DOCUMENT RESUME

ED 312 842 EC 221 300

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TITLE Infant--Toddler Evaluation.
PUB DATE Jun 88
NOTE 13p.; In: Kemp, Faye, Ed.; And Others. New Directions in Resources for Special Needs Hearing Impaired Students: Outreach '88. Proceedings of the Annual Southeast Regional Summer Conference (8th, Cave Spring, Georgia, June 14-17, 1988); see EC 221 298.
PUB TYPE Reports - Descriptive (141) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Early Intervention; Evaluation Methods; *Hearing Impairments; *Home Programs; Infants; *Multiple Disabilities; Occupational Therapy; Physical Therapy; Preschool Education; State Programs; Toddlers; *Visual Impairments

ABSTRACT

The Georgia Parent Infant Network for Educational Services (PINES) is a home intervention program currently serving over 300 hearing impaired, visually impaired, and multihandicapped sensory impaired (MHSI) preschoolers. The infant-toddler evaluation component is described, with sections on screening and diagnosis, parent education concerning other handicapping conditions, developmental assessment, infant/toddler evaluation in deafness, assessment of the MHSI, and use of the Callier Azusa Scale and the Insite Developmental Checklist. The physical/occupational therapy component is also described, including training of therapists, purpose of therapy, and assessment in 12 areas by physical/occupational therapists. References conclude the paper. (DB)

INFANT - TODDLER EVALUATION

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8th Annual Southeast Region Summer Conference
June 15, 1988
Cave Spring, Ga.

Introduction

The Ga. PINES Program (Georgia Parent Infant Network for Educational Services) has expanded tremendously over the last 10 years. It is a home-intervention program for the hearing impaired, visually impaired and multihandicapped sensory impaired (MHSI) preschoolers within the state of Georgia. We are currently serving over 300 preschoolers 0-5 and have over 100 parent advisors who work with the children and their families.

Over 30 physical or occupational therapists provide supportive services. Further parent advisor and therapy/consultant training is scheduled yearly. The Ga. PINES' SkiHi program serves the hearing impaired and Ga. PINES' Insite Project serves the blind, deaf-blind and multihandicapped sensory impaired.

Screening and Diagnosis

Screening and diagnoses of the preschool children's handicaps have usually been carried out before they are referred to Ga. PINES. It is because of audiological, medical and ophthalmological diagnosis or indications of delayed sensory skills that most of our children have been referred to the program by medical professionals, social workers and others.

Documentation of the children's handicaps are also part of the eligibility criteria for continuation in the program. To that end, ongoing audiological, functional vision and therapy evaluations are carried out to determine changes as they occur as the child matures.

Assessment and Knowledge of Other Handicapping Conditions

The population of hearing impaired and vision impaired preschoolers is changing due to etiologies that are documented such as cytomegalovirus, meningitis, prematurity and newly recognized syndromes such as the C.H.A.R.G.E. syndrome. Parents are encouraged to learn more about their children's handicapping conditions and how they impact on the child's development. This is done through parent discussion modules. The depth of the discussions depends on the parent's needs or wishes. Parents are tested on knowledge and skills which are documented as they are acquired.

Through this background information, knowledge (and a concerted effort in building trust, support and communication on the parent advisor's part) the parent can more readily become involved in informal observation and sometimes record keeping of the child's behaviors. Parents are asked to keep a notebook. The parent advisor not only addresses the child's needs but also works toward the parent's assessment of the child's needs. Sometimes the parent's and parent advisor's assessment of the child's needs differ. If this is the case, the parent advisor can model some of the skills they feel needs to be addressed while deferring to the parent's needs.

Developmental Assessment

When you work with preschoolers 0-2 and 3-5, the emphasis in assessment is developmental. Observation of sensory-motor responses and skills, and early learning behaviors are emphasized. Assessment is geared more toward functional skills versus intellectual skills as language and communication are evolving but are usually somewhat delayed due to the handicaps themselves.

Parents vary in their knowledge and exposure to early child development. They are usually more aware of normal development if there are older children, or children in their neighborhood or young relatives. When this is not the case they must be taught how to observe emerging behaviors or lack of behaviors which in early development can be predictable and sequential.

Any new parent is unconsciously assessing an infant or toddler's skills. Can he hear, see, respond to stimuli? Can he roll over, crawl, stand up, walk around, etc. because other kids his age do? (Age related.) In other words, "Is my child meeting the major developmental milestones?" In many cases, parents, mothers in particular, identify or suspect developmental delays before the pediatrician does.

With the hearing impaired or multihandicapped hearing impaired INTERVENTION emphasizes stimulating the skills that do not occur or develop spontaneously. Thus we say we are observing and assessing to identify strengths and weaknesses and to determine BASELINE INFORMATION.

The baseline information derived from assessing and observing is used: (1) to plan sequential activities to address needs; (2) to strengthen skill areas; (3) to re-evaluate to form new goals and objectives or to modify existing goals on the IEP or IFSP (parent's needs and skills are also addressed); (4) to provide updated information at periodic staffings; and, (5) to determine support services needed. Since parents are with the child for a greater part of the day and night and have information others would not possibly have, it is vital that they are part of the overall assessment process.

Infant/Toddler Evaluation in Deafness

Few tests have been normed using the hearing impaired as subjects. This is especially true with the preschoolers. When tests are used that have been normed on the hearing child, data derived must be cautiously interpreted and this fact noted. Testing results are usually skewed because of many factors but a most important variable is the language and communication level of the hearing impaired child which is in most cases developmentally delayed in quality and quantity when compared to the hearing.

Adaptation or omission of some portions of the tests may be made. Developmental tests such as the Learning Accomplishment Profile - Developmental Edition (LAPD) or the Battelle are examples of developmental tests from which a functional age or level can be obtained for some domains particularly the motor and basic skills. However, the language skills of some HI or MHHI preschoolers preclude using them in their entirety since the child needs language skills or concepts to perform many of the tasks.

For the hearing impaired preschoolers in the Ga. PINES program there is an emphasis on language and communication assessment performed on a regular basis. The Ski Hi Language Development Scale is informally administered every three months or on regular intervals using a checklist to determine linguistic skills. The Ski Hi Receptive Language Test, administered every six months is used to determine the child's ability to comprehend single word utterances as well as up to four critical element utterances. There are 50 test plates with 4-5 stimulus pictures to each plate in ascending order of difficulty. The child must demonstrate comprehension of the ascending order of critical element utterances taken from 100 core vocabulary items.

Audiological testing is carried out through pediatric audiological conditioning procedures on an on-going basis.

The school's diagnostic and evaluation team usually administers a battery of test instruments at age three if the child is to be enrolled in our center based program or if required for other reasons. The battery may include: developmental skills, cognitive items, learning readiness, etc.

Also used is a checklist which samples parents language as they interact with the child.

Assessment of the MHSI

Usually the MHSI child requires an inter disciplinary evaluation along with a developmental to assess the major areas of: language-communication, social-emotional, cognitive, self-help, sensory and gross and fine motor.

The child's motor skills can be more formally assessed by a physical or occupational therapist or more informally by the parent advisor.

The audiological must be carried out by a professional who has understanding and experience with multihandicapped preschoolers. The audiologist is looking for behavioral manifestations of a response to sound be it a cessation of activity, eye blink, startle response or a change in breathing patterns among many behaviors.

Since many of the MHSI are deaf-blind or just visually impaired, an informal visual functioning assessment may also be required to supplement the formal. Most times, ophthalmologists do not provide us with enough visual functioning versus acuity information to help in educational programming. Both pieces of information are supplementary to each other.

The Callier Azusa Scale

The Callier Azusa Scale is a formal measure of a preschooler's skills across the areas mentioned above. Furthermore, it was standardized on a deaf-blind population and has been used nationally with other handicapped children. Parent advisors with parental input address skills through observation, questions and answers from the parents or tasks set up to determine those skills.

The Callier results are plotted on a profile which describes chronological age range in which behaviors are expected to occur (0-6 mos.), (6-12 mos.), (12-18 mos.), (18-24 mos.), etc. in normal development. The results describe the actual functioning level of the individual child. The results point out the discrepancies between chronological and functioning level be it a developmental delay or average or above average skills in all of the major areas.

The resultant profile is used for many purposes, among them are: baseline data for planning programs, sharing information with other agencies and is used to compile national data for funding purposes and so forth. Pre and post tests are given each year to determine progress though it may be given more frequently.

The Insite Developmental Checklist

The Insite Developmental Checklist is being modified, refined and standardized on the MHSI. There are many more discrete items than the Callier at present.

These developmental assessment tools can be supplemented by the Hawaii Early Learning Profile (HELP), the Uzgiris-Hunt, the Carolina Developmental Scale, the Vulpe and the Oregon Project for Visually Impaired and Blind Preschool Children.

It is important to note that assessment is cyclical and on-going. The tools used depend on the level of the child, his ability to communicate and his multiple needs. A developmental scale is an appropriate tool for preschoolers just as achievement and intellectual tests are appropriate for school aged children.

Training

Once the multihandicapped sensory impaired (MHSI) portion of the Ga. PINES program was added, parents and parent advisors alike saw a need for more input into their children's motor deficits. Therefore, in February, 1987, we began training physical and occupational therapists to work as consultants to the program.

Therapists are recruited from across the state and are required to have pediatric experience, Georgia licensure and to carry personal liability insurance. Since, in the field of pediatrics, therapists are working on developmental skills which build one on another across the various domains of gross and fine motor, sensory integration, cognition, self-help and personal-social, much overlap exists between the treatment content and approaches followed by physical and occupational therapists. Therefore, in the Ga. PINES program, assignment of a PT versus an OT to a particular referral is based more on geographic location than on area of specialization.

Training for therapists occurs over 4 days, in conjunction with the parent advisor training, thereby allowing sharing of ideas and encouraging a "team approach" toward working with the program's MHSI children and their families. During the training, the therapists are given information on vision loss, hearing loss, communicating with MHSI children and a variety of other topics. Training content is not just focused on motor issues but rather relates to the total child.

Why Therapy?

Why did the Ga. PINES' parents and parent advisors see a need for therapy input? As has already been mentioned, early development is sensory-motor in nature. Young children learn about themselves, their environment, language, etc. through movement experiences which relate their bodies to themselves and to objects outside themselves.

Many MHSI children have motor delays which interfere with this learning. For example, hearing impairment of a meningitic etiology can also be accompanied by severe, temporary motor problems and possible long term balance and coordination difficulties. This motor involvement occurs due to sensory hair cell damage not only in the cochlea, the organ of hearing, but also in the vestibular mechanism in the inner ear which contributes to controlling various motor functions, balance being a primary factor. Extreme prematurity can also result in visual impairment (retinopathy) and cerebral palsy as a consequence of brain damage. It is also important to note that sensory impairments alone can also effect motor development, with delays being common due to lack of sensory stimulation from the environment. Motor development frequently does not occur at a normal rate or in a normal fashion.

Perhaps most important as a rationale for including therapy services in the Ga. PINES program was parental need to understand their children's problems and to receive assistance in how to encourage motor skill development to occur as normally as possible. Parents assess their child's early development through the child's acquisition of motor milestones, these skills being the first visible signs of early maturation. Is the child holding his/her head up, rolling over, sitting up, etc.? With MHSI children, the motor area is, therefore, an early area of concern for parents. Therapy consultants, working with the family and the parent advisor can be of tremendous help in assisting with the explanation, assessment and remediation (if possible) of these motor delays/problems.

The MHSI child, then, in addition to vision and hearing deficits, can also exhibit delays in achieving: (1) gross motor milestone; (2) eye-hand coordination and fine motor skills; (3) body awareness and spatial concepts; (4) language concepts; (5) personal-social skills - ability to interact appropriately with other people or objects in the environment; (6) self-help skills such as eating, dressing, personal hygiene, toileting, etc.; and, (7) integration of other sensory information coming into the CNS through the tactile, vestibular and proprioceptive avenues (with potential fear or dislike of touch, movement, etc). This wide variety of potential delays indicates why good team assessment of the total MHSI child is so important in the first few years of life.

Assessment by Physical/Occupational Therapists

As has been already mentioned, the Ga. PINES program utilizes several standardized tests for assessment of the hearing impaired or the MHSI children within the program (the Callier Azusa Scale for example). Therapy consultants frequently assist the parent and parent advisor with giving the motor portions of these tests and planning motor activities based on the test results.

Specific tests used in the therapy fields vary greatly among PT's and OT's based on training, work experience, etc. When a standardized test is used, a developmental checklist format is normally chosen. (For example, the Miller Assessment, Bayley Scales, HELP, Vulpe, etc.) However, with a child who has cerebral palsy, these tests which are usually based on "normal" development may be inappropriate and incomplete. For this reason, therapists tend to use some informal assessment and pull from a variety of sources in order to do a more complete evaluation of such a child. From a therapy perspective, additional areas which might be tested are as follows:

(1) Muscle tone - the tension in muscles. Can range from low (floppy) to high (spastic).

(2) Joint range of motion - flexibility around joints. Abnormal tone can effect muscle length and joint structure creating decreased movement in joints.

(3) Sensation - ability to feel temperature, pain, touch, etc. This also may include the child's ability to integration/interpret tactile stimuli or other stimuli such as movement appropriately. Many of our MHSI children are fearful of and "defensive" about movement and/or touch due to traumatic hospitalizations early on and/or misperceptions of the sensory stimuli coming into the CNS.

(4) Reflexes/reactions - at times, "primitive" reflexes (normal within the first year of life) can remain apparent long beyond their normal time frame due to CNS damage. Additionally, some MHSI children never acquire higher level reactions which allow us to become motor proficient upright in space against gravity. These would include, for example, righting, protective and equilibrium reactions.

(5) Muscle strength

(6) Movement patterns - not only whether or not the child is performing gross motor developmental skills such as sitting, crawling and ambulating but how the child moves himself from one position to another. Is the movement pattern such as to cause problems with joint range of motion, further achievement of other development milestones down the road, etc.?

(7) Coordination and balance - eye-hand, eye-foot, bilateral integration of the two sides of the body, dominance, etc.

(8) Fine motor - grasp, release, etc.

(9) Oral motor - muscle tone, oral sensitivity (hypersensitivity being a big problem with children who are or have been gastrostomy tube fed), reflex activity, tongue and lip movements, suck-swallow and chewing patterns, self-feeding difficulties.

(10) Respiration - chronic congestion, breath control and breathing pattern (especially important for speech production).

(11) Visual/perceptual skills - ranging from visual focusing and tracking to body awareness, motor planning and spatial concepts.

(12) Self-help - dressing, feeding, grooming, toileting, etc. and evaluation of the need for special equipment for the above named skills or for general positioning and mobility.

The role of the physical and occupational therapist in assessment of the MHSI child, then, is: (1) to assess the above named "specialized" areas which affect normal development; (2) to help the PA and parent devise remediation activities which fit into the normal day-to-day routine of the child and the family, keeping in mind and addressing at the same time the child's other sensory problems and needs; (3) to help the PA and family circumvent the physical handicap to allow for functional independence through adaptive devices, when remediation of the motor problems is not possible. Many MHSI children will never achieve totally normal levels of development due to the multiplicity of their problems. The goal should be to make these children as independent and functional as possible and to show their familes how to handle and position them appropriately in order to make daily care easier.

When assessing infants and toddlers, consideration of several other factors can help us to obtain more complete and accurate information. Including parents in the evaluation process, through parental reporting of skills not observed in the evaluation or parental assistance in positioning and handling the child effectively "puts the parents on the team" from the onset and usually gives more complete information on the child's abilities. Keeping environmental factors consistent and familiar to the child (for example, performing the evaluation in the home with familiar toys, etc.) can also help the child to feel more secure, less upset and assists with "integrating" incoming sensory inputs. Finally, performing assessment over time, being cognizant of the child's state at the time of evaluation is critical to assessment of the infant or young child.

A number of researchers have reported on the presence of a variety of states of awareness in normal babies which affect their ability to take in sensory stimuli. Further studies with premature babies have shown that these babies have a very different set of states and needs. Stimuli not only can't be taken in in the same way or at the same rate but can much more easily overwhelm the premature infant resulting in "shutting down" attention to the stimuli, aversive behavior and changes in heart rate, breathing, temperature, etc. which can be dangerous to the baby's health.

Many of our MHSI babies and even older children also show these same problems with state control. When evaluating these children, this issue needs to be kept in mind and should guide the assessment, essentially precluding the standard one hour, one time assessment at the examiner's convenience. The question should not just be "Can this child do what I want him to do, when I want him to do it and in the way I want him to do it?" but rather "How is this child responding to incoming stimuli?" which may include sound, sight, touch, movement, etc. either alone or in combination. Infant-toddler assessment should be thought of as a feed-back loop. What the examiner does in testing the child can directly impinge on the child's responses. Therefore, any evaluation results need to be examined in term of the totality of the test situation in addition to the skills required for the specific tasks and how these tasks are carried out by the child.

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