

Developing a Treatment Program for Children with Auditory Neuropathy

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Abstract. Auditory neuropathy/dys-synchrony is a relatively new diagnosis that has challenged parents and professionals to identify appropriate treatment strategies. Parents may be confused by the diagnosis and confounded by the treatment options. This article offers guidelines to be used by parents and professionals to develop a treatment plan for each child. The goal of treatment, language development, can be accomplished through a variety of methods, each one suitable for different children and for different families. The value of visual communication approaches and the efficacy of cochlear implantation are presented. The therapeutic/education team is encouraged to obtain a profile of each child's skills in all developmental domains and to consider a child's unique developmental profile as an effective, individualized treatment plan is created. The therapeutic/education team should include professionals who are familiar with the diagnosis of auditory neuropathy/dys-synchrony and the implications of this diagnosis on a child's development.

Key Words. Assessment, treatment, language development, communication methods

Learning Objectives.

1. To learn to create an individualized treatment plan for each child with auditory neuropathy/dys-synchrony
2. To use assessment tools to evaluate all developmental domains of a child with auditory neuropathy/dys-synchrony

CEU Questions

1. In order to create a treatment program, a developmental developmental profile of the child is obtained. The developmental profile considers:
 - a. audiologic test results
 - b. functional auditory skills
 - c. communication and language skills
 - d. cognitive skills
 - e. all of the above**

2. The treatment plan for a child with auditory neuropathy should *always* include:
 - a. Cued Speech
 - b. visual communication**
 - c. hearing aids
 - d. cochlear implants
 - e. American Sign Language

3. Learning language is a challenge for a child with auditory neuropathy because
 - a. input to the auditory system and processing of auditory stimuli are compromised
 - b. the child may depend on visual communication strategies that are not available
 - c. most children have additional neuropathies that affect cognition
 - d. a & b**
 - e. all of the above

4. A functional auditory training program includes
 - a. identifying the conditions when the child hears
 - b. documenting variability in the child's auditory behavior
 - c. determining if the child follows a typical hierarchy of auditory skill development
 - d. defining the unique characteristics of a child's auditory profile
 - e. all of the above**

5. The best way to collect assessment information is to
 - a. query the parents
 - b. request records from all professionals involved in the child's care
 - c. administer specific norm-referenced tests to the child
 - d. observe the child
 - e. all of the above**

INTRODUCTION

Auditory neuropathy is a relatively new diagnosis that has been investigated in recent years. Berlin ¹ suggests the term auditory dys-synchrony as a more accurate definition of the disorder for some children. Whether called auditory neuropathy or auditory dys-synchrony, this new diagnosis has challenged parents and professionals as they try to identify appropriate treatment strategies.

The diagnosis is difficult for parents to understand. There may be more than one site of lesion that is causing the disorder ². The course of the condition is unpredictable. For some the condition resolves, for some hearing thresholds fluctuate, and for others the condition gets worse ^{3,4}. Pure tone thresholds indicate awareness of sound in the normal range to the profound range ⁵. Speech recognition for children with auditory neuropathy/dys-synchrony may be poorer than expected, based on pure tone thresholds ⁴. Hearing in noise is usually more challenging than hearing in quiet conditions ¹.

This article offers guidelines to be used by parents and professionals as they develop a treatment plan for each child. The goal of treatment for each child is the development of language. Language learning can be accomplished through a variety of methods, each one suitable for different children and for different families. The intervention/education team must obtain a profile of the child's skills in all developmental domains. Each child's unique profile needs to be considered in order to create an effective, individualized treatment plan. The intervention/education team should be composed of

people who are familiar with the diagnosis and the implications of auditory neuropathy/dys-synchrony on a child's development.

AN ACTION PLAN

Helping parents during the diagnostic process. In order to confirm a diagnosis of auditory neuropathy, a specific audiologic test battery needs to be administered⁴. This can take more time than the diagnosis of a child with sensory or conductive hearing loss. One reason for the extended diagnostic process is that some audiologists do not have the equipment to perform the complete battery of tests and, consequently, need to refer to another audiologic clinic to complete the test battery. Second, many audiologists do not have experience making the diagnosis of auditory neuropathy. If this is the situation, the audiologist may refer the child to another clinic for a second opinion. While this practice is appropriate, it often requires more time for the diagnosis to be made. And, during this process, parents often experience strong emotions and heightened concern.

It is reasonable to assure the family that the diagnostic process takes time. Families benefit by knowing what to expect and the reasons for the procedures that are scheduled.

Helping parents locate treatment. Habilitation is available to all children with disabilities. Children with auditory neuropathy should have access to appropriate early intervention and/or education programs. While the intent of each child's Individualized

Family Services Plan (IFSP) or Individual Education Plan (IEP) ⁶ is to create a personalized plan, children with auditory neuropathy often challenge the system because, in many situations, the professionals are unfamiliar with the diagnosis. It also can be challenging for an intervention/education program to assure their staff members are proficient using the recommended treatment procedures.

The system in Colorado works effectively. When a hearing loss of any degree is diagnosed, the family is offered the services of a Colorado Hearing Resource Coordinator. These coordinators link diagnostic and therapeutic services. There are eleven coordinators in the state covering specific geographic regions. These coordinators are experts, receiving ongoing training in all hearing disorders. They provide the family with information, offer emotional support, and help the family to navigate the intervention/education system. These specialists assist the family as the family identifies the members of the team.

Each child is unique. We know that each child with auditory neuropathy follows a unique course. In a sample from Berlin et al ⁷, 7% of the children with auditory neuropathy had a unilateral condition, 19% had additional disabilities, and 6% outgrew the condition. Berlin, et al ⁸ reported that for some infants auditory function declines and in others an improvement is observed. Even the ABR may improve ⁸. Sininger and Oba ⁹ reported that the hearing loss could change. In their sample, 29% demonstrated fluctuating hearing loss, 14% had progressive hearing loss, and the hearing thresholds in 2% of the sample improved. When looking at the auditory thresholds in the sample,

47% had a low frequency hearing loss of moderate degree, 23% had mild hearing loss, and 30% had severe-profound hearing thresholds. This variability of the disorder is confounding for professionals and can create stress for parents.

It becomes the responsibility of the intervention or education team to discern the functional profile of each child. Best practice in the field of hearing loss^{10, 11, 12, 13} acknowledges that children with hearing loss have a unique developmental profile that can be identified through assessment. Assessment needs to measure skills in a variety of developmental domains. This includes assessment of communication, language, functional auditory skills, speech, and cognition. The intervention/education program needs to repeat testing at regular intervals to monitor achievement of identified goals. By doing this, the family, along with their professional team, can identify when progress is being made, the rate of progress, and when to adapt or adjust the therapy to improve performance.

TREATMENT

Individualized treatment plan: Children benefit from an individualized treatment plan. It is important to remember that a choice is not irrevocable. A choice may be appropriate for a period of time and need to change in the future. Recommendations about the habilitation program for children with auditory neuropathy should be individualized. It cannot be assumed that the approach that works for one child will be an appropriate approach for any other child.

Some trends have been identified. While the use of amplification is controversial ¹⁴, it can be considered when managed by an audiologist who has experience working with children with auditory neuropathy. Cochlear implants also have provided excellent benefit to some children with auditory neuropathy ¹⁵.

Experience of interventionists and therapists to date supports use of visual communication ^{1, 3, 16, 17}. The dependence of a child on visual communication is related to the child's ability to benefit from auditory input. If the child can process auditory information, there will be less dependence on visual information. There are several visual communication approaches that may be selected including speechreading, English-based signs, and Cued Speech.

Work with children with sensory and conductive hearing loss has been laden with debate over the most efficacious method of communication. It is important that these debates do not spill over into the treatment of children with auditory neuropathy. Since auditory neuropathy is a relatively new diagnosis, one should not be so presumptuous as to think they know which communication method is the appropriate one for all children. Rather, each child should be viewed as an individual, in a unique family, with distinct needs and inherent skills.

Ensure language development. It takes some time to determine the impact of auditory neuropathy on a child. But one thing is paramount and that is facilitating the

development of the child's language. The rate at which the child learns language and the mode through which language learning takes place need to be carefully monitored.

For most families, the goal is for their child to develop the language spoken in the home. The development of literacy skills is dependent on having full access to the spoken language. For the majority of children with auditory neuropathy, input to the auditory system and processing of auditory stimuli are compromised ². This presents an obstacle to learning spoken English through audition. English can be learned, however, using visual communication methods that represent the English language including English-based sign, Cued Speech, and speechreading.

We know that some children eventually process auditory information. Some children spontaneously recover from the disorder and then have the ability to process auditory information that supports the development of speech. Other children are given the opportunity to process auditory information as a result of treatment, such as successful use of a cochlear implant.

Selecting a visual communication method. Visual communication can take many forms. Speechreading permits the child to “see” the sounds that are produced on the lips. When considering this approach, one must be cautious knowing that only a percentage of the sounds of the English language are visible on the lips. It has been estimated ¹⁸ that as much as 60% of speech sounds are not visible on the mouth or cannot be seen readily.

Use of Cued Speech ¹⁹ has been successful for many children ¹. This system of handshapes is designed to clarify speechreading by using simple hand movements (cues) around the face to indicate the exact pronunciation of any spoken word. Many spoken words look exactly alike on the mouth and cues allow the child to see the differences between them. Parents using Cued Speech often report that the method helps to develop their child's receptive language. Most children do not use the cues to express themselves.

The use of sign language has been popular ¹⁶. More than 50% of the children in one sample ¹ are using sign language as a method to learn language. It is strongly recommended that children using sign language use an English-based system. Manually Coded English (MCE), Pidgin Signed English (PSE), and Conceptually Accurate Signed English (CASE) are examples of English-based sign systems. Each of these sign systems can be paired with spoken English. It is important to pair signs with spoken English if the family wants to support speech development in the future. In order to be prepared to learn spoken English, it is important that the child have a foundation in the English language.

Only if a family chooses to immerse their child in Deaf culture would the use of American Sign Language (ASL) be recommended. If a child were to learn ASL, the child would be learning the rules and grammar of a language that is very different from English. ASL does not incorporate spoken English.

While auditory-verbal therapy has been successful for many children with sensory hearing loss, it has been ineffective for children with auditory neuropathy (C. Berlin, personal communication, January 28, 2002). This approach depends exclusively on the use of audition to learn language. In that the auditory system is not working well for children with auditory neuropathy, the auditory-verbal approach has proven ineffective. If a child with auditory neuropathy is successfully implanted, the use of auditory verbal therapy can be reconsidered (C. Berlin, personal communication, January 28, 2002).

Auditory Training. The therapist can expect to observe auditory behaviors that are different from both hearing children and from deaf and hard of hearing children. An auditory training hierarchy^{20, 21, 22, 23, 24} should be used to quantify how a child listens, to identify the conditions when the child hears, and to document variability in the child's auditory behavior. An auditory hierarchy also is useful to determine if the child follows a typical hierarchy of auditory skill development or, more typical for children with auditory neuropathy, to define the unique characteristics of that child's auditory profile.

An auditory training program needs to be used if and when the child starts to demonstrate the ability to listen to and process auditory stimuli. When a child can use audition to learn language, the auditory training program is useful to identify discrete goals for therapy and to monitor success. If a child has a trial with amplification, functional auditory skills should be reevaluated in light of the new listening opportunity. A traditional, structured auditory training program should also be used when a child

receives a cochlear implant. One can expect the implanted child's auditory skill development to resemble that of children with sensory hearing loss ¹⁵.

Use of amplification. The use of amplification with children with auditory neuropathy has been questioned and debated. We do know that children with auditory neuropathy do not benefit from hearing aids in the same way as children with sensory hearing loss. Rance et al ²⁵ showed that approximately 50% of affected children benefited from amplification. In another sample ⁷, 50% of the children tried amplification. Of this group only 17% received benefit, according to subjective ratings made by the child's parents. It is significant to note that the amount of benefit they experienced was not sufficient to support auditory learning of language.

There are two questions to consider when determining if a child is benefiting from amplification. One is if the child hears more sound. The more important question is if the child's speech and language are benefiting. Berlin ³ reports that hearing aids simply do not work the way the audiogram predicts. While some children enjoy hearing more sound, if they are not able to process auditory stimuli to develop speech and language, the use of the hearing aids must be questioned. All too often, the sounds a child hears become louder with amplification but the integrity of the signal does not improve. Ultimately, hearing aids are considered to be useful when they improve the child's auditory discrimination of speech. Some parents want to try hearing aids because it is a tangible attempt to remedy the condition. While it is important to acknowledge this

benefit to parents, amplification can be justified only when it helps the child to hear sound more clearly and, consequently, to communicate more effectively.

When hearing aids are used, there are some precautions to consider. According to Hood ², the aids should be fit conservatively, with a low maximum power output. This is important so the outer hair cells are not exposed to loud noise that could damage them. The fitting is often done by trial and error ²⁶. An audiologist should monitor cochlear function using otoacoustic emissions. There is documentation that some patients with auditory neuropathy may experience poorer speech perception in background noise ²⁷, ²⁸. To accommodate this, the audiologist may consider the use of directional microphones or personal FM systems to improve the signal-to-noise ratio ¹⁶.

It is important to conduct an evaluation of the functional benefit a child receives from amplification. This evaluation is conducted by observing the child in daily routines, in the sound suite, and in therapy. There are many good auditory training materials available for this purpose ^{20, 21, 24}.

Cochlear implantation. The use of cochlear implants has been quite remarkable for some children with auditory neuropathy while other children have experienced less dramatic success ²⁹. Miyamoto ²⁹ studied several children with cochlear implants and found less than optimal results when comparing their progress on vowel, consonant, and word-recognition scores to implanted children with sensory hearing loss. More recent studies are more positive. Shallop ¹⁵ followed five children with auditory

neuropathy who received implants. All of the subjects in his study demonstrated significant improvements in sound detection, speech perception abilities, and communication skills. Indeed, their progress followed the same developmental patterns as implanted children with sensory hearing loss. Berlin³ reported on nineteen children with cochlear implants, seventeen of whom were demonstrating good auditory and speech results.

The primary reason to implant a child with auditory neuropathy is to improve the auditory and speech skills of that child. This is accomplished by providing a good auditory signal to the auditory nerve in the implanted ear. Determining candidacy for a cochlear implant for a child with auditory neuropathy requires some special considerations. The implant candidacy team is responsible for taking a cautious approach in determining candidacy while trying to determine the underlying etiology of a child's auditory neuropathy. First, sufficient time must be allowed to know if the child will recover and/or receive sufficient benefit from auditory stimulation to develop speech and language without the implant. Furthermore, candidacy cannot be determined, as it is for children with sensory hearing loss, based on pure tone hearing levels. Rather, the determining factor in sound field testing is the auditory discrimination abilities of the child³⁰. Auditory discrimination should be tested in two modes, using auditory cues alone and pairing speechreading and auditory cues. Lastly, the cause of the disorder needs to be investigated to determine if the auditory nerve is intact and able to interpret auditory information. Perhaps those succeeding with a cochlear implant are the children for whom the site of lesion resides in the cochlea or the transmission of

information from the cochlea to the auditory nerve^{31, 32}. Conversely, if the probable cause of the disorder is a true neuropathy of the auditory nerve, more likely when other peripheral neuropathies are present³¹, then a child would not be a good candidate for a cochlear implant.

Keep in mind that learning language is the goal for all children. When a child receives an implant, the treatment plan should consider the language level of the child and the methods that have been used to help that child acquire language before implantation. If a child is using a visual form of communication before implantation, it is strongly recommended that this approach continue to be used as the child acquires auditory and speech skills. If a child was successfully learning language before implantation, this language, whether it was acquired through Cued Speech, sign language, or speechreading, will facilitate the acquisition of spoken language using audition.

CREATING A FUNCTIONAL DEVELOPMENTAL PROFILE

Areas to assess. The first person working with the child with auditory neuropathy is the audiologist who diagnoses the condition. The audiologist might want to immediately contact a representative of the early intervention system for children under three years of age or the educator in the local school district for children over three years of age. Upon entry into the intervention/education system, there is a need to obtain a baseline of the child's skills, to identify strengths, and to identify the developmental areas that have been challenged by the disorder.

Just as the audiologist is responsible for documenting the audiologic profile of the child, the therapy program is accountable for monitoring developmental progress. Because children with auditory neuropathy present a varied profile of auditory, speech and language development, the individual profiling of each child's development is essential. Ongoing assessment provides information about the progress a child is making. The expectation is for a child to make developmental gains at a rate that is commensurate with that child's cognitive growth. The development of language, irrespective of the communication mode that is being used, should occur at the same rate as the child's cognitive development. Ongoing developmental assessment provides assurance that the therapeutic program is appropriate, and provides an opportunity to review the communication method that is being used³³.

Assessment Procedures. There is a variety of procedures that can be used to collect information. The parents and other caregivers can report on the child's development³⁴, direct observation of the child provides data, and observation of the child's interaction with a parent is another method. In addition, videotaped interaction can be analyzed, or a professional can administer specific assessments to the child. Assessment is a collaborative process and depends on input from the professionals involved in diagnosing the condition, professionals responsible for the re/habilitation, and the parents.

Assessment should be multidisciplinary, gleaning information from a variety of developmental domains. An interdisciplinary approach to assessment employs several professionals who work cooperatively and systematically to obtain information. When using this approach, professionals discuss the diagnosis and generate treatment recommendations that reflect some degree of group consensus³⁵. The transdisciplinary approach more fully integrates the roles of team members from a variety of disciplines.

The Family Assessment of Multi-disciplinary Interactional Learning for the Young Child¹¹ is one model of assessment that can be used for children up to three years of age. It was designed specifically for children with hearing loss and currently is being used to follow children with auditory neuropathy living in several states. The clinical data collected from the individual assessments will, in the future, support research about treatment for children with auditory neuropathy.

Developmental Areas to Assess.

Cognitive skills: A determination of a child's overall potential is an integral part of assessment. Crais³⁶ recognizes, in the young child, the relationship between cognition, play skills, and communication. An evaluation of cognition can be conducted through play, for children under three years of age, or by administration of standardized instruments for children older than three years. The goal is to have an estimate of the child's developmental potential. The intervention/education team can expect the child's language development to be commensurate with the child's cognitive age. When

language development falls below a child's cognitive age, program modifications need to be considered.

Auditory skills. A child with auditory neuropathy usually demonstrates atypical or unusual listening behaviors. A scale measuring functional auditory skills is, therefore, an important part of the assessment. It is important to determine if and in what way the listening skills of the child follow or deviate from the norm. The Functional Auditory Performance Indicators ²⁰ is a new instrument used to create a profile of a child's auditory skills. This scale assesses the functional auditory skills of a child with hearing loss. The profile lists auditory skills in hierarchical order. Performance is quantified by obtaining percentage scores in each of seven categories. There are many other tools ^{21, 22, 23, 24} that serve the same purpose.

Communication and language skills. For children with hearing loss, communication and language are usually the most noticeably affected developmental areas. Children with auditory neuropathy are no exception. Communication starts when a baby is born and includes a child's use of gesture, communication intention, facial expression, turn-taking, and vocalizations. Assessment of the young child's communication can start in infancy. It is important to be familiar with developmentally appropriate communication skills and to identify if and in what way an individual child's communication departs from these developmental norms.

When assessing a child's language, one evaluates both receptive and expressive development. The assessment of receptive language includes how the child understands syntax, morphology, semantics, and pragmatics of language. Since the expectations for a child's comprehension of language depend on the chronological age of the child, the professional conducting the assessment must be familiar with the normal stages of language development. In addition to language comprehension, it is important to assess expressive language. Expressive language includes imitation, initiation of communication, and production of a variety of sounds, words, and sentences³⁷. By monitoring skills in all of these areas, and by observing the changes in the child's skills at regular intervals, the professional can identify areas of strength and concern at any point in time.

The assessment of receptive and expressive language is important regardless of the communication mode being used (visual, manual, auditory) and the language itself (English, American Sign Language, Spanish, etc.).

Speech skills. Since children with auditory neuropathy usually do not hear a clear and intact speech signal, speech production is consequently affected. It is important to monitor the child's vocalizations, the sounds a child makes before learning first words. The number of utterances a child makes and the quality of these utterances provide important information. An inventory of specific phonemes, including vowels and consonants, can be collected. When a child starts to use real words, the intelligibility of these words should be analyzed. This can be a subjective rating of speech intelligibility

³⁸ or an objective measure of the accuracy with which the child's words match the target words. Use of computer programs ³⁹ are helpful to measure the percentage of vowels and consonants that accurately match the words the child produces.

Mode of communication. Choosing the communication method often has been based on the method available in the community or in the local school district. This approach is not recommended. If the selection process depends on what is available, the choice is limited, the choice may not match the family's commitment, and, perhaps most important, the choice may not support positive outcomes for the child. What is most important is making a decision based on objective and measurable criteria ⁴⁰. By evaluating communication and language skills at frequent and regular intervals, we obtain objective information to identify a child's strengths and needs. When communication and language skills are within normal limits, we can assume the communication approach being used is appropriate and effective. It is the responsibility of the early intervention team and/or the local school to accommodate the needs of the child. The best approach is the one that promotes the development of age-appropriate communication and language.

Interpreting test results. There are several ways to measure development and to determine how much progress is being made. Norm-referenced tests measure a child's development compared to typically developing peers. Comparing a child's development to typically developing peers sets an important expectation. The critical element is to identify the communication method that promotes language development. Criterion-

referenced testing establishes a baseline of an individual child's skills. Progress is monitored based on an expectation that a child will make developmental gains commensurate with the amount of time that has elapsed. The intervention/education team needs to be vigilant and frequently measure a child's performance using this measure.

In recent years, norms for deaf/hard of hearing children have been developed for some diagnostic tests ⁴¹. These norms should be used with caution when testing children with auditory neuropathy. These children generally do not follow the same developmental patterns, especially in the area of functional hearing, as children with sensory or conductive hearing loss. The norms for communication and language development, however, could be used.

It is important to monitor progress at regular intervals since the course of auditory neuropathy can be unpredictable. Assessment information can be used to help professionals and families make informed choices and to establish goals and objectives at an IFSP or IEP meeting. The objective developmental information needs to be updated at frequent intervals in order to determine if the intervention is appropriate. Perhaps more frequent therapy sessions are warranted or different strategies may be needed to develop the child's language. Frequent review of the child's developmental profile will allow the intervention team to adjust the treatment plan, as necessary, to assure language is developing and to identify the mode through which language learning takes place.

TEAM EFFORT

Team members. While it is often a challenge to bring professionals together, this is of heightened importance for children with auditory neuropathy. A team includes the audiologist who is diagnosing and monitoring the course of the condition. The audiologist also has the responsibility for monitoring the use of amplification, if it is used, and for recommending candidacy for a cochlear implant. The ENT or otologist can provide medical information about the condition. The early interventionist or educator is included to provide information about the development of communication, language, functional auditory skills and speech. This role may be filled by a Speech/Language Pathologist or a teacher of the deaf/hard of hearing. Input from a neurologist may determine if the child has other peripheral neuropathies. The child's primary care physician, a developmental pediatrician and an ophthalmologist may be included to share their expertise. In most areas of the country, some of these team members will, no doubt, be unfamiliar with auditory neuropathy and its impact on development. Those members of the team who are inexperienced will benefit from those who have worked with children with this condition.

Audiologic management. The managing audiologist monitors the audiologic profile of the child. After the initial diagnosis, this includes monitoring of both cochlear and neural sensitivity. Ideally, a professional from the therapeutic and/or education program will work collaboratively with the audiologist so that information from objective tests can be

interpreted in light of the child's functional listening behaviors. The audiologist has a primary role in determining if amplification is used or if a cochlear implant seems appropriate.

One clinic in Colorado involves an expert on treatment and management during the diagnostic process and at follow up appointments. Parents of older affected children also have been invited to follow up appointments. Parents report that they appreciate having information about therapy options and communication options as soon as possible.

Therapeutic management. It is important to have a designated person to assist the family in creating the intervention program. Ideally, this professional is familiar with auditory neuropathy and the implications of the disorder. If this is not the case, consultation from a colleague with experience with children with this condition should be solicited.

While the intervention program needs to be individualized for each child, there are some general considerations that apply to most children with auditory neuropathy.

Intervention should be competency-based. Using this paradigm, the interventionist identifies the strengths exhibited in the child's developmental profile and identifies strategies to address delays. Next, a visual approach to language learning must be considered. A visual approach should be selected for any child who is unable to understand auditory information. Last, auditory skill development most likely will be

compromised. Therefore, a careful evaluation of a child's functional auditory skills needs to be performed on a regular basis.

For children under three years of age, the Part C system of IDEA ⁶ requires each family to have an Individualized Family Service Plan. An Individual Education Plan is developed for children three years of age and older. This plan is created as a team. This provides an opportunity for team members to collaboratively identify strengths, to monitor a child's progress, and to adapt treatment as needed.

Parent & Family Involvement. Parents have the ultimate responsibility for treatment decisions. But, in order to make informed decisions, they need information. Parents need to learn to observe their child. The therapy/education program can provide assistance to parents so they can learn what they need to observe. Children under three years of age are eligible for services from Part C. The Part C system, by statute, supports family-focused intervention.

An excellent source of support is available to parents from an electronic listserv that has been operating for several years ⁴². This list serve was organized by a parent of a child with auditory neuropathy.

CONCLUSION

When a child is diagnosed with auditory neuropathy, parents are confronted with a scenario that most parents fear. Their child has a disorder with an unpredictable course. The disorder manifests in a unique way for each child affected. While researchers are working diligently to identify the site of lesion causing the disorder, this work is still evolving. Parents report feelings of helplessness and are often dissatisfied when they encounter professionals who are, themselves, just learning about the disorder. There are established criteria for diagnosis and treatment of children with sensory and conductive hearing loss. Conversely, families of children with auditory neuropathy often encounter more questions than answers.

It is to be hoped that, in the future, intervention and education for children with auditory neuropathy will be more prescriptive. At this time, however, professionals have the responsibility to work as a team. They have a responsibility to identify the developmental profile of each child in an effort to identify the appropriate intervention strategies. And, as professionals, we have a responsibility to remain committed to the method or methodology that works for each child.

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