments participate in activities and their level of participation, will depend on a number of factors, including those adaptations previously stated, and whether or not certain rules and expectations per activity can be modified. For example, during a game of "Duck, Duck, Goose," a child with no vision and no speech can have peer assistance walking around the circle of children and be expected to tap each child's head once and the head of the child chosen two or three times instead of saying the words. During musical chairs, this child will be allowed to keep in constant contact with chairs while the music is playing. Children with no speech and limited or no vision can be offered simple yes/no questions following stories versus being asked to come up with a specific answer to a question. Children can "sign" their names to art work by peeling off self-adhesive braille name labels (for those with no vision). Children without vision may not be expected to know colors, but rather the object the color pertains to. For example, instead of asking the child to identify the color of an apple, the child can be asked to find the apple from other common objects and then can be told the color. The emphasis for all participation accommodations is to deemphasize the reliance on visual information and encourage active involvement via other modes.

Children with hearing loss

How the child with limited or no hearing participates in activities will depend on creative and alternative ways that teachers accommodate for the hearing loss. Responding to verbal information may not be expected, but rather the child will be expected to respond to visual information. For example, the child will not be expected to follow the actions required by a song, but will be expected to imitate peers and/or teachers. For self-expression, this child will be expected to point to pictures, shake/nod head for no and yes questions, produce some signs when appropriate to make requests or comments, use natural gestures, and/or show the teacher or peer what would normally be expressed in words by others.

Children with physical disabilities

Children with physical disabilities should be expected to participate to the maximum extent possible using many of the adapted materials and assistive technological adaptations previously mentioned. When the child cannot physically perform the steps of an activity (e.g., coloring), then the child should be expected to communicate to the teacher or teaching assistant what color he or she would like, where that color should go, and what size coloring instrument should be used, etc. The child is expected to make choices and decisions and thus, take control of the situation, just as other students are doing. The main difference is that the actual physical steps are completed by someone else. Of course the child should be given every opportunity to engage in the physical properties of the activity as well. For example, the child may be able to slightly squeeze clay or playdough in his hands, though unable to actually form a clay pot or clay snake.

Outcome adaptations

Children with visual impairments

When a child has limited or no vision, it may be particularly important not to expect his or her performance or outcome to be the same as sighted peers. Children will need to perform in a manner that is most meaningful and efficient with or without visual abilities. Accomplishing certain tasks is likely to take longer than children who have normal vision. For example, Carla, who has multiple disabilities, including a severe visual impairment, can find her own cubby, but because she doesn't walk, it takes her longer than her peers to crawl to the cubby and tactually search for her textured name. In this case, the outcome is the same, but the manner of reaching that outcome is slightly different.

The child may not have the same understanding of visual concepts such as colors, sunsets, drawings, shadows, very large objects (airplanes, elephants) and very small items (patterns on spider webs, mosquitoes). Children who are visually impaired will develop a nonvisual concept of such things, which will be just as important and far more meaningful. Though a child may learn that a banana is yellow, what is more important is that the child recognize the feel of a banana, learn how to peel one, request one, and decide if it is preferred or not.

While much of what is done in preschool results in a visual outcome (e.g., art projects), allowance must be made for the child having a visual impairment. The same final product cannot be expected for this child. Instead, the emphasis should be placed on what the child can create in whatever form. The focus is on the child's involvement and creative expression, not the end product. For example, a preschool class is engaged in coloring pictures of pumpkins to decorate their classroom for Halloween. Maria has both a severe cognitive impairment as well as very limited functional vision and dislikes coloring. She does like puffed stickers, especially those having scent, and uses a variety of these to decorate her picture of the pumpkin. As all the children also like these stickers, they each get to ask Maria for one to put on their pictures. In this way all of the children contribute to the activity of decorating the room and Maria is provided numerous opportunities to interact with her peers.

Children with hearing loss

Perhaps the most obvious difference in expected outcomes for children who are hearing impaired, compared to children who can hear, will involve the use of spoken language. Children who can speak may not articulate words clearly, demonstrate expected tonal qualities, or make themselves clearly understood. However, all efforts to produce speech should be rewarded and accepted as a desired outcome. Children with no speech will demonstrate their knowledge via the use of sign, gestures, recognition of pictures, demonstrating the skill/activity, and self-expression via coloring, drawing, and painting. Their outcomes will be primarily visual in nature.

Children with physical disabilities

The child with physical disabilities may not be able to demonstrate acquired skills in exactly the same way as children with no physical disability. Expected outcomes for this child could involve increased strength and control to be able to participate in activities and the demonstration of acquired knowledge via augmentative communication systems and assistive technology. For instance, this child may not be able to verbally interact with others, but should be able to communicate requests and comments by looking at, reaching toward, or grasping a choice of pictures or objects. This child may master the ability to make decisions for himself and communicate those decision to others, but not in the same form (e.g., speech) as others might.

Key points to remember with children with physical disabilities

- Lots of visually interesting stimulation
- Safe, accessible environment
- Adaptations to allow easy manipulation of toys/items (e.g., elongated, widened handles, magnetic boards, nonslip mats)
- Positioning equipment to facilitate participation in activities
- Close proximity to others
- Support to partially participate in activities (from both adults and peers)
- Emphasis on the communicative aspects of an activity (decision-making, choice-making)
- Emphasis on active and interactive play

Understanding unconventional behavior

When children have multiple impairments, especially when those impairments involve sensory losses, it is not uncommon for these children to have developed unique behaviors that meet certain needs. All children (and all adults) engage in a number of unique behaviors for a variety of different reasons, but typically to alleviate boredom or to relax. If the behaviors engaged in by children with severe and multiple disabilities do not approximate the behaviors engaged in by children without disabilities, it may be due to lack of appropriate models to observe, hear, or greatly reduced ability to engage in the physical aspects of the behavior. However, the need to stimulate or calm oneself will be present regardless of a disability (and in fact, may even be more necessary). The child therefore, will engage in whatever behaviors address these needs. The critical point to remember from a teacher's (and parent's) perspective is that these behaviors meet very normal needs and therefore, should never be punished. The following paragraphs will offer some description and interpretation of these possible behaviors, and ways to address them.

Unique behaviors of some children with severe and multiple disabilities

Children with severe and multiple disabilities could have unique and unusual behaviors that may at first exacerbate differences and make it harder for teachers to treat a particular child like other children. It is important to understand what these behaviors are and their purposes for children.

An initial tendency may exist to target the behaviors that appear at first to be aberrant in an effort to reduce or eliminate them. Unfortunately, this effort can have very negative effects of actually increasing some behaviors by attending to them (particularly if these behaviors serve the purpose of drawing adult attention), taking valuable time away from teaching the child other skills, and creating a punitive tone to interactions between the child and teacher. Knowing *why* a child engages in a particular behavior(s) helps the teacher understand and better deal with it.

Self-stimulatory behavior

Young children with severe and multiple disabilities may exhibit some unique behaviors to alleviate boredom and keep themselves amused. Due to limitations in stimulation they can see, hear, or create by moving and handling items, these behaviors may look somewhat different than the behaviors of their classmates who do not have disabilities. For example, without visual stimulation to perceive, the child who is blind may resort to rocking back and forth, flicking fingers

CASE STUDY Angelina

Angelina is a 3 year old Hispanic little girl who lives with her mother, grandmother, and two older brothers. Angelina is an active member of her very close family and well-known in her neighborhood. Angelina loves to make a variety of interesting sounds, loves music, loves to play with her brothers, and really enjoys eating pudding. When aided Angelina can hear most sounds, but normal speech is not clear. Angelina communicates by smiling, making various sounds, reaching for things, moving toward things, crying, and resisting. She can stand, and is learning to walk when holding onto a hand or using a walker. She has no functional vision, and therefore, could be labeled deaf-blind.

Angelina attends a preschool located near her mother's place of employment. The majority of young children who attend this preschool do not have disabilities. Angelina is one of five children who have been identified as having a disability in the class. Teaching assistants (TA) and parent volunteers assist the teachers.

PRESCHOOL SCHEDULE	ADAPTATIONS/ACCOMMODATIONS
Arrival. Put personal items in cubby. Greet teacher.	Mother helps her into the room and to the cubby, which is tactually marked for her to recognize. Teacher and TAs greet Angelina by holding her hands and saying "hi" and giving positive feedback if Angelina smiles or makes a sound.
Good Morning Circle. Calendar. Movement to songs. Theme for the Week.	Angelina is assisted to the circle area where she is encouraged feel the rug as a landmark for this activity. She sits close to other children with extra support when needed (provided from behind). When children are shown their names and asked to respond by taking it and putting it on the Attendance Board, Angelina is shown two cards (one in print and one in braille). She is to feel both, grab the braille card and help to get it on the board. She is not learning to read braille, but to recognize differences tactually. Through the songs she is encouraged to wear her hearing aid and to try the movements of the songs given tactual cues. The directions from songs are repeated more clearly and close to her by the teacher or TA.
Centers: Dress Up, Blocks, Water Table, Listening to Taped Stories, Clay	Choices are given to her every 10 minutes by handing her the objects (2 at a time) which represent each center, telling her what her choices are, and encouraging her to grab the one she wants. She is provided sighted guide to the centers, where she sits

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against different body parts, turning around in circles, pressing against eyelids with hands, and making interesting noises. Children who can't hear may make interesting noises that create internal vibrations. Children with severe physical disabilities may exhibit unique sounds and movements.

While unique self-stimulatory behaviors should *not* be punished, if they draw negative attention to the child, or prevent the child from interacting with people or materials, the teacher will want to have the child engage in other, more conventional behaviors that serve the same or similar purpose for the child. The teacher will want to redirect the child to engage in a behavior that provides similar stimulation (visual, auditory, vibratory, tactual, or kinesthetic) but in a way that is more accepted and conventional. For example, a child who pats her face with her hands may be directed to squeeze a small koosh ball or small piece of playdough. It will be the teacher's responsibility (with specific input from parents) to recognize the need that the child has to engage in certain behaviors, decide if the behavior could draw negative attention from others, and then provide the child with another and more acceptable means of meeting the same basic needs.

Recognizing that all children need to engage in certain self-stimulatory behaviors as a normal occurrence will help to see past the initial determination of the unconventionality of the behavior. Children twirl their hair, doodle, fiddle with items, and play with different parts of their body (e.g., pick scabs, rub their heads). Children with severe and multiple disabilities need ways to engage in conventional or expected self-stimulatory behaviors. Even when children are actively engaged in an appropriate activity (which is the first thing to ensure), they may still need a means to appropriate self-stimulation. For example, children listening to a story could still need to engage in a number of self-stimulatory behavior (especially if they cannot see pictures). Making sure that the child with severe and multiple disabilities has an acceptable means to self-stimulate and is taught how to engage in this behavior will be important for the teacher to consider. For example, Michael often places the back of his hand against his forehead and repeatedly taps himself. Since he has quite limited hearing and vision, he appears to enjoy feeling this form of tactile and proprioceptive stimulation. This behavior usually occurs when Michael is waiting for an activity or is bored with the present activity. Since this behavior makes Michael look quite different than the other children, he needs another behavior to engage in when he is bored. A wide covered elastic band is placed on his wrist and Michael is taught to replace his forehead tapping with pulling on or twisting the elastic band. This interaction with the elastic band is also tactile in nature and so he receives similar stimulation from this behavior as he did from tapping his forehead. This behavior more closely resembles the same kind of nervous activity demonstrated by his classmates and is therefore, much more acceptable. (Of course, if Michael en-

CASE STUDY Angelina

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PRESCHOOL SCHEDULE	ADAPTATIONS/ACCOMMODATIONS
	close to other children (so she can feel them). She is learning certain routes to where daily activities occur. The teacher or TA provide guidance only when necessary to encourage exploration. They offer her many choices in each center, and facilitate her interactions with other children.
Outside Play	Choices are provided to Angelina by showing her objects or parts of objects representing different outside play activities (e.g., a sand toy for sandbox play, chain for swinging, wood handle for the seesaw). She is paired with other children wanting to play in the same activity. She works on her walking while going outside.
Snack	TA makes sure Angelina is sitting close to others, offers support from behind (e.g., reminds her to keep her hands on the food or spoon while bringing it to her mouth). Her snack is contained for her on a small tray so she can easily find it.
Group Storytime on Theme for the Week (Color, Animal, Family)	Angelina sits close to the teacher and when possible gets to hold and explore an item related to the story's theme. Key words are emphasized for language comprehension and speech production.
Free Play	The teacher gives Angelina two choices at a time for each activity using objects or parts of objects that represent the activities. The teacher facilitates interactions with other children by encouraging her to reach toward them and by having them share items with her.
Art Projects on Theme for the Week	Teacher makes sure that Angelina is sitting close to a classmate and has access to a variety of different materials she can manipulate (on a tray). TA shows her a sample of a finished tactile project (a collage) and then offers her 3 choices of materials for her to start with. She asks Angelina where she wants each piece glued to the cardboard using speech, gestural cues, and pausing. Then helps her to use the glue appropriately.

gages in this behavior to the exclusion of other activities, then his program must be modified to make it more meaningful and stimulating.)

Aggressive or noncompliant behavior

All children can engage in undesired behavior that conveys their unwillingness to participate in a given activity. These are typical occurrences even when a child can thoroughly understand what is expected and can easily express preferences. Children who may not fully understand the activity or what is expected and who cannot communicate their preference for another activity or the reason for their irritation will display behaviors that signal their frustration. Children may cry, scream, hit, refuse to move, spit, scratch, etc. As in dealing with the self-stimulatory behavior, the teacher needs to recognize that the child is attempting to convey his or her feelings about the activity, some aspect of the activity or something else entirely. Treating the behavior as an attempt to communicate versus punishing the child in an effort to eliminate the behavior is imperative. Punishing the child's efforts will have the impact of reducing the child's attempts to communicate. Every effort should be made to try to understand what the child is trying to say and to teach the child an alternative and more acceptable way to convey the same meaning (Carr & Durand, 1985; Durand, 1993).

The teacher does not ignore the unconventional and undesired behavior, but recognizes the need to replace this way of communicating with a more conventional and acceptable means. For example, Juan often scratches to indicate when he is unhappy with an activity and wants it to end. This behavior has been successful in the past because when he scratches, the person assisting him with the activity stops and he is not forced to continue. Since Juan is labeled deaf and blind and has no formal communication system, he may have learned that scratching is an appropriate way to communicate the desire to stop an activity and be left alone. To help Juan learn an alternative, more appropriate and equally effective way to convey the same message, Juan's teacher closely watches Juan for signs of irritation (facial expressions) that lead to the scratching. When she thinks he is about to scratch or when he starts to scratch, she quickly shows him how to push the items in the activity away. She then offers him choices of other activities to do using representative items. By consistently pairing this preferred behavior with his desire to finish an activity, Juan no longer needs to scratch. Of course the teacher must be very responsive to Juan's wishes so that he understands that this is another way to get what he needs.

CASE STUDY Robbie

Robbie is a 3½ year old Caucasian boy who lives with his mother and father and a large dog. Robbie has a terrific smile, enjoys being with people, has strong preferences, and tries hard to please. Even when aided Robbie is unable to hear and has cortical visual impairment, but does respond to some visual information, such as bright colors, lights, and movement. Robbie also has a serious medical condition, seizures, eats through a tube, and is nonambulatory. Robbie can move his body, but has very limited fine motor skills. Robbie makes his needs known by making happy/content sounds, crying, using a variety of facial expressions, body movements, and touching objects.

Robbie attends a preschool in his neighborhood. Though a few children with disabilities also attend this school, Robbie has the most significant impairments. The teacher has additional supports from a teaching assistant (TA), practicum students from a university early childhood teacher preparation program, and parent volunteers.

PRESCHOOL SCHEDULE	ADAPTATIONS/ACCOMMODATIONS
Arrival. Greet teachers and classmates. Put things away.	Father or mother helps Robbie into room and pushes him in wheelchair to cubby area. His cubby is the first one and outlined in bright orange reflective tape. They wait until he makes a movement with his arms toward his cubby. Then he is helped to put his things in. His teacher greets him by touching his hand and guiding it to a ring she always wears. She waits for him to smile or wave his hands a bit or make a sound as his greeting.
Good Morning Circle, Calendar, Songs	Teacher makes sure Robbie is positioned close to her on the floor. When calling attendance, the teaching assistant shows him his tactile name card which he is learning to grasp and recognize as belonging to him. Robbie uses a vibrating touch switch to activate the music on the cassette recorder when cued tactually by his teacher. Moving to the music is aided by the teaching assistant who works physical therapy (stretching, range of motion) into this activity.
Cooking Project	Robbie is seated close to his peers so they can easily touch him and vice versa. He is learning to grasp different utensils, hang on to them while stirring or scooping, and pass them to a peer. He can also turn on a blender via the use of his switch. He is

Continued on page 289

CASE STUDY Robbie

Continued from page 288

PRESCHOOL SCHEDULE	ADAPTATIONS/ACCOMMODATIONS
	encouraged to smell and taste different ingredients with the other children. Even though he cannot eat most of the goodies made, he can taste the different food items, learning to distinguish differences, develop preferences, and hopefully, encourage more oral intake of food over time.
Outdoor Play	Robbie makes choices of activities he enjoys doing outside. Two choices are offered (one preferred and one not preferred). Both are presented tactually to him using parts of the object that represents each choice (e.g., piece of plastic rope for his swing and toy car and ramp for car play). Robbie chooses by reaching for one or hitting at it. Robbie has an adapted swing seat that provides sufficient support. Robbie also likes the merry-go-round,to play in sand, water, and to go for very fast stop/start "walks" in his wheelchair.
Storytime	Robbie is positioned in a chair on the floor close to the teacher and other children. Since Robbie cannot hear the story and has difficulty seeing the pictures, he is allowed to fiddle with a small inflated balloon attached to the side of his chair. He also receives some physical and occupational therapy from specialists or the teaching assistant while sitting with the children. If the story is about something that Robbie can activate with his vibrotactile switch, he will do this when prompted (e.g., battery-operated toy animals, cars, train).
Centers (Music, Finger Painting)	Robbie is offered choices of centers by having him tactually explore objects or parts of objects that represent the centers. He is given two choices (preferred and nonpreferred). Once he chooses an activity, he is helped

Continued on page 290

CASE STUDY Robbie

Continued from page 289

PRESCHOOL SCHEDULE	ADAPTATIONS/ACCOMMODATIONS
	to get there. Adaptations allow him to participate, such as built-up handles on the toys used for measuring in the rice table. He is taught to share with the other children by having him respond to their tactile cues on his shoulder by turning to that peer and relinquishing his toy if they tap on it. He is also encouraged to explore with his hands to find out what the other children are doing.
Snack	Robbie joins his classmates at the snack table and sits in his wheelchair close to them. While he cannot eat a snack orally, he does take in nutrition through his tube. However, he also is encouraged to taste things like yogurt, applesauce, fruit smoothie to indicate preferences, enjoy the taste of food and hopefully, encourage the oral eating process. Robbie's facial expressions and movements either toward or away from the food offered are accepted as his means of expressing his preferences and dislikes.
	Note: Throughout the day Robbie uses objects and parts of objects to anticipate what the daily activities will be and when they will occur. These items are placed in several sequentially arranged boxes that are convenient to the adults in the room. After every activity Robbie is assisted to return the representative item to its container (box) and then tactually explores the next box in the sequence to find the item that signals the next activity.

Summary

This chapter has addressed the specific learning styles and needs of young children labeled severely and multiply disabled. The intent of this chapter has been to help preschool teachers, teaching assistants, related service providers, and parents in their efforts to educate children together despite different abilities.

Young children with multiple disabilities, which include sensory impairments, require a quality preschool program as do their nondisabled peers. They need a safe, nurturing, enriched and supportive environment in which to learn. They do not need a separate facility that keeps them apart from other young children. Rather, they need a program that will meet their unique needs while allowing them to grow and develop with other children. In this environment they will learn from their peers, while their peers learn from them.

References

Bailey, B., & Downing, J. (1994). Using visual accents to enhance attending to communication symbols for students with severe multiple disabilities. *RE:vew,* 26, 101-118.

Baumgart, D., Johnson, J., & Helmstetter, E. (1990). *Augmentative and alternative communication systems for persons with moderate and severe disabilities.* Baltimore: Paul H. Brookes.

Buysse, V. (1993). Friendships of preschoolers with disabilities in community-based child care settings. *Journal of Early Intervention*, 17, 380-395.

Campbell, P. (1993). Physical management and handling procedures. In M. E. Snell (Ed.), *Instruction of students with severe disabilities*, 4th edition (pp.248-263). New York: Macmillan Publishing Co.

Carr, E. G., & Durand, V. M. (1985). Reducing behavior problems through functional communication training. *Journal of Applied Behavior Analysis,* 18, 111-126.

Carta, J. J. (1995). Developmentally appropriate practice: A critical analysis as applied to young children with disabilities. *Focus on Exceptional Children*, 27(8), 1-14.

Demchak, M., & Drinkwater, S. (1992). Preschoolers with severe disabilities: The case against segregation. *Topics in Early Childhood Special Education*, 11, 70-83.

Diamond, K. E. (1994). Evaluating preschool children's sensitivity to developmental differences in their peers. *Topics in Early Childhood Special Education*, 14(1), 49-62.

Downing, J. (1996). *Including students with severe and multiple disabilities in typical classrooms: Practical strategies for teachers.* Baltimore: Paul H. Brookes.

Downing, J., & Bailey, B. (1990). Developing vision use within functional daily activities for studies with visual and multiple disabilities. *RE:view,* 21, 209-220.

References, continued

Downing, J., & Eichinger, J. (1990). Instructional strategies for learners with dual sensory impairments in integrated settings. *Journal of the Association for Persons with Severe Handicaps*, 15, 98-105.

Durand, V. M. (1993). Functional communication training for challenging behaviors. *Clinics in Communication Disorders*, 3(2), 59-70.

Fad, K. S., Ross, M., & Boston, J. (1995). We're better together: Using cooperative learning to teach social skills to young children. *Teaching Exceptional Children*, 27(4), 28-34.

Flexer, C. (1994). *Facilitating hearing and listening in young children*. San Diego, CA: Singular Publishing Group.

Flippo, K. F., Inge, K. J., & Barcus, J. M. (1995). *Assistive technology: A resource for school, work, and community*. Baltimore: Paul H. Brookes Publishing Co.

Gee, K. (1995). Facilitating active and informed learning and participation in inclusive school settings. In N. G. Haring & L. T. Romer (Eds.), *Welcoming students who are deaf-blind into typical classrooms: Facilitating school participation, learning, and friendships*, (pp. 369-404). Baltimore: Paul H. Brookes.

Greenspan, S. I. (1992). *Infancy and early childhood: The practice of clinical assessment and intervention with emotional and developmental challenges*. Madison, WI: International Universities Press.

Guralnick, M. J., & Groom, J. M. (1987). The peer relations of mildly delayed and nonhandicapped preschool children in mainstreamed playgroups. *Child Development*, 58, 1556-1577.

Guralnick, M. J., & Groom, J. M. (1988). Peer interactions in mainstreamed and specialized classrooms: A comparative analysis. *Exceptional Children*, 54, 415-425.

Hill, A., & Rabe, T. (1992). Preschool mainstreaming: Ideals and reality. *Issues in Special Education and Rehabilitation*, 7(2), 25-39.

Hoffman, S. & Wundram, B. (1984). Sharing is...Views from 3-year-olds and thoughts from teachers. *Childhood Education*, 60, 261-265.

Jan, J. E., & Groenveld, M. (1993). Visual behaviors and adaptations associated with cortical and ocular impairment in children. *Journal of Visual Impairments and Blindness*, 87(4), 101-105.

Leutke-Stahlman, B. (1994). Procedures for socially integrating preschoolers who are hearing, deaf, and hard-of-hearing. *Topics in Early Childhood Special Education*, 14, 472-487.

Levack, N. (1994). *Low vision: A resource guide with adaptations for students with visual impairments* (2nd edition). Austin, TX: Texas School for the Blind and Visually Impaired.

Lindner, T. W. (1993). *Transdisciplinary play-based assessment: A functional approach to working with young children* (Rev. ed.). Baltimore: Paul H. Brookes.

McInnes, J. M., & Treffry, J. H. (1982). *Deaf-blind infants and children: A developmental guide*. Toronto, Ontario, Canada: University of Toronto Press.

Martin, S. S., Brady, M.P., & Williams, R. E. (1991). Effects of toys on the social behavior of preschool children in integrated and nonintegrated groups: Investigation of a setting event. *Journal of Early Intervention*, 15, 153-161.

References, continued

Mirenda, P., & Mathy-Laikko, P. (1989). Augmentative and alternative communication applications for persons with severe congenital communication disorders: An introduction. *Augmentative and Alternative Communication,* 5, 3-13.

Odom, S. L., McConnell, S. R., & Chandler, L. K. (1993). Acceptability and feasibility of classroom-based social interaction interventions for young children with disabilities. *Exceptional Children,* 60, 226-236.

Prickett, J. G., & Welch, T. R. (1995). Adapting environments to support the inclusion of students who are deaf-blind. In N.G. Haring, & T. L. Romer (Eds.), *Welcoming students who are deaf-blind into typical classrooms: Facilitating school participation, learning, and friendships* (pp. 171-194). Baltimore: Paul H. Brookes.

Rab, V. Y., & Wood, K. T. (1995). *Child care and the ADA: A handbook for inclusive programs.* Baltimore: Paul H. Brookes.

Rogers, S. (1988). Review of methods for assessing young children's play: A review. *Journal of the Division for Early Childhood,* 12, 161-168.

Rosenberg, S., Clark, M., Filer, J., Hupp, S., & Finkler, D. (1992). Facilitated active learner participation. *Journal of Early Intervention,* 16, 262-274.

Strain, P. S., & Odom, S. L. (1986). Peer social initiations: Effective intervention for social skills development of exceptional children. *Exceptional Children,* 52, 543-551.

Tanchak, T. L., & Sawyer, C. (1995). Augmentative communication. In K. F. Flippo, K. J. Inge, & J. M. Barcus (Eds.), *Assistive technology: A resource for school, work, and community* (pp. 57-86). Baltimore: Paul H. Brookes.

Tompkins, M. (1991). Active learning: Making it happen in your program. In N. A. Brickman & L. S. Taylor (Eds.), *Supporting young learners: Ideas for preschool and day care providers* (pp. 5-13). Ypsilanti, MI: High/Scope Press.

Van Tatenhove, G. M. (1993). *What is augmentative and alternative communication (AAC)?* Wooster, OH: Prentke-Romich Co.

Wolf, A., & Fine, E. (1996). The sharing tree: Preschoolers learn to share. *Teaching Exceptional Children,* 28(3), 76-77.

BLANK Forms

- Initial Program Self Review
- Annual Program Self Review
- Infant Medical Summary
- Functional Hearing Screening: Questions for the Family
- Interviewer's Directions
- Questions to Ask the Infant's Audiologist
- Functional Vision Screening: Questions for the Family
- Interviewer's Directions
- Questions to Ask the Infant's Ophthalmologist or Optometrist
- Communication Options Worksheet
- Routine Analysis

EFFECTIVE PRACTICES IN EARLY INTERVENTION

Initial Program Self Review

For early intervention programs serving infants who are deaf-blind (birth to 36 months) and their families

PROGRAM ______________________________

DATE OF REVIEW ______________________________

I. Program Organization

(To be completed by program administrator: 30 minute discussion)

1.1. Organizational Structure

1.1a. How are your program policies and procedures developed and reviewed?

1.1b. Who is represented on your decision-making committee?

1.1c. Who is represented on your program advisory committee?

1.1d. What is your mechanism for family/professional collaboration and joint decision-making?

1.1e. What is your mechanism for monitoring the timelines for making and acting on decisions?

Initial Program Self Review, continued

1.1f. What is your mechanism for procedural safeguards?

1.2. Location and service population

1.2a. Where are services provided?

1.2b. Who do you serve ? Eligibility criteria? Age? Languages?

1.2c. How many families do you serve?

1.2d. What is your geographic service area?

1.2e. How long has your program been providing early intervention services?

Initial Program Self Review, continued

1.3 Public Awareness

1.3a. How does the community find out about your program?

1.3b. What are your referral sources?

1.3c. What community support do you receive? Donations? Volunteers? Other? (describe)

1.4 Funding

1.4a. How is your program funded?

1.4b. What factors determine how much you receive?

1.4c. In what way is the funding process flexible to meet changing program priorities?

Initial Program Self Review, continued

1.5 Personnel

1.5a. How many staff positions are there in your program? Are they all filled?

1.5b. What kinds of qualifications (degrees, credentials, training and competencies) does the staff have?
Administrators:
Early interventionists:
Early intervention assistants:
Specialized consultants (e.g., health personnel, physical and occupational therapists, speech and language specialists, orientation and mobility specialists, teachers certified in the areas of deaf-blind, visual impairments, hearing loss):

1.5c. What are their roles and responsibilities?

1.5d. In what languages are your services offered?

1.5e. In what languages do your services need to be delivered? Do you need to use interpreters?

Initial Program Self Review, continued

1.5f. What staff development opportunities are available? Based on needs assessments? Use of existing resources (program)? Access to community, regional, and state resources?

1.5 g. What staff development opportunities are available to staff who work with infants with learning needs beyond their professional area of training and expertise?

1.5h. How are staff (a) supported, (b) mentored, and (c) supervised?

II. Program Philosophy

(To be completed by program administrator and direct service staff: 30 minute discussion)

2.1 Guiding principles

2.1a. Is there a clearly articulated program philosophy and are measurable program goals in place?

2.1b. What program practices and activities reflect program philosophy and goals?

Initial Program Self Review, continued

2.1c. List program activities that support active family participation and family/professional collaboration.

2.1d. What is your early intervention curricular model?

Programs for infants/toddlers with multiple disabilities:

☐ AEPS

☐ HELP

☐ Activity-based approach to early intervention

☐ Other (describe)

Programs for deaf and hard of hearing infants/toddlers:

☐ SKI *HI

☐ Other (describe)

Programs for visually impaired infants/toddlers:

☐ Reach Out and Teach

☐ PAVII

☐ VIISA

☐ Other (describe)

2.1e. What program are you using with infants and toddlers who are deaf-blind?

☐ INSITE

☐ A deaf-blind baby: A programme of care

☐ Deaf-blind infants and children: A developmental guide

☐ Other (describe)

Initial Program Self Review, continued

2.1f. What other curricular resources are you using to work with infants and toddlers who are deaf-blind?

III. Program Services

(To be completed by direct service staff: 30 minute discussion)

3.1 Intervention Activities

3.1a. Indicate which of the following your program offers to infants and toddlers who are deaf-blind:

☐ Home-based services to infants (birth–18 mos.)

☐ Home-based services to toddlers (18–36 mos.)

☐ Center-based services for________(age range)

☐ Other (describe)

3.1b. Indicate whether your assessments and intervention strategies address the specialized needs of infants with multiple disabilities/vision and hearing loss and these diagnoses and rate their effectiveness (1 = needs to be developed, 2 = somewhat effective, 3 = highly effective):

☐ Low vision. What do you do/use?

☐ Blind. What do you do/use?

☐ Hard of hearing. What do you do/use?

☐ Deaf. What do you do/use?

Initial Program Self Review, continued

3.1c. Indicate which of these are used consistently with infants whose multiple disabilities include vision and hearing loss in your early intervention program and provide examples:

☐ Developmentally appropriate practices (e.g., play-based curriculum, interactions with typical peers, age-appropriate schedule and activities)

☐ Functional activities in daily routines

☐ Nonoral communication modes

☐ Preverbal communication strategies

☐ Movement and exploration/orientation and mobility

☐ Compensatory strategies

☐ Environmental modifications

☐ Activity adaptations

☐ Active learning opportunities

☐ Responsive learning environments

Initial Program Self Review, continued

☐ Prosthetic devices

☐ Adaptive equipment

3.1d. Which of these etiologies (a) do infants in your program have, and (b) does your program have specific interventions for each of them?

(a)	(b)	
☐	☐	Central auditory processing problem
☐	☐	Sensorineural hearing loss
☐	☐	Conductive hearing loss
☐	☐	Cortical visual impairment
☐	☐	Low vision
☐	☐	Totally blind
☐	☐	Deaf-blind/combined vision and hearing loss
☐	☐	Severe neurological impairments (e.g. seizures)
☐	☐	Severe orthopedic impairments
☐	☐	Medically fragile
☐	☐	Others (describe)

3.2 Family/Professional Collaboration Activities

(To be completed by families and direct service personnel: 30 minute discussion)

3.2a. What does your program offer to individual families (parents, siblings, extended family members)?

☐ Home visits

☐ Support groups

☐ Family training opportunities

Initial Program Self Review, continued

☐ Family recreation opportunities

☐ Information and access to community resources

☐ Referral services

☐ Other (describe)

3.2b. What are the families' roles/responsibilities?

Specific to the infant/toddler:

Within the program:

3.2c. How are these roles and responsibilities identified with families and agreed upon?

3.2d. Does your IFSP process include the following?

☐ Team approach includes families

☐ Family's concerns, priorities, and resources

☐ Service coordinator

☐ Services in natural environments for infants and toddlers

☐ Interagency collaboration

3.2e. List other family/professional collaboration activities supported by your program:

Initial Program Self Review, continued

3.3 Transition Planning Activities

3.3a. How and when do families gain information about preschool program options? What are your timelines for planning transitions?

3.3b. Who composes the transition planning team?

3.3c. How are families supported during the transition process?

3.3d. How are toddlers who are deaf-blind supported during program changes?

3.3e. How do you collaborate with the receiving program?

IV. Program Evaluation

(To be completed by program administrator: 10 minutes discussion)

4.1a. How often do you evaluate your program?

Initial Program Self Review, continued

4.1b. Date of last formal program evaluation:

4.1c. Conducted/facilitated by:

4.1d. Participants:

4.1e. What program components were evaluated?

- ☐ Philosophy
- ☐ Goals
- ☐ Personnel
- ☐ Services
- ☐ Intervention practices
- ☐ Other (describe)

4.1f. What evaluation measures were used?

- ☐ Child change
- ☐ Staff change
- ☐ Family outcomes
- ☐ Family satisfaction
- ☐ Community and other agency satisfaction
- ☐ Program change
- ☐ Other (describe)

4.1g. Who received the evaluation results?

Initial Program Self Review, continued

4.1h. How are these results shared?

4.1i. How are evaluation results used for program development?

4.1j. Who monitors recommendations for program development and changes?

V. Program Development Goals

(To be completed by all participants: 15–30 minute discussion).

5.1a. Based on this Program Self Review, identify current program accomplishments and strengths:

5.1b. Based on this Program Self Review, identify this year's program development goals and priorities: What is most important to work on? What can be addressed during this year given time, personnel, funding, and other resources?

D. Chen

EFFECTIVE PRACTICES IN EARLY INTERVENTION

Annual Program Self Review

For early intervention programs serving infants who are deaf-blind (birth to 36 months) and their families

PROGRAM ______________________

DATE OF CURRENT REVIEW ______________________

DATE OF PREVIOUS REVIEW ______________________

I. Program Organization

(To be completed by program administrator: 15–30 minute discussion)

1.1. Organizational Structure

Since the last Program Self Review, identify any changes in...

1.1a. Program policies and procedures

1.1b. Representation on your decision-making committee

1.1c. Representation on your program advisory committee

1.1d. Program mechanisms for family/professional collaboration and joint decision-making

1.1e. Program mechanisms for monitoring the timelines for making and acting on decisions

Annual Program Self Review, continued

1.1f. Procedural safeguards

1.2. Location and service population

Since the last Program Self Review, indicate changes in the following...

1.2a. Services provided

1.2b. Population served (eligibility criteria, age, languages)

1.2c. Numbers of families served

1.2d. Geographic service area

Annual Program Self Review, continued

1.3 Public Awareness

Since the last Program Self Review, list the following...

1.3a. Community outreach activities

1.3b. New referral sources

1.3c. New sources of community support

1.4 Funding

Since the last Program Self Review, identify any changes in...

1.4a. Program funding sources

1.4b. Level of funding

1.4c. How funding is allocated and used

Annual Program Self Review, continued

1.5 Personnel

Since the last Program Self Review, identify changes in...

1.5a. Number and type of staff positions

1.5b. Staff qualifications (degrees, credentials, training and competencies)

Administrators:

Early interventionists:

Early intervention assistants:

Specialized consultants (e.g., health personnel, physical and occupational therapists, speech and language specialists, orientation and mobility specialists, teachers certified in the areas of deaf-blind, visual impairments, hearing loss):

1.5c. Staff roles and responsibilities

1.5d. Languages used by staff

1.5e. Languages used by families

1.5f. Staff development opportunities that were provided/supported

Annual Program Self Review, continued

1.5g. How staff were:

Supervised?

Mentored?

Evaluated?

II. Program Philosophy

(To be completed by program administrator and direct service staff: 15–30 minute discussion)

2.1 Guiding principles

Since the last Program Self Review...

2.1a. Has a clearly articulated program philosophy and measurable program goals been in place?

2.1b. What program practices and activities reflect program philosophy and goals?

2.1c. List program activities that support active family participation and family/professional collaboration.

III. Program Services

(To be completed by direct service staff: 15–30 minute discussion)

3.1. Intervention Activities

Since the last Program Review, identify changes in...

3.1a. Assessments being used with infants who are deaf-blind and their families

Annual Program Self Review, continued

3.1b. Early intervention curricula being used by a majority of staff

3.1c. Early intervention curricula being used with infants who are deaf-blind and their families

3.1d. Intervention strategies being used systematically with infants who are deaf-blind and their families

3.2 Family/Professional Collaboration Activities

(To be completed by families and direct service personnel: 30 minute discussion)

Since the last Program Self Review, identify changes in...

3.2a. What your program offers to individual families (parents, siblings, extended family members):

- ☐ Home visits
- ☐ Support groups
- ☐ Family training opportunities
- ☐ Family recreation opportunities
- ☐ Information and access to community resources
- ☐ Referral services
- ☐ Other (describe)

Annual Program Self Review, continued

3.2b. The IFSP process

3.3 Transition Planning Activities

Since the last Program Self Review...
3.3a. How many families have transitioned to preschool?____

3.3b. List activities that have supported their transition:

3.3c. List activities that have supported toddlers who are deaf-blind in their transition to preschool:

3.3d. How many families will transition to preschool during this school year?____

3.3e. Identify activities and timelines planned to support their transition:

3.3f. Identify activities and timelines planned to prepare toddlers who are deaf-blind who will be transitioning by the end of the school year.

Annual Program Self Review, continued

IV. Program Evaluation

(To be completed by program administrator: 10 minutes discussion)

4.1a. How often do you evaluate your program?

4.1b. Date of last formal program evaluation:

4.1c. Conducted/facilitated by:

4.1d. Participants:

4.1e. What program components were evaluated?

- ☐ Philosophy
- ☐ Goals
- ☐ Personnel
- ☐ Services
- ☐ Intervention practices
- ☐ Other (describe)

4.1f. What evaluation measures were used?

- ☐ Child change
- ☐ Staff change
- ☐ Family outcomes
- ☐ Family satisfaction
- ☐ Community and other agency satisfaction
- ☐ Program change
- ☐ Other (describe)

Annual Program Self Review, continued

4.1g. Who received the evaluation results?

4.1h. How are these results shared?

4.1i. How are evaluation results used for program development?

4.1j. Who monitors recommendations for program development and changes?

V. Program Accomplishments and Development Goals

(To be completed by all participants: 15–30 minute discussion).

5.1a. Based on this Program Self Review, identify current program accomplishments and strengths:

Infant Medical Summary

Infant's Name ______________________________

DOB ______________ C.A. ______________ as of ______________ (today's date)

Adjusted Age ______________ (if applicable)

FAMILY INFORMATION

Mother's Name ______________________________

Father's Name ______________________________

Other Primary Caregiver ______________________________

Siblings ______________________________

Others in Home ______________________________

Languages Spoken in Home ______________________________

Other family information that is relevant to the infant's medical needs:

____

____

SERVICE PROVIDERS **Private and Public Agencies**
(i.e.: Department of Health, Local Educational Agency, Regional Centers, etc.)

Name of Agency ______________________________

Address ______________________________

____

Phone ______________________________

Public or Private (circle one)

Service Coordinator ______________________________

Brief description of services receiving:

____

HEALTH INSURANCE

How is infant's health care paid for? (cash, insurance, Medicaid, etc.)

____

Name of insurer or public agency? ______________________________

Contact Person ______________________________

Phone ______________________________

Identification # ______________________________

Type of coverage: (fee for service, PPO, HMO, etc.) ______________________________

Deductible/Co-Payments family is responsible for ______________________________

Family concerns regarding paying for Infant's health care:

____

____

Infant Medical Summary, continued

Summary of all professionals involved in the infant's care

INFANT'S NAME ______________________ **DOB** __________________

HOSPITAL/DOCTOR/THERAPIST/EDUCATOR	AGENCY	PHONE	DATES SEEN

Infant Medical Summary, continued

INFANT'S NAME ________________________________ DOB ____________

Summary of Medical History

(Obtained from reports and records reviewed)

Diagnosis	Medications
Hospitalizations	Surgeries
Equipment Prescribed	Precautions
Vision Status and Date of Last Test	Hearing Status and Date of Last Test

Infant Medical Summary, continued

INFANT'S NAME ______________________ DOB __________

Summary of Developmental Concerns

(Note known areas of concern as well as those that you have questions about as a result of information from medical records.)

Gross Motor	Fine Motor
Communication	Cognition
Eating	Social/Behavior
Sleep Patterns	Other

P. Haag Schachter

Functional hearing screening

Questions for the family

Interviewer Form

CHILD'S NAME ______________________

AGE ______________________

DATE RECORDS REVIEWED ______________________

MEDICAL AND HEALTH INFORMATION

1. What have you been told by medical professionals about your baby's hearing?

2. Has your baby had an ear infection? How frequently?

3. Is your infant often congested? Having frequent colds?

OBSERVATIONS (Note: If parents are unable to answer these questions you will need to help structure observations of the infant's responses to sound and to model how to observe for the parent.)

4. What is your impression of the infant's hearing?

Continued.

Functional hearing screening

Interviewer Form

Questions for the family, continued

CHILD'S NAME ______________________________

5. What sounds seem to get your baby's attention? How does your baby respond to these sounds?

6. What does your baby do when you call his/her name?

7. How does the baby react to sudden loud noises (dog barking, honking car horn, vacuum cleaner)?

8. Does your baby seem to respond differently to your vocalizations when the radio or television is on?

9. Does your baby enjoy toys that "talk" or make noise?

10. Does your baby enjoy you talking or "when you talk," cooing or singing to him/her?

D. Chen & P. Haag Schachter

Functional hearing screening
Questions for the family

Interviewer's Directions

NOTES & CONSIDERATIONS

MEDICAL AND HEALTH INFORMATION

1. What have you been told by medical professionals about your baby's hearing?

[Look for diagnoses that may signal concerns about hearing. Ask if the parent knows if a hearing test has ever been conducted. Parents are often unaware that a Brainstem Auditory Evoked Response (BAER) was done during a hospitalization. A thorough search of medical records will be necessary.]

2. Has your baby had an ear infection? How frequently?

[Frequent ear infections can cause a fluctuating level of hearing and are an indicator of risk of hearing loss that may affect development of communication skills.]

3. Is your infant often congested? Having frequent colds?

[Infants who have frequent colds or are often congested may have fluid in the middle ear (without there being an infection) which can cause intermittent hearing loss.]

OBSERVATIONS (Note: If parents are unable to answer these questions you will need to help structure observations of the infant's responses to sound and to model how to observe for the parent.)

4. What is your impression of the infant's hearing?

[Parents often have a "sense" about their infant's hearing — it may differ from what medical professionals have told them. Urge parents to share their thoughts and concerns with you.]

Continued.

Functional hearing screening

Interviewer's Directions

Questions for the family, continued

5. What sounds seem to get your baby's attention? How does your baby respond to these sounds?

[Note particularly high or low sounds or use of varied intonation to get the baby's attention. Notice what the baby's reaction is to the sounds; eg. increased movement, quieting, startle, vocalization.]

6. What does your baby do when you call his/her name?

[Note the baby's responses to speech — this may be different than non-speech sounds. Note how the parent says the baby's name — are intonation, volume and pitch varied to increase attention?]

7. How does the baby react to sudden loud noises (dog barking, honking car horn, vacuum cleaner)?

[Note the baby's responses to loud non-speech sounds. Lack of response may indicate a hearing problem. Children with other neurological problems may have an exaggerated startle or lack of startle that may make these responses more difficult to interpret.]

8. Does your baby seem to respond differently to your vocalizations when the radio or television is on?

[This item tells you if the baby has difficulty attending when there is background noise. Background noise makes it more difficult to hear speech, especially if there is a hearing loss. Infants with cortical vision impairment/neurological impairments may have difficulty attending to more than one stimulus at a time.

9. Does your baby enjoy toys that "talk" or make noise?

[Find out if these are available for the baby. If so, if the baby does not enjoy them, ask more questions to determine if the baby is not hearing them or if they are loud and annoying to the baby.]

10. Does your baby enjoy you talking or "when you talk," cooing or singing to him/her?

[This item may be culturally based and need to be worded in a manner that is familiar to the parent. Give examples of songs or games familiar to this parent. Lack of response to this item may indicate a hearing loss.]

D. Chen & P. Haag Schachter

Questions to ask the Infant's Audiologist

CHILD'S NAME ______________________

AGE ______________________

DATE RECORDS REVIEWED ______________________

1. What kinds of hearing tests were conducted?

2. What were the test results?

3. How did the test go—how was the baby during the testing situation? How reliable are the results?

4. What do results mean in terms of the baby's ability to understand speech?

5. With this hearing loss would this baby benefit from amplification?

6. What can we expect this baby to hear? With and without amplification?

Continued.

Questions to ask the Infant's Audiologist, continued

CHILD'S NAME ______________________________

7. Are more tests needed? When? What kind?

8. What do you think is the best way to assess this infant?

9. When should this baby be retested? (If questions remain about baby's hearing, s/he should be seen at least once annually to see if hearing has changed or if aid is appropriate and setting of aid is appropriate.)

10. How can I help prepare this child for further testing?

11. Can I participate in further testing?

12. [If present at the exam.] Can the parents and I listen through headphones to what the baby is hearing to help us better understand the baby's hearing loss?

13. When does the baby need new ear molds made? (If wearing aids.)

You should be able to answer questions #1–7 from an audiological report. If the written report does not provide this information, you will need to discuss the results with the audiologist.

D. Chen & P. Haag Schachter

Functional vision screening

Questions for the family

Interviewer Form

CHILD'S NAME ______________________________

AGE ______________________________

DATE RECORDS REVIEWED ______________________________

MEDICAL AND HEALTH INFORMATION

1. What have you been told by medical professionals about your baby's vision?

2. Have you noticed if one of your baby's eyes turns inward, outward, upward or downward? If so, when does this occur?

3. Do your infant's eyes look normal?

4. Does anyone in your family have a vision problem? Amblyopia or "lazy eye"? Far/nearsightedness/ astigmatism? Color blindness?

5. What is your impression of your infant's vision?

OBSERVATIONS (Note: If parents are unable to answer these questions you will need to help structure observations of the infant's responses to visual stimuli and to model how to observe for the parent.)

6. What does you baby like to look at?

Continued.

Functional vision screening

Interviewer Form

Questions for the family, continued

CHILD'S NAME ______________________________

7. What does your baby do when you're about 8–12 inches away and look at him/her?

8. Does your infant use both eyes to look at objects or your face when close to him/her (about 4 inches away)?

9. Does your baby use both eyes to follow a moving object that crosses from the one side of the body to the other (e.g.: from left to right)?

10. Does your baby swipe at, reach for, and grasp colorful objects that are close to him/her? If so, please explain.

11. Does your baby seem to respond to your face or brightly colored toys? If so, how far away, or how close, and in what positions are they noticed?

12. How does your baby respond if many toys are presented at the same time (e.g.: several toys on a quilt during playtime)? Will he/she notice a favorite toy?

13. What toys does your baby prefer? Toys that make sounds? Toys that are bright and colorful? Shiny toys?

I. Topor

Functional vision screening
Questions for the family

Interviewer's Directions

NOTES & CONSIDERATIONS

MEDICAL AND HEALTH INFORMATION

1. What have you been told by medical professionals about your baby's vision?
   [Look for diagnoses that may indicate the infant is at risk for visual impairment. Ask the parent whether the infant has ever had a vision test. If so, what kind of test? If the infant is very premature, has an ophthalmologist checked whether or not the infant had retinopathy of prematurity?]

2. Have you noticed if one of your baby's eyes turns inward, outward, upward or downward? If so, when does this occur?
   [Eye muscle imbalance (strabismus) can cause vision problems if left untreated. Children do not grow out of crossed eyes. Strabismus can often lead to a lazy eye of not treated, or may be an indication of another undetected vision difficulty.]

3. Do your infant's eyes look normal?
   [The infant's eyes should look clear, be free of discharge, and have distinct colors. For example, the iris (usually colored brown, green/hazel, blue) should be pigmented with color throughout the whole iris, the pupil (black hole in the middle of the iris) should be a complete closed curve, the white part of the eyes (sclera) should be white, not yellow or red. The lids should not be droopy (ptosis condition). The eyes should be free of redness, encrustation, or infection. Nystagmus, involuntary movement of the eyes, should not be present.]

4. Does anyone in your family have a vision problem? Amblyopia or "lazy eye"? Far/nearsightedness/astigmatism? Color blindness?
   [Early identification is essential. Amblyopia or lazy eye can be treated in infants at 10 months of age. The earlier the treatment, the better the chances that the infant will develop binocular vision. In cases of extreme far sightedness or nearsightedness and/or astigmatism, the infant's vision can be corrected with lenses. Though color deficiency (color blindness) cannot be treated and is more prevalent for males than females, the family may be alerted to the genetic tendency for boys to have blue/green color deficiency if a male relative has the color deficiency.]

OBSERVATIONS (Note: If parents are unable to answer these questions you will need to help structure observations of the infant's responses to visual stimuli and to model how to observe for the parent.)

5. What is your impression of your infant's vision?
   [Parents often have a "sense" about their infant's vision — it may differ from what medical professionals have told them. Urge parents to share their thoughts and concerns with you.]

Continued.

Functional vision screening

Interviewer's Directions

Questions for the family, continued

6. What does you baby like to look at?
[Research indicates that infants are first attracted to features of the human face, black and white concentric designs, stripes that alternate black and white, and brightly colored toys. Looking away from (gaze aversion) any of these stimuli is reason to refer the infant to an eye health care professional.]

7. What does your baby do when you're about 8–12" away and look at him/her?
[Note the baby's responses to primary caregivers and other family members. Determine if the baby responds differently when the person looks at, smiles, and talks to the baby versus just looking at the baby and smiling. Note whether the baby is using both eyes and the infant's head position when looking at the caregiver.]

8. Does your infant use both eyes to look at objects or your face when close to him/her (about 4" away)?
[Note the infant's use of eyes at this distance. Both eyes "converging" together at this distance is considered typical for the infant whose vision is developing normally.]

9. Does your baby use both eyes to follow a moving object that crosses from the one side of the body to the other (e.g.: from left to right)?
[At two months of age, babies use both eyes to follow objects that move horizontally, vertically, circularly, and diagonally. Lack of coordinated eye movements that follow a visually attractive object or face may indicate a visual difficulty.]

10. Does your baby swipe at, reach for, and grasp colorful objects that are close to him/her? If so, please explain.
[Note baby's reaching and grasping behaviors. At three months of age, the baby is swiping (even though inaccurate at first) at interesting toys (such as mobiles). Poor reach and grasp behaviors could indicate a visual difficulty and delayed development of eye-hand coordination.]

11. Does your baby seem to respond to your face or brightly colored toys? If so, how far away, or how close, and in what positions are they noticed?
[Note the baby's "visual sphere" or area that s/he appears to visually attend to stimuli and then loses visual attention. Research indicates that babies as young as 6 months see at distances to twenty feet (albeit not with best detail). Interest in visual events beyond 1 foot is considered typical at young ages. If the baby appears to see toys on one side of his body but not the other when the head is stable, then a visual difficulty may be present (e.g., limited visual fields).]

12. How does your baby respond if many toys are presented at the same time (e.g.: several toys on a quilt during playtime)? Will he/she notice a favorite toy?
[This item tells you if the baby has difficulty attending when there is "visual clutter" present. Infants with cortical visual impairment/neurological impairments may have difficulty attending to more than one stimulus at one time if too many stimuli are presented at once.]

13. What toys does your baby prefer? Toys that make sounds? Toys that are bright and colorful? Shiny toys?
[Find out what toys are available for the baby. Note what colors attract the infant's attention. If a variety of toys are available and the baby responds well only to sound-making toys, determine whether the baby can see them or if the sound adds to the baby's enjoyment of these toys. Ask whether or not the baby responds to seeing the spoon or bottle during feeding times.]

I. Topor

Questions to ask the Infant's Ophthalmologist or Optometrist

CHILD'S NAME ______________________________

AGE ______________________________

DATE RECORDS REVIEWED ______________________________

1. What kinds of vision tests were conducted?

2. What were the test(s) results?

3. How did the test go—how was the baby during the testing situation? How reliable are the results?

4. What do results mean in terms of the baby's ability to see clearly?

5. With this vision loss would this baby benefit from glasses or contact lenses?

6. What can we expect this baby to see with and without lenses?

7. Are more tests needed? When? What kind?

Continued.

Questions to ask the Infant's Ophthalmologist or Optometrist, continued

CHILD'S NAME ______________________________

8. What is the best way to assess an infant with multiple disabilities?

9. When should this baby be retested? (If questions remain about baby's vision s/he should be seen at least once a year to see if vision has changed or if glasses or contact lenses have been prescribed and to see if the strength and fit of glasses/contract lenses is appropriate.)

10. How can I help prepare this child for further testing? (For example, for acuity tests which require a matching or verbal response, or tests performed at distances beyond 16 inches.)

11. Can I participate in further testing? (Recognition acuity tests.)

12. [If present at the exam.] Can the parents and I look at the Forced Preferential Looking Cards from the point of view of the tester? Of the baby? To better understand the baby's vision loss?

13. If the baby is wearing contact lenses or glasses, when does he/she need to be checked for a new prescription?

You should be able to answer questions #1–7 from a complete vision report. If the written report does not provide this information, you will need to discuss the results with the optometrist or ophthalmologist.

I. Topor

Communication options worksheet
Model demonstration project

NAME ______________________ DATE ____________

			COMMUNICATION OPTIONS	
CHILD'S STRENGTHS AND NEEDS			**INPUT**	**OUTPUT**
Vision				
Hearing				
Motor				
Tactile				
Responses to Movement				
Cognitive Level	Awareness			
	Recognition			
	Discrimination			
		Selected Options		
		To discuss		
		with family		

Routine analysis

INFANT ______________________ ACTIVITY ______________________ DATE ______________

STEPS IN ROUTINE	NATURAL CUES	INFANT BEHAVIORS TO ENCOURAGE	INPUT AND ADAPTIVE STRATEGIES	AREA *(Discipline)*
For example: Preparing for the activity, marking the beginning, middle and end of activity, and transition to another.	*For example: Characteristics of the environment, what adult does to engage the infant's attention and participation.*	*For example: Ways the infant can indicate anticipation and participate actively.*	*For example: Ways to provide appropriate communication input, may include: speech, sign, touch cues and object cues or handling and positioning, ways to encourage functional vision and hand use.*	